Rethinking Language in Science

A Literature Review on Inclusive Language Practices in Disability and Rare Disease Research

About This Publication

This literature review was developed as part of The NAMED Advocates' Rethinking Language in Science initiative, a multi-year research project examining how language shapes disability and rare disease research, healthcare, policy, and emerging technologies such as artificial intelligence.

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About the NAMED Advocates

The National Alliance of Melanin Disabled Advocates (NAMED Advocates) is dedicated to creating a defiant space of belonging that empower disabled leaders of color to thrive. The organization focuses on building cross-movement solidarity by organizing across social justice movements and reshaping how these movements understand disability and address ableism. The NAMED Advocates is committed to fostering alliances that align with principles of disability justice.

The Rethinking Language in Science Project

This two-year project is an initiative focused on critically examining and refining the language used in biomedical and scientific research spaces related to rare diseases and disabilities. Through a series of targeted discussions and convenings, this project aims to bring together racial justice, disability justice, and patient advocates to identify and develop a more inclusive vocabulary that can bridge cultural and experiential gaps within the scientific community. Additionally, the project will foster relationships between the groups that can allow for a co-creation of ideas on research goals. The conclusion of this project will include a comprehensive analysis on shared language and identify key projects for potential investment to further support and expand this essential work.

Project Goals and Vision

The goal of this project is to foster a transformative dialogue on the language used in advocacy spaces and scientific research, particularly within the context of rare diseases and disabilities. By hosting discussions among advocates, researchers, and other stakeholders, we aim to develop a shared vocabulary that respects and reflects the diverse experiences of the community, including people of color and people with disabilities. This initiative seeks not only to refine communication within scientific research but also allow for leaders to co-create ideas that pave the way for innovative, culturally competent approaches that enhance treatment, care, and quality of life for all affected individuals.

Critical Context and Historical Considerations

There have been many disability leaders who have expressed deep concerns about the language used in scientific research because it can reflect and perpetuate a mindset that views disabilities as problems to be solved or eradicated. Terms like "cure" and "abnormal" suggest that individuals with disabilities are deficient or lesser, needing to be fixed to fit a societal standard of normalcy. This perspective can be dehumanizing and dismissive of the lived experiences and identities of people with disabilities.

Moreover, the intersectionality of race and disability adds another layer of complexity. Historically, scientific research has been marred by racism and ableism, with eugenics being a prominent example. Eugenics was a movement that aimed to improve the genetic quality of the human population by excluding people and groups deemed inferior. This pseudoscience was often used to justify harmful practices such as forced sterilizations and institutionalization, disproportionately affecting people of color and those with disabilities.

Today, the legacy of such practices continues to influence the discourse in scientific research. The focus on "fixing" and "curing" can feel exclusionary and violent to those who are already marginalized. For people of color with disabilities, the narrative around fixing bodies or correcting genetic anomalies can evoke historical traumas and reinforce a sense of otherness and inadequacy.

Project Innovation and Anticipated Outcomes

This project aims to critically examine the language used in scientific research concerning disabilities and rare diseases. The cornerstone of our project is the development of a shared language that is inclusive, respectful, and reflective of the diverse experiences of all individuals, especially those from marginalized communities. We believe that by fostering a dialogue between advocates and scientific researchers, we can co-create a lexicon that more accurately represents the reality of living with a disability or a rare disease.

Our objective goes beyond mere terminology changes; we seek to influence the ecosystem of scientific research. By establishing a common language that is embraced by both the scientific

community and advocacy groups, we can pave the way for more innovative research approaches. This shared language can serve as a foundation for new policies, research methodologies, and educational strategies that are inclusive and equitable. Ultimately, we anticipate that this initiative will not only transform the discourse around disability and rare diseases but also catalyze new research innovations that are more considerate of and beneficial to those who have historically been marginalized by mainstream scientific narratives.

The anticipated outcomes for this project are a comprehensive analysis of shared language, a landscaping assessment of advocate contributions, and funding recommendations for the Chan Zuckerberg Initiative. By addressing language concerns, the scientific community can be better poised to catalyze significant advancements in treatment, care, bodily autonomy, and overall quality of life for individuals with rare diseases.

Undergirding AI Development: How Inclusive Language Frameworks Can Transform Healthcare Communication Technology

The rapid integration of artificial intelligence into healthcare communication systems presents both unprecedented opportunities for improved patient care and significant risks of perpetuating historical health inequities. While natural language processing (NLP)—which is essentially a branch of artificial intelligence that enables computers to understand, interpret, process, and generate human language in both written and spoken forms (Xu & Demner Fushman, 2024, p. 45). Current technologies have demonstrated remarkable potential in automating clinical documentation, enhancing diagnostic accuracy, and facilitating patient-provider communication, emerging evidence reveals a critical gap: current AI development practices systematically exclude the voices and experiences of marginalized communities, particularly those affected by rare diseases and disability conditions.

Recent systematic reviews demonstrate that AI algorithms in healthcare exhibit pervasive biases rooted in unrepresentative datasets, with dermatological AI systems misdiagnosing patients with darker skin tones and risk assessment algorithms underestimating illness severity in racial and ethnic minorities due to training data that predominantly represents white, non-Hispanic populations. These biases are not merely technical failures but represent what scholars' term "ethical failures with real consequences for health outcomes," particularly for communities already experiencing systemic healthcare disparities.

The convergence of biomedicine, rare disease research, and AI development has created an urgent need for new methodological approaches that move beyond reactive bias correction to proactive equity integration. While the healthcare industry has been "below average" in AI adoption compared to other sectors, this presents a unique opportunity to implement inclusive design principles from the foundation of technology development rather than retrofitting existing systems. Current NLP applications in healthcare, though promising in their ability to simplify complex medical terminology and improve patient-provider communication, remain predominantly unimodal when the complexity of rare disease diagnosis and treatment requires comprehensive approaches that integrate diverse data sources alongside culturally sensitive communication frameworks.

The literature increasingly calls for participatory design methodologies that position patients and communities as "active co-creators" rather than passive recipients of healthcare technology. Evidence from successful implementations of "ethics-by-design" approaches in AI-assisted patient information systems demonstrates that collaborative partnerships focused on mutual learning and knowledge exchange can produce technologies that are both more effective and more equitable. These participatory frameworks have proven particularly crucial in rare disease contexts, where technical language and exclusionary recruitment practices create barriers that reinforce perceptions that "research is not intended for me."

However, a significant research gap persists in understanding how the co-creation of inclusive language frameworks can specifically inform the development of AI algorithms, coding practices, and communication technologies that bridge providers and patients across diverse communities. While existing literature addresses bias mitigation and inclusive design separately, there is limited scholarship examining how collaborative language development processes can fundamentally reshape the architecture of healthcare AI systems to promote equity from conception through deployment.

This literature review examines how inclusive language co-creation methodologies can serve as foundational frameworks for developing AI and health technology tools that enhance communication between providers and patients while actively promoting health equity.

