

Part 9: Policy

International Classification of Functioning, Disability and Health and the Convention on the Rights of Persons with Disabilities as a Framework for AT Classification and Categorization

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Background: Assistive technology is a powerful enabler of the person's participation in the different environments. Assistive technology is however understood to be many things by many stakeholders and this limits its potential. Dominant medical and rehabilitative discourses have shaped assistive technology language, terminology, scope, research priorities and outcome measures. The rights-based model considers assistive technology as a human right, a need and an enabler of full participation in all aspects of life of the person. This paper considers this history, reconciles the AT approaches, and proposes a new model drawing on two powerful contemporary frameworks.

Method: The constructivist argues that knowledge can be generated through critical discourse analysis (CDA) and we reflect on early claims of knowledge manifested in academic and non-academic literature related to ways of codifying assistive technology. The research paper is also informed by the standpoints of the authors and AT user experience of the first author. A content analysis of three pivotal articles is conducted utilizing UN CRPD as an AT categorization framework model and WHO ICF model as a classification framework model. The authors critically analyse the difference between AT classification (classes with fixed boundaries) and AT categorization (categories with flexible boundaries) systems and their implications for framing assistive technology.

Key results: Existing studies on AT Classification systems do not take the UN CRPD into consideration

or differentiate between AT solution classification and categorisation. The AT Functioning, classification and categorisation (ATFCC) model organizes AT solutions (AT products, services and users) into both classes and categories under a one framework model. AT Classification system is based on the WHO-ICF model (body functions, and compensation of the body structure functions), medical and social model approaches towards persons with disabilities. AT categorization is based on the human rights-based approach and the Functional Diversity model towards persons with disabilities. AT solution classes are outcome of the interaction of AT solution with the person's body parts with function limitations and body function limitations. AT solution categories are outcome of the interaction between AT solution and a person's environmental or participation context. This model enables holistic AT assessment because it captures both the body function or body structure function difficulties and the full participation context of a person with functional difficulties in need of AT. Such a model may facilitate equitable allocation of resources for diverse AT users and purposes.

Conclusion: This model enables holistic AT assessment because it captures both the body function or body structure function difficulties and the full participation context of a person with functional difficulties in need of AT at the same time. Such a model may facilitate equitable allocation of resources for diverse AT users and purposes. ATFCC framework model influences formation of AT information and data management system by organizing AT solutions in classes and sub-classes and categories and sub-categories based on the WHO-ICF and UNCRPD respectively. It can facilitate the development of AT policies and AT funding models to cover a wide range of AT needs to enable participation in all aspects of life.

Keywords: Functioning, Rights, Assistive Technology, Classification, Categorisation.

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Political factors and assistive technology: A Multiple Streams Framework analysis of assistive technology landscape

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Background: To maximize the promise and sustainability of the assistive technology (AT), AT interventions need to be recognized in legislations and policies. However, this is not the case within the Canadian AT landscape, which creates a significant variation in the availability and accessibility of the AT interventions. These discrepancies lead to system-level barriers that prevent AT professionals from effectively supporting AT users. The aim of this paper is to:

- 1) understand political complexities impacting the Canadian AT landscape and the potential for AT policy advancement;
- 2) identify how AT professionals can support the AT policy advancement by considering political complexities.

Method: This paper draws on the Kingdon's Multiple Streams Framework (MSF) to identify actions and conditions necessary to place AT policy advancement on the government agenda to stimulate policy relevant changes to optimize the AT provision. The MSF is a political theory that examines how issues get onto the policy agenda and how proposals are translated into policy changes. Kingdon generates MSF's key theoretical constructs by outlining meaningful categories of policy formulation into three streams: problem recognition, generation of policy proposals and politics.

