Research Square

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Adults with NDDs as Research Participants: A Cross-Sectional Survey of Researcher Knowledge, Attitudes, and Perceptions

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Abstract

Background: The focus on NDDs as a pediatric concern leaves a gap in evidence-based care for their aging-related health needs in adulthood. This gap is compounded because their health outcomes are worse than for people with disabilities (PWDs) overall. The causal chain for the near-universal absence of persons with NDDs from research originates with researchers. We present initial findings from our Disability as Difference: Reducing Researcher Roadblocks study, which surveyed research teams' knowledge, attitudes (implicit and explicit), and perceptions about NDDs and research engagement, assessed the psychometrics of novel measures, and piloted an exploratory implicit association test (IAT).

Methods: A convenience sample (n=118) of researchers who primarily studied non-disabled adults completed online measures of: Knowledge-10 novel multiple-choice items on NDD definitions, prevalence, etiquette, etc.; Attitudes (explicit & implicit) - a validated (2006) explicit measure toward PWDs, and a novel keystroke-based implicit association tool pairing 5 NDD stimuli terms with positive/negative attributes; and Perceptions- novel 5-point Likert items spanning Awareness, Desire, Knowledge, Ability, and Reinforcement, per Prosci's ADKAR® model of change. We report descriptive statistics, Cronbach alphas to assess subscale reliability, and bivariate correlations between total and subscale scores.

Results: Factual knowledge was relatively high (73.7% correct). ADKAR subscale alphas ranged from .71 to .90, supporting their reliability. Just under a third of researchers reported high/very high knowledge and ability on the pragmatics of engaging people with NDDs (adapting consents, modifying protocols, minimizing risk, justifying study exclusions), underscoring knowledge and ability as key barriers. Conversely, structural reinforcements were viewed as stronger facilitators: a majority of researchers reported high/very high impact for funder mandates (70%), IRB expectations (53%) and journal policies (52%). The pilot NDD IAT revealed no preference for people with vs. without NDDs (mean 6.16 vs. 3.77), in contrast to strong pro-abled preference on an established physical-disability IAT. General disability attitude data were uninterpretable.

Conclusions: Findings indicate need for practical tools and guidance for researchers and IRB staff, paired with structural mandates from funders, IRBs, and journals. Meaningful change will require multiple strategies (e.g., education, practical guidance, policy) across individual, institutional, and regulatory levels, guided by implementation science and change management principles.

Terminology- The majority of developmental disabilities (DDs) are neurodevelopmental in origin, reflecting disruptions in early brain development that persist across the lifespan.[1] We use the term NDD, unless DDs are specifically referred to.

Introduction

The National Institutes of Health (NIH) formally designed people with disabilities (PWDs) as a population with health disparities in 2023, citing evidence of poorer health outcomes, greater disease burden, and reduced access to quality care.[2-5] While »27% of US adults report a disability,[6] only »5% of NIH-funded relates to disability.[7] This misalignment yields inadequate evidence to inform clinical management, perpetuating disproportionately suboptimal healthcare and outcomes of care.[8] Structural barriers, e.g., inaccessible testing environments, lack of multi-format materials, and transportation compound experiences of stigma and ableism.[2-4] and a legacy of unethical treatment in research that fuels wariness and reluctance to participate.[9-13] [Ableism refers to beliefs and practices that positions a particular kind of body and mind as normative, casting disability as a diminished or lesser state of being human.[14]] Still, the most pervasive barrier to PWD participation in research remains broad and poorly justified study exclusion criteria,[15] driven by negative attitudes towards certain groups, unexamined assumptions about risk, vulnerability, and consent capacity.[8,16,17] For example, eligibility criteria for 60% of clinical trials across the 10 leading causes of disability-adjusted life-years (n = 2,710 trials) exclude PWDs.[17]

Individuals with neurodevelopmental disabilities (NDDs) experience even poorer health and worse outcomes than PWDs broadly,[18-26] and a near universal absence from research on common conditions such as diabetes, gastrointestinal disease, heart disease, and Alzheimer's/dementia.[9,16,27,28] As an example, individuals with Down syndrome face a 90% lifetime Alzheimer's risk[29] yet ClinicalTrials.gov lists only two interventional trials targeting them[30] despite Alzheimer's ranking among the top NIH-funded diseases.[31] Individuals with NDDs are disproportionately impacted by the "protection vs. participation" dilemma: Institutional review boards are instructed to apply "additional safeguards" to *protect* persons with "impaired decision-making capacity," while emphasizing the importance of increasing the *participation* of groups under-engaged in research. In practice however, systematically leaving persons with intellectual and related NDDs out of research has become the default safeguard.[32,33]

