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Adam M. Politis
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White House Office of Science and Technology Policy
1650 Pennsylvania Avenue
Washington, D.C. 20504

RE: Notice of Availability and Request for Information; Federal Evidence Agenda on Disability Equity

Dear Mr. Politis, the White House Office of Science and Technology Policy (OSTP), and members of the Disability Data Interagency Working Group (DDIWG),

In January 2021, President Biden signed an Executive Order on Advancing Racial Equity and Support for Underserved Communities Through the Federal Government (E.O. 13985 of Jan 20, 2021). We understand that the current RFI is to inform the development of the *Federal Evidence Agenda on Disability Equity* under direction from Executive Order 14091 on Further Advancing Racial Equity and Support for Underserved Communities Through the Federal Government (E.O. 14091 of Feb 16, 2023). The Disability Data Interagency Working Group (DDIWG) was created to oversee the development and implementation of this Agenda. However, it is unclear from an outside perspective whether and to what extent there is coordination and alignment between the DDIWG and the Interagency Committee on Disability Research (ICDR) Subcommittee on Disability Statistics (SDS), whom we have cc'd on this letter.

Given that President Biden's E.O. on racial equity is the mechanism behind this initiative, we are concerned that this RFI appears to overlook considerations of race/ethnicity and other intersecting identities crucial for achieving data equity to address the pervasive disparities extant. The current RFI only briefly mentions race/ethnicity in regard to disaggregation of data alongside a long list of demographic categories (i.e. disability, race/ethnicity, gender identity, sexual orientation, geography, income level, veteran status, rural/urban location, and other factors). However, it fails to recognize the intersection of these statuses and identities and the profound impact of multiple disadvantages on the disability data equity questions posed.

We write on behalf of the Center for Racial and Disability Justice at Northwestern Pritzker School of Law. Our objective is to share information from the research evidence base with a focus on racial and disability justice and put forward critical recommendations to inform the development of this *Federal Evidence Agenda on Disability Equity*. We write with the hope that the rhetoric employed by this Administration and the OSTP does not ring hollow and that the intent for sustained and lasting change in how we approach disability data is sincere in the pursuit of equity. Equity is more than simply including disability as a question set or disaggregating datasets by disability. One cannot simply tick a box for diversity and expect to achieve equity. This is the impetus behind our letter and recommendations.

RECOMMENDATIONS

1. Develop Disability Data Equity Standards & Principles
2. Equity Must Address Intersectionality
3. Invest in Disabled Researchers
4. Develop New Measures & Methods, Not Adapt Ableist Ones

DISABILITY DATA BARRIERS & LIMITATIONS

The disability community is a historically hard-to-count (HTC) population, putting them at risk of being undercounted and misrepresented in Federal data (Koo & Hudson, 2021). This is especially true among immigrant and minority groups who also have been historically undercounted (DREDF, 2022; Lee, Hudson, & Brumfield, 2019; Pettinicchio & Maroto, 2021). The current limitations of disability data "fail to reflect the complexity and diversity of disability, leading to the exclusion of vulnerable populations and hindering a comprehensive understanding of the disability landscape" (Mont & Madans, 2023, p. 4).

Disability data is collected in order to assess disability prevalence, for accommodation provision to ensure equitable care and support, to identify and address disparities affecting disabled people, and for the purposes of intersectional research (Breslin & Yee, 2024). Lack of systematic data collection about the lives of disabled people results in oversight and neglect in not only research agendas but also in programs/services and policy priorities (Gorman, 2024). Overall, disabled people are typically absent from statistical data collection efforts due to three reasons: (1) *underrepresentation in the numerator* that stems from problems identifying and counting a HTC population; (2) *underrepresentation in the denominator* that stems from population-based statistical reliance on definitions that exclude groups to which disabled people are more likely to belong and wherein often they are over-represented; and (3) lack of disaggregation according to disability status. This leads to several barriers that have been identified and strategies developed to address them (UNICEF, 2020):

