Standard terminology is critical to advancing rehabilitation and assistive technology: a call to action

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ABSTRACT
This perspective piece discusses inconsistencies in assistive technology (AT) language as a barrier to communication in AT provision, research, development, trade, and policy. The imperative to improve communication is explored in relation to AT stakeholder endeavours. This commentary is a call for action to develop a terminology standard through the aggregation of evidence-based concepts and terms to inform and optimize stakeholder outcomes.

IMPLICATIONS FOR REHABILITATION
- Standardized terminology supports the gathering, aggregation, analysis, and interpretation of valid data and the development of tools used for needs and outcomes assessment.
- Standardized terminology also supports effective and efficient documentation, practice, collaboration, and capacity building by stakeholders in both national and international contexts.

Introduction
Advancing rehabilitation and assistive technology (AT) through health process and systems research relies on data collection and exchange using a common language and set of expectations. Person-centred rehabilitation is provided across disabilities and age groups by integrated teams comprising multiple disciplines across diverse cultural and physical environments, supported by diverse stakeholders in the supply ecosystem [1]. Development and consistent use of a standardized international language is critical to this endeavour.

This observation is not new. Calls for shared language, uniform and valid data collection, and systematic outcome measurement, led by the Global Cooperation on Assistive Technology (GATE) [2] and partners, have been made from the 2017 WHO Global Priority Research Agenda [3] to the WHO-UNICEF Global Report on Assistive Technology [4,5]. A standardized terminology could facilitate efficient and effective delivery of health and rehabilitation services by assuring interoperability between systems that coordinate overall information about an individual [6] and facilitating the exchange of medical and health care information in national and international markets [7]. However, lack of globally recognized terminology for AT is a barrier to research, development and trade [8].

Current inconsistencies in terminology act as barriers to research and development on the good practices required for effective provision of AT. Information exchange between all stakeholders in the AT value chain can only become interoperable when terminology standards for concepts, terms, and definitions are established and utilized. These stakeholders include product users, product providers (e.g., designers, manufacturers, distributors, and suppliers), service providers (e.g., clinicians, counsellors, educators, engineers, specialists, & technologists), systems administrators, policymakers, researchers, and academics [9].

The problem
An estimated one billion individuals globally need assistive products and their related services and systems, collectively termed AT [4]. Despite urgent global imperatives to improve access to AT, “little data has been systematically collected and analysed to understand the need and unmet need for AT in various populations” [10]. Why? Despite the presence of international standards with terminology relating to AT, the lack of harmonization between these standards results in fragmented, conflicting, and divergent information [11]. An international vocabulary standard is needed to ensure communication for AT is effective and difficulties in understanding are minimized locally, regionally, and globally as we argue below.

Communicating across discipline boundaries
Hearing aids, walking frames, communication aids, spectacles, prostheses, pill organizers and memory supports are all examples of assistive products. We could describe each of these products with entirely different vocabulary, for example, hearing supports, gait aids, information and communication technologies, eyeglasses, artificial limbs, medication management systems, and prompting aids.
Communicating across regional boundaries

Over 100 terms representing perhaps a dozen service concepts were uncovered during work to convert the Assistive Technology Service Method (ATSM), a user-centered, evidence-based, interdisciplinary, cross-disability and trans-environmental process standard, from the U.S. to a global model. Without standardized terms and concepts for AT, as the infrastructure upon which to build service and research models, interdisciplinary and international collaboration could not advance.

Communicating across languages boundaries

AT stakeholders may not share a common vocabulary for core concepts even when speaking the same language. Silvana Contepomi of the Argentinian AT Association and GAATO Board reports that within the Spanish language, three different terms describe AT: Technology of Assistance (Tecnología de Asistencia), technology for support (Tecnología de Apoyo), and AT (Tecnologia Asistiva). Stakeholders across Mexico, Colombia and Argentina attempting to share knowledge, research, or statistics, must clarify they are referring to the same concept.

Communicating across global stakeholders

In 2001, efforts to develop a shared common language resulted in the International Classification of Functioning, Disability and Health (ICF). These globally applicable descriptors of health and health-related states enabled communication between different users "such as health care workers, researchers, policy-makers and the public, including people with disabilities". In 2022, efforts continue. Aligned with the 2022s Global Disability Summit, several initiatives focussed on progress on increasing access to AT. Taking a partnerships approach, the Global Partnership for Assistive Technology (https://atscale2030.org/), called for global cross-sector partnerships to coordinate activities, measure progress, and share best practices to close the gap for accessible AT.