Adults with NDDs are especially impacted. There is a "striking paucity of research" on disease progression in this population.[34] Among adults in the United States (US), DD prevalence is »1%-8% depending upon definition;[35] intellectual disability (ID) prevalence is »1%.[36] Yet NDDs are often framed as pediatric concerns, even as lifespans increase.[20,37] The inaugural *NIH Strategic Plan for Disability Health Research: FY 2026-2030*, explicitly cites the intersection of (general) disability health research with aging, mental health, and chronic conditions[38] A recent paper's title- *Where Do Neurodevelopmental Disorders Go? Casting the Eye Away from Childhood towards Adulthood*?-[39] reflects how consistently overlooked adults with NDDs remain. A disability advocate living with cerebral palsy and spastic quadriplegia describes her fears about the consequences of this exclusion:

"As a research population as a whole, we are never mentioned publicly and it's not right. When it comes to disability and aging, I'm just concerned when it comes to things like cancer research or joint replacement that we may be overlooked as not a viable population in situations that may extend our lives. (D Lanzetta)" [40]

Her words emblematize the inaugural NIH Strategic Plan for Disability Health Research's four cross-cutting themes for disability health research: whole-person health ("centers the *person*, not the *disability*"), inclusion of PWDs in research, interdisciplinary collaboration, and technology. While the causal chain

of not engaging with disability begins long before enrollment and involves multiple stakeholders, *researchers* are the ones who initiate the research lifecycle via ideation of a hypothesis or question. Yet, little is known about their knowledge, attitudes, biases and perceptions regarding disability health. To address this gap, our Disability as Difference: Reducing Researcher Roadblocks (D2/R3) study: 1) measured researcher knowledge, attitudes and perceptions about the health and engagement of adults with NDD in research (Aim 1); 2) engaged adults with NDDs and researchers in dialogue sessions to co-create an eLearning module (Aim 2); and 3) conducted an RCT of the module's efficacy (Aim 3).

D2/R3 focuses on adults with NDDs-- a population whose childhood onset, lifelong impact, and often non-visible features challenge the common heuristic of disability as an age-acquired motor impairment. Their heterogeneity and varying functional impacts make any findings grounded in NDDs more likely to generalize to PWDs broadly than vice versa, strengthening cross-disability reach.

Our Aim 1 activities of D2/R3 advance the field in several ways. First, they extend studies of on clinician attitudes towards persons with NDDs, to researcher knowledge, attitudes and perceptions of NDDs and their participation in research. Second, we developed novel Perception items grounded in a change management framework. Third, we created an exploratory implicit association test (IAT) to measure implicit attitudes towards individuals with NDDs. This paper reports on these three components.

Human Ethics and Consent to Participate- This study was approved by the Office of Human Research Affairs and its institutional review board of Albert Einstein College of Medicine-Montefiore Medical Center. Every human participant provided their consent. This Office is guided by the principles set forth in the Ethical Principles and Guidelines for the Protection of Human Subjects of Research (often referred to as the Belmont Report).

Clinical trial number: not applicable.

Positionality- The authorship team brings experience of disability, including NDDs, through personal experience, caregiving, and advocacy.

Methods

Aims. The present study reports Aim 1 findings, which were designed to generate foundational data and measures for subsequent D2/R3 phases. Specifically, this study's aims were to: 1) measure researcher knowledge, attitudes, and perceptions regarding engaging adults with NDDs in research; 2) develop and assess the psychometric properties of novel Perception items mapped to Prosci's ADKAR® model of change;[41] and 3) evaluate the feasibility of an exploratory NDD-oriented IAT.

Design/Data Collection- This was a cross-sectional convenience sample, with an initial target sample size of n= 200. Prospective participants accessed a REDCap-based eligibility screener, consent and survey via a QR code or link.

Setting. Our site's CTSA program partnered with 9 US institutions each hosting a CTSA, Intellectual and Developmental Disabilities Research Center (IDDRC) for basic/clinical research, and University Center for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD) programs. Prior interviews with leaders of these programs informed the survey items reported here.[42]

Recruitment- From October 2024–February 2025, institutional partners and additional CTSA programs recruited via email, flyers, and online presentations. Eligibility criteria were a) conduct of human subjects' research in past 3 years, b) as an investigator, research assistant, study coordinator, interventionist, etc., c) for common health conditions (e.g., diabetes, heart disease, gastro-intestinal conditions), d) in general adult (vs. disability-specific) populations.

