

# Towards an agenda of action and research for making health systems responsive to the needs of people with disabilities

Thi Vinh Nguyen and Sumit Kane\*

Nossal Institute for Global Health, Melbourne School of Population and Global Health, The University of Melbourne, Victoria, 3010, Australia



## Summary

Ensuring health systems responsiveness is crucial for health equity and outcomes of all individuals, particularly disadvantaged groups such as people with disabilities. However, attention to and discussions on health system responsiveness for people with disabilities remains lacking. This viewpoint highlights the pervasive issues within health systems rooted in ableism and proposes an agenda to tackle ableism, aiming to make health systems responsive to the needs of people with disabilities. Their needs are complex and diverse, varying with the disability, its severity, progression, and intersection with other factors. Ableism creates significant obstacles to identifying and addressing their needs and expectations, damages provider–patient interactions, poses multiple challenges in healthcare, and impacts the overall responsiveness of the health system to the populations it is meant to serve. The proposed agenda outlines areas for action and research across six building blocks of health systems as a way forward to enhance the health system’s responsiveness to the needs of people with disabilities.

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## Introduction

Approximately 16% of the world population, equalling 1.3 billion people, have disabilities.<sup>1</sup> Although attention to healthcare related needs and expectations of people with disabilities has been increasing, inequities remain stubbornly persistent, and their right to the highest attainable standard of healthcare is far from being realised and reached.<sup>1,2</sup> For instance, all-cause mortality among people with disabilities is 2.24 times higher than that of people without disabilities, and there is a 13.8-year gap in life expectancy between the two groups.<sup>3</sup> In almost all parts of the world, people with disabilities are regarded as a vulnerable population, their needs and rights, including healthcare rights, are still frequently overlooked.<sup>4</sup> To promote health equity and rights, it is crucial that the needs and legitimate expectations of people with disabilities are appropriately responded to within health systems and healthcare services. WHO (2000) noted that “where health and responsiveness are concerned, achieving a high average level is not good enough: the goals of a health system must also include reducing inequalities, in ways that improve the situation of the worst-off”.<sup>5(pviii)</sup>

Responsiveness to the expectations of the population is one of the three primary goals of national health systems, along with achieving good health and ensuring fairness of financial contribution.<sup>5</sup> The conceptual

framework on health systems responsiveness proposed by Mirzoev and Kane (2017) (Fig. 1) sees people’s expectations from and the experience of interactions with their health system along eight domains, and recognises that both health systems and community side factors (e.g actors, processes) shape these expectations and experiences of interactions. The framework argues that these interactions are in turn embedded within and influenced by both, the broader, entrenched historical, political, cultural, social, and economic context, and the entrenched social and relational dynamics within communities and families. The premise being that it is important to recognise many ways in which this layered, often entrenched context influences people’s interaction with the health system that is meant to serve them.

Despite advancements in disability rights, ableism continues to hinder healthcare access and quality to people with disabilities.<sup>7</sup> Ableism refers to “a system of historical and contemporary policies, institutions, and societal norms and practices that devalue and disadvantage people who are disabled...and privilege people who are positioned as able-bodied and able-minded”.<sup>7(p1)</sup> It systemically discriminates people with disabilities based on their disabilities.<sup>8</sup> Ableism arises from the biomedical model of disability, which views disability primarily as “a negative deviation from normal”<sup>9(p.50)</sup> and as a medical issue that requires treatment or cure.<sup>10</sup> This view has been criticised for excessively focusing on the impairment rather than considering and recognising disability as integral to and as a part of human diversity. This ableist deficit oriented view not only leads to the

\*Corresponding author.

E-mail addresses: [sumit.kane@unimelb.edu.au](mailto:sumit.kane@unimelb.edu.au) (S. Kane), [thivinh.nguyen@unimelb.edu.au](mailto:thivinh.nguyen@unimelb.edu.au) (T.V. Nguyen).