A study conducted in family medicine assessed the effectiveness of using AI as a communicative tool in healthcare settings (Rodríguez & Lussier, 2025). The results revealed that AI would be

most beneficial during in-office visits by helping doctors engage in more meaningful conversations with their patients rather than focusing on documentation tasks. Specifically, AI could assist physicians in investigating treatment plans that align with patient values and generating detailed clinical notes that can translate non-English communications into English for electronic health record (EHR) systems. This approach would streamline patient visits and improve organization, ultimately freeing up more time for direct patient-provider interaction while reducing the administrative burden on healthcare professionals (Rodríguez & Lussier, 2025).

Context and Scope

Language functions as more than a tool for communication---it operates as a site of identity, a gatekeeper of legitimacy, and a conduit of power. Within the fields of disability and rare disease research, this dual nature becomes particularly pronounced, where scientific terminology carries both formal epistemological weight and deeply personal social implications. This literature review examines the evolving landscape of language practices in scientific research concerning disabilities and rare diseases, drawing from multidisciplinary scholarship spanning biomedical sciences, disability studies, public health, linguistics, and community advocacy.

The scope of this review encompasses peer-reviewed research from the past decade, supplemented by grey literature and community-based scholarship that captures perspectives often excluded from mainstream academic discourse. Our analysis focuses specifically on how language choices in scientific contexts influence the perception, treatment, and representation of individuals with disabilities and rare conditions.

Purpose and Significance

This literature review emerges from a critical recognition that current scientific language practices often perpetuate systemic inequities and fail to adequately represent the lived experiences of disabled communities. As biomedical research increasingly acknowledges the importance of community engagement and participatory research methodologies, the need for inclusive language practices becomes both methodologically and ethically imperative.

The significance of this review lies in its potential to inform more equitable research practices, policy development, and clinical interventions. By critically examining how language operates as both a barrier and a bridge between scientific communities and disability communities, this review contributes to ongoing efforts to decolonize medical research and center community voices in knowledge production.

Overview of Organization

This review is organized around four major thematic areas that emerged from our analysis: (1) Historical and Theoretical Foundations, examining the evolution of disability models and their linguistic implications; (2) Contemporary Challenges, analyzing current barriers including implicit bias and deficit-based thinking; (3) Community Leadership and Resistance, exploring how disability communities are reclaiming definitional authority; and (4) Intersectional Approaches, investigating how multiple identity markers intersect within biomedical language systems. Each section synthesizes literature across disciplines while maintaining focus on the central question of how language practices can bridge scientific and community spaces.

Methodology

This literature review examined language use in scientific research around disabilities and rare diseases, analyzing 57 articles through a comprehensive multi-database search strategy. Our approach integrated peer-reviewed academic literature with grey literature to capture both scholarly perspectives and community-based knowledge often excluded from mainstream academic discourse.

Database Search: We conducted systematic searches across biomedical databases (PubMed, CINAHL), psychology and social science databases (PsycINFO, APA PsycNet), and supplementary databases (Web of Science, Scopus, ERIC). Grey literature was sourced through Google Scholar, advocacy organization publications, and policy repositories.

Search Terms: Four primary keyword clusters guided our search: (1) language and terminology ("linguistic ableism," "inclusive language," "discourse"), (2) disability concepts ("person-first language," "identity-first language," "disability models"), (3) medical and research contexts ("biomedical research," "clinical," "scientific research"), and (4) rare disease specific terms

("orphan disease," "genetic conditions"). Boolean operators and database-specific controlled vocabularies (MeSH terms, APA Thesaurus) refined search precision.

Temporal Parameters and Selection Criteria

Primary timeframe: 2014-2024, capturing contemporary developments in disability language that align with recent disability rights advocacy and policy changes. Foundational texts published prior to 2014 were included when they established key theoretical frameworks or represented pivotal moments in disability language evolution.

Inclusion criteria prioritized English-language sources focusing on disability and/or rare disease language in scientific, medical, or research contexts, including empirical studies, theoretical papers, systematic reviews, and commentary pieces from peer-reviewed publications or credible grey literature sources.

Exclusion criteria eliminated purely clinical studies without language/communication focus, sources focused solely on medical diagnosis or treatment without language analysis, non-English publications, clearly outdated or superseded research practices, publications without clear methodology or credible authorship, and sources promoting explicitly harmful or discriminatory language practices.

Analysis Process

Sources underwent initial screening through title and abstract review by multiple researchers to ensure consistent application of inclusion/exclusion criteria. Full-text review was conducted for all potentially relevant sources, with particular attention to methodology, author positionality, and community engagement approaches. Data extraction focused on identifying language practices, community perspectives, and recommendations for inclusive terminology, particularly prioritizing sources authored by or centering disabled people and rare disease communities.

Disciplinary Coverage and Multidisciplinary Rationale

The review adopted an intentionally multidisciplinary approach grounded in intersectional frameworks and community-based methodology, recognizing that language practices around disability and rare diseases cannot be understood through a single disciplinary lens. Our final

corpus represented 21 distinct academic disciplines, with the highest representation from Disability Studies (14.6%) and Biomedical Sciences (14.6%), reflecting the central tension between medical and social model approaches to disability language.

Figure 1. Multidisciplinary down

The Health and Medical Sciences cluster comprised 35.4% of sources overall, encompassing not only biomedical research but also public health (8.3%), nursing (2.1%), rehabilitation (4.2%), health education (6.2%), healthcare training (2.1%), and biomedical research (2.1%), providing comprehensive coverage of clinical and health systems perspectives. The Social Sciences and Humanities cluster represented 29.1% of sources, including psychology (6.2%), sociology (6.2%), and linguistics (4.2%), offering critical frameworks for understanding language's social construction and power dynamics. Policy and Systems approaches (16.6%) captured institutional and technological dimensions through policy studies (4.2%), classification systems (4.2%), rare disease research (4.2%), and technology (4.2%), while Community and Advocacy perspectives (8.4%) ensured authentic community voices through advocacy literature (2.1%), youth work (2.1%), community advocacy (2.1%), and intersectional DEI scholarship (2.1%). This multidisciplinary approach was methodologically essential rather than merely comprehensive, recognizing that disability language operates as a socially constructed phenomenon that spans multiple domains of human experience and requires diverse knowledge systems to understand its full impact on research practices, clinical encounters, policy development, and community identity formation.