Measures- The study sample's background, research practices and their knowledge, attitudes, and perceptions outcome measures are described below.

Background and Research Practices: We collected basic demographics, along with data onaccommodations, participant engagement, and eligibility criteria of their studies.

Knowledge: We created this 10-item multiple-choice measure with a scoring range of 0%–100%. During co-design sessions with our site's UCEDD Self-Advocate group (adults with DD), we developed several vignette-based items about recruitment. Other items addressed the definition and prevalence of NDD, disability etiquette, and common misconceptions (e.g., among all persons with intellectual disability [ID], the percentage with mild vs. moderate, severe, or profound ID).

Attitudes (Explicit): As a generalized measure of attitudes toward PWDs, we used the Attitudes to Disability Scale (ADS), created by a WHO working group in consultation with persons with physical and intellectual disabilities. Its 16 items factor into 4 subscales representing aspects of disability: Inclusion, Discrimination, Prospects, and Gains. Items are scored on a 3-point scale (Disagree [1], Uncertain [2], Agree [3]). The publication reporting the ADS's derivation and psychometrics provides no guidance on scoring (e.g., reverse-scoring) or on interpreting total or subscale scores as reflecting more vs. less positive attitudes toward PWDs, though it describes the "Gains" subscale as having "an explicitly positive focus.[43] The ADS has been used in general population and workplace settings, and with caregivers and persons with physical disabilities.

Attitudes (Implicit): Implicit Association Tests (IATs) measure implicit attitudes via response times to concept-evaluation pairings (e.g., disability/good or bad) and are less prone to social desirability effects than self-reported explicit measures.[44-47]Existing disability IATs remain narrow in scope; the most widely used, from Project Implicit (https://implicit.harvard.edu/implicit/takeatest.html), addresses only physical disability, while others target physical disability, intellectual disability (a subset of NDDs), or specific conditions. [48,49] Because 75% of disabilities, including most NDDs, are non-visible,[50] we used words rather than images as stimuli, which required a multi-step process to identify terms that were both intuitive and of neutral valence. Candidate terms were first generated through literature and AI platform searches, then reviewed by a self-advocacy group of adults with NDDs, our D2/R3 and UCEDD teams, and

parents of children and young adults with NDDs. This process yielded 14 terms, which CTSA members (n=35) rated for intuitiveness (high) and valence (neutral) on a 7-point scale, producing five final stimuli: *autism, impairment, learning disability, neurodivergent, and special needs*.

Participants were randomized to complete either the established Project Implicit IAT, or our exploratory IAT. Both were scored by MinnoJS, an open-source Javascript library developed by Project Implicit using default timing cutoffs and criteria per Greenwald et al.[51] To reduce participant fatigue, we used the brief IAT format, which has 1/3 the number of trials of the standard IAT Scoring yields seven categories ranging from strong preference for people with disabilities (Category 1) through moderate (2) and slight/weak (3) preference, to no preference at the midpoint (Category 4), then slight/weak (5) and moderate (6) preference for abled persons, to strong preference for abled persons (Category 7). For sorting categories, both IATs used the terminology "abled person" and "disabled person." The physical disability IAT used twelve images of ability and disability as stimuli.

Perceptions: To our knowledge, no validated instrument existed to assess researcher perceptions of including people with NDDs, or disability more generally, in research. We developed a novel 17-item survey grounded in the literature,[8,16,52,53] interviews with CTSA and UCEDD program leaders,[42] and input from nine partnering institutions. Items were mapped to D2/R3's conceptual framework, which applied the five components of Prosci's ADKAR® model of change management,[41] to researcher behavior:

1. ***Awareness***- understanding of need for change (e.g., health differentials of PWD/IDDs; 1 item)
2. ***Desire***- motivation to support /enact change (e.g., modify consent process; 2 items)
3. ***Knowledge***- of how to change (e.g., universal design, plain language; 4 items)
4. ***Ability***- to apply new skills and behaviors (e.g., training, funds for extra time; 4 items)
5. ***Reinforcement***- to sustain change (e.g., funder mandates disability inclusion plan; 6 items)

Perception items were scored from "1" (e.g., very low, never) to "5" (e.g., very high, always). Higher scores represented more positive views or attributes (e.g., greater desire or ability) or greater impact of reinforcing policies.

