A transformative approach to disability awareness, driven by persons with disability

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Disability-awareness programmes tend to be driven by people who are not disabled. However, opportunities exist to facilitate transformation in the South African context and for persons with disabilities to drive such awareness programmes.

Disability awareness may not always be optimal, especially in resource-constrained settings. Moreover, disability-awareness programmes tend to be driven by people who are not disabled. However, opportunities exist to facilitate transformation in the South African context and for persons with disabilities to drive such awareness programmes. Two-fold transformation will be addressed in this chapter, using the People for Awareness of Disability Issues (PADI) project as an example. Two-fold transformation includes empowering persons with disabilities to be educators, and transforming the views and perceptions of students in therapeutic professions at institutions of higher learning.

This chapter explores how the therapeutic professions view disability, namely using the World Health Organization's International Classification of Functioning, Disability and Health (ICF). The chapter goes on to present the PADI project as an experiential educational teaching and learning approach to facilitate the implementation of policies and practices surrounding disability within a community of practice. Lastly, the chapter illustrates the role reversal that occurs when persons with disabilities become the educators and providers of a service, compared with when they are recipients of services.

The information provided highlights the need for curriculum transformation that is inclusive, incorporating persons with disabilities in the planning and in the execution of theory in practice. A key factor that needs to be highlighted is the benefit of utilising persons with disabilities as educators to shape the views of students via real-life encounters in urban and rural contexts. There needs to be collaboration between the relevant stakeholders to ensure that policies and procedures are implemented on the ground during therapeutic service, thus ensuring disability awareness and practice.

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Introduction

Disability is not only a physiological descriptor. It is a nuanced and layered concept and experience because it includes biological, cultural, linguistic, and other dimensions. This nuance and layering is reflected in the words used to describe disability. A medical perspective, which focuses attention on the medical aspects of disability, was previously espoused by the World Health Organization (WHO), which initially distinguished between impairment, disability and handicap, where the word 'impairment' referred to "any loss or abnormality of psychological or anatomical structure or function".[1] 'Disability' was described as a consequence of 'impairment' since it referred to "any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being".[1] 'Handicap' referred to "a disadvantage for a given individual, resulting from an impairment or disability that limits or prevents the fulfilment of a role". The terminology used in this earlier classification is problematic since it appears to benchmark people around normality, as in use of the phrase "normal for a human being",[1] suggesting that persons with disabilities are abnormal.

It has been suggested that disability is also a social construct with implications for people's participation in society,[2] and that it may be "a form of social oppression where the appropriate response would be political action rather than medical or social care".[3] More specifically, disability is created by society through an unaccommodating physical environment, brought about by attitudes and/or other features of the social environment rather than by an attribute of an individual.[4] For example, a person using a wheelchair during recovery from bilateral lower-limb fractures, and a permanent wheelchair user due to paraplegia, will require the same transport system adjustments when travelling in their respective communities. If the public transport system is not accessible to a wheelchair user, both these individuals will experience disability and participation restriction. Their disability experienced is not related to the permanence of the physical injury sustained, or their level of motivation, but relates rather to the restrictive physical environment that they encounter.

In response to the medically dominant stance and the contrasting social model of disability, the WHO formulated the International Classification of Functioning, Disability and Health (ICF), which is a measure used to describe and assess health and disability.[4-6] The ICF framework covers a wide range of possible health domains described at physical, individual and societal level, including contextual concepts. The first part of the ICF reviews aspects related to individual body structure and function and whether differences are present that result in impairments; this section also reviews the person's ability to perform activities of daily living, and/or lastly, the person's ability to participate in his/her community. The second part of the ICF describes contextual factors that may influence disability, namely the environment that the person functions in, and lastly, the person's personal factors. Contextual factors may be internal personal characteristics, such as coping styles, which can influence the extent to which a person participates in society. They may also be external factors relating to physical and information access, as well as to policies, service delivery systems and institutional arrangements. Knowledge and attitudes are also environmental factors that have a significant impact on service provision and level of participation. Figure 1 provides an outline of the ICF framework.

