Community Brief: Data Chat and ReDDDoT Workshop Findings

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Employing Public Interest Technologies to Promote Access in Education and Employment for People who have Physical Disabilities

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Introduction

The history of assistive technology shows that when people with lived experience co-lead development, the outcomes are more effective, innovative and inclusive. For example, the PneuChair, a low-cost, waterproof wheelchair designed for rugged terrain and powered by pneumatic energy, was developed through collaboration between engineers (including wheelchair users) and other wheelchair users. This process improved the technical design and promoted agency and mobility for people with disabilities. It provides joy to people of all ages at an all-accessible waterpark and has tremendous potential for emergency use during natural disasters. However, these stories are still the exception. Despite universities having tremendous potential for innovation, significant barriers (including financial constraints, complex insurance rules, discrimination, and knowledge gaps) prevent transformative technologies from reaching their full potential to advance accessible mobility. This Community Brief highlights the key findings and recommendations from two main gatherings that focused on the role of Public Interest Technology to address these challenges.

With a grant from the National Science Foundation ReDDDoT Program, we implemented a DataChat and a Research Workshop on Employing Public Interest Technologies to Promote Access in Education and Employment for People who have Physical Disabilities. Both events were held at Case Western Reserve University on May 15 and June 9-10, 2025, respectively.

In preparation for the Workshop, we hosted a DataChat with community members with lived experiences of physical disabilities to talk about barriers to advancing accessible mobility. The goal was to learn directly from people most affected by barriers to mobility across health care, transportation, technology, and the built environment, ensuring that the voices and experiences of stakeholders were front and center in the discussions around technology and research for accessible mobility.

The Workshop brought together researchers, policymakers, and educators, among them, people with lived experience of physical disabilities, to discuss how innovative knowledge, education, and technologies can effectively advance accessible mobility, understood as the ability of people with disabilities to navigate safely and independently the built environment to access opportunities for human development.

We share findings and calls for action from both events below.

DataChat Findings

Unlike traditional research, DataChats see participants as collaborators, not subjects. Our team at CWRU invited collaborators through a recruitment and consent process reviewed by the university's ethics board. The session was held in a hybrid format (in person and online) to ensure accessibility.

Our collaborators represented a wide range of backgrounds (sociology, psychology, design, pharmacy, business, IT, engineering, and culinary arts) and worked in areas like advocacy, community health, workforce development, and sports. Their interests were just as diverse: outdoor activities, exercise, travel, comics, model-building, music, and more.

During the conversation, we shared and discussed two system maps, one related to transportation and another to technology development and deployment for accessibility. We listened to the collaborators' concerns within these systems and the built environment. We also engaged in a cognitive mapping exercise about the causes and consequences of increased accessible mobility. The discussion highlighted several key themes:

Standardization and reliability in tech development matter: Participants noted that wheelchairs and other devices break down quickly and do not seem designed to be fixed but rather replaced. They called for universal standards and reliable technology that truly supports independence and dignity. Referring to locking devices for wheelchairs, a collaborator said: "*...some chairs can be locked down [for travel]. Others, they have to find a spot, when certain things should be standard. The technology should be standard.*"

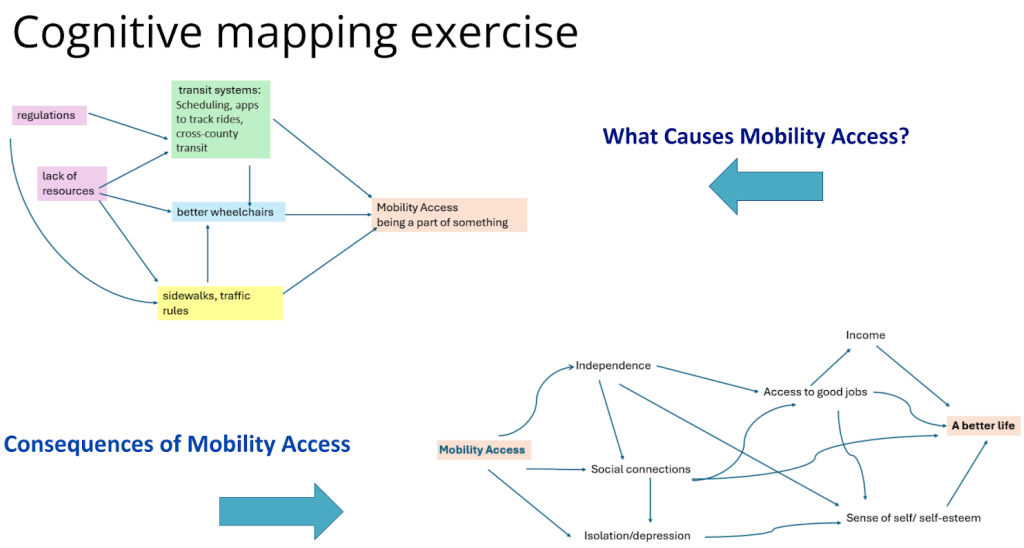
Transportation system and infrastructure gaps: Limited cross-county transit, weight restrictions for wheelchair users on buses, unreliable medical transportation, and a lack of roadside support leave people stranded or missing important medical or family appointments. Uneven sidewalks, broken elevators, and poor ramp access show the need for consistent national accessibility standards. A collaborator mentioned that the lack of cross county transit *"makes it very challenging to get to doctor's appointments."* Regarding city planning, another said *"My sidewalks here are always on the slant... you gotta be very careful, because you can be thrown right into traffic."*

