



NATIONAL HEALTH COUNCIL

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Office of Science and Technology
Executive Office of the President
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RE: Request for Information; Federal Evidence Agenda on Disability Equity

The National Health Council (NHC) appreciates the opportunity to comment on the Federal Evidence Agenda on Disability Equity. As an organization dedicated to advocating for patients and promoting patient-centered health policy, we fully support the Office of Science and Technology Policy (OSTP)'s initiative to gather insights and develop a comprehensive agenda that advances disability equity.

Created by and for patient organizations more than 100 years ago, the NHC brings diverse organizations together to forge consensus and drive patient-centered health policy. We promote increased access to affordable, high-value, equitable, and sustainable health care. Made up of 170 national health-related organizations and businesses, the NHC's core membership includes the nation's leading patient organizations. Other members include health-related associations and nonprofit organizations including the provider, research, and family caregiver communities; and businesses and organizations representing biopharmaceuticals, devices, diagnostics, generics, and payers.

General Comments

The NHC emphasizes the importance of the following key themes that are critical to ensure that the Federal Evidence Agenda on Disability Equity is robust, inclusive, and effective.

Intersectionality

The DDIWG should prioritize understanding how disabilities intersect with other aspects of identity such as race, gender, socioeconomic status, age, and culture. This intersectionality can create unique opportunities for individuals, providing enhanced support networks and resilience. However, it can also amplify challenges and lead to unique forms of discrimination and inequity such as inadequate medical care, higher unemployment rates, lower educational attainment, and greater social isolation. Specifically, challenges for individuals with disabilities are often exacerbated by social drivers of health (SDOH) such as inadequate housing, limited access to quality education, and insufficient employment opportunities. Understanding the varied impacts of these intersecting identities is crucial for developing policies and interventions that are truly equitable and inclusive.

To address intersectionality effectively, data collection must capture the multiple dimensions of identity that intersect with disability. This involves incorporating qualitative insights to understand the lived experiences of individuals with intersecting identities and then enhancing quantitative data collection to capture these dimensions comprehensively. Quantitative data collection should include disaggregated data that encompass not only disability status but also race, gender, socioeconomic status, age, sexual orientation, and other relevant variables. The NHC encourages the alignment of disability statistics with race and ethnicity standards from the new Statistical Policy Directive No. 15 (Directive No. 15): Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity.¹ Disaggregated data allows for a more nuanced analysis of how different identities intersect and how these intersections impact individuals' experiences. For instance, analyzing health outcomes by both disability status and race can reveal disparities that might be invisible in aggregate data. The DDIWG should ensure that data collection methodologies are designed to capture these intersections and that the data is analyzed in ways that highlight intersectional disparities.

Policies and interventions should be designed to meet the unique needs of individuals with intersecting marginalized identities. This means moving beyond a one-size-fits-all approach and developing targeted strategies that consider the unique experiences of different groups. For example, job training programs for people with disabilities should incorporate cultural competence training for staff that is reflective of local demographics to address the specific needs of marginalized communities; by focusing on local context, this training can be more precisely aligned with the needs and experiences of the community, making them more effective in promoting equity and inclusion. Similarly, health care initiatives should ensure that providers are trained to recognize and address the distinct barriers faced by women with disabilities or older adults with disabilities.

Developing policies that address intersectionality requires meaningful engagement with diverse communities. The DDIWG should actively seek input from individuals with disabilities who also belong to other marginalized groups, such as people of color, LGBTQ+ individuals, and low-income communities. Too often the formal notice and comment process does not reach these marginalized communities and federal agencies must actively work to seek their input in non-traditional ways. Engaging these communities in the policy development process ensures that their voices are heard and that their unique perspectives are incorporated into policy decisions. This participatory approach can lead to more inclusive policies and help foster trust through cross-communication and collaboration between policymakers and the communities they serve.

Addressing systemic barriers is essential for achieving health equity and social justice, particularly for marginalized groups impacted by ableism and other forms of

¹ Office of Management and Budget, "Revisions to OMB's Statistical Policy Directive No. 15: Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity," *89 Fed. Reg. 18530* (2024) (to be codified at 44 C.F.R. pts. 1, 2, and 3).
<https://www.federalregister.gov/documents/2024/03/29/2024-06469/revisions-to-ombs-statistical-policy-directive-no-15-standards-for-maintaining-collecting-and>

discrimination. Systemic racism and ableism can intersect to create significant barriers in accessing quality education for students of color with disabilities. Economic inequality, including challenges such as food insecurity and reliance on Social Security Disability Insurance for financial coverage, further exacerbates the difficulties faced by low-income individuals with disabilities. To promote health equity, it is crucial to address the SDOH that contribute to these disparities. This requires a comprehensive approach that includes policy reforms, adequate resource allocation, and strong community support. The DDIWG should prioritize efforts to identify and dismantle these systemic barriers, ensuring that all individuals, regardless of their intersecting identities, have equal opportunities to thrive.