BARRIERS	AFFECT ON MONITORING	INCLUSION STRATEGIES	CROSS-CUTTING STRATEGIES
INSTITUTIONAL AND STRUCTURAL BARRIERS • Insufficient priority and insufficient funding available for inclusive data collection and monitoring	*Planning and design do not consider persons with disabilities:* Sample design or eligibility rules exclude or underrepresent persons with disabilities Data cannot be disaggregated by disability status	Develop study designs to collect key data across all residential settings, including households and residential care facilities Ensure persons with disabilities are not excluded from enumeration	Ensure data is collected and used to inform improvements in inclusive practice
ATTITUDINAL BARRIERS • Negative attitudes about the capabilities of persons with disabilities	Measurement tools reflect ideas about disability that foster exclusion or stigmatization Persons with disabilities are not listed as household members due to stigma or shame	Use adequate data collection tools to allow for disaggregation according to disability status Intentional probing should be used by interviewers to encourage the disclosure of information about all household residents, including persons with disabilities	Engage with organizations comprised of persons with disabilities during all stages of data collection
COMMUNICATION BARRIERS • Lack of materials in accessible formats or the lack of sign language interpreters during data collection and dissemination of results	Persons with disabilities are excluded from data collection due to the lack of accommodation instruments and protocols Dissemination of results is not accessible to persons with disabilities	Adapt data collection protocols and adequately train fieldworkers to use such protocols Follow standards for inclusive dissemination of statistics, which can entail the production of materials for persons with vision, hearing and cognitive impairments	Empower persons with disabilities to become active stakeholders

Current disability data collection methods are hindered by several limitations, including exhibiting a narrow focus (Mont & Madans, 2023). Quantitative approaches tend to collapse disability into a single homogenous category, which can overlook risk factors and opportunities for targeted intervention (Mueller, Forber-Pratt, & Sriken, 2019). Identifying subgroups within the broad category of "disability" is challenging, necessitating caution about overinterpreting and overgeneralizing any group or subgroup (Breslin & Yee, 2024; Koo & Hudson, 2021; Mueller et al., 2019). Further exacerbating these limitations is the fact that disability data collection efforts often use inconsistent and problematic definitions of disability to begin with (Mueller et al., 2019). This is especially true when it comes to data specific to intellectual and developmental disabilities (I/DD) (Dhopeshwarkar, Jiménez, Ryan, Plourde, & Karimi, 2024; Landes & Turk, 2024). Additional limitations include small sample sizes and fixed question sets that are limited in length (Mont & Madans, 2023) as well as insufficient aggregation and disaggregation of disability data (Koo & Hudson, 2021). The data that is collected and data tools provided are often inaccessible to disabled people. This is due in part to limited engagement with the disability community (Koo & Hudson, 2021), arguably the most significant limitation in achieving equitable disability data collection.

DISABILITY, RACE & THE DATIFICATION OF SOCIETY

Despite contemporary strategies to address disability data barriers, it is vital to recognize the reverberance of historically racist, ageist, classist, and ableist social systems (Breslin & Yee, 2024; Genova, 2023). These regimes have perpetuated data injustices shaping power dynamics within our society's ongoing "datafication" influenced by long-standing social, political, economic, and cultural issues (Dencik, Hintz, Redden, & Treré, 2019; Gorman, 2024).

> *"Throughout its history, disability advocacy movements have shifted what counts as credible data on disability from deficit-focused statistics to qualitative and quantitative evidence of rights violations and social barriers, and this is the kind of data which is valuable for policy advocacy and human rights reporting" (Gorman, 2024, p. 34).*

This is of particular concern given the increasing role technology and artificial intelligence (AI) has been playing and the implications for disability programs and policies going forward. There is growing evidence of algorithmic bias and discrimination based on race and disability, as well as the use of data taken from minority communities, especially Black and Indigenous communities, without proper consent for the purpose of training AI models (Gorman, 2024; Moura, 2023).

