'One size fits all' health policies crippling rural rehab – therapists

A physiotherapist in the deep rural Eastern Cape goes the extra mile to deliver a much-needed wheelchair.

Picture: Karen Galloway, Zithulele Hospital.

Scarce rehabilitation services in rural areas, driven by a skeletal cadre of resolute therapists, are being undermined by 'one size fits all' policies that starve their departments of staff, budgets and vehicles, therefore shortening patients' lives and reducing their chances of any lasting quality of life.

This meant that those scarce, functional vehicles that were available were first allocated to doctors and administrative staff, leaving outreach services and home care for disabled patients (who are already at a huge disadvantage) either very thin or non-existent.

An *Izindaba* survey of occupational therapists (OTs), speech therapists (STs) and physiotherapists (PTs), in the deep rural provinces of the Eastern Cape, KwaZulu-Natal (KZN) and Mpumalanga, indicates that team work, innovation, voluntary unpaid overtime and use of their own vehicles to treat patients seem to come standard with the job. An estimated 5 - 10% of South Africa's population suffer from a disability (even higher in rural and low socio-economic communities). While accurate, up-to-date adult disability data are difficult to come by (i.e. Census 2001), intellectual disability is the commonest childhood disability in rural African children, affecting 41 per 1 000 kids aged 2 - 9 years.[1] Autism prevalence across South Africa is estimated at 10 per 1 000 children.[2] An estimated 25 000 babies are born with fetal alcohol syndrome disorder every year nationally,[3] while 17 babies are born with or will develop hearing loss every day in South Africa – 85% in the public sector.[4]

'It's all fair and well saving a child's life, but what happens afterwards? What happens if that child is unable to walk, talk, see or hear, or has intellectual impairment? What is the quality of life of the child, and how much stress will it place on the immediate family/caregiver?

Jennie McAdam, an OT who managed Mpumalanga's OT and professional development and training services from Witbank Hospital for 15 years, singled out policies on bed occupancy duration, mismatched placement of professionals and community service therapists and technical support staff, plus insufficient, dedicated transport as top issues. Her views on transport were loudly echoed by colleagues as far apart as the KZN north coast and Zithulele (near Coffee Bay, Eastern Cape). McAdam, now in private practice in Tzaneen (Limpopo Province) where she supervises the rural community block-training component for OT students at the University of the Witwatersrand, said that far too often hospital administrators without any clinical background made transport allocation decisions. (According to provincial organograms, transport falls under administration.) This meant that those scarce, functional vehicles that were available were first allocated to doctors and administrative staff, leaving outreach services and home care for disabled patients (who are already at a huge disadvantage) either very thin or non-existent. This and policy on bed occupancy duration kept the emphasis on immediate cure rather than prevention of disease, promotion of wellness and rehabilitation, contrary to the new national primary healthcare approach.

Save a life, then what?

Said a district hospital PT on the KZN north coast (who declined to be identified for fear of victimisation): 'It's all fair and well saving a child's life, but what happens afterwards? What happens if that child is unable to walk, talk, see or hear, or has intellectual impairment? What is the quality of life of the child, and how much stress will it place on the immediate family/caregiver? This is where rehab and social work are required.' (E.g. ten in every 1 000 children between 0 and nine years old in the Manguzi district suffer from cerebral palsy.[5])

Added McAdam dryly: 'Take a para[plegic]; they are supposed to be managed at primary healthcare level to reduce the overall demand on transport (if they can get to their local clinic) – unless they develop say a urinary tract infection and need secondary or tertiary level urology consult'. Says Karen Galloway, a PT at Zithulele and vice-chairperson of the 5-month-old Rural Rehabilitation, South Africa (RuReSA) group: 'Reliable transport is crucial for rehab work in the community. People eventually get tired of being let down and it makes it difficult for us to get buy-in. We've been lucky lately with our community trust. I think our success is closely related to us often taking our own vehicles so as not to let down patients to whom we've made promises' (raising legal culpability transport issues). McAdam added that community-based rehab workers were often not issued with subsidised vehicles and had no access to official 'pool' vehicles.

The rehab building at Mmametlhake Hospital in deep rural NW Mpumalanga, close to the border with Limpopo.

Referral often 'a waste of time'

Galloway said referral (only by doctors) of patients to Nelson Mandela Academic Hospital or Bedford Orthopaedic (also in Mthatha) was often 'near impossible'. 'You need to get through on the phone first, then find a sensible doctor [at NM Academic] who cares enough to get your patient time

in the hospital for theatre or a scan and then hope that our [Zithulele] patient transport decides to actually go. Once they get there, more often than not the patient doesn't get touched, let alone examined. It's such a waste of valuable time and scarce money. The whole process just kills the [referring] doctor's will to try again. They end up asking themselves whether it's worth spending three hours trying to make this whole sad event happen, or whether they should rather go to outpatients and help those who are there now, today!' She cited eight patients currently at Zithulele suffering from 'neurological fallout', whose vital CAT scans at Nelson Mandela Academic had disappeared without trace, adding that the tertiary hospital's reputation among her district health colleagues remained 'pretty grim'.

