Viewing disability

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INVITED EDITORIAL

Viewing disability: Seeing the other side

Across the world, many disabled people are still being maltreated. Infanticide, exploitation, and ostracization are just a few stark examples. More subtle, sometimes even unintended, injustices frequently occur towards those with a disability. Raising awareness is the first step to achieving change.

The International Classification of Functioning, Disability and Health: Children and Youth version (ICF-CY)[1] describes disability as the outcome from the interaction between impairment, environmental, and personal factors, evidenced by activity limitations and restricted participation. Some people view disability purely as a social construct: a product of a disabling society. Clearly, disability is not a fixed entity. Activity limitations can be reduced through support; for example, powered mobility for children who are not independently ambulant. Participation is achievable despite impairments and activity limitations: it simply means taking part, being connected to the world and to others, and is influenced by the environment.

ATTITUDES TOWARDS INDIVIDUALS

The effect of body posture on social status is deeply entrenched, and is reflected in everyday language. Attitudes towards those who use a wheelchair may be unconsciously influenced by their relative position – being 'looked down upon' may equate to a reduction in perceived status and elicit unwanted parenting behaviours towards someone who cannot 'stand up for themself'.

Erroneous assumptions are often made during interactions with disabled individuals. Those with physical and/or communication impairments may be wrongly assumed to have significant cognitive impairment. For schoolchildren this can lead to placement in a less rigorous academic environment, with long-term consequences.

SOCIETAL ATTITUDES: STIGMA, ABLEISM, MICROAGGRESSIONS

Stigma exists 'when elements of labelling, stereotyping, status loss, and discrimination co-occur in a power situation that allows these processes to unfold'.[2] Drivers of disability-related stigma are listed in Appendix S1. The biomedical model of disability, with its problem-focussed lens, inadvertently perpetuates an ableist perspective. Ableism is strongly present in the media, which over-represents people tending towards culturally defined corporeal ideals.

Whilst in many societies overt discrimination has lessened, covert discrimination (intentional or otherwise) persists in the form of microaggressions.[3] Examples include defining people by their disability; not respecting privacy regarding the cause of disability; and infantilization (Appendix S2). For individuals with communication impairments, microaggressions manifest as being repeatedly interrupted, or being avoided in conversation.

SOCIETAL DIFFERENCES

Globally, disabled children are twice as likely as other children to experience violence.[4] However, there are also societal differences. The consequences of disability for children and their families in many parts of the developing world are often dire (Table S1). Where the birth of a disabled child is regarded as a bad omen, curse, or retribution, families face a stark choice between infanticide and ostracization.[5] Children may be hidden away with distant relatives, abandoned, or institutionalized. Families who support their child can experience economic disadvantage.

Early detection and intervention services are not universally available;[6] if present, they may be viewed unfavourably. For example, in some settings the concept of screening newborn infants for a hidden abnormality (e.g. hearing loss) may not appeal.

HUMAN-MADE CHANGES TO THE ENVIRONMENT

A key issue for individuals who use assistive devices is the accessibility of the environment. When an environment is not accessible or welcoming to disabled individuals, it prevents full participation. This impacts those excluded, their families, and the entire culture of that environment, be it a business, educational institution, or city. When disabled individuals can not engage fully due to environmental constraints, this entrenches prejudices about their potential for and/or interest in active participation, and erodes their sense of belonging.

Legislation mandates accessibility to public spaces in many countries (Appendix S3).

In the UK, the Equality Act 2010 requires reasonable adjustments to the environment if their absence substantially disadvantages those with disability. Adjustments go beyond physical access, and include auxiliary aids and services such as providing extra staff assistance.

PRACTICAL STRATEGIES FOR CHANGE

Strategies to support those with disability exist at international, national, and local levels (Appendix S4). Here, we suggest some everyday solutions to help change attitudes and further understanding.

SUGGESTIONS FOR CHILDREN AND FAMILIES

Disabled children have their own strengths and limitations, with varying dependence on interaction with others, as do we all. A need for assistance is an opportunity for positive interaction; equally, opportunities for unwanted assistance should be minimized. For example, when a child can use a wheelchair, consider choosing removable handles so that the child is in control.

