

# THE REPORT INTO THE 'CIRCUMSTANCES SURROUNDING THE DEATHS OF MENTALLY ILL PATIENTS: GAUTENG PROVINCE'

NO GUNS: 94+ SILENT DEATHS AND STILL COUNTING

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HEALTH OMBUD: Republic of South Africa



#### **ACKNOWLEDGEMENTS**

'Listen to your patient, he/she is telling you the diagnosis' William Osler

This Report is the work of teams: The Expert Panel, the Office of Health Standards Compliance (OHSC) Inspectors and all the 73 individuals, families and relatives of the deceased, who came to give evidence during the investigations. We listened and somewhere in your voices we should have heard the 'diagnosis'.

For all the support I received from: Ms. Linda Jiyane: Executive Personal Assistant (PA) to the Ombud, who was responsible for all the logistics of the investigation; Advocate Makhwedi Makgopa-Madisa, Director: Certification and Enforcement, OHSC, who administered all the Oaths, Mr. Monnatau Tlholoe: Director of Complaints and Assessment, OHSC, who made the notes during the interviews and Mr. Bafana Msibi, the Acting CEO, OHSC.

I am equally grateful to organisations that provided documents and/or background information. These organisations included the office of MEC of Health in Gauteng Province ,the Directorate of Mental Health, the Gauteng Mental Health Review Board (GMHRB), the National Department of Health (NDoH), Life Healthcare Esidimeni (LE), some NGOs, Section 27 and the South African Human Rights Commission (SAHRC).

'There are only two sorts of doctors; those who practice with their brains, and those who practice with their tongues.' William Osler

The Report has drawn significantly from the analysis of the Expert Panel. I am also very grateful to my family for all the sacrifice and support through-out this investigation.

For all the troubles I have put you through, I am grateful to you all. Le ka moso.

#### GLOSSARY OF ABBREVIATIONS AND TERMINOLOGY USED

#### **ACRONYMS AND ABBREVIATIONS**

**AG** Auditor-General

**CCRC** Cullinan Care and Rehabilitation Centre

CEO Chief Executive Officer of the Office of Health Standards

Compliance including anyone appointed to act in that capacity

CMHS Community Mental Health Services
CTR Care, Treatment and Rehabilitation

DID Department of Infrastructure Development

ID Intellectual Disability

GDOH Gauteng Department of Health
GDMH Gauteng Directorate of Mental Health
GMMP Gauteng Mental Health Marathon Project
GMHRB Gauteng Mental Health Review Board

HAI Health Advanced InstituteLE Life Healthcare EsidimeniMAC Ministerial Advisory Committee

MEC Member of the Executive Council for Gauteng Health
MHCA Mental Health Care Act, 2002 (Act No. 17 of 2002

MHCU Mental Health Care User (used interchangeably with "patient" in the text)

MH Policy National Mental Health Policy Framework and Strategic Plan 2013 – 2020

MHRB Mental Health Review Board

MNS Mental, Neurological and Substance Use Disorders

MOA Memorandum of Agreement
MOU Memorandum of Understanding
MHRB Mental Health Review Board
NDOH National Department of Health

NGO Non-Governmental Organisation (equivalent to "residential care homes")

NHI National Health Insurance

NPO Non-Profit Organisation (interchangeable with 'NGO')

OHSC Office of Health Standards Compliance

Primary Health Care

SADAG
South African Depression and Anxiety Group
SAFMH
South African Federation for Mental Health
SAHRC
South African Human Rights Commission
The South African Society of Psychiatrists

**SLA** Service Level Agreement

**SAHRC** South African Human Rights Commission

TOR/s Terms of Reference

#### **DEFINITIONS**

(Includes definitions adapted from the MH Policy and the MOA between the GDoH and NPOs)

- Assisted Care Treatment and Rehabilitation (CTR): The provision of health care under the MHCA to people who
  lack the capacity to make an informed decision due to their mental health status or intellectual ability and who
  do not refuse the health care.
- Assisted Mental Health Care User (MHCU): A person receiving assisted CTR under the MHCA.
- Care and Rehabilitation Centres: Health care facilities established for the CTR of people with intellectual disabilities.
- Care-worker: Voluntary staff member, usually a lay person, at an NGO who provides basic health care, including
  mental health care, to the residents of that NGO.
- Community-based care: CTR that is provided outside of institutional and hospital settings, as near as possible to
  the places where people live and work. This includes CTR provided by District Health Care Facilities to people living
  in residential homes within the community.
- Community Mental Health Services: Mental health services delivered at the community level, supported by
  psychiatrists and specialist mental health professionals and incorporating the provision of residential care homes,
  day care facilities, ambulatory psychiatric care and primary mental health care.
- Day care facility: A facility, building or place which provides lay supervision, rehabilitation and /or some form of occupation to MHCUs during daytime hours. These may be staffed by care-workers and occupational therapists or occupational therapy assistants.
- Expert Panel (also referred to as "the Panel"): The investigative Expert Panel established by the Ombudsman of Health at the request of the Minister of Health for the investigation herewith reported on.
- Health Care Facility: A community health centre, clinic, hospital or any institution which provides health care in
  any form including that of treatment, nursing care, rehabilitation, palliative, preventative or other health services to
  members of the public.
- Health Establishment: means a whole or part of a public or private institution, facility, building or place, whether for
  profit or not, that is operated or designated to provide inpatient or outpatient treatment, diagnostic or therapeutic
  interventions, nursing, rehabilitative, palliative, convalescent, preventative or other health services (Section 1 NHA,
  12 of 2013).
- Involuntary CTR: The provision of health interventions under the MHCA for the period in which a person lacks the
  capacity to make an informed decision due to their mental health status and/or intellectual disability and who
  refuses the health interventions but requires such interventions for their own protection and/or the protection of
  others.

### **DEFINITIONS (CONTINUED)**

- Involuntary MHCU: A person receiving involuntary CTR under the MHCA.
- MEC for Gauteng Health (referred to as the "MEC"): The Member of the Executive Council for Gauteng in the Health Portfolio.
- **Medical Practitioner:** A person registered as such in terms of the Health Professions Act, 1974 (Act No. 56 of 1974) as amended.
- Medium to long-stay facilities: Health care facilities which provide long term care with 24-hour skilled nursing
  care for people with severe mental illness and /or neurological disorders who lack the capacity to independently
  care for themselves, such as Assisted MHCUs. Medical and specialist psychiatric care is provided on site by visiting
  doctors. These facilities include long-stay hospitals and nursing homes.
- Mental Health Care Practitioner: A psychiatrist or medical practitioner or a nurse, occupational therapist, psychologist, or social worker who has been trained to provide prescribed mental health CTR services.
- MHCA Status: The status of a MHCU according to the MHCA; i.e. as an assisted, involuntary or voluntary MHCU.
- National Health Amendment Act: The National Health Amendment Act, 2013 (Act No.12 of 2013)
- Ombud: The person appointed as Ombudsman of Health in terms of Section 81(1) of the National Health Amendment Act
- Residential care home: A home in a residential area for voluntary MHCUs who are unable to live independently
  and who require a structured, supportive home environment. These are staffed by care-workers, administrative
  personnel and a visiting or part time nurse. They include group homes and are referred to as 'NGOs' in this
  document. Ambulatory medical and psychiatric care is generally provided off-site by the nearest district clinic or
  hospital.
- **Terms of Reference:** Plans, courses of action or guiding principles intended to influence or determine decisions or actions of relevance to the objective of OHSC and the Ombudsperson
- Voluntary CTR: The provision of health interventions to an individual according to his/her health care needs who has the capacity to make an informed decision and consents to the respective health care. The MHCA is not invoked in such instances, or the MHRB is notified of the change in MHCA status via a Form 03 or 13B.
- Voluntary MHCU: A person receiving voluntary CTR.
- Voluntary Staff: Persons who are not formally employed by the NGO, but who regularly assist in the delivery of
  services to those with severe psychiatric disability resident at the NGO and who may be paid an honorarium or
  compensated in recognition of expenses incurred in providing that assistance.

### **EXECUTIVE SUMMARY**

#### 1.1. The Ombud established that:

- A total of ninety-one (94+) and not thirty-six (36) mentally ill patients (as initially and commonly reported publicly in the media) died between the 23<sup>rd</sup> March 2016 and 19<sup>th</sup> December 2016 in Gauteng Province.
- All the 27 NGOs to which patients were transferred operated under invalid licenses.
- All patients who died in these NGOs died under unlawful circumstances.
- On the date, 13<sup>th</sup> September 2016, when the MEC made the public announcement of 36 deaths, 77 patients had already died.
- Between May and September 2016, 77 MCHUs died.
- The OHSC inspectors and Ombud identified and confirmed 73 deaths, while the Ministerial Advisory Committee on Mental Health identified and confirmed 66 deaths during the course of their investigations.
- At the time of writing the Report, 94 patients had died in 16 out of 27 Non-Governmental Organisations (NGOs) and 3 hospitals.
- 75 (79.78%) patients died from 5 NGO complexes (Precious Angels 20, CCRC/Siyabadinga/Anchor 25, Mosego/Takalani 15, Tshepong 10 and Hephzibah 5).
- There were 11 NGOs with no deaths, 8 NGOs with average deaths and 8 NGOs with 'higher or excess' death.
- Only 4 MCHUs died in hospitals compared to 77 MCHUs deaths at NGOs; in absolute numbers for every 1 death at the hospitals there were 19 deaths at the NGOs but correcting for the total base population the ratio is 1:7. This ratio is very high. This finding is consistent with the interpretation that the problem was in the NGOs.
- 95.1% Deaths occurred at the NGOs from those MCHUs directly transferred from Life Healthcare Esidimeni (LE).
- 81 deaths were LE-associated while 13 deaths were not.
- The Gauteng Directorate of Mental Health (GDMH)
  could only identify 48 deaths. These differing numbers
  are symptomatic and pathognomonic of an institution
  with poor data integrity (lack of accuracy and lack
  of consistency) and the lack of reliable and quality
  information systems found during the investigation.
- 1.2. Available evidence by the Expert Panel and the Ombud showed that a 'high-level decision' to terminate the LE contract **precipitously** was taken, followed by a 'programme of action' with disastrous outcomes/

- consequences including the deaths of Assisted MCHUs. Evidence identified three key players in the project: MEC Qedani Dorothy Mahlangu, Head of Department (HoD) Dr. Tiego Ephraim Selebano and Director Dr. Makgabo Manamela. Their fingerprints are 'peppered' throughout the project.
- The decision was unwise and flawed, with inadequate planning and a 'chaotic' and 'rushed or hurried' implementation process.
- The decision to terminate the contract **precipitously** contradicted the National Mental Health Policy Framework and Strategy, the cost rationale could not be justified above the rights of the mentally ill patients to dignity and the state's constitutional obligation to accessible health care. This precipitous approach was not supported by available research experience or legislative prescripts.
- The project has brought 'pain and anguish' to many families, it has also brought national and international disrepute and embarrassment to South Africa, particularly its Health System **Annexure 1a-b** (UN Expert Report).
- 1.3. Several factors in the 'programme of action' were identified independently by Expert Panel, OHSC Inspectors, Ombud and MAC that contributed and precipitated to the accelerated deaths of mentally ill patients at NGOs. The transfer process particularly, was often described as 'chaotic or a total shamble'.
- The Gauteng Mental Health Marathon Project (GMMP), as it became known was: done in a 'hurry/ rush'; with 'chaotic' execution; in an environment with no developed, no tradition, no culture of primary mental health care community-based services framework and infrastructure.
- This 2013-2020 policy framework and strategic plan were selectively interpreted, misrepresented and contravened in this project to drive the overall universally-accepted objective of deinstitutionalisation, the core of the Mental Health Care Act, (MHCA), 2002 (Act No. 17 of 2002).
- The policy and the strategy are clear. 'Deinstitutionalisation of patients must be done systematically and with adequate provision made for community services'. Evidence in this report did not find that this was the case in this project.
- Mentally ill patients were transferred 'rapidly and in large numbers with a short timeframe' from the 'structured and non-stop caring environment' of LE into an 'unstructured, unpredictable, sub-standard caring environment' of the NGOs; this decision was

not only negligent and a violation of the rights of the mentally ill patients but also goes totally against the principle of health, i.e. the preservation of life and not the opposite.