A “grand challenge” approach, by the Global Alliance of Assistive Technology Organizations (www.gaato.org/grandchallenge), undertook to identify the biggest and most important issues in the field of AT, and is discussed below in relation to the role of a standard vocabulary.

Contemporary evidence of the critical need for a standard vocabulary

Through the GAATO Grand Challenge in AT Outcomes collaborative consensus process, over 350 regional AT stakeholders from 57 countries and across 12 language groups identified 109 AT outcome challenges of importance to them. A further consensus-building phase which included 28 global stakeholders distilled the resulting challenges into a longlist of 39 and a final shortlist for action. One challenge explicitly called for a shared language:

Terminology across outcomes and outcome measures are not consistent or standardized.

Addressing the terminology Grand Challenge is foundational to resolving the following related challenges:

Research and development: Irrespective of the underlying technology, assistive products are only effective if they account for the user’s needs and preferences, abilities, and environments of use. Terminology standards facilitate co-creation in the design, development, and commercialization of assistive products.

Information to guide product selection: After product commercialization, well-known online tools are used by persons with disabilities and service providers to identify and select assistive products. To the extent that searches employ ad hoc keywords or that the description and classification of assistive products employ ad hoc terminology, the identification and selection of optimal assistive products will be ineffective.

International trade: Communication is essential to understanding the characteristics of physical, service, and supply chain infrastructures as barriers or facilitators. The World Trade Organization Agreement on Technical Barriers to Trade [12] recognizes that international standards contribute to improvements in the efficiency of production, and the facilitation of trade internationally. As products are traded internationally, the creation and adoption of AT device and service standards are a natural and logical extension and require a foundational vocabulary.

Communication at the research, policy and practice nexus: Improved access to AT requires robust research to inform public policy funding priorities and regulatory measures. Effective communication in science and technology, cross-cultural communication, the exchange of goods and services, as well as the formulation of policies and strategies at national, regional, and international levels and development of terminology standards must be “multi-lingual”. Communication is essential to understanding and prioritizing disability-related needs at a local and national scale, characterizing assistive product requirements, and making decisions whether to develop assistive product solutions nationally or to acquire such solutions internationally.

Resource allocation: At the macro context, policy defines and interprets concepts that determine access to resources. Policies are then implemented at the micro context of practice, where practitioners and administrators are responsible for acting on the priorities and funding in line with the intent of policy [13]. The result of these actions should then be demonstrated as outcomes, but research suggests that AT outcomes have never been consistently reported or linked to legislated mandates or policy goals [14]. Policies intending to address complex social and economic problems are often not realized because of different understandings that create problems in implementation. Consistent terminology is necessary to bridge AT academic research, policy formulation, and implementation science. Without terminology standards, inconsistencies and assumptions about AT will continue to be implicit in policy, education and practice and will remain unchallenged.

The solution: a standardized terminology to strengthen AT services, systems, and policies.

This perspective article points to a preponderance of major initiatives and projects which demonstrate the need for standardized terminology on AT as a critical component of rehabilitation. Drawing together this contemporary evidence, and building on the call made in the 2019 proceedings of WHO Global Perspectives on Assistive Technology for “Adoption of standard terminology related to AT” [14], it is clear that a vocabulary is required to support data collection, research and development, international trade; co-creation and searchability of assistive products; and AT stakeholder communication through the multilingual bridging of research, policy and practice. International terminology standards are the foundation for effective communication between key stakeholders, capacity building, and good practices across international contexts. This call to arms suggests: the development of an initial standard vocabulary is rapidly achievable through the aggregation of existing knowledge and international
consensus, funding for the development of vocabulary and terminology standards must be supported.

**Conclusion**

Standardized terminology is critical to naming complex problems, collectively envisioning solutions, collecting data, measuring outcomes, and documenting services provided thereby increasing access to appropriate and effective AT. This perspective article supports the development of an evidence-based vocabulary of key terms and concepts for AT as essential infrastructure components. Establishing these common data elements is critical to ensure data quality for research that generates evidence informing policy and practice decisions that affect all rehabilitation and AT stakeholders.

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