Figure 1: Outline of the International Classification of Functioning, Disability and Health, 2020
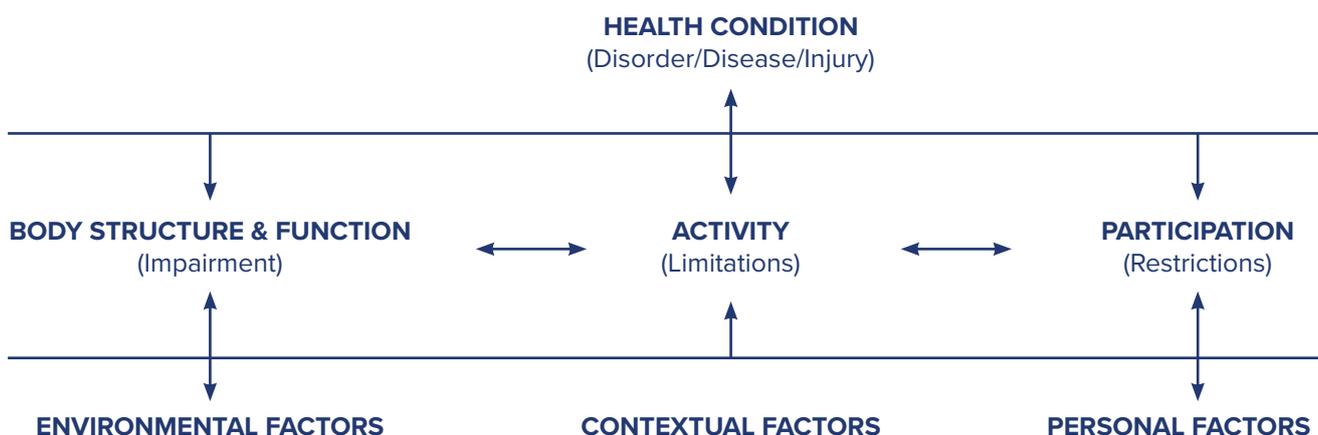
Source: World Health Organization, 2020.[6]

Within this view, it seems that disability per se is not considered problematic, but that interactions between factors may be problematic, hindering level of participation and activity. More specifically, the role of context is accentuated in the ICF framework because factors within the environment are recognised as being able to assist or facilitate participation (facilitators), or they may limit or even prevent such participation (barriers).[6]

Use of the ICF therefore encourages a bio-psycho-social and person-centred approach to health care,[7,8] and provides a shared language for healthcare practitioners to enhance interprofessional learning and promote a multidimensional view of individual health and disability.[9,10] Recent literature also suggests that the ICF framework can be utilised in higher education as a conceptual framework and assessment tool to ensure that the physical built environment (e.g. buildings) and educational environments (e.g. teaching platforms) are accessible to and inclusive of both students and educators.[11] The ICF framework can thus be utilised in health care and healthcare education, as well as in the higher education sphere.

Disability awareness

Context drives prioritisation

Disability-awareness programmes have the capacity to augment disability knowledge, awareness, attitudes, and acceptance among students in therapeutic professions.[12] Disability awareness is shaped by people's contexts. In resource-constrained contexts, as is often the case in South Africa, public resources and facilities tend to be fewer in poorer areas, and this may be compounded by restricted personal resources.[13] Therefore, in a context such as South Africa, where resources must often be diverted to other needs, funding for disability-awareness programmes may not be prioritised. Furthermore, the prioritisation and diversion of resources away from disability-awareness programmes may be driven by shortages in essential services related to education, health, and finance, resulting in limited opportunities for people who are able-bodied to interact with persons with disabilities, and vice versa.[14] Therefore, there is a call to include material resources, employment, education, health, social participation, and community membership considerations when trying to foster opportunities for disability awareness.[15] Also, within our context of competing and limited resources, opportunities for social participation and community membership may be compromised for persons with disabilities, as are opportunities for them to raise disability awareness. Therefore, contextual factors may "either exacerbate or reduce disability",[16] and influence engagement with and awareness of disability.