> *"The threat of algorithmic bias to people with disabilities is inseparable from the longstanding role of technology as a normalizing agent, and from questions of how society defines shared values, quantifies ethics, conceptualizes and measures risk, and strives to allocate limited resources." (Moura, 2023)*

Technology acts as a normalizing agent, yet also serves as a mode of surveillance that disproportionately intrudes upon the rights of disabled people and people of color (Crooks, 2022; Hilton, 2017; Pucciarelli & May, 2023; Saltes, 2013). For these communities, notably where they intersect, data poses a double-edged sword given our country's history of colonial violence and the erasure, neglect, and exploitation that has occurred in the name of "research" counterposed against the power that comes with being counted (Gill & Erevelles, 2017; Gorman, 2024).

CRITICAL DEFINITIONS MAKING DISABILITY COUNT

Demographic disability data is "data about an individual's functional capacity that is maintained to a sufficient currency and with enough granularity and consistency to allow for both meeting the individual's accommodation needs and performing population health analyses that includes disability as a demographic characteristic" (Breslin & Yee, 2024, p. 10). We will critique this hyperfocus on functioning more later on in this letter.

Data equity is a set of principles and practices that guide the collection and reporting of data so that it is without bias or exclusion; an imperative for public administration (Landes & Turk, 2024; Whitebread, Dolamore, & Stern, 2023). The CDC Foundation has developed five principles specific to health data equity (Kristi Durazo, Mills, Sanchez, & Johnson II, 2024), whereas the Education-to-Workforce (E-W) framework has developed seven principles aimed at centering the lived experiences of diverse voices (E-W, 2024). While not generalized, these principles can provide a basis for the development of national disability data equity principles to drive the collection of disability data at the Federal, State, and Local levels of government:

CDC FOUNDATION DATA EQUITY PRINCIPLES	E-W FRAMEWORK DATA EQUITY PRINCIPLES
1. Recognize and define systemic factors	1. Restoring communities as data experts
2. Use equity-mindedness for language and action	2. Employing ethical behavior
3. Allow for cultural modification	3. Protect privacy
4. Create shared data agreement	4. Questioning default methods and assumptions for data collection and analysis
5. Facilitate data sovereignty	5. Identifying root causes of disparities
	6. Disaggregating data to help analyze disparities and guide action
	7. Promoting inclusion and awareness

Data justice is a critical aspect of disability justice. It is a social movement approach to the "analysis of data that pays particular attention to structural inequality, highlighting the unevenness of implications and experiences of data across different groups and communities in society" (Dencik et al., 2019, p. 875). It "focuses on the way digital information describes and/or erases marginalized and oppressed communities, and the way those communities access information" (Gorman, 2024, p. 30). Data justice has implications for developing data governance principles to address and make explicit the inequalities and power imbalances in data handling. It also advocates for justice in the design process through participatory practices that involve communities and build alternative infrastructures to center and empower marginalized groups (Dencik et al., 2019).

Disability data justice begins with a critique of all forms of data ableism and prioritizes the democratization of data and digital literacy from the perspective of diverse disability communities. Disability data justice insists on moving beyond mere access to information to the co-production of knowledge, community-based education, and social movement learning (Gorman, 2024). Swenor (2022) developed six recommendations for disability data justice in public health that serve as catalyst for development of disability justice principles beyond:

DISABILITY DATA JUSTICE IN PUBLIC HEALTH:

1. Disability data must be a core dimension of all demographic information.
2. The collection of disability data should be comprehensive and not limited to just "disability issues."
3. Public health must have a growth mindset about disability data.
4. Partnerships with the disability community are needed.
5. Data must be shared with and accessible to the disability community.
6. Diverse public health professionals are needed, including leaders with disabilities.

Data Ableism/Disablism refers to ableist assumptions and approaches to how knowledge is produced and information is accessed. This phenomenon, termed “digital ableism,” encapsulates the “’privileged digital ability expectations pertaining to data production,’ while ‘its flipside, data disablism, refers to the resulting forms of exclusion that are prevalent in automated societies… [and] the disabling marginalization resulting from the failure to meet such ability standards’” (Charitsis & Lehtiniemi , 2023, as cited in Gorman, 2024, p. 28). Moreover, it is critical to recognize the intersections of data ableism/disablism and race.