Comprehensive Data Collection

Robust data collection is essential for identifying and addressing disparities in health care and other sectors affecting people with disabilities. Comprehensive data allows for the accurate identification of needs, evaluation of outcomes, and development of targeted interventions. The NHC recommends the development of standardized data collection methods that ensure comprehensive and accurate representation of the disability community. Incorporating insights from organizations such as the National Minority Quality Forum (NMQF), which specializes in data-driven approaches to health equity, can enhance these efforts. For example, NMQF's initiatives like the Lupus Multi-Cultural Engagement Partnership highlight the importance of diverse participation in clinical research to address health disparities effectively.² Standardizing these methods helps mitigate inconsistencies and ensures that data collected across various sectors are comparable and actionable. This approach can help foster a health care system that prioritizes equity and inclusivity, ensuring that the specific needs of the disability community are met effectively.

The NHC has consistently called for enhanced data collection practices that include disability status as a key demographic variable.³⁴ Accurate and detailed data collection is pivotal in understanding the full scope of challenges faced by people with disabilities.⁵ Furthermore, the integration of patient-reported outcomes (PROs) is crucial for capturing the lived experiences of individuals with disabilities. By incorporating PROs, data collection efforts can reflect the subjective perspectives of patients, providing insights into their quality of life, treatment satisfaction, and overall well-being.⁶ This data

² National Minority Quality Forum. (2024). Improving diversity in lupus clinical trials. Retrieved from https://nmqf.org/wp-content/uploads/2024/04/NMQF_LupusReport_04122024-1-compressed.pdf

³ National Health Council. (2020). Consensus statement on health equity. Retrieved from <https://nationalhealthcouncil.org/additional-resources/consensus-statement-on-health-equity-01-27/>

⁴ National Health Council. (2021). Primary data collection. Retrieved from <https://nationalhealthcouncil.org/primary-data-collection/>

⁵ Mont, D., Madans, J., Weeks, J., and Ullmann, H. (2023). Harmonizing disability data to improve disability research and policy. *Health Affairs*, 41(10), 1442-1448. doi: 10.1377/hlthaff.2022.00479

⁶ Bull, C., Teede, H., Watson, D., and Callander, E. (2022). Selecting and implementing patient-reported outcome and experience measures to assess health system performance. *JAMA Health Forum*, 3(4). doi:10.1001/jamahealthforum.2022.0326

is invaluable for shaping patient-centered policies and practices. The NHC emphasizes that without these inclusive data practices, policies may overlook critical aspects of care that impact individuals with disabilities, leading to gaps in services and support.

To support these efforts, the NHC has developed [Patient-Centered Core Impact Sets](#) (PC-CIS), which provides a consistent framework for capturing patient experiences and outcomes, ensuring the inclusion of diverse disability perspectives. PC-CIS are designed to ensure that the diverse needs and perspectives of patients are accurately captured and represented in health data. This tool plays a critical role in informing health policies and practices that are truly patient-centered and inclusive of the disability community.

The NHC underscores the importance of collecting comprehensive data on health outcomes to better understand the unique needs of individuals with chronic conditions and disabilities. Detailed data collection is necessary to inform targeted interventions and improve patient outcomes. Furthermore, targeted data collection is essential to address specific disparities in care and to provide comprehensive overviews of how detailed data collection can inform better health policies and practices. This holistic approach to data collection not only helps in identifying existing disparities but also in tracking progress over time, thereby ensuring that interventions are effective and that resources are allocated where they are most needed.

Health Care Access and Quality

Access to high-quality health care services for individuals with disabilities is paramount. Barriers such as physical inaccessibility, cost, and inadequate provider training often prevent individuals from accessing necessary care.^{7,8} The NHC supports provisions that recognize the importance of restoring regulatory protections and ensuring that Medicaid, Medicare, the Affordable Care Act's state and federal Marketplaces, and other commercial health plans adhere to non-discriminatory policies. This is essential for promoting equitable access to health care across various systems.

The NHC supports patient-centered care models that include people with disabilities in decision-making processes and emphasizes the importance of cultural competence, inclusive of disability, among health care providers. Patient-centered care involves recognizing patients as the primary authority on their health care needs. It is crucial to incorporate their perspectives in defining value and shaping health care policies. This approach ensures that care models are tailored to meet the specific needs and preferences of individuals with disabilities, leading to better health outcomes and higher patient satisfaction.⁹

⁷ Matin, B., Williamson, H., Karyani, A., Rezaei, S., Soofi, M., and Soltani, S. (2021). Barriers in access to healthcare for women with disabilities: a systematic review in qualitative studies. *BMC Women's Health*, 21(44). <https://doi.org/10.1186/s12905-021-01189-5>

⁸ Butkus, R., Rapp, K., Cooney, T., and Engel, L. (2020). Envisioning a better U.S. health care system for all: reducing barriers to care and addressing social determinants of health. *Annals of Internal Medicine*, 172(2). doi:10.7326/M19-2410

Comprehensive training programs for health care providers are also critical. These programs should focus on sensitizing health care professionals to the nuances of various disabilities and providing clear guidelines on how to adapt care and assessment tools accordingly. Such training will help mitigate implicit biases and ensure that health care providers are equipped to deliver equitable care to all patients, regardless of their disabilities.

