Alliance for NIDILRR Grantees

Advancing Disability Research and Development

Welcome to the Alliance!

At our annual meeting on April 14, 2026, the NARRTC formally adopted a new name: the *Alliance for NIDILRR Grantees (ANG)*. This change goes beyond branding to reposition the organization as strategically grounded in the history of federal disability research and the realities of today's policy environment. The purpose of the Alliance for NIDILRR Grantees is to improve the quality of life, independence of life choices, and the inclusion of individuals with disabilities and their families through relevant research, training, technical assistance, knowledge translation, development, and demonstration activities. ANG organizes an annual meeting that is the primary forum for NIDILRR grantees to network with one another and with NIDILRR staff, promoting collective knowledge that advances the disability research and development field.

At this time, as NIDILRR faces potential funding cuts in the face of longstanding underfunding, the Alliance for NIDILRR Grantees additionally offers you the opportunity to unite your voice with other NIDILRR grantees and those of like mind so that together we have a unified voice, a coordinated strategy, and a clear account of what is at stake.

Why this name?

Intentionally inclusive, the ANG aims to represent the full community of current, former, and prospective grantees funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR): researchers, engineers, clinicians, service providers, community-based organizations, and, critically, people with disabilities themselves as partners in knowledge production.

Centering NIDILRR in our name signals our shared concern, across disciplines and institutions, to maintain and adequately fund this essential research agency. To understand why NIDILRR matters so much to the disability research and advocacy communities, it is important to review the Institute's creation and evolution.

From Civil Rights to Research

The modern disability research enterprise in the United States is rooted in the Rehabilitation Act of 1973. Widely recognized as the first civil rights law prohibiting disability discrimination in federally funded programs, its passage followed sustained political pressure from disability activists after an initial presidential veto. While the Act is often remembered for its civil rights provisions, it also established a national commitment to disability research.

Section 202 of the Act authorized "research, demonstrations, and related activities" aimed at improving vocational rehabilitation and independent living outcomes, particularly for individuals with significant disabilities. Importantly, this mandate emphasized applied disability research,

work intended not only to generate scientific knowledge, but to directly inform policy and practice. To operationalize this vision, Congress created several core funding mechanisms that continue to define the field, including:

- **Rehabilitation Research and Training Centers (RRTCs)**, focused on advanced research and workforce development
- **Rehabilitation Engineering Research Centers (RERCs)**, designed to apply technology and interdisciplinary science to rehabilitation challenges
- **Model Systems programs**, beginning with spinal cord injury and later expanding to traumatic brain injury and burn injury, demonstrating the value of integrated systems of rehabilitation care

These programs established a durable architecture linking federal funding to applied, outcomes-oriented research. The National Institute of Handicapped Research (NIHR), created in 1978, was tasked with administering this portfolio. Its formation reflected collaboration among policymakers, disability advocates, and rehabilitation professionals. This alignment would shape the field for decades.

Yet early implementation revealed structural tensions. NIHR funding initially flowed disproportionately to medical schools and rehabilitation hospitals, reflecting the institutional dominance of the medical model of disability over one focused on efforts to promote the full participation of people with disabilities in all aspects of society. Over time, this imbalance would be challenged and partially corrected through the demonstrated benefits of NIDILRR-funded projects for the lives of people with disabilities and consequent policy reforms.

Redefining Disability Research: "Nothing About Us Without Us"

A defining feature of disability research has been the integration of lived experience into the research process itself. Disability leaders such as Ed Roberts, Judy Heumann, and Lex Frieden emphasized that policy gains required credible, relevant scientific evidence. The principle of "nothing about us without us" expanded from a political demand into a methodological framework.

This shift reshaped NIDILRR-funded research. Requests for proposals required the inclusion of people with disabilities in defining research questions, designing studies, interpreting findings, and disseminating results to increase the likelihood that research outcomes are relevant to the practical needs of the disability community. NIDILRR grant review processes have reinforced this evolution. Disabled scholars and advocates are recruited for each grant review, and scoring criteria include specification of beneficial impacts on the target population. Embedding participatory principles within NIDILRR's funding structures ensures the production of relevant research and development products, and similar approaches are now being adopted in other federal research agencies.

Institutional Evolution, Financial Stagnation

Over time, the federal disability research enterprise evolved in both name and structure. NIHR became the National Institute on Disability and Rehabilitation Research (NIDRR) in 1986, and later NIDILRR in 2014, reflecting an expanded focus on independent living and community participation.

The move to the Administration for Community Living (ACL) further aligned the agency with broader health and human services systems. Conceptually, these changes represented progress. Financially, the picture is less encouraging.