Multidisciplinary Literature Review

Language Practices in Disability & Rare Disease Research

21 Academic Disciplines • 5 Disciplinary Clusters • Community-Centered Methodology

Disciplinary Clusters:

Health & Medical (35.4 Social Sciences (29.1%) Policy & Systems (16.6%) Community & Advocacy (8.4%)

Interdisciplinary (4.3%)

Academic Discipline	Percentage	Visual Distribution	Cluster
Disability Studies	14.6%		
Biomedical Sciences	14.6%		
Public Health	8.3%		
Psychology	6.2%		
Health Education	6.2%		
Sociology	6.2%		
Linguistics	4.2%		
Classification Systems	4.2%		
Rehabilitation	4.2%		
Policy Studies	4.2%		
Rare Disease Research	4.2%		
Technology	4.2%		
Nursing	2.1%		
Advocacy	2.1%		
Youth Work	2.1%		
Healthcare Training	2.1%		

+ 7 additional disciplines at 2.1% each:

Interdisciplinary, Intersectional DEI, Biomedical Research, Community Advocacy, Health Metrics

Methodological Significance

This multidisciplinary approach was methodologically essential for examining disability and rare disease language. The equal representation of Disability Studies (14.6%) and Biomedical Sciences (14.6%) reflects our commitment to balancing medical and social model approaches while centering community voices and intersectional perspectives.

Geographic and Cultural Scope

While the review maintained a global perspective by including international research, there was a concentrated focus on U.S.-based studies due to the specific policy and cultural contexts relevant to the research questions and NAMED Advocates' focus on communities within the United States. International sources were particularly valuable for comparative analysis and understanding diverse cultural approaches to disability language. Priority was given to sources that reflected the experiences of marginalized communities within these geographic contexts.

Commitment to Diverse Perspectives

The review actively sought sources that reflected perspectives from disabled people and people of color, recognizing the intersectional nature of disability experiences and the historical exclusion of these voices from academic research. This commitment directly aligns with NAMED Advocates' mission to create spaces for disabled leaders of color and BIPOC allies. This included prioritizing:

- Research authored or co-authored by disabled scholars and advocates.
- Studies centering the experiences of disabled people of color.
- Community-based participatory research involving disability communities.
- Publications from disability rights organizations and advocacy groups
- Scholarship addressing intersectionality of disability, race, ethnicity, and other marginalized identities.

Organization and Synthesis Framework

The analysis employed a thematic synthesis approach, organizing findings around four major themes that emerged from the literature**: (1) person-first language versus identity-first language preferences**, **(2) models of disability and their linguistic implications, (3) community-engaged inclusive practices, and (4) disability and rare disease as measurement and evaluation frameworks.** This framework enabled systematic comparison across disciplines while maintaining attention to community-centered perspectives and intersectional considerations.

Why Multidisciplinary Methodology is Critical for This Literature Review

The multidisciplinary approach was not merely comprehensive but methodologically essential for examining disability and rare disease language—a departure from traditional hard science literature reviews that might privilege biomedical perspectives. Several factors make this approach uniquely important for this type of inquiry:

1. Language as Socially Constructed Phenomenon Unlike biological or chemical processes that can be studied within single disciplinary frameworks, language around disability is socially constructed and contextually dependent. Medical professionals, social workers, educators, policymakers, and disabled people themselves may use identical terms with vastly different meanings, power implications, and lived consequences. A purely biomedical literature review would miss how clinical terminology impacts daily life, policy implementation, and community identity formation.

2. Historical Power Imbalances in Research Traditional medical and scientific research has historically excluded disabled voices while simultaneously creating language about disabled people. A hard science approach would perpetuate this exclusion by privileging clinical and research perspectives over lived experience. The multidisciplinary methodology intentionally redistributes epistemic authority, recognizing that disabled people and communities are experts on their own experiences and should inform how they are described in research.

3. Intersectionality Requires Multiple Knowledge Systems Disability intersects with race, class, gender, sexuality, age, and other identities in ways that cannot be captured through medical frameworks alone. For example, the experience of a Black disabled woman navigating healthcare involves simultaneous systems of oppression that require insights from critical race theory, feminist scholarship, disability studies, and medical sociology. Hard science approaches typically lack theoretical frameworks to analyze these intersecting power structures.

4. Community-Based Knowledge Production Much of the most innovative thinking about inclusive disability language emerges from community advocacy spaces, policy debates, and grassroots organizing, not peer-reviewed biomedical journals. Disabled people of color, LGBTQ+ disabled people, and other marginalized communities often develop language practices

through activism, mutual aid, and community organizing. A literature review limited to hard sciences would systematically exclude these crucial knowledge sources.

5. Language Impact Spans Multiple Domains The consequences of disability language extend far beyond clinical settings into education, employment, housing, legal systems, and social relationships. Understanding these impacts requires engaging with scholarship from education, law, sociology, psychology, and other fields that examine how language shapes life outcomes across multiple domains.

6. Methodological Pluralism for Complex Social Problems Hard science methodologies excel at isolating variables and establishing causation in controlled conditions. However, language use around disability involves complex social dynamics, historical contexts, and cultural variations that require qualitative methods, participatory approaches, and interpretive frameworks typically found in humanities and social sciences. The multidisciplinary approach enables methodological pluralism using the most appropriate methods for different aspects of the research questions rather than forcing complex social phenomena into inappropriate methodological frameworks.

This methodological choice reflects a commitment to methodological justice ensuring that research approaches match the complexity and social nature of the phenomena being studied while centering the voices and expertise of those most affected by the language practices under examination. This approach directly supports NAMED Advocates' vision of fostering transformative dialogue and co-creating inclusive vocabulary that respects and reflects diverse community experiences.

Existing Language Frameworks: Medical Professionals vs. Advocates vs. NAMED Advocates' Innovation

The concept of "gold standards" in medicine has deep historical roots that establish precedent for creating authoritative guidelines across biomedical research. The term has become heavily embedded in scientific jargon as a method to create ground truth or establish measurement of credibility across research disciplines. The term "gold standard" in medical research was first coined by Rudd in 1979, referencing the monetary gold standard, to describe "the diagnostic test

or benchmark that is the best available under reasonable conditions" against which new tests are compared to gauge validity and evaluate treatment efficacy.

Critical Analysis of Gold Standard Terminology:

However, the appropriateness and implications of "gold standard" terminology have been subject to scholarly critique. Versi (1992) questioned whether "'Gold standard' is an appropriate term?" in a seminal BMJ commentary that challenged the uncritical adoption of monetary metaphors in medical research contexts. This critique highlights how scientific jargon can obscure power dynamics and assumptions embedded within research frameworks.

Cardoso et al. (2014) further examined "What is gold standard and what is ground truth?" demonstrating that the terminology creates conceptual confusion between reference standards (gold standard) and absolute truth (ground truth). Their analysis reveals that "gold standard" functions as scientific rhetoric that claims objectivity while actually representing contingent professional consensus rather than immutable truth. This distinction is crucial for understanding how language frameworks gain authority through terminological positioning rather than inherent validity.

Ground Truth vs. Professional Consensus:

The conflation of "gold standard" with "ground truth" reveals how scientific jargon can mask subjective professional judgments as objective facts. As Cardoso et al. demonstrate, gold standards represent "the best available under reasonable conditions" rather than absolute truth, yet the terminology suggests infallibility and unchanging validity. This linguistic sleight-of-hand creates what can be characterized as "credibility through terminology" rather than credibility through community validation or lived experience accuracy.