It appears that the South African context has contributed to the exclusion of persons with disabilities from societal interactions, and that this exclusion is amplified because of "shame, stigma, or cultural standards".[7] Despite political advances since the 1994 general election, South Africa still has one of the highest income inequality ratios in the world, paired with an increase in inequality between races.[17] The current situation serves as a reminder that poverty is not a stagnant or universal experience, and that there are social, political, cultural, and historical variables involved in its manifestation.[18] The South African landscape is characterised not only by financial resource limitations, but also by restrictions in individual domains (e.g. age, health status, gender) and social domains (e.g. access to education, gender roles and expectations)[19] because of the country's particular history, potentially resulting in very vulnerable livelihoods.[20] This vulnerability appears to be especially significant at the juncture of poverty and disability, often referred to as the disability-poverty nexus.[19]

The South African situation is one of juxtaposition. The interplay between poverty and disability is acknowledged because "poverty cannot be understood only in terms of deprivation of income. Rather it may be that there is inequality of access to basic capabilities linked to that disability status…. [That is], poverty is the impossibility for individuals to be and do what they value because of lack of opportunities".[21]

Participatory and self-advocacy approach within a community of practice

In advancing the rights of persons with disabilities, self-advocacy programmes have fostered the premise that "individuals with disabilities who are strong self-advocates often challenge the perceptions of others who view them as incapable of making decisions about their own lives and needing professionals for guidance and protection".[22] In their argument for the social understanding of disability, Barnes et al.[1] encourage a different way of thinking about pre-established categories, especially regarding disability. Disability-awareness programmes tend to be offered in a variety of ways, including presentations, academic and curriculum-based programmes, multi-media programmes, contact with a person with a disability, simulations, classroom activities, plays and puppet shows.[11] However, in the South African setting, it appears necessary to have a participatory approach to disability-awareness activities. Historically, persons with disabilities have not participated in strategic and operational activities here due to the disability-poverty nexus[21] that emerged from the socially disruptive and unstable apartheid period. As such, there is a need for inclusion and full participation of persons with disabilities in matters pertaining to them as espoused by the United Nations Convention on the Rights of Persons with Disability (UN CRPD) which proposes that "persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them."[23] Since persons with disabilities have been marginalised for so long, self-advocacy is needed; persons with disabilities can and should participate in the leadership component

to reach individual and common goals.[22] Because of the importance of contextual considerations in the experience of disability, due consideration ought to be given to engaging in contextually appropriate interactions that are respectful of linguistic and cultural diversity, traditions and preferences, historical factors, and a deep appreciation of individual and group variation to minimise the risk of a preconceived and stereotyped view of persons with disabilities.[24] By bolstering participatory rather than paternalistic interaction, persons with disabilities can lead disability-awareness programmes that account for diversity and enhance agency. Furthermore, persons with disabilities can be agents for change and promote disability-awareness progammes for personal and social development via skills training and the design of context-specific interaction programmes, especially in understaffed and developing contexts.[25,26]

Communities of practice are "an aggregate of people who come together around mutual engagement in an endeavour. Ways of doing things, ways of talking, beliefs, values, power relations—in short, practices—emerge in the course of this mutual endeavour"[27] and the communities "are comprised of individuals who share common concern or enthusiasm about a topic or problem and who deepen their knowledge and expertise about the area by frequently interacting with one another".[28] Within communities of practice, participatory opportunities exist for collaborative approaches to advancing the disability-awareness agenda and the knowledge base relating to disability. This is also true for particular contexts where tacit knowledge and experience can merge with theory and pre-established knowledge to fine-tune that knowledge, apply it, and evaluate it within other contexts, such as universities. Therefore, it seems that a community of practice can enhance agency in persons with disabilities as the latter contribute their experience and knowledge; this collaboration can enhance efficacy in persons with disabilities and collective efficacy.[26]

Community support could reinforce the value of a community of practice, especially among persons with disabilities who are advocates for disability and who drive disability-awareness programmes. The concept of ubuntu or humanity may also be envisioned, although in this setting it may not always be attainable due to limited resources in the community. If disability-awareness programmes are exclusively led and driven by able-bodied-people, albeit people with deep insight into disability, then competence in disability matters more than lived experience. This may create a scenario where interaction with persons with disabilities is reduced to a technical skill, with a checklist of do's and don'ts.[29,30]