- The transfer project occurred against widespread professional, expert and civil society stakeholders' warnings and advice; these advice and warnings have sadly come true.
- Newly-established NGOs were mysteriously and poorly selected, poorly prepared, 'not ready', their staff was not trained, not qualified and was unable to distinguish between the highly specialized non-stop professional care requirements of 'assisted' Mental Health Care User (MCHU) from LE and a business opportunity; there were often mismatches between MCHU functionality with NGO fitness for purpose.
- Patients were transferred to far away places from their homes and their communities, at times without the knowledge of the families, often bringing additional financial burden and stress on the family.
- Some patients were transferred into overcrowded facilities which are more restrictive and contrary to the policy of the deinstitutionalisation.
- Transferring mentally ill patients to unfamiliar unstructured environments and to too far away, NGOs defeated and rendered the concept and purpose of mental health community services null and void.
- Some MCHUs ended up in NGOs not originally selected, others were transported to several NGOs; these further exacerbated anxieties and added instability on the mentally ill patience.
- 1.4.The NGOs where the majority of patients died had neither the basic competence and experience, the leadership/managerial capacity nor 'fitness for purpose' and were often poorly resourced. The existent unsuitable conditions and competence in some of these NGOs precipitated and are closely linked to the observed 'higher or excess' deaths of the mentally ill patients. These NGOS were not only unsuitable to care for the high specialised non-stop needs of the 'assisted' MCHUs they received but were also not adequately prepared for the task.
- This project demonstrated clearly that basic professional care skills for community mental health care, cannot be acquired through seminars or workshops but through professional education, training and qualifications.

#### 1.5. Human Rights Violations

There is *prima facie evidence*, that certain officials and certain NGOs and some activities within the Gauteng Marathon Project violated the Constitution and contravened, the National Health Act (NHA), (Act No. 61 of 2003) and the Mental Health Care Act (MHC), (Act No. 17 of 2002). Some executions and implementation of the project have shown a total disregard of the rights of the patients and their families, including but not limited to the Right to Human dignity; Right to life; Right to freedom and security of person; Right to privacy, Right to protection from an environment that is not harmful to their health or well-being, Right to access to quality health care services, sufficient food and water and Right to an administrative action that is lawful, reasonable and procedurally fair.

Some patients were transferred directly from 'sick bays' to NGOs; others were transferred with co-morbid medical conditions that required highly specialized medical care ('bedsores and puss oozing out of sores' or medical conditions such as epilepsy and hypertension) into NGOs where such care was not available, and yet other frail, disabled and incapacitated patients were transported in inappropriate and inhumane modes of transport, some 'without wheel chairs but tied with bed sheets' to support them; some NGOs rocked up at LE in open 'bakkies' to fetch MCHUs while others chose MCHUs like an 'auction cattle market' despite pre-selection by the GDMH staff; some MCHUs were shuttled around several NGOs; during transfer and after deaths several relatives of patients were still not notified or communicated to timeously; some are still looking for relatives; these conducts were most negligent and reckless and showed a total lack of respect for human dignity, care and human life.

- 1.6.A combination of **1.2, 1.3, 1.4, 1.5** above contributed to the different pattern of deaths and to more deaths experienced in some NGOs.
- 1.7.The Premier of the Gauteng Province must, in the light of the findings in this Report, consider the suitability of MEC Qedani Dorothy Mahlangu to continue in her current role as MEC for Health.
- 1.8. The GMMP must cease to exist.

### INTRODUCTION AND BACKGROUND

- 2.1. During October to December 2016, the Ombud was requested by the National Minister of Health to investigate the 'circumstances surrounding the deaths of mentally ill patients in the Gauteng Province'. 91 Assisted MCHUs were found to have died. They all died silently!
- 2.2. In general, **0.4%** of all deaths in Gauteng or in South Africa are due to mental health diseases; this pattern is consistent over the past 5 years 'Statistics South Africa (StatsSA)'. However, people with mental illness have a higher premature mortality than the general population, dying from associated medical and surgical conditions.
- 2.3. The Gauteng Health Department (GDoH) terminated its contract formally with LE Health Care Centre on 31st March 2016 and extended the contract for 3 further months to 30th June 2016. From 1st April to 30th June 2016, an estimated 1371 chronic mentally ill patients were rapidly transferred to hospitals and NGOs in Gauteng. Between 1st April 2015 to 31st March 2016, an estimated 160 patients were transferred from LE. The rate of transfer rose sharply from transferring 13.3 patients/month during 2015 to transferring 457 patients/month during 2016 in a period of 3 months. The scale and speed of transfer were exponential and vastly different between the two transfer periods reaching a peak of 817 patients in May.
- 2.4. Since the announcement by Ms. Qedani Mahlangu, MEC for Health on 13<sup>th</sup> September 2016 in the Gauteng Provincial Legislature that 36 mentally ill patients had died, there has been 'shock', 'anguish and pain', international outrage, a major public interest and outcry that is captured in the various media outlets national and international (Media Report attached); the Ombud followed, studied and evaluated these reports.

The announcement by Ms. Qedani Mahlangu, MEC Health was in reply to a question raised by Mr. Jack Bloom, DA Shadow MEC on Health in the Gauteng Legislature.

2.5. It was following this announcement and the public interest that the Minister of Health, Dr. Aaron Motsoaledi took two actions:

(i) requested the Ombud to undertake an investigation into 'The circumstances surrounding the deaths of mentally ill patients: Gauteng Province and advise

- **on the way forward'**. He requested the investigation in terms of:
- Section 81A (1-11) of the National Health Amendment Act (NHM), Act No. 12 of 2013). 'The Ombud may, on receipt of a written or verbal complaint relating to norms and standards, or on his or her own initiative, consider, investigate and dispose of the complaint in a fair, economical and an expeditious manner'. When dealing with any complaint in terms of the Amendment Act Section 81B (2), the Ombud, including any person rendering assistance and support to the Ombud—(a) is independent and impartial; and (b) must perform his or her functions in good faith and without fear, favour, bias or prejudice.
  - (ii) The Minister's Ministerial Advisory Committee on Mental Health, chaired by Prof. Solomon Rataemane was dispatched even before the Ombud was appointed to urgently visit and assess conditions in NGOs to intervene where necessary and make the necessary recommendations to save life and prevent more deaths or further loss of life. The impact of this intervention was positive and is highly valued as one NGO with 18 deaths was immediately closed and all MCHUs transferred to hospitals. This approach became replicated throughout the investigation leading to the closure of 4 additional NGOs whenever it became necessary and where further loss of life needed to be saved. These were Bophelong Suurman, Anchor, Bokang and Siyabathanda.

On 20th October 2016, the Ombud wrote on the need for urgent intervention at CCRC/Anchor Complex: 'relatives of patients are complaining about the poor quality of care of loved ones in terms of nutrition and medication. Some patients are simply wasting away and some are reported to be staring death in the eye in front of relatives'. Anchor was closed.

- 2.6. South Africa is a state party to the United Nations Convention on the Rights of Persons with Disabilities, having ratified the Convention and its Optional Protocol in 2007. As such, South Africa is required to fulfil its commitments of implementation and reporting under the Convention 11, 12.
- \*The Report is the culmination of the Ombud's investigation and interrogations as well consideration of the Ministerial Advisory Committee on Mental Health Report.



### **METHODOLOGY & APPROACH**

Following the request from the Health Minister, Dr. Aaron Motsoaledi to investigate 'the circumstances underlying or contributing to the of deaths of mentally ill patients in Gauteng Province', the following approach was adopted:

 A Request for clinical records and any relevant information/documents of the 36 deceased patients was made to the MEC for Health (Honourable Qedani Dorothy Mahlangu), HoD Dr. Tiego Ephraim Selebano; Director of Mental Health Directorate, Dr. Makgabo Manamela and the Health Services Operations Executive at Life Esidimeni (Dr. Nilesh Patel); this request was fully complied with;

Established an Expert Panel of 8 independent clinical mental and public health experts to examine and analyse the clinical records, investigate and report, the list is provided below:

Table 1. Composition of the Expert Panel

	NAME	DESIGNATION
1.	Bodemer, Wilhelm (Prof)	Psychiatrist*
2.	Janse van Rensberg, Bernard (Prof)	Psychiatrist
3.	Mkize, Dan (Prof)	Psychiatrist
4.	Nkonzo-Mtembu, Lulama (Dr)	Mental Health Clinical Nurse Specialist. PhD. RN. (Chairperson)
5.	Rangaka, Thabo (Dr)	Psychiatrist
6.	Robertson, Lesley (Dr)	Psychiatrist (Deputy Chairperson)
7.	Shasha, Welile (Prof)	Public Health Consultant
8.	Seape, Sebolelo (Dr)	Psychiatrist

- \* Resigned from the Expert Panel during the investigatory process due to personal reason
- Established a team of two OHSC Inspectors –
  Mr. Tebogo Dioka and Ms. Deborah Lamola to
  conduct onsite visits, inspections and interviews at the
  26 NGOs to establish the facts of the circumstance/
  conditions at the NGOs and the number of deaths
  and report;
- The Expert Panel and the OHSC Inspectors focused on the 'patient'. The patient was the objective, either through clinical records, analysis or the conditions/circumstances to which patients were subjected;
- Considered the Ministerial Advisory Committee on Mental Health (MAC) Report p.1-17;
- Studied and Reviewed Reports of Selected Media Coverage articles Annexures 2a-c, Radio (702 and Power FM) and Television programmes (eNCA Checkpoint);
- Received and studied Documents and Case Presentations with Affidavits from Section 27 Documents and the clients they represented; LE mangers and psychiatrists and the Producer of Checkpoint. These were studied and some used for the interrogations.

- The South African Human Rights Commission (SAHRC) referred a Complaint which the Ombud was already investigating about Precious Angels Home, which forms part of its investigation;
- Requested Discharge Summaries and/or transfer documents from the Gauteng Mental Health Review Board (GMHRB);
- Requested StatsSA to assist with 'Death Analysis';
- Listened and Conducted Interrogations/Interviews under Oath or Affirmation with persons from various stakeholders. The Oath was administered by Advocate Makhwedi Makgopa-Madisa and the notes were taken by Mr. Monnatau Tholoe. The Ombud interrogated 73 individuals under Oath or Affirmation as prescribed in Section 81 of the National Health Amendment Act 2013;
- Other Relevant Documents included:
   The Constitution; the National Health Act No. 61 of 2003; the National Health Amendment Act No. 12 of 2013; the Mental Health Care Act No. 17 of 2002; the National Mental Health Policy Framework and Strategic Plan 2013-2020 (MH Policy) and the National Core Standards for Health Establishments 2011.

NB\*: During the course of the investigation, the Ombud received full cooperation from the MEC but poor cooperation from the GDoMH. The Ombud also received letters from lawyers instructed by the very GDoH questioning the investigation, its process and the Ombud's mandate. The MEC distanced herself from these. This was strange to say the least.

## 4 FINDINGS

#### 4.1. Ombud Interrogations/Interviews

The list of those interviewed is attached as Annexure 3:

Below is a translated article brought by Mrs. Colitz to the Ombud. Its translated from Die Beeld newspaper, 20<sup>th</sup> September 2016, and aptly summarises the issues and conditions mentally ill patients were subjected to NGOs and what the Ombud heard recurrently on 7<sup>th</sup> November 2016 from relatives and their representatives.

## 4.1.1. 'Ill-Treatment Suspected MAN'S DEATH A WORRY "He shouldn't have died like that" Reneilwe Dhludhlu

Two hours before Freddie Collitz (61) passed away in the care of the Mosego Home in Krugersdorp, an old age home for psychiatric patients; he apparently had a wound to the head, blisters around the ankles and a sore on his nose.

He was a depression sufferer that the GDoH moved from the Randfontein LE Institution to the Krugersdorp NGO.

Marie Collitz (58) from Meyerton said she will never make peace with how her husband passed away.

"He should not have died that way, not the man I shared my life with"

Marie said she saw her husband on 07 August 2016, at least two hours before he was declared dead.

When the family asked the care givers about his injuries, they said he fell on the lawn.

She believes he was ill-treated.

"He didn't want to eat his doughnut and desert and they told me he ate bread and oats. If he could not eat his desert, how could he eat that?

She said the care givers only gave him one type of pill. When she asked them about it, they said they know nothing about other pills.

Freddie's death certificate indicated that he passed away at 17:00 from **natural causes**.

"They also did **not inform me immediately when he passed away,**" said Marie.

"That evening I phoned at about 17:30 and all they told me, is that **he is asleep**".

When their oldest son, Freddie jnr., phoned the next day, he was asked if **he didn't know that his father passed away**.

Marie said she could visit her husband only once a month, because she works two Sundays in a month.

She said he lost a lot of weight and believe he was dehydrated.

A post-mortem was not done.

According to Marie they were never allowed into the Mosego house.

"They could only visit him on the veranda"

One day Riaan (30) the youngest son, insisted to take his father inside.

"There were no sheets, pillows or blankets on their beds" Rigan said.

They were never allowed to bring Freddie clothes Walter Skosana, manager of the home said family members were allowed to bring clothes for the patients.

"Every time he had big clothes on and his pants were always tied with shoe-laces", said Riaan.

Marie said **the NGO lied to them** and said Freddie was a while before his death in the hospital, "however they could never proof it".

"If she (Qedani Mahlangu, Gauteng MEC for Health) could not care for our people, then she should have said so. We would have cared for them ourselves".

Skosana did not want to talk about Freddie's passing away and said it is confidential information.

Jgs/Complainant Ms. M Collitz'.