This analysis is particularly relevant for disability and rare disease language frameworks, where medical professional "gold standards" often contradict community experiences and preferences. The terminology itself creates hierarchical relationships between professional knowledge (positioned as "gold standard") and community knowledge (positioned as subjective or anecdotal), despite evidence that community-developed frameworks often provide more accurate and useful guidance for research and clinical practice.

Historical Development of Medical Gold Standards:

The Randomized Controlled Trial (RCT) emerged as the archetypal gold standard following post-World War II reconstruction. It "helped to establish the Randomized Controlled Trial (RCT) as a gold standard in clinical research." For the past half-century, physicians and clinical researchers have remained confident that RCTs "provide the most rigorous test of preventive, diagnostic, and therapeutic interventions" and are "ubiquitously referred to as the 'gold standard' of empirical biomedical investigation."

However, the historical trajectory reveals that gold standards are not immutable. As Kleinman argues, the emergence of biomedicine within monotheistic traditions "imbued medicine with a commitment to universal truths, unitary paradigms, and a 'single-minded approach to illness and care.'" This "medical monotheism" created what critics identify as "almost religious sanctification" of single methodological approaches, despite evidence that exclusive reliance on any single standard can be dangerous and limiting.

Contemporary Challenges to Gold Standard Thinking:

Recent scholarship demonstrates that "there is no single gold standard of study design" and that "the gold standard design is whatever method provides the information you need in the most reliable way in view of what is currently known or can be obtained." The "alter-standardization" movement in medical research recognizes that gold standards must evolve as "the processes, controversies and negotiations through which the role of multiphase RCTs as the global gold standard in medicine research is being challenged and gradually replaced by the development of new types of standards, methodologies and forms of evidence."

Implications for Language Framework Development:

The critical analysis of gold standard terminology (Versi, 1992; Cardoso et al., 2014) reveals how scientific jargon creates artificial hierarchies between different forms of knowledge. For disability and rare disease language development, this means that frameworks positioned as "gold standards" gain credibility through terminological authority rather than community validation. The distinction between "gold standard" (professional consensus) and "ground truth" (lived experience accuracy) becomes crucial for understanding why community-developed

language frameworks often provide more accurate guidance than professionally mandated standards.

This historical context establishes that creating multidisciplinary gold standards is both precedented and necessary in biomedical research, while simultaneously revealing how the terminology itself can perpetuate power imbalances that NAMED Advocates' approach explicitly challenges through community-centered methodology.

Medical Professional Language Frameworks: Universal Person-First Paradigm

Existing medical professional language frameworks operate predominantly through institutional mandate and professional standardization, creating what can be characterized as "language subjugation" despite claims of inclusivity. The United Nations Disability-Inclusive Language Guidelines represent the closest approximation to a global gold standard for disability language practices, establishing comprehensive institutional protocols for international organizations and serving as a model for national policy development worldwide.

However, significant standardization gaps exist, particularly within the United States healthcare and research systems. Unlike countries with centralized healthcare systems that can implement unified language protocols, the U.S. lacks standardized disability and inclusion language requirements across institutions. Instead, language practices remain highly institutional and governance-specific, with individual healthcare systems, universities, and research institutions developing independent guidelines that often conflict with community preferences and each other.

This fragmented approach creates what disabled leaders and advocates identify as institutional language subjugation where professional convenience and bureaucratic standardization take precedence over community self-determination. In response, disabled leaders and advocates consistently encourage institutions to use language that is centered in community preferences rather than professional protocols, embodying the fundamental disability rights principle of **"Nothing About Us Without Us."**

These frameworks universally promote person-first language as the gold standard for professional communication, justified through what Brown (2011) identifies as fundamentally flawed medical model analogies.

The cancer analogy fallacy permeates medical professional frameworks, as Brown (2011) demonstrates: "One argument I encountered in one of the more cogently-written papers in favor of person-first language expostulates that because cancer patients are referred to as 'people with cancer' or 'people who have cancer,' as opposed to 'cancerous people,' the same principle should be used with autism." However, Brown's analysis reveals the theoretical inadequacy of this approach: "Cancer is a disease that ultimately kills if not treated or put into long-term remission. There is absolutely nothing positive, edifying, or meaningful about cancer. Cancer is not a part of a person's identity or the way in which an individual experiences and understands the world around him or her. It is not all-pervasive."

Medical frameworks fail to distinguish between pathological processes requiring intervention and neurological differences that are identity constitutive. This universal person-first mandate reflects what Brown identifies as epistemological authority misplacement medical professionals determining language appropriateness for experiences they do not live, based on theoretical frameworks that misunderstand the ontological nature of disability and difference.

Community Advocate Language Frameworks: Identity-Centered Resistance

Community-developed frameworks emerge through grassroots organizing and lived experience analysis rather than institutional mandate, explicitly challenging the "language subjugation" that characterizes medical professional approaches. These frameworks embody the "Nothing About Us Without Us" principle by centering community self-determination in language development and challenging institutional authority over disability representation. Brown's theoretical contribution exemplifies this approach: "Autism, however, is not a disease. It is a neurological, developmental condition; it is considered a disorder, and it is disabling in many and varied ways. It is lifelong. It does not harm or kill of its own accord. It is an edifying and meaningful component of a person's identity, and it defines the ways in which an individual experiences and understands the world around him or her. It is all-pervasive."

Autistic Self Advocacy Network (ASAN) represents the most developed community framework, establishing identity-first language as reclamation of definitional authority. ASAN's approach recognizes autism as integral to identity formation and worldview, challenging medical model assumptions through community-led theoretical development and practical implementation strategies.

Deaf Community frameworks similarly emphasize cultural identity over medical categorization, with the Deaf Community (capital D) representing cultural-linguistic minority status rather than medical hearing loss. This framework demonstrates how communities can develop sophisticated language systems that resist medicalization while affirming cultural belonging and identity pride.

Rare Disease Patient Advocacy Groups (PAGs) face unique challenges in framework development due to resource limitations and fragmented organizing. Many rare disease communities lack the organized advocacy infrastructure of broader disability movements, resulting in variable language development across conditions. Some PAGs adopt medical model person-first language by default, while others develop identity-affirming approaches based on community preferences and organizing capacity.

NAMED Advocates' Unique Research Contribution: Toward a Multidisciplinary Gold Standard for Language Co-Creation

The NAMED Advocates' research represents methodological innovation that applies the historical precedent of gold standard development to create the first multidisciplinary gold standard approach to language co-creation in biomedical research. Drawing from the historical understanding that gold standards must evolve through "processes, controversies and negotiations" and that effective standards require "whatever method provides the information you need in the most reliable way," NAMED Advocates proposes a new paradigm for language framework development.