The NHC supports the implementation of universal design principles in health care facilities to improve accessibility. Accrediting bodies, such as the Joint Commission, can play a vital role in enforcing these ergonomic concepts.¹⁰ Universal design ensures that health care facilities and services are physically accessible and cater to the diverse needs of individuals with disabilities.¹¹ This holistic approach not only addresses physical barriers but also promotes an inclusive environment that supports the full participation of individuals with disabilities in their health care.¹² Robust accessibility standards for digital health platforms, including web, mobile, and kiosk interfaces, are also essential to guarantee seamless access to health care information and services.

Addressing the various social drivers of health, such as housing, education, employment, and social support systems, is also crucial for ensuring good health outcomes for people with disabilities. The NHC supports a comprehensive approach that includes these factors to create a more supportive and effective health care environment for individuals with disabilities throughout their lifespan.

Employment and Economic Security

Economic stability is a significant determinant of health. Employment opportunities and economic security are crucial for the well-being of individuals with disabilities. The NHC supports initiatives that promote inclusive employment practices and provide necessary accommodations to enable individuals with disabilities to thrive in the workforce. Some states have implemented successful job training programs that create pipelines for

⁹ Centers for Medicare & Medicaid Services. (n.d.). Person-centered care. Retrieved from <https://www.cms.gov/priorities/innovation/key-concepts/person-centered-care>

¹⁰ Centers for Medicare & Medicaid Services. (2023). Modernizing health care to improve physical accessibility. Retrieved from <https://www.cms.gov/About-CMS/Agency-Information/OMH/Downloads/OMH-Modernizing-Health-Care-Physical-Accessibility.pdf>

¹¹ Halawa, F., Madathil, S., Gittler, A., and Khasawneh, M. (2020). Advancing evidence-based healthcare facility design: a systematic literature review. *Health Care Management Science*, 23, 453-480. <https://doi.org/10.1007/s10729-020-09506-4>

¹² Centers for Medicare & Medicaid Services. (2021). Modernizing health care to improve physical accessibility: a primer for providers. Retrieved from <https://www.cms.gov/files/document/cmsmodernizinghealthcare.pdf>

individuals with disabilities entering the workforce, particularly those aged 18 to 25.^{13,14} Observing and potentially integrating the approaches from these state programs could provide valuable insights for developing effective federal employment initiatives. Economic stability for people with disabilities is closely linked to their ability to secure and maintain employment that offers adequate benefits and a living wage. Without this stability, individuals with disabilities are more likely to experience poor health outcomes, limited access to necessary health care services, and increased stress and anxiety due to financial insecurity.¹⁵

Employment opportunities must be inclusive and supportive, accommodating the unique needs of people with disabilities. This includes not only physical accessibility in the workplace but also accommodations such as flexible work hours, telecommuting options, extended time to complete work assignments, added instruction and/or supervision, training tools to aid task completion, and the provision of assistive technologies. Inclusive employment practices help to ensure that individuals with disabilities are not unfairly disadvantaged in the labor market and can compete on an equal footing with their non-disabled peers.¹⁶

The NHC also emphasizes the importance of providing necessary accommodations to enable individuals with disabilities to thrive in the workforce. Accommodations can include modifications to the work environment, changes in work tasks, and the provision of additional support services such as job coaching and vocational training. These measures are essential for removing barriers to employment and ensuring that individuals with disabilities can perform their job duties effectively and safely. Employers who implement these accommodations not only comply with legal requirements but also benefit from the diverse skills and perspectives that employees with disabilities bring to the workplace.¹⁷

Furthermore, promoting economic security for individuals with disabilities requires addressing systemic barriers that contribute to their economic disadvantage. This includes advocating for policies that support income security, such as disability benefits, paid leave, and access to affordable health care. Ensuring that individuals with

¹³ Zhang, S., Grenwelge, C., and Petcu, S. (2018). Preparing individuals with disabilities for inclusive employment through postsecondary access and training in human services (PATH) program. *Inclusive*, 6(3), 224-233. <https://doi.org/10.1352/2326-6988-6.3.224>

¹⁴ Riesen, T., Morgan, R., and Griffin, C. (2015). Customized employment: a review of the literature. *Journal of Vocational Rehabilitation*, 43(3), 183-193. <https://doi.org/10.3233/JVR-150768>

¹⁵ Matin, B., Williamson, H., Karyani, A., Rezaei, S., Soofi, M., and Soltani, S. (2021). Barriers in access to healthcare for women with disabilities: a systematic review in qualitative studies. *BMC Women's Health*, 21(44). <https://doi.org/10.1186/s12905-021-01189-5>

¹⁶ Baldwin, M., Marcus, S. (2021). Perceived and measured stigma among workers with serious mental illness. *Psychiatric Services*, 57(3):388-92. <https://doi.org/10.1176/appi.ps.202100145>

¹⁷ Feuerstein, M., Berkman, L. F., Kawachi, I., and Theorell, T. (2014). Working conditions and health. In *Social Epidemiology* (pp. 153-181). Open University Press.

disabilities have access to these supports is critical for their ability to maintain financial stability and achieve long-term economic security.¹⁸

Education and Training

Educational institutions play a crucial role in shaping the future opportunities for individuals with disabilities. Equitable access to quality education, including vocational training and higher education opportunities, is essential for the empowerment and advancement of the disability community. Research indicates that assistive technologies can greatly enhance the inclusion of students with disabilities in educational settings, facilitating easier access to the curriculum and full classroom participation.¹⁹

The NHC emphasizes the importance of accessible education in promoting health equity and educational quality. Policies should ensure that schools and universities provide appropriate accommodations and support services for students with disabilities. Ensuring these supports is vital for creating an inclusive educational environment that can cater to the diverse needs of students with disabilities. Studies have demonstrated that inclusive education policies, such as those mandated by the Individuals with Disabilities Education Act (IDEA), play a critical role in providing equitable access to educational opportunities for all students with disabilities.²⁰ Such policies ensure that students with disabilities receive the support they need to succeed academically, socially, and economically.

