THE LIFE ESIDIMENI CASE

What happened?

- In **October 2015**, the MEC for Health in Gauteng, Qedani Mahlangu, announced the termination of the contract between the Department of Health and Life Esidimeni. Around 2000 people, who were receiving highly-specialised chronic psychiatric care, were to be moved out of Life Esidimeni to families, NGOs and psychiatric hospitals providing acute care.
    - Why close? The MEC claimed:
        - To save money
        - To deinstitutionalize (the policy says to do so slowly, over several years, after developing and capacitating community care)
- From **March to June 2016,** mental health care users were discharged from Life Esidimeni in large numbers, with the last discharges happening in June.
- In **September 2016**, the MEC reported to parliament that 36 former residents of Life Esidimeni had died, including Virginia Machpelah, who died along with a number of others at the same NGO.

What were the legal consequences of the move?

The way in which mental health care users were discharged from Life Esidimeni was in breach of their rights under the Constitution and the Mental Health Care Act, including the following:

- The right to health care services under section 27 of the Constitution, and the National Health Act and the Mental Health Care Act: not only were they not receiving the care that they required, but the discharge of these patients resulted in a poorer level of heath care than what they received at Life Esidimeni
- The right to dignity under section 10 of the Constitution and the Mental Health Care Act
- The right to life under section 11 of the Constitution
- The protection given to mental health care users against neglect, guaranteed by the Mental Health Care Act

JUNE 2015 – MAR 2016

- **June 2015** – SASOP sent letter to MEC and team warning about the likely consequences of terminating the contract with Life Esidimeni
- **October 2015** – MEC announced termination of contract with Life Esidimeni
- **November 2015** – SADAG, SASOP, SAFed and families engaged with Department about concerns
- **December 2015** – concerns not adequately responded to, litigation launched; Settlement Agreement reached with the Department
- **December 2015 to March 2016** – parties engaged but the Department provided insufficient information to allow for consultation. It was clear from the information provided that the Department's plan had serious flaws
- **18 February 2016** – Department press statement announces extension of contract – All mental healthcare users would be out of Life Esidimeni facilities by end June 2016
- **March 2016** – it emerged that the Department planned to move 54 people, with various diagnoses including "severe intellectual disability", "hyper sexuality" and "psychosis" to Takalani Home. SADAG, SASOP, SAFed and families litigated against the Department to prevent the move. The Department denied these patients needed mental healthcare services and the court ruled in its favour.

Did anyone try to stop the move?

Families, civil society organisations and professional associations all tried desperately to convince the Department it was placing patients in danger by moving them to places that could not give them the care they required. They were even forced to take the Department to court twice.

- **June 2015** – the South African Society of Psychiatrists (SASOP) wrote to the MEC about the risks. SASOP warned the closure was "premature" and "in contradiction" of the policy. It predicted the negative outcomes that have now occurred.
- **November 2015** – South African Depression and Anxiety Group (SADAG), SASOP, the SA Federation for Mental Health (SA Fed), and families of Life Esidimeni residents met the Department and asked it to slow down and follow the correct procedure to ensure proper care for the patients.
- **December 2015** – Litigation against the Department led to a settlement agreement in which the Department committed to a consultation and a safe process, in the best interests of the mental health care users. It undertook that nobody would be moved until there was agreement on the process and facilities.
- **March 2016** – Litigation against the Department to try to stop the transfer of 54 people to Takalani NGO. The Department argued that patients had been assessed and were no longer in need of professional care and Takalani was safe. Although they had previously agreed to consult with stakeholders, they made this decision without consultation, arguing that they had no obligation to consult. The court ruled that the Department could transfer the patients. Patients sent to Takalani, it turned out, were actually diagnosed as having "severe intellectual disability" and being entirely dependent on others for care. The Department had misled the court and allowed the transfer of patients to a facility that was not able to meet their needs.
- **Families met with the Department repeatedly** to demand safe, dignified care and marched against the Department with their demands three times. They received no substantive response.

JUNE – NOV 2016

- **June 2016** – all mental healthcare users moved out of Life Esidimeni
- **July 2016 to present** – families searched for loved ones – some had been moved without their families being told where they were going to; others moved multiple times before their families found them
- **August 2016** – Christine Nxumalo found out about the death of her sister, Virginia Machpelah, who had been moved without her knowledge to Precious Angels NGO. She discovered after a trip to the funeral home that 8 others from the same NGO had died. Christine requested an inquest into her sister's death
- **13 September 2016** – MEC announced, in response to a question in Parliament, that 36 former residents of Life Esidimeni had died since their move
- **15 September 2016** – Minister of Health requested, after a "marathon meeting" with the MEC, the Health Ombud to investigate the deaths
- **16 September 2016** – request made to the SAPS to conduct inquests into all deaths of former residents of Life Esidimeni
- **November 2016** - High Court in Port Elizabeth stops similar closure of frail care centres in the Eastern Cape and appoints a curator to look after the interests of all residents at the facilities

How could they have known it would go so wrong?

The national and provincial health departments' own policies predicted this outcome. In addition, experts and families uniformly and repeatedly warned of the consequences. Finally, the Department was told what would happen in the course of two rounds of litigation

- **National Mental Health Policy**
    - Notes "Deinstitutionalisation has progressed at a rapid rate in South Africa, without the necessary development of community-based services. This has led to a high number of homeless mentally ill, people living with mental illness in prisons and revolving door patterns of care." (page 16)
    - Warns of the dangers of further premature deinstutionalisation and the current insufficiency of community based care
- **Gauteng Mental Health Policy**
    - Plans for a gradual reduction of beds at Life Esidimeni (10% a year), leaving 1200 by 2019/20 with accompanying development of community based care
- **SASOP letter to Department of Health in June 2015**
    - Warned "unintended, costly, negative consequences" would result
    - Noted it would worsen the "revolving door of care" where people move out of facilities, through prisons and homelessness and back into facilities where they have to be restabilized
    - Warned that it would cause "greater district health costs as [users] get re-hospitalised"
    - Warned community based care facilities were too few and do not have space, equipment, staff or expertise to deal with the patients. Warned also that the psychiatric wards and hospitals were already over-capacity

JAN 2017 – 1 FEB 2017

- **6 January 2017** – Ombud sent his report to the MEC; MEC agreed to make submissions on the report by 13 January 2017
- **12 January 2017** – Ombud invited media and interested parties to a briefing on 18 January 2017 to release the report
- **13 January 2017** – MEC asked for an extension until 24 January 2017
- **24 January 2017** – MEC made submissions on the report
- **1 February 2017** – Ombud's report released

- **2015 litigation**
    - Department presented documents that showed that it knew that most people needed higher levels of care than provided in NGOs/at home
    - Applicants laid out problems with facilities identified
    - Expert psychiatrist gave evidence that Life Esidimeni had accommodated people who had already unsuccessfully been to other facilities. While deinstitutionalization is desirable for patients who can cope with it, Life Esidimeni would always be the most appropriate level of care for some people
    - Family members gave evidence of vulnerability of loved ones and the inability of families to provide the needed care

What should happen now?

- Political, civil and criminal accountability for those responsible
- Inquests into all deaths to establish causes and the appropriate steps that should follow
- Appointment of a curator for each former Life Esidimeni resident to look after their safety and interests
- Remove surviving former residents of Life Esidimeni out of dangerous NGOs and into safe, dignified facilities that cater to their needs
- Appropriate plan in place for mental health care services in Gauteng to avoid a similar incident in the future