Original Article

Disability-inclusive compassionate care: Disability competencies for an Indian Medical Graduate

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ABSTRACT

The new curriculum of the Medical Council of India (MCI) lacks disability-related competencies. This further involves the risk of perpetuating the medicalization of diverse human experiences and many medical students may graduate with little to no exposure to the principles of disability-inclusive compassionate care. Taking into consideration the UN Convention, the Rights of Persons with Disabilities, Act 2016, and by involving the three key stakeholders – disability rights activists, doctors with disabilities, and health profession educators – in the focus group discussions, 52 disability competencies were framed under the five roles of an Indian Medical Graduate (IMG) as prescribed by the MCI. Based on feedback from other stakeholders all over India, the competencies were further refined into 27 disability competencies (clinician: 9; leader: 4; communicator: 5; lifelong learner: 5; and professional: 4) which the stakeholders felt should be demonstrated by health professionals while they care for patients with disabilities. The competencies are based on the human rights approach to disability and are also aligned with the competencies defined by accreditation boards in the US and in Canada. The paper describes the approach used in the framing of these competencies, and how parts of these were ultimately included in the new competency-based medical education curriculum in India.

Keywords: Accessibility, autonomy, competency-based education, dignity, disabled persons, equality, healthcare disparities, human rights, nondiscrimination, participation

Introduction

Induct disability as a component for all education courses for schools, colleges and University teachers, doctors, nurses, para-medical personnel, social welfare officers, rural development officers, asha workers, anganwadi workers, engineers, architects, other professionals and community workers.[1]

Sec 47 (1)(b) of the Rights of Persons with Disabilities Act 2016

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The WHO's world report on disability states that people with disabilities have the same general healthcare needs as others but they are two-times more likely to find healthcare providers' skills and facilities inadequate, three-times more likely to be denied healthcare, and four-times more likely to be treated badly in the healthcare system.[2] The similitude of the "elephant in the room" has been used to chronicle the experiences of patients with disabilities with the medical profession–they are "present but unnoticed."[3] Perhaps, the reason for this neglect is that scant attention is being given to disabilities education in the medical curriculum. The outdated Medical Council of India (MCI) curriculum treated disability as a purely medical issue instead of a human rights issue.

The United Nations Convention on the Rights of Persons with Disabilities (CRPD), was the first legally binding instrument on the issue of disability, and it aimed to "promote, protect, and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and to promote respect for their inherent dignity."[4] It is both a developmental and a human rights instrument which is cross-disability, cross-sectoral, and legally binding. Around 80% of people with disabilities worldwide live in developing countries and 60–75% of these live in rural areas. The Delhi declaration of the 15th WONCA World Rural Health Conference recognized the need of primary care professionals to move away from a narrow medical model and identified equity and access to care as a key priority area to achieve "Health for All Rural People."[5] The recent UN Flagship report to examine disability and the Sustainable Development Goals (SDGs) of the 2030 agenda also stresses on mainstreaming the disability perspective in healthcare services (SDG 3) and in education (SDG 4).[6]

In the wake of India ratifying the convention, it became incumbent on India's part to harmonize all its relevant domestic laws and policies with this international treaty. Consequently, parliament enacted the CRPD-compliant Rights of Persons with Disabilities Act (RPDA), 2016 and the Mental Healthcare Act (MHCA) in 2017. After 22 years, the MCI updated its undergraduate curriculum to a competency-based model to conform to global standards; however, it still relies on the medical model of disability[7] and the competencies are out of sync with the two disability legislations, in general, and with CRPD, in particular. In addition, in designing the new curriculum, the MCI neglected the involvement of the disability sector. This approach runs the risk of further perpetuating the medicalization of diverse human experiences and many medical students may graduate with little to no exposure to the principles of disability-inclusive compassionate care.

Taking into consideration the recommendations of the world report and the CRPD, the authors developed disability competencies in consultation with the disability sector that should be acquired by health professionals during training so that they can provide quality care to patients with disabilities. The goal of this paper is to showcase how, through consensus, global competencies were created which are applicable to the Indian Medical Graduate (IMG) as well.