Formation of student clinicians in disability awareness

Universities may champion disability rights and diversity as well as inclusion of persons with disabilities, but disability awareness may not be their primary focus as they may have other priorities. Moreover, students may come from resource-constrained contexts and they may have primary foci and pressures other than disability matters. Curricula and lecturers need to provide encompassing programmes where student clinicians can internalise the value of disability awareness and in which they are expected to exhibit more than just competence in disability-related matters. The term 'competence' implies achieving a level of technical skill, whereas contextual sensitivity implies harmony in the interactions between healthcare personnel and their clients, families, and communities. There is a need to foster fuller engagement between universities, student clinicians, and persons with disabilities so that, in the clinical setting, students and qualified clinicians offer a courteous service in which persons with disabilities feel confident and empowered.[31] This can be done by offering services that include sensitivity in the use of language, appropriate information-sharing strategies, attainable goal setting, accessibility, and engagement in agency and power-enhancing interactions that are respectful of people. Within this fully-engaged and participatory approach, there is also the opportunity to espouse values such as "fidelity, altruism, confidentiality, integrity, empathy, and compassion", while also demonstrating "respect for persons, deference for elders, reverence for authority figures, family centeredness, compassion, [and] empathy".[32]

This combined participatory and community-of-practice approach suggests the need for practice that is in harmony with people's contexts. In more seriously considering context, agency, structure, self-efficacy, and other concepts raised earlier, biomedical attempts at proposing more social frameworks, such as the ICF, can lead to closer, more sensitive and appropriate interactions.[31] This combined approach proposes that frameworks such as the ICF should include the abovementioned concepts (context, agency, structure, self-efficacy, etc.) so that frameworks are all-encompassing, humanist, and considerate. Contextual sensitivity is not a technical competence but is nurtured and applied within a specific context, while recognising the impact of that particular context and transcending the checklists and lip service paid to disability competence and abilities in medical settings.

This blending is crucial in clinical settings where the social perspective and participatory approach may not dominate, so that persons with disabilities can know that they matter and have the opportunity to talk about their experience as part of the consultation, because failure to engage with end-users' agenda can lead to misunderstandings, dissatisfaction and poor outcomes.[31] Moreover, by fostering communities of practice in which persons with disabilities can interact with others, including student clinicians, the necessary checks and balances can be maintained so that the community of practice does not become another instrument to exert power over persons with disabilities. For similar reasons, the composition ought to be diverse, including a range of people who show an interest in disability, have disabilities, or have a relationship with persons with disabilities, among others. Communities of practice can offer recognition of the contributions, value, and resources of different people,

which all members can benefit from, and confirm "the importance of a consulting and supporting strategy using a resource-oriented approach aimed at empowerment".[33]

Cognisant of context-specific needs and the intrinsic knowledge of persons with disabilities, true agency means "the capacity to transpose and extend schemas to new contexts".[29] This means that especially within a community of practice, persons with disabilities can share their knowledge and experience and mould the support framework accordingly, so that it is pertinent and relevant to the specific context. In being able to support others, including student clinicians, in even the smallest ways, persons with disabilities can build their own personal resources. This also boosts their psychological and overall well-being because there is "mutuality and a common focus regarding the key issues among members", which "inspires them to contribute their knowledge and ideas".[28,34] This is particularly true when the existing structures, which are meant to offer opportunity for agency, are inefficient or unavailable, as is the predominant situation in South Africa.[15,17]

Transformation

Transforming education on disability issues
Transformation and decolonisation were debated during apartheid at underground meetings of activists who fought against the government of the time, with a view to establishing a democratic South Africa, aka 'Azania'.[35] Post 1994, the debates became a reality and South Africa started an era of development towards fair policies and practices to transform the country. The South African Disability Rights Movement (DRM) began to actively challenge the barriers that existed as a result of apartheid, and birthed the slogan 'nothing about us without us'.[35] The DRM pressured the newly instated democratic government to stand accountable for the inclusion of persons with disabilities in policy-making processes. The higher education sector in South Africa has led the movement for freedom and transformation,[36] however, South African society has a role to play in transforming the present to account for the injustices of the past, and active participation is warranted in every sector. Disabling normative teaching and learning practices in the South African context may be long and arduous,[37] but interrogation of these old yet still-used teaching and learning pedagogies is necessary to ensure transformation of the teaching, learning, and practices of student clinicians.[38]

Historically, persons with disabilities have had no agency in South African teaching and learning pedagogies, with dominant able-bodied teachers being the sole providers of knowledge and experience. There is a dearth of programmes and projects developed and dominated by the lived experience of people with disability, despite an existing body of literature highlighting the need for a role reversal

and power shift to ensure that the voice and actions of people with disability are received.[39-43] Transformation and change are dynamic and ongoing processes in any context, akin to the transformation of teaching and learning practices at higher-education facilities in developing countries such as South Africa.