Statistical Analyses

Descriptive statistics, including means (sd) or percentages for each item, were calculated and examined using R statistical software. Ordinal scales (e.g., very low to very high) were converted to numeric equivalents (e.g., 1-5) to compute descriptive statistics. Multi-item constructs were consolidated into composite scores by averaging constituent items. To assess the Perception ADKAR subscales' reliability and internal consistency, we calculated Cronbach alphas, Missing values were imputed using item-level means. Bivariate correlations among study variables were computed using R's *psych* package [54] to examine associations across constructs. To simplify presentations, 5-point Likert scaled items were consolidated into 3 categories.

Results

Demographics: We excluded 75 respondents for not fully completing >= of either the Knowledge, Attitudes or Perception measures, yielding an analytic sample of n=118). Few in this predominantly female (n= 85, 72%), sample reported a disability (n= 15, 12.7%) and a plurality were investigator (n= 48, 40.7%). On the Knowledge survey, 73.7% of items were answered correctly. Attitudes (*explicit*) subscale scores ranged from 1.13-2.58. The mean physical disability IAT score [i.e., Attitudes (*implicit*)] was markedly higher than the mean NDD IAT score (6.16 vs. 3.77). [see Table 1, next page].

Research Practices. Plain language was the most frequent accommodation (86% often /always), compared with text-to-speech (14%) and large print (26%). Participants were rarely engaged to develop research topics or analyze findings; only 26% and 30%, respectively, did so often /always. Mobility, hearing, and visual disabilities rarely prompted exclusion, compared to cognitive (68%), speech/communication (56%), or psychiatric disability (45%). [Figure 1, below]

Aim 1: Perceptions (ADKAR)

Awareness of health and research gaps among PWDs and persons with NDDs was modest, 42% "high" or ""very high" (hereafter "high"). *Desire* to change protocols to engage this population was greater than the desire to consider them during study conceptualization/design, 67% vs. 49%, respectively. *Knowledge* and *Ability* were uniformly low in terms of adapting consents, modifying protocols, justifying/narrowing study exclusions, and minimizing excess risks in this population (range 22%-33% "high'). In contrast, Reinforcement strategies were perceived as impactful: funder (70%), IRB (53%), and journal (52%) disability data mandates would highly impact on study designs and protocols. [Figure 2, next page]

Aim 2: Psychometrics of Novel Knowledge and Perception Measures; Exploratory IAT

We report zero-order correlations and Cronbach alphas for multi-domain measures.[Table 2, next page] On the Knowledge and Perceptions measures higher scores signify greater knowledge and "ADKAR," respectively, about people with NDDs and inclusion , i.e., more positive. In contrast, higher scores on the IATs signify more negative implicit attitudes towards PWDs. Interpretation of ADS subscales, aside from Prospects, is more complicated (see Discussion).

Knowledge-. On the novel Knowledge (about NDDs) measure, higher scores correlated with having less negative implicit attitudes on the Physical Disability IAT (r= -0.36, p<.01) and more positive explicit attitudes towards PWDs future potential on the ADS Prospects scale (r= -0.66, p < .01). Knowledge was not correlated with any of the Perception ADKAR items.

Perceptions- Cronbach alphas for the Knowledge, Ability, and Reinforcement components ranged from .71 (acceptable) to .90 (excellent).[55] Correlation for the Desire component was lower (0.54), likely because it included just two items. These findings support consolidating each component's items into a single construct. Except for Reinforcement, the ADKAR constructs largely correlated with each other (Rs = .21-.61), affirming a structure in which perceptions of

change tend to co-occur. The ADKAR and ADS Prospects scores were negatively correlated; greater perceived ability and predisposition toward engaging PWDs in research corresponded to less pessimistic attitudes about PWDs futures, supporting convergent validity between our novel Perceptions measure and the established ADS subscale.

Aim 3: Feasibility of NDD Oriented IAT

Randomization yielded comparable numbers of physical disability (n= 57) and NDD (n= 61) IAT respondents. Higher scores for both IATs reflect stronger preference for able (vs. disabled) people. Both IATs had significant low-moderate correlations with the ADS Prospects scale, 0.28 ($p<.05$) and 0.30 ($p<.05$), respectively, indicative of more ableism. The NDD IAT score was negatively correlated with the Perception "Awareness" item, indicating that greater awareness of health disparities among people with NDDs is associated with more favorable implicit attitudes toward them.

