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Opening the GATE: systems thinking from the global assistive technology alliance

Natasha Layton, Diane Bell, Mary Ellen Buning, Shih-Ching Chen, Silvana Contepomi, Vinicius Delgado Ramos, Evert-Jan Hoogerwerf, Takenobu Inoue, Inhyuk Moon, Nicky Seymour, Roger O. Smith & Luc de Witte

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CASE REPORT



Opening the GATE: systems thinking from the global assistive technology alliance

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ABSTRACT

Purpose: This paper describes international actions to collaborate in the assistive technology (AT) arena and provides an update of programmes supporting AT globally.

Methods: The World Health Organisation (WHO) identifies the severe global uneven distribution of resources, expertise and extensive unmet need for AT, as well the optimistic substantial capability for innovations and developments in appropriate and sustainable AT design, development and delivery. Systems thinking and market shaping are identified as means to address these challenges and leverage the ingenuity and expertise of AT stakeholders.

Results: This paper is a 'call to action', showcasing emerging AT networks as exemplars of a distributed, but integrated mechanism for addressing AT needs globally, and describing the Global Alliance of Assistive Technology Organisations (GAATO) as a vehicle to facilitate this global networking.

Conclusion: Partners in this Global Alliance aim to advance the field of assistive technology by promoting shared research, policy advocacy, educating people and organisations within and outside the field, teaching, training and knowledge transfer by pulling together broad-based membership organisations.

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Collaboration; assistive technology; systems; sustainability; innovation

► IMPLICATIONS FOR REHABILITATION

- Collegial, cross discipline and multi-stakeholder collaborations support assistive technology research and practice.
- Knowledge exchange within and across countries and regions is mutually beneficial.
- Self-organising assistive technology communities are emerging and supported by global movements such as WHO GATE and GAATO.

Introduction

Assistive technology

The International Organisation for Standardisation (ISO), aligning with the WHO, defines assistive products as 'any product, including devices, equipment, instruments and software, especially designed and produced or generally available, whose primary purpose is to maintain or improve an individual's functioning and independence and to facilitate participation' [1] (p.1). Assistive technology (AT) as a term encompasses both assistive products and the assistive services, including human factors design, required to ensure good person-environment-fit [2]. Technology itself is rapidly evolving, with 'mainstream' products such as smart phones and home automation potentially replacing previous 'specialised' products such as

electronic communication devices and environmental control units. Assistive technology users embrace the potentials offered by these developments [3], suggesting that the scope of assistive technology ought to include the combination of mainstream and specialised devices and services which enable consumer-valued outcomes [4]. It is also acknowledged that in many parts of the world there is neither access to mainstream nor specialised AT and potential users are substantively disadvantaged [5].

Assistive technology is a powerful change agent, which is increasingly being recognised and acknowledged for its potential to remediate body structures and functions, to facilitate activities of daily life, to turn environmental barriers into enablers, and to support participation in the life of one's choosing. The full potential of AT requires 'an environmental approach to functioning, in contrast

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to the medical model that has historically been dominant' [6] (p. 435). A 'capability approach' identifies the role of AT as filling the 'gap' between a person's capabilities and their aspirations. In line with the social model of disability, the capability approach identifies needs regardless of whether the gap comes about through personal factors such as disability or contextual factors such as poverty or lack of opportunity [7]. Evidence demonstrates that AT can fill the 'capability gap' [8] and that assistive products are instrumental in achieving each of the seventeen United Nations Sustainable Development Goals [9].

But are we realising the full potential benefits of technologies? This changing landscape, and the shifting scope of technology itself, may make it difficult for AT users, practitioners, services, researchers and funders to keep abreast with the diversity of assistive products and the most effective ways to provide them. These types of technological disruptions both shape the market and challenge past demarcations around assistive technologies, particularly for funders. The recent World Health Assembly Resolution on Improving Access to Assistive Technology (EB142.R6) states that,

Today only 1 in 10 people in need have access to assistive products, owing to high costs and a lack of financing, availability, awareness and trained personnel. For example, 70 million people need a wheelchair but only 5–15% have access to one, and hearing aid production meets only 10% of global need and 3% of the need in low-income countries. Moreover, 200 million people with low vision do not have access to spectacles or other low-vision devices [10] (p. 1)

