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Strengthening Data Systems, Tracking Practices, and Digital Tools to Support Evidence-Informed Engagement of People with Disabilities

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Abstract

Reliable, well-disaggregated data on persons with disabilities remain scarce in many national statistical and programmatic systems, and this gap continues to undermine evidence-informed policymaking, service delivery, and accountability. This paper examines how strengthened data systems, harmonized tracking practices, and accessible digital tools can support more meaningful, evidence-informed engagement of people with disabilities across health, education, employment, and humanitarian sectors. Drawing on global frameworks such as the Convention on the Rights of Persons with Disabilities and the 2030 Agenda for Sustainable Development, the paper reviews the rationale for disability-disaggregated data, the role of standardized instruments such as the Washington Group Questions, the contribution of digital and assistive technologies to inclusive data collection and service engagement, and the persistent barriers of financing, capacity, and meaningful participation by organizations of persons with disabilities. These themes are further examined through practitioner-generated findings from a disability rights NGO peer-learning session on data and digital infrastructure, which illustrate how global-level barriers manifest in the day-to-day tool choices, tracking practices, and peer-support needs of frontline organizations. The paper concludes that strengthening data systems is not a technical exercise alone; it requires co-designed, rights-based, and adequately resourced approaches that center the lived experience of people with disabilities throughout the data value chain.

Keywords: disability data, data systems, Washington Group Questions, digital accessibility, evidence-informed engagement, disability-inclusive development.

Introduction

People with disabilities make up roughly one in six people worldwide, yet they remain among the least visible populations in official statistics, programme monitoring systems, and digital services (Mörchen et al., 2019). This invisibility is not incidental; it is the product of fragmented data systems, inconsistent definitions of disability, limited financing for disability statistics, and digital infrastructures that were never designed with disabled users in mind. The consequence is a persistent evidence gap that weakens the ability of governments, humanitarian actors, and service providers to design, target, and evaluate disability-inclusive policies and programmes (Global Disability Summit, 2025).

Strengthening data systems, harmonizing tracking practices, and deploying accessible digital tools are therefore not peripheral technical concerns; they are foundational to evidence-informed engagement of people with disabilities. As the United Nations Educational, Scientific and Cultural Organization (UNESCO, 2025) argues, when people with disabilities remain invisible in data, they remain unaccounted for in the policies meant to serve them. This paper reviews the current evidence based on disability data systems and tracking practices, examines the contribution of digital tools and assistive technologies to inclusive engagement, and identifies the structural barriers and opportunities that determine whether evidence-informed approaches translate into meaningful inclusion.

The paper's contribution to broader literature is twofold. First, it brings together three strands of scholarship that are typically examined in isolation, standardized measurement instruments, digital and assistive technology, and the financing and governance barriers that shape whether data are used, and treats them as interdependent components of a single evidence-informed engagement pathway rather than as separate technical domains. Second, it extends this largely policy- and instrument-focused literature with grounded, practitioner-generated evidence from a disability rights NGO peer-learning session, a type of source that is rarely incorporated into published scholarship on disability data systems. Taken together, these two moves allow the paper to connect macro-level debates about data disaggregation, measurement validity, and digital accessibility directly to the everyday tool choices, tracking practices, and peer-support needs of frontline organizations, a link that much of the existing literature leaves implicit rather than examined directly.

The Case for Disability-Inclusive Data Systems.

The rationale for investing in disability data systems rests on both a rights-based and a practical foundation. The Convention on the Rights of Persons with Disabilities (CRPD) and the 2030 Agenda for Sustainable Development both call explicitly for data to be collected and disaggregated by disability status, yet implementation remains uneven across countries and sectors (Global Disability Summit, 2025). Harmonized disability data are needed to support comprehensive, evidence-based policies and programmes; without standard definitions and comparable measurement approaches, administrative and survey data cannot be meaningfully compared across time, place, or population subgroup (Houtenville & Boege, 2023).

