

DESAI et al.

39th WEDC International Conference, Kumasi, Ghana, 2016**ENSURING AVAILABILITY AND SUSTAINABLE MANAGEMENT
OF WATER AND SANITATION FOR ALL****Sanitation for all: a framework for research and practice to
improve equity for people with disabilities***G. Desai, J. Wilbur, P. Ram, J. N. Jensen, J. Lenker & K. Smith (India/UK/USA)***BRIEFING PAPER 2497**

More than 15% of the world's population has some form of disability, 80% of whom live in low- and middle-income countries, where basic needs, such as sanitation, often go unmet. People with disabilities often face environmental, social, and institutional barriers to accessing sanitation facilities, presenting a major hurdle to achieving the UN's Sustainable Development Goal of sanitation for all by 2030. Providing individuals with Assistive Technology Devices (ATDs) is a common approach to increasing sanitation access and use, the efficiency of which needs to be considered in broader cultural and economic contexts. With a general motivation to make progress toward the sanitation-for-all goal, this paper discusses a sanitation-for-all framework and describes the role of ATDs in improving access to sanitation. The framework includes three interacting, mediating elements that influence sanitation access—personal/individual, social, and environmental factors. It also includes one moderating element: institutional structures.

Introduction

The United Nations Convention on the Rights of People with Disabilities emphasizes equitable access to food, clothing, and housing, as well as the continuous improvement of living conditions, such as safe water and sanitation (UN, 2006). Despite this, the basic needs of many people with disabilities, who form more than 15% of the population of the world and 80% of whom live in low- and middle- income countries, often go unmet. (WHO, 2011, WHO, 2014). Approximately 360 million people with disabilities lack access to improved sanitation, nearly 150 million of whom practice open defecation, which, in turn, presents health risks to themselves and the broader population (WHO, 2011, WHO/UNICEF, 2015).

Although disability does not equate to a lack of access, people with disabilities often face environmental, attitudinal, and institutional barriers to accessing sanitation facilities, presenting a major hurdle to achieving the UN's Sustainable Development Goals, particularly 'sanitation for all' by 2030. Existing literature mostly comprises case studies that emphasize the problems that individuals with disabilities face and the problem-specific solutions that organizations have implemented. A second body of literature focuses on the types of problems that people with disabilities face while accessing sanitation facilities, with little emphasis on solutions and their scalability. Moreover, the literature shows a heavy reliance on localized solutions, particularly the use of assistive technology devices (ATDs). In contrast, the science and practice of inclusive design (and its variants: design for all, universal design, etc.) have not been widely integrated with mainstream sanitation science and practice. WaterAid is one of the few organizations working to mainstream disability inclusion in sanitation, such as the 'Undoing Inequity' action-research project—consisting of peer reviewed papers, data collection tools for water, sanitation and hygiene initiatives in Zambia and Uganda (Danquah, 2015), partnership with the Ministry of Drinking Water and Sanitation in India, and the launch of the *Handbook on Accessible Household Sanitation for Persons with Disabilities* (MDWS/WaterAid, 2015).

While ATDs can improve functioning and access, the lack of systematic piloting and data collection impedes the scaling up of solutions across geographies. In complement, it is uncertain if the reliance on ATDs is the most efficacious, or just, strategy. For instance, ATDs might promote increased physical functioning while further exacerbating social isolation, as 'persons of any age...can feel stigmatized by devices', such as wheelchairs, hearing aids, or medical braces, 'that signal loss of function' (Parette and

Scherer, 2004, p.217). Nevertheless, the value and appropriateness of ATDs need to be considered within larger cultural and economic contexts. In order to facilitate the evaluation processes for researchers and practitioners, a common framework is needed. The proposed sanitation-for-all framework has three objectives: (1) to build upon existing frameworks in order to understand the multiple, dynamic factors involved in providing sanitation for people with disabilities, (2) to understand the strengths and limitations of utilizing assistive technology devices in improving sanitation access, and (3) to propose expanding the World Health Organization's (WHO) and UNICEF's 'sanitation ladder' to include current sanitation-for-all initiatives.