#### 4.1.2. The Voices of 12 Relatives of the Deceased

- Two members in this grouping were family representatives.
- All relatives were informed and knew that LE was 'closing down'; they attended several meetings to raise their concerns.
- The 'LE closure' came as a 'shock and upset' to many relatives
- The 'short notice' and 'rush' were problematic.
- While the MEC was unambiguous and forthright about the 'cost cutting' reason for the closure, she was not so forthright about the quality of care the NGOs would provide to the patients. The message was 'mixed'. The quality of care was the relatives' major concern.
- The process of LE closure and transfers unfolded in a 'chaotic manner and with little information provided to relatives', some relatives were not informed at all, others were informed at short notice; others did not know where their relatives were transferred to or that they had died; for some it took 2-3 weeks to be informed of deaths despite 2 or 3 contact details being available in the files; dates of transfer would suddenly change, some were moved 3 or 4 times between LE and NGOs and between NGOs themselves; others would be moved further away from homes and communities.
- Lack of explanation or provision of proper answers about the deaths made closure difficult; some

NGOs seem to 'hide information or not willing to share information for fear of 'someone above'; the notion of 'Natural Death' on certificates was very confusing to many relatives; it needed explanation.

- The NGOs that must close immediately (Anchor, Rebafenyi, Mosego, Takalani, Thuli, Bophelong (Suurman), Precious Angels), as their continuity poses high risks; 3 of these 7 have been closed.
- The NGOs managers told relatives they 'were not ready' to accommodate or receive patients, but were 'prevailed upon' by some members of the GDMH i.e. Dr. Manamela and some of her team.
- All relatives were satisfied and happy with the care at LE compared to some of the NGOs.
- The NGOs were not 'fit for purpose' as some were still undergoing major renovations and others did not have staff, but patients were already placed there (e.g. Bophelong Suurman, Ubuhle Benkosi and Shammah).
- Some relatives were unexpectedly offered 'food parcels' by the Director of Mental Health, Dr. Manamela 'possibly to quieten them down' (Mr. Sibiya's relatives).
- Some NGOs were 'like concentration camps', overcrowded with in-kept and hungry patients, several relatives reported severe weight loss captured on photos (Reverend Maboe about Bophelong Suurman and Ms. Colitz on Mosego).
- Most relatives seek justice first and the truth about 'what really happened'.
- They all said the 'MEC is to blame and must account' as she 'would not listen' and 'ignored our repeated pleas'.
- She 'must pay for deaths'.
- She was negligent; put relatives to 'insecure, unsafe, filthy, poorly staffed and uncaring places with no food or clothes'.
- There was 'no food and clothes'; some complained of 'rotten bread, meal of cabbage and porridge and only one meal a day' e.g. Mosego.
- Mistreated and disrespected, felt 'the State had abandoned us'.
- Malnutrition and poor care were recurring themes.
- Patients who had files were smaller than what LE had, some had no IDs or medical records.
- Patients treatment was not supplied; left dirty and poorly groomed.
- Some corpses had unexplained bruises on their bodies.
- General poor information flow and notifications about the relatives' whereabouts and deaths.

### 4.1.3. The Voices of 2 Family Representatives who visited NGOs

- The MEC had requested that Mr. Andrew Pietersen, a family representative be asked to testify.
- They could not identify the number of families they represented but were chosen in a regular meeting.
- Set up a 'WhatsApp' chat group to update the families.
- Visited the following NGOs: (CCRC, Anani, Shammah, Anchor, Takalani, Mosego and Tshepong).
- Were promised a list of 50 NGOs but this list never came, despite repeated requests.
- They found the NGOs were 'not ready'; Committee representatives requested a feedback/progress report of when the NGOs would be fully ready for further verification and inspection.
- The feedback report was never provided by the Director, Dr. Manamela.
- At the time of their visits some NGOs were already 'licensed and hosting MCHUs' despite 'not being ready', Examples were Anani, Shammah, Mosego, Anchor and Takalani.
- Most NGOs did not 'provide good security', some had several issues to fix like Mosego; Mosego had space limitations and the fencing did not provide adequate security, so was Anani.
- The GDoH ran the transfers 'without dignity', 'it was hurried'.
- There was no physical manpower to assist the move as MCHUs needed assistance to get into transport.
- Some family members did not know where their relatives were and some still do not know to this day.
- As family representatives, they received no support from the GDMH and were promised financial reimbursements by Dr. Manamela that never materialised to this day.
- 'The project deadline was unrealistic' and 'hurried' there seemed to be an attitude that the 'mentally ill patients do not matter'; they were 'shocked' by this attitude.
- Families did not know how NGOs were selected; they
  were never provided with the criteria or document
  for NGO selection.
- NGO preparation was unrealistic and not properly resourced.
- Andrew's (one of the family's representative) uncle went for 2 weeks without medication and was wasted.
- Many family relatives were complaining about 'poor medication programmes, food, malnourished relatives'.

- Several NGOs were **not funded** in time to become sustainable; this was part of the chaos.
- Many patients were still at risk at some of these NGOs;
   they must be rescued.
- They felt being 'used as rubber stamps' for a process that was chaotic.
- Suggested a curator be appointed to assist each family.
- The Gauteng Provincial Government must take full responsibility. All those responsible must be held to account and families must be compensated.
- There should be a memorial stone with the names of the deceased and an educational programme about de-institutionalisation.

The 14 NGOs (Precious Angels, Shammah, Kanana, Lapeng, Takalani, Mosego, Rebafenyi House 1 & 2, Ubuhle Benkosi, Hephzibah, Bophelong Suurman, Bophelong Mamelodi, Anchor, Tshepong, Tumelo House 2):

#### **Planning Process**

- The NGOs were informed in a meeting about the intention to place users from LE in the community and were requested to submit proposals;
- Pre-placements audits were done and licenses applied for; some operated without licenses until later. In particular, Mosego has not to date received the license for the 200 approved users. According to Weskoppies CEO criteria for licensing was not clear nor forthcoming;
- Inadequate preparations of the NGOs were done prior placement of users; words such as "hash-hash" and "rush" were used by some NGO directors;
- Most NGOs were without professional experience of managing MHCUs;
- No "piloting" of the NGO placement especially for new NGOs.

#### **Placement Process**

- Users were not placed as initially agreed; numbers were increased in some instances and males instead of women received;
- NGOs such as Precious Angel, Takalani and Mosego had the opportunity to be involved in identifying users needing placement in their respective NGOs and most did not:
- Patients were received in an ungroomed state;
   smelly, without proper clothing (torn); either with no shoes or one shoe and "skinny";
- The GDoH started making additional requirements of infrastructure improvement;
- No gradual reduction from LE;
- Some NGOs were thrown in the deep end as they

have never initially been licensed to care, treat and rehabilitate MHCA users, e.g. Precious Angel only had experience to care for children with severe and profound intellectual diseases, Ubuhle Benkosi intended to care for orphaned children, Rebafenyi dealt with women empowerment, Shammah housed poor and homeless people, etc.

#### **Staffing**

- Some of the NGOs did not have qualified nor adequate staff, operated only with care givers without professional nurses;
- Most could not increase capacity due to lack of funds or due to late payment of subsidies.

#### **Support**

- Inadequate support, the GDoH especially that some were inexperienced in managing MHCUs;
- ill MCHUs would be sent to health establishments;
   waited long before being assisted and delays of EMS;
- Subsidies paid 3 months later leading to NGOs incurring debts to ensure users are clothed, accommodated and fed;
- Prescription refills in Tshwane District is based on 14day cycle which was not communicated with NGOs; implication of relapse;
- Families not visiting patients.

#### **Patient files**

 Only patient profiles and treatment charts were received from LE; impact on continuity?

#### **Routine** care

- Most NGOs provided fundamental care; bathing, feeding, etc;
- 5 of the 14 provided other special services; daily vital signs and/or clinical assessment;
- Patient relapses possibly due to staffing skills, medicine administration and placement of huge numbers of patients;
- Ubuhle Benkosi directors used this phrase "It is like running a hospital or clinic" to provide his narration of the state of health of the users.

#### **Death of patients**

 Some patients died because they were not well when received; some had signs of respiratory conditions, e.g. breathing abnormally, coughing and turning

- blue, chronic conditions such as TB, Hypertension, CCF, carcinoma, jaundice, etc.;
- Death in NGOs occurred while users were asleep or after falls and others in health establishments after referral.

### 4.1.4. The CEO and Psychiatrist Weskoppies, Acting CEO and CEO Cullinan Rehabilitation Centre

- De-institutionalisation plan was never received but only a narrative;
- Too many new NGOs;
- Large number of patients without testing (piloting);
- Tshwane received high numbers >900 MCHUs;
- Criteria for licensing was not coming forth;
- NGOs not paid subsidy in time;
- Relapse related to high placement of users without considering staffing levels and medicine administration;
- Users received without files/records and medication with poor hygiene and nutritional status from LE;
- Some users received where outside their package of care, e.g. blind, violent;
- Academia opinion.

#### Timelines of great concern

#### Short time frame

- Readiness of the system to absorb the users;
- Patients taken by "truck loads" (inhumane);
- To date no formal discussion of the deaths to stakeholders.

#### 4.1.5. The Voices of LE Staff

- All LE psychiatrists provided signed affidavits;
- All 5 professional psychiatrist interrogated were not comfortable with the decision to 'rapidly close and transfer MCHUs to NGOs but 'had no choice'; all were promised MCHUs would 'be provided better facilities than LE'; this was also confirmed in Court papers; the decision to close was 'not negotiable' the GDoH made this clear;
- They were concerned about: MCHUs' co-morbid conditions, MCHUs' relapse; Not adjusting well; staff skills at the NGOs; conditions at NGOs;
- Some were part of the selection, assessment and matching process team;
- 'Very frail and sick MCHUs' were transferred to hospitals and some of those to NGOs who were assessed as 'frail but stable'; they 'did not transfer or discharge any dying MCHUs to NGOs', they were resolute on this; while some MCHUs were 'frail', there were nevertheless 'stable', consistent with the Expert Panel findings, Table 2 in the annexures;

- Not sure about the conditions at the NGOs and the quality of staffing;
- Breach of patient's autonomy; LE had installed heaters as way back as 2007 and MCHUs were given vaccinations. Would these basic services be available at NGOs?:
- LE had built a relationship with MCHUs and families over a long period;
- Most families were 'happy' with their relatives at LE; this was confirmed by all relatives interviewed;
- Some MCHUs started to relapse at the end of 2015 long before the closure;
- Staff became anxious and demotivated towards end of 2015;
- MCHUs were promised transfers to local NGOs, this did not take place; this was a big disappointment;
- Dignity of MCHUs not respected, NGOs without trained and professional staff;
- Transfer 'too fast over a short period';
- NGOs not ready to 'absorb such large numbers';
- Community Centres/district clinics not ready;
- Notice of closure and 6 months' notice came as a 'shock';
- Transfer period was 'too short; created stress amongst staff', LE offered to assess NGOs but this was turned down, LE offered the facility be bought and taken over by GDoH, this was also turned down;
- LE staff wondered about the readiness of NGOs but had no way of knowing;
- One psychiatrist described the project as 'madness' and that it cannot be 'done';
- Out of conscience she resigned;
- All the others who did not resign 'trusted the MEC words contained in court submissions that MCHUs would be provided better places' despite their reservations; this is contained in their affidavits; they tried their 'best under trying circumstances and against their consciences and better judgements; they had "No choice'.
- The MEC was 'simply taking her patients away and not closing LE'.
- The project needed at least 5 years with proper planning and NGOs provided with psychiatrists and nursing staff;
- Concerned about patient relapse; 'deaths were unbearable but uncalled for';
- The transfer was 'too fast and rushed', LE was dedicated, knew the patients, had built a 'relationship' with patients and relatives and most were 'happy'.
- MEC said 'she was taking her patients' and 'would provide better places than LE';
- The speed and suddenness were problematic and stressful because of the large numbers with less staff;
- There was general lack of information provided to families; the public facilities i.e. hospitals and PHC were not ready;

- Dr. Manamela promised that 'care would not be compromised and MCHUs would be moved to facilities that provided similar care as LE; LE staff begun to observe MCHUs relapses;
- The transfer process was 'chaotic', no project plan was forthcoming from Dr. Manamela; LE would be requested by the GDoH to prepare e.g. 10 low functioning MCHUs, a clinical assessment would take place followed by proper documentation, then the following day, the goal post would suddenly change to e.g. now we need 20 high functioning MCHUs;
- The executive did not believe in the project and somehow knew it would collapse;
- When deaths occurred some said 'I told you so'
- Community-based clinics and PHC must be properly resourced and made ready for de-institutionalisation, currently these are not ready.