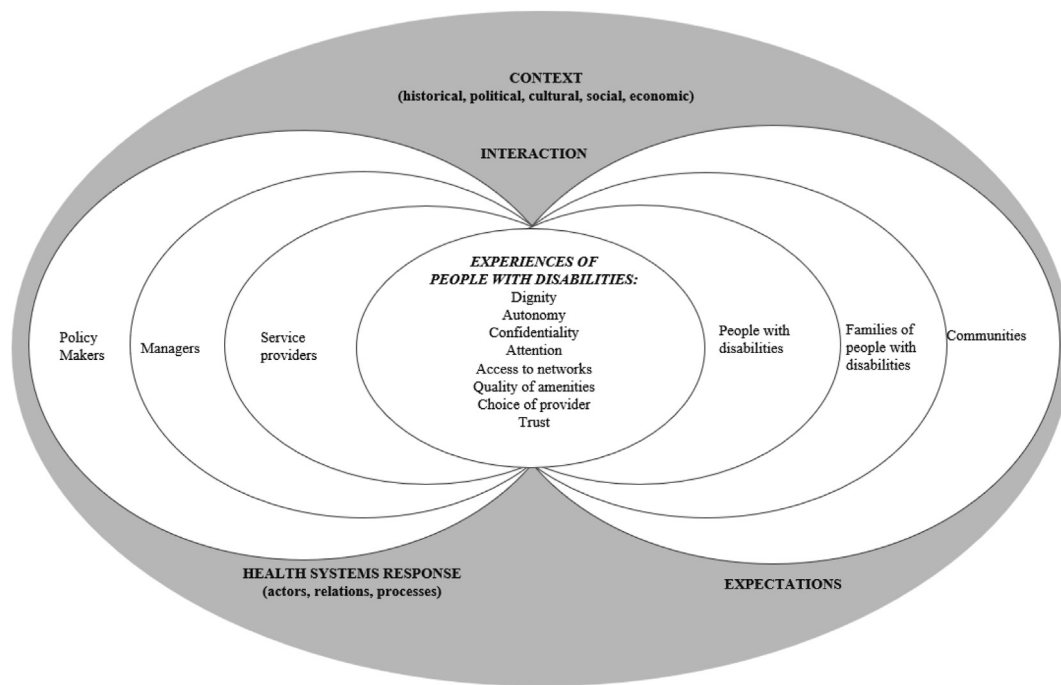


Fig. 1: Conceptual framework for health systems responsive to people with disabilities (Slightly adapted from Mirzoev and Kane 2017 to focus specifically on people with disabilities<sup>6</sup>).

devaluation of people with disabilities, it leads to the neglect of the role of social-structural factors in determining whether and to what extent people with disabilities can achieve their potential and live the lives they would like to live.<sup>11</sup>

This viewpoint highlights the pervasive issues within health systems rooted in ableism and proposes an agenda to tackle ableism with a view to make health systems responsive to the needs of people with disabilities. To address ableism effectively, it is crucial to challenge the deficit-oriented model and to shift towards human rights model that conceptualises people with disabilities as equal rights holders, embraces disability as a part of human variation, and recognises disability as also resulting from barriers within the society.<sup>12</sup> We argue that disability responsiveness requires a whole of system approach and that ableism should be addressed in every aspect of health systems. WHO's six building blocks will be used illustrate areas for actions and research in the agenda.<sup>13</sup> This viewpoint seeks to trigger a broad-based discussion on ableism in health systems and the health systems responsiveness literature, and calls for further research and actions in this important field.<sup>7</sup>

### Ableism: a barrier to health systems responsiveness to people with disabilities

In health systems, ableism manifests in many ways, through pervasive stereotypes, biases, prejudices, and

discrimination against individual with disabilities.<sup>7</sup> Despite advances in disability scholarship that emphasise the social construction of disability, the traditional biomedically informed deficit oriented view of disability persists in health systems, perpetuating ableism across its various facets.<sup>7,10,14</sup> People with disabilities are assumed to be passive, voiceless and powerless recipients of care, rather than as persons with the autonomy and capability to make informed decisions regarding their own well-being and care.<sup>15</sup> For instance, it is not uncommon for healthcare administrators, support staff, and providers to view individuals with disabilities as being “disabled” in their ability to make decisions, so they choose to communicate with their escorts instead.<sup>16</sup> Consequently, their voices are unheard, their expectations and needs are under-recognised, and their experiences and agency within healthcare interactions are inadequately understood. Importantly, ableism within health systems can influence and obstruct the recognition of what is considered legitimate as ableist attitudes and assumptions can undermine and distort the needs and expectations of people with disabilities. A truly responsive health system would acknowledge and appropriately respond to the needs and legitimate expectations of people with disabilities.<sup>5,6</sup> Unless the legitimate expectations and needs of people with disabilities are fully acknowledged and integrated throughout the health systems, healthcare practices and services will continue to be delivered in