Methodology

This was a collaborative effort between the faculties of the University of Chicago, Chicago and University College of Medical Sciences, University of Delhi. The qualitative study was conducted from July 2018 to May 2019 and consisted of two phases. In the first phase, an observational visit was made to international disability management centers in Chicago, USA and in the second phase, focus group discussions were held in Delhi, India.

The observational visit: In September 2018, two of the authors visited disability centers in the University of Chicago (adult developmental disabilities clinic and Parkinson and movement disorders clinic) and held formal and informal discussions with healthcare providers experienced in managing disabilities (including the authors KC & TX, and others), with medical educators who had published work on disability competencies, and with patients and caregivers with disabilities. Based on the learning, three key stakeholders – disability rights activists, doctors with disabilities, and health profession educators – were identified with whom focus group discussions (FGDs) would be carried out in India to arrive at disability competencies under the five roles of an IMG.

The Focus Group Discussions: The selection of participants for the FGD was geared towards including a diverse range of perspectives and thus, involved purposive sampling. Participants were recruited through email and through telephonic communication from three broad areas. The doctors with disabilities group consisted of doctors having lived experience of disability from private as well as public sectors. The disability rights activists represented organizations working in the cross-disability sector as well as in special areas such as physical disabilities, leprosy, autism, thalassemia, learning disabilities, deafblindness, and mental health. The health profession educators consisted of medical educators teaching in medical institutions.

FGD guides were prepared based on the experiences gathered through the observational visits to Chicago, from discussions among authors, and from a review of the literature about disability. The FGD guide consisted of the following triggers to initiate discussion: i) participants' personal experiences as patients with disability (PtwD), as caregivers of a PtwD, or as healthcare providers (HCP) to a PtwD; ii) the barriers faced by PtwD in a healthcare delivery setup; iii) the factors which facilitated management of patients with disabilities, and iv) their expectations from the healthcare providers with respect to their disability component. To get a comprehensive understanding regarding developing a curriculum, an attempt was made to specify the participants' opinions in terms of knowledge, skills, and attitude during the discussion itself.

The FGDs involved less than minimal risk to the participants. Written and verbal consent was obtained from each participant prior to study participation. The consent form assured voluntary participation and confidentiality and sought permission to audio record the discussion. Participants had the option of being interviewed in and responding in either *Hindi* or English. There was no monetary compensation given but an onsite meal was provided. The transcripts were not shared with anyone outside of the investigation team.

The FGDs were conducted in the University of Chicago Center in Delhi during November 2018 and were moderated by two of the authors (SS and KAM). A total of six FGDs, two each with each of the three identified stakeholder groups were done. The number of participants in each FGD ranged from four to eight. Each FGD lasted from 1.5 to 2 h.

The FGDs were audiotaped and subsequently transcribed verbatim into a Microsoft word document with the names of participants mentioned alongside. The long pauses, interruptions, and nonverbal communication signs were noted within the text. Two of the authors checked all transcripts for errors by listening back to the audio-recording and reading the transcripts simultaneously. Each transcript was supplemented with notes made during and immediately after the interview, for example, noting background information and instances where views were given after the recorder was switched off.

Data analysis: We used a grounded theory approach to determine themes emerging from the transcripts of the FGDs which were independently coded by two authors using NVivo 12.2.0 qualitative data analysis software. Codes were assigned inductively to every key phrase that suggested a possible disability competency. After coding independently, the coders came together to resolve differences in coding and to merge similar codes.

The second step utilized a framework approach where the generated codes were conceptualized as fitting into one of the five roles of an IMG as prescribed by the MCI. These five roles were clinician, communicator, lifelong learner, professional, and leader. The third step involved the taking of similar concepts and framing competency statements through a consensus-building exercise between the two researchers involved in coding. Internal validity was sought by circulating this initial set of competencies to the other authors and to the participants of the FGDs. Suggestions were incorporated and an amended list of competencies was prepared. For external validity, the amended list of competencies was shared via Listservs, Google Groups, and emails with disability rights organizations and medical educators all over India who were not a part of the FGDs, for their feedback and suggestions. The comments received were incorporated and a consensus document of final competencies was prepared and disseminated.

To disseminate the findings, a public engagement and faculty sensitization on these disability competencies was done in February 2019. All the authors moderated this workshop which included representatives from the MCI, Ministry of Health, state commissioner (disabilities), bioethicists, participants from the FGDs, medical students and representatives of disability rights organizations, and health profession educators. Some participants shared their lived experiences under the specified disability competencies.

