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The IDEAL PROCESS for developing Assistive Technology policy

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ABSTRACT

Policy development and implementation are key to improving access to Assistive Technology (AT). In this paper, we describe a strength-based framework for doing this at national level. We used an action research approach, with the United Nations Conventions on the Rights of Persons with Disability (UNCRPD) as the primary frame of reference. Primary data were collected using the World Health Organisation's rapid Assistive Technology Assessment (*rATA*). We describe the process of applying our emergent framework and how our findings support it. We identified seven guiding principles for effective policy process: *Participatory*, *Resource aware*, *Outcomes focused*, *Collaborative*, *Evidence-informed*, *supporting good practices*, and *System strengthening* – which can be summarized by the acronym PROCESS. Five crucial building blocks for effective AT policy development emerged: *Identification* of the assistive technology ecosystem, *Demography* of disability and AT use, *Evaluation* of inclusion and participation in existing policy, *Alignment* with UNCRPD and Sustainable Development Goals (SDGs), and *Locality* of implementation – which can be summarized with the acronym IDEAL. The IDEAL PROCESS incorporates key content building blocks and core process principles, constituting a systematic framework for guiding the development of context sensitive AT policy and a strength-based pathway to improving access AT.

ARTICLE HISTORY

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KEYWORDS

APL; Assistive Technology; IDEAL PROCESS; policy development

Background

The Global Report on Assistive Technology (WHO, 2019), jointly published by the World Health Organization (WHO) and United Nations Children's Fund (UNICEF), estimates that 2.5 billion people are in need of access to assistive products. By 2050, it is estimated that 3.5 billion people will require assistive products (World Health Organization, 2022). Assistive technology (AT) is critical for social inclusion and participation of persons with disabilities, people living with chronic conditions and older people. AT refers to “the development and application of organized knowledge, skills, procedures, and policies relevant to the provision, use, and assessment of Assistive Products” (AP) (Khasnabis et al., 2015). According to the 2022 global report on AT, AT is an umbrella term for assistive products and their related systems and services' (World Health Organization [WHO], 2022). APs include devices, equipment, instruments, and software that are specifically designed and produced for the purpose of maintaining and/or improving functioning (Khasnabis et al., 2015). They are crucial mediators for achieving universal health coverage (UHC) (Layton et al., 2020), the Sustainable Development Goals (SDGs) (Tebbutt et al., 2016) and implementing the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (United Nations, 2006). AT products are often not available to most persons who need them, and globally as many as 90% of those who

need assistive technology do not have access to it (World Health Organization [WHO], 2016).

AT policy is the cornerstone of improving access to AT and delivering on the recommendations of the WHO and on equitable access to AT (WHO, 2022). The Global cooperation on Assistive Technology (GATE) was established by the WHO in 2014 to address the high level of unmet need for AT (Khasnabis et al., 2015; World Health Organization [WHO], 2014). The development of the priority Assistive Product List (APL) and subsequent recommendation of the World Health Assembly (WHA), including the adoption of Resolution 71.8 (WHA71.8) for countries to develop their own context suitable version, was a means to support equitable development and use of AT (World Health Assembly, 2018; World Health Organization [WHO], 2018). The development of national AT policies is therefore integral to realizing the implementation of global reports and conventions (MacLachlan et al., 2018).

Inclusive policy development is key for health services and health system change/development and the achievement of the SDGs. According to Amin et al., inclusive policy development ensures equitable participation of all stakeholders and also safeguards the human rights principle which is at the heart of the recommendations of the 1978 Alma Ata declaration for ensuring health for all persons (Amin et al., 2011). Current evidence from around the world indicates that often, policy

development is not inclusive and that efforts at participation may be mere attempts to tick the boxes rather than a genuine desire to include stakeholders (Ebuenyi et al., 2020). This is antithetical to the ethos of the GATE which sought from the outset to put people at the center of efforts on AT development and access (Desmond et al., 2018).

Since the establishment of GATE, several countries have strived for the development of an APL and related AT policy. In Tajikistan, Mishra et al. developed and documented the process of APL development (Mishra et al., 2020). Similarly, the governments of Nepal and Sierra Leone, working with stakeholders on disability in their respective countries, have developed their own APLs (Government of Nepal, 2018; Government of Sierra Leone, 2019). Findings from these studies indicate the relevance of AT for rehabilitation and for realization of the UHC.