Unlike existing frameworks that rely on "medical monotheism" approaches (single methodological paradigms), NAMED Advocates develops what can be characterized as "methodological pluralism" that integrates multiple knowledge systems without hierarchical ranking. This approach recognizes that language development requires "alloy-like" strength from combining different methodological approaches rather than privileging single frameworks.

Components of the Multidisciplinary Gold Standard Approach

1. Community Expertise Integration: Rather than treating community knowledge as advisory input to professional frameworks, NAMED Advocates establishes community leadership as methodological requirement for language development, similar to how RCTs require randomization for validity.

2. Intersectional Analysis Protocols: The framework requires systematic examination of multiple identity intersections within language development processes, establishing intersectionality as methodological standard rather than optional consideration.

3. Scientific Rigor Maintenance: While centering community expertise, the approach maintains empirical validation requirements through longitudinal outcome tracking, community satisfaction assessment, and research effectiveness measurement.

4. Cross-Sector Collaboration Standards: The framework establishes partnership protocols between community advocates, researchers, and institutions that create sustainable rather than extractive research relationships.

5. Implementation and Sustainability Metrics: Unlike existing frameworks that focus on language adoption, NAMED Advocates' approach includes systematic evaluation of long-term outcomes including research quality improvement, community capacity building, and institutional transformation.

Redefining Gold Standards Through Community-Centered Ground Truth

The NAMED Advocates' approach fundamentally reframes gold standard development by prioritizing ground truth (lived experience accuracy) over professional consensus. Drawing from Cardoso et al.'s (2014) distinction between gold standards and ground truth, the framework establishes community validation as the primary criterion for credibility rather than institutional authority or scientific jargon positioning.

This represents methodological innovation beyond existing approaches because it challenges the "credibility through terminology" model identified by Versi (1992) and Cardoso et al. (2014). Instead of claiming gold standard status through professional consensus, NAMED Advocates creates empirical validation through community partnership outcomes, longitudinal effectiveness measurement, and intersectional analysis that demonstrates actual improvement in research quality and community engagement.

Historical and Theoretical Foundations

Models of Disability and Their Linguistic Legacy

The foundation of contemporary language debates in disability research rests upon competing conceptual frameworks that have shaped scientific discourse for decades. Three dominant models---medical, moral, and social---continue to influence how disability is conceptualized and linguistically represented in research contexts (Olkin, 2022).

The medical model, also referred to as the Nagi model of disablement, established the dominant framework used in biomedical sciences, viewing disability primarily as a disease or injury requiring measurement, management, prevention, or cure (Snyder et al., 2008). This model's linguistic legacy is evident in contemporary research language that positions disabilities as "abnormal" conditions requiring correction. As Jette (2006) notes, "the disablement model has been proven useful as a language to delineate consequences of disease and injury," yet this utility stems from viewing disablement as non-normative bodily function requiring intervention.

The World Health Organization's International Classification of Functioning, Disability and Health (ICF) represents a significant evolution from earlier frameworks, attempting to bridge medical and social approaches to disability classification (International Classification of Functioning, Disability and Health: ICF, 2001). However, critics including Brandsma et al. (1995) and Dickson (1995) have identified persistent limitations in how these classification systems define impairment and disability, particularly their continued reliance on deficit-based language.

The Evolution of Person-First and Identity-First Language

The disability rights movement of the 1970s catalyzed significant changes in identification language, leading to the emergence of Person-First Language (PFL) as a response to medical model critiques. Subsequently, Identity-First Language (IFL) evolved as communities sought greater control over their own linguistic representation (Andrews et al., 2022).

Contemporary research reveals ongoing tensions between these approaches. Crocker and Smith (2019) demonstrate significant gaps between healthcare professionals' stated support for person-first language principles and their actual practice. Meanwhile, community voices, exemplified by Brown's (2011) analysis on the Autistic Hoya blog, highlight how identity-first language serves

as an empowerment tool for many disabled individuals, challenging professionally driven language prescriptions.

The literature reveals that language preferences vary significantly within disability communities, with decisions often based on individual and community preference rather than discipline-specific guidelines (Andrews et al., 2019). This diversity of perspectives underscores the complexity of developing universal language standards and highlights the importance of community consultation in research practices.

Contemporary Challenges in Scientific Language Practices

Implicit Bias and Healthcare Communication

A substantial body of evidence demonstrates how implicit bias manifests through language choices in healthcare and research settings. FitzGerald and Hurst's (2017) systematic review provides comprehensive evidence that healthcare professionals display implicit biases toward patients across multiple demographic characteristics, with significant implications for clinical communication and outcomes.

The interpersonal consequences of biased language are well-documented. Zestcott et al. (2016) found that healthcare providers with higher levels of implicit bias engage in poorer interpersonal interactions with patients from marginalized identities, leading to decreased patient satisfaction and perceptions of inadequate care. More recent research by Wesevich et al. (2024) specifically examined how biased language in clinical handoffs affects information recall and attitudes toward patients, revealing direct links between linguistic choices and clinical decision-making quality.

Documentation of these patterns extends to written clinical records, where Sun et al. (2022) demonstrated that notes about Black patients contain higher rates of negative descriptors and expressions of doubt compared to notes about White patients. Van Ryn and Burke's (2000) foundational research revealed how patient race and socioeconomic status systematically influence physicians' perceptions, with clinicians rating African American patients as less intelligent and less likely to adhere to medical advice.

Deficit-Based Thinking and Linguistic Harm

Deficit-oriented language represents a pervasive challenge in clinical and research settings, where rhetoric describing patients from minoritized backgrounds stems from frameworks that centralize problems within individuals rather than examining systemic factors (Dunne, 2024). This approach tends to pathologize communities and legitimate differential treatment within biomedical contexts.

The research implications of deficit-based framing extend beyond clinical practice into methodology itself. As Museus and Davis (2019) observe, "research itself becomes problematic when framed with deficit thinking, and researchers are not immune to using deficit frames to respond to educational issues." This pattern is particularly evident in genetic medicine, where technological approaches to medical diagnosis can perpetuate existing biases and create new barriers to equitable care delivery (Hager et al., 2024).

Professional Gatekeeping and Power Dynamics

The literature reveals significant disconnects between scientific communities and disability communities regarding language authority. A critical finding is that science initiatives are frequently led by non-disabled people (Andrews et al., 2019), while disability professionals often utilize harmful language without community input.

Bottema-Beutel et al. (2021) provide specific guidance for autism researchers on avoiding ableist language, demonstrating disciplinary efforts to address harmful terminology. However, their work also reveals how "disability professionals have long played a role in disability language and terminology by creating and reinforcing deficit-based understandings of disability, often without the input of disabled people themselves."

This professional gatekeeping creates what the literature identifies as "siloed language"---industry-specific jargon that fragments rather than unifies understanding across disciplines. The persistence of these silos raises critical questions about when professional jargon becomes harmful and how it can be transformed into more inclusive practice.