For the purpose of this paper, exemplary quotes from the transcripts, many of which were bilingual, were translated into English by one of the authors who is a native speaker of English.

Results

The observational visit to the University of Chicago helped us identify the three key stakeholders that should be involved in the FGDs for the framing of the disability competencies – disability

rights activists, doctors with disabilities, and health profession educators – and that the disability competencies should consider the five roles expected of an IMG and also, to have global relevance, be aligned to the competencies framed by the medical councils of other major countries. Table 1 shows the roles of an IMG that are congruent with the competencies expected from American and Canadian medical graduates.

Thirty-seven participants were recruited for the FGDs. These included seven Disability Rights Activists for an FGD conducted on the morning of day-1 and six for an FGD in the afternoon, five doctors with disabilities in the morning of day-2 and seven in the afternoon, and five health profession educators in the morning of day-3 and seven in the afternoon. There were 18 women, 18 men, and one transgender person; 16 (43.2%) had a disability and six were caregivers to a person with a disability (16.2%). The disabilities included locomotor disability including cerebral palsy, polio, and meningomyelocele ($n = 10$; 62.5%), dwarfism ($n = 1$; 6%) visual impairment ($n = 2$; 12%), hemophilia ($n = 1$; 6%), dyslexia ($n = 1$; 6.3%), and deafblindness ($n = 1$; 6.3%).

Each FGD lasted between 1.5 to 2 h (mean time duration 108.5 min; SD 10.25 min). After the transcription of the FGDs and the analysis, an initial 52 disability competencies under the five roles of an IMG were framed (clinician: 20; leader: 9; communicator: 11; lifelong learner: 5; and professional: 7). Based on feedback from the authors, from the participants and from other stakeholders all over India, the competencies were further refined and/or clubbed into 27 disability competencies (clinician: 9; leader: 4; communicator: 5; lifelong learner: 5; and professional: 4; box 1). Thirty-seven organizations throughout India endorsed these competencies by the deadline of 26th January 2019.

To demonstrate how the qualitative analysis of FGD transcripts led to the framing of disability competencies [Tables 2–6], exemplar quotes, paraphrased for clarity, and translated into English (where required) are presented below. The initials after each quote refer to the person speaking: DRA = disability rights activist, DwD = doctor with a disability, and HPE = health

Table 1: Alignment of the five roles of an Indian medical graduate with the competencies defined by accreditation boards in the US and in Canada

Five Roles of an IMG	Six ACGME Core Competencies	Seven Physician roles (CanMEDS)
Clinician	Medical Knowledge Patient Care and Procedural skills	Medical expert
Leader	Systems-based practice	Collaborator Leader
Communicator	Interpersonal and Communication Skills	Communicator
Lifelong learner	Practice-based learning and improvement	Health advocate Scholar
Professional	Professionalism	Professional

Abbreviations: IMG, Indian Medical Graduate; ACGME, Accreditation Council for Graduate Medical Education; CanMEDS, Canadian Medical Education Directives for Specialists

professions educator. To keep the word count down to acceptable limits, only the most relevant quote is shared.

The corresponding author of this paper has live experience of a person with a disability; he is not only a doctor (with a disability) but a health profession educator, as well as a disability rights advocate. These attributes made him a cohesive force as he kept alive the connections between the three experientially diverse yet topically interconnected groups of key stakeholders. While conducting the FGD, he spoke little apart from supplying the triggers. Thus, knowingly, he withheld his thoughts during the discussions to avoid introducing bias.

Discussion

Ensure that the rights of persons with disabilities are included in the curriculum in Universities, colleges and schools…[1]

Sec 39 (2)(f) of the Rights of Persons with Disabilities Act 2016

Social accountability of educational and regulating institutions

Ten years ago, Kirschner *et al.* identified a lack of disability education in US medical education programs and suggested 6 core competencies for healthcare professions education about

Table 2: Examples of the quotes that prompted framing of disability competencies expected from an Indian medical graduate in the role of a clinician

The clinician (medical knowledge+patient care)
Who understands and provides preventive, promotive, curative, palliative, and holistic care with dignity and compassion. (Can be equated with ACGME competency of *Medical knowledge* and *patient care*).