Discussion

With adults with NDDs living longer and in greater numbers, [20,37 56-58] closing the research gap on the chronic conditions of aging, e.g., diabetes, heart disease, dementia that increasingly affect them is urgent.[9,16,27,28] Here we report on researcher KAP regarding participation of adults with NDDs in research, the psychometrics of novel Perception items mapped to Prosci's ADKAR® model of change,[45] and our exploratory NDD-oriented IAT. Researchers demonstrated moderate general Knowledge about NDDs and relatively strong but limited capacity to implement inclusive practices. We examined funder, institutional review board and journal mandates as potential levers for engagement; funder mandates were perceived as the strongest reinforcement ("R" in ADKAR). Finally, our team successfully created and piloted the NDD-oriented IAT.

Researchers answered nearly three-quarters of the brief knowledge measure correctly. Greater knowledge was associated with less *explicitly* negative expectations about PWDs' futures ($r = -0.66$ with ADS Prospects), and lower *implicit* negative attitudes toward physical disability ($r= -0.36$ with IAT). Contact and experience with PWDs is linked to greater knowledge about disability and reduced negative attitudes towards PWDs.[48,59,60] Similarly, in a qualitative study of researchers, one participant described how experience builds comfort with engaging PWDs over time: "once you've got your head around it... it's relatively easy for me, whereas for a researcher who's maybe doing this for the first time, it's not so much."[61] Yet, this same knowledge measure was unrelated to researchers' perceived ability to implement participatory research practices, highlighting the classic "know-do-gap" in health.[62,63] Likewise, a study of investigator and research team training needs found broad recognition of the importance of varied participant backgrounds in the abstract, but far less prioritization or implementation of this in practice.[64]

The ADKAR findings reinforce the above-cited "know-do" gap and affirm the utility of specific leverage points. Just under a third of researchers reported "high/very high" knowledge and ability on the pragmatics of engaging PWDs (adapting consent, modifying protocols, minimizing risk, and justifying study exclusions), underscoring knowledge and ability as key barriers. Conversely, structural reinforcements were viewed as relatively strong facilitators; a majority of researchers reported high/very high impact for funder mandates (70%), IRB expectations (53%), journal policies (52%), and NIH designation (45%). This asymmetry is instructive: researchers' perceived capacity lags behind what external structures could compel them to do. Education can raise awareness and desire- but won't close the gap without structural reinforcements that make accommodating practices the default, not the exception. In a study of researchers navigating consent for adults who lack capacity, one participant described the process as "it feels like just an insurmountable black box of horrendousness that I dare not go into... if you get this wrong you will be illegal... So, we just try and avoid it."[61] This reluctance echoes broader findings: in a recent Canadian study, nearly 80% of (non-medical) researchers reported being deterred from undertaking research, even minimal-risk research, by IRB processes.[65]

Adults with NDDs are disproportionately impacted when excluding them becomes the "additional safeguard" applied to protect individuals *perceived* to lack consent capacity.[32,33] Too often, lack of competency is presumed, regardless of individual capacity.[66] Precise data on the proportion of adults with DD (let alone NDDs) who have ID are lacking. Among children, 7%[67] to 16%[68] of those with DD are estimated to have an ID and since 85% of ID is mild,[69] roughly 12% (the pediatric midpoint) × 15% (the non-mild share of ID presumed unable to consent) = 1.8% of adults with NDD would lack decisional capacity. This gap between presumed and actual incapacity is precisely the kind of unfair selection the Belmont Report's principle of Justice was designed to guard against: just as respect for persons underlies consent and beneficence underlies risk/benefit assessment, Justice requires fair procedures and outcomes in the selection of research subjects.[70] On this point, no mandate exists for leaving PWDs out of NIH research absent a compelling reason, as it does for women, children and other groups.[71,72]

Our findings on researcher practices- eligibility criteria, accommodations, and engagement- align with prior studies. Our sample rated adults with cognitive, communication, and psychiatric disabilities as more likely to be excluded from their studies than those with mobility, hearing, or visual disabilities (Figure 1c), consistent with both quantitative analyses of clinical trial exclusions.[16,17] and qualitative research on researcher decision-making.[62] That qualitative work found researchers tended to offer accommodations reactively, rather than proactively.[64] Likewise, our sample more often reported "in-the-moment" accommodations (e.g., extra time, read aloud) than prepared materials or technology (e.g., large print, text-to-speech). Plain language was the most frequently offered accommodation overall, though whether this reflects written or verbal practice is unclear.