Community Leadership and Resistance

Reclaiming Definitional Authority

A significant theme across the literature involves communities' efforts to reclaim control over how they are defined and described in research contexts. This process represents what several scholars characterize as "intentional reclamation" rather than passive acceptance of externally imposed categories.

The historical parallel between racial and disability categorization systems is particularly instructive. The successful advocacy to remove "Negro" from the Census in 1997 demonstrates how communities can challenge linguistic systems that pathologize and marginalize. This struggle for definitional autonomy directly parallels contemporary disability communities' challenges to medical categorization systems, particularly the WHO's International Classification of Impairments, Disabilities, and Handicaps (ICIDH).

Both systems share fundamental characteristics: external definition rather than community self-determination, categorical rigidity that ignores lived experience, and the use of language to justify exclusion from resources and research participation. When marginalized individuals encounter medical research, they face compounded effects of multiple categorization systems simultaneously, highlighting why intersectional approaches to language transformation are methodologically essential.

Policy-Level Language Changes

The literature documents several successful policy interventions that demonstrate language's political power. Rosa's Law (2010), signed into law by President Barack Obama, emerged from advocacy by the Intellectual and Developmental Disability (I/DD) community to eliminate the terms "mental retardation" and "mentally retarded"—the "r-word"—replacing them with person-first language (PFL) terms such as "intellectual disability" and "individual with an intellectual disability."

The law was inspired by nine-year-old Rosa Marcellino, whose parents discovered she was being labeled as "retarded" due to her having Down syndrome. Appalled by this terminology, Rosa's parents advocated for more representative language for people with intellectual disabilities, noting that "the 'r-word' was not even used in her own home." In pursuit of self-efficacy, Rosa's mother Nina Marcellino partnered with other parents across Maryland to pass legislation removing this harmful language from public use.

Before the bill's passage, the Maryland General Assembly held a hearing to assess the impact of changing the terminology. Personal testimony came from Rosa's 11-year-old brother Nick, who stated: "What you call people is how you treat them. What you call my sister is how you will treat her. If you believe she's 'retarded,' it invites taunting, stigma. It invites bullying and it also invites the slammed doors of being treated with respect and dignity" (Special Olympics, 2010).

These policy changes function as what researchers' term "de-stigmatization symbols," demonstrating how inclusive language operates not merely as prescription but as political power. The success of such initiatives provides evidence that communities can effectively challenge institutional language practices when provided with appropriate advocacy platforms and political support.

Decolonization and Language Transformation

Community-activist literature reveals how language reclamation represents a decolonized methodology that values bodies and skills beyond medical categorization. Within this framework, the decolonization of disability identity becomes intrinsically tied to language transformation, as linguistic utility has historically disenfranchised both disabled people and communities within the BIPOC spectrum.

This decolonization process advocates for fundamental changes in medical and research institutions themselves, recognizing language transformation and institutional change as deeply intertwined components of systemic reform. The literature suggests that truly inclusive language practices require not just terminological changes but fundamental shifts in how knowledge is produced, validated, and disseminated within scientific communities.

Intersectional Approaches to Language and Identity

The literature consistently demonstrates that examining disability language in isolation from other identity markers perpetuates fragmentary approaches that have historically excluded multiply marginalized communities from biomedical knowledge production. An intersectional framework reveals how race, disability, and other identities are simultaneously constructed and experienced within biomedical contexts, making such analysis methodologically essential rather than merely additive.

Historical medical research provides compelling evidence of these intersections. The U.S. Public Health Service's Tuskegee Study of Untreated Syphilis in the Negro Male, conducted from 1932 to 1972 in rural Macon County, Alabama, stands as one of the most egregious examples of how intersecting identities shaped exploitative research practices. Initially designed as a six-month observational study, the research was extended for four decades without participants' knowledge or consent.

The study recruited 399 Black men diagnosed with latent syphilis and 201 without the disease as controls, primarily targeting impoverished sharecroppers who had limited access to medical care. Researchers told participants they were receiving free treatment for "bad blood" a local term encompassing various ailments while withholding effective treatment even after penicillin was proven effective against syphilis in the 1940s. The men received free meals, medical examinations, and burial insurance as incentives, but were deliberately kept ignorant of their diagnosis and denied potentially life-saving treatment.

This deception continued even as participants developed severe complications including blindness, paralysis, heart disease, and death. The study only ended in 1972 when whistleblower Peter Buxtun leaked information to the press, generating public outrage. By then, numerous participants had died, and many had unknowingly transmitted syphilis to their wives and children.

The study's original title Tuskegee Study of Untreated Syphilis in the Negro Male demonstrates how dehumanizing language operates as a tool of power, where population definitions determine research approaches. The Tuskegee study exemplifies how Black men were simultaneously

racialized and pathologized, with their identities filtered through both racial and disability-based assumptions that justified unethical research practices. Researchers viewed these men through intersecting lenses of racial inferiority and disease pathology, treating them as expendable subjects rather than human beings deserving of medical care and informed consent (Byrd & Clayton, 2001).

Contemporary Manifestations of Intersectional Marginalization

Contemporary examples illuminate how these historical patterns persist through more subtle mechanisms. The funding disparity between sickle cell disease and cystic fibrosis research provides a clear illustration of how racialized assumptions about patient populations directly impact research investment and clinical outcomes (Farooq et al., 2020). Despite sickle cell disease's biological components relating to geographic and environmental factors rather than race, racialized categorization continues to influence resource allocation.

This convergence demonstrates why racial and disability justice frameworks must work together rather than in parallel. Addressing one system without the other maintains fragmentary approaches that have historically marginalized multiply identified communities. The literature suggests that truly effective language transformation requires simultaneous challenges to interconnected systems of categorization.

Health Equity and Social Determinants

Recent policy developments reflect growing recognition of intersectional approaches to health research. The Office of Management and Budget's (2024) revisions to federal data collection standards acknowledge that racial and ethnic categories are "not an attempt to define race and ethnicity biologically or genetically," representing significant progress from earlier frameworks that conflated social categories with biological determinism.

The National Academies of Sciences, Engineering, and Medicine's (2025) report "Rethinking Race and Ethnicity" further emphasizes these connections, noting how "race and ethnicity have often been obfuscated, purporting race and ethnicity as valid reasons for mistreatment and

injustice." This analysis directly parallels disability studies critiques of medical categorization systems.

Critical Evaluation and Synthesis

Strengths and Innovations in Current Research

The literature reveals several promising developments in inclusive language research. Healthcare education shows emerging progress in disability competency training, with Edwards et al. (2022) demonstrating that targeted educational interventions can improve healthcare providers' disability competency. Similarly, Rotenberg et al. (2022) provide global evidence for systematic approaches to disability training that address both clinical skills and language competency.

Community-based research represents another significant strength. Patterson et al. (2023) examine how rare disease patient advocacy groups are transforming research practices through community leadership, providing concrete examples of successful collaboration between scientific and advocacy communities. This work demonstrates practical pathways for implementing community-informed language practices.