Insurance and health system hurdles: Navigating insurance for mobility equipment is often confusing and fragmented, forcing individuals to invest time and resources to coordinate between disconnected systems. A collaborator mentioned *"insurance is the last people who want our input on anything."* Others acknowledged the need for closer coordination: *"our whole system needs to change. It doesn't have to be erased. But they can come together to the table. All the insurance companies, the tech people. There's a way."*

ADA as the "bare minimum": The Americans with Disabilities Act (ADA) provides a baseline, but participants said it falls short of real inclusion. *"ADA does not mandate universal accessibility when it comes to transit."* They urged stronger enforcement and broader coverage—especially across transportation systems.

Through a mapping exercise, collaborators linked mobility to independence, dignity, and community participation. Increased mobility increases participation in key life areas like education, employment, and social inclusion, leading to a "better life." As one participant expressed, **it's the difference between being in a community and *"being a part of it."***

***Image Description:** The top map (to the left) shows factors that influence accessible mobility according to DataChat collaborators. The bottom map (to the right) shows the consequences of accessible mobility, ultimately leading to a better life.*



DataChat insights were shared at the start of our workshop to ensure all discussions began with lived experience at the center; a central tenet of Participatory Research and Public Interest Technology.

Workshop Findings:

The workshop explored *Public Interest Technology (PIT),* an interdisciplinary approach that explicitly centers lived experience to advance social good. PIT refers to developing and using technology for the public interest - that is to help society as a whole, with a focus on accessibility.

PIT is rooted in core values:

- **Accessibility and Equity:** Technology should be used to serve the public good.
- **Human-Centered Design:** Centered on ensuring equitable access and outcomes.
- **Expert Innovators:** The workshop emphasized that individuals with disabilities are often **"expert innovators"** because they navigate an inaccessible world daily, making their insights crucial for technological advancement.

Policymakers often set policy agendas without the participation of people with disabilities. Attitudinal barriers also persist due to centuries-old stigma that ignore the creative talent that people with lived experiences carry.

Positive policy change is possible, as exemplified by the updated Americans with Disabilities Act (ADA) regulation for digital accessibility in state and local government (including K-12 and higher education)[1]. This change resulted directly from engaging professionals with lived experiences in policy settings.

Key Areas Needing Transformation:

The workshop discussions highlighted persistent issues in neurotechnology, transportation, and academic-community collaboration, demonstrating that *systemic barriers require structural, not just technical solutions.*

Transportation:

Transportation emerged as a consistently problematic area, underscoring that transportation systems currently fail people with disabilities due to systematic barriers and a culture of ableism. These failures often stem from treating transportation as a collection of competing commercial services rather than a coordinated public good.

Critical Transportation Failures Identified:

- **Cross-Jurisdictional Barriers:** County and municipal lines create artificial limits on mobility. For instance, some county transit systems cannot cross into neighboring

[1] https://www.ada.gov/resources/2024-03-08-web-rule/

counties, forcing residents to miss essential appointments or rely on costly private transport. Weight limits on public transportation also arbitrarily exclude many power wheelchair users.

- **Emergency Response:** There is inadequate support infrastructure for system failures. The absence of specialized emergency services, such as *AAA-equivalent services for power wheelchairs,* means users are often stranded or require emergency medical transport for non-medical incidents.
- **Inconsistent Accessibility:** Bus platforms vary widely, driver training is inconsistent, and vehicles lack standardization (e.g., essential tie-downs for wheelchairs might be missing).
- **Infrastructure Design:** Uneven sidewalks, potholes, steep slopes, inaccessible bus stops, and poorly timed traffic signals create daily hazards.
- **Autonomous Vehicle (AV) Risk:** Emerging AV technology currently focuses on the "sighted driver of the present," risking the exclusion of the disability community through touchscreen-centric environments and reliance on visual indicators. Personalized AVs also raise critical *data privacy concerns* about who owns the personal data generated and whether marginalized populations must sacrifice privacy to access essential services.