CRITIQUE OF FUNCTIONAL APPROACHES TO DISABILITY

There has been significant emphasis on defining disability through functioning/functional limitations, which dominates disability data practices. The World Health Organization (WHO) uses disability as an umbrella term and relies upon the International Classification of Functioning, Disability, and Health (ICF) framework to define and measure it. The ICF uses a biopsychosocial model of disability, which defines disability as a limitation in a functional domain that results from the interaction between an individual’s capacity and environmental and personal factors (Genova, 2023; Mont & Madans, 2023). Since the WHO endorsed the ICF in 2001 it has been the international standard (Genova, 2023). However, applying the ICF consistently across countries poses challenges due to contextual variations.

Another critical issue with the ICF is its complicated terminology and the subjective nature of its interpretation by assessors (Ptyushkin, Vidmar, Burger, Marinček, & Escorpizo, 2011). For instance, interpretation varies given that disability is compared to “normal functioning” (Genova, 2023). Additionally, only body functions are assessed, which poses the risk of undercounting psychiatric disabilities (Ptyushkin et al., 2011). It is also important to recognize that not all disabled people experience functional limitations. Ultimately, the ICF and defining disability solely through functioning/functional limitations does not recognize “the complexity of disabled populations” (Landes et al., 2024).

International disability data collection efforts, driven by the UN Convention on the Rights of Persons with Disabilities (CRPD) Article 31 on ‘statistics and data collection’ and the inclusion of disability in the Sustainable Development Goals (SDG), have deferred to the WHO’s reliance on the ICF. In particular, the Washington Group Short Set on Functioning (WG-SS) questions, which were developed based on the ICF framework and a focus on activity limitations. However, the creators of the WG-SS have been clear that there are only specific situations wherein this question set should be used and not all of these applications are appropriate (O’Reilly & Jagoe, 2024). Further, research conducted with disabled people of color found that participants felt the WG-SS questions did not address equity in intersectional ways (Gorman, 2024).

CRITIQUE OF THE DISABILITY QUESTION SET

In October 2023, the U.S. Census Bureau released a request for comments on proposed changes to the American Community Survey (ACS) from the existing set of six disability questions that have been used (ACS-6) to the WG-SS questions. The disability community responded in alarm as it has been established that while the ACS-6 already undercounts disability by 20%, the WG-SS would increase that undercount to 43% (Hall, Kurth, Ipsen, Myers, & Goddard, 2022). This was concerning given the impact of the COVID-19 pandemic as a mass-disabling event, and one that has disproportionately impacted low-income and minority communities. You can read CRDJ's public comment letter on this issue here.

In February 2024, the Census Bureau issued a press release in response to the comments they received stating that they would not be changing the questions at this time. That said, the disability question set does need to be improved, especially in a way that takes into consideration the concerns raised by the disability community. The issue remains in determining the best approach to improving these questions, an issue that goes hand-in-hand with the current RFI for information regarding disability data equity. Below is a list of current sources of demographic disability data and which question set they use (Breslin & Yee, 2024):

SOURCES OF DEMOGRAPHIC DISABILITY DATA

Data Type	Examples	Has Current Disability Questions	How Collected	Useable to Track Patient Accommodation	Useable for Health Disparity Analysis	Based on ACS-6, WGSS, or Another Option
Federal Census	Decennial Census of entire U.S. population	No	Mandatory to answer, data protected	No	No	ACS-6 data used in place of direct data
Federal Surveys (Population Samples)	American Community Survey, National Health Interview Survey, Behavioral Risk Factor Surveillance System, Healthcare Cost and Utilization Project	Some do	Mandatory to answer if chosen, data protected	No	Yes	Mostly ACS-6,25 though the National Health Interview Survey and a few others use WGSS
State Administered Surveys	California Health Interview Survey, New Jersey Behavioral Risk Factor Survey	Mostly No	Core questions mandatory, data protected	No	Yes	A mix
Administrative Data	Databases compiled from Medicaid & Medicare applications, claims and encounter data, and patient equity and quality data	Mostly No	Voluntary self-report, data protected	Maybe	Yes	ACS-6+ where disability is included
Healthcare Eligibility and Encounter Data	EHRs, Managed Care databases	Mostly No	Voluntary self-report, data protected if held by certain entities	Yes	Yes	ACS-6 + where disability is included