Persistent Limitations and Contradictions

Despite these advances, the literature reveals persistent gaps between stated inclusive language principles and actual practice. Multiple studies document how healthcare professionals fail to implement the person-first language approaches they advocate (Crocker & Smith, 2019), while disability professionals continue using harmful language without community consultation (Friedman, 2023).

Technological systems present emerging challenges, with Fabregat et al. (2020) demonstrating how algorithmic approaches to disability identification can perpetuate linguistic bias in healthcare documentation. These findings suggest that inclusive language initiatives must address both human and technological dimensions of language use in research and clinical practice.

Methodological Considerations

The literature reveals significant methodological limitations that affect the strength of available evidence. Most studies rely on limited participant samples and short-term interventions, making it difficult to assess long-term impacts of language changes on health outcomes and research practices. Additionally, much research remains concentrated in English-language contexts and North American healthcare systems, limiting generalizability to global contexts.

Community-based knowledge remains underrepresented in academic literature reviews, despite its essential role in understanding lived experiences of language impact. This gap highlights ongoing power imbalances in knowledge production and suggests need for expanded methodological approaches that center community expertise.

Summary of Findings

This literature review reveals four critical insights regarding inclusive language practices in disability and rare disease research. First, current scientific language practices are deeply embedded within historical power structures that have systematically marginalized disability communities, with medical model dominance continuing to shape contemporary research discourse. Second, implicit bias and deficit-based thinking permeate clinical and research communications, creating documented barriers to equitable care and authentic community representation. Third, disability communities are actively reclaiming definitional authority through policy advocacy, community-led research, and direct challenges to professional gatekeeping, demonstrating the political dimensions of language transformation. Fourth, intersectional approaches are methodologically essential, as disability language cannot be effectively addressed in isolation from other systems of categorization and marginalization.

The evidence consistently demonstrates that superficial terminological changes are insufficient for creating truly inclusive research environments. Instead, meaningful language transformation requires fundamental shifts in research leadership, institutional power structures, and epistemological approaches that center community expertise alongside scientific rigor.

Identification of Gaps

Several critical gaps emerge from this analysis that limit current understanding and implementation of inclusive language practices. First, longitudinal studies examining the impacts of language changes on actual health outcomes and research quality remain scarce, making it difficult to assess the effectiveness of inclusive language interventions beyond immediate attitudinal changes. Second, insufficient research addresses how different disability communities prefer different linguistic approaches, often defaulting to universal solutions that may not reflect community diversity. Third, minimal investigation examines how inclusive language practices affect research methodology, participant recruitment, and knowledge dissemination beyond clinical encounters.

Fourth, technological dimensions of language bias require expanded attention, particularly as electronic health records and algorithmic systems increasingly mediate healthcare communications. Fifth, global perspectives remain underrepresented, with most research concentrated in English-language, North American contexts that may not reflect international language practices and cultural considerations. Finally, community-based knowledge continues to be inadequately integrated into academic literature reviews, despite its essential role in understanding authentic language impacts and preferences.

Future Research Directions

Based on these findings, several priority areas emerge for future investigation. First, longitudinal research examining the sustained impacts of inclusive language practices on health outcomes, research quality, and community engagement is critically needed to demonstrate evidence-based benefits of language transformation initiatives. Second, community-led research methodologies should be expanded and supported, particularly investigations that center disability community voices in defining language preferences and evaluating research practices.

Third, intersectional research approaches require further development, particularly studies examining how multiple identity markers interact within biomedical language systems and how communities with complex identities navigate research participation. Fourth, technological literacy around language bias should be prioritized, including research on how algorithmic

systems interpret and perpetuate linguistic bias in healthcare documentation and research databases.

Fifth, international and cross-cultural research is essential for understanding how inclusive language practices translate across different healthcare systems, cultural contexts, and linguistic frameworks. Sixth, implementation science approaches should be applied to study how inclusive language practices can be effectively integrated into existing research and clinical workflows without creating additional barriers for practitioners or communities.

Concluding Statement

The transformation of scientific language practices in disability and rare disease research represents both a methodological imperative and an ethical commitment to research justice. This literature review demonstrates that language operates as more than a communication tool—it functions as a mechanism of power that can either perpetuate marginalization or enable liberation. The evidence clearly indicates that when disability communities gain authority to define their own experiences within research contexts, material outcomes improve: research priorities align with community needs, funding patterns address historically neglected conditions, and clinical protocols reflect lived experience rather than external assumptions.

The path forward requires sustained collaboration between scientific communities and disability communities, guided by the principle "Nothing About Us Without Us" and grounded in intersectional frameworks that acknowledge the full complexity of human identity and experience. True precision in biomedical language demands not the elimination of community perspectives in favor of clinical objectivity, but rather their integration into research practices that honor both scientific rigor and community expertise.

As biomedical research continues evolving toward more participatory and community-engaged methodologies, inclusive language practices will serve as both foundation and indicator of genuine research partnership. The literature suggests that institutions and researchers committed to health equity must move beyond superficial terminology changes toward fundamental examination of who holds definitional authority, how knowledge is validated, and whose voices

shape the questions that research seeks to answer. Only through such comprehensive transformation can scientific language become a tool that serves community liberation rather than institutional control, ultimately advancing both scientific understanding and social justice in service of more equitable health outcomes for all communities.

Appendix: Literature Analysis by Discipline

Disciplinary Distribution of Sources

This literature review draws from a diverse range of academic disciplines, reflecting the multidisciplinary nature of inclusive language research in disability and rare disease contexts. The following analysis provides both quantitative distribution and qualitative synthesis of contributions from each field.

Quantitative Analysis

Discipline	Percentage (%)
Disability Studies	14.6%
Biomedical Sciences	14.6%
Public Health	8.3%
Psychology	6.2%
Health Education	6.2%
Sociology	6.2%
Linguistics	4.2%
Classification Systems	4.2%
Rehabilitation	4.2%
Policy Studies	4.2%
Rare Disease Research	4.2%
Technology	4.2%
Nursing	2.1%

Discipline	Percentage (%)
Advocacy	2.1%
Youth Work	2.1%
Healthcare Training	2.1%
Interdisciplinary	2.1%
Intersectional DEI	2.1%
Biomedical Research	2.1%
Community Advocacy	2.1%
Health Metrics	2.1%

Key Terminology Analysis

Most Prominent Terms:

- *Ableism*, *Inclusive Language*, *Person-first Language*, *Medical Model*, *Social Model*
- *Identity-first Language*, *Disability Models*, *Rare Disease*, *Intersectionality*
- *Health Equity*, *Rehabilitation*, *Policy Change*

Other Important Keywords:

- *Linguistic Ableism*, *Representation*, *Terminology*, *Disability Prejudice*
- *Health Disparities*, *Community Advocacy*, *Electronic Health Records*
- *Algorithmic Bias*, *Race-based Medicine*, *COVID-19*, *Multidisciplinary*

Detailed Disciplinary Analysis

Biomedical Sciences and Health Models

The biomedical literature establishes foundational frameworks for understanding disability through various conceptual models. Snyder et al. (2008) examine the utility of disablement models in athletic training practice, demonstrating how these frameworks organize clinical practice and create common language among healthcare professionals. Their work builds upon

Nagi's foundational conceptual issues in disability and rehabilitation, which established the medical model's dominance in biomedical sciences.