The People for Awareness of Disability Issues (PADI) project at the University of the Witwatersrand is an example of the rare transformation process that occurs when the teaching and learning curriculum includes a programme developed, organised, and facilitated solely by persons with disabilities. The project was established in 1987 to bridge the gap within South African society in relation to understanding disability and the lives of individuals with these disabilities. Thus PADI has been in existence for over 32 years, and the project has been facilitating "experiential learning life skills programmes and workshops" in rural and urban areas throughout the country. All PADI facilitators are persons with disabilities who serve as advisors in their respective communities and who offer peer counselling and advice on accessibility issues. PADI has outlets in Ehlanzeni District in Mpumalanga and the peri-urban town of Pietermaritzburg in KwaZulu-Natal, with the head office located in urban Johannesburg. The organisation has linked with various public-sector departments such as the South African Department of Social Development, as well as with schools and universities to educate and create awareness on matters related to disability.

At the University of the Witwatersrand, transformation of teaching and learning practices is evident in the audiology, physiotherapy, and speech-language pathology degrees from year one of study, as disability is taught through the lived experience of PADI facilitators and through interaction with them. PADI challenges the norm and status quo of teaching within the healthcare sector. The project is run by persons with disabilities who assume the role of 'educator' instead of the role of client or patient. A shift in agency and power is evident as the PADI project allows the student to consciously and practically engage with, and learn directly from, the person with a disability.

Disability project

Undergraduate audiology, physiotherapy, and speech-language pathology curricula at the University of the Witwatersrand include teaching and learning activities to educate students progressively about the ICF framework. Teaching and learning activities include theoretical tuition, practical application of concepts taught, and clinical experience when senior students work in different healthcare sectors. The first-year PADI project was implemented more than a decade ago as a means of educating the student body on concepts related to disability. The PADI group holds seminars with the respective student

cohorts in which they share real-life personal experiences through interactive games and talks about the challenges they face. In sharing these experiences, the students get to have a better understanding of everyday issues faced by persons with disabilities. Students are also made aware of how to be an advocate for the social inclusion of a person with a disability.

During the project students are placed in small groups (of approximately six students) and introduced to a representative from the PADI group. This enables students to understand the difficulties faced by a person with a disability, thus allowing them to think beyond the individual's impairments. Students spend time with their representative, during which they enquire about the representative's disability, as well as the multidisciplinary healthcare team that has managed the representative over the years to optimise his or her health and wellness. In addition, they observe how the PADI representative functions in his or her work, leisure and home environments, and the students self-reflect on what could be adjusted to make the community environment more accessible. The students also get an opportunity to assess their immediate environment, such as the university premises, for issues related to accessibility for persons with disabilities who depend on wheelchairs or other mobility assistive devices. Stemming from their interaction with PADI, students are able to make the wider community more aware of daily activity challenges for persons with disabilities, thus making the environment more responsive to the needs of persons with disabilities. This includes aspects such as improving wheelchair access, identifying enablers and barriers that may influence a student with disability's ability to function independently in his or her environment, as well as a better understanding of the caregiver's role and needs when taking care of or living with a person with a disability.

Anecdotal learning outcomes from students' feedback received on completion of the project include:
- Spending time with their representative during the year taught the students how to be more accepting of persons with disabilities and those of other races, religions and cultures.
- Students learned that family and community support are essential for the wellbeing of an individual with a disability.
- Students became more aware of the daily physical, social and environmental struggles that people with disability must overcome.
- Students realised that although having a disability can be very difficult at times, it should not define or stop one from living one's life.