Self-organising systems to address the AT capability gap

There are many reasons for this gap between needs and the availability of solutions. These include the lack of awareness, lack of expertise, resistance and absence of legislative frameworks, the difficulties of small scale AT companies and initiatives, etc. [11,12] This creates a very fragmented and complex AT landscape with challenges at every turn. Alongside a lack of AT in many contexts, provision systems are inadequate or immature; there is a huge variety of procedures and service models with very little or no evidence of what works best. Addressing the intersections of policy, provision, products, people and personnel requires a broad understanding of complex adaptive systems and solutions. Contemporary thinking about assistive technology systems suggests the 'disruption to the way in which APs are designed and distributed, and therefore to the system of AT provision, may include new elements/actors or changing of the roles of established elements/actors within a system' [13] (p. 4) [14]. A key element in the necessary changes is improvement of service delivery models and procedures. There is also need for internationally agreed quality frameworks, assessment and outcome measures and terminology frameworks to enable sharing of experiences and best practices.

The capability gap for individuals, and access to assistive technology as enabler to close the gap (or open the gate), is of deep concern to AT stakeholders internationally [15]. A rights-based lens on AT practice suggests national and international responsibilities [16]. Various bodies have emerged to address aspects of this complex system. Exemplars of new strategic networks are developing. Individual leaders with aspirations for improved AT services are organising networks to learn from each other and speak about common goals. They have begun to formulate organisations, and the impetus provided by WHO in the form of GATE is recognised and applauded in this regard.

Exemplar: African community on assistive technology (ACAT)

Africa, with around 1.3 billion people (2019), accounts for approximately 16.75% of the world's population. It is also the second largest continent, comprising of 54 countries. About 43.4% of its inhabitants live in urban areas and there are around 1250–3000 native languages¹.

A vision for a community of practice on AT in Africa was proposed at the inaugural Global Research, Innovation, and Education in Assistive Technology (GREAT) Summit [17]. Assistive technology practitioners from Australia and South Africa reflected on the status of assistive technology upon their continents. Although half a world apart, both are large, and sparsely populated with harsh climates and diverse populations. Common issues included supply and logistics limitations and the need for culturally appropriate and sustainable solutions which withstand salt, heat, dust and rural terrains. Many individual innovations could be shared, for example, scalable pockets of local innovations in Africa, and the availability of good practice networks and guidelines from Australia [18].

In seeking a model structure, the International Alliance of Assistive Technology Professional Associations was considered. Australia is connected to the international network through its AT peak body, ARATA², however Africa does not yet have such a structure within or known to the Alliance or identified within AFRO entities at the WHO GREAT Summit. These shared reflections led the authors to:

Imagine the possibilities when individual champions collaborate, building an international network and community of practice for the African continent...in this way contributing towards achieving the Sustainable Development Goals. [19], p. 1

In May 2018, an invitation was issued to participants of the GREAT Summit who had expressed an interest in AFRO regional connections (n = 23), as well as interested attendees (n = 6) of the International Standards Organisation meeting in Nairobi, Kenya (May 2018). A community of practice was formed with local and international AT stakeholders for the purpose of:

- i. Knowledge translation through the exchange of practice wisdom
- ii. Collegial support and mentorship
- iii. Broadening of horizons, with a view to sharing and scaling AT related ideas

The African Community on Assistive Technology (ACAT) is now an active and growing virtual network comprising eighty individuals from twelve countries. Exchanges include the sharing of information, grey literature and practice guidance, troubleshooting sustainable product design and deployment, and the instigation of small research trials, all supported by an accessible online resource portal. As a community of practice, the ACAT is built upon three key principles to ensure broad representation and to create a space for all [20].

A first principle is to value the intersectionality of roles and voices within the AT arena. Discussions as to 'what good practice looks like' occur between practitioners, researchers and AT users. These multiple viewpoints enable the sharing of rich and diverse information about resources, about evidence gaps, and about ways to bridge these gaps.