normative and historically routinised ways that do not appropriately consider and mainstream their specific needs. Therefore, it is crucial to examine how these expectations are framed within the broader context of ableism and to ensure meaningful engagement with people with disabilities to correct faulty, ableist assumptions about their needs and expectations.<sup>11</sup>

People with disabilities are a diverse group with a range of unique needs depending on disability (e.g. physical, sensory, intellectual, psychosocial, etc.), severity of disabilities, number and state (progressiveness) of disabilities.<sup>1</sup> Needs are further complicated by their unpredictability and due to the intersection of disability with other factors such as gender, employment, income, family status, educational level, residential conditions, and motherhood.<sup>11,15</sup> As outlined in the conceptual framework (Fig. 1), the essence of a responsive health system lies in its ability to effectively interact and collaborate with this diversity—of persons with disabilities, of their families, and of communities to understand and address their unique and diverse needs and legitimate expectations at these intersections.<sup>17</sup> However, ableism, manifests in and often operates through legacy policies, guidelines, standards of care, and routine practices—what has been called institutional logics - and compromises the ability of the health system and the providers that inhabit the system, to be responsive to those with disabilities. Briefly, institutional logics are ‘systems of ideas (logics)’ that govern societal actions and interactions.<sup>18</sup> They are the rules of the game, the organising principles and assumptions that guide practices and actions within an entire field of organisations.<sup>19</sup> These logics are the means by which power, status and legitimacy are gained, maintained (and lost) in and between organisations. Ableism, operating thus, often insidiously undermines the flexibility, autonomy and resources of healthcare providers in meeting the needs, changing needs, and legitimate expectations of people with disabilities. This translates into the health system, paradoxically, and we argue, deeply problematically, contributing to further entrenching and increasing disparities in care, denying or delaying people with disabilities with equitable access to necessary care, support and services.<sup>7</sup>

Despite the United Nations Convention on the Rights of Persons with Disabilities’s (UNCRPD) mandate for the highest attainable standard of health and healthcare without discrimination (Article 25), health systems worldwide continue to fall short in being responsive to the needs and legitimate expectations of people with disabilities.<sup>1,4,20</sup> Looking at care provision, just one of the six building blocks of the health system as a case helps illustrate this point. Research continues to reveal that care provision settings, particularly in low and middle-income countries (LMICs), continue to be designed such that they are inaccessible and unfriendly

for people with disabilities, long administration processes, inadequate communication and information access, unaffordable cost of services, and disability unaware and incompetent healthcare providers.<sup>1,16,21</sup> All of these ableist challenges may undermine people with disabilities’ autonomy, dignity, privacy and independence, risk their safety, and limit their choice of adequate, respectful, and dignified care—key aspects of health system responsiveness outlined in the conceptual framework -resulting in an unresponsive care experience. Such ableism can undermine patient-provider interaction and trust, further exacerbating the challenges in achieving health systems responsiveness for people with disabilities.<sup>22</sup> This situation with care provision can be understood in light of the body of evidence that suggests that healthcare providers—in LMICs and also in high-income countries<sup>23</sup>—often lack disability awareness and confidence because their training and continuing professional development activities do not address these areas.<sup>24</sup> Healthcare providers are socialised within their trainings and professional routines to work with the biomedical deficit oriented view of disability as the norm—a norm that perpetuates ableist attitudes instead of challenging and addressing them.<sup>10</sup>