#### 4.1.6. The Voices of NDoH Senior Staff:

(This must be read in conjunction with Ms Matsoso's statement on page 12)

- They are Advocates for the de-institutionalisation of users into community facilities;
- Prof. M Freeman provided a document on his reflections on the Project and his email struggles with Dr. Manamela (attached as Annexure 4a & 4b);
- Had Concerns on the GDoH Project:
  - Haste approach
  - No one believed in it and were concerned with the 'approach';
  - Money to follow the user principle was not followed;
  - Proper facilities; NGOs without capacity allowed to take care of vulnerable users;
  - Move rationalised for cost saving instead of human rights:
    - Further abuse of users;
    - Increased mortality;
    - Increased re-admission;
  - The NDoH was not asked for advise nor technical support or guidance;
  - The DG was accidentally alerted to the matter by Section 27
  - Prof. Freeman prepared a memo to brief the National Minister. The memo was without the Project Plan as Dr. Manamela had not yet provided it. The Minister noted the memo and requested that Prof Freeman 'come and explain to me'. This formal briefing never took place as events overtook the matter.
  - No project plan received despite several; email requests to the Director of Mental Health Dr. Manamela;
  - The Director Mental Health Services **signing the licenses**;
  - Licensing failures; management capacity, infrastructure;
  - The MHCUs were pushed behind; not a priority call:
  - Most HEs are not complaint to infrastructure; norms and standards to meet the needs of MCHUs.

#### The Voice of the Districts:

- Brought in very late into the project;
- Project was 'hurried' which impacted on:
  - Categorisation of patients; inappropriate; placement of users;
  - Budget requirements;
  - Appropriate accreditation/licensing of NGOs;
  - Involvement of MHRB;
  - Evidence-based decision;
  - Closure of LE lead to patients requiring high level care placed at NGOs;
  - Mismatch between the required level of care and the NGO capacity.
- Placement process came with gaps:
  - NGOs not well prepared;
  - Missing documentation; IDs, discharge summaries not comprehensive, some without treatment;
  - Placement of high volumes in inexperienced NGOs.
- Cost per user in NGOs is more than what GDOH is giving;
- NGO capacity, dedication and knowledge (professional and finances):
  - Care givers not trained to manage MHCUs;
  - Consistency of staff;
  - Overcrowding;
  - Resources;
- Many patients had to be redirected to hospitals;
- Licensing process was flawed;
- Deaths:
  - Either patients had physical illnesses;
  - Lack of clinical skills at NGOs.

## 4.1.7. The Voice of GDoH Mental Health Directorate Team:

- Project 'hurried' and against the policy framework of gradual downscaling:
  - Time was prioritised over the safety of users;
    - Haste process with large numbers of users;
    - Time frame was too short and impossible to do such a project;
- Voices of reason and advice not listened to, as such followed instructions blindly;
  - "difficult for us as "implementers", "it was tough" and 'very stressful' (culture and climate of fear);
  - no one believed or bought into this 'rushed approach', this view matches the views of managers at LE;
- District health services not capacitated to manage the users:
  - New NGOs;

- Overcrowding;
- Deaths:
  - Existing Medical problems, social circumstances, NGO appropriateness, adaptation in new environments, stress, NGO capacity and competence;
  - 'patients that died at Precious Angels contributory factors to their deaths could be hunger and cold. The rooms were very cold and there was no food to feed them due to the delay that the Department took 3 months to pay them. So they were struggling to buy food also Tshepong the same with food and Dr. Manamela was informed about this'.
- · Licensing errors acknowledged;
- Changing (swopping) pre-selected MCHUs to different NGOs by the Director of GDMH.

#### 4.1.8. The Voice of SADAG

- The GDoH was not engaging in good faith:
  - Humored stakeholders but went ahead with plan;
  - Reports, especially figures were changing;
  - Variation in information.
- Whole project poorly planned;
- Were never given the plan despite request;
- Assistance, support and advise offered not taken.
- The move had many challenges:
  - Users could not be traced by families;
  - The GDoH helpline not helpful;
  - Receiving many reports of unsatisfactory; conditions in NGOs;
    - Food, clothing, payments of NGOs, NGO conditions, state of patients (wasted).
- Deaths:
  - Newly registered NGOs;
  - Received patients before registration- e.g.
     Bophelong (Suurman); Siyabathanda Care
     Centre, Precious Angels, Takalani and
     Anchor. Some were still awaiting licenses, others
     were registered for Children and not for Adults;
  - Delayed payments to NGOs;
  - NGOs not ready and appropriate for users;
  - Physical security;
  - Staffing levels;
  - Availability of food.

#### 4.1.9. The Voice of SA Federation for Mental Health-Ms. Bharti Patel

- 'Rights of all individual' including MCHU was in the MHCA 2002 and the NDoH Strategy 2013-2020;
- 'There was lack of understanding by duty bearers of de-institutionalisation';
- 'Too much rush':
- 'Lack of information to families to assist decisionmaking';

- 'Provided figures did not make sense';
- 'Important to treat people with care and dignity';
- 'Important to acknowledge the deaths';
- · 'Accept that what happened was wrong';
- Re-look at the system and turn to best practices;
- Some NGOs could not manage because of 'lack of subsidy';
- It was important to 'identify NGOs that needed training'; look at 'staff ratios'; 'patient's needs' and 'prepare the patients';
- Important to upscale 'community services', 'clinics and improve psychosocial rehabilitation';
- 'Stigma and discrimination' still problem.

#### 4.1.10. The Voice of SAHRC

- Lack of information available to parties involved;
- Visit to Precious Angel; found it abandoned;
- Inquest case for 13 deaths;
- Possible human rights violations include:
  - Right to life, access to healthcare, right to dignity, right to freedom and security of the person, access to information and proper consultation;
  - Cruel and inhumane care; allegations that users died of hunger and dehydration - right to sufficient food and water;
- Received a complaint and is currently investigating.

#### 4.1.11. The Voice of Section 27

- Settlement agreement that users will move once a proper plan is developed but the plan never emerged;
- Decision taken contrary to National Policy Framework;
- Costing decision is illogical; LE R10 000 vs R16 000 acute care in GDoH facilities;
- NGOs forced to take users when they were not ready:
  - Insufficient food;
  - Security;
  - Inadequate care.
- Criteria for NGO assessments not provided;
- Will provide formal submission of the violations of the relevant laws:
  - Constitutional breaches \$10, \$11, \$27, \$32, & \$195;
  - Common law duty of care;
  - MHCA obligations by the MEC and HOD not met.
- Deaths:
  - Horrified that warnings were not heeded.
- Remedial actions suggested:
  - Keep well capacitated and sustainable NGOs and upscale them;
  - Close all NGOs without capacity;
  - Develop adequate community infrastructure;
  - Accountability of office bearers;
- Individual liability negligence.

#### 4.1.12. The Voice of Director Mental Health Services

- Could not confidently give the final death total but finally settled for 48;
- Indicated the marathon project has resulted in loss of work, business and South African Social Security Agency (SASSA) benefits for the families but had to be done;
- Understood the risks raised by specialists and tried to develop a mitigation strategy;
- Admitted to 'no letter of delegation that authorizes her to sign licenses';
- Queried this practice once but did not get an answer save that her predecessor signed licenses.
- Placement:
  - Two clinical teams assessed the users at LE;
  - CCRC full, she sent pre-selected MCHUs to Precious Angels because of "experience and expertise", we know there was no such expertise at Precious Angels that could be better than CCRC;
  - Community services for Intellectual Disabilities not well established/developed.
- Licensing:
  - License of Precious Angel was for amendment in the next year;
  - All licenses were with the District Coordinators;
  - She places flaws in the licensing process on districts.
  - Admits that she is the signatory to all licenses and has no written delegation.
  - 5 NGOs were closed and patients moved back into hospitals.
- NGO Capacity:
  - Realises that the NGOs need support;
  - NGOs adopted for support.
- Deaths:
  - Asserts users did not die from the placement processes;
  - Requested the MHRB to investigate;
  - Relates the deaths to winter due to vulnerability of the users:
  - Tests for therapeutic levels not done at LE.
- Responsibility evaded to respond to the question.

#### 4.1.13. The Voice of the HoD

- Not sure of the total deaths but thinks it is slightly above 36 and later slightly above 40;
- NGOs:
- Differ in capacity; new ones struggling;
- Placement:
  - Admits to error in increasing numbers; "pressure was too high for staff";
  - Haste of the project;
  - Approach to buy LE was halted though funds were available;

This is consistent with the voice from LE staff:

- The HoD requested that Mr. Mosenogi, the former Project Manager be requested to testify.
- Deaths:
  - Does not correlate the deaths to poor planning;
  - Gaps in "fit for purpose" assessment;
  - Unfair to Precious Angel because of the type of patients placed there;
  - Reshuffling of patients between NGOs was very gross and inhumane.
- Licensina:
  - Confirms there is no written delegation for Dr.
     Manamela and insists the license is a certificate not a license;
  - The practice was inherited from the GDoH and Social Development and was never regularised;
  - Pressure of the project led to staff to cutting corners and making errors during implementation.
- Responsibility:
  - Accepts to take accountability even though was isolated from the process but junior staff given direct instructions;
  - "I will take the sword for my staff as a matter of principle";
  - "Administrators must be allowed to do their jobs".

#### 4.1.14. The Voice of the Project Manager

- Mr. Mosenogi provided documentary proof of his statement (attached as Annexure 5);
- He had managed the Selby Park transfer Project successfully;
- He was appointed by the MEC in a meeting to project manage the Mental Health Project;
- He established a Project Team;
- He visited the sites Waverley, Randfontein and Baneng;
- He had a meeting with parents and relatives at Waverly: this meeting was volatile;
- He had another meeting with relatives at Randfontein with the HoD: this was even more volatile, this meeting affected both profoundly;
- Both he and the HoD came to the conclusion that to close LE and transfer MCHUs rapidly 'was not the correct decision';
- They both came with the ideas of trying 'to procure one site at LE and phasing in the transfer project over a year. He concluded that three months would not be enough to undertake the project;
- He discovered that 'Data on 2000 beds was a projected figure and not actual beds';
- A cost analysis exercise was conducted but no due diligence study was undertaken;
- He felt the MEC was 'misled';
- He and the HoD worked with Section 27, South African Depression and Anxiety Group (SADAG) and the South African Society of Psychiatrist (SASOP) to build trust and

- suspend the 'court action' but trust levels became low again as it became obvious that the closure and transfers were going ahead;
- He communicated his concerns to the MEC via emails which were provided as evidence; these were clear, well considered and consulted upon;
- He was asked whether he was the spokesperson for LE
- He was very much concerned about the potential of Baneng closure;
- Baneng needed protection from closure as this hosted the 'most vulnerable children';
- This was secured but as far as he was aware there was 'no signed Baneng contract yet';
- The situation and environment became difficult to work in as 'panic struck' and 'reality dawned'.

#### 4.1.15. The Voice of the Chair of MHRB

- The Board in said to be independent but when the Ombud requested for information it was copied the Director Mental Health as per her instruction;
- Joined the Board January 2016 and received a convincing presentation from Dr. Manamela;
- She states that 'LE was also not providing quality care'.
- Never provided with or saw a project plan;
- She was later nominated to be in the family representative team; families were very unhappy with the decision;
- As far as she knows family representatives visited the NGOs with the GDoH team;
- Admitted that the process was done 'in a disorderly manner';
- Mental Health Review Board's involvement was minimal:
- Concerns raised with Director MHC services were not addressed:
- Investigated a complaint about Bophelong Suurman
- The MHRB was assigned to audit the deaths at Siyabadinga. The conditions 'were found appalling'. Deaths:
  - Winter/change in environment/ quality of care/ NGO managers not skilled/capacity of caregivers/medication administration/ poor diet;
- Responsibility; she accepted responsibility.

## The Voice of Ms. MP Matsoso, DG in the NDoH 25<sup>th</sup> November 2016

- The purpose, a brief overview and an update on the complaint was given.
- The DG was given the opportunity to give an affirmation that he will tell the truth to the Ombud.
- The evidence presented by the DG is as follows:
  - She came to know about the project when Section 27 threatened to take the Minister to court. She then called Section 27 to establish the basis and sway them otherwise.

- She made contact with the GDoH HoD to ascertain the facts that they intend to discharge patients.
   She wanted to schedule a meeting and the HoD was very responsive.
- She requested that Prof Freeman should be available in that meeting but the GDoH never invited him to the meeting.
- She requested that the HoD should give her regular updates, as well as Section 27 (copied the DG in all their correspondence with the GDoH).
- She then requested Prof Freeman to prepare a submission for the Minister, Dr. Aaron Motsoaledi. The submission also detailed that the manner in which this project was carried out may have contravened the MHCA.
- Through exchange of Short Messaging Services (SMSs), she received a response from the HoD that they are ready with a plan and don't want this to be a court order. Subsequently the DG called Section 27 to inform them that a plan is ready. She persuaded them against the court order, which in hindsight she regrets (this she repeated throughout her interview) doing because the HoD convincingly we can't have a court force them to agree to do something that they have an understanding on.
- The DG received a draft plan without LE' signature but only the GDoH and Civil Society.
- In March 2016, the DG was shocked by the headline that the GDoH wins a court case against Civil Society. DG called the HoD to establish what this was all about but was promised to be informed. She understood that the plan was never detailed.
- Disturbing fact was that Prof Freeman was never invited to any of the meetings and not given information. She relied more on Civil Society for reports as the GDoH was not forthcoming.
- She stated that signing of licences; the law (MHCA) is specific on how issuing of licences. She further indicated that this is the HoD's competency unless he delegates (provisions of the law). As for the Director Mental Health signing licences that is a huge responsibility with serious consequences.
- She presented a copy of the Norms Manual Severe Psychiatric Conditions to the Ombud as part of her evidence.
- The principle of deinstitutionalisation needs preparation of facilities
- On the issue of concurrent competence, she argued that in her view it never happens. How the NHA was written outstripped most of the powers from the Minister. Her view is that the Intergovernmental Relations Act because of its fiscal provisions it weakens the concurrence. It reinforces provincial powers in rendering services. She asserted that conditional grants give NDoH an ability to exert influence on provinces.