Providing necessary accommodations, such as assistive technologies, personalized learning plans, specialized staff, and modifications to the physical environment, is essential for fostering an inclusive educational environment. These measures help ensure that students with disabilities can engage with the curriculum and succeed academically. Moreover, the inclusion of these accommodations has been shown to promote a sense of belonging and improve educational outcomes for students with disabilities.²¹

In addition to accommodations, comprehensive training programs for educators and administrative staff are crucial. These programs should focus on raising awareness

¹⁸ U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Institute for Occupational Safety and Health. (2020). Employer-reported workplace injuries and illnesses (annual) news release. *CDC.gov*. <https://www.cdc.gov/niosh/docs/2004-146/pdfs/2004-146.pdf?id=10.26616/NIOSH-PUB2004146>

¹⁹ Fernández-Batanero, J.M., Reyes-Rebollo, M.M., and Montenegro-Rueda, M. (2020). Assistive technology for the inclusion of students with disabilities: A systematic review. *Educational Technology Research and Development*. doi: 10.1007/s11423-019-09658-2

²⁰ Russo, C. (2019). The rights to educational self-determination under the Individuals with Disabilities Education Act. *International Journal of Inclusive Education*, 23(5), 546-558.

²¹ UNESCO (2023). Promoting access to education for students with disabilities through inclusive technologies. *Global Education Monitoring Report*. Retrieved from <https://www.unesco.org/gem-report/en/2023-technology-inclusion>

about the unique challenges faced by students with disabilities and providing strategies to address these challenges effectively. Educators must be equipped with the knowledge and tools to create inclusive lesson plans and learning environments that cater to the diverse needs of their students.²²

Community and Civic Engagement

Participation in community and civic activities is vital for the well-being and empowerment of individuals with disabilities. The NHC supports efforts to enhance accessibility and inclusivity in all aspects of public life, including transportation, public spaces, and digital platforms. Ensuring equal access to these areas fosters a sense of belonging and active participation in society for individuals with disabilities.

We commend the OSTP for prioritizing disability equity and urge the inclusion of patient organizations in the development and implementation of the Federal Evidence Agenda. Collaborative efforts with stakeholders, including those with lived experiences of disability, will be essential in creating policies that truly reflect the needs and aspirations of the disability community.

Topics and Key Questions

Describing Disparities

1. What disparities faced by individuals with disabilities are not well-understood through existing Federal statistics and data collection?

Existing Federal statistics often overlook the nuanced disparities faced by individuals with disabilities and the differences between different types of disabilities, particularly in areas such as access to technology, transportation, and specialized health care services. Disparities faced by individuals with disabilities in pain management and mental health services are not well-understood. For example, individuals with invisible disabilities such as fibromyalgia face skepticism and bias, resulting in under-treatment and unnecessary suffering. Similarly, those with physical disabilities may face barriers in accessing mental health services due to provider biases or misconceptions about their ability to benefit from such services. Additionally, there is significant room for improvement in gathering long-term outcome data on employment and education for individuals with disabilities, which can provide deeper insights into their ongoing challenges and successes in these critical SDOH.

2. What types of community-based or non-Federal statistics or data collections could help inform the creation of the Federal Evidence Agenda on Disability Equity?

Community-based research such as the National Council on Disability's reports and studies on chronic pain and mental health services could provide critical insights.

²² Toutain, C. (2020). Barriers to accommodation for students with disabilities in higher education: a literature review. *Journal of Postsecondary Education and Disability*, 32(3), 297-310.

Engaging the disability community in informatics research and leveraging data from patient organizations can gather more detailed information about these challenges. Additionally, occupational data that lists disabilities acquired in the workplace, as collected by various organizations, can offer valuable insights. Partnering with agencies such as the Occupational Safety and Health Administration (OSHA) and the Equal Employment Opportunity Commission (EEOC) can enhance understanding of workplace-related disparities by providing expertise and resources. Importantly, a comprehensive approach that includes data on both disability status and the severity of disabilities is crucial.²³ Data on the severity of disabilities can provide a deeper understanding of the varying levels of support needed by individuals. Collecting information on both disability status and the extent of functional limitations ensures a complete picture of the needs and challenges faced by individuals with disabilities. This comprehensive understanding is essential for informing health policies and interventions aimed at improving the overall health and well-being of individuals with disabilities, addressing both their immediate health care needs and long-term outcomes in employment and education.

3. Community-based research has indicated that individuals with disabilities experience disparities in a broad range of areas. What factors or criteria should the DDIWG consider when considering policy research priorities?