A second principle is respect for difference – embracing all forms of diversity, particularly important as the author team, and indeed the community of practice members, may be members of communities who have held or hold differing positions of

privilege and power, for example by virtue of location in minority or majority worlds with overlays of colonisation [21].

A third principle is the recognition of user wisdom and practice knowledge within a network which contains practitioners, AT users, academics and representatives of organisations (some of whom are AT users). This emphasises equity by recognising some voices are more often privileged within discourses. These principles are built on the foundation of user centricity, seeking applied solutions to real-world problems [20]. This community is committed to addressing the needs and concerns of users of AT.

Next steps include a critical review of these foundations in collaboration with other African initiatives and developments. ACAT stakeholders suggest development of the ACAT web portal, collaboration with the European Assistive Technology Information (Eastin³) network, to build an AT search engine and comprehensive African AT database for Africa leveraging off their existing platform and competencies. One envisioned future is development of ACAT into a professional body for AT stakeholders in Africa.

Exemplar: Latin American alliance for AT (ALATA)

Latin America and the Caribbean is a diverse region that stretches from the northern border of Mexico to the southern tip of South America. Its population accounted for 641,3 million in 2018. Almost 80% of its inhabitants living in urban areas and indigenous peoples represent around 8% of the total population [23]. A swift demographic transition and an increasing life expectancy at birth result in a rapidly aging population, with 20% of the regional population being expected to be older than 65 years by 2050.

A range of AT stakeholders are working to progress assistive technology in Latin America. These include for example Argentina's Association of Assistive Technology (AATA)⁴ and Brazil's PAHO/WHO Collaborating Centre for Rehabilitation based at the Physical and Rehabilitation Medicine Institute of the University of Sao Paulo Medical School General Hospital⁵

The mission and support of WHO GATE can clearly be seen as a facilitator of action in Latin America for individuals, for countries, and for the region. Gathering 280 therapists and physicians among its members, AATA encourages individuals to join the GATE community and connect with their global peers. AATA is now a founding member of the GAATO, which provides a 'systems' connection into the global network of AT organisations. And the idea of ALATA continues to grow.

This idea of a Latin American Alliance for AT (ALATA) as a regional forum for GATE in Latin America came about when stakeholders from the region had opportunities to meet and to discuss common issues at relevant educational forums. Initially, ALATA was imagined during an ISPO meeting in Buenos Aires in 2016. Further discussion at an International Seminar on Rehabilitation and AT in Sao Paulo occurred in 2017, paving the way for a meeting of AT experts from Argentina, Brazil, Chile and Colombia.

ALATA's vision is one of acknowledgment by professionals, governments, international organisations and organisations of persons with disabilities and their families as a key forum to discuss and foster access to good quality, affordable assistive products in the Latin American region, from both the functioning and cost-effectiveness perspectives. This would be accomplished by gathering together stakeholders who promote access to assistive technologies in the Latin American region in a forum that could regionally move forward with the initiatives carried out at the international level by GATE.

ALATA aims to i) overcome information barriers (such as language) and raise the awareness about current developments in the field (such as GATE, GREAT, APL, the Research Agenda, the WHA resolution) and ii) create a community through international cooperation. As an initial exercise, starting interests were proposed including: research on usability, quality and abandonment of assistive products; identifying available products (an EASTIN-like effort); collecting information on national AT systems/policies; market characteristics (manufacturing, distribution, financing); and, education for research and development, prescription/selection, and service delivery. Utilising the WHO MedNet platform, ALATA MedNet community (which people can join at: www.mednet-communities.net/gate/alata) has 58 individual members and organisations from 14 countries, including a few outside of Latin America. Countries with more representatives are Argentina (11), Brazil (10), Chile (8) and Colombia (7). In addition to taking part in international fora such as the GREAT Summit in 2017 and the GRaAT Consultation in 2019, the ALATA community strives to keep this momentum and build a regional community.