- LE used to be a national contract and was handed over to the province.
- She gave suggestions that:
  - The powers of different spheres of government; needs review and realignment;
  - Centralisation of certain functions and powers of the MHCA to the Minister;
  - Health should be run by qualified health officers;
  - Need for chief medical officer in the NDoH.
- Even if these facilities are closed there will be overcrowding;
- Level of readiness of the NGOs was not taken into consideration;
- Deaths cannot be really dissociated with the move; the key question is whether the deaths were preventable. You don't take **very sick patients** and put them in a facility where they **do not have care**. At least LE did have access to reasonable services with professional people. She cannot say that for those other facilities that are unlicensed that they could provide this care;
- The person who issued licences should have known (about the Norms Manual for Severe Psychiatric conditions);
- The DG's concern stemmed from the HoD's progress report in June that "most families are not in favour of the decision hence regardless of being part in meetings and facility visits they continue to report their dissatisfaction to politicians and other stakeholders...renovated 295 hospital beds and followed with 400 beds; 931 beds were available". Clearly this was not done;
- She gave her suspicion that the HoD was later excluded from the project (this corroborates the HoD's submission);
- She is convinced that if there was a court order, the outcome would be different;
- She asserts that the users were failed; need for recourse and closure for the families.

## The Voice of Dr. Selebano, GDoH Interview Date: 23rd November 2016

- The purpose and a brief overview was given about the investigation.
- The HoD was given the opportunity to give an affirmation that he will tell the truth to the Ombud.
- Asked of the number of patient that died to date he indicated he cannot give the correct figure but thinks slightly it may be above 36. In the process the 36 occurred at a particular period of time. He also said he does not want to guess but could be anything above 40. He insisted that the Mental Health Directorate has the data and can give an up-to-date number as to how many of this and how many of that. He justified this as the difficulty that comes

- due to the fixed number over a specific period of May to September. People became fixated on the number. He stated that it unfortunately became a number game whether 36 patients have died in the facilities within that period of time. He asserted that ordinarily with the practice of medicine you would have mortality around that. The tragedy was that that mortality now was more like if its anybody else its fine and it should not be LE patients. Which is an anomaly because ordinarily chronic psychiatric patients have a high mortality than ordinary patients. The reason they have a shorter lifespan is that they take psychotropic drugs and are more prone to diabetic, hypertension and renal problems and demise earlier.
- He was surprised by the huge number the Ombud brought to his attention. He declared that he was not aware of that data, as they have been working with the 36. Indicated they were counting strictly only the LE patients.
- The Ministerial Advisory Committee did not indicate numbers. No report was received from them. He stated that the meeting was initiated by the MEC and himself. In that meeting they agreed to disperse into the province to visit the NGOs.
- He stated that he moved patients from Precious Angels, anybody who tells you anything they should come to him. He indicated that some were moved to Kalafong, Pretoria West and Tshwane District. Subsequently some to Weskoppies to completely emptied Precious Angels. Moved some from Bophelong Suurman, some from Siyabadinga in Cullinan due to poor records management and handed them to the hospital. Patients in Bokang and Siyabathanda were also moved to Sterkfontein.
- Asked why move patients out of a licenced NGO, he indicated it was not about suitability but about saving the department. His impressions about NGOs is that they differ and what matters is the availability of food, kitchen, parameter fencing and programmes. Newer ones were struggling due to upping the numbers. The pressure on the staff was too high and he accepts to "take the sword" for them because he was not there for the staff and things go wrong you can't blame them. The pressure led to many mistakes. He could not reveal where the pressure came from. Due to increasing and increasing, especially for new NGOs missed to recognise when the patients were ill.
- Haste in moving patients was a second error he raised (he cautioned against this haste, it was too much); "it could have been done in a phased approach". He was not responsible for the turn/change but will take responsibility as the head of administration. He did not want to elaborate further on who and what lead to the change.
- He suggested that Mr. Mosenogi be called to give further evidence as he was the project leader.

- Many alternatives were put on the table but they were not accepted; one of which was to buy (and still believes in this option; money was available). This well planned alternative was stalled. He did not want to explain by who.
- However, he does not want to correlate the deaths to the poor planning. Some patients were not properly taken care of at LE. After Prof Makgoba gave him the statistical analysis of the deaths, he indicated he was not part of the provincial analysis. He indicated what they should have done was a proper fit for purpose and accepts that they were unfair to Precious Angels because they sent too many different types of patients; a mixture of patients was sent, intellectually disabled, demented, chronic, elderly, bedridden, etc.
- Lesson learnt is that due to socio-economic conditions NGOs accepted more numbers. This put pressure on the NGOs. Some could not say no to the increased numbers.
- When you take a leadership role, whether you know or not you take accountability. He states he takes direct responsibility but rather accountability. He repeated his statement that he will "take the sword".
- Asked about the Director signing the licence of NGOs, he argued vehemently that that is a certificate and not a licence and that NGOs are different from Health establishments. He claimed that if read carefully it is a certificate. He was shown a copy that read 'License' and not 'Certificate'. He indicated he queried it at one stage when Dr. Manamela had signed for Carstenhof. He claimed that this was a practice inherited from Department of Health and Social Development and it is a bad practice (contradicting his argument) and agrees it needs correction.
- On the issue of licences issued after patients were placed, he specified that staff were under extreme pressure and these errors happened as a result. He could not provide guidance because he was not attending some meetings because it was bad. Junior officials were put under pressure to do as directed.
- Asked what should happen moving forward, he appealed that administrators and relevant people must be allowed to do their jobs so that when such errors occur they can take responsibility and accountability. Sometimes it is a matter of principle "not that you own up to it". He indicated that there was no "evil intentions" though unintended consequences occurred. He pointed out that communities have not matured to that extend of deinstitutionalisation. He urged the committee not to go on a witch hunt. He contended that leadership must learn to allow people who have been dealing with these things to infuse us with better knowledge and understanding and do things differently not to rely on our wisdom. He further used an analogy of an eagle and an ant... "the eagle must listen to an ant". He asserted that

- leadership got too much involved in this project and made the managers to commit serious errors in execution...it could be done differently.
- His regret is that they worked hard and had a better plan. The journey was painful, when met families at Randfontein he came back very sad and informed Mr. Mosenogi that they will throw people into turmoil. He claims in pursuit of what they want to achieve they forgot the families that's when he noted they are doing it the wrong way. He does not blame the families that they are unhappy with the department. They could have done things differently; when ideas of buying where thrown and being isolated from the process and decision were made with juniors. He still maintained that as the accounting authority he will take responsibility.
- The media in their endeavour to shame the department has harmed families and stripped them off their dignity...contributed to taunting of patients by the community. Their involvement also made it difficult for the department to reach out to families.

## The Voice of Ms. Mahlangu Q, Gauteng Department of Health Member of the Executive Committee Interview Date: 29th November 2016

- The purpose and a brief overview was given about the investigation, as well as an update to date.
- MEC was given the opportunity to give an affirmation that she will tell the truth to the Ombud.
- Responding to the number of patients that have now died, the MEC indicated that the numbers at the time of responding to the question in the legislature there was about 37 excluding those number being run by the department (Sterkfontein, Weskoppies and Cullinan). She responded to the question on who provides her with information on the transfers and the deaths as Dr. Manamela (overall responsible) and the respective Districts mental health coordinators. In all meetings responsible managers responsible for specific programme will give report. Its only recently that they have implemented an Information Technology (IT) system to pin down performance to each manager and clinic by clinic.
- She was made aware that by the time the Ministerial Advisory Committee on Mental Health had finished its report around the 25th of September 2016, 66 patients had died after visiting 17 NGOs. She pointed out that 5 or 6 years ago the department informed LE about the intention to reduce the patients. She informed the Ombud that the history is that there were lots of deaths and the department instituted processes as part of active management of the contract. 2014/2015 engaged Life and fewer companies with unmanageable contracts as stemming from the Auditor General audit findings. Formal Letter was send

- to Life to give them 6 months' notice (later extended with 3 months), after numerous engagements to inform them of intention to de-instutionalise patients.
- She alleged that subsequently Life started reducing the quality of care and staff started leaving Life. Things became unbearable. Several meeting were held with Life but she would get reports of the number of places identified. She explained that in December 2015 the HoD and the DG of the NDoH started engagements with Section 27 due to their objection of the process, especially for people being taken to Takalani. She admitted that besides the corruption issue of Takalani good clinical care was provided. Two or three weekly reports were given in meetings; these included doctors (Weskoppies, Tara and Sterkfontein) and CEO's of relevant hospitals. Patients who needed to go to Sterkfontein went there.
- She pointed out that decision was taken by her team, the Mental Health Directorate. First briefing of patients who went to Weskoppies, one of the Professors gave a picture of how patients appeared; two were severely malnourished and two were immediately send to Kalafong and died subsequently. She stated that during their visit with the Ministerial Advisory committee, Prof Rataemane noted that patients were not well groomed and their clothing was torn.
- May, June July she was busy with political work and participated in one meeting end July due to her concern on media reports that patients had no food, NGOs not being paid and patients not having medicines. She went to Cullinan and visited Anchor and Siyabadinga NGOs and instructed that both share the unused hospital kitchen; built another cold room, one stove and put in washing machines. An intervention of nurses was also made. Siyabadinga took the department to court and was "kicked out" of the premises.
- She further stated that she asked the HoD and the CFO to pay the NGOs and that was executed.
   Furthermore, all hospitals nearby NGOs must ensure that they have food.
- She admitted that information that comes from civil servants is very difficult to stand with it. Hence they have Aurum Institute on board to build a system in the department that will obtain credible information.
- When asked if she was aware that Siyabadinga did not have a licence; she indicated yes and that is why the hospital CEO was suspended and disciplinary processes are underway. Her reflection on how she can justify mental health users accommodated in an unlicensed NGO in the premises of her hospital, was that she gave also support for legal action and the nursing intervention to manage those patients; the hospital was overseeing these patients.
- The Ombud pointed out that some people interviewed indicated that the decision was hers (some said principals); she indicated it was a collective

- decision and not her individual decision, it would be wrong for her to give an illegal instruction and to be feared to that extend. She alluded the Mental Health Review, the Ministerial Advisory Committee, the National Department of Health indicated that the decision was long overdue. She argued that she has never said "my way or the high way" she works with the collective. There was no dissenting view in the meeting. To prove her point, she gave an example that when Mr. Mosenogi raised a concern about Baneng a decision was taken to take it out of the equation.
- On following up on Mr. Mosenogi's assertion that when he was given a responsibility to be the project manager of the LE closure he discovered that the "plan" was actually a cost accounting plan and the 2000 beds were estimates, the MEC acted puzzled that she appointed Mr. Mosenogi as project manager.
- It was pointed to her that most departmental staff were not happy with the decision of changing from phased approach to LE closure and were fearful and warnings of consequences were not taken. In her response the MEC indicated that she was not aware of the NGO prevalence or state of depth in the province. She clarified that she was not involved in the identification of beds. She stated she did not hold people at gun point to do as she pleased.
- She gave evidence that she was to answer questions in the Legislature and was advised by Dr. Sokudela and Dr. Madigwe that patients need to be discharged in phases. The next three months will allow this process to unfold better.
- In a meeting with the families attended by herself, Mr. Mosenogi and Dr. Manamela she made a proposal to establish a family committee. The families were given the right to inspect the places. She indicated she committed to the families that they want to give the same or better care to the patients. She further elaborated that she cannot say that to the families and when she is at the department say something different.
- She presented that Mr. Mosenogi was engaging with the families. She advised that families should be allowed to visit the NGOs before settling people. She appealed it would be incorrect for her to give wrong instructions because the law is clear what her responsibilities and those of officials are.
- A memo pointing out possible risks of the project written by the clinicians to Dr. Manamela and copied to the MEC and HOD was brought to her attention and in response the MEC asked when did she see the memo. The Ombud further pointed out that the risks identified have come to pass; relapses which led to NGO closure, patients moved back into hospital, quality of care low if not absent in NGOs. Some of the observations/experiences of the care provided at NGO was given to the MEC.