Key results: The current categorization of the AT provision under the healthcare umbrella prevents government actions towards optimization of the AT system. Currently, the AT concerns are not perceived as pressing problem when compared to more easily understood medical priorities (e.g. shortage of hospital beds). To stimulate actions from the government, AT professionals must highlight a mismatch between the current AT situation and the government's conception of the optimal state. For example, repositioning AT concerns from the healthcare to a social justice issue that impacts one's ability to enjoy fundamental rights re-defines the current AT concerns as a problem appropriate for a

prompt governmental action. For the policy to be enacted, AT professionals must generate policy proposals that are technically and politically feasible, grounded within the language and value system practiced by the policy makers. The AT professionals must recognize a long gestational process for the proposal to be considered a 'go-to' solution, thus, AT professionals must concentrate their efforts on preparing both policy and public communities to the proposed solutions. Currently, the Canadian national mood is not receptive of the AT policy advancement, thus AT professionals need to lay the groundwork for shaping the receptiveness of national mood to the AT policy reform by engaging with people in and around government. Once the policy window opens, it will allow AT professionals to 'push' proposed solutions by coupling them to the emergence of pressing problem and political events.

Conclusion: Within the current Canadian AT landscape, policy windows are tightly closed, as the inadequate AT system has not been defined as a problem and the national mood is not receptive to the AT reform. However, as policy windows are short-lived opportunities for change that require immediate and well-thoughtout actions, present environment is favourable for the AT professionals to initiate the AT policy advancement process with the clear understanding of the political factors influencing the AT landscape.

Keywords: AT, political realities, AT policy advancement.

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Re-thinking the Advancement of Assistive Technology Systems from the Human Rights Perspective

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Background: Despite a social advancement in the notion of disability and the identification of the assistive technology (AT) as a human right by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), the constructs of the medical model of disability still underlie many of today's

AT policies and practices. With the momentum created by the Global Cooperation on Assistive Technology's (GATE) call for user-central redevelopment of AT systems, an important question arises of how to address the structural discriminations rooted deep within the existing AT systems and re-frame these systems to reflect users' decision making over the resources that impact their lives. A possible answer lies in critically examining and re-framing the existing AT systems through a human rights perspective.

Method: This paper draws on the United Nation's Human Rights Based Approach (HRBA) to explore a paradigmatic framework shift necessary to advance AT systems to best serve its intended beneficiaries. The HRBA is a conceptual framework that seeks to understand and address the root causes of systemic problems by analyzing implicit inequalities and discriminations within the existing systems.

Key results: The application of the HRBA to AT, shifts the way AT and AT systems are conceptualized. A HRBA framework positions AT as a tool that responds to human diversity and fosters an inclusive society. It further conceptualizes AT system as a system that aims to maximize social inclusion and the exercise of equal rights through user-driven AT provision. Furthermore, the application of the HRBA to AT, redefines unequal power-relations and establishes new roles and relationships between:

1. people with disabilities (PwD) as rights holders and active members of society – who can make their own decisions and claim their rights to AT and
2. government bodies as duty-bearers - who are obligated to respond to PwD claims and fulfill their rights to AT.

Transformation of the power-relations illuminates discrimination and injustices within the current AT systems which stems from the outdated conceptualization of disability rooted deep within existing AT policies and practices.

Through the identification of systemic discrimination within the current AT system and through recognizing PwD as key actors in the decision making process that impacts their lives, the HRBA:

1. empowers PwD to challenge inequities within the current AT systems;
2. emphasizes the responsibility of the government bodies to respect, protect and fulfill the right of PwD to appropriate AT.

Conclusion: The HRBA brings forward a novel perspective to the AT field as it focuses on recogniz-

ing structural causes behind the inadequate AT systems and addresses these by transforming the unequal power-relations between PwD and government bodies, thus stimulating a fundamental change within AT systems. However, in order to translate HRBA efforts to meaningful actions, it requires a deep political knowledge of AT context, mapping of actors and alliances, and understanding dynamics of policies that prevent effective enjoyment of AT rights. The effectiveness of HRBA application to AT and its proposed potential requires collaboration with and 'buy-in' from those who currently have power.

Keywords: Human rights approach to AT.