UNESCO (2025) further notes that the Jakarta Declaration recognizes the continuing shortage of reliable information on persons with disabilities and commits signatory states to strengthening national and subnational capacity to track disability-inclusive development. Achieving this requires producing comparable, quality data disaggregated by gender, age, and disability status across sectors, so that policymakers can identify where learners, workers, and service users with disabilities are being excluded and respond accordingly (UNESCO, 2025). The needs that such data must capture evolve across the life course: a child with a disability may require accommodations to remain enrolled in school, a working-age adult may need accommodations to retain employment, and an older adult may require support to participate in civic life, and each of these needs can only be tracked once the population with disabilities has first been identified within routine data systems (Houtenville & Boege, 2023).

At the same time, several scholars and practitioners caution against treating data disaggregation as an end. A realist evaluation of disability disaggregation in humanitarian programming found that the assumption that simply generating more disaggregated data will automatically produce more inclusive outcomes does not hold consistently across contexts (Card et al., 2024). The authors advocate moving away from a

uniform, blanket approach to disaggregation toward more context-specific applications that are tied to a clear plan for how the resulting data will be used to inform decisions and resource allocation. This distinction between data collection and data use is a recurring theme across the literature: data systems must be embedded within decision-making pathways, not treated as a standalone reporting exercise (Schiavo et al., 2025).

Standardized Tracking Practices: The Washington Group Questions

Among the most widely adopted tools for harmonizing disability tracking is the Washington Group Short Set of Questions (WG-SS), a six-item module measuring functional difficulty across domains such as seeing, hearing, walking, cognition, self-care, and communication (Card et al., 2024). The WG-SS was developed to provide a comparable way of identifying populations at risk of exclusion, in line with the CRPD's framing of disability as arising from the interaction between an individual's functional limitations and environmental and attitudinal barriers (Card et al., 2024). Respondents who report 'a lot of difficulty' or 'cannot do at all' on at least one functional domain are classified as having a disability for the purposes of data disaggregation, including for the disability-related Sustainable Development Goal indicators (Washington Group on Disability Statistics, 2020).

The practical value of the WG-SS lies in its low cost, ease of administration, and capacity to be embedded into existing or planned surveys and administrative systems, which allows disaggregation of outcome indicators, such as school enrollment or employment status, by disability status within the same data collection exercise (Washington Group on Disability Statistics, 2020). A hospital-based application of the WG short and extended question sets in an eye department in Paraguay illustrated this utility directly: among 999 patients who completed the WG-SS, 27.7% were classified as having a disability, with communication difficulties identified as the second most common functional limitation after visual difficulties, and older patients showing substantially higher odds of disability classification (Mörchen et al., 2019). Such findings demonstrate how routinely embedding standardized disability questions into health information systems can surface previously invisible patterns of need and inform service planning.

Save the Children's technical guidance on the WG question sets emphasizes that effective use of the tool requires more than survey insertion; it requires staff training, a clear understanding of the tool's value and limitations, and integration into monitoring, evaluation, and programme quality systems across development and humanitarian contexts (Save the Children, 2025). Without this surrounding institutional capacity, even a well-validated instrument like the WG-SS risks producing data that are collected but never analyzed or acted upon, reinforcing the earlier caution that disaggregation alone does not guarantee inclusive outcomes (Card et al., 2024).

Literature Review: The Evidence Base on Disability Measurement Instruments

Beyond the descriptive and applied studies discussed above, a wider body of psychometric literature has directly tested how well the WG-SS performs against clinically confirmed impairment, and this evidence complicates any simple account of the tool as a fully resolved measurement solution. Using population-based survey data from five countries, Boggs et al. (2022) found that WG-SS classification thresholds identified people with clinically confirmed vision, hearing, mobility, and cognitive impairments with highly variable sensitivity, ranging from approximately 44% to 79% depending on the functional domain and cut-off applied, meaning a meaningful share of people with confirmed impairments would not be captured as disabled by the instrument.