The DDIWG should consider factors such as the intersectionality of disabilities and other identity aspects (race, gender, socioeconomic status, age) when setting policy research priorities. This intersectionality can lead to unique forms of discrimination and disadvantage, which must be recognized and addressed to develop truly equitable and inclusive policies and interventions. In addition, we need further understanding of the different disparities faced by people with different types of disabilities. The experience of someone with a physical disability may be very different than someone with an intellectual disability.

Informing Data Collections and Public Access

1. Disability can be defined and measured in multiple ways. Federal surveys and administrative data collections use different definitions of disability and measure it in different ways depending upon the goal(s) of data collection. What frameworks for defining and measuring disability or specific considerations should the DDIWG be aware of?

The DDIWG should integrate both the medical and social models of disability into its framework for data collection. The medical model focuses on the physiological and psychological aspects of disability, considering it primarily as a health condition that requires medical intervention. This model is essential for understanding the clinical aspects of disabilities, such as diagnosis, treatment, and management of symptoms. On the other hand, the social model views disability as a result of the interaction between individuals with impairments and societal barriers that hinder their full participation in society. This model emphasizes the importance of removing physical, attitudinal, and

²³ Breslin, M. and Yee, S. (2024). *Charting equality: why demographic disability data is good for everyone*. National Health Law Program and Disability Rights Education and Defense Fund.

systemic barriers to create a more inclusive society. By combining these models, the DDIWG can develop a more comprehensive understanding of disability that addresses both individual health needs and broader societal challenges.

Disabilities are not always constant; many individuals experience episodic impairments or conditions that go into remission. For instance, conditions like multiple sclerosis, bipolar disorder, and lupus can have periods of exacerbation and remission. It is crucial for data collection efforts to recognize and capture these fluctuations. This is also relevant for neurodivergent individuals, whose disabilities reflect personal experiences and can vary widely. Standard survey instruments and data collection tools should include questions that allow respondents to indicate the episodic nature of their disabilities and any periods of remission. This approach ensures that data accurately reflects the experiences of individuals whose disabilities are not consistently present but still significantly impact their lives.

The impact of disability varies widely among individuals, even for those with the same diagnosis. Factors such as the severity of the condition, availability of support systems, and personal coping strategies can influence how a disability affects a person's daily life. Individuals with less severe or invisible disabilities may struggle to obtain an accurate diagnosis and often lack the support systems available to those with more apparent or severe limitations. This is particularly true for people with long-COVID or other emerging conditions that are not yet fully understood. Therefore, assessments must be individualized to capture the unique experiences and needs of each person, ensuring that the federal government comprehensively understands the diverse spectrum of experiences among people with disabilities. Standardized tools should be flexible enough to allow for customization based on individual circumstances. This may involve using open-ended questions, incorporating patient-reported outcomes, and allowing respondents to provide additional context about their disabilities.

While flexibility is important, there is also a need for consistency in how disability is defined and measured across different data collection efforts. Consistent definitions and measurement approaches enable comparisons across studies and over time, facilitating a better understanding of trends and disparities. The DDIWG should develop and promote standardized definitions and measurement criteria that can be adopted by various federal surveys and administrative data collections. These standards should be developed in consultation with stakeholders, including people with disabilities and their advocates, to ensure they are relevant and inclusive.

To capture the full scope of disability, data collection efforts should be comprehensive and include a wide range of indicators. This includes not only health-related measures but also social determinants of health, such as education, employment, housing, and access to services. Comprehensive data collection helps to identify the multiple and intersecting factors that contribute to the experiences of people with disabilities. It also enables the development of targeted interventions that address the root causes of disparities and promote equity.

The methods used for data collection must be accessible and inclusive to ensure that all individuals with disabilities can participate. This includes providing materials in multiple formats (e.g., Braille, large print, digital), offering assistance for completing surveys, and

ensuring that data collection platforms are compatible with assistive technologies. Additionally, data collectors should be trained in disability awareness and cultural competence to interact effectively and respectfully with respondents with disabilities.

When collecting disability data, it is vital to protect the privacy and confidentiality of respondents. This involves implementing robust data security measures, obtaining informed consent, and ensuring that individuals understand how their data will be used. For individuals who cannot consent, there is a role for assent to ensure ethical participation in registries or data collection studies. Assent involves seeking a participant's agreement to take part in a study when they are not legally able to provide full informed consent, often involving children or individuals with cognitive impairments. This process respects their autonomy by involving them in decision-making to the extent that they are able. Privacy protections help to build trust and encourage participation, which is essential for collecting accurate and comprehensive data.

2. In some instances, there are multiple surveys or data collection tools that could be used to collect data about a particular disparity faced by the disability community. In addition to factors like sample size, timeliness of the data, and geographic specificity of related data products, what other factors should be considered when determining which survey or data collection tool would best generate the relevant data?

Other critical factors include an inclusive survey design that addresses health literacy, accessibility of data collection methods, and cultural competence of data collectors. It is also important to ensure that data collection tools are capable of capturing the full range of benefits and challenges experienced by individuals with disabilities, beyond traditional health outcomes.

3. Are there any Federal surveys or administrative data collection tools for which you would recommend the Federal Government should not explore collecting disability data due to privacy risk, the creation of barriers to participation in Federal programs, or other reasons? Which collections or type of collections are they, and why would you make this recommendation?

