Disability: beyond the medical model

6 months ago, 13-year-old Yeng Wally fell out of a tree while gathering mangoes. She fractured her spine at L3-4 and is currently lying paralysed in a hospital bed. Her muscles have wasted and she has a large pressure sore on her sacrum. She gets frequent urinary tract infections because of her catheter. She has no access to a wheelchair. Even though her quality of life is severely impaired, she still smiles a lot. But the funding for her hospital stay will soon run out and she is not well enough to go home. Yeng lives in Bansang, The Gambia. Her present situation would be very different if she lived in Bristol, UK.

Staggeringly, of the 10% of the world’s population who have some form of disability, 80% live in low-income countries and have little or no access to basic health services, including rehabilitation facilities. However, as The Lancet today shows, old and young people, those living in rich and poor countries, and everyone else in between, are affected by disability in some way.

Today’s special issue, published ahead of World Disability Day on Dec 3, does not look at disability through a purely medical lens. In line with the International Classification of Functioning, Disability and Health, and the UN Convention on the Rights of Persons with Disabilities, our issue views disability as the outcome of complex interactions between health conditions and the physical and social environment. For example, poverty might cause disability through malnutrition or poor living and working conditions, but disability can also cause poverty by excluding individuals from education and work. Yet, as the Comments in The Lancet today show, the health needs of people with disabilities are ignored in the Millennium Development Goals, often not catered for in emergency situations, and are generally neglected by the research community.

There has always been tension between the medical model of disability, which emphasises an individual’s physical or mental deficit, and the social model of disability, which highlights the barriers and prejudice that exclude people with disabilities from fully engaging in society and accessing appropriate health care. In a Health Policy paper in today’s issue, Mark Tomlinson and colleagues show that the top research priority for the health of people with disabilities is ensuring that health systems provide adequately for all individuals with disabilities. Their findings highlight that access to appropriate health care for people with disabilities needs urgent attention, especially in low-income and middle-income countries.

Unfortunately, one of the biggest barriers to accessing appropriate health care is the attitude of health professionals, which might further isolate and stigmatise people with disabilities. Despite what many health professionals might assume, people with disabilities can be healthy, do not necessarily need to be “fixed”, are often independent, and might well be consulting for a reason unrelated to their disability. Conversely, people with chronic conditions, such as chronic obstructive pulmonary disease, are often debilitated by their condition yet are often not perceived by health professionals as having a disability. Such perceptions matter: people with disabilities still have the same health needs as other people and are also entitled to specific rights, including the right to make choices about their health care. More exposure to people with disabilities, including colleagues, might help health professionals improve their attitude and change their assumptions. But as Tom Shakespeare points out in an Art of Medicine piece, although useful, such contact is no substitution for specific training in disability issues for all health undergraduates and professionals.

The medical profession has little to be proud about regarding its treatment of individuals with disabilities. Health professionals can sometimes behave appallingly towards people with disabilities. It is also often very difficult for people with a disability to enter the health professions, not because of any personal inability, but because of attitudinal obstacles. Consultant in emergency paediatric medicine Will Christian and paediatric nurse Rachael Johnson share their personal experiences of the rocky road from student entry to specialist training. Interestingly, both think that their disability has made them better health professionals.

Disability is not a homogeneous entity. The Personal Accounts show that, although there are some common experiences, every story is different depending on personal circumstances, environmental factors, type of disability, and the care received. There are 650 million people with disabilities in the world who all have their unique story to share. People with disabilities are individuals who do not all think or act according to the “disabled” label that society has assigned them. Health professionals and policy makers please take note. ■

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