These validity concerns are not evenly distributed across disability types. Using national survey data from the United States, Hall et al. (2025) found that the WG-SS questions classified more than half of respondents with self-reported serious mental illness as non-disabled, raising concern that programmes and funding decisions built on WG-SS-based prevalence estimates may systematically under-resource psychosocial disability needs. Read alongside the applied and normative literature reviewed earlier in this paper, this evidence suggests that the WG-SS's often-cited strengths, low cost, ease of administration, and cross-national comparability, coexist with real measurement trade-offs, particularly for population groups whose disabilities are not primarily physical or sensory in nature. This reinforces, rather than contradicts, the broader argument of this paper: standardized instruments are a necessary but not sufficient foundation for disability data systems, and their limitations, like their strengths, must be treated as part of the evidence base that shapes how, and for whom, such systems are designed.

Digital Tools and Assistive Technology for Evidence-Informed Engagement

Beyond standardized survey instruments, digital tools and assistive technologies increasingly mediate how people with disabilities engage with services, data systems, and decision-making processes. Assistive technologies span communication aids such as speech-generating devices and text-to-speech software, computer-access tools such as eye-tracking systems and switch-access devices, and software tools such as screen readers that allow people with visual, hearing, mobility, or cognitive disabilities to interact independently with digital systems (BeAccessible, 2026). When digital experiences are designed with these technologies in mind from the outset, people with disabilities are better positioned to participate fully in digital data collection, service applications, and feedback mechanisms rather than being excluded by design (Level Access, 2026).

Mobile health (mHealth) applications illustrate both the promise and the conditions required for accessible digital engagement. A pilot mHealth intervention for people with disabilities that met recognized accessibility certification standards sustained user engagement beyond the study period and enabled visually impaired participants to use the application independently, demonstrating that accessibility compliance is achievable and can support continued use rather than one-off adoption (Jang et al., as cited in Maita et al., 2026). Similarly, a qualitative study of the iMHere 2.0 client application found that incorporating customizable accessibility features improved usability for people with dexterity-related impairments, underscoring the importance of involving disabled users in design and testing rather than retrofitting accessibility after launch (Zhou et al., as cited in Maita et al., 2026). At the same time, researchers caution that not all technologies marketed as assistive are designed with genuinely inclusive intent; some tools function primarily as compliance mechanisms oriented toward behavioral normalization rather than toward enhancing independence, which can recreate barriers under the guise of accessibility (Maita et al., 2026).

Accessibility considerations extend to digital mental health tools, where reviewers have found that many applications still fail to incorporate basic system-level accessibility features such as captioning and screen-reader compatibility, despite a foundational accessibility principle that a digital resource should be usable by a person with a disability for the same purpose, with similar effectiveness, and within a comparable amount of time and effort as a non-disabled user (Levin et al., 2021). Emerging technologies such as augmented and virtual reality are also being applied to inclusive healthcare, including object-recognition and auditory-feedback features that help users with visual impairments navigate physical and digital environments, and virtual therapy applications that support mobility and motor rehabilitation for users

with motor disabilities (Khan et al., 2025). Collectively, this literature suggests that digital tools can substantially expand opportunities for evidence-informed engagement, but only when accessibility is treated as a design requirement embedded from the earliest stages of development rather than an optional add-on.

Inclusive data communication is a closely related and often overlooked dimension of digital tool design. Research on co-designing data visualizations with people with intellectual and developmental disabilities highlights that inclusive data representation is essential to democratizing access to data-driven insight, since people interact with data differently depending on their sensory processing needs, educational background, and cognitive abilities (Tran et al., 2024). Multisensory and tangible approaches to data interaction have been proposed as ways to engage groups who are otherwise excluded from interpreting and acting on data produced about their own circumstances, reinforcing the principle that evidence-informed engagement must include not only collecting data about people with disabilities but also returning that data to them in accessible, meaningful forms (Tran et al., 2024).

