



# Make or break? The influence of street-level bureaucrats on access to healthcare (Part 1)

## Introduction

The right to access healthcare in South Africa is constitutionally protected and part of a socio-political effort to bring justice after apartheid. Yet, 20 years into democracy, access barriers such as high transport costs, large distances to services, varied quality of care and a fragmented health system continue to disproportionately affect many who experienced the dispossession and violence of apartheid - poor, black, rural and informal-urban communities – as well as newer marginalised groups, including migrants and refugees.

Little attention has been paid to the potential role of the health system and those working in it, in helping to transform the repressive institutions and practices that entrenched the injustice of apartheid.

Street-level bureaucrats (SLBs) – frontline health workers such as doctors, nurses and police officials - are a gauge of both individual and institutional transformation. With discretionary power and flexibility in dealing with clients (e.g. patients or prisoners), SLBs should be well-placed to promote democracy by delivering services in ways that are restorative and participatory, rather than punitive or paternalistic. However, authoritarian provider practices have been identified in post-apartheid health services and negative, even abusive, street-level bureaucracy may impede the right to access health care. In addition, the volume of new policies and their ‘top-down’ imposition have contributed to providers often prioritising the demands of their managers over patients’ needs.

## Highlights and policy implications

- Street level bureaucrats have discretionary power in dealing with clients, allowing them to shape and practice policy.
- Negative street-level bureaucracy may be a major barrier to care for patients and continue a culture of disempowerment and deprivation.
- Conversely, positive provider practices are vital for improving access and contributing to the restoration of justice and health in society.
- Strengthening provider accountability and fostering respectful practices that promote patient-provider dialogue are critical for improved access to healthcare, and a transitional justice agenda for reconciliation and equality.
- To foster positive practices, accountability needs to be vertical (to managers, and to patients/ communities), *and* horizontal (to colleagues).
- Individual actions, attitudes and advocacy count and can overcome negative street-level bureaucracy.

This policy brief was based on an article entitled: “Bringing Justice to Unacceptable Health Care Services? Street-level reflections from urban South Africa”, Bronwyn Harris<sup>1,2</sup>, John Eyles<sup>1,2,3</sup> Loveday Penn-Kekana<sup>1,4</sup>, Jana Fried<sup>5</sup>, Harry Nyathela<sup>1,2</sup>, Liz Thomas<sup>2</sup>, and Jane Goudge<sup>1,2</sup>. *The International Journal of Transitional Justice*, 2013, 1-21. References available on request.

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## Methods

This study is part of the Researching Equity and Access to Health Care (REACH) project\*, a five-year multi-method study of equity in access to TB treatment, ART and maternal deliveries in four South African provinces.

We interviewed 29 patients and 49 providers about their access experiences in Cape Town and Johannesburg (June 2009 - July 2010), then engaged with stakeholders (February 2011 to April 2012). We developed eight cases from this data; four are included here to reflect on street-level bureaucracy as either improving or impeding access to health care and social justice. We spotlight a patient case where street-level bureaucrats exacerbated the injustice of inaccessible health care; a provider reflection on access barriers; and two cases where street-level bureaucracy has restored justice. Names have been anonymised.

### Access denied

Mark Kriel (30) was an unemployed TB patient on directly observed treatment, short course (DOTS). A former drug user who still smoked marijuana, he slept in a car outside his mother's house and was largely ostracised by his family and neighbours. He often went without food, making it difficult to tolerate his TB medication. Transport costs prevented him from making daily visits to the clinic, and he stayed away for two weeks. When he returned, he was 'scolded' by the nurses and told to come daily 'or die':

*"It is as if they don't listen when I talk to them. If I tell them I can't make it then they will just say, 'you must make a way to come [daily].' Uhmhm, then I asked them, 'Is there no way to get something [a grant, weekly treatment] to make it better for me?' because they know my circumstances. There is no way that I can get transport to here. It is like I talk but they don't listen to me, they don't hear me. I just get negative answers."*

Poverty led this patient to default from his TB treatment. DOTS aims to minimise defaulting by placing those at risk under surveillance, yet in this case it emphasised the risk. The nurses' indifference and lack of sympathy intensified the injustice of unaffordable health care and further marginalised him.

### Rights deferred

Nonhlanhla Dube (early 50s) was the operational manager of a busy clinic in a poor community where many patients had no food or accommodation. While sympathetic, her response to patients defaulting from TB treatment was one of frustration, anger and blame towards democracy and patients' rights:

*"Before [democracy] we could do our work properly. Our patients were like school children: we could teach them...they would comply with their TB treatment and they got cured. Now patients have rights, the person can refuse to take treatment, and what if he refuses to take treatment? It complicates to MDR [multidrug-resistant TB] (and) XDR [extensively drug-resistant TB]. The person with MDR needs to be admitted so that he doesn't infect other people...these rights they have disrupted a lot of things. I blame all this mess with TB on patients' rights."*

She reflected a sense of lost identity and a fall in her professional status, shared by many providers interviewed, leading her to 'want to take your epaulets and hide them because being a nurse is being nobody, is being a doormat where...even the patients, they don't take us seriously.'