Neurotechnology: Addressing the "Valley of Death"

Neurotechnology encompasses devices and systems that interact with the brain or nervous system to regain some level of mobility after paralysis or injury. However, this technology faces significant barriers to widespread adoption.

A major challenge is the *Translational Valley of Death*, where promising interventions fail to become commercial products due to low profit potential given the relatively small product demand. This failure often leads to *abandonment*, where users lose access to information, support, and safety updates for their crucial devices once clinical trials end or companies cease operations. Abandonment has far-reaching consequences, including loss of regained function, health risks, and psychological distress for users.

A Sustainable Solution: *Cleveland's Open Source, Modular Implant Innovators Community (COSMIIC)* was presented as an innovative, PIT-aligned approach to combating abandonment. COSMIIC makes comprehensive information (software, blueprints, regulatory documentation) on implantable devices available through an open-source framework. This initiative aims to promote standardization of components and maintain long-term support of mobility devices, thus promoting increased development and use.

Recommendations for Action

To realize the full potential of Public Interest Technology and advance accessible mobility, the workshop generated recommendations focused on systemic change, true collaboration, and sustained commitment.

I. Centering Lived Experience and Policy Reform

- **Meaningful Inclusion:** The involvement of people with disabilities must be secured throughout all stages of research and technology development—from problem identification to design and evaluation.
- **Design for Universal Accessibility:** Technology design must assume that nearly everyone will require different adaptations over time, necessitating *universal accessibility embedded in all systems* from the outset, not as a later accommodation.
- **Expand the ADA:** While foundational, there is a need to strengthen the Americans with Disabilities Act (ADA) to insure compliance proactively. There is a strong call for an *expanded ADA mandate* to cover all transportation modes and require proactive enforcement to ensure true inclusion and independence.
- **Protect User Agency and Data:** As technology becomes more personalized (e.g., in autonomous vehicles), *explicit protections for data privacy and user agency* (like the desire for manual override capabilities) must be built into design and governance.

II. Ensuring Sustainable Technology and Infrastructure

- **Structural Solutions for Mobility:** Financial and structural barriers, such as fragmented transportation systems and inconsistent standards, require policy reform and *cross-jurisdictional coordination*. Transportation must be treated as a coordinated public good.
- **Standardization and Consistency:** National standards are needed for service and infrastructure (like sidewalks and bus stops). Universal design standards must be used across all transportation modes and jurisdictions to ensure predictable, safe access.
- **Mitigate Abandonment:** Research can be developed under funding and regulatory systems that sustain assistive technologies over time. This includes support for open-source initiatives in neurotechnology development like COSMIIC and implementing *regulatory guidance for transition plans and end-of-life device planning.*

III. Fostering True University and Community Partnerships

Successful Public Interest Technology requires *interdisciplinary collaboration* that integrates technical expertise and community engagement.

- **Funders Must Demand Partnership:** Funding agencies should prioritize programs that require proposals to *specify partnerships with community groups* that actively contribute to the research.
- **Fair Compensation:** It is crucial to *directly pay community partners* for their time, expertise, and connections. University administrative barriers to compensation must be addressed.
- **Collaborative Problem Identification:** Researchers must work *with* community partners to define problems, avoiding the imposition of pre-determined technological solutions.
- **Building Capacity and Trust:** Collaborations should aim to help community organizations build capacity and advance their mission, not solely serve academic research needs. Building trust requires demonstrating humility, listening, and following through on commitments and long term relationships.
- **Knowledge Dissemination:** Research findings must be reported back to community partners in *plain, accessible language, open source formats, and through community presentations* to foster accountability and ongoing collaboration.

Only through these collective, interdisciplinary, and community-driven efforts can transformative research and technologies reach their full potential to serve the public good.

Notes & Acknowledgments:

COSMIIC - Collaborative Open Source Modular Implantable Interfacing & Control is an open-source ecosystem focused on neuromodulation research and therapies. By making the system open and broadly available, researchers seek to accelerate translation from theory to therapy without having to “re-invent the wheel” for every lab or project. https://docs.cosmiic.org/

PneuChair: Daveler, B., Gebrosky, B., Grindle, G., & Cooper, R. A. (2018). Development of the PneuChair: Pneumatic-Powered Wheelchair. Technology and Innovation, 20(1–2), 11–19. https://doi.org/10.21300/20.1-2.2018.11

Full Report: Richter, F., Gran, B., Robertson, C., Bryden, A. (2025) ReDDDoT Phase 1 Workshop: Employing Public Interest Technologies to Promote Access in Education and Employment for People who have Physical Disabilities. Case Western Reserve University, Center on Poverty and Community Development Policy Brief.

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