Artificial Intelligence Applications in Mathematics Education for Students with Disabilities

A focused case example of digital tool integration comes from mathematics education, where artificial intelligence has emerged as a specific area of activity within the broader digital and assistive technology landscape discussed above. Vortia (2025) conducted a narrative literature review of AI use in mathematics instruction for students with learning disabilities in the United States, synthesising peer-reviewed research, policy documents, and grey literature published between 2020 and 2025. This example is instructive because it demonstrates, within a single subject area and national context, how the promises and limitations of AI-enabled digital tools identified elsewhere in this paper play out in practice.

Vortia (2025) grounds the analysis in Universal Design for Learning (UDL) and Constructivist Learning Theory, arguing that these frameworks jointly justify AI-supported differentiated instruction: UDL supplies the rationale for accommodating learner variability through multiple means of representation, action, and engagement, while constructivist theory explains how AI-generated materials can scaffold students as they build mathematical understanding at their own pace. This pairing of a rights-oriented design framework with a learning-process theory echoes the emphasis, discussed earlier in this paper, on embedding accessibility as a design requirement rather than an afterthought (Level Access, 2026).

Within mathematics instruction specifically, the review identifies a cluster of AI-enabled tools, including Photomath, Mathway, Socratic, Century, and the MACS Curriculum, that provide real-time, step-by-step problem-solving support and adapt content delivery to individual learner profiles (Vortia, 2025). These tools are reported to reduce mathematics-related anxiety and to promote academic independence among students with dyscalculia and related learning difficulties by allowing them to progress through material at their own pace rather than relying solely on teacher-paced instruction. A related application involves AI-driven screening systems that use pattern-recognition techniques to identify early indicators of dyscalculia and dysgraphia in children as young as six, with pilot implementations in United States schools reportedly associated with improved student confidence and mathematics performance (Vortia, 2025).

At the same time, the review identifies barriers closely paralleling those discussed elsewhere in this paper. Classroom adoption of AI mathematics tools remains inconsistent, constrained by infrastructural limitations, uneven policy support, and gaps in teacher preparedness (Vortia, 2025). Accessibility gaps persist for students who rely on braille or other assistive technologies, since many AI platforms were not designed with these needs in mind, a limitation that became particularly visible when remote mathematics

instruction during the COVID-19 pandemic left some students with disabilities without adequately accessible options. Ethical concerns, including data privacy, algorithmic bias, and unregulated student use of AI tools outside institutional policy, further complicate adoption. Comparative evidence from China, where more supportive national policy frameworks and structured teacher training have accompanied AI adoption in mathematics classrooms, suggests that the policy and training environment surrounding a tool matters as much as the tool's technical design (Vortia, 2025).

Read alongside the broader literature reviewed in this paper, the mathematics education case reinforces a recurring conclusion: AI and other digital tools can meaningfully advance accessibility, personalisation, and early identification of need, but only were accompanied by sustained investment, teacher training, and policy frameworks that treat inclusive design as foundational rather than optional (Vortia, 2025). Without this surrounding institutional support, AI-enabled tools risk reproducing the same pattern identified throughout this paper, in which promising technologies and instruments are adopted unevenly and fail to translate into consistent, equitable outcomes for people with disabilities.

Barriers to Strengthening Disability Data Systems

Despite growing normative commitment to disability-inclusive data, structural barriers continue to constrain progress. Chief among these is financing: disability data collection remains chronically underfunded relative to the scale of need, and data systems are infrequently designed in collaboration with organizations of persons with disabilities (OPDs), which results in indicators that neither reflect lived experience nor inform practical decision-making (Global Disability Summit, 2025). Representatives from disability-led organizations have emphasized that participatory data sources, gathered directly through OPD-led initiatives, capture lived realities that official administrative systems frequently miss, and that meaningful inclusion requires OPDs to lead, not merely consult on, data collection design (Global Disability Summit, 2025).