In other countries and continents there is evidence that the AT field is slowly organising itself. For example, in India the second conference on AT, entitled EMPOWER2019⁶, took place in October 2019, marking the start of a movement in India. The inaugural Pacific Rehabilitation and Mobility Conference⁷ brought together service providers, disabled persons organisations, users of rehabilitation or mobility device services, development partners and donors from Fiji, Kiribati, Papua New Guinea, Samoa, Solomon Islands, the Cook Islands, The Marshall Islands, Tonga, Vanuatu, Australia, New Zealand and the United States of America to identify priority areas for strengthening and building the professions of the sector.

The Latin American Alliance for AT and the African Community on Assistive Technology as previously introduced, describe two emerging exemplar groups beginning to organise. Of some importance, these new entities have organisational mentors. Among the mentors are key rehabilitation engineering and assistive technology organisations that many years ago experienced the need for an additional layer of networking. The more experienced organisations have a formalised leadership, activities, and membership of professionals that revolve around the advancement of assistive technology and rehabilitation engineering for the benefit of the local, national or regional populations they serve. In the year 2000, in Tokushima, Japan, four such professional organisations with a focus in rehabilitation engineering and assistive technology met and created a formal, but loosely defined group called the Alliance of Assistive Technology Professional Organisations. The rationale and evolution of this group is described in the next section.

Integrating systems via Inter-Organisational networks for a more global impact

Assistive Technology Professional Organisations are essentially the 'peak bodies' for their countries, continents or regions, knowing that assistive technology is a much needed solution for millions of people, understanding the significant global challenges to providing these technologies, especially as our populations age; and recognising that while some of these challenges are unique, many more are shared across nations and cultures.

The Tokushima agreement (2000)

In the year 2000, professionals in rehabilitation engineering (RE) and assistive technology formed four organisations based in

Table 1. Signatories to the Budapest Agreement are the founding members of the International Global Alliance of Assistive Technology Professional Organisations.

Association	Demographics	Strategic goals	Activities
AAATE	AAATE has 218 members among which 41 institutions mostly from academia, providers, industry. The board is composed of 7 members including a president and president elect.	<p>A strategic objective is that in Europe and worldwide an increasing number of persons with disabilities that might benefit from it have access to and effectively use appropriate assistive solutions.</p> <p>The implementation of the UN Convention on the Rights of Persons with disabilities, in particular the articles that acknowledge the importance of assistive technology, accessibility and universal design.</p> <p>The development of policy and programmes in all areas of disability and technology. International collaboration and exchange. Support work that enhances accessibility legislation and standardisation.</p>	<p>A biannual conference</p> <p>Workshops</p> <p>Communication and dissemination activities</p> <p>Project participation</p> <p>Technology and Disability journal</p> <p>International networking and related activities</p> <p>Support to the ENTELIS network</p>
ARATA	Board of 10 plus individual or associate membership. 220 members including AT professionals (all allied health, professions education, engineering, nursing); AT users, AT suppliers, educators, policymakers and funders	<p>i. Influence policy and sector reforms to embed good practice and equitable service delivery;</p> <p>ii. Support and develop assistive technology knowledge and skills by:</p> <ul style="list-style-type: none"> - promoting specialised skills and knowledge in assistive and rehabilitation technologies; - supporting good practice principles in service delivery; <p>iii. Develop, strengthen and support assistive technology research, practice and profile, locally and globally;</p> <p>iv. Ensure ARATA's sustainability, financial viability and relevance</p>	<p>Biennial conference</p> <p>Education events</p> <p>Member listserv</p> <p>Policy advisory activities</p> <p>Australian and international standards representation</p> <p>International liaison</p> <p>Policy change activities</p>
RESKO	<p>In 2007 RESKO (Rehabilitation Engineering and Assistive Technology Society of Korea) was established based on the RESNA model.</p> <p>RESKO has about 170 members including student members. The affiliated organisations are academy, institute, government, hospitals and welfare organisation, industry manufacture, and associations.</p> <p>Board committee is composed a total of 20 members including president, president elect, and three vice-presidents.</p>	<p>The primary goal of RESKO is to contribute to academic research on RE & AT for persons with disability and elderly persons. The details are as follows:</p> <ol style="list-style-type: none"> 1. Investigation, research and exchange of academic studies 2. Publish journal 3. Host of regular conference, special interesting group, training workshop, and committee meetings 4. Standardisation research 5. Education and training programme on RE & AT 6. International and domestic cooperation activities related to RE & AT 	<p>Two conference per year</p> <p>Project participation</p> <p>One domestic journal publication</p> <p>AT Licence education</p> <p>International networking and other activities</p>
RESNA	Board of Directors of 15; Approximately 1300 members who are engineers, occupational therapists, physical therapists, rehabilitation counsellors, manufacturers, suppliers, technologists, AT users, policy makers	<p>Established in 1979 our mission is to promote the health and well-being of people with disabilities, and those who are aging, through technology solutions; Strategic Plan:</p> <ol style="list-style-type: none"> 1) Advance the professional and educational development of RESNA members, students, and others in the field. 2) Increase RESNA's value to members and potential members. 3) Raise our profile in the field and position RESNA as a credible leader and expert resource. 4) Pursue new financial resources to strengthen Society while benefitting the field. 5) Strengthen RESNA's role in AT/RE research and knowledge translation 	<p>Special interest groups (SIGs)</p> <p>Professional Specialty Groups (PSGs)</p> <p>ISO & ANSI Standards Professional Standards Board, Certification (ATP, SMS, RET)</p> <p>Educational webinars</p> <p>AT Forum listserv</p> <p>Annual conference Government Affairs</p> <p>AT Journal</p> <p>AT Education Accreditation</p>
RESJA	714 individual members including AT professionals (all allied health, professions engineering, education, nursing, vocation), AT users, AT suppliers, educators, policymakers and funders; and 20 institutional members. 14 elected board members.	RESJA, established in March 1986, is an organisation for all persons with disabilities, pursuing to develop and popularise assistive technologies in the rehabilitation field. RESJA continues to contribute to the academic research, culture and industry by utilising assistive technologies.	<p>Annual conferences (JCAART)</p> <p>Annual AT Competitions</p> <p>Rehabilitation Engineering Journal (4 books per year)</p> <p>10 Special Interest Groups</p> <p>6 Local Area Groups</p> <p>ad hoc committees</p> <p>Seminars and training programmes</p> <p>International activities</p>