Our team successfully piloted the selection of stimuli terms, design and implementation of an exploratory measure of implicit attitudes towards persons with NDDs. In contrast to strong preferences for (physically) abled persons on an established IAT, our pilot IAT revealed no preference for people with vs. without NDDs (mean 6.16 vs. 3.77; range 1-7). Both IATs correlated with ADS Prospects scores, suggesting convergent validity across explicit and implicit measures. Subsesquent to our study, Project Implicit and Special Olympics initiated a collaboration on an IAT to measure associations between IDD related concepts

(e.g. “Developmental Delay”, “Typical Development”) and positive or negative evaluations (e.g., “Worthy”, “Incompetent”). (see LINK). Clearly, the Project Implicit–Special Olympics collaboration brings substantial expertise and resources to IDD-specific IAT development Our team successfully piloted the selection of stimuli terms, design and implementation of an exploratory measure of implicit attitudes towards persons with NDDs. In contrast to strong preferences for (physically) abled persons on an established IAT, our pilot IAT revealed no preference for people with vs. without NDDs (mean 6.16 vs. 3.77; range 1-7). Both IATs correlated with ADS Prospects scores, suggesting convergent validity across explicit and implicit measures. Subsesquent to our study, Project Implicit and Special Olympics initiated a collaboration on an IAT to measure associations between IDD related concepts (e.g. “Developmental Delay”, “Typical Development”) and positive or negative evaluations (e.g., “Worthy”, “Incompetent”). (see LINK). Clearly, the Project Implicit–Special Olympics collaboration brings substantial expertise and resources to IDD-specific IAT development. **We hope to build on the experience gained through our pilot to develop a similarly rigorous, but more holistic, IAT, that** spans the range of disabilities seen in adult clinical practice, using the term-selection and validation methodology reported here as a foundation.

The ADS findings warrant interpretive caution. We considered several attitude surveys[73] before selecting the ADS for its iterative design inclusive of persons with physical and intellectual disabilities, strong psychometrics, brevity, and cross-population use.[74-77] Yet the original publication offers no scoring guidance,[47] and its subscales are not easily interpretable as reflecting more vs. less ableism. To illustrate, all seven co-authors rated each subscale as "ableist," "mixed/unclear," or "able to include," masked to one another’s ratings. Only Prospects achieved a clear consensus, with 7/7 rating it ableist (e.g., "PWDs shouldn't be optimistic about their future") compared with “mixed/unclear” ratings on the Gains (3/7), Inclusion (4/7) and Discrimination (7/7) subscales (supplementary material). The Gains subscale also raises a question: higher scores on it reflect greater endorsement of compensatory disability attributes (i.e., PWDS as “stronger,” “more determined”), a framing some now consider benevolent ableism, embedding objectification and paternalism in ostensibly positive narratives.[78,79] These interpretive challenges are compounded by the scale's age: as explicit negative attitudes toward physical disability declined 37% from 2007–2020, while implicit attitudes remained stable[80] and moderately negative,[48] questions arise about the continued relevance of a scale published in 2010. .

This study has several strengths: novelty, measures co-developed with self-advocates and disability experts, and application of the multi-dimensional ADKAR change management framework that directly informed creation of the D2/R3 eLearning module. Our study is also timely: PWDs were designated a health differentials population in 2023,[4] the National Council on Disability reported on PWDs exclusion from research in 2024,[15] and the NIH issued its inaugural strategic plan for disability health in 2026.[38] Together, this trajectory, from federal recognition of disability as a health gap for PWDs, to documentation of PWDs' exclusion from research, to a national strategic plan for disability health, signals growing federal momentum toward supporting research for and with PWDs, against which our findings offer timely, actionable baseline data. Key limitations include its cross-sectional design, convenience sampling from CTSA-affiliated institutions (which may bias towards disability inclusion), and the novelty of our Knowledge and Perceptions “ADKAR” measures, which nonetheless were shown to perform acceptably from a psychometric perspective.