Sanitation-for-all framework

Though focused on improving access to sanitation, the proposed sanitation-for-all framework is grounded in a broader social justice perspective. People with disabilities face barriers in accessing both basic needs—e.g., food, water, and sanitation—and higher-order institutions—e.g., education, health services, and employment. Additionally, barriers in the former can diminish, sometimes revoke, participation in the latter, such as the case of inadequate sanitation design in schools.

The sanitation-for-all framework, generated through Maxwell's four complementary domains of framework development (Maxwell, 2012) —(1) experiential knowledge, (2) prior research and existing theories, (3) pilot and exploratory research, and (4) thought experiments—integrates academic and practitioner perspectives from public health, rehabilitation sciences, anthropology, environmental engineering, architecture, planning, and development. Likewise, the framework builds upon the International Classification of Functioning (WHO, 2001), as well as various person-environment models (e.g., Webb, 2010).

The framework includes three interacting, mediating elements that influence sanitation access—personal/individual, social (norms and attitudes), and environmental factors. These mediating elements are in the pathway between the people with disabilities and accessible sanitation, and might be facilitating or intervening factors. It also includes one moderating element: institutional structures, which affects the strength of the relationship between people with disabilities as a group, and accessible sanitation (Fig.1). The sanitation-for-all framework, similar to WaterAid's and the Water, Engineering and Development Centre's barrier analysis approach (Jones, 2013), describes the types of barriers that people with disabilities face in accessing sanitation facilities. Barrier analysis provides a tool for assessing the current state of sanitation access for people with disabilities, as well as solutions to identified barriers. The framework differs from barrier analysis in illustrating not only a cross-sectional assessment but also the importance of phasing and change over time—i.e., the 'near future' and the 'aspirant future', built upon the WHO and UNICEF 'sanitation ladder'. This longitudinal framework provides the basis for development and planning.

Personal factors

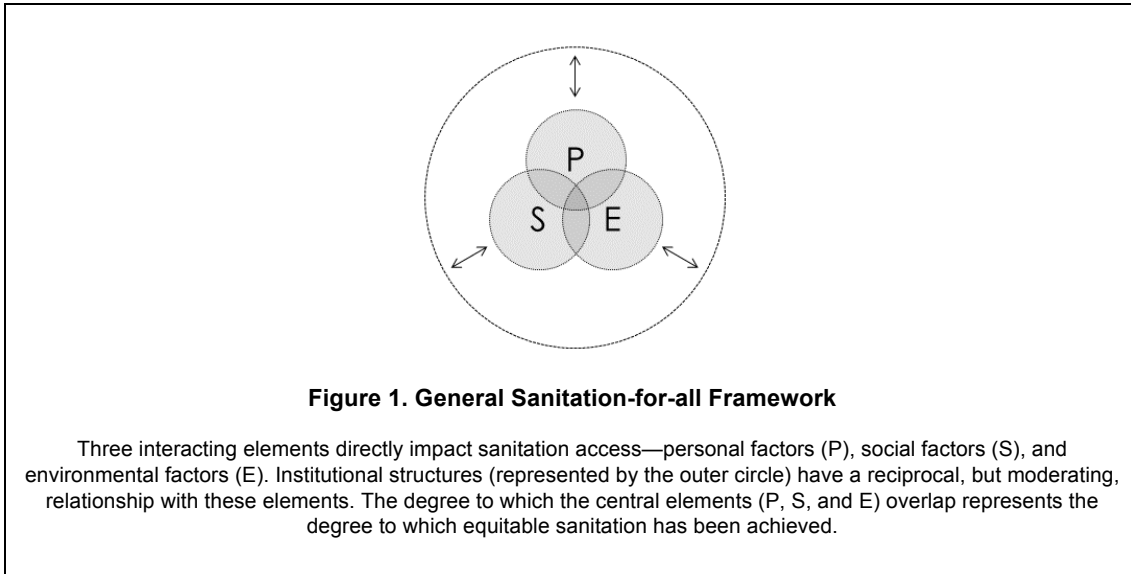
Individual and collective identities are comprised of a variety of attributes, e.g., age, ethnicity, gender, education, ability, and personality. Cultural and scholarly definitions of each of these have changed considerably over the past century, as has the understanding of their role in matters of social justice. The concept of disability has particularly evolved in higher-income countries.