Theoretical background

The importance of policy in AT access and use has been underscored in its inclusions among the 5Ps relevant for achieving improved access to AT (WHO, 2018). National AT policies were conceived as relevant for driving access to AT. MacLachlan and Scherer in their 10Ps of systems thinking also highlight policy among the 10Ps relevant for AT access as shown in Figure 1 (MacLachlan & Scherer, 2018). To achieve equitable access to health care, both the Alma Ata convention and various health policies and legislations underline the relevance of underpinning/embedding health products in policies. The United Nations Convention on the Rights of Persons with Disabilities (CRPD) argues for this and conferred on state parties the responsibilities of immediate and progressive realization of the commitments to policy development (United Nations, 2006).

Article 4 of the CRPD clearly stipulates that state parties must consider the promotion of the human rights of persons with disabilities in all policies and programs (United Nations, 2006). To realize this goal, policies and programs must be developed with persons with disabilities in an inclusive manner. Historically, policies have not been developed inclusively

and may explain why many policies exist without being adequately implemented. Also, the process and manner of policy development may predict which policies are implemented and the ones that are not (Amin et al., 2011). But most importantly, without effective policies, it may be difficult to achieve health and social system objectives (World Health Organization, 2012).

The process and outcome of policy development is often unpredictable and dependent on several contextual factors (Huss & MacLachlan, 2016). These contextual factors may sometimes reflect challenges in the local health system and/or political factors that affect other aspects of human development. Factors such as political will, social and cultural norms, perceptions, and stance on human rights determine the process and manner of policy development and whether it is implemented (Amin et al., 2011; Huss & MacLachlan, 2016). Also, important are factors related to inequity that led to the development of policies in LMICs by actors from outside the setting, who often lack knowledge of local factors that drive or hinder policy development and implementation.

These understandings and reflections informed the rationale for the development of a framework for policy development based on an action research approach in collaboration with local stakeholders (Ebuenyi et al., 2020). This paper outlines an IDEAL PROCESS for Assistive Technology Policy Development. This is derived from the experience of the authors in developing AT policy in Malawi, and in other AT policy development projects ongoing throughout Africa.

The IDEAL PROCESS development

The authors have worked with governments and coordinating organizations across multiple countries in Africa to develop APLs and evaluate the process of APL development. The IDEAL PROCESS has been informed by those experiences. We have illustrated this process below with examples of the work done to develop the APL in Malawi in partnership an Action Research Group (ARG) drawn from a wide range of engaged local stakeholders, from civil society, service users and service providers (including industry partners), to government ministries. Further details on the roles of the ARG and research team are reported in the project research protocol (Ebuenyi et al., 2020) and in the paper describing the development of the APL previously published (Munthali et al., 2023). In the next section, we describe the specific components of the IDEAL PROCESS (Figure 2) and how it can contribute to strengthening AT ecosystems in national contexts.

The IDEAL PROCESS for developing Assistive Technology Policy is an iterative and emergent process toward AT policy and APL development that responds to the needs and realities of the setting in which it is undertaken. The IDEAL PROCESS, seen in Figure 2, is comprised of seven principles, five building blocks, and three key actions. The sections below describe each of these, with examples from the AT policy and APL development process in Malawi.

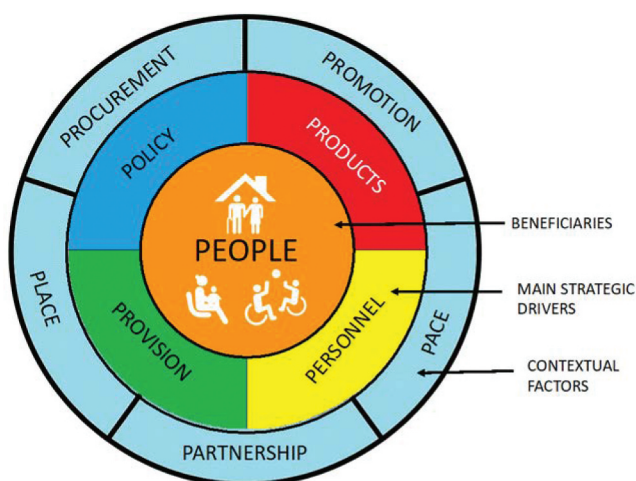


Figure 1. The 10 Ps of systems thinking for assistive technology (adapted from MacLachlan & Scherer, 2018, with permission).