(continued)

Table 1. Continued.

Association	Demographics	Strategic goals	Activities
TREATS	Board of 22 plus individual or associate membership. 193 members including AT professionals (all allied health, education, engineering, nursing); AT users, AT suppliers, educators, policymakers and funders.	<ul style="list-style-type: none"> i. Assist the government to develop policies related to assistive technology ii. To participate in international affairs and related activities iii. Attending relevant conferences to improve knowledge and skills iv. Promote the alliance of “health industry, government and science research” in TREATS v. Promote the development of members related matters 	<ul style="list-style-type: none"> Annual conferences Newsletter (4 per year) Ad-hoc committees Seminars and training programmes International activities Workshops Education events Project participation: International networking and other activities

Australia, Europe, Japan, and North America. The AAATE (Association for the Advancement of Assistive Technology in Europe)⁸, ARATA (Australian Rehabilitation & Assistive Technology Association)⁹, RESJA (Rehabilitation Engineering Society of Japan)¹⁰, and RESNA (Rehabilitation Engineering and Assistive Technology Society of North America¹¹) convened in 2000 to define and facilitate common worldwide goals. This resulted in and became the Tokushima Agreement that provided modest inter-organisational recognition and support such as sharing use of logos to promote each other, and reciprocal conference registration privileges. This agreement also created a culture of collegial respect and openness to learn from and support each other across membership.

The Budapest agreement (2015)

In 2015, the four organisations that signed the Tokushima Agreement formally met in Budapest, Hungary, to update the agreement and consider two new organisations who were subsequently admitted into the Alliance: RESKO (Rehabilitation Engineering Society of Korea)¹² and TREATS (Taiwan Rehabilitation Engineering and Assistive Technology Society)¹³. Table 1 highlights the characteristics of the 6 organisations behind the Budapest Agreement.