In this vein, we should be looking at how the Census Bureau invested time, energy, and funding to change their question set relating to race/ethnicity. This was accomplished by consolidating several questions on race and ethnicity into a single question to better reflect the ways people identify. The Census Bureau conducted extensive focus groups, interviews, and statistical testing of different question formats through the 2010 Alternative Questionnaire Experiment (AQE) and the 2015 National Content Test (NCT), intentionally oversampling communities of color. These efforts build on the history of Statistical Policy Directive No. 15: Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity (SPD 15). In March 2024, OMB published a set of revisions to SPD 15 following a process that began in June 2022 and involved reviewing over 20,000 comments and holding almost 100 listening sessions. Given the similarities between the problems associated with the race/ethnicity question set and the disability question set (i.e. an undercount that did not reflect how people actually identified), it seems the reasonable solution would be to follow the same process to update and improve the disability question set.

Landes et al. (2024) responded to the current RFI by proposing specific goals to this effect: Their immediate goal is to continue using the ACS-6 question set for now. The mid-range goal is to expand the ACS-6 to capture more disabled people. One possibility to improve this question set is to look at the Oregon Race, Ethnicity, Language, and Disability (REALD) initiative, which has gone beyond the ACS-6 and WG-SS to include nine self-identified disability questions (Breslin & Yee, 2024). The long-range goal is a three-step process to create new disability measures that will more accurately reflect the disability community starting with (1) conducting a consensus study to assist in developing new questions; (2) content testing potential new questions; and (3) including a "standardized disability measurement as a core demographic component across all federal surveys and data collection mechanisms" (Landes et al., 2024). These suggestions are conservative compared to the approach taken by the race/ethnicity question set, implying there is room for more extensive changes to the disability question set.

DISAGGREGATION ALONE IS NOT THE ANSWER

For decades advocates have been calling for self-identified disability demographic data to improve data equity, a change which could have saved countless lives during the COVID-19 pandemic (Breslin & Yee, 2024; Landes & Turk, 2024). To be clear, these lives are countless because we failed to count them.

Mueller et al. (2019) assert that oppressive systems must be named if we are to confront ableism and the violence it causes. Doing so necessitates centering the voices of disabled people and systematically and intentionally collecting disability data in all national efforts, especially when it comes to issues that have been neglected such as violence and violence prevention. Other gaps in Federal disability data collection include but are not limited to criminal justice, health care inequities, racial disparities, and the socio-economic toll of differing definitions of disability across Federal agencies (Koo & Hudson, 2021).

There can also be a mismatch between the data that is being collected and analyzed and the experts responsible for ensuring these processes, and how the data is actually being used and on-the-ground experts relying upon using this data in real-world applications; leading to situational and contextual errors in disability data use, particularly during times of crisis response (Rohman, Pitaloka, Erlina, Dang, & Prastyani, 2023). Regardless, the collection and disaggregation of data itself will not result in addressing equity concerns unless it is being utilized in day-to-day policymaking (Skempes, 2023).

There is a need to develop a disability data infrastructure, in particular one that is inclusive, collaborative, and centers intersectional data priorities (Gorman, 2024; Mont & Madans, 2023; Skempes, 2023; UNICEF, 2020). Most of the Federal data currently being collected homogenizes racialized experiences and fails to disaggregate disability by race/ethnicity and vice versa (Koo & Hudson, 2021). Disaggregation of data alone, however, will not achieve data equity. The underlying assumption is that data disaggregation will lead to more inclusive outcomes. However, disaggregation can result in too much focus being paid to generating statistics at the expense of tangible disability inclusion efforts – e.g. the mere generation of the number is seen as inclusion enough (O'Reilly & Jagoe, 2024). One method that would be useful here is prioritizing "quantitative intersectionality," which aims to reduce social inequity by representing the complexity of identities and oppression in public administration. This is done by examining intersectional relationships using quantitative methods; looking beyond single-dimension analysis to a three-dimensional matrix (see Whitebread et al., 2023).