Surveys and data collections related to sensitive areas such as credit applications, employment records, or interactions with the legal system may pose significant privacy risks. Collecting disability data in these contexts could lead to stigmatization or discrimination, and careful consideration must be given to balancing data collection with the protection of individuals' privacy.

Credit applications, for instance, often involve sensitive financial information. If disability data were included, it could potentially be used to unfairly judge an individual's creditworthiness, leading to discriminatory lending practices and further economic disadvantages for people with disabilities. Ensuring that credit-related data remains focused solely on financial metrics is crucial to preventing potential biases that could arise from the inclusion of disability status.

Employment records are another sensitive area where the inclusion of disability data could lead to unintended consequences. Employers may misuse this information, consciously or unconsciously, leading to discrimination in hiring, promotions, or job assignments. This could reinforce barriers to employment for people with disabilities, who may already face significant challenges in the job market. Strong protections and clear guidelines must be in place to ensure that disability data, if collected, is used strictly for promoting inclusivity and not for discriminatory practices.

Interactions with the legal system also present complex challenges. Individuals with disabilities who have been wrongfully accused of crimes or have a history of incarceration may face additional stigma and barriers to reentry into society. This can exacerbate their marginalization and hinder their access to necessary services and support. The stigma associated with a history of incarceration or interaction with the legal system can create significant barriers to employment, housing, and social services. When combined with the challenges of living with a disability, these individuals may encounter compounded discrimination and systemic biases. People with disabilities, especially those with mental health conditions, are particularly vulnerable to incarcerations and face heightened challenges if they are also African American or Hispanic.^{24,25}

Similarly, data collections related to health insurance applications, housing applications, and educational records could lead to discrimination if disability data is not handled with strict confidentiality. Health insurance providers might use disability data to adjust premiums unfairly or deny coverage. Housing applications might see landlords discriminating against potential tenants with disabilities, exacerbating housing instability. In educational settings, students with disabilities might face biases that affect their opportunities and support services, further hindering their academic progress.

To address these concerns, it is essential to make all surveys accessible for people with disabilities, implement robust privacy protections and ensure that any data collected is used solely for the purpose of improving services and support for individuals with disabilities. This includes obtaining informed consent, anonymizing data, and clearly communicating how the data will be used and protected. By prioritizing the privacy and confidentiality of individuals with disabilities, particularly in sensitive areas, the risks of stigmatization and discrimination can be mitigated.

4. How can Federal agencies increase public response rates to questions about disability in order to improve sample sizes and population coverage?

Federal agencies can improve response rates by ensuring surveys and forms are accessible in multiple formats (e.g., Braille, large print, electronic formats), conducting outreach through trusted community organizations, and providing assurances of

²⁴ Yelton, B., Friedman, D., Noblet, S., Lohman, M., Arent, M., Macaуда, M., Sakhuja, M., and Leith, K. (2022). Social determinants of health and depression among African American adults: a scoping review of current research. *International Journal of Environmental Research and Public Health*, 19(3). doi: 10.3390/ijerph19031498

²⁵ Wildeman, C. and Muller, C. (2012). Mass imprisonment and inequality in health and family life. *Annual Review of Law and Social Science*, 8, 11-30. <https://doi.org/10.1146/annurev-lawsocsci-102510-105459>

confidentiality. Additionally, simplifying the process of responding to surveys and providing support during the process can help increase participation. Additionally, highlighting the benefits of participation – such as contributing to better services and policies for individuals with disabilities – can motivate respondents. Emphasizing the positive impact that their input can have on advancing disability equity and improving community resources can encourage individuals to better engage with the survey process.

5. What barriers may individuals with disabilities face when participating in surveys or filling out administrative forms?

Individuals with disabilities may face a range of barriers when participating in surveys or completing administrative forms. Physical accessibility issues, such as the inability to reach or use survey kiosks, can prevent participation. Cognitive load can also be a significant barrier, as complex or lengthy forms may be overwhelming and difficult to navigate. Additionally, a lack of assistive technologies, such as screen readers or speech-to-text software, can hinder the ability of some individuals to complete forms independently.

Privacy concerns is another critical issue. Many individuals may worry that their personal information could be misused or not kept confidential, which deters participation in surveys. This fear is particularly concerning when surveys are not accessible, and individuals with disabilities must rely on family members or acquaintances for assistance. Requiring individuals to disclose personal information to others can increase the risk of compromised confidentiality and skew survey results if respondents are uncomfortable sharing sensitive information. Providing strong assurances of confidentiality and robust data protection measures can help alleviate these concerns and encourage participation.

Ensuring that health literacy is addressed is also crucial. Recognizing different learning capabilities and providing information in plain language are essential for helping individuals understand what is being asked in surveys and on administrative forms. This can include using clear and straightforward instructions, avoiding technical jargon, and incorporating visual aids to make the content more accessible.

To overcome these barriers, it is essential to provide tools that facilitate objective, individualized assessment methods. This includes offering assistance tailored to various learning needs and ensuring that forms are available in multiple formats (e.g., Braille, large print, electronic formats) to accommodate different disabilities. Ensuring effective, empathetic communication by engaging people with disabilities to help codevelop surveys and training staff to interact respectfully and supportively with individuals with disabilities can also make a significant difference.