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“Equipping, Empowering, enabling”: Center-staging Assistive Technologies in Disability and Rehabilitation Policy Discourse in India

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Background: Global demographic and epidemiological transition reflects an upsurge in NCDs, ageing and injuries with manifold rise in disabilities and functional impairment. World Health Assembly Resolution (2018) called for greater emphasis on Assistive Technology (AT) including strengthened data, policy, standards and investments. South-East Asia (SEAR) has the second highest prevalence rate of moderate disability (16%) and third highest prevalence rate of severe disability (12.9%), as per the World Disability Report (2011). The 2011 Indian census recorded 2.21% of the total population (26.8 million persons) as Persons with Disabilities (PwDs). WHO estimates indicate 90% of the PwDs have no access to ATs; the inability to afford and maintain ATs result in exclusion, poverty and increasing burden on affected families/communities, especially in low and middle income countries.

This review is a critical analysis of the evolution of contemporary global mandates and priority areas in AT

research; and, how the Indian Council of Medical Research (ICMR) plans to align Indian research and programmatic priorities along the global dialogue.

Method: Policy review and analysis was undertaken by a three member inter-disciplinary team of public health experts, selected by the ICMR's Disability and Rehabilitation Unit. Key international and national documents of the last ten years including policy documents, reports, WHO technical papers, academic articles and advocacy pieces were reviewed and triangulated.

Key results: The results have been divided in two sub sections

- A) *Emerging priorities articulated across global and national agenda which need to be addressed by policy decisions and revised research strategies* – A review of global and national type and quality of data on estimates of unmet need found it to be incomplete and fragmented. To bridge the gap in policy and practice a comprehensive national policy for people with disabilities and functional impairments was identified to strategically channelize available resources. Program priorities for ATs ought to address both service provisioning as well as research; and to establish linkages across primary, secondary and tertiary levels of care.
- B) *India specific initiatives undertaken by ICMR* Disabilities or functional impairments need to be treated/managed as distinct epidemiological entities, for which ATs constitute the core intervention (for rehabilitation). The AT industry as well as the policies regarding its design, manufacturing, marketing and provisioning is evolving in India. The WHO recommends a distinct program for ATs that needs to take account of demand, manufacturing, standards, availability, affordability, reach, maintenance and sustainable use. The ICMR plans to align its research priorities as per the international conventions and WHO recommendations; national priority areas for research were also identified.

Conclusion: Research for ATs needs to take into account demand, manufacturing, standards, affordability, reach, maintenance, and sustainability. Public health care systems and sub-systems requires comprehensive package for disabilities and functional impairments attributed to ageing, NCDs, mental health disorders and injuries along with prioritizing cost-effective approaches in LMICs. Strategy should not be just about availability of devices or technologies but comprehending the complex lived experience of the PWDs across age, socio-economic groups and shaping a flexi-

ble and sustainable system that is equitable to this vastly disadvantaged group.

Keywords: Assistive Technology, India, Policy, LMICs.

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Access to Assistive Technology in Hungary – What is (Not) Done About it?

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Background: There are almost 500.000 people who consider themselves disabled in Hungary. There is no available statistical data regarding the number of people in need for an assistive device, although 1.5 million people, 15% of the whole population face difficulties in everyday-life activities based on the latest (2016) available representative, self-reported data. The number of people in need for an assistive device is increasing as the population ages and most of them are in need of financial support to access: families which include at least one person with disabilities earn 15 percent less in average than a family without a disabled member and the risk of social exclusion and poverty is 22 percent higher among people with disabilities than in the non-disabled population. What kind of assistive devices and related services does the Hungarian state provide, for whom, under what eligibility conditions and why? The presentation will conclude the partial results of a doctoral research (2017–2020) which will examine the role of the state in assistive technology provision in Hungary compared to 4 other European countries (IT, DE, DK, UK).