RECOMMENDATIONS

1. Develop Disability Data Equity Standards & Principles

The purpose of this RFI is to create a Federal Agenda for Disability Data Equity. Doing so will necessitate establishing disability-centered standards and principles. Research has established a critical need for enhanced engagement with the disability community in this area, involving diverse disabled people at every step (Breslin & Yee, 2024; Koo & Hudson, 2021). This must start with the development of these standards and principles. Also ensuring sustainable progress in disability data moving forward requires coordination and alignment of these standards and principles in disability data equity between Federal, State, and Local governments so that equitable comparisons can be made cross-scale.

Developing *National Disability Data Equity Standards* must begin by addressing the problems associated with differing definitions of disability and the disability question set (addressed in more detail below). Standards should also include those specific to disaggregation of data collected using the same definition of disability and disability question set (Mont & Madans, 2023). Additionally, we need to be able to disaggregate not just by disability, but also by race/ethnicity, sex/gender, LGBTGIA+ status, etc. Equity cannot be achieved if the disparities are not identified. Disaggregation is a powerful tool in accomplishing this. Disability data also needs to be significantly better centralized, more transparent, and more easily publicly available. There must be a comprehensive effort to make all data and data tools, not just those specific to disability, accessible and easy to use/understand – ensuring equitable access (Breslin & Yee, 2024; Koo & Hudson, 2021). This will necessitate that all data and data tools comply with WC3 Accessibility Guidelines as well as Federal Plain Language Guidelines, all of which are vastly overdue.

With regards to developing *National Disability Data Equity Principles*, the CDC Foundation and E-W Framework's principles provide a strong starting place. We do not recommend developing a set of principles using listening sessions, as this is not the appropriate method to be effective. Rather, we recommend using the Delphi method with focus groups of various stakeholders that are diverse, utilizing heterogenous sampling and oversampling disabled people so that they comprise a majority (at least 51%) of the stakeholders in each group.

2. Equity Must Address Intersectionality

Disability data equity must include intersectional data and analyses, especially looking at interactions between race/ethnicity and disability (Mueller et al., 2019). This approach is crucial given the compounded historical underrepresentation of HTC populations and a history of disproportionate bias and discrimination. We must identify imperative comparisons, not just interesting ones, and do so by leaning on feedback from advocacy groups and the public (Whitebread et al., 2023). That said, disaggregation alone will not be enough to address intersectional equity needs as bias begins with the very definition of disability, the development of measures, and the collection of data determining who is or is not counted. There is also bias in who is doing the research and how data is being analyzed, knowledge translated, and disseminated (discussed in more depth below). It is not just about who is counted, but also who is doing the counting and how they are being counted. This must be accomplished through centering disability data justice in every step of this process.