Stakeholder collaboration to ensure disability awareness and practice

Post-apartheid South Africa saw a transformative shift in policies relating to persons with disabilities. The vision of the 1997 Integrated National Disability Strategy (INDS) White Paper is "a society for all, one in which persons with disabilities are actively involved in the process of transformation".[44] The philosophy of the PADI group promotes the acknowledgement of persons with disabilities as equal members of society who contribute immensely to the development of society. The INDS recognises that services for persons with disabilities can only be successfully implemented through the involvement of such individuals themselves.

Since publication of the INDS, many other public policies have recognised the need to include persons with disabilities in society. Examples include the White Paper for Post-school Education and Training of 2013, which was a transformative policy advocating for improvement in access to higher education for persons with disabilities.[45] At the University of the Witwatersrand, PADI lives up to this transformative approach by engaging the university's Disability Rights Unit and exploring innovative ways of making the university an accessible environment for persons with disabilities. The university has established its own policy for students with disabilities; this policy is committed to creating equal opportunities for persons with disabilities and ensuring their integration in all areas of student life. All university departments have put individual measures in place to ensure that the vision of this policy is realised.

Another policy document pertaining to persons with disabilities (due for review in 2020) is the Framework and Strategy for Disability and Rehabilitation Services in South Africa.[46] This framework aims to improve access to services, particularly rehabilitation services for persons with disabilities, and recognised the need to involve persons with disabilities during the policy process. The outcome of this policy document reflects the South African government's commitment to an increasingly equitable and inclusive society, which aims to ensure "a long and healthy life for all South Africans". However, recent policy documents, such as the National Development Plan vision for 2030, do not state explicitly how the South African government aims to develop things for persons with disabilities. Their specific needs are not addressed, creating a flaw in the policy.[47] Nonetheless, there appears to be a shift in most policies in the South African context towards a more "disability friendly" policy environment. While these policies are well-intentioned, there is lack of collaboration among different stakeholders in terms of implementing disability policies on the ground to ensure disability awareness and practice.

The changing landscape

As professional programmes develop, so opportunities arise for inclusive and wide-ranging transformation. When students interact with persons with disabilities, their education moves from being predominantly didactic to more insightful and holistic, based on participation, community of practice, experience, and context. These learning opportunities provide potential for growth among academics as well as students. Programmes that currently do not offer such opportunities would benefit from such inclusion so that professionals can garner an appreciation of the lived experience of disability. In future, when curricula are reviewed, curriculum-development teams could include a person with a disability, such as a client or patient, to give input on the content. Curricula ought to be respectful of the population that the profession serves – including people with disability fosters the relationship between healthcare professionals and the people who access their services. Inclusion acknowledges that the curriculum needs to be 'for the people by the people'. Student learning should be dynamic to ensure that maximum gain is achieved by all parties. PADI is an example of such dynamism and mutual benefit, and offers a glimpse into the potential that exists for collaboration between different communities, for example between healthcare professionals and service users in South Africa. Universities should always strive to make student learning inclusive, so that agency rests with the people with disability, and their knowledge, insight, value and power are recognised. Organisations for persons with disabilities should be routinely involved during national policy development.

References

1. Barnes C, Mercer G, Shakespeare T. Culture, leisure and the media. In: Barnes C, Mercer G, Shakespeare T, editors. Exploring disability: A sociological introduction. 1st ed. Cambridge: Polity Press; 1999. p. 182-210.

2. Barnes C. The social model of disability: A sociological phenomenon ignored by sociologists. In: Shakespeare T, editor. The disability reader: Social science perspectives. New York: Continuum; 1998. p. 65-78.

3. Goode J. 'Managing' disability: Early experiences of university students with disabilities. Disabil Soc. 2007;22(1):35-48.

4. World Health Organization. Towards a common language for functioning disability and health: ICF The International Classification of Functioning, Disability and Health; 2002. Geneva: WHO; 2002. URL: http://www.who.int/classifications/icf/training/icfbeginnersguide.pdf.

5. Young A, Hunt R. Research with d/Deaf people. 1st ed. National Institute for Health Research; 2011. URL: http://eprints.lse.ac.uk/41800/.