- Asked when looking back if she thinks it was a good decision, the MEC gave an account that when a policy decision is taken you don't know how it will unfold and what is going to happen...the risk associated with it. In every single meeting the plan seemed and looked clear and the NGOs seemed to know what they were doing. Should she anticipated that the plan was not going well? She stated that the Infrastructure team from the Department of Infrastructure Development (DID) was roped in to renovate the wards in Sterkfontein, Weskoppies, Cullinan. The decision was informed by the desire brought in policy terms to ensure that patients are care of. She explained that the decision to take patients to different places is not an MEC, Minister or Premier's decision...those decisions are residing in the officials. The execution of the plan lies with those people employed to executive government decisions.
- She was reminded to respond to the question on whether the decisions to move patients rapidly was a good decision; patients died because of negligence. There was lack of professional care in the NGOs after being moved from LE.
- In response to the ignored advice, she argued the concerns/advise of SASOPS was send to the HoD and Dr. Manamela not directly to her otherwise she would have addressed the issued. She also argued that in all the meetings none of the psychiatrists raised these concerns with her.
- She asserts that if they could have done things differently they would have communicated better with families and all other stakeholders, could probably have taken longer time to transfer patients and ensured supervision of individuals. She regrets the death of users. She argued that when taking decisions, you never know how right or wrong they are. She reiterated that in her discussion with the Mental Health Review Board colleagues who have been in the system for some time, it was clear that the decision was correct and long overdue. If she knew patients were going to die, she would have not taken the decision. She has not felt the passive resistance till now. She indicated that people have differed with her before in meetings. She also indicated that she has invited Sifiso (Phakathi) to some meetings and the climate was open.
- The MEC disputes availability of budget and the option to buy LE as presented by the HoD in the enquiry. She claims that it is interesting that when people are on the back foot they find someone else to be blamed. She stated that the plan was to renovate old government property as the care at LE was poor.
- Giving her opinion on why the DG of the NDoH was not consulted, the MEC indicated that the HoD will be better placed to respond. The MEC reminded the Ombud that health is a constitutional function for provinces and that provinces and the national

- department have particular responsibilities to fulfil.
- She elaborated that in her visit to Precious Angel there was no food, this and that, and space issues.
   MEC provided that she had instructed Dr. Lebethe to request Forensic to do autopsies so that they can be transparent.
- She is willing to meet the families anytime, which is an offer she made with family representatives earlier through Andrew but was not taken up.
- She presented that the deaths are giving her sleepless nights because deaths.
- Asked if she takes responsibility she stated: "we should, we will take responsibility". She will accept the findings and take responsibility so that everyone can have closure.
- She sourced the Ombud's opinion about family members who never took care of their families, never bought them anything and now are coming forward to make claims. The Ombud indicated that it is all about closure.
- In her closing, she indicated that the reason not to want to release numbers of death is that it has become a political game in which institutions are characterised as killing people. She presented that she is circumspect to share information in the legislature and requested the ombudsperson to provide her with contact of the families to reach out to them.
- The MEC was blowing hot and cold in responding to most questions.

## 4.1.16. CONCLUSIONS of the Ombud Interrogations/ Interviews

- It was of grave concern that 3 of GDoH most senior officials did not know how many patients had died.
- Most of those interviewed blamed the MEC and so called 'principals for the project and its outcomes;
- Three decision-makers and implementers were identified through the evidence presented: MEC Mahlangu, Dr. TE Selebano and Dr. M Manamela;
- There was irretrievable loss of trust accompanied by 'anger and frustration' against the MEC by the relatives of the deceased, her HoD and the Director, Mental Health; in addition, there was loss of confidence in their leadership and a 'fear' of the MEC, the HoD and Director of Mental Health by staff interviewed within the Directorate;
- 'The Deaths cannot be really dissociated with the move; the key question is whether the deaths were preventable. You don't take very sick patients and put them in a facility where they do not have care. At least LE did have access to reasonable services with professional people. She cannot say that for those other facilities that are unlicensed that they could provide this care' Ms. P Matsoso, the DG of the NDoH. The Expert Panel and the Ombud arrived at the same conclusion as the DG;
- Some NGOs were not 'ready';
- There is no question that some of the NGOs were

- characterised by 'appalling conditions', woefully substandard of care and overcrowding;
- The majority of those interviewed easily recognised the 'critical clinical and health care professional requirements' for this cohort;
- Dr. Selebano's evidence was both evasive and contradictory;
- Dr. Selebano despite knowing that project approach was 'wrong' and having noted they were 'doing it the wrong way', that he and Mr. Mosenogi had an alternative approach that they believed in, having identified several errors committed during the implementation, having identified inhumane conduct during the execution of moving patients to NGOs, having identified patients with co-morbid conditions and being aware that Dr. Manamela had no legal authority to sign for and issue licences and being an experienced health professional himself whose responsibilities are spelt out in the NHA and despite being 'sidelined', he nevertheless continued to administer and preside over as head of GDoH;
- The evidence of the MEC contradicted the evidence of the HoD:
- The evidence showed the MEC and HoD did not share the same vision and later the HoD was 'sidelined' and 'junior officials were put under pressure to do as directed':
- 94+ patients died; the deaths of so many citizens are no small matter in the life of any nation.
- These 3 'dramatis personae' were the decision-makers and implementers of this project and in pursuit of a 'flawed and an irrational decision', their fingerprints within and throughout the project (except for the Project Team members who were disempowered and who failed in the decision-making process, the poor planning, the hurried and chaotic execution, poor oversight and their refusal to listen, take advice and warnings from professional experts and professional organisations;
- The 3 have brought so much 'pain and anguish' and disrepute to our nation and are not exemplars of good public servants and service;
- They have through their decision and actions denied a vulnerable group of assisted MCHUs the right to health care;
- The decision was irrational and totally against the fundamental principle of health care practice, i.e. to consciously remove a patient let alone a 'frail and sickly' patient from an environment of stable professional care to an insecure environment of less quality health care or unpredictable and unprofessional health care; this decision was made despite and against professional and expert advice and warnings; this amounted to negligence;
- The decision went against the assurances provided

- to the court by the GDoH i.e. that the MHCU's health would not be compromised by the transfer to NGO's (Section 27 and LE Executive Summary);
- The evidence provided by the relatives of the deceased and their representatives; the evidence presented by civil society organisations; and the letters of evidence by professional experts; the evidence presented by staff of NDoH and staff of GDoH and the evidence uncovered by the Expert Panel and the Ombud, which contravened the Constitution, the National Health Act and the Mental Health Care Act, all point to this trio as the main orchestrator of this 'total disaster' or 'flawed relocation process' as described by some UN Experts;
- Dr. Manamela was responsible for several faulty decisions that at times changed the final course of events in the project and are at the center of this disastrous episode. She is a health professional herself;
- Both the HoD and MEC accepted responsibility and accountability for this Project during their evidence;
- They both agreed it could have been done differently.
- It is common cause that the NDoH and National Health Minister were not formally consulted, advised nor informed of the project nor was advice sought from them, only the DG was alerted by Section 27;
- The failure to listen or to take advice is of grave concern;
- Most interviewed were adequately informed and knew that LE 'was closing' and 'would close';
- Some interviewed supported and were enthusiastic about deinstitutionalization as the cornerstone of the MHC Act 2002 and as the long-term way forward;
- Nobody interviewed supported the current 'precipitous, rushed or hurried' approach to the 'closure', transfers and placements;
- All the relatives interviewed were still traumatised by the episode and the experience; many broke down during the process and all would benefit from counseling and support; many feel a void and that there is 'closure' on these deaths;
- The majority of those interrogated were 'shocked' or 'surprised' at the 36 deaths announced and the 'numbers' that occurred at the NGOs, as these were 'unexpected' and 'not intentional';
- Many described the project as 'without plan or objectives' and the implementation as 'rushed, hurried and chaotic';
- The MEC is alleged by many to have said her 'decision was final and non-negotiable and the project had to be done', she left no room for 'engagement';
- Many staff members felt 'powerless and having to implement and deliver the outcome of a project they 'did not believe in'; an outcome they thought impossible to achieve and an outcome not do-able 'within the short time frame' given. They did not 'shape

- the project's evolution' as they were 'not participants in the decision-making processes';
- Staff and many stakeholders felt 'not being listened to' and 'being left out' during the process; authority had spoken and 'ours not to reason why, ours but to do and die';
- There was a general climate and culture of 'fear and disempowerment' observed among staff members to challenge or engage with authority or 'principals' as they referred to them during interrogation. There was a fear even to name the so called 'principals', so no principal was named;
- Professionals, psychiatrists, professional bodies and many experts were against this 'shotgun approach, one psychiatrist described it as 'madness' and resigned from service, they were worried and concerned about the time frame, the unintended consequences of such bulk transfers within such a short time period, they communicated their concerns in writing with dignity and respect; again they were not 'listened to';
- With this background, the current approach was 'doomed to fail';
- There was minimal involvement of the MHRB; the MHRB's independence was questionable;
- Several senior officials including those at NDoH were never provided with the so called LE Plan;
- The professionals' predictions and concerns have now come true and become reality: patients have relapsed; NGOs and the primary health care clinics were not ready, not adequately resourced and not

- developed; the 'revolving door' has begun and the retransfer of patients into acute psychiatric hospitals is likely to spiral the costs rather than reduce the costs; the quality of mental Health Care at NGOs is lower; the chaotic placements of MCHUs into far away NGOs has defeated the very essence of community care; these represent the failure or predicted 'collapse' of the project;
- While research has shown that MCHUs have a shorter lifespan than a normal person; that death is inevitable, and some deaths would be inevitable in this cohort, the high calculated death rates, the high percentage deaths and the more than expected deaths at the NGOs, left one with the inescapable conclusion that some deaths were both avoidable and thus preventable in this cohort, had a more phased out approach been adopted, had professional advice been heeded to; with strengthened primary health care clinics and carefully selected, properly licensed and appointed and adequately prepared NGOs;
- The cost per patient per day is R320.00 at LE compared to at Weskoppies, Sterkfontein and CCRC; what service or care can be provided with R112.00 per patient per day? The project is more likely to cost more rather than reduce cost as was initially intended; The Average Cost per Patient per day at 3 Public Psychiatry Hospitals:

• Weskoppies Hospital R1 960.41

Sterkfontein Hospital R1 386.13

Cullinan Care and Rehabilitation Centre R1486.04

### THE OHSC INSPECTORS

#### 5.1. Background on NGOs

- 5.1.1. Bophelong Suurman, Mosego, Precious Angels, Rebafenyi 1, 2 and 3, Thekganang, Solutions care, Areyeng, Lapeng and Sebo sa Rena were found to be residential premises, without suitable infrastructure and not fit for the purpose to house mentally ill patients. Takalani, Odirile, San Michelle and Anchor were designed as health institutions. Furthermore, Precious Angels, Rebafenyi, Anchor and Bophelong Suurman were found to be new and in an early phase of establishment without any procedures and systems in place to ensure quality of care for mentally ill patients;
- 5.1.2. Anchor Precious Angels, Rebafenyi, Ubuhle Benkosi; and Bophelong Suurman existed for only one (1) month prior to being appointed as service providers by the GDoH and did not have a demonstrable track record and capacity to take care of mentally ill patients;
- 5.1.3. The infrastructure limitations and lack of the skill and expertise in the NGOs were observed to be posing a risk to patient safety;
- 5.1.4. During investigation it was also detected that residential areas which were converted to be NGOs were prone to security risks common in the neighbourhood. There was a break-in that took place at Lapeng, which poses a safety risk to the mentally ill patients. There was also a reported neighbourhood risk at Rebafenyi reported in the Daily Sun posed by the MCHUs.

#### 5.2. Licensing Issues

- 5.2.1. Letters of designation to function as mental health care institution were available regardless of lack of evidence that there would be skilled staff or health professionals to provide adequate care for the specialised psychiatric function;
- 5.2.2 During the investigation, the GDoH confirmed that an accreditation process did take place, however, there was no documentary proof of the criteria used for accreditation. None of the NGOs received a signed copy of the accreditation although a status (to operate as NGO) was granted;
- 5.2.3 No formal contractual relationship existed between the GDoH and the NGOs on the transfer of the mentally ill patients from LE. The

- NGOs continued to operate without Service Level Agreements (SLAs) regulating the relationship and the levels of service expected by the GDoH. The SLAs were only signed at a later stage with parties signing two (2) months apart from each other;
- 5.2.4 The SLA did not make it obligatory on the NGOs to provide adequate amount of meals to meet patient's needs;
- 5.2.5 It was also established during the investigation that the licensing process was unlawful because:
  - unauthorised officials signed documents without proper delegation;
  - NGOs were issued with licences without being properly inspected for compliance;
  - The licence did not specify the service requirements;
- 5.2.6 Some facilities were found to be operating without a valid licence on investigation (e.g. Mosego, Hephzibah, Takalani and Shaping);
- 5.2.7 Mosego's licence was invalid because the number of patients received (181) was not aligned to the licensed capacity of 171. Mosego and El Shaddai were requested by the GDoH to accommodate more patients than the number stipulated in their licences and they were promised that the licences will be amended accordingly, which was never done;
- 5.2.8 Precious Angels was issued with a licence to operate prior to its registration as a legal entity (NGO);
- 5.2.9 El Shaddai and Precious Angels received their licences to operate as such 3-5 months after the date of their actual operation;
- 5.2.10 Tshepong Centre is not a duly registered entity, however, the GDoH issued a mental health care licence and is paying the monthly subsidy to the non-existing entity;
- 5.2.11 All NGOs obtained Mental Health Care License ("the licence") in April 2016 for the financial year (will expire in March 2017), the investigators were advised that such is common practice by GDoH. However, some of the licences were issued in retrospect.
- 5.2.12 Ubuhle Benkosi moved premises four (4) times and none had an assessment report by the GDoH. Were all these places licensed.;
- 5.2.13 A conclusion can be drawn that:
  - The SLA was entered into way after licenses were issued, it may not be said that the conditions in the SLA were conditions for purposes of licenses.