A rare sight for the rural disabled: A hospital vehicle approaching a far-flung khaya.

The KZN PT said that at her hospital primary healthcare supervisors, allied health, community health facilitators, and HIV and TB tracing teams shared vehicles, meaning 'either you're overloaded or you cut services'. Crises, such as urgent home visits for mental healthcare patients or paraplegics, as well as urgent tracing requests for defaulters, were often simply not addressed. Due to the rough terrain, vehicle break-downs were a constant threat. In an already strained system, even one 4x4 broken down could impact dramatically on the ability to deliver outreach services. Authority to purchase additional vehicles was held provincially, which further retarded their ability to respond effectively to individual, institutional and community needs. All this leads to (largely preventable) further disability, longer hospital stays (when eventually admitted with complications) and decreased community trust. Low community and even doctor expectations and understanding of disability and rehabilitation contributed to a debilitating lack of awareness. 'Rehab is all about early intervention. The older the problem, the less likely we are to be able to do something about it ... rural rehab, with its currently crippled home visits programme, cannot expect to reach the patients that will never be able to make it to their closest clinic.' These patients remain confined to their homes, often developing severe contracture and pressure sores, with caregivers and community members unable to understand their condition or care for them appropriately. They end up with very poor quality of life in 'truly miserable conditions'. 'By the time some therapist does eventually "discover" them, the damage is done and irreversible,' she added.

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Speedy patient bed turnover vexes therapists

McAdam, named the Health Professions Council of South Africa (HPCSA)'s Healthcare Worker of the Year in 2007, said budget or policy-stipulated maximum length of bed occupancy (the national indicator for district hospitals is three days) 'is possibly the biggest issue for me'.

The entire system was prejudicial to patients with disability or the potential for disability. 'The minute they're vaguely stable, off they go, home. There's no possibility for a transfer to another ward. Our health system is geared towards curative care/mortality issues, without adequate rehab around morbidity and quality of life.' This leads to re-admissions (if the patient survived, and further disability), thus affecting the entire family. She said if dedicated rehab beds were provided, a more appropriate acute rehab indicator could be crafted, taking into account differing lengths of stays required for stroke versus amputation versus spinal injuries.

The current global indicator automatically set up an unwelcome adversarial relationship between rehabilitation and medical staff and created 'limited or zero access to rehabilitative inpatient care'. Health managers and doctors often misunderstood the difference between 'step down' facilities and (mostly non-existent) dedicated multidisciplinary rehab wards. Another 'policy madness' was again 'the provincial organogram', which led to a mismatch of human resources. She explained that in certain provinces that employed community-based rehabilitation workers, the majority of (more senior) rehabilitation therapists were appointed to regional directorates while most community-based rehabilitation workers (mostly community service officers and allied health professions technicians (mid-level workers)) were appointed to district directorates – with completely different lines of authority. Transport challenges aggravated this. Although there was a sprinkling of qualified therapists in district directorates, the system made proper, effective supervision nigh impossible. HPCSA rules stipulated that OT and PT technicians could only practise under supervision, creating a catch-22 conundrum. 'You have to ask, what does supervision mean: once a month or full time?' she added. (McAdam stressed however that there were 'high level' moves to revise these rules.)

A community-based caregiver with a rural Kwa-Zulu-Natal patient.

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Jennie McAdam with children and parents from the Vosman, Witbank community who benefited from the Isibindi Toy Library, opened in May 2008.

'Also, heaven forbid that a therapist takes a hospital vehicle into a neighbouring district to help out a colleague,' she added. A related issue was professional support where a rehab community service officer was expected to not only render, but also manage clinical services in 'some back of beyond hospital – there's a very high need for profession-specific support,' she said. One ready solution would be a provincial structure where a senior therapist could 'move around a province to supervise and guide'. Added Zithulele's Galloway heatedly: 'Naïve urban professionals fight over their territory and make policy that is unworkable in rural areas. Physios are scared of assistants (mid-level workers) taking their private practice work when every rural therapist knows that assistants are often the only rehab workers in a district hospital who provide continuity and often the only advice and information!'

Red tape killing proper healthcare

McAdam ruefully confessed that in her 15 years in the public healthcare sector bureaucracy often bedevilled delivery. Now planning her PhD on patients qualifying for Road Accident Fund claims but not gaining access to rehabilitation, she said 90% of patients currently privately referred to her by an attorney in Secunda had no access to public sector rehabilitation.