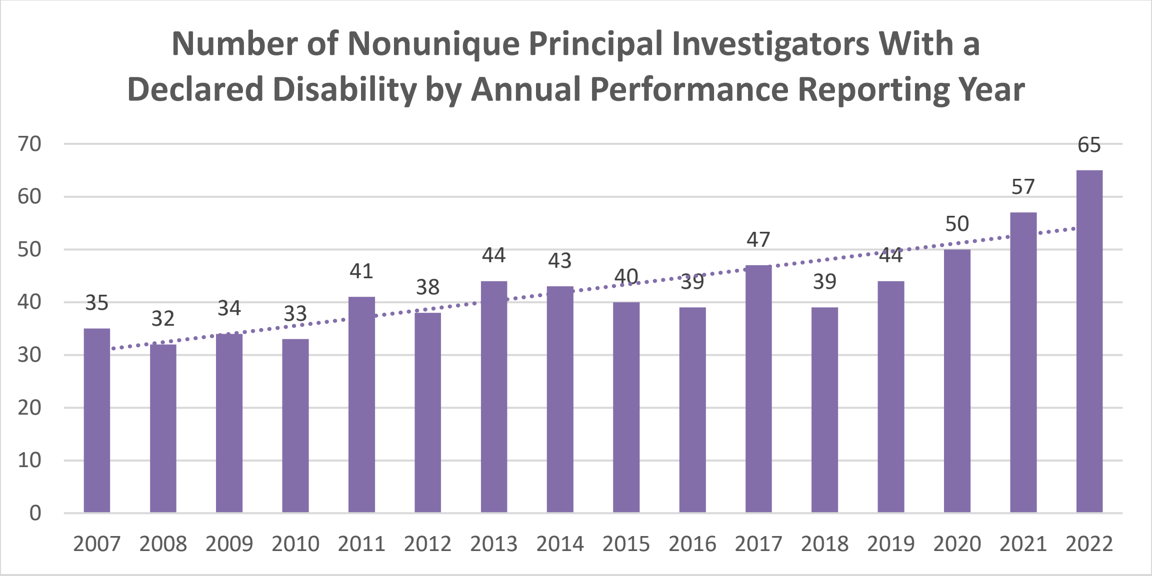
One glaring issue herein is the focus of data on “civilian noninstitutional populations” and subsequent exclusion of those in institutional settings. It is important to recognize that those in institutional settings, who are disproportionately disabled, people of color, and disabled people of color, are often overlooked. For this Agenda to genuinely achieve disability data equity, it must reckon with how to ethically and responsibly include this population moving forward. If it fails to do so, then this effort will forever have an asterisk next to its name.

Finally, while it is pivotal to continue (and start in some cases) single-dimension and qualitative analyses, these must be supplemented with multi-dimensional quantitative intersectional analyses in order to adequately address gaps, increase equity, and maximize efficiency (Whitebread et al., 2023).

3. Invest in Disabled Researchers

Likewise in response to E.O. 13985, the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) published a final rule in August 2022 that updates 45 CFR part 1330. This update aims to promote the hiring of disabled people and other underserved/underrepresented populations among "project staff" for entities applying for Federal grants.

The NIDILRR Long Range Plan 2024-2028 states that they have “increased emphasis on inclusion of people with disabilities in all aspects of the disability, independent living, and rehabilitation research enterprise.” NIDILRR claims these efforts have led to a higher prevalence of “investigators and staff with disabilities involved in NIDILRR-sponsored research” and show the chart below of the increasing number of Principal Investigators (PI) with disabilities:



While it is true that this trend has been increasing significantly ($r^2 = 0.71$), it is notable that the mean number of disabled PIs is 42.56 with a standard deviation of 8.59. In 2022, only 15% of grants were being led by a disabled PI and 28% of staff between 2018-2022. Among National Institutes of Health (NIH) PIs, the numbers are even lower, showing a downward trend from 2% reporting a disability in 2008 to 1.3% in 2022 ($p<0.001$) for both grant applicants and grant awardees (Lauer, 2022; Swenor, Munoz, & Meeks, 2020). This is far below the national prevalence of disability, calculated at 27% by the CDC. Overall, they found that grant success rates differed by disability status as well as by disability type, with applications and awards among those with visual impairments lower than those with mobility/orthopedic or hearing disabilities (Swenor et al., 2020).

In reality, members of our Center have experienced being added to and contributing to Federal grant applications to increase its disability representation, only to later be summarily removed for no discernable reason. There is currently no mechanism in place to track these occurrences nor hold accountable those who exploit these data and procedural loopholes. Universities and research institutions are no better when it comes to reports of stigma, bias, discrimination, and harassment on the basis of disability.