6. World Health Organization. International Classification of Functioning, Disability and Health. Geneva: WHO; 2020. URL: https://www.who.int/classifications/icf/en/.

7. Department of Social Development, United Nations Children's Fund. Children with disabilities in South Africa: A situation analysis: 2001-2011. Pretoria: DSD/Department of Women, Children and People with Disabilities/UNICEF; 2012. URL: https://www.unicef.org/southafrica/reports/children-disabilities-south-africa.

8. Alford VM, Ewen S, Webb GR, McGinley J, Brookes A, Remedios LJ. The use of the International Classification of Functioning, Disability and Health to understand the health and functioning experiences of people with chronic conditions from the person perspective: a systematic review. Disabil Rehabil. 2015;37(8):655-66.

9. Allan CM, Campbell WN, Guptill CA, Stephenson FF, Campbell KE. A conceptual model for interprofessional education: The International Classification of Functioning, Disability and Health (ICF). J Interprof Care. 2006;20(3):235-45.

10. Snyman S, van Zyl M, Müller J, Geldenhuys M. International Classification of Functioning, Disability and Health: Catalyst for interprofessional education and collaborative practice. In: Forman D, Jones M, Thistlethwaite J, editors. Leading research and evaluation in interprofessional education and collaborative practice. London: Palgrave Macmillan; 2016. p. 285-328.

11. Lindsay S, Edwards A. A systematic review of disability awareness interventions for children and youth. Disabil Rehabil. 2013;35(8):623-46.

12. Macintyre S, Macdonald L, Ellaway A. Do poorer people have poorer access to local resources and facilities? The distribution of local resources by area deprivation in Glasgow, Scotland. Soc Sci Med. 2008;67(6):900-14.

13. Sekome K. Perceptions on and quality of clinical practice guidelines for stroke management in a rural health district. In: Rispel LC, Padarath A, editors. South African Health Review 2018. Durban: Health Systems Trust; 2018.

14. Bencini GML, Garofolo I, Arenghi A. Implementing universal design and the ICF in higher education: towards a model that achieves quality higher education for all. Stud Health Technol Inform. 2018;256:464-72.

15. South African Human Rights Commission, United Nations Children's Fund. Poverty traps and social exclusion among children in South Africa. Pretoria: SAHRC; 2014.

16. Danermark B, Cieza A, Gimigliano F, et al. International classification of functioning, disability, and health core sets for hearing loss: a discussion paper and invitation. Int J Audiol. 2010;49(4):256-62.

17. Bradshaw D. Determinants of health and their trends. In: Barron P, Roma-Reardon J, editors. South African Health Review 2008. Durban: Health Systems Trust; 2008.

18. Jansen A, Moses M, Mujuta SC, Yu D. Multifaceted poverty: Absolute, relative and subjective poverty in South Africa. Biennial Conference of the Economic Society of South Africa, Bloemfontein; 25-27 September 2013. URL: https://scholar.google.com/citations?user=RZwKEi0AAAAJ&hl=en.

19. Graham L, Moodley J, Selipsky L. The disability-poverty nexus and the case for a capabilities approach: evidence from Johannesburg, South Africa. Disabil Soc. 2013;28(3):324-37.

20. Goudge J, Russell S, Gilson L, Gumede T, Tollman S, Mills A. Illness-related impoverishment in rural South Africa: Why does social protection work for some households but not others? J Int Dev. 2009;21(2):231-51.

21. Groce N, Kett M, Lang R, Trani JF. Disability and poverty: The need for a more nuanced understanding of implications for development policy and practice. Third World Q. 2011;32(8):1493-513.

22. Test DW, Fowler CH, Wood WM, Brewer DM, Eddy S. A conceptual framework of self-advocacy for students with disabilities. Remedial Spec Educ. 2005;26(1):43-54.

23. United Nations. Convention on the Rights of Persons with Disabilities: resolution / adopted by the General Assembly; 24 January 2007. URL: https://www.refworld.org/docid/45f973632.html.

24. Petriwskyj A, Gibson A, Webby G. Participation and power in care: Exploring the "client" in client engagement. J Aging Stud. 2014;31:119-31.