Exemplar quote	Disability Competency framed An IMG should be able to:
1.1	"But if we go [in] to the definition of the act, I am a person [with] disability. Why? [Because] I have got something called gluten sensitivity. So, if we see the definition given by, say, WHO-ICF or the definition given by UNCRPD, that has to be understood in totality. Today they are not disabilities tomorrow they might become a disability." (DRA)	Describe disability as per United Nations Convention on the Rights of Persons with Disabilities while demonstrating acceptance of and respect for the differences and capacities of persons with disabilities as part of human diversity and humanity
1.2	"They just said, "See this young boy, he does not cry." They just poured the hot paraffin on my leg and I was supposed to not react and to [be a] He-man kind of a thing.I finally figured that this has to stop because I am not sick." (DRA and a person with a disability)	Understand the human rights model of disability and compare and contrast it with the medical and social model of disability
1.3	"Just to give my example I did my MBBS and MD (specialization) from KEM Hospital, Mumbai, which has a very good thalassemia unit. Since we were exposed to the care of thalassemia patients, and there was a lot of emphasis from our college side also that we should learn about thalassemia, a lot of my own batch mates got themselves screened, you know, before marriage." (HPE)	Provide for and encourage genetic testing and counseling for families, where there may be suspected genetically related disability issues
1.4	"My son was diagnosed with autism four years back.the entire process of getting him diagnosed and starting the therapy was a very harrowing experience. Both of us are doctors but we hardly read about autism during our entire MBBS curriculum. It was a small part of Ghai (the book). Even the teachers, they never gave much importance to it. So we could not pick up the signs. Had we picked up the signs earlier, the therapy would have started earlier and he would have recovered." (HPE)	Make an early diagnosis and suggest methods to prevent the common disabilities present in the community, using a lifecycle approach
1.5	"With respect to periods.you see girls with mental, intellectual disability. [There was] a teenage girl in a special school where we had gone.it was only when she became 6 months pregnant was it detected that some sort of assault had taken place. Parents were also not monitoring it." (DRA)	Identify the additional healthcare needs of a patient with disability including sexual and reproductive health needs
1.6	"At the very least, doctors should know the basic principles of rehabilitation. For example, in polio, the MBBS doctor should know why and how a patient may benefit from a caliper (brace). Many people can manage without a caliper, but I myself suffered because I did not wear a caliper during MBBS out of embarrassment and shame. Nobody offered any solution, nor was it ever covered in the syllabus." (DwD)	Demonstrate awareness of the range of assistive devices for patients with disabilities and counsel them to choose the appropriate one
1.7	"Disability should be assessed with aids and appliances. If a person has a 90% disability but is walking about with crutches or with a caliper, then he is less disabled than 90%." (DwD)	Assess and document disability on a functional basis
1.8	"He had hemophilia; one doctor certified him as 40% disabled, another as 70%, and a third doctor said he is 100% disabled." (DWD)	Interpret and critically analyze a disability certificate
1.9	"So, doctors have a role to play right from preventing disability to rehabilitation. If they don't have the knowledge, then naturally they won't be able to prevent, manage or guide them for rehabilitation. They don't necessarily have to provide every service themselves but doctors should know how-to guide, say, for example, after a post diabetes amputation." (DWD)	Discuss long-term management of the common disabilities in the community

Table 3: Examples of the quotes that prompted framing of disability competencies expected from an Indian medical graduate in the role of a leader

Leader and member of the healthcare team and system
With capabilities to collect, analyze, synthesize, and communicate health data appropriately (Can be equated with ACGME competency of systems-based practice).