The medical paradigm of disability remains prevalent in many contexts, as do more traditional definitions of disability as a defining feature in caste-based societies or as a form of 'divine justice' (e.g., Baquer, 1997). In contrast, the emancipatory paradigm of disability emphasizes environmental and social constructs—i.e., that disability is not a condition of the person, but is due to cultural prejudices and 'disabling' building conventions. Although disabilities are a part of a continuum of minor and major difficulties in performing activities of daily life and although WHO does not classify disabilities by 'type' (WHO, 2011), individual differences in physical, sensory, and cognitive abilities play a role in the access and use of sanitation facilities. For example, a person with vision problems might face different challenges in accessing and using sanitation facilities compared to a person with weak lower limbs. These factors govern the types of solutions that are necessary to address the challenges.

Social factors

Discriminatory societal norms—including stigmas, ignorance, misinformation, pity, and prejudice—pose major barriers for people with disabilities in accessing sanitation facilities (Gosling, 2010, Snider and Takeda, 2008). The specific manifestations of these attitudes, such as verbal abuse, vary according to country and culture. In certain Asian countries, for example, the practice of cleaning oneself with the left hand after toileting is prevalent; people with disabilities who cannot use the left hand may be subject to

stigmatization and maltreatment (Jones et al, 2002: 11). Likewise, in Madagascar, disability is viewed as a punishment from God for a past sin; a person with a disability may be regarded as useless and may often be denied the expression of his/her needs (Jones et al., 2012). In Uganda, many people with disabilities are forbidden from using shared sanitation facilities by the community members because they are viewed as dirty (Danquah and Wilbur, 2015). Social barriers are often difficult to identify and hard to overcome, since they are rooted in a society's culture for generations (Komerdjaja, 2001). Moreover, in some contexts, people with disabilities may modify behaviours, self-censor, or further marginalize themselves based on adopted social norms or pressures, e.g., avoiding using shared sanitation facilities, thereby increasing the burden on caregivers. The attitudes and behaviours of both society and individuals with disabilities, in turn, can contribute to inadequate design (Daruwalla and Darcy, 2005).



Environmental factors

Long distances to sanitation facilities, muddy roads, and steep slopes are barriers that disproportionately affect access to sanitation facilities for people with disabilities. Other physical barriers include: high steps that lead to facilities, narrow entrances, slippery floors, limited space inside facilities, the height of taps and sinks inside facilities, and a lack of handles for support (Jones et al., 2002). Squat toilets are common in Asia and Africa, and are particularly challenging for people with mobility impairments, diminished strength, or instability. Such barriers often force people with disabilities to practice unhealthy behaviours, such as crawling into facilities or not washing hands after toileting (Jones et al., 2002, Norman, 2010). People with sensory impairments, such as low or no vision, face parallel challenges. Public facilities may not be conveniently located or easily accessed, or may not provide adequate privacy and security. Household facilities may not be designed to promote good self-care or may not be easy to maintain. Often, it is the design and construction of the built environment, not the physiological characteristics of the individual, that leads to diminished ability (Sawadsri, 2011).

Institutional structures

While society and the environment serve as mediating variables, i.e., with direct impacts on equitable access to sanitation, institutional structures play a moderating role. This includes public policies, government and non-government organizations, funding systems and priorities, and social supports and programs. Examples include building codes that assist disabilities, disability advocacy organizations, funding provisions for production of assistive technology devices, and training programs for caregivers. Individual needs and preferences, social values, and building traditions often inform these institutional structures. Reciprocally, institutional structures can be leveraged to vindicate or transform societal norms, used to validate or modify building standards, or directed toward or away from various groups or individuals.