A scoping review of disability-inclusive decision-making in low- and middle-income countries similarly found that the sources of evidence informing decisions were highly variable, drawing on both empirical and experiential evidence, and that barriers to evidence use depended heavily on the type of evidence available; beyond the data itself, decisions were also shaped by government legislation, power dynamics among stakeholders, funding availability, and prevailing attitudes toward disability within the implementing institution (Olaleye et al., 2024). This finding reinforces that strengthening data systems alone is insufficient; the institutional environment, political will, and resourcing around data use must be addressed concurrently for evidence to translate into inclusive practice.

Digital divides compound these data and institutional gaps. Rural populations and people with disabilities frequently encounter overlapping barriers, including unreliable broadband connectivity that restricts access to video-based telehealth and online information services, alongside a shortage of digital tools that meet recognized accessibility standards such as compatibility with screen readers and adherence to mobile accessibility guidelines (Maita et al., 2026). Where digital systems are not built around the Convention on the Rights of Persons with Disabilities' principle of universal design from the outset, even well-funded digital transformation initiatives risk reproducing the same exclusion that paper-based systems historically created (United Nations, 2024).

Toward Evidence-Informed Engagement: Integrating Data, Tracking, and Digital Tools

The literature reviewed in this paper points toward an integrated model of evidence-informed engagement

rather than a single intervention. The United Nations Disability Inclusion Strategy frames this integration explicitly around five reinforcing priorities: embedding disability inclusion through strategic planning and disaggregated data, delivering inclusive programming at multiple levels, ensuring digital systems and facilities are accessible through universal design, building an inclusive workforce, and strengthening partnerships with persons with disabilities through their representative organizations (United Nations, 2024). This framing is instructive because it positions data systems, digital accessibility, and OPD partnership not as separate workstreams but as mutually reinforcing components of the same inclusion agenda.

Similarly, institutional frameworks for disability inclusion emphasize that evidence-informed practice depends on combining a detailed understanding of context and individual difference with robust methodology, embedding evaluation within all organizational systems and processes, and centrally involving disabled people themselves in the design, delivery, and evaluation of provision (Eleanor Glanville Institute, n.d.). Applied to data systems specifically, this suggests that strengthening tracking practices should not be understood narrowly as a statistical exercise but as part of a broader cycle in which disabled people help define what is measured, how it is measured, and how the resulting evidence is used to shape policy and service delivery.

Practical examples from across sectors illustrate what this integration can look like. In health systems, embedding the Washington Group Questions into routine information systems allows disability status to be tracked alongside service utilization data, enabling providers to identify and respond to access barriers (Mörchen et al., 2019). In humanitarian response, pairing WG-based disaggregation with a clear, context-specific theory of how the data will be used helps avoid the trap of collecting disability data that is never analyzed or acted upon (Card et al., 2024). In digital health and education technology, co-designing tools with disabled users from the outset, rather than retrofitting accessibility later, produces applications that sustain engagement and genuinely expand independence rather than merely achieving formal compliance (Maita et al., 2026; Tran et al., 2024). In mathematics education, AI-enabled tools grounded in Universal Design for Learning and constructivist pedagogy show similar promise for personalisation and early identification of need, but, as in other sectors, their benefits depend on accompanying investment in infrastructure, teacher training, and policy support (Vortia, 2025). Across each of these examples, the common thread is that data, tracking instruments, and digital tools function best as parts of a single accountability loop that includes disabled people as designers and users of the evidence, not only as its subjects.

Practitioner Perspectives: Findings from a Disability Rights NGO Data and Digital Infrastructure Engagement Session

To complement the literature-based analysis above with grounded practitioner experience, this section draws on a facilitated peer-learning session convened among partner organizations working on disability rights (personal communication, July 2026). The session centered on a structured discussion of NGO partners' data and digital infrastructure, organized around breakout groups that addressed four guiding questions: what is currently working in each organization's data and digital infrastructure and why; which indicators are tracked because they are genuinely useful versus because funders or institutional leadership expect them; which outcomes related to member engagement currently lack an adequate measurement approach; and how each organization arrived at its current tools through building, buying, or borrowing, and whether it would make the same choice again. Breakout discussions were followed by a plenary share-

back in which each partner offered one key insight and named one peer or resource from which it sought support. The resulting qualitative findings, summarized below, illustrate how the structural barriers identified in the literature underfinancing, digital divides, and the gap between data collection and data use manifest concretely in the day-to-day practice of disability rights organizations.