Exemplar quote	Disability Competency framed An IMG should be able to:
2.1	"Parents are not aware of the exact nature of the problem (disability). For example, in cerebral palsy, their only question is, "when will my child be able to walk?" (HPE)	Promote patient-centered, supported decision-making approach involving family members in delivering effective healthcare to patients with disabilities
2.2	"No nobody even bothered that I had some difficulty in getting to places and in working so was sometimes late. You are imposed on them, they think because you chose to take admission into the medical course." (DwD)	Build an understanding of the concept and practical application of reasonable accommodation in healthcare, both in in-patient and in out-patient departments.
2.3	"I have meningomyelocele. [My teachers or seniors] could have guided me to some orthopedician if they knew that it could be corrected or some prosthesis could be given or physiotherapy could make my life easier. It was when I reached the final year and was posted in the orthopedic OPD that I realised that physiotherapy was possible. There is a lack of sensitization and awareness of this." (DwD)	Engage healthcare staff and all members of an interprofessional team to collaborate towards multidisciplinary assessment and management of patients with disabilities to provide disability-inclusive compassionate care.
2.4	"He asked me again and again - although he had observed me during senior residency for 3 years - "will you be able to do all the work required of a doctor?" Despite my assurances, he wrote on my file, "Despite having disability he can do such and such work." (DRA)	Advocate social inclusion by raising awareness of the human rights of persons with disabilities through training and the promulgation of ethical standards for public and private healthcare

Table 4: Examples of the quotes that prompted framing of disability competencies expected from an Indian medical graduate in the role of a communicator

Communicator
With patients, families, colleagues, and community. (Can be equated with ACGME competency of *Interpersonal and Communication Skills*).

Exemplar quote	Disability Competency framed An IMG should be able to:
3.1	"Recently, I went to a diabetologist to get myself checked and, strangely, even though the doctor observed me being escorted into his cabin and being directed to sit on the stool next to him, he did not lift his face from the laptop while he spoke so I couldn't even lip read. (DRA)	Demonstrate the use of verbal and non-verbal empathetic communication techniques while communicating with patients with disabilities and their caregivers in a manner acceptable to the specific disability culture
3.2	"Sometimes, the consent for intervention is requested from the attendants even for adult patients with noncognitive disability. It is taken for granted that because he has a disability, he is incompetent to give consent." (DwD)	Assess the capacity of a patient with a disability to give informed consent and demonstrate the ability to take informed consent from a patient with disability
3.3	"For pressure sore management in spina bifida, it becomes the caregiver's responsibility to go to one hospital after another since there is no management at the primary health center (PHC) level. The doctors say there's no point keeping such children alive and surgery will cause even more nerve damage." (DRA)	Explain the need for referral and the referral procedure to a patient with disability
3.4	"Whether it is a patient with special needs or a child with special needs, they have lots of questions and I have to give some special extra time to educate them beyond the treatment so that their general health does not deteriorate. For example, it may be a child with autism who is stammering and losing confidence." (DwD)	Check to understand the medical advice related to treatment, prognosis, follow-up, and/or referral given to patients with disabilities
3.5	"For epilepsy, especially in rural areas when people go to the PHC where doctors come once in a week, they don't talk about the management and just give the medicine, that's all. How regular he should be or what he should do if he has fits - those things are missing. If they refer, they do not tell them how to reach that hospital and why they are referring."(DRA)	Provide health education to patients with disabilities, their caregivers, their families, and at the community level in a culturally appropriate manner

patients with disabilities to reduce inequities.[8] Despite the global calling, a recent survey found that only 52% of the 75 responding medical schools in US offer disability education.[9] A recent study across six allied health professional disciplines in the University of Sydney's Faculty of Health Sciences compared the degree to which their competency documents exhibit a rights-based approach to disability and rehabilitation.[10] Of the 349 units taught

across all allied health professional disciplines in 2014, only 24 were identified as focusing on disability. Within the primary-care professionals, a recent study reported their inadequate awareness of tools to communicate with people with disabilities.[11]

The new MCI competency-based curriculum which was launched from August 2019 did not address disability competencies

Table 5: Examples of the quotes that prompted framing of disability competencies expected from an Indian medical graduate in the role of a lifelong learner

Lifelong learner
Committed to the continuous improvement of skills and knowledge (Can be equated with ACGME competency of practice-based learning and improvement).