She felt undermined by democracy and new health system challenges such as staff shortages and increased workloads, lack of political support, disdainful patients and communities, and immense pressures from senior officials and the media.

### Justice restored

Peter Isaacs (49) was a diabetic and HIV positive, living in a cold, cramped council house when he was diagnosed with TB. He was fired from his job because he was too ill to work, and was not able to access a social grant due to a technicality. He moved in with his sister and niece who cared for him, and where a community health worker visited him daily to administer his medication.

*"She encouraged me to go on with life. She said it is just a disease that can be cured and she encouraged me to drink my pills, eat right and healthy...the second month I started to get an appetite and from that time I started to eat and gained weight and felt to live."*

\*Reach partners: CHP (Wits); Health Economics Unit (UCT); McMaster Institute of Environment and Health; Centre for Health Economics and Policy Analysis (McMaster); School of Public Health (UWC); Africa Centre for Health and Population Studies (UKZN); Rural AIDS and Development Action Research (Wits).

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Once stronger, he completed his treatment at a clinic that provided bread daily for TB patients. He looked forward to the clinic visits, mostly to engage with the staff:

*"They will ask you how you feel...they were very helpful, they helped me a lot. [The TB coordinator] was my pillar here, she was making me happy. She always smiled and she encouraged me to say that it was worth it to live. It was a pleasure to come to this clinic."*

While Peter Isaacs also experienced poverty, unemployment and housing insecurity like Mark Kriel, he received a positive, supportive response through home visits, bread at the clinic, and importantly, provider encouragement and engagement.

Precious Khomo was a private sector occupational nurse who returned to nursing seven months after retiring at 60 to 'give back' to her community. She was placed in the maternity ward of a busy public sector academic hospital, one of two nurses responsible for making the facility 'baby friendly' for accreditation by the UNICEF/WHO 'Baby Friendly Hospital Initiative'.

Here she encouraged mothers to breastfeed and trained colleagues about kangaroo mother care and respectful communication with patients. She introduced a new style of engagement which saw patients as 'customers deserving of a holistic service', rather than being instructed how to breastfeed:

*"It's a customer service because we don't just talk breastfeeding...patients come to us and say, 'Sister, I want to talk to you about something' then you talk to them...you allay their fears."*

She emphasised the value of modelling this new behaviour for nurses:

*"If I behave the right way and you keep on seeing me behave the right way towards the patients: being customer friendly, the patients talking to me, being happy greeting me, I greeting them. Then you'll also think, 'Is this not nice?' It won't be everybody changing but most of the nurses will think, 'Hey, this is good,' and they'll also change."*

Beyond the immediate benefits for patients and providers of positive staff attitudes, she felt that modelling respectful, polite and friendly behaviour was important for the next generation of nurses. She hoped that by improving the hospital's reputation and creating a pleasant working environment, such an attitude shift would help to attract private nurses to the public sector. Specifically employed to change practices, her post reflects a justice-oriented institutional response to 'unfriendly' baby and mother care. Her individual response of 'changing through doing' was based on modelling an alternative, respectful style of interaction.

## Conclusion

Many providers felt powerless to improve access for patients or make a difference. Yet, for patients, provider actions could make or break their healthcare-seeking efforts. Nurses reflected that problems at home made them harsher with patients and each other, a reminder that street-level bureaucrats are also individuals like other citizens.

A small but important response to the findings of our study was that providers agreed to be more considerate of each other in the hope that this would also rub off on how they treated patients.

There is a need to examine institutional culture and power relations between providers and patients critically, particularly with South Africa's history of patient abuse which has continued into democracy. Street-level bureaucrats are located in the middle of a 'web' of multi-dimensional relationships and institutions, and are well placed to be agents of change to support a restorative justice agenda. Conversely, without a transformative shift in institutional norms and individual practices, they are potentially agents of resistance, frustrating efforts at social reconstruction.

Restorative justice focuses on identifying and repairing 'broken relationships and communities' through dialogue, community participation and finding locally relevant 'solutions'. Reforms in the South African health system through the National Health Insurance system may invigorate spaces for community dialogue and present opportunities for bringing justice through improved access to health care. Strengthening street-level accountability and building trust for transforming patient-provider relationships is important for creating an acceptable, accountable health system, and a broader restorative justice agenda aimed at nurturing reconciliation and equality.