NIDILRR's budget, approximately $119 million, has remained essentially flat for decades. Adjusted for inflation, the agency has lost substantial purchasing power since the early 2000s. A FY2001 budget of $110 million would exceed $190 million in today's dollars. At the same time, the need for the type of applied disability research that NIDILRR funds has increased. The U.S. population with disabilities has grown, driven by aging, improved survival rates, and broader recognition of disability. Enrollment in major federal programs—SSI, SSDI, Medicaid, and Medicare—has expanded accordingly. Policymakers are increasingly reliant on evidence to document the real-world benefits of NIDILRR-funded interventions and products that can guide decisions in areas such as employment, long-term services and support, and community integration.

In short, the need for rigorous, policy-relevant disability research has never been greater, yet the primary federal entity responsible for producing that research has not kept pace.

Recent Political Developments: From Constraint to Risk

Recent policy developments have sharpened this mismatch between demand and capacity.

During the Biden administration, disability gained greater recognition within federal policy, including designation as a health disparity population within the Department of Health and Human Services. This created opportunities for integrating disability into broader public health and research frameworks.

However, these conceptual advances were not matched by increased appropriations for NIDILRR. According to Office of Management and Budget documents, funding remained largely flat across recent fiscal years, resulting in continued erosion of real capacity.

More concerning are emerging policy proposals that introduce structural risks to NIDILRR itself.

Federal budget resolutions have called for significant reductions in non-defense discretionary spending, targeting FY2022 funding levels or lower in future years. Under such constraints, smaller research programs are particularly vulnerable. Appropriations language has increasingly emphasized consolidation of "duplicative" programs—categories into which NIDILRR is sometimes placed, despite its distinct statutory mandate.

At the same time, proposals to reorganize the Department of Health and Human Services have raised the possibility of consolidating smaller operating divisions, including the Administration for Community Living. Because NIDILRR is housed within ACL, such changes could alter its institutional alignment, reduce its visibility, and expose its funding to internal reallocation.

Additional signals point to operational risks. Shifts toward block-granting and state-directed funding models, while not directly targeting NIDILRR, indicate a broader move away from federally coordinated research investment, which could, ironically, lead to redundant, scattered efforts.

Finally, federal research priorities have increasingly focused on biomedical innovation, artificial intelligence, and national security. Disability and rehabilitation research—particularly work focused on services, participation, and policy—does not align neatly with these categories and risks being deprioritized in their shadow.

Taken together, these developments represent a transition from incremental fiscal constraint to systemic vulnerability.

A Minimum Threshold for Capacity

Within this context, the disability community's request for $150 million in FY2027 is a baseline, not an expansion. It would partially restore inflation-adjusted funding levels, stabilize grant competitions, and help maintain a viable research pipeline.

Even at that level, NIDILRR would remain small relative to other federal research agencies. But it would be better positioned to fulfill its statutory mandate and respond to increasing demand for evidence-based policy.

Absent such adjustments, the likely trajectory is continued erosion—not only in funding, but in institutional influence and research capacity.

Why the Alliance Matters

For decades, the people and institutions doing disability research have worked largely in isolation from one another: separate programs, separate institutions, separate conversations with policymakers. The result was a field that is scientifically productive but politically underrepresented: one whose importance was rarely communicated with the coherence or consistency that federal appropriations decisions require.

That fragmentation was always a weakness. In the current policy environment, where NIDILRR faces consolidation pressures, budget cuts, and potential institutional displacement, the field can no longer afford it as a liability.

The Alliance for NIDILRR Grantees is built to address that directly. By uniting researchers, engineers, clinicians, community organizations, and people with disabilities under a shared mission, ANG creates the collective infrastructure the field has lacked: coordinated advocacy in appropriations discussions, a unified presence in federal policy processes, and a platform that makes the breadth and impact of disability research visible to those who control its future.

Critically, ANG centers people with disabilities not as beneficiaries of this work, but as architects of it. The participatory principles that have strengthened NIDILRR's research must also shape how the field advocates for itself.

Our name change reflects a deliberate strategic decision to meet this moment with the kind of organized, cross-sector advocacy the field has never had but has always needed. A fragmented field could not prevent decades of flat funding. A unified one has a better chance of reversing it.

Looking Forward

The history of NIDILRR is a history of hard-won progress built through decades of research and the insistence that people with disabilities deserve both civil rights and the evidence base to support them. That progress has never been automatic. It has required sustained attention to the policy environments in which research is funded, conducted, and used.

The current moment is one of genuine risk. The threats facing NIDILRR are not hypothetical. Flat funding has already eroded real capacity, and structural proposals now in circulation could do lasting damage to an agency that took fifty years to build. The disability research community cannot afford to treat these as abstract policy developments.

Research funded by NIDILRR has changed lives. It has shaped policy, driven technological innovation, and expanded what is possible for people with disabilities nationwide. The Alliance for NIDILRR Grantees exists to support that capacity by strengthening coordination across the field and ensuring that disability research remains visible, relevant, and adequately resourced within the federal policy landscape.

For more information, go to:

www.joinANG.org

Join our LinkedIn group, the Alliance for NIDILRR Grantees, at:

www.linkedin.com/groups/16004105/

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