#### THE VALUE OF VOCABULARY STANDARDS TO DISCUSS AT OUTCOMES AND IMPACT

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## ABSTRACT

Recognizing the need for effective access to assistive technology, the World Health Organization (WHO) published the Proceedings of the GReAT Consultation, Global perspectives on assistive technology 2019 [1]. The proceedings contain over 80 manuscripts presenting international perspectives on "the current need, demand and supply of assistive technology, as well as to outline good practices for innovation and recommendations to improve access" [1] (p. i). Accepted for publication in this document was the manuscript by the authors titled "*The value of vocabulary standards towards improving access to assistive technology (AT)*.

This present paper justifies the need for a vocabulary standard comprising key concepts, terms, and definitions to ensure that communication in the domain of assistive product services is complete, unambiguous, and efficient within national and across international contexts. It illustrates important applications of this standard by stakeholders that include product users, product providers, service providers, systems administrators, policy makers, researchers, and academics. Exemplar applications include interdisciplinary AT service provision, professional capacity building, development of scientific tools, consistent gathering, analysis, and description of internationally comparable data, and support for coordinated global actions increasing access to AT.

The purpose of this paper is to describe development of an International Standards Organization (ISO) Assistive product services – vocabulary as a critical component of the infrastructure necessary to transform individual and system capacities. Methodology will follow international standards development guidelines and mandates. Development of this standard will be rapidly achievable through the aggregation of existing knowledge and international consensus. As with all standards, this vocabulary standard will be reviewed and revised as new knowledge becomes available including development on AT outcomes and impact.

## INTRODUCTION

Internationally, consensus is building that global research infrastructure for assistive technology (AT) is a priority and must include all stakeholders: users, industry, and services [1,2]. However, the field currently lacks consensus terminology, classification or taxonomy of devices, products or service models [3,4]. Global efforts to improve access to AT will remain inconsistent and inequitable while stakeholders lack a common language through which to build and translate knowledge. Semantic specificity is critical to facilitate data sharing, pooled computational analysis and comparisons, and measuring interdisciplinary AT outcomes and impact [5].

At the international level, the International Organization for Standardization (ISO) leads development of ATrelated classification and terminology standards through *ISO/TC 173 Assistive products* [6], and specifically Sub-Committee 2, i.e. *ISO/TC173/SC2 Classification and Terminology*. In 2018, *ISO/TC173*'s scope expanded to include services for assistive products. *ISO/TC173/SC2* initiated discussion to establish a new standard related to classification and terminology of assistive product services.

This paper outlines the proposed content and methodology for developing a new ISO standard on *Assistive product services – Vocabulary*. This standard would fit under the broader umbrella of a standard envisioned on assistive technology fundamentals and vocabulary. This paper also discusses benefits of the proposed standard, including potential to facilitate successful collaboration and attainment of multiple United Nations Sustainable Development Goals (UN SDGs) [7].

## METHODS

ISO standards are developed through six stages: proposal, preparatory, committee, enquiry, approval, and publication [8]. Under ISO rules, new work items (NWIs) may be proposed by member bodies of ISO, TC secretariats, TC sub committees and working groups, organizations in liaison, the Technical Management Board or by one of the advisory groups, or the Secretary-General (ISO/IEC Directives Part 1, Clause 2.3.2) [8,9].

The authors are working on the first stage, "proposal". This stage aims to confirm need for the standard. The proposed method established by *ISO Form 4: New work item proposal (NP)* states "The proposer(s) of the new work item proposal shall:

- make every effort to provide a first working draft for discussion, or at least an outline of a working draft
- nominate a project leader
- discuss the proposal with the committee leadership prior to submitting the appropriate form, to decide on an
  appropriate development track (based on market needs) and draft a project plan including key milestones and
  the proposed date of the first meeting" [8].

Upon satisfying Form 4 requirements, a new work item proposal (NP) for standards development is submitted for vote by members of the relevant TC or SC to determine inclusion in the program of work. NPs are accepted if (i) two-thirds of participating member countries (P-members) voted in favor and (ii) at least five P-members declare a commitment to actively participate [8]. The Standard development track can be either be 18, 24, 36, or 48 months in length [8].

## RESULTS

ISO protocols for the proposal stage are being followed to initiate this NP. The Americans National Standards Institute (ANSI) is the US Member Body of the ISO. Linda-Jeanne Elsaesser as Head of Delegation (HoD) to ISO/TC173/SC2 and ISO/TC173/SC2/WG12 discussed a working draft which addressed Form 4 requirements. The working draft's proposed scope is modeled on the Scope of *ISO 26000:2010 Guidance on social responsibility* [9].