- Lack of license conditions particularly service conditions are a material aspect of a license, failure to include such, implies that there was no agreement on the terms;
- If an NGO deliver poor standards of service, the basis for action against it may not be on failure to abide by license conditions but rather on failure to perform in terms of the SLA.

#### 5.3. Patient Transfers or Movement

- 5.3.1 The GDoH was actively involved in the transfer of mentally ill patients from LE to the NGOs, however, the sub-standard care still prevailed under the GDoH's oversight. The GDoH did not raise this matter of sub-standard care;
- 5.3.2 The patients were transferred to and received by NGOs without any health professionals in their staff complement;
- 5.3.3 It was also observed that patients who were transferred to Tshepong during the inter-transfer of patients between the NGOs, were transferred without any record of physical, psychological or mental conditions;
- 5.3.4 The investigators also observed that lack of patient's clinical records on previous medical history stating the diagnoses, care, mental status and treatment history together with the lack of skill and experience of some of the NGOs receiving patients led to an interruption of continuity of care for the mentally ill patients;
- 5.3.5 Due to the lack of capacity, skills and competence to care for the patients, some frail patients were thus transferred further to general hospitals or other NGOs for better care:
- 5.3.6 Dates in the GDoH reports were inaccurate in relation to the transfer of patients and as such, the report causes doubt on the validity of the sequence of events and accuracy of information;
- 5.3.7 During the investigation, it was established that some of the patients transferred from LE were transferred to the NGOs in districts far away from their families. This type of transfer then whitewashed the GDoH's concept of de-institutionalisation of mentally ill patients from Hospital settings into community care because the principle thereof is to bring people closer to their families and homes;

#### 5.4. Capacity and Staffing in NGOs

- 5.4.1 Out of the twenty-five (25) NGOs visited, twenty-two (22) did not have the capacity, skill and competence to deal with the influx of mentally ill patients at the time of the investigation (See Annexure 6a-b);
- 5.4.2 It was established during the investigation that most NGOs did not have the required skill and competence to care for mentally ill patients, except for Odirile;
- 5.4.3 The NGOs started recruiting health professionals only 2-3 months after patients were received. This could be the probable cause of deaths within the NGOs;
- 5.4.4 The investigators also identified from the health professionals who were appointed that the working and living conditions at the NGOs on commencement of their professional work were poor and there was lack of skill and experience by the staff who was employed to care for the patients;
- 5.4.5 The NGO managers stated that some of the mentally ill patients received from LE were in poor state of health and appeared to have been receiving sub-standard care days prior to their transfer to the NGOs.

#### 5.5. Infrastructure

- 5.5.1 The GDoH conducted assessments to check suitability of infrastructure of the NGOs for placement of mentally ill patients and recommendations for improvement of conditions in the NGOs were made. However, documentary evidence provided by the GDoH points to the contradictions in the findings; patients were placed in these facilities prior to implementation and/or completion of the improvement;
- 5.5.2 The investigators findings contradicted the reports by GDoH that maintained that improvements had taken place because some of the NGOs (e.g. Bophelong Suurman, Solution Care, Rebafenyi 1) were found to be still conducting renovations whilst others (e.g. Shammah, Tumelo Home) where disclosing their plans to improve and renovate as advised by the GDoH on their subsequent visits; Ubuhle Benkosi moved premises four (4) times and none of the premises was assessed for suitability by the GDoH.

#### 5.6. NGO Staff Interviews

- 5.6.1 The decision to terminate the long term contract with LE and de-institutionalise was based on a cost analysis;
- 5.6.2 The NGO managers during the interviews stated that the NGOs were invited to attend a meeting held by GDoH and were informed about the opportunity of housing mentally ill patients. Some of the NGOs were residential homes and families moved out and relocated to accommodate conversion of their homes into centres of care because they saw a business opportunity in the transfer project.

#### 5.7. Stipend Payments

- 5.7.1 There was a discovery that the NGOs only received financial support from the GDoH 3-4 months after receiving patients from LE. This suggests that there could have been financial constraints on NGOs leading to shortage of essential resources such as food, linen and clothes;
- 5.7.2 The investigators also noted that there was lack of payments/ remuneration to the staff employed by NGOs and existence of other unstated labour conditions which left the staff agarieved.

## 5.8 Project Implementation and After-the-fact Process

From the documentary evidence received from the GDoH as evidence, the investigators established the following facts:

- 5.8.1 Of the documents requested by the OHSC and the Ombud for the purpose of the investigation, some were not furnished by the GDoH and reasons for such were not provided, or were invalid because they were not signed by the relevant authority and some were found to be irrelevant and did not address the request for further information by the Ombud (see Annexure 6c):
- 5.8.2 The investigation confirmed that there was a policy decision by the GDoH to de-institutionalise mentally-ill patients from hospital settings into community care. The long term contract between the GDoH and LE was terminated and that all mentally-ill patients who were residing at LE, depending on their condition, were transferred to Public Hospitals and NGOs within Gauteng Province;
- 5.8.3 It was also established that there was a 'rush in implementing the plan' within three (3) months whereas it could take up to five (5) years to implement successfully as stipulated in the MH Policy. Further that as a result of the 'rushed implementation', no proper due diligence was conducted which led to 'chaotic' implementation of the plan;

- 5.8.4 Investigators also established that quality of care, safety of patients, compliance with legislative prescripts and National Core Standards were not prioritized in the planning and were overshadowed by a rush to move patients out of LE;
- 5.8.5 It was also confirmed during the investigation that the GDoH was aware that the NGOs were not ready to receive and care for mentally ill patients from LE. However, despite the GDoH's observations on the readiness of NGOs, the plan was implemented and patients were transferred to the same NGOs;
- 5.8.6 Monitoring reports that were compiled by the GDoH after the placements continued to confirm the poor state of infrastructure and unsuitable conditions of care for the mentally ill patients. A key question is why licence if NGO not meeting all licencing requirements? This is total disregard of the law;
- 5.8.7 Reports for monitoring the NGOs after the transfer of patients from LE, by another team in the GDoH reported unsuitable living conditions in the NGOs. This confirmed that patients were placed when NGOs were neither ready nor suitable to provide care for the patients;
- 5.8.8 The investigating team from the OHSC also found mental health officials from the GDoH were still conducting assessment visits to the NGOs as late as September 2016. This occurrence begs the question why were patients placed in those centres when they were still not ready to accommodate the mentally ill patients;
- 5.8.9 The assessment reports by the GDoH contained inaccurate information in relation to information about the NGOs. However, the information was confirmed during the investigation by the OHSC team. Assessment report of Precious Angels is inaccurate and misleading.

#### 5.9 Conditions in the NGOs that posed a threat to patients' life and that could have contributed to the death of patients

- 5.9.1 Omissions to carry out critical patient care steps that are outlined in domain 2 created clinical and safety risks that would result in deaths of patients;
- 5.9.2 No evidence of medical authorisation that transfer or discharge should take place in the form of a discharge summary or Mental Health Care Act Form 03. Some patients were medically unfit for transfer or discharge to NGOs;
- 5.9.3 Lack of evidence of clinical assessment within 24 hours preceding discharge or transfer. The NGOs received patients that did not have records of assessments and did not know what the patients' medical condition were and did not have care plans according to patients' conditions and needs;
- 5.9.4 Not recording patients' conditions during transportation constitutes an omission. Risk

conditions that patients were subjected to were not reported and patients' conditions were not monitored. Potential injuries or harm of any nature which may have occurred were not observed nor recorded. Vulnerable patients were subjected to long distance travelling without food and medical care;

- 5.9.5 Unskilled, non-professional or untrained staff manned the NGOs that received patients from LE at the time of receipt. Such staff were not in a position to assess medical conditions of patients and the medical records. They were also not in position to attend to the incomplete patients' records;
- 5.9.6 Lack of proper handover/takeover and improper control of supplies of medication that came in with patients on their arrival;
- 5.9.7 Lack of competence or skill to administer medication leading to relapse of some patients
- 5.9.8 Lack of proper systems for storage of medication at the time of receipt of patients;
- 5.9.9 Irregular monitoring of vital data of patients and unstructured or poorly structured systems of reporting on such including noting of progress notes;
- 5.9.10 Lack of financial capacity contributed to inability to procure nutritious food, proper linen and staff (professional and care givers); All of the above are conditions that compromised the quality of care and made the patients vulnerable to death;
- 5.9.11 The following factors were observed at NGO facilities where no death occurred:
  - Some had previous experience as NGOs catering for health and/or related field;
  - The NGOs chose to take minimal number of patients;
  - Some were self-sufficient and had financial support from sources other than the GDoH;
  - They had patient care systems in place.
- 5.9.12 The OHSC investigators looked into the deaths that occurred during the period of March 2016 to September 2016 and found that the highest number of deaths occurred between May and August 2016, majority of which were of patients transferred from LE.
- 5.9.13 Majority of deaths occurred in newly established NGOs some of which existed for less than six (6) months and lacked previous experience in caring for mentally ill patients. The following factors were observed to be challenges in those NGOs:
  - Lack of capacity in relation to skills, knowledge and competence to manage patients, particularly mentally ill patients;
  - Lack of financial resources;
  - There were no patient care and management systems in place, particularly medication administration, control and storage;
  - Delays in identifying need for and seeking medical attention.
  - Infrastructural constraints resulting in

restricted patients' movement, security risk, lack of patients' recreational space.

#### 5.10 Liability of NGOs

- 5.10.1 Services for the mentally ill commenced prior to issuing of licenses to serve as psychiatric care facility as such being unlawful;
- 5.10.2 Evidence that if accreditation took place as a process that should have preceded the issuing of license, it failed to consider lack of skill and competence of staff as well lack of systems to administer patients care.

#### 5.11 Conclusion

- 5.11.1 Based on the analysis of documentary evidence and the interviews conducted, the findings are that sub-standard care existed at some NGO facilities:
- 5.11.2 Further that, the concept of deinstitutionalisation of mentally ill patients into community was not achieved through the process;
- 5.10.3 Further that, the process of transferring mentally ill patients from LE into the NGOs was conducted in a rushed manner, without 'piloting' not allowing the GDoH to conduct due diligence in planning and implementation and as such did not ensure that mentally ill patients are transferred into suitable and functionally matched the NGOs wherein there shall be continuity of care;
- 5.10.4 Furthermore, the licensing process did not comply with the procedures for issuing of licenses and was therefore unlawful. At the time they received patients, some of the new NGOs had no licenses thereby operating illegally;
- 5.10.5 The NGOs were lured into what appeared as a business opportunity not to be missed and as such received patients knowing that they neither had capacity, expertise nor the requisite infrastructure to care for mentally ill patients;
- 5.10.6 Whereas only four (4) of facilities are designed for purpose of health care services, generally, no residential home would be fit for mental healthcare;
- 5.10.7 Fourteen (14) NGOs were found for professional, legal or infrastructural reasons to be so substandard that they should not be in operation. Nine (9) were not fit for purpose for infrastructural reasons and five (5) have various license irregularities (See Annexure 6b);
- 5.10.8 Our finding is that the GDoH overlooked and/or failed to properly anticipate the consequences that may arise from the rushed transfer of patients and that the negligent conduct led to making unsound decision that did not seek to prioritise the health care and safety of patients and the quality, thereby putting the life of patients at risk.



## THE MINISTER'S ADVISORY COMMITTEE ON MENTAL HEALTH

The reports from the Province show that seventeen (17) NGO's, 2 psychiatric hospitals and 1 care and rehabilitation centre have received the patients that were transferred from LE.