Expanding the Ladder of Sanitation

The current global state of sanitation for people with disabilities varies greatly. This parallels the WHO and UNICEF's sanitation ladder, the lowest rung of which is open defecation (one form of 'unimproved

sanitation’) and the top rung of which is ‘improved sanitation facilities’. For people with disabilities, the challenge of improved sanitation is two-fold: facilities need to be brought up to WHO/UNICEF standards and, where improved facilities are not universally accessible, ATDs are required to use improved facilities.

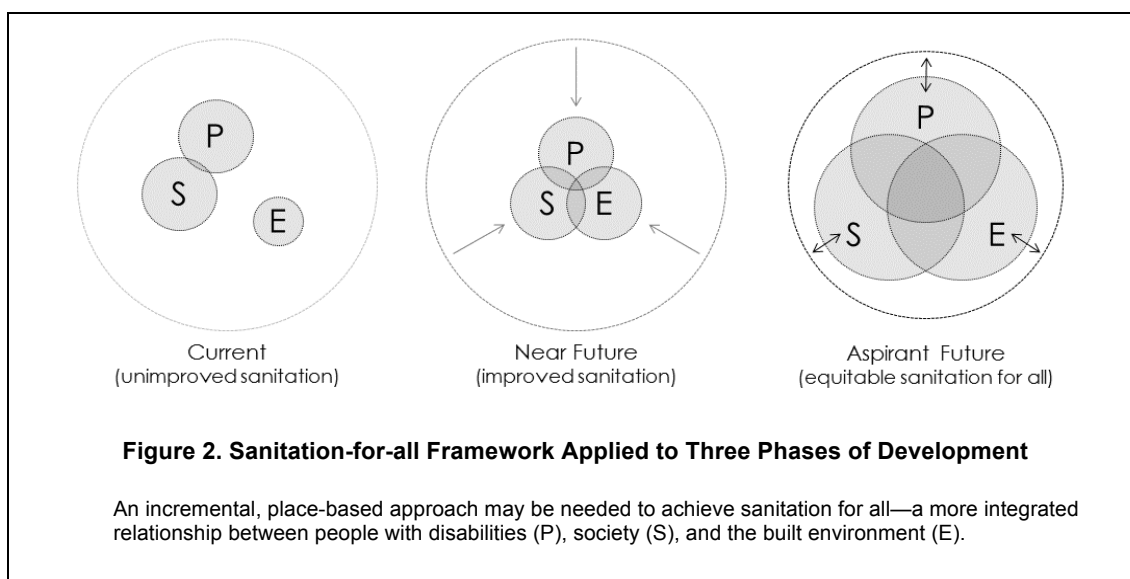
Broadly stated, ATDs include any device, system, or equipment used to improve or maintain the functioning of individuals with disabilities (Congress, 1998). Sophisticated ATDs have been studied and developed for high-resource settings, whereas ATDs in low-income settings are based on simpler, often ad hoc, technologies and materials. This has led to widely varied solutions, particularly in toileting: a wheelchair with a hole cut in the centre of the seat (Werner, 1987), handrails attached to the ground on the side of a squat toilet, a rope hanging from the ceiling to facilitate balance while squatting, and a toilet chair with a removable horizontal bar to assist with stability (Jones and Reed, 2005). This variability in use and, by extension, health and behavioural outcomes, points to three major issues. First, there are different levels of technological sophistication in the design and deployment of ATDs. Second, scalar differences need to be considered, as the design and construction of public facilities may address the needs of a wider spectrum of the population in comparison to the often ad-hoc toilets at the household level. Third, the current sanitation ladder espoused by the WHO-UNICEF represents only the current and near-term paradigms; progress in eliminating within-household inequities is not captured in the sanitation ladder. A higher rung is needed in order to represent the aspirant future of sanitation: ‘sanitation for all’ or equitable sanitation (Table 1).