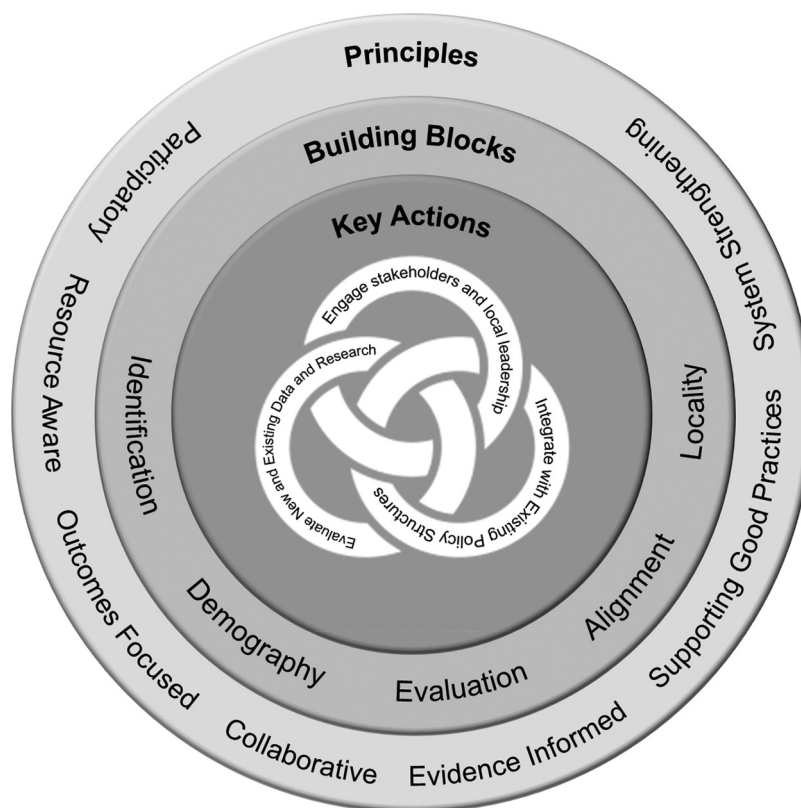


Figure 2. The IDEAL PROCESS for Assistive Technology policy.

The principles of the PROCESS of developing AT policy

The seven principles underpinning the policy development PROCESS are as follows: *Participatory*, *Resource aware*, *Outcomes focused*, *Collaborative*, *Evidence-informed*, *Supporting good practices*, and *System strengthening* (PROCESS). These principles are demonstrated by deliberate effort to ensure the participation and collaboration of all stakeholders through wide consultation, and mapping of evidence on policy development, disability, and AT needs, led by local partners poised to utilize and build a realistic system using available resources in the setting.

A *participatory* policy development process begins by identifying and involving key stakeholders on AT in the setting (Ebuenyi et al., 2020). To undertake this step, policy developers might consider a series of questions: *who are the key actors in AT? Which ministries or organizations provide AT? Who is providing leadership in the area? Who is contributing to the current effort for AT policy?* This stage can be enhanced through further probing stakeholders and the use of a network analysis (Smith et al., 2022a). Network analysis is considered relevant in identifying the relationship between actions and to use such knowledge to drive interventions and system deployment (Network, 2014; Ryan et al., 2014). Our network analysis helped us to answer some of these questions (Figure 3).

In all settings, it is critical to be *resource aware* in order to take advantage of what is already available in that setting and to consider what might be done within the existing resource limits. The Assistive Technology Capacity (ATA-C) assessment, which

had previously been completed Malawi (Clinton Health Access Initiative [CHAI], 2019) as well as other countries where we were working, is a system-level tool for evaluation of a country's capacity to finance, regulate, procure and provide AT (World Health Organization [WHO], 2021a).

Outcomes data may be both country specific and comparative. Bespoke indicators that measure outcomes specific to different country contexts are important. These can be complimented by using the WHO rapid Assistive Technology Assessment (*rATA*) (World Health Organization [WHO], 2021b). The *rATA* provides a snapshot of assistive product use within the country. It can be repeated in order to assess outcomes that reflect meaningful changes over time, which may be compared to those in other countries. Other bespoke outcome measures can be developed to consider following policy implementation to evaluate progress. The *rATA*, when combined with other existing sources of disability data, can also serve to inform the policy by contributing to an understanding of the existing demography of disability and AT use, described later.