Method: The PhD research focuses on the role of the state in Hungary, the examined variables are legislation, financing, provision and control concerning AT accessibility. The methods used for the presented Hungarian study are qualitative: besides the literature review, comprehensive legislation analysis, sociological professional interviews and user interviews were made. The thesis will include sociological illustrative case studies about Italy, Germany, Denmark and the United Kingdom which can demonstrate good practices or, in any event, different patterns of accessibility. With the exception of Hungary, the case studies are built upon ongoing short study trips to the founding member institutions of the European Assistive Technology Information Network.

Key results: It was found that there are large inequalities between Hungarian people who can afford a product themselves and the ones who need financial support to do so. One of the most important human rights is flouted depending on the financial status of the user: freedom of choice. There is a national list of medical aids, those can be granted through social insurance, but the list has not been updated for ages meaning the ISO 9999:2003 is used. The provision system is obsolete and there appears to be a considerable obstacle to modernize it: the financial-economic aspects appear to have precedence in policy-making over professional and user-orientated considerations. The greatest losers of the obsolete system are people with communication disorders and severe disabilities as well as people with mental health conditions and children.

Conclusion: The presented section of the PhD research is the first analysis of the Hungarian AT provision on the field of social policy that creates the possibility of international comparisons. The study points out significant inequalities in accessibility which can contribute to forming the main indicators of the national policy-making.

Keywords: assistive technology, accessibility, social policy, service delivery, Hungary.

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Young women, Disability and Technology: A Survey Study from the RISEWISE Project

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Background: The “RISEWISE”-project (Horizon 2020, GA690874) investigates barriers that women with disabilities meet in their life. Technology can either be an enabler or a barrier for them. Within the project a survey was carried out to investigate the relationship between technology and disability and to compare the perceptions of young women with (WD) and without disabilities (WW).

Method used: The survey, targeting women belonging to the digital generation (age between 15 and 29 years old), was developed in English and translated in three languages (Italian, Spanish, Turkish) to obtain a cross cultural data set. The survey consists of 234 items in different sections: autonomy, frequency of technology use, satisfaction with technology, software, apps and social media preferences, confidence in using smartphones, interaction with technology, benefits and impact of using technology, barriers for technology use, support needs and perceptions regarding gender differences in technology use. The survey was administered to the participants online. Non-random, snowball sampling was used in data collection between September 2018 and March 2019.

Key results: Preliminary results arise from 228 women that have completed the survey, of which 27 by WD's: (motor (6), visual (14), hearing (2), emotional-relational (1) and multiple (4)). Bivariate correlations among variables showed that for the entire group there is a significant positive relationship between frequency of technology use and level of satisfaction ($r = 0.83$, $p < 0.01$), expected benefits ($r = 0.31$, $p < 0.01$) and empowerment ($r = 0.28$, $p < 0.01$). As the perceived benefits of using technology increase, there is a significant increase in empowerment ($r = 0.80$, $p < 0.01$), in needs and wishes regarding technology ($r = 0.41$, $p < 0.01$) and in support needs ($r = 0.44$, $p < 0.01$). No significant differences were found between WD and WW, except in the main areas of felt empowerment: both indicated “education” and “information gathering”, while WD highlighted also “employment” and WW “communication”. Further, WD indicated “to find more appropriate solutions for my needs”, “to have better skill in using technology” and “to have more information about the options” to be strongly related to their needs regarding technology. The barriers that prevent technology use are different for the two groups. WD mentioned the lack of support from public institutions, accessibility issues and lack of information and support while WW mentioned lack of time, money and interest. WD expected support mostly from paid experts, AT centers and producers/companies. Both groups agree that gender differences between men and women impact on the purpose of using technology, the choice and the intensity of use. For both groups, society “as a whole” is to blame for the underrepresentation of women in technology related disciplines and careers.

Conclusions: In terms of confidence, frequency of technology use and positive attitudes towards technol-

ogy use there does not seem to be a big difference between WW and WD. Both groups do not hesitate to engage with technology and benefit from it. Nevertheless, there are differences in information and support needs. This might indicate that if this support is not provided

many women with disabilities may remain excluded from fully benefiting from technology.

Keywords: Women with disabilities, Digital divide, Risewise project, Empowerment, Gender.

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