## Scope of the proposed deliverable

This International Standard is intended to ensure that communication in the domain of assistive product services is effective and difficulties in understanding are minimized. The standard will provide guidance to all types of individuals and organizations, regardless of their size or location on:

- a) Concepts, terms, and definitions related to assistive product services
- b) The background, trends, and characteristics of assistive product services
- c) Principles and practices relating to assistive product services
- d) The core subjects and issues of assistive product services
- e) Integrating, implementing, and promoting socially responsible behavior throughout assistive product services and, through its policies and practices, within its sphere of influence
- f) Identifying and engaging with stakeholders
- g) Communicating commitments, performance and other information related to assistive product services

#### Purpose and justification of the proposal

The main purpose of this international standard is to provide a normative vocabulary through systematic identification of concepts and relations, designation of terms, and descriptive definitions for the field of assistive product services [4]. The standard will support the work of other committees by providing the terminology to draft linguistically and conceptually consistent standards and documents.

The manuscript, "*The value of vocabulary standards towards improving access to assistive technology*" providing evidence of need by five international key stakeholders was accepted for presentation at the WHO GReAT Summit 2019 and published in the proceedings [4]. The proceedings are considered a first step to inform development of the planned *Global Report on Assistive Technology 2021* on good practices for innovation and recommendations to improve access.

The proposed ISO document will meet the identified need for building global infrastructure to increase education, practice, information-sharing, and collaboration between countries.

#### Work plan

The project team will comprise the international authors of the original manuscript. Additional content experts will be recruited to assure representation from stakeholders including academics, consumers, researchers, and providers of products and services, systems, and policies. Sajay Arthanat has been identified as project leader. The project will initiate immediately following project approval and resource allocation.

The project evidence base will include applicable ISO standards for terminology and concepts, the Oxford English Dictionary to ensure consistent understanding by international members, the Convention on the Rights of Persons with Disabilities, the United Nations Sustainable Development Goals, and publications from the World Health Organization, and other peer-reviewed sources. The project development track will be 18 months.

# DISCUSSION

While this standard will provide monolingual terminological entries, to facilitate communication in science and technology, cross-cultural communication, the exchange of good and services, as well as the formulation of policies and strategies at national, regional and international levels, the potential need for development of multilingual entries is recognized.

Development of a vocabulary standard is at the core of efforts to improve access to assistive products and services, for the vast portion of underserved individuals with disabilities. Examining and comparing the utilization of and demand for assistive products and services both within and across nations requires a consistent and replicable survey framework and language. For viable analysis and comparisons, it is important to implement a standard nomenclature to classify and denote AT products and services. Long term, a vocabulary standard can facilitate creation of: a) uniform funding codes that logically identify functional and contextual need for an assistive product; b) consumer-driven AT product databases; c) systems for tracking impact and outcomes, and; d) interdisciplinary and international education and training for AT workforces.

Prerequisites for reference standards include identification of theoretical background, target groups, and purpose. Terminology must be operationalizable, comprehensive, generalizable, extendable, flexible, unambiguous, and consistent. Use is intended to support connectable and interoperable domain-independent typology including causal, instrumental, and associated relations on a continuum of simplicity to complexity. While this may seem new to some AT stakeholders, these are established expectations in clinical terminology standards such as the Systematized Nomenclature of Medicine - Clinical Terminology (SNOMED-CT) published by the International Health Terminology Standards Development Organization (IHTSDO). Based on consensus, vocabulary standards are tools upon which to base good practice, guidelines, and regulations assuring effective, efficient, and satisfactory AT outcomes and impact. ISO notes in its guide to contributing to the UN SDGs that:

"To be successful, the process requires consensus, collaboration, and innovation with contribution "from all elements of society, including local and national governments, business, industry and individuals" [7].

Our manuscript published in WHO GReAT 2019, describes key concepts on the value of a vocabulary standard to include findings, opportunities and challenges by stakeholders representing:

- Clinicians- provider capacity, common language and framework, translation of research to practice, process standard, international collaboration
- Administrators improve the efficiency and clarity of communication within and between government entities and improve data gathering, analysis and interpretation in support of evidence-based policy and administration
- Manufacturers- international trade, AT and medical device lifecycle management, medical device regulatory affairs (including pre-market authorization activities and regulatory compliance, specification & adjustment
- Academics research, education, and policy development
- Engineers- AT development and innovation, co-creation, field-based innovation, classification and terminology [4].

Diffusion of Innovation (DOI) describes the steps, barriers, and facilitators governing the adoption and use of an innovation such as the vocabulary standard [10]. Reference to DOI concepts and success cases has potential to speed vocabulary standard adoption within and across international contexts [11]. International organizations such as the WHO GATE and the Alliance of Assistive Technology Professional Organizations will be engaged to inform and potentially to help carry out this strategy [11].

Diffusion of innovation strategies that include awareness, development of positive attitudes, decision to adopt, and continued use of standardized terminology will be critical for international stakeholders to effectively discuss evidence of AT outcomes and impact.

# CONCLUSION

Development of this International Standard is intended to ensure that communication in the domain of assistive product services is effective and difficulties in understanding are minimized. It is essential that the various

participants, both individuals and organizations, use the same concepts and concept representations to strengthen capacity for development of international strategies advancing access to AT services and AT products.

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