Throughout the process of policy development, actions must be *collaborative* (Michaud-Létourneau et al., 2019; Wolff et al., 2017). This collaboration must be present not only among stakeholders but also in consideration of future implementation of the policy. To that end, it is important to ensure equitable representations of all ministries relevant to AT, using a collective leadership approach (Ebuenyi et al., 2020; Michaud-Létourneau et al., 2019). As AT is a cross-cutting issue, there must be ownership of the final policies by a range of ministries. In the case of Malawi, although the disability policy was being developed by the ministry responsible for

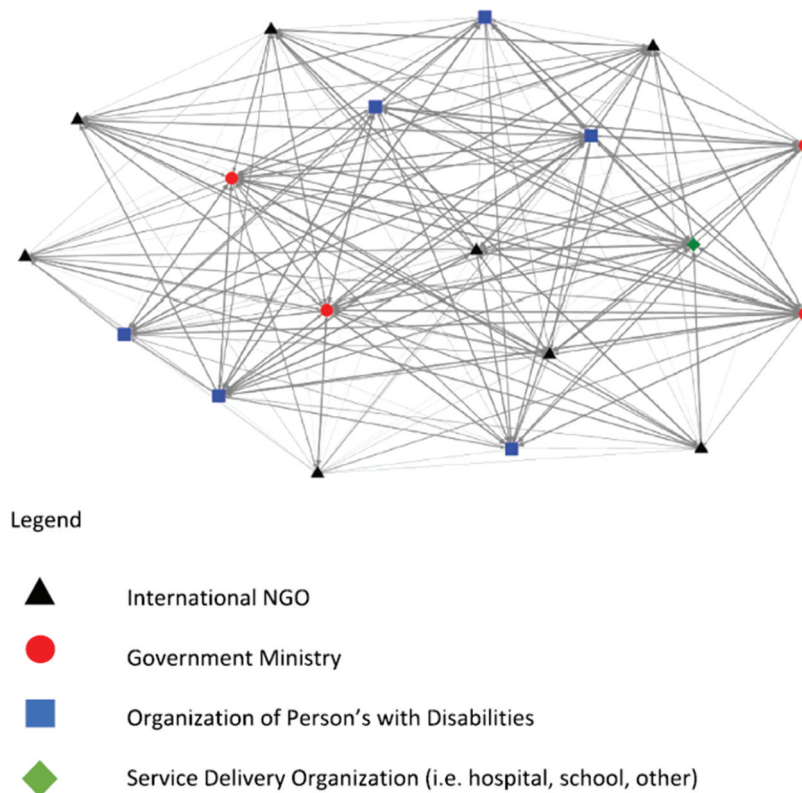


Figure 3. Network of Assistive technology organizations in Malawi (Smith et al., 2022a).

Box 1. Some guiding questions for the development of AT Policies and APLs

- What policies exist? To what extent do they include AT?
- How inclusive were the development process of existing policies?
- Does AT require a new policy? Are other relevant policies under development?
- Are there other guidelines or standards which should apply?
- What data already exists? How can it be used?
- Can existing datasets be combined to answer key questions?
- How connected are existing services to one another?
- Do government ministries consider AT relevant to achievement of the SDGs?
- What is the role of civil society in the AT community?
- Do ministries have existing relationships with service providers and users?

disability, other ministries such as Health; Education; Labour, Skills and Innovation; Economic Planning and Development; and Information, Communication and Technology contributed to the policy development process. Hence, the Ministry of Health and other ministries were actively involved during the stakeholder meetings and collectively led the data collection process for the policy and APL. Collaboration was enhanced through a network analysis which helped to identify the relevant stakeholders on AT (CHAI, 2019; Smith et al., 2022a).

To ensure effective policy implementation, processes should be *evidence-informed*, considering the best available evidence in the field of AT and in other relevant fields of practice. With a growing body of evidence in AT, including publications detailing the development of AT policy and APLs in several countries (Government of Nepal, 2018; Government of Sierra Leone, 2019; Mishra et al., 2020; ATScale, 2021). Furthermore, the recent Global Report on Assistive

Technology, among other publications by leading AT research and practice organizations, provide a framework from which to begin (WHO, 2022). The policy must also be informed by existing evidence in the country from previous or similar policy implementations, as well as existing evidence in the area of disability and assistive technology. Although evidence on disability and/or AT may be available, they are often not used (Ebuenyi et al., 2021). Using existing data and a statistical matching technique may help to address data deficiencies to understand the need for AT in the country (Jamali-Phiri et al., 2021). Further evidence may need to be acquired in the process of policy development. For example, it may be helpful to undertake a review of assistive technology products and services provided (Smith et al., 2020). In the case of Malawi, we also sought to understand how age affects AT use, so we undertook a study to explore the age-related increase in impairment across the life course (Ebuenyi et al., 2022) and multicountry comparisons of AT use in countries with similar experience (Jamali, 2022). Age-related data help to predict future AT requirements and to understand how these may differ from country to country (p. 34).