6. Disaggregated data—data about groups separated out by disability, race/ethnicity, gender identity, sexual orientation, geography, income level, veteran status, rural/urban location, and other factors—are essential for identifying and remediating disparities in how the government serves American communities. Which data disaggregated by disability that are currently collected by Federal agencies are useful? Which data

disaggregated by disability are not currently collected by Federal agencies and would be useful, and why?

Useful data currently collected include those related to health care access, educational attainment, and employment status. However, there is a need for more detailed data on the intersectionality of disability with other factors such as race, socioeconomic status, and geographic location to fully understand and address disparities.

7. How can Federal agencies best raise public awareness about the existence of sources of disability data? How can Federal agencies best communicate with the public about methodological constraints to collecting data or publishing disability statistics?

While this RFI is an important step towards raising awareness of disability data, it is crucial that the federal government continually engages people with disabilities to ensure comprehensive and accurate data collection. The federal government should establish a committee of external experts, including individuals with disabilities, to evaluate best practices in data collection and to test and implement effective statistical methods. This committee should actively seek input from organizations like the NHC and other groups representing people with disabilities. Engaging with these stakeholders will help raise awareness about the importance of collecting better disability data and ensure that the process is inclusive and representative.

A key principle of the disability movement is that decisions and policies affecting people with disabilities should be made with their direct involvement and input. Federal agencies should recognize the invaluable insights that individuals with disabilities can provide on these issues. Public service announcements and social media campaigns can play a significant role in raising public awareness about the need to collect disability data. However, it is essential that these communication methods are fully accessible to all people with disabilities.

To effectively communicate methodological constraints, federal agencies should prioritize transparent reporting, public forums, and educational materials that clearly explain the limitations and ongoing efforts to improve data collection methods. These strategies will help build trust and ensure that the public is well-informed about the challenges and advancements in disability data collection.

8. How do individuals and organizations external to the Federal Government utilize data from Federal surveys and administrative data collections? Which practices employed by Federal agencies facilitate access to and use of these data? Are there additional practices that would be beneficial?

Individuals and organizations external to the Federal Government utilize data from federal surveys and administrative data collections for a variety of purposes, including research, advocacy, and program development. Academic institutions and research organizations, for example, use this data to study health disparities, access to services, and the social determinants of health. By analyzing these datasets, researchers can identify patterns and trends that inform public health interventions and policy decisions. Patient organizations leverage federal data to support policy changes, highlighting the

specific needs of their constituents to policymakers and the public. This data-driven advocacy is crucial for securing funding, improving services, and enacting legislative changes that benefit individuals with disabilities.

Nonprofits and community-based organizations also rely on federal data to develop and evaluate programs tailored to the needs of individuals with disabilities. By using evidence from federal surveys, these organizations can design more effective interventions and measure their impact over time. Platforms like data.gov facilitate access to these datasets, making it easier for various stakeholders to find and use the information they need. Federal agencies enhance this usability by providing data in multiple formats (for example, such as CSV, JSON, RDF, and/or XML) and offering data visualization tools that help users analyze and interpret the data more effectively.

Technical assistance and training provided by agencies such as the Centers for Disease Control and Prevention and National Institutes of Health (NIH) further support the utilization of federal data. Programs like the NIH's All of Us Research Program offer workshops and webinars to help users navigate their data resources, ensuring that researchers and advocates can make the most of the available information. Increased transparency about data collection methods, including detailed metadata and documentation on how data is collected, processed, and any limitations, also plays a key role in facilitating access and use. This transparency helps users understand the context and constraints of the data, leading to more accurate and reliable analyses.

Enhanced collaboration with external organizations is another beneficial practice employed by federal agencies. By establishing partnerships to co-create data collection tools and methodologies, agencies can ensure that the data collected meets the needs of all stakeholders. This collaborative approach not only improves the relevance and usability of the data but also fosters trust and cooperation between the government and external entities. Overall, these practices enable individuals and organizations to effectively utilize federal data, driving advancements in research, advocacy, and program development that support individuals with disabilities.

Privacy, Security, and Civil Rights

- 1. What specific privacy and confidentiality considerations should the DDIWG keep in mind when determining promising practices for the Federal collection of data for administrative purposes, such as applications for programs or benefits, compliance forms, and human resources and restrictions on their use or transfer?**

Privacy and confidentiality are paramount when collecting disability data for administrative purposes. The DDIWG should ensure that individuals provide informed consent, fully understanding how their data will be used. Clear communication about data usage and the steps taken to protect personal information can help build trust and encourage participation. This is particularly important in immigrant communities where legal residence of the individuals and/or their family members is uncertain or undeclared. Individuals in these communities may have heightened concerns about the potential misuse of their data, fearing that it could be used against them or their families, leading to legal repercussions or deportation. Assuring these individuals of strict

confidentiality and limited use of their data is crucial for gaining their trust and cooperation. Participation from immigrant communities is essential to improve health outcomes and ensure that health services are inclusive and equitable. By understanding the specific needs and challenges faced by these communities, policies and interventions can be better tailored to address health disparities. Without their input, data will be incomplete, leading to gaps in services and support that fail to meet the diverse needs of all individuals with disabilities.