Table 1
Summary of NGO Partner Findings on Data and Digital Infrastructure Practice

Theme	Key Findings	Connection to the Literature
Current data collection and communication practices	Most partners rely on WhatsApp and phone calls; some use Google Docs; spreadsheets are used but fragmented; one organization keeps a donor-mandated email list despite low member literacy; a subset uses JotForm for more structured tracking.	Reflects digital-divide and accessibility gaps that push organizations toward low-cost, informal channels (Maita et al., 2026).
What is working, and why	Direct phone calls to check on members' wellbeing strengthen connection and surface information that transactional methods miss; gaming and interactive activities are used as an alternative to material incentives.	Resonates with participatory, OPD-led approaches that capture lived realities missed by administrative data (Global Disability Summit, 2025).
Useful versus expected tracking	An ineffective, donor-mandated email list persists despite low literacy among members because it satisfies external reporting expectations rather than member needs.	Illustrates the risk that uniformly imposed tracking, without a clear plan for use, does not automatically improve inclusion (Card et al., 2024).
Unmeasured outcomes in member engagement	Organizations can count participation (e.g., attendance) but lack tools to assess engagement depth or quality; one organization struggles to tailor engagement for members in countries with small national memberships.	Reinforces the need to embed disabled people's own definitions of meaningful engagement into monitoring design (Eleanor Glanville Institute, n.d.).
Build, buy, or borrow	One NGO is building its own CRM; another has built a bespoke member management system; others borrow free, general-purpose tools (WhatsApp, Google Docs, spreadsheets, email); no partner purchased commercial CRM outright.	Shows tool acquisition concentrated at the build and borrow ends of the spectrum, shaped by capacity and cost rather than deliberate procurement.
Consequences of weak data systems	Weak data practices are linked to reduced funder credibility, diminished ability to serve beneficiaries, weakened strategic planning, and erosion of organizational	Confirms that data systems function as a foundation for accountability and service delivery (Global Disability Summit, 2025).

	identity; spreadsheet fragmentation complicates reporting.	
Cross-organizational learning and peer support requests	One partner requests peer input on incentive alternatives and phone-based outreach practice; another requests CRM good practices; cross-departmental collaboration during events is cited as an enabler of accurate records.	Supports peer-to-peer learning as a complement to external technical assistance, consistent with OPD-led capacity building (Global Disability Summit, 2025).

Synthesizing Practitioner Experience with the Evidence Base

Read alongside the literature reviewed earlier in this paper, the session findings suggest that the barriers to disability-inclusive data systems identified at a global, policy level underfinancing, fragmented systems, and a gap between data collection and data use (Global Disability Summit, 2025; Card et al., 2024) are experienced by frontline NGOs as very practical, everyday constraints: donor-mandated tools that do not fit member realities, spreadsheets that fragment rather than consolidate information, and CRM systems built without access to peer-tested good practice. At the same time, the practitioner data point to underused sources of strength that a purely top-down reading of the literature might understate, particularly the relational value of direct member contact and the appetite among partners for peer, rather than solely external, learning. Standardized instruments such as the Washington Group Questions and universal design principles for digital tools, discussed above, offer partners a way to make their existing data collection more comparable and accessible; however, the session findings indicate that partners are equally in need of practical support for tool selection, CRM development, and measurement of engagement quality areas that are less directly addressed by standardized disability measurement instruments alone. This reinforces this paper's central argument that strengthening disability data systems requires attention not only to what is measured, but to how organizations choose, build, and sustain the tools through which that measurement takes place.