Conclusion

The prevailing focus on NDDs as a pediatric concern[20,37] leaves a gap in evidence-based care, as rising numbers of children with NDDs have transitioned to adulthood over the past decades. Future research must broaden knowledge, characterize the course of NDDs across the lifespan, and clarify patterns of aging-related concerns in adults with an NDD.[39] Prevention efforts for chronic health conditions must encompass, and be evidence-based within the NDD and broader disability communities. [26] Our findings point to the need for practical tools and guidance for researchers and IRB staff, paired with structural mandates from funders, IRBs, and journals. IRB accreditation-body membership, for example, was identified as a particularly strong lever in an analysis of top US research institutions.[81] Because meaningful change spans multiple strategies (education, practical guidance, policy change) and levels (individual, institutional, regulatory), efforts to promote it should be guided by implementation science and change management principles[61,82,83] Finally, this work must be grounded in the disability rights movement's credo of 'nothing about us without us.” As the NIH Strategic Plan for Disability Health Research states:

"Inclusion in research goes beyond enrollment. It requires researchers to thoughtfully consider the needs, experiences, and perspectives of disabled people when planning, designing, and conducting studies and communicating study results. To be maximally effective, this must be done in partnership with people with disabilities, their families, and their care partners" (p. 9).”

Declarations

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Figures

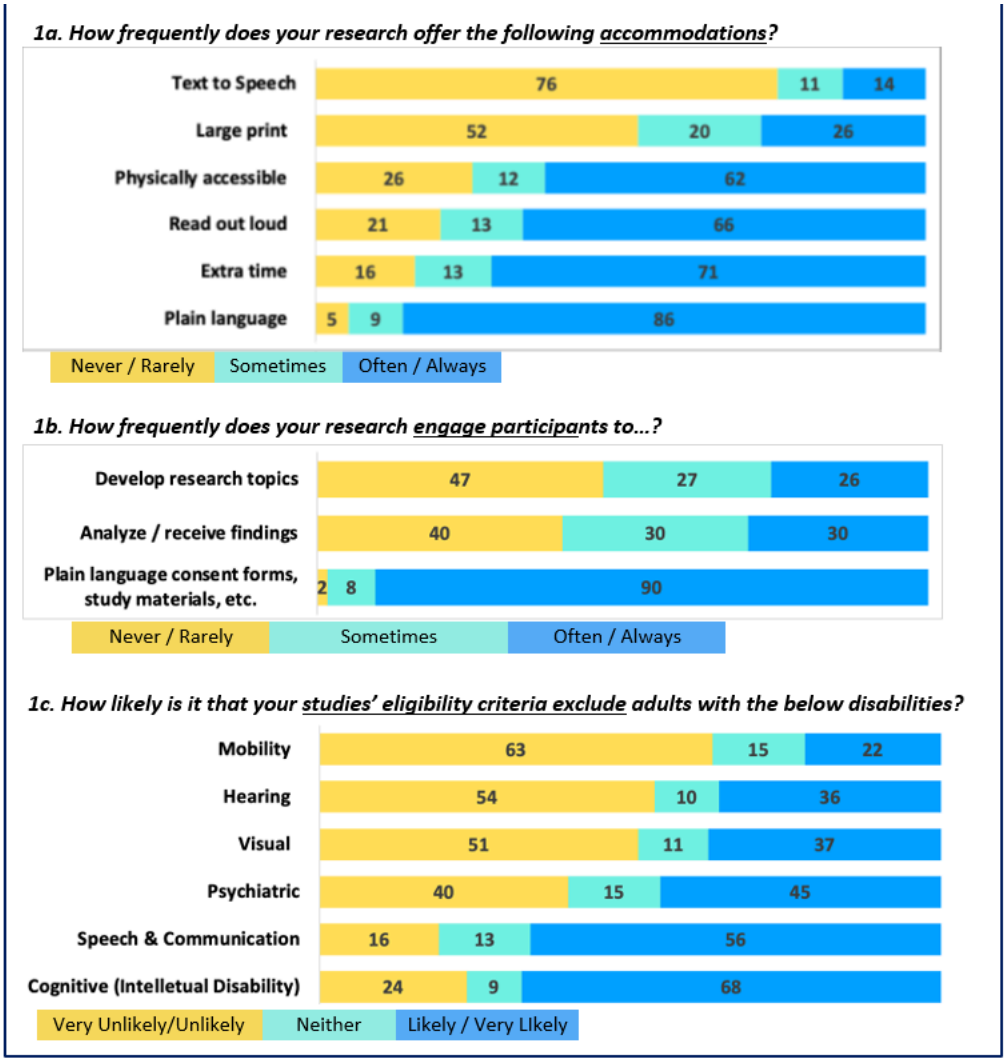


Figure 1

Research Practices: Accommodations, Participant Engagement and Disability Exclusions (%)