Addressing the diverse needs of people with disabilities requires recognising that what gets counted is often all what counts. Disability identification is often not recorded in national health information systems in both high-income and low-and middle-income countries, making it difficult to recognise the needs of people with disabilities and to develop policies, programs, and services based on routine health service data.<sup>15,25</sup> The UNCRPD recommends disaggregating routine data by disability to identify and address barriers faced by persons with disabilities in healthcare.<sup>4</sup> Tools such as the “Missing Billion” disability-inclusive health system framework can be useful to monitor whether routine health data is disaggregated by disability and whether the health system is inclusive of disability.<sup>26</sup> Such approaches can enhance the understanding of the needs and expectations of people with disabilities, improve the monitoring and reporting of disability-related inequalities, and better inform health systems responses.<sup>25,26</sup>

The broader historical, political, socio-cultural, and economic context perpetuates and reinforces ableism throughout the entire system (Fig. 1). Negative socio-cultural attitudes towards disability, lack of health policies and programs targeting people with disabilities, inadequate budget allocation to their healthcare, and the presence of disability-unfriendly infrastructure and inaccessible information contribute to this systemic issue.<sup>27</sup> These factors not only influence the healthcare-seeking decisions of people with disabilities but also determine the types of services available and offered to them. More problematically perhaps, these contextual influences perniciously constrain and limit disabled

people’s “horizon of expectations”.<sup>28</sup> Although disability rights and human rights advocates have made significant strides in challenging and tackling entrenched ableist norms and practices within health systems and in society at large, ableism persists across all social spheres.<sup>10</sup> As a result, many people with disabilities come to accept low levels of health system responsiveness as their lot and as the norm, and do not have the social space to imagine, let alone demand, what should be reasonable, rightful, and legitimate expectations to have.<sup>6,17</sup> People with disabilities not just need healthcare providers, administrators and all individuals involved in their care to be disability competent, they need everyone to embrace and champion anti-ableism.

## Tackling ableism: towards an agenda for health systems responsive to the needs of people with disabilities

Despite people with disabilities being the largest minority, they receive disproportionately less attention within health systems and continue to face significant inequities.<sup>1,2</sup> These inequities are particularly pronounced in LMICs, where resources are often limited, and health systems may be inadequately equipped to address their complex needs.<sup>1</sup> These challenges derive not only from

physical and attitudinal barriers within healthcare facilities but also from entrenched ableism within the health systems. A disability-responsive health system recognises ableism and understands the diverse and unique needs, expectations, and experiences of people with disabilities. It however needs to go further to actively implement policies, practices, and services tailored to the needs of disabled persons, integrating disability-specific considerations into all aspects of the health system.<sup>2,29</sup>

Health systems that are responsive to the needs and expectations of people with disabilities are more likely to enhance service uptake, improve treatment adherence, and ultimately ensure better health outcomes and equitable care.<sup>5,30</sup> We propose an agenda for actions and research across the six WHO building blocks for health system responsiveness—here, we call to reimagine these building blocks as disability-responsive service delivery, disability-responsive health workforce, disability-responsive medical technologies, disability-responsive health management information systems (HMIS), disability-responsive financing, and disability-responsive leadership and governance.<sup>13</sup> In [Table 1](#), we present example areas for action and research that have been identified based on current evidence and from human rights and health systems responsiveness