Discussion

Taken together, the literature and practitioner findings presented in this paper point to a set of recurring tensions rather than a single, resolvable problem. The first is a tension between standardization and lived experience: instruments such as the WG-SS make disability data comparable across countries and sectors, yet the psychometric literature reviewed above shows that comparability can come at the cost of undercounting specific populations, while practitioners in the peer-learning session described member realities that formal tracking tools, whether standardized questionnaires or donor-mandated spreadsheets, did not fully capture. The second is a tension between data collection and data use, evident both in the caution documented by Card et al. (2024) against assuming that disaggregation alone produces inclusive outcomes and in the practitioner report of an ineffective, donor-mandated tracking tool that persisted because it satisfied external reporting requirements rather than member needs. The third is a tension between technical access and genuine accessibility, echoed across the digital tools, artificial intelligence, and barriers sections of this paper, in which technologies that are formally compliant with accessibility standards do not automatically translate into meaningful, independent use by people with disabilities.

Positioned against the wider literature, this is where the paper makes its clearest contribution. Prior scholarship has tended to document these three tensions separately and within single domains,

psychometric critiques of the WG-SS within measurement science (Boggs et al., 2022; Hall et al., 2025), accessibility critiques within digital-health and assistive-technology research (Levin et al., 2021; Maita et al., 2026), and calls for institutional use of data within humanitarian and development studies (Card et al., 2024; Olaleye et al., 2024), without connecting them as manifestations of a shared underlying pattern. By reading these domain-specific bodies of work alongside one another and alongside firsthand practitioner testimony, this paper contributes a cross-sectoral account of why disability data systems persistently underperform their stated goals, spanning health, education, humanitarian response, and digital technology. It further contributes a source rarely drawn on in this literature, direct NGO practitioner reflection, which surfaces relational, low-cost practices, most notably direct member contact and peer-to-peer learning, as an underexamined resource that formal data-strengthening initiatives could draw upon more deliberately.

These tensions suggest that strengthening disability data systems is best understood as an ongoing negotiation among competing goods, comparability, cost, sensitivity, and participation, rather than a single technical fix. The practitioner findings add an important layer to this picture that the literature alone does not fully supply; they show that under-resourced organizations often resolve these tensions informally, through relational practices such as direct member phone calls, and through peer-to-peer learning, rather than through the formal instruments and institutional frameworks emphasized in global policy literature. This discussion should be read with some caution, however, since it draws on a single peer-learning session with a limited set of partner organizations and a narrative, rather than systematic, review of the published literature; the patterns identified here are illustrative rather than generalizable, and future research using broader practitioner samples and more systematic review methods would help confirm whether these tensions hold across a wider range of organizational and national contexts.

Limitations of the Study

Several limitations should be considered when interpreting the findings and arguments presented in this paper. First, the literature component was conducted as a narrative rather than a systematic review; sources were selected to illustrate recurring themes across sectors rather than through a predefined search strategy, dual independent screening, or a registered protocol. As a result, relevant studies may have been omitted, and the balance of evidence presented may reflect the authors' judgment about which sources best illustrate the paper's argument rather than a comprehensive account of the full evidence base.

Second, the practitioner component draws on a single facilitated peer-learning session involving a self-selected group of partner organizations affiliated with one disability rights network, recorded as personal communication rather than as a published or independently verifiable source. This session generated rich, situated insight, but the small and non-random sample means the practices, tools, and challenges reported cannot be assumed to represent disability rights organizations more broadly, particularly those operating in different regions, funding environments, or organizational structures. The findings from this section are therefore best read as illustrative rather than generalizable, as acknowledged in the Discussion above.