> *"Despite being the largest minority in the nation, disabled people like us have been structurally and institutionally obstructed from entering research-dominated fields. When they do manage to break through, they are seldom given the support and accommodations needed to sustain employment and thrive in their professional lives." (Weaver & Jackson, 2024)*

While there are several articles addressing the methodological and ethical issues that present with non-disabled and disabled people doing disability research (Kitchin, 2000; Stone & Priestley, 1996; Tregaskis & Goodley, 2005), there is a lack of research and data specifically looking at the experiences of disabled researchers in academia. This is especially true for disabled researchers at the intersection of multiply marginalized identity categories. This has never been more vital than now, at a time when legislatures and educational institutions are plagued with anti-diversity-equity-and-inclusion Bills (Weaver & Jackson, 2024) and lawsuits that erode DEI programming and target scholars that are disabled, women and gender non-conforming, people of color, and/or LGBTQIA+. This is only the tip of a very large iceberg.

We know that disabled researchers are underrepresented in academia, encountering endless systemic barriers in educational institutions wherein their employment relies on their ability to compete for grants, perform, and publish or perish – often without equitable supports, resources, or accommodations (Castro et al., 2024). Investing in disabled researchers must be an integral part of a Federal Disability Data Equity Agenda.

4. Develop New Measures & Methods, Not Adapt Ableist Ones

Recommendations from the literature center around a call to build on what has already been done in the U.S. and internationally (Breslin & Yee, 2024). This includes moving beyond overly-reductionist and problematic functional models of disability, which fail to accurately measure disability, towards measures that draw upon a human rights model (Mont & Madans, 2023) and/or allow for self-identification (Breslin & Yee, 2024).

The concern is that undercounting disability will continue to impact services and resources for the disability community. There is also a fear, particularly in the wake of the pandemic as a mass-disabling event, that policymakers may use further undercounting to cut funding to programs disabled people rely upon. This would make it harder to ensure disabled people have equitable access to housing, health care, education, employment, emergency and disaster response, etc. It would also serve to skew government statistics and make it more difficult to do accurate research in these areas.

At the very least, the suggestions made by Landes et al. (2024) should be followed as they are methodologically reasonable and ethically responsible. Clearly, what is needed is a concise set of shared questions integrated into data tools (Mont & Madans, 2023) that has evaluation baked in, especially for granular information on intersecting marginalized identities. Further, this evaluation should incorporate feedback loops to help refine questions, especially for race/ethnicity and other marginalized identity categories (Breslin & Yee, 2024). How to accomplish this feat need not be overcomplicated as there is already precedent to draw upon. Oregon's REALD initiative, for instance, uses existing functional-focused measures with self-identification. While it is unclear at this juncture whether it can or should be used as is, it can serve as a starting point for developing a disability question set that allows for self-identification of disability status that is more in line with human rights approaches. Regardless, the method for updating the disability question set should follow the method used to update the questions relating to race/ethnicity. Not doing so sends the message to the disability community that their lives and livelihoods simply do not count.

CONCLUSION

Addressing the profound inequities faced by the disability community demands a bold and comprehensive data equity agenda. Our recommendations underscore the urgent need to establish National Disability Data Equity Standards & Principles that ensure data collection and analysis are disability-centered, coordinated and aligned between different levels of government, and ensure disability data is better centralized, disaggregated, transparent, publicly available, and accessible. Recognizing the intersectional nature of disability data is essential for capturing multifaceted experiences within this community. This can be accomplished by engaging a diverse disability community in every step of the process, finding ways to include data for institutionalized persons, and supplementing data with multi-dimensional quantitative intersectional analyses. By prioritizing investments in disabled researchers to address bias, discrimination, and structural barriers, we can ensure that data is interpreted and applied in ways that authentically reflect the needs and insights of those it represents. Moreover, it is crucial to innovate and develop new measures and methods that are not merely adapted from ableist frameworks but are specifically designed to address the unique experiences of disabled individuals. These transformative steps are vital to fostering a more equitable and just society for all. Thank you for considering our recommendations.

If you have any questions, please feel free to contact Dr. Kate Caldwell at kcaldwell@law.northwestern.edu.

Sincerely,

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CC: ICDR Subcommittee on Disability Statistics (SDS) c/o

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