25. Vaux A. An ecological approach to understanding and facilitating social support. J Soc Pers Relat. 1990;7(4):507-18.

26. Gona JK, Newton CR, Hartley S, Bunning K. Persons with disabilities as experts-by experience: using personal narratives to affect community attitudes in Kilifi, Kenya. BMC Int Health Hum Rights. 2018;18:18.

27. Bandura A. Self-efficacy mechanism in human agency. Am Psychol. 1982;37(2):122.

28. Ahearn LM. Language and agency. Annu Rev Anthropol. 2001;30(1):109-37.

29. Moodie ST, Kothari A, Bagatto MP, Seewald R, Miller LT, Scollie SD. Knowledge translation in audiology: Promoting the clinical application of best evidence. Trends Amplif. 2011;15(1):5-22.

30. Sewell Jr WH. A theory of structure: Duality, agency, and transformation. Am J Sociol. 1992;98(1):1-29.

31. Kleinman A, Benson P. Anthropology in the clinic: the problem of cultural competency and how to fix it. PLoS Med. 2006;3(10):e294.

32. Chiegil RJ, Zungu LI, Jooste K. End-user centeredness in antiretroviral therapy services in Nigerian public health facilities. South African Family Practice. 2014;56(2):139-46.

33. De Andrade VM. Traditional values in modern practice. South African Family Practice. 2011;53(4):352-4.

34. Hintermair M. Parental resources, parental stress, and socioemotional development of deaf and hard of hearing children. J Deaf Stud Deaf Educ. 2006;11(4):493-513.

35. Hocoy D. Clinical implications of racial identity in the legacy of Apartheid in South Africa. In: Dinne DL, Forgays DK, Hayes SA, Lonner WJ, editors. Merging past, present, and future in cross-cultural psychology. London: Garland Science; 2020. p. 308.

36. Charlton JI. Nothing about us without us: Disability oppression and empowerment. Berkeley: University of California Press; 2000.

37. Naidoo LA. The role of radical pedagogy in the South African students organisation and the Black Consciousness Movement in South Africa, 1968-1973. Education as Change. 2015;19(2):112-32.

38. Msila V. From apartheid education to the Revised National Curriculum Statement: Pedagogy for identity formation and nation building in South Africa. Nordic Journal of African Studies. 2007;16(2).

39. Lotz-Sisitka H, Wals AE, Kronlid D, McGarry D. Transformative, transgressive social learning: Rethinking higher education pedagogy in times of systemic global dysfunction. Curr Opin Environ Sustain. 2015;16:73-80.

40. Watermeyer B, Swartz L, Lorenzo T, Priestley M, Schneider M. Disability and social change: A South African agenda. Cape Town: Human Sciences Research Council Press; 2006.

41. Barratt J, Penn C. Listening to the voices of disability: Experiences of caring for children with cerebral palsy in a rural South African setting. In: MacLachlan M, Swartz L, editors. Disability & international development: Towards inclusive global health. New York: Springer; 2009. p. 191-212

42. Görgens T, Ziervogel G. From "No One Left Behind" to putting the last first: centring the voices of disabled people in resilience work. In: Watermeyer B, McKenzie J, Swartz L, editors. The Palgrave handbook of disability and citizenship in the Global South. London: Palgrave Macmillan; 2019. p. 85-102

43. Chappell P. Situating disabled sexual voices in the Global South. In: Chappell P, de Beer M, editors. Diverse voices of disabled sexualities in the Global South. London: Palgrave Macmillan; 2019. p. 1-25.

44. Office of the Deputy President. White Paper on an Integrated National Disability Strategy. Pretoria: Office of the Deputy President; 1997. URL: https://www.gov.za/sites/default/files/gcis_document/201409/disability2.pdf.

45. Department of Higher Education and Training. White Paper for Post-School Education and Training. Pretoria: DHET; 2013. URL: https://www.dhet.gov.za/SiteAssets/Latest%20News/White%20paper%20for%20post-school%20education%20and%20training.pdf.

46. South African National Department of Health. Framework and Strategy for Disability and Rehabilitation Services in South Africa 2015-2020. Pretoria: NDoH; 2015.

47. National Planning Commission. National Development Plan 2030. Pretoria: NPC; 2012. URL: https://www.gov.za/issues/national-development-plan-2030.