Third, the evidence base reviewed is uneven across disability types, sectors, and geographies. Much of the psychometric literature on the Washington Group Short Set concerns physical and sensory impairment, while evidence on psychosocial disability rests on a narrower set of studies (Hall et al., 2025), and the artificial intelligence case example is confined to mathematics education within a single national context, the United States (Vortia, 2025). Some sources are also secondary or practitioner-oriented rather than peer-reviewed, including several assistive technology findings drawn from Maita et al. (2026) rather than

the original primary studies, which introduces some risk of interpretive drift from the underlying research. The literature consulted is also predominantly English-language and concentrated in the past several years, which may underrepresent older or non-English scholarship relevant to disability data systems.

Finally, this paper synthesizes existing literature and practitioner reflections rather than collecting new primary or quantitative data of its own. The relationships proposed between data systems, tracking practices, digital tools, and evidence-informed engagement are therefore best understood as associational patterns drawn from the reviewed sources rather than as causal claims tested through original empirical analysis. Future research that combines systematic review methods with a larger, more geographically diverse sample of practitioner organizations would help establish how far the tensions and recommendations identified here extend beyond the sources examined in this paper.

Conclusion

Strengthening data systems, harmonizing tracking practices, and expanding accessible digital tools are each necessary, but individually insufficient, conditions for evidence-informed engagement of people with disabilities. Standardized instruments such as the Washington Group Questions have substantially improved the comparability and feasibility of disability measurement across health, education, and humanitarian settings, while digital and assistive technologies have expanded the channels through which disabled people can interact with services and data systems. However, the literature consistently shows that data collection without adequate financing, institutional use, and disabled people's leadership in design risks producing statistics that are gathered but not acted upon, and digital tools that are technically accessible but not genuinely inclusive. Future efforts to strengthen evidence-informed engagement should therefore prioritize co-design with organizations of persons with disabilities, sustained investment in disability data infrastructure, and the consistent application of universal design principles across digital systems, so that data and technology function as instruments of inclusion rather than as additional sources of exclusion. The practitioner findings presented above lend concrete support to this conclusion: NGO partners themselves identified donor-driven rather than member-driven tracking, fragmented spreadsheets, and under-resourced in-house system development as the practical, day-to-day manifestations of the financing and institutional gaps documented in the broader literature, while also pointing to relational engagement practices and peer-to-peer learning as underused resources for strengthening data systems from within.

Recommendations

Building on the literature review, discussion, and practitioner findings above, this paper offers the following recommendations for funders, national and international data bodies, disability rights organizations, and digital tool developers seeking to strengthen evidence-informed engagement of people with disabilities:

- Pair standardized instruments with supplementary measures. National statistical offices and programme evaluators should pair the WG-SS with domain-specific or population-specific supplementary questions where feasible, particularly for psychosocial and less visible impairments, so that its comparability benefits do not come at the cost of systematically undercounting specific groups (Boggs et al., 2022; Hall et al., 2025).

- Fund data use, not only data collection. Donors and governments should require and resource an explicit plan for how disability-disaggregated data will inform decisions before funding its collection, closing the gap between generating statistics and acting on them (Card et al., 2024).
- Resource member-driven, not only donor-driven, tracking tools. NGO funders should allow, and where possible fund, tracking systems that partner organizations identify as genuinely useful to their members, rather than requiring tools designed primarily to satisfy external reporting expectations.
- Embed universal design and co-design from the outset. Developers of digital and assistive technologies should involve people with disabilities in design and testing from early stages, rather than retrofitting accessibility after launch, consistent with the accessibility literature reviewed in this paper.
- Invest in peer-to-peer learning infrastructure. Given the value practitioners placed on peer support in the engagement session discussed above, funders and disability rights networks should create structured, ongoing opportunities for frontline organizations to exchange practical guidance on data tools, CRM systems, and member engagement measurement, complementing formal technical assistance.
- Expand context-specific and mixed-methods research. Future research should test whether the tensions identified in this paper, between standardization and lived experience, and between data collection and data use, hold across a wider range of organizational, sectoral, and national contexts, using systematic review and broader practitioner samples than this paper's single peer-learning session.

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