Supporting good practices in policy development requires the identification of those practices, and evaluation of their use by stakeholders. Studies indicate that AT is critical to the achievement of the Sustainable Development Goals (SDGs) (Tebbutt et al., 2016). Furthermore, the WHO has established the use of the rATA and ATA-C tools to provide a consistent approach to understanding the need for AT and capacity of countries to provide it (WHO, 2021a, 2021b). In the case of Malawi, we sought views of AT stakeholder regarding the relevance of AT to their efforts to achieve particular SDGs. In fact, we found that

the relevance of AT was crosscutting, being considered relevant by all stakeholders to the work that they were doing across the range of SDG (Smith et al., 2022b). Thus, much of the existing work of AT stakeholders, including many civil society organizations, were already engaged in what could be considered supporting practices for the development and adoption of a more systematic approach to AT provision (Mishra et al., 2020).

The process of policy development should also be *system strengthening* in itself. During the APL development, we were guided by Mishra et al. (2020) who recommend the use of the WHO rATA to collect data on AT use and assistive products, the use of Focus Group Discussions to explore stakeholder preferences for AT, and the review of national AT systems. All of these were fed into a consensus workshop to agree on the APL. We also collected data in rural areas to gain a broad knowledge of perceptions of stakeholders who are often not included in policy development process (Munthali et al., 2023).

We would advocate for data collection being co-led by the ministries responsible with NGO partners, including organizations of persons with disabilities (OPDs), in a collaborative manner (MacLachlan & Scherer, 2018).

The building blocks of AT policy

The IDEAL PROCESS also identifies five IDEAL building blocks: *identification* of the assistive technology ecosystem, *demography* of disability and AT use, *evaluation* of inclusion and participation in existing policy, *alignment* with international policy including the UNCRPD and SDGs, and *locality* of implementation including the local policy landscape.

The *identification of the assistive technology ecosystem* is integral to the policy development process. This requires a systematic exploration of who does what and how in terms on AT in the setting, and the identification of pathways to change. This process also serves to identify key stakeholders who may not be known or considered prior to the work being conducted. Evidence from research policy supports the understanding of the setting and important stakeholders in the development of new policy (WHO, 2022). Identification of the AT ecosystem can be completed using a network analysis to understand the interrelationship between AT stakeholders, industry actors, and providers to support AT access and provision (Smith et al., 2022a).

Understanding the *demography of disability and AT use* is crucial to establishing realistic policy. While data is not always apparent or readily available, it is possible to identify data sources which can provide relevant information from data which has already been collected or available in the country (Jamali-Phiri et al., 2021). Ideally, the acquisition and analysis of disability and AT data will be co-produced with persons with disabilities and/or users of AP. This approach is supported by the 5P's and 10P's framework of AT which places the users of AP at the center (MacLachlan & Scherer, 2018; WHO, 2018).

An *evaluation of existing policy to assess inclusion and participation* provides an opportunity to review existing policies which may be relevant to assistive technology, or which may be adjusted or reframed to include AT. Several tools exist to complete this evaluation, including the EquiFrame and EquIPP frameworks (Ebuenyi et al., 2021) which have

previously been used in many countries across different policy challenges to promote inclusive policy development process and content (Huss & MacLachlan, 2016). Where deficiencies are identified, these policies may be amended or modified in the process of AT policy and APL development.

Policies should *align with international policy including the UNCRPD and the SDGs* (Smith et al., 2022b, 2022c; Tebbutt et al., 2016). The relevance of AT to each of these international policy instruments has already been demonstrated, with worked through examples of how AT delivers on each of the articles within these key instruments (Smith et al., 2022b, 2022c; Tebbutt et al., 2016). For example, article 9 of the CRPD makes a case for accessibility and studies indicate that AT is central to achieving access in the environment, in relation to transportation and fostering equitable communication (Bigonnesse et al., 2018; Smith et al., 2022c; United Nations, 2021). Those developing AT policies and APLs at the national level must be aware of these international agreements and the application of their principles. While policy development must be nationally led, the international context may be informed by a rich blend of international actors working together, challenging and sharing their diverse experiences.