Table 1. Adding the equity dimension to the sanitation ladder.			
Four factors—personal factors, social factors, environmental factors, and institutional structures—contribute to assessing the phase (ladder) of sanitation development. The current paradigm of unimproved sanitation relies heavily upon caregivers or self-reliance, while the near-future paradigm of improved sanitation relies on the use of assistive technology devices or environmental modifications. To achieve equitable sanitation (the aspirant future), social, environmental, and institutional values need to embody principles of equity.			
	Current Paradigm (unimproved sanitation)	Near-future Paradigm (improved sanitation)	Aspirant Paradigm (equitable sanitation)
Personal Factors <ul style="list-style-type: none"> • cognitive abilities • physical abilities • sensory abilities 	Disability is seen as an unchanging characteristic of the individual.	Disability is seen as a somewhat modifiable characteristic of specific groups.	Ability and disability are seen as part of the continuum of human life and diversity.
Social Factors <ul style="list-style-type: none"> • attitudes • norms 	There is a heavy reliance on caregivers and/or high self-reliance.	Public and/or individual educational and behaviour-change programs are modest in scale and scope.	Social norms embody principles of equity and inclusion.
Environmental Factors <ul style="list-style-type: none"> • climate • geography • ecology • infrastructure • buildings/products 	Environmental factors remain largely unmoderated.	Assistive technology devices or environmental modifications are the primary tools for improving access.	Diversity, equity, and social participation are central considerations in all planning, engineering, and design decisions.
Institutional Structures <ul style="list-style-type: none"> • public policies • funding • organizations • programs 	Institutional structures are not equipped to have a meaningful influence.	There is low utilization of major institutional structures and a high reliance on advocacy organizations.	Principles of equity are integrated into all policies, organizations, funding, and programs.

While ATDs focus on individual differences and needs, and often address shortcomings in the design of the built environment, inclusive design views disability as part of a larger continuum of human diversity, where planners, engineers, and designers aspire to meet the needs of the broadest spectrum of the population (Smith, 2015). The inclusive design approach has gained favour in many upper-income settings, particularly those with strong disability advocates and scholars, and ultimately seeks full equity among all members of society.

Economic, technological, and (expert) human resources need to be assessed to determine capacity and whether the ATD approach is more appropriate than an inclusive design approach. Other approaches might also improve access to sanitation, such as physical therapy (improving strength and agility) or occupational therapy (altering the techniques of an activity or modifying one’s immediate surroundings).

Taken collectively, these strategies illustrate an incremental, place-based approach to achieving sanitation for all—moving from the current situation, where disability is seen as the responsibility of the individual and her/his immediate social network, to better leveraging institutions' influence on society and the built environment, to an aspirant future of mutual influence and support in service of equity (Fig.2).



The inclusive design approach has been used in some low-income countries, particularly in schools. In Indonesia, 2000 junior secondary schools have been built using the inclusive design approach (Spicer, 2012). Similar success is seen in Tanzania and Vietnam (Francis, 2011, Hanley, 2011, Jones, 2013). These examples illustrate the first step toward the inclusive design approach; however, scaling up of this approach to include all schools and other public buildings depends on the availability of resources but, more fundamentally, an equity-oriented climate change in the water, sanitation and hygiene sector from global policy to local implementation.

Conclusion

The sanitation-for-all framework provides a cross-sectional assessment of the factors influencing access to sanitation for people with disabilities, and provides a place-based approach to achieve a cohesive relationship among these various factors. Building on existing frameworks, the sanitation-for-all framework extends the sanitation ladder to include a goal for the aspirant future - equitable sanitation.

WaterAid and other organizations have realized that without an emphasis on sanitation design for people with disabilities, SDG #6 cannot be attained. While the aim is to develop processes and strategies that can lead to sanitation for all, specifically for people with disabilities in low- and middle-income countries, the sanitation-for-all framework provides a useful concept for addressing the needs of other marginalized populations and societies as a whole.

In addition to people with disabilities, other groups—e.g., low-income individuals, women and children, rural residents and those living in informal settlements—face social, environmental, and institutional discrimination that places them, their caregivers, and larger society in serious peril. Lack of access to equitable sanitation is but one barrier, but it is one with residual effects. Achieving equity, therefore, requires not only a comprehensive, interdisciplinary view but also necessitates an understanding of the sometimes well-hidden vectors of influence, such as the role of caregivers, advocacy organizations, policy makers, educators, and designers.

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