

Vital service reaches far too few

PEOPLE with disabilities are not a visible population because many of them are not on the streets, in the workplace or in the taxi. Children with disabilities are still found locked away by ashamed families. Nonetheless, the World Report on Disability estimates that at least 15 percent of our population has a disability of some kind. South African sources, however, estimate the number at somewhere between three percent and 10 percent, due more likely to different definitions of disability rather than actual population differences. The figures in poor communities will be higher, and in rural or peri-urban areas with poor infrastructure, more minor impairments will be more significantly disabling: Terrain is harder to cross, distances are greater, scarce and overcrowded taxis are unlikely to stop for disabled people, and buildings are less likely to be accessible. Disability obstructs livelihoods, incurs a wide range of costs, and plunges entire households deeper into poverty because the family foregoes income generation opportunities to provide care, and must spend disproportionate amounts on private transport hire, accessing health services, and so on. The vicious cycle of poverty and ill health is well known. If we are serious about addressing either factor, we cannot ignore disability. And yet we have. Across the country, provincial departments of health fail to allocate budgets to rehabilitation. We are not talking cosmetic surgery here - these are the services that seek to remediate impairments such as back pain, depression and hearing loss, as far as possible, and facilitate the reintegration of people with disabilities into schools, workplaces and communities, where they can be productive members of society, rather than a burden to their caregivers and to the system.

Community service

But until community service was launched for rehabilitation therapists in 2002, hundreds of hospitals had never seen such a thing. Eleven years later, community service therapists in outlying areas are still initiating brand-new departments - most often without a budget or a place to work from, let alone supervision. South Africa is said to suffer from a "quadruple burden of disease": maternal and child mortality, HIV and TB, non-communicable diseases and violence and injury. The Department of Health pours money into the first two, in particular, and rightly so. But the only numbers that seem to matter to our health officials at the end of it all are the burden of disease, mortality rates and life expectancy. The message is clear: we care whether you live or die, but that is it. What kind of life you are able to live, what contribution you make, the protection of your rights to dignity and self-determination, are not our concern. Disability is the shadow side of public health. When we do not cure (and sometimes even when we do), impairments remain that change people's lives forever. HIV is a good example. Almost every child born with HIV suffers progressive neurological damage that antiretrovirals can halt, but not reverse. Higher rates of cerebral palsy and developmental delay are found in HIV-positive infants. Adults with HIV suffer strokes, meningitis and a host of other debilitating diseases. Co-morbidity of HIV and TB has increased rates of TB outside the lungs, particularly in the bones and spine,

resulting in more spinal cord injuries. Mental health conditions occur at significantly higher rates among the HIV-positive population, not least because of the stresses of living with the disease. At the same time, people with disabilities are more vulnerable to HIV infection because of poor access to information and prevention services, and particularly because of vulnerability to sexual abuse.

In 2011, the Central African Journal of Medicine published a small study carried out at an HIV clinic in Zimbabwe, where conditions are comparable to many rural and peri-urban areas in South Africa. In this research, 61 percent of participants (all attendees at the clinic) reported having their basic daily activities significantly reduced by the physical impact of their illness, in spite of being on antiretrovirals. Whether through impairments of vision, hearing, mobility, movement or mental functioning, this directly affects the well-established public health goals of access and capacity to adhere to treatment, yet I have yet to see a rehabilitation therapist employed by a state HIV programme that targets these issues. The national strategic plan on HIV, sexually transmitted infections and TB lists people with disabilities as a vulnerable group requiring targeted attention, and includes rehabilitation among the services required for "sustaining health and wellness". But core indicators remain focused on the burden of disease, treatment coverage and mortality. As we know, if you cannot count it, it does not exist. The National Health Insurance (NHI) plans are a particular cause for concern. The green paper on the NHI purports to support comprehensive health service provision, including preventive, promotive and rehabilitative care, as well as curative care. But the report on the pilots is out, and rehabilitation has not yet been considered in any of the costing exercises or human resources planning. We have still to agree on a basic service package.

Things are slowly beginning to change. The Health Department has announced its intention to launch (after prolonged civil society pressure) a national task team on rehabilitation. Having postponed the first meeting in May, the initiative is now due to begin in July. Its purpose will be to formulate a rehabilitation service delivery strategy within the primary healthcare framework.

We will be watching - but so should the five million-odd people infected with HIV, the 3.5-million with (diagnosed) diabetes, all those who will be involved in the 500 000 road accidents expected this year, the 1.1-million women who will give birth, as well as anyone who cares about someone in any of these groups. Let us just hope we can catch up.

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