Building block	Example areas for action	Example areas for research
Disability-responsive leadership and governance	<ul style="list-style-type: none"> <li>Identifying and developing a consensus around the legitimate expectations of people with disabilities from the health system.<sup>5</sup></li> <li>Implementing and enforcing disability-inclusive health policies to eliminate ableism and enhance health systems responsiveness.<sup>31</sup></li> </ul>	<ul style="list-style-type: none"> <li>Exploring expectations and needs of people with disabilities regarding health system responsiveness and investigate the effectiveness of health policies and governance frameworks in promoting anti-ableism, thereby informing disability-responsive leadership and governance.<sup>6,30</sup></li> <li>Evaluating governance and leadership models and approaches aimed at eliminating ableism and enhancing health system responsiveness for people with disabilities.</li> </ul>
Disability-responsive service delivery	<ul style="list-style-type: none"> <li>Encouraging health personnel to address ableist stereotypes and establish zero-tolerance policies for discrimination. Promoting diversity, equity and inclusion in health systems.<sup>32</sup></li> <li>Developing accessible healthcare facilities and services for people with disabilities as mainstream users.<sup>33</sup></li> </ul>	<ul style="list-style-type: none"> <li>Regularly assessing the health system’s responsiveness to people with disabilities across different service contexts.</li> <li>Evaluating innovative health interventions for reducing ableism and improving care for people with disabilities.</li> </ul>
Disability-responsive health workforce	<ul style="list-style-type: none"> <li>Providing ongoing disability training, that integrates ableism, rights, and needs of people with disabilities, for healthcare providers, managers, policy makers, and support staff.<sup>34</sup></li> <li>Ensuring a supportive, anti-ableism workplace for employees with disabilities in health systems.<sup>35</sup></li> </ul>	<ul style="list-style-type: none"> <li>Conducting research to identify effective training approaches and evaluating their impact on providers’ competence, quality of care, and patient outcomes.<sup>34</sup></li> <li>Investigating barriers to implementing disability training and involving people with disabilities in those training.</li> </ul>
Disability-responsive medical technologies	<ul style="list-style-type: none"> <li>Innovating and adapting medical technologies, including assistive products, telehealth, etc. to be accessible and affordable for people with disabilities.<sup>36</sup></li> <li>Including people with disabilities designing and testing medical technologies and products.<sup>36</sup></li> </ul>	<ul style="list-style-type: none"> <li>Evaluating the suitability and impact of medical technologies for people with disabilities.<sup>37</sup></li> <li>Researching ableism in the design and implementation of medical technologies.</li> </ul>
Disability-responsive HMIS	<ul style="list-style-type: none"> <li>Integrating disability data and anti-ableism and disability-responsive indicators in HMIS.<sup>29,38</sup></li> <li>Establishing data linkages between health systems and social services for people with disabilities and routinely assessing service coordination.<sup>25</sup></li> </ul>	<ul style="list-style-type: none"> <li>Identifying challenges and strategies for integrating disability data and anti-ableism and disability-responsive indicators into HMIS.</li> <li>Researching the use of disability-integrated data in HMIS for evidence-based policy making and resource allocating.</li> </ul>
Disability-responsive financing	<ul style="list-style-type: none"> <li>Ensuring equitable resource allocation, inclusive health insurance, and private sector engagement in supporting disability-responsive health systems.<sup>31</sup></li> <li>Providing adequate funding to develop integrated, innovative services that tackle ableism and promote responsiveness to people with disabilities.<sup>39</sup></li> </ul>	<ul style="list-style-type: none"> <li>Conducting economic analysis of programs to enhance the health system’s responsiveness to people with disabilities.</li> <li>Identifying barriers to equitable resource allocation for disability-responsive health systems and proposing strategies to address them.</li> </ul>

**Table 1:** Examples of action and research areas for making health systems responsive to people with disabilities.

perspective. These examples are illustrative rather than definitive. They are, as Lakin & Kane (2023)<sup>40</sup> have argued, meant to serve as starting points and as triggers to create spaces for equitable and meaningful participation, contestation, and negotiations to arrive at a common understanding of what people with disabilities can legitimately and rightfully expect from their health systems. It is crucial that all actions and research involve disability organisations and people with disabilities to ensure comprehensive insights into how ableism manifests in health systems, and how it should be tackled.<sup>2,7,35</sup>

## Conclusion

Addressing ableism in health systems is essential for advancing health systems responsiveness and promoting equitable healthcare access for people with disabilities. This viewpoint underscores the importance of identifying, calling out, and tackling pervasive ableism in health systems, and highlights the importance of doing so if we wish to make our health systems truly responsive and equitable. It proposes an agenda with various example areas for action and research aimed at systematically addressing ableism, with the ultimate goal of making health systems more inclusive and responsive to the diverse and unique needs of people with disabilities. Health policymakers, managers, and care providers should work alongside people with disabilities, their families, and communities to design and implement comprehensive reforms that dismantle ableist practices and ensure disability inclusive and responsive health systems.

## Contributors

TVN and SK contributed to the conceptualisation, methodology, literature search, writing—original draft, and writing—review & editing.

## Declaration of interests

The authors report no declarations of interest.

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