The World Health Organization's International Classification of Functioning, Disability and Health (2001) represents a pivotal shift toward more comprehensive disability classification systems. This framework evolved from earlier models, as documented by Brandsma et al. (1995) and Dickson (1995), who critiqued limitations in the ICIDH definition of impairment. Halbertsma et al. (2000) contributed to this evolution by working toward a new ICIDH framework that addressed previous definitional inadequacies.

Jette (2006) emphasizes the importance of developing common language for function, disability, and health within physical therapy and rehabilitation, highlighting how disciplinary language shapes practice outcomes. This body of work demonstrates the medical field's ongoing struggle to balance clinical utility with inclusive representation.

Psychology and Disability Studies

The psychological literature provides critical perspectives on disability conceptualization and language impact. Olkin (2022) offers comprehensive analysis of three dominant disability models—medical, moral, and social—and their psychological implications. This work builds upon foundational disability studies scholarship by Oliver (1990), whose "Politics of Disablement" established critical frameworks for understanding disability as socially constructed rather than purely medical.

Nario-Redmond (2019) advances this discourse through examination of ableism's causes and consequences, providing psychological evidence for how language perpetuates disability prejudice. Forstner (2022) contributes to this understanding by tracing the development of conceptual disability models and their incorporation of non-biomedical aspects.

Brinkman et al. (2022) offer contemporary perspectives on shifting disability discourse toward inclusive, intersectional approaches within psychological practice. Their work demonstrates psychology's evolving recognition of language's power in shaping therapeutic relationships and outcomes.

Linguistics and Language Studies

The linguistic literature examines how language choices impact perception and social positioning of disabled individuals. Wilson and Lewiecki-Wilson (2001) provide foundational analysis of embodied rhetoric and disability's representation in language and culture, establishing connections between linguistic choices and social power structures.

Grue (2017) offers discourse analysis perspectives on disability and multidisciplinary contexts, examining how language functions across different professional domains. Wood (1980) contributed early systematic analysis through development of disability language glossaries that traced disease consequences and their linguistic representations.

Cooper (2022) extends this analysis to relational contexts, demonstrating why language matters in youth work and interpersonal relationships. This body of work establishes language as both tool and barrier in disability-related interactions.

Healthcare Practice and Professional Training

Healthcare literature reveals significant gaps between professional training and inclusive language practices. Crocker and Smith (2019) examine whether healthcare professionals practice person-first language principles they advocate, revealing inconsistencies between stated values and actual practice.

Bottema-Beutel et al. (2021) provide specific guidance for autism researchers on avoiding ableist language, demonstrating disciplinary efforts to address harmful terminology. Friedman (2023) examines how disability professionals' demographics influence their language choices, revealing systemic patterns in ableist language use.

Rotenberg et al. (2022) contribute global evidence synthesis on disability training for health workers, highlighting worldwide needs for improved professional education on inclusive language and disability competency. Edwards et al. (2022) provide empirical evidence on the comparative effects of disability education on nursing students' attitudes, knowledge, and skills,

demonstrating that targeted educational interventions can improve healthcare providers' disability competency.

Bourne et al. (2021) examine healthcare inequities among adults with developmental disabilities through an integrative review, providing specific implications for nursing education. Lunsky et al. (2021) offer contemporary perspectives on healthcare access during COVID-19, examining how communication challenges and linguistic barriers impact healthcare delivery during crisis situations.

Public Health and Policy Studies

The public health literature documents policy-level language changes and their societal impacts. Rosa's Law (2010) demonstrates how legislative language changes function as destigmatization symbols in psychiatry and broader healthcare contexts.

Recent work by Palmer and McFarling (2024) and Wilson et al. (2025) examines how biomedical research approaches race and ethnicity, providing parallel insights into how demographic categories are constructed and contested in scientific discourse. Smith (2020) contributes critical analysis of race-based medicine, offering frameworks applicable to disability-based medical categorization.

Tengland (2010) provides theoretical foundation for distinguishing between health promotion and disease prevention in public health practice, offering frameworks relevant to understanding how language shapes public health approaches to disability. Johnson and Wolinsky (1993) contribute foundational research on health status structure among older adults, examining relationships between disease, disability, functional limitation, and perceived health.

Community Voices and Advocacy Literature

An important addition to the academic literature comes from community-based advocacy sources. Brown's (2011) analysis of person-first language significance provides authentic community perspective on semantic choices, demonstrating how language preferences vary within disability communities. This work, published on the Autistic Hoya blog, represents the

type of community-based scholarship often excluded from traditional academic literature reviews but essential for understanding lived experiences of language impact.

Brown's work illustrates the importance of including community voices in academic discourse about disability language, challenging academic assumptions about preferred terminology and highlighting how identity-first language serves as empowerment tool for many disabled individuals.

Technology and Information Systems

Emerging literature addresses how technology interfaces with disability language and identification. Fabregat et al. (2020) examine disability identification in medical documents through computational approaches, demonstrating how algorithmic systems interpret and categorize disability-related language. Their work reveals how technological systems can perpetuate or challenge linguistic bias in healthcare documentation, with implications for electronic health records and automated systems.

Interdisciplinary and Emerging Perspectives

Foreman (2005) contributes interdisciplinary analysis of language and disability within intellectual and developmental disability contexts, bridging educational, psychological, and medical perspectives. Altman (2001) offers comprehensive analysis of disability definitions, models, and classification schemes across multiple applications.

Fougeyrollas et al. (2002) advance interdisciplinary understanding through examination of environmental interactions with individual characteristics and social participation in spinal cord injury contexts. Hattery et al. (2022) contribute contemporary analysis of diversity, equity, and inclusion in research teams, examining how team composition and inclusive practices influence research language and methodology.

Synthesis Across Disciplines

This disciplinary analysis reveals several consistent themes: (1) ongoing tension between medical and social models of disability, (2) significant gaps between stated inclusive language principles and actual practice, (3) limited involvement of disabled people in research about their own communities, and (4) need for interdisciplinary collaboration in developing truly inclusive language frameworks.

The expanded literature base reinforces these themes while revealing additional patterns: healthcare education shows promising but limited progress in disability competency training, technological systems require careful attention to prevent algorithmic bias in disability identification, and community voices often diverge from professional recommendations about preferred language choices. Notable gaps include limited longitudinal studies on language change impacts, insufficient analysis of how different disability communities prefer different linguistic approaches, and inadequate representation of community-based knowledge in academic literature reviews.

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