Exemplar quote	Disability Competency framed An IMG should be able to:
4.1 "Doctors do not know that blood disorders and dyslexia are also listed as disabilities. They still consider only blindness, locomotor, deafness, and neurological disorders as disabilities." (DwD)	Demonstrate awareness of the disabilities included in the Rights of Persons with Disabilities Act, 2016 and keep abreast of updates
4.2 "Doctors should be aware of the requirements for disabled patients. If the buildings are made disabled-friendly, if he [the doctor] sees ramps everywhere, if there are disabled-friendly toilets, if he sees the facilities in the college as well as in the hospital, then he will become aware." (HPE)	Demonstrate an understanding of accessible healthcare setting for patients with disabilities, including universal design to ensure physical accessibility, and accessible formats of information and communication
4.3 "You have a fracture so you take medical leave. I need disability leave. Heads of the department should know this." (DwD)	Demonstrate familiarity with government-run programs, schemes, legislation and legal services available for persons with disabilities, and keep abreast of updates
4.4 "In other parts of the world, young doctors from medical colleges are encouraged to join support groups like societies for multiple sclerosis because they give out awards for research. In that way, there is a benefit to the doctor, the support group, and patient welfare is also taken care of." (DRA)	Demonstrate awareness of rights-based and disabled people's organizations in the community
4.5 "In every batch [of medical students], there are some who go through depression. It's a big problem. I never realized it till I actually faced it myself at some time. Nobody wants to talk about it. You just want to push it under the carpet. People say, 'she's gone mad.' Everybody needs to be sensitized." (HPE)	Encourage research on disabling conditions, their prevalence, and their management, so as to add to the body of knowledge on the issue

Table 6: Examples of the quotes that prompted framing of disability competencies expected from an Indian medical graduate in the role of a professional

Professional
Who is committed to excellence, is ethical, responsive and accountable to patients, community and profession (Can be equated with ACGME competency of Professionalism).

Exemplar quote	Disability Competency framed An IMG should be able to:
5.1 "A friend (also blind, like me), had piles for which he was referred from the Jawaharlal Nehru University healthcare centre to the Safdarjung hospital. The doctor there asked him to lower his pants and lie on the examination table. The room was full of patients and my friend did not know that there was a curtain that could be pulled to screen him from the other patients. The doctor didn't bother about it." (DRA)	Demonstrate respect for inherent dignity and autonomy of patients with disabilities and their caregivers.
5.2 "She's identified as a dentist who is sensitive to the needs of children with disability. What she does is, in the morning slot, she will see a child with autism and complete the treatment and move them out before other people start crowding up the clinic. That level of sensitivity is so important - it's not just about understanding the diagnosis, but also understanding what is the impact on the individual and how do I adapt my treatment as a doctor." (DwD)	Demonstrate commitment to give priority to patients or caregivers with disabilities in outpatient departments of health facilities
5.3 "Even when they are checking them (people affected by leprosy) or testing them, they will not like to touch them. So they will take a pen and pull the eyelids up." (DRA)	Demonstrate a nondiscriminatory behaviour towards patients or caregivers with disabilities and a commitment to provide them care of the same quality as to others
5.4 "In the physiology practical, male students are expected to volunteer to take off their shirts, lie down on the bed, and be examined by the other students. But for a transgender person to remove the shirt and lie down and for someone to touch them or examine them, that's absolutely like someone is molesting you." (HPE)	Demonstrate integrity in treating patients with disabilities who are vulnerable to physical, mental, sexual, social, and financial exploitation

adequately and lacked the human rights approach to disability.[7,12] Their longitudinal ethics module "AETCOM (Attitude, Ethics, and Communication)" mentioned "disability" only at one place.[13] None of the three volumes of MCI's discipline-specific competencies mentions the keyword "dignity" which finds a central place in CRPD and in the preamble of the RPDA.[7]

Our disability competencies are RPDA, MHCA, and CRPD compliant along with two important competencies missing from the current curriculum but stated in Government of India's think-tank NITI Aayog as 3-year action agenda[14] – Access to aids and assistive technologies (DC 1.6) and disability certification (DC 1.7, 1.8).

Leave no one behind

One of the key features in curriculum development is the representation of real stakeholders. While framing nursing competencies in caring for people with disabilities, disability experts were consulted in a Delphi study[15]; however, disability competencies are designed without taking into consideration the lived experiences of people with disabilities. We believe that people with disabilities are the real experts when it concerns their disabilities and hence, we made an attempt to leave no one behind by involving patients with disabilities as well as their caregivers. A similar approach has been advocated in the curriculum of an interprofessional training program incorporating advocacy for future psychologists, where individuals with disabilities and their family members shared experiences.[16] During feedback on the original 52 competencies, a few stakeholders were of the opinion that certification, early identification, and genetic screening are rooted in the medical model of disability and could be done away with. The authors felt that it would be improper to fully embrace the social model while neglecting the medical model hence, we favoured the middle ground, basing the competencies on the human rights model of disability.