Finally, to get traction policies must be realistic and achievable, which means *taking locality into account, in terms of understanding the existing policy landscape, settings and conditions, culture, context, and how the services systems – health, education, employment; work, or could work* (CHAI, 2019; Smith et al., 2020). Those responsible for the development of any new policy must carefully consider existing contextual factors, including those policies which exist or are under review within relevant departments. In the case of Malawi, the Ministry responsible for disability was working on reviewing and revising the existing policy at the same time as the research partnership was working to develop an APL. Following discussions with stakeholders and based on the understanding that it was better to have an inclusive disability policy with specific reference to AT rather than multiple policies, it was agreed that the resources planned for the AT policy development should be devoted to support an all-encompassing disability policy with AT as an integral component. Although AT is not solely for persons with disabilities, a large percentage of assistive products are used by persons with disabilities, and AT is an integral part of achieving inclusion for persons with disability.

Key actions

There are three key actions which must be undertaken in the process of policy development, aligned with the principles and building blocks of the IDEAL PROCESS. These are *engagement with key stakeholders and local leadership, integration with existing policy structures, and evaluation of new and existing data and research*. Each of these actions is comprised of those activities which have been described in the sections above.

Discussion

Our project set out to develop a national AT policy for Malawi and at the same time to contribute to the development of

a framework which might be relevant in other countries too. What we have done in this paper is to document the IDEAL PROCESS, which is a strength-based framework for AT policy development which we believe it relevant across diverse contexts. Although we did not develop a standalone policy for AT in Malawi, the development of an AT section in a new policy comprised a similar process and step to what we believe would be required for a stand-alone policy in order for it to be inclusive and evidence based. Further, while this process was used specifically in the area of assistive technology, readers may note that the language used to describe the components of the process is broad and could be relevant to the development of inclusive and evidence-based policies in other content areas, with relatively minor modifications.

The setup and action research methodology of the project meant that we anticipated changes and were prepared to respond to the needs of the process rather than be limited to a rigid process that would accept only pre-determined deliverables. That indeed is the hallmark of the action research process and responsive policy development paradigm (Coghlan & Brydon-Miller, 2014). In responding to the needs of the setting, we demonstrated the participatory and collaborative nature of the policy process, which must be embraced by individuals charged with the task of policy development. These principles are integral to the development of the AT component of the new disability policy and align with the mission-oriented approach for AT proposed by Albala et al. (2019). It is noteworthy that without the adoption of such a flexible approach by the primary funder of this project, we would not have had the scope to adapt to changes in circumstances or to opportunistically align our research to country-led initiatives which arose during the lifetime of the project. This suggests that, in some cases at least, research funders should be open to deviations from initial plans, if they hold the possibility for greater impact. If this is the case more generally, then we believe it is not widely understood in the research community.

The IDEAL PROCESS principles and the building blocks outlined in the framework allow for a reflective and wholistic approach to policy development with beneficiaries of the policy. Furthermore, the iterative nature of the policy and framework development ensured the buy-in across stakeholders and different ministries. Following the policy development, the implementation plan and budget and costing were also developed in a collaborative process to ensure that there was buy-in not only from the users of AT but the policymakers and managers who will drive its implementation.

The IDEAL PROCESS provides a realistic policy development method which offers an opportunity to utilize context relevant strategies and options in policy development. It allows countries to achieve a realistic and strength-based approach toward improving access to AT without reliance on significant additional data collection at the national level. The feedback from the various stakeholders in the policy and research process makes it an acceptable framework for policy development.

In the case of Malawi, the process was not, of course, without challenges, which were resolved through deliberation and consultation. This deliberation and consultation has resulted in the

process which we have described above. For example, one of the earlier challenges was the collective leadership approach which was alien to Malawi and was resisted by some stakeholders and members of the ARG. However, through iterative discussions, all the line ministries contributed to the disability policy and in data collection. The APL is presently being used by the Ministry of Health in the making of the essential health package through delineation of the type of AT to be provided at different health-care levels in Malawi. The COVID-19 pandemic was another major challenge to the deliberative and participatory nature of the policy development. A few months after the inauguration of the project the pandemic hit, leading to transfer of most of the activities of the ARG and research team online. Finally, working with several team members with different background meant that decision-making was achieved through a collaborative process that required management of group dynamics, expectations, and interest.

In conclusion, the IDEAL PROCESS presents a systemic framework incorporating context-specific realities and resources, which can guide AT policy and APL development. The growing need for access to AT has been given greater impetus by the 2022 Global Report on AT. AT policy development and implementation is pivotal to realizing the SDGs and the UNCRPD. The IDEAL PROCESS is a tool for contributing to this important work.

Disclosure statement

No potential conflict of interest was reported by the author(s).

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