Galloway raised another major issue, especially at Zithulele Hospital – the growing AIDS-driven burden of disabled patients. While antiretroviral therapy 'will make you miraculously well, it won't fix irreparably damaged neural tissue or a TB-damaged spine, for example'.

'People love saving lives, but who looks after patients after the event? HIV programmes should have a rehab component built into them,' she added. She revealed that her department had not had any budget for three years and still owed one supplier R8 000, meaning the supplier had withdrawn services (now going on five years). 'There are really good reasons to get you disheartened, but some reasons are stupid and not necessary to tolerate,' she added.

Education department slack on kids with disabilities

The therapists said there was a dearth of schools for children with special needs in rural areas. Some had hundreds of children on the waiting list for such schools and hundreds more teenagers/young adults on waiting lists for skills centres.

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School support services from the Department of Education (DoE) did not reach a large number of referred cases and were unable to provide the remedial support required by an alarming number of learners in rural schools. As a result many children remained unassessed, unassisted, and unplaced. The KZN PT added: 'Even when kids secure a place at the school, there's no place in the hostel. Poor communication between schools and parents often end up in parents withdrawing the kids after a year.' She said parents of deaf children at one local KZN school for the deaf were no longer taught sign language, so kids were unable to communicate at home, which led to a breakdown in relationships and behavioural problems. Unless the DoE ensured an adequate number of remedial teachers and therapists (per school), any screening that was done was unethical because there was no service to offer after a problem was identified, she added. According to Department of Basic Education statistics (2010/2011), there are 423 special schools, of which 261 have hostel facilities (62%), countrywide.

Galloway said she was looking forward to the community-orientated national health insurance (NHI) bringing about much-needed change at rural hospitals.

Other challenges identified by the rural therapists included:

- Constant staff turnover among doctors as well as therapists.
- Insufficiently skilled or motivated human resource departments (adverts passively placed on the provincial health website), with little support given to staff retention, and snails-pace staff replacement. Scant attention was paid to individual human resource development, especially considering the high staff turnover and largely junior staff component.
- Unclear operational mandates of the Department of Health (DoH) and DoE that prevent children with disabilities from accessing their right to rehabilitation. No clarity regarding which department is responsible for the provision of assistive devices for school-age children, particularly those already placed at DoE special schools.
- Unequal implementation across staff categories of procedures for access to continuing professional development opportunities.
- Significant educational, geographical and socio-economic barriers leading to delays in access to care, poor return to function and sub-optimal rehabilitation outcomes in patients with families of (on average) 6.5 people living on one or two social grants and earning between R1 200 and R1 500 per month.
- A weak multisectoral approach that included poor clinical pathway protocols.
- Insufficient budget (no 'ring-fencing') for appropriate assistive devices (wheelchairs, hearing aids, walking aids, prostheses, etc.), which are the equivalent of chronic medication for handicapped patients.

Karen Galloway, chief physiotherapist at Zithulele Hospital in the deep rural Eastern Cape with her child, Tessa.

Ms Manthipi Molamu, a director in the (national) Department of Social Development's Directorate of Services to People with Disabilities, said a 2010 costing of its policy on disability showed a 'huge gap in ensuring accessibility of our services to people with disabilities, especially in rural areas'. Her department was subsidising a number of NGOs rendering rehabilitation services (which received no such help from public health departments), including 126 residential facilities and 300 'pro-active workshops' in all nine provinces. 'We are all overwhelmed by the needs out there but it's compounded by a lack of co-ordination, working in silos and in isolation,' she added. Ensuring accessible public transport remained 'the key issue' to foster independence in people with disabilities.

'All our residential facilities for children with disabilities are full of children who have been rejected at formal schooling as they could not proceed with their education due to their mental state,' she said, adding that many could not access remedial education. Parents had no alternative but to register their children in these residential facilities.

Ms Sandhya Singh, Director of Chronic Diseases, Disabilities and Geriatrics in the national DoH, said she could only respond to questions if they were channelled through Mr Fidel Hadebe, Acting Director of Communication in the national DoH, *and* provided that two prerequisites were complied with. These were that the issues first be put to her relevant provincial peers and verification obtained that their responses were 'passed' by the relevant provincial health chief. 'I don't want to sound bureaucratic, but unfortunately that's the protocol,' she said.

While it may be a case of a 'one size fits all' health policy vexing rural patient rehabilitation, national health department media policy is obviously more refined. It is hoped that *Izindaba* will bring you more pertinent official responses next month.

McAdam stressed that she was speaking in her personal capacity.

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