Data minimization practices should be employed, collecting only the data necessary for the specific purpose. This reduces the risk of privacy breaches and ensures that sensitive information is not unnecessarily exposed. Robust anonymization and encryption techniques should be implemented to protect personal data from unauthorized access or disclosure.

Transparency in the investigation process is critical. Individuals should be informed about how their data will be stored, used, and protected. Providing support during the complaint process and ensuring that individuals have recourse if their data is misused can further enhance trust and participation.

Implementing strict access controls is another key consideration. Ensuring that only authorized personnel can view or use the data helps safeguard privacy. Regular audits and compliance checks can ensure that these controls are adhered to, and that data is handled responsibly.

2. Unique risks may exist when collecting disability data in the context of both surveys and administrative forms. Please tell us about specific risks Federal agencies should think about when considering whether to collect these data in surveys or administrative contexts.

Collecting disability data can lead to stigmatization and discrimination if not handled properly, as individuals may fear that disclosing their disability status could result in negative consequences, such as being denied services or facing bias in employment or health care settings. Ensuring that data collection is voluntary and providing strong privacy protections can help mitigate these risks. However, strong privacy protections must be complemented by robust cybersecurity measures to prevent data breaches, as the exposure of sensitive disability data can lead to identity theft, discrimination, and other harms. Federal agencies must protect the data and respond quickly to any breaches that do occur.

Misidentification due to inadequate data collection methods is another risk. Inaccurate data can lead to improper allocation of resources and ineffective policies. Ensuring that data collection methods are accurate, inclusive, and regularly updated can help prevent misidentification and ensure that the data reflects the true needs of individuals with disabilities. Additionally, providing clear information about the purpose of data collection and how the data will be used can help address concerns about misuse. Individuals should know that their data will be used to improve services and support for people with disabilities, not to penalize or stigmatize them.

Engaging people with disabilities in the development of survey questions can further ensure that the questions are understandable and free from stigmatization. This collaborative approach helps create a more inclusive data collection process that more accurately reflects the experiences and needs of individuals with disabilities.

3. Once disability data have been collected for administrative or statistical purposes, what considerations should Federal agencies be aware of concerning retention of these data? Please tell us how privacy or confidentiality protections could mitigate or change these concerns.

Federal agencies should establish clear data retention policies that define how long data will be kept and when it will be securely destroyed. Retaining data only as long as necessary for the specific purpose reduces the risk of unauthorized access or misuse. Ensuring that data is securely destroyed when no longer needed is a critical aspect of data management.

Implementing strict access controls can help protect data during its retention period. Only authorized personnel should have access to sensitive disability data, and robust authentication methods should be used to verify their identities. Regular audits and compliance checks can ensure that these controls are maintained, and that data is handled responsibly.

Privacy and confidentiality protections, such as anonymization and encryption, can help mitigate concerns about data retention. By anonymizing data, agencies can reduce the risk of identifying individuals if the data is accessed without authorization. Encryption ensures that even if data is intercepted, it cannot be easily read or misused.

Transparency about data retention practices can also help build trust. Providing clear information about how long data will be kept, the measures in place to protect it, and the processes for securely destroying it can reassure individuals that their information is being handled responsibly. This transparency can encourage more individuals to participate in data collection efforts.

4. Where administrative data are used to enforce civil rights protections, such as in employment, credit applications, healthcare settings, or education settings, what considerations should the DDIWG keep in mind when determining promising practices for the collection of these data and restrictions on its use or transfer?

Ensuring equitable data use is crucial. Data collected for civil rights enforcement should be used to protect and support individuals with disabilities, not to harm or discriminate against them. Limiting the use of data to the specific purposes for which it was collected can help prevent misuse and ensure that it is used ethically.

Purpose limitation is another important consideration. Data should only be used for the purposes explicitly stated at the time of collection. This helps prevent data from being repurposed in ways that could negatively impact individuals with disabilities. Clear guidelines and policies on data use can help enforce this principle.

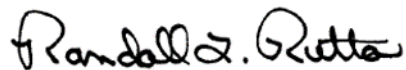
Maintaining transparency and accountability is essential. Individuals should be informed about how their data is used and have recourse if it is misused. Establishing accountability mechanisms, such as regular audits and oversight by independent bodies, can help ensure that data is used responsibly and that any misuse is promptly addressed.

Protecting individuals' privacy and confidentiality is also critical. Strong data protection measures, including anonymization and encryption, can help safeguard personal information. Ensuring that data is stored and transferred securely can prevent unauthorized access and misuse. Providing clear information about these protections can help build trust and encourage more individuals to participate in data collection efforts.

Conclusion

The NHC appreciates the opportunity to provide input on this important issue and look forward to continuing our collaboration with the OSTP. Please do not hesitate to contact Eric Gascho, Senior Vice President of Policy and Government Affairs, at egascho@nhcouncil.org if you or your staff would like to discuss these comments in greater detail.

Sincerely,

A handwritten signature in black ink that reads "Randall L. Rutta". The signature is written in a cursive, slightly slanted style.

Randall L. Rutta
Chief Executive Officer