Nothing about us, without us

Many of the doctors with disabilities in the FGD questioned the disability certification process. With the introduction of 14 new disabilities in the RPDA 2016, the MCI framed new guidelines for candidates with disabilities which were challenged by doctors with disabilities as discriminatory, illegal and unethical.[17] A case in point is that of a candidate with mobility impairment who despite having successfully acquired an undergraduate degree in medicine, was declared ineligible by the MCI for admission to the postgraduate course as he had more than 80% disability.[18] He challenged the decision in court and was awarded admission. Our list of competencies addresses this issue as it focuses on the assessment of "ability" and not on disability assessment (DC 1.7). The same point has since been amended by the MCI in their gazette guidelines for admission.[19] This competency was developed through discussion with doctors with disabilities which strengthens the argument to do "nothing about us, without us."

Strengths and Limitations of the methods used

The strength of this study is the involvement of people with disabilities in our FGDs. The lived experience project by Meeks *et al.*,[20] advocate involving those with lived experiences of disability to address the healthcare disparities faced by individuals with disabilities. Such engagement with disability community has been highlighted among the best practices for building an inclusive environment for people with disabilities in the biomedical workforce and reducing stigma and stereotypes about people with disabilities.[21] The evidence for the impact of having such an approach was provided in the recent follow-up survey in US medical schools which compared the prevalence of disability and accommodation practices between 2016 and 2019.[22] The increase in disclosure shows increased awareness of

the availability of accommodations as well as a student getting comfortable in their disability identity.

The use of disability-inclusive practices within the University of Cape Town curriculum enabled "the *humanness* of disability" not only to create awareness and showcase role models but also to enrich the curriculum.[23] CRPD and subsequent national legislations address disabled people's right to participate in research conducted for them.[24] Consequently, the provisions of the CRPD and RPDA extend and expressly apply to MCI's new curriculum as well as healthcare involving all persons with disabilities. We supplemented the lacuna in MCI methodology. A similar approach was used by General Medical Council of UK (the equivalent of MCI) while framing guidance for disabled learners in medical education during training.[25]

We observed that while the disability rights activists were most vocal about human rights, many of the doctors with disabilities, despite having the lived experience and having faced discrimination, were not aware of their rights. One of the reasons might be that the dominant theme in the traditional medical curriculum is still the medical model of disability. These competencies, thus, seem to have come at the perfect time when the country is moving to a human rights-based approach towards disability, and when the MCI is integrating competencies into medical education.

With the number of disabilities having been increased from 7 to 21 in the new RPDA, it would have been relevant to include representatives from all communities. Since that would have been logistically difficult to manage considering manpower, space, and finances, we restricted ourselves to a few. The competencies thus generated may not be generalizable across all the different disabilities; however, we did our best to nullify this effect by seeking feedback from other disability representatives who could not participate in the FGDs. That may have helped in generating the current competencies which are more general than specific and appear to apply broadly regardless of the type of disability.

Implications and the way forward

After disseminating the findings of this project to the three stakeholder groups, the central and the state statutory bodies on disability were apprised of the developed competencies, and they recommended them to the Ministry of Health and Family Welfare (MoHFW) and to the MCI.[26] This judicial activism successfully paved the way for the MCI to include seven of these competencies into the foundation course which is a mandatory part of the new competency-based curriculum in place since August 2019.[27,28]

Unlike in other countries, the disability competencies in our curriculum now are not optional but are an integral part of the curriculum. This was heralded as a big victory for those promoting disability as a human rights issue. The competencies

could well be applied globally as they are in sync with the US and Canadian competencies [see Table 1]. They can also be used in other health professions such as nursing and dentistry.

Conclusions

The focus group discussions with people involved intimately with disability in one way or the other, resulted in a list of competencies that they felt should be demonstrated by health professionals while they care for patients with disabilities. The competencies are based on the human rights approach to disability and are aligned to the recommendations of the world report and the CRPD. Therefore, they are general enough to be applicable regardless of the type of disability and there is a strong likelihood that they would have relevance in the global medical education scenario.

Conflicts of interest

There are no conflicts of interest.

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