The partners in the Budapest Agreement have been trying to change the landscape on a national level (RESKO, RESJA, TREATS) and continent level (RESNA, AAATE, ARATA). Together, these six organisations shared a mission to advance the field of assistive technology and rehabilitation engineering to benefit people with disabilities and functional limitations of all ages in concert with the developments of the WHO GATE activities. As of May 2018, when the World Health Assembly ratified the Resolution on Assistive Technology [10], the public face of the Budapest Agreement was the “International Alliance of Assistive Technology Professional Organisations (IAATO)¹⁴.”

The international alliance of AT professional organisations

The Alliance at this stage is a collaboration of membership-based (professional) societies and associations. Committed to working towards equitable and reliable access to assistive technology through research, policy advocacy, educating people and organisations within and outside of the field. Alliance members engage in communication and information exchange, support each other’s efforts, and speak with a unified voice on international issues. The signatory organisations consider each other as being “sister organizations” in other geographical areas, not competitors, respecting the different characteristics created by culture, political environment, membership, mission statement and situation of people with disabilities in their respective geographical areas.

However, there remained no true entity that formally engaged local and regional associations of AT and RE members to work together as a global network. As will be described, this changed in 2019 and sets the stage for a growing community of assistive technology and rehabilitation engineering organisations.

The Bologna launch of the global alliance of assistive technology organizations (GAATO) (2019)

In 2018 and through 2019, the six organisations of the International Alliance began meeting regularly online to develop a more formal charter of the organisations of assistive technology and rehabilitation engineering member organisations. This resulted in the creation of procedures and a more formal application and review process to accept members. Importantly, this phase also articulated a roadmap for growth, and an updated definition of the Alliance and its qualifications for membership. A “Call for Collaboration” invited new members for which three were inducted at a general assembly meeting in Bologna in the Summer of 2019. The Asociación Argentina de Tecnología Asistiva³, The Assistive Technology Industry Association¹⁵, The British Assistive Technology Association¹⁶, and the EASTIN Network² joined the Alliance, bringing the membership of IAATO to ten organisations. Additionally, the IAATO general assembly formally updated its name to GAATO, for Global Alliance of Assistive Technology Organisations¹⁷.

Contemporary developments: The time is right for a step forward

As mentioned above, the emerging focus on assistive health technologies by WHO, with the formation of the Global Access to Assistive Technology (GATE) initiative¹⁸ has provided both the impetus and the opportunity for individuals and organisations globally to connect, guided by the Global Priority Research Agenda for Assistive Technology [24]. That is why the partners that earlier signed the Tokushima agreement decided to expand and intensify their collaboration by transferring the existing alliance into this emerging Global Alliance of Assistive Technology Organisations. Organisations who share the same goals, are not-for-profit member entities can join the Alliance and contribute to achieving its goals. This will spark the development of new AT organisations in countries where no such organisations existed as the previous examples show. In the view of the founding members the GAATO will provide the ideal framework for gearing existing efforts of members towards shared goals, to develop joint actions, and support the collaborative work of assistive technology efforts around the globe. By linking to more networks it is hoped that GAATO will enhance the learnings of contextual

challenges affecting the sector and further develop global advocacy efforts 'upstream'.

Conclusion

A major step for any community is to critically reflect on how it might open doors, evidence good practice, and avoid reinventing wheels. The World Health Assembly has declared that the inclusion of assistive technology (AT) in health systems is critical to achieving progress towards the Sustainable Development Goals (SDGs) targets of universal health coverage, inclusive quality education, inclusive and sustainable economic growth [10]. The Global Disability Summit¹⁹ and AT 2030²⁰ are just two of the exciting developments unfolding for AT right now. With the foundations in place, groups such as the ACAT, ALATA, and others will continue to connect assistive technology stakeholders and support these global endeavours, influencing assistive technology Products, Personnel, People, Policy and Provision within our countries and regions, and beyond. It is hoped that these initiatives, through the building of community and the sharing of information and good practice, will serve to increase access for those most in need of AT.

Notes

1. <https://www.worldometers.info/world-population/africa-population/>
2. www.arata.org.au
3. <http://www.eastin.eu>
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7. <https://www.motivation.org.au/pacificconference/>
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11. RESNA <https://www.resna.org/>
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17. <http://www.gaato.org/>
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Disclosure statement

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