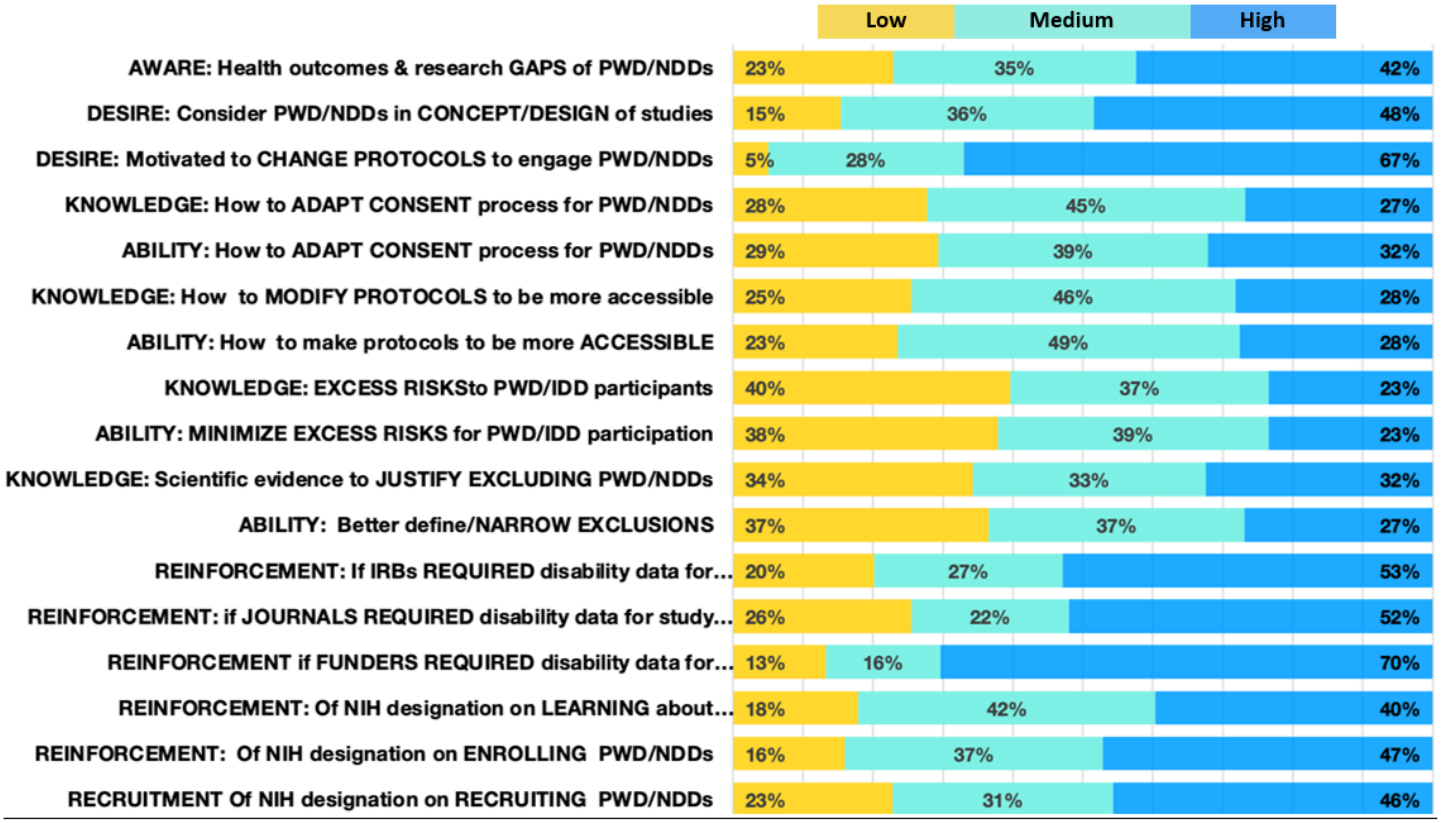


Figure 2

Perceptions of Health and Study Inclusion of PWD/NDDs,* By Prosci ADKAR[â] Model of Change (%)**

Supplementary Files

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