Body language strategies such as eye contact, social smiles, and assertive but friendly postures and gestures facilitate communication. It may help all children to know how to use these strategies. Awareness of the impact of posture and positioning on communication should influence the choice and optimal use of assistive devices.

Constantly overcompensating for a condition (e.g. masking autistic traits) can adversely affect mental health. There needs to be acceptance of children as they are. Families can help to educate others about their child's disability (Appendix S5). However, the responsibility of educating others and responding to negative behaviours can be exhausting and should ideally be shared.

SUGGESTIONS FOR HEALTH PROFESSIONALS

Every meeting with a health professional carries the unspoken message 'something is wrong with you – you need to be repaired'. The biomedical model has been criticized for its focus on disability as a personal medical tragedy. Professionals must understand the ICF framework, and the influence of societal factors. They should prioritize activities and participation as goals of management. Early implementation of powered mobility and assistive devices providing postural support facilitate interaction with the environment and should not be perceived as failure.

It is vital to avoid making assumptions about the difficulties and needs of the child and family – the best solution is simply to ask and then listen.

SUGGESTIONS FOR EDUCATIONAL PROFESSIONALS

Educators can foster change by modelling inclusive behaviours and positive attitudes. They can create environments of awareness and respect by providing tips for interacting with disabled peers. An example curriculum, 'Just Say Hi' (https://www.yourcpf.org/just-say-hi-in-schools/), was launched in New York City public schools in 2016. Delivery of education about disability by those with lived experience could broaden student perspectives (including those in healthcare), as could reading relevant autobiographies.

SUGGESTIONS FOR SOCIETY

Individuals often shy away from situations they do not understand, or which make them feel uncomfortable. Education, explanation, and efforts to engage could shift this stance. Employers should include education about unconscious bias and sensitivity toward disabled individuals.

If a child stares at someone disabled, this is an opportunity to explain disability, rather than telling them to stop staring. Adults should model acceptance and friendliness. Sometimes, children ask seemingly inappropriate questions, but non-judgmental curiosity is typically welcomed. Some of the most powerful modifiers of attitudes towards disability include familiarity and the amount and quality of interactions with disabled individuals.

Suggestions for respectful interactions with people with communication impairments include giving them enough time to speak, and not interrupting or completing sentences for them. Leadership can create a culture of inclusivity by modelling active listening to all voices. This benefits society: diverse groups outperform homogeneous groups in problem-solving, and workplaces benefit financially and culturally from inclusive approaches.

Two authors of this editorial are members of the Global Research on Developmental Disabilities Collaborators group, seeking solutions for disabled children worldwide. Mutual respect and really seeing and valuing others is the foundation of any healthy society and is ultimately the way forward.

DATA AVAILABILITY STATEMENT

Not required

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REFERENCES

1. World Health Organisation. International classification of functioning, disability and health: children and youth version: ICF-CY. World Health Organization; 2007.
2. Link BG, Phelan JC. Conceptualizing Stigma. Annu Rev Sociol 2001; 27: 363–85.
3. Keller RM, Galgay CE. Microaggressive experiences of people with disabilities. Microaggressions and marginality: Manifestation, dynamics, and impact. Hoboken, NJ, US: John Wiley & Sons Inc; 2010. 241–67.
4. Fang Z, Cerna-Turoff I, Zhang C, et al. Global estimates of violence against children with disabilities: an updated systematic review and meta-analysis. Lancet Child Adolesc Health 2022; 6: 313–23.
5. Rodríguez P, Ahern L, Bradshaw J, et al. Infanticide and Abuse: Killing and confinement of children with disabilities in Kenya. Disability Rights International (Kenyan Association for the Intellectually Handicapped) 2018.
6. Cieza A, Kamenov K, Sanchez MG, et al. Disability in children and adolescents must be integrated into the global health agenda. BMJ 2021; 372: n9.

SUPPORTING INFORMATION

The following additional material may be found online:
Appendix S1: Drivers of disability-related stigma
Appendix S2: Microaggressions
Appendix S3: Accessiblity to public spaces
Appendix S4: Examples of strategies at a range of levels supporting those with disability
Appendix S5: Personal reflection on the benefit of direct education about disability
Table S1: Burden of childhood disabilities in developed vs developing countries