#### Salient issues:

- Most NGO facilities did not have dedicated management structures. Each facility must have a dedicated management structure. It was found that for an example, Mosego Home is said to be trading as Takalani Home (has Mosego Home taken over Takalani?). Rebafenyi with three houses and three different managers is another example;
- Licenses were not facility specific, which cast doubt on the legal status of the licenses that were issued by the Province. Licensing should be facility specific to ensure that infrastructure requirements, human resources requirements, materials and services are appropriate for the type of patients that will be placed at that facility;
- In many cases patients arrived at the NGO's without clinical records and identification records. Where records were available, they were incomplete. Where most deaths occurred, the NGO's did not know the diagnosis and treatment that the patients were taking;
- No evidence was found to show that patients were evaluated for to determine functionality or acuity levels prior to placement with NGOs. Neither were patients medically and functionally examined and assessed upon admission to the NGO's;
- Where most deaths occurred, did not have the requisite health professionals to render care (Enrolled nurse, Professional nurse, visiting medical doctor. Patients were left in the care of care workers, that do not have basic medical knowledge, e.g. Precious Angels. Care workers are forced to practice outside

- their scope of practice and handle scheduled medications and complex medical conditions;
- Response times for Emergency medical services were poor;
- It was reported that district hospitals and clinics did not prioritise and give attention to the patients that were brought by NGO's;
- The majority of the homes did not have emergency equipment, fire extinguishers, nor appropriate storage facilities for medical supplies and food. Facilities did not have systems for disposal of medical waste;
- Prescriptions are not filled immediately and patients can be without medication (up to 14 days waiting time), e.g. Rebafenyi Houses 1-3. Some of the Primary health care facilities, e.g. Pretoria North were providing the much needed support to the NGO's;
- Where the most deaths had occurred, patients had arrived at the facilities already very ill, frail, weak and with severe bedsores and the majority were profoundly disabled (without clinical notes, e.g. Precious Angels).
   The Health Ombud must determine who discharged these patients from LE (Were discharge procedures followed?);
- Some NGO's had not received any payments for up to 3 months since the patients were admitted. Many of the owners indicated that they provided supplies from their personal funds and were now bankrupt;
- Rehabilitation programmes are non-existent in almost all facilities;
- The NGO's that operate within the specialized psychiatric hospitals such as Sterkfontein Hospital and Cullinan Care and Rehabilitation Centre seems to be functioning much better, in terms of laundry, supply and storage of medication, food preparation, medical care and cleaning services;
- The majority of the facilities were overcrowded;
- The managers of the NGO's indicated that the province had promised that they will provide training.

'The independent findings of the Expert Panel, the OHSC inspectors, the Ombud and the MAC corroborate and correlate with each other strongly throughout the Report.'

### **ANALYSIS AND DISCUSSION**

## 7.1. The sample analysis from clinical records

The sample of deaths investigated were described by the Expert Panel as follows:

#### Sample population

As 38 deaths had been identified at the start of the Expert Panel investigation, these deaths served as a sample population of the overall deaths that occurred. Of the 38 patients, 22 were men and 16 women. The average age at death was 58 years, with the youngest being 26 years and the eldest 86 years (Table 2). Clinical data was missing for only one of the patients, Koko Nene, whose surname remained unknown. Only the hospital records at the time of her death could be found. Neither the NGO nor the LE (LE) records could be located.

The most frequent diagnosis was severe intellectual disability (N = 15), followed by epilepsy (N = 13), dementia and schizophrenia (each N = 12) and cerebral palsy (N = 8). Valproate was the most frequently prescribed medication (N = 18), followed by high potency typical antipsychotics (N = 11), risperidone (N = 9), clonazepam (N = 9) and carbamazepine (N = 8). Only seven patients were on specialist level medications; clozapine in six and topiramate in one.

All were at best poor functioning, 17 out of the 38 were extremely low functioning, due mainly to intellectual disability and severe cognitive impairment. However, most were stable although frail. Only 3 patients had had a deteriorating course at LE.

## [**Table 2**. Clinical characteristics of the sample] **Annexure 7a**

LE provided care, treatment and rehabilitation (CTR) to Assisted MHCUs under Section 26 of the MHCA of 2002. This means that to be admitted to an LE facility, there needed to be evidence of the MHCU's inability to consent voluntarily to CTR and evidence that CTR was necessary for the MHCUs own health or safety or for the health or safety of others. The capacity to consent is related to the MHCU's insight into their illness and understanding of the need for CTR, the potential consequences of not receiving CTR and an independent willingness to receive CTR. Thus, the MHCUs admitted to LE were unable to consent due to

the severity of the mental illness itself and/ or the lack of intellectual capacity to comprehend the need for CTR or consent with free will, as in the case of those with severe or profound ID.

The relevant MHCA forms required on admission to an LE facility would have included an application for admission (Form 04) and the findings of two mental health care practitioners confirming that the MHCU requires CTR but is unable to consent to CTR for whatever reason (two Forms 05). The application must then be approved by the Head of the health establishment making the application. The MHRB would have to confirm the need to provide CTR as an Assisted MHCU using a Form 14. Each year a repeat evaluation of the MHCU's need for CTR and ability to consent is performed. If the need to remain an Assisted MHCU is established clinically, this is reported to the MHRB on a Form 13A. The MHRB then evaluates the application for ongoing CTR as an Assisted MHCU and responds accordingly on a Form 17.

Should the condition of the MHCU improve to the extent that he/she is able to provide free, informed consent, they would then be discharged to outpatient care as a Voluntary MHCU using a **Form 03**. Thus, in order for an Assisted MHCU to be discharged from any mental health care facility, a **Form 03** is required together with clinical evidence of a recovery in the capacity to consent of that MHCU.

Should there be no improvement in the capacity to consent, as in the case of people with severe ID or acquired cognitive impairment (e.g. in dementia or cognitive decline due to a psychiatric disorder), and ongoing CTR is deemed clinically necessary as an outpatient or inpatient, the MHRB would continue to be notified of this using the periodical report Form 13A. The MHCA does not specify the Forms by which the MHRB should be notified of any transfer of an Assisted MHCU from one health care facility to another, or the transfer from inpatient to outpatient care. These are only specified for Involuntary MHCUs (Form 10 for outpatient care and Form 11 for transfer to another inpatient facility). However, if they are not discharged with a Form 03, they must continue to be cared for as Assisted MHCUs in appropriately resourced facilities and the Form 13A should follow the patient from facility to facility as they have not regained the capacity to make an informed decision regarding their mental health care.

Regarding the sample of 38 MHCUs, all would have been Assisted MHCUs at LE (**Table 3**), although periodical reviews

were not available on all patients due to the incomplete nature of the patient records. Form 03s were completed in 11 patients as discharge forms. However, there was clinical evidence of a recovered capacity to consent to CTR as a voluntary MHCU for only one patient. The other 10 in whom a Form 03 was completed had no evidence of recovered capacity due to the irreversible nature of the primary cognitive impairment; therefore, the Form 03 is clinically invalid in these patients. Four of the Form 03s were undated, rendering them technically invalid.

Form 11s were completed on 11 MHCUs (one of whom also had a Form 03), informing the MHRB of a transfer to another health care facility. For 27 of the 38 patients, Form 13As were received by the respective NGOs, albeit some of them out of date. Therefore, there was documentation of a 'transfer' with either or both a Form 11 and Form 13A in 31 of the 38 patients, and of clinically invalid discharges in 10 of the 38 patients. In this case the NGOs should have been specifically licensed to receive Assisted MHCUs, due to the increased intensity of care required.

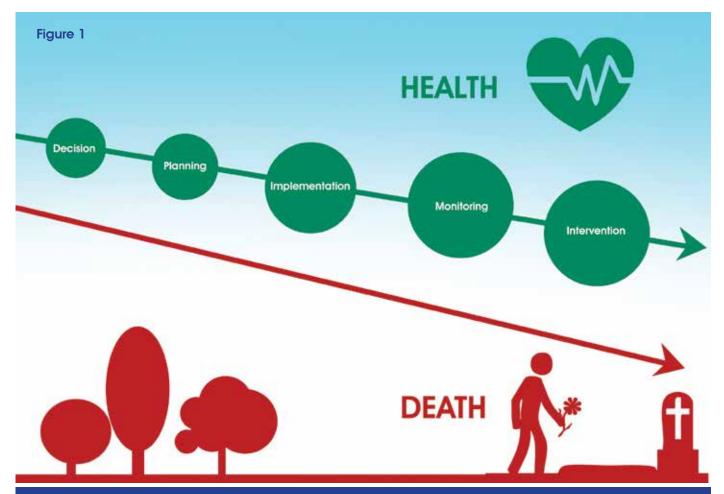
On examining the files, a judgement was made by the Panel number for each case as to their fitness for transfer to another facility in terms of their mental and physical health. From the notes available, it was deemed that 13 of the 38 could have been regarded as fit enough to be transferred to a sufficiently resourced health facility and if cared for appropriately during the transfer.

**[Table 3.** MHCA status and transfer details of the sample] *Annexure 7b* 

Summary 1: The analysis of the 38 MCHUs formed the nucleus and focus of this investigation. All MCHUs at LE were 'Assisted MCHUs'. This in-depth clinical record analysis by the Expert Panel gave a better understanding and characteristics of this cohort. Through this analysis a better picture of the vulnerabilities emerges and are illuminated. Importantly, these were the most vulnerable people who needed protection in our society.

**Mahatma Gandhi said,** 'The true measure of any society can be found in how it treats its most vulnerable members'.

## THE CHAIN OF EVENTS TO THE DEATH OF 38 MENTAL PATIENTS



Note: The green line represents normal course of events, and red line is the deviation from the green line, and leads to more deaths of patients

Decisions about and on Health affect and impact on well-being, the quality of life and the preservation of life and consequently, life-span.

When such decisions go wrong, well-being, quality of life and life-span are all compromised. Thus Decisions stands between Health on the one hand and Death on the other. This fluctuation between health and death is a continuous and dynamic process that is not a simple straight line. The cumulative impact of deviations from the normal course results in death as illustrated in the above figure. Thus all of decisions and health provisions are first about the preservation of life.

Simply put, it was the cumulative impact of deviations from the normal course, starting with a 'flawed'

decision along the chain of events that led to the 'higher numbers or excess' deaths of patients at NGOs.

Let's first state the obvious i.e. the goal of deinstitutionalisation is the corner stone of the MHCA 2002. This is universally accepted and was confirmed throughout this investigation by the testimony of almost every witness. The difficulty was not the concept itself but how the concept was translated in reality on the ground. The selective interpretation and usage of the legislative framework and strategy was at the heart of the Project. The project which was aptly named 'the Gauteng Marathon Mental Health Project' instead became the 'Gauteng sprint'!

## THE DECISION\* BY THE GDoH TO TERMINATE THE CONTRACT PRECIPITOUSLY WITH LE

The findings of the investigation indicated that the decision taken by the GDoH to terminate and relocate/transfer patients from LE Centres precipitously was fundamentally flawed, irrational, unwise and inhumane. The consequences, the responsibilities and accountability of such a decision are inextricable and closely-linked. The decision was based on:

 The lack of reduction in bed capacity by LE over a period of 8 years;

A reduction in bed capacity is dependent upon the strengthening of the other services in the overall system for mental health care. As highlighted by the Heads of Unit and SASOP letters, the numbers of acute hospital unit beds and NGO beds were grossly inadequate and unable to manage the existing demand for care. Evidence for this was provided in terms of escalating numbers of psychiatric patients in prison awaiting forensic observation;

 The inability of MHCUs to adapt to the community after discharge;

The ability for MHCUs to adapt to living in the community after extended hospitalisation is well documented to be problematic. There are two essential factors necessary for adaptation to living in the community. Firstly, the MHCU must have the capacity to adapt and be integrated into the community. Secondly, comprehensive, specialist level Community Mental Health Services (CMHS), providing psychosocial and medical care, have to be in place in order to provide the level of support required. The GDoH was informed in two letters from psychiatrists in Gauteng that there was a subpopulation of MHCUs who would not be able to live in the community and that the CMHS in Gauteng were severely deficient. However, the GDoH opted to not respond to these letters and to persist with their decision;

 The evaluation by the Health Advanced Institute (HAI) that the CTR at LE was not consistent with the service level agreement (SLA) in that it was insufficiently aimed at rehabilitation and re-integration of MHCUs into the community;

According to the executive summary, the HAI evaluation regarding consistency with the SLA

was performed through assessing the attitudes to rehabilitation of the MHCUs amongst the LE staff members. No assessment was made of the capacity of the MHCUs to be rehabilitated to the extent required by the SLA. No question was made of the suitability of this aspect of the SLA to the category of long-term MHCUs cared for by LE; mainly those with high comorbidity between severe intellectual disability or dementia, mental illness and epilepsy;

That the cost of care at LE was not sustainable;

Only the direct LE costs were cited in the GDoH report to support the decision to terminate the contract. No feasibility studies or costing exercises were performed in order to examine the alternative strategies of care. In addition, the HAI evaluation had found the costs of LE, and the increment requested, to be below market related health care costs;

 A lack of reasoning and humane considerations were applied to the two aims of the "LE Project," which were:

To fast-track the development of community mental health care;

Although community based mental health care is advocated by the MHCA and the MH Policy provides a plan for CMHS, the implementation of the policy is not included in the Health Strategic Plan or the NHI white paper. The re-engineering of PHC in South Africa does not cater specifically for mental health care at community level as evident by the fact that the district clinical specialist teams do not include a psychiatrist;

No attempt was made by the GDoH to include a structure for community psychiatry during the LE Project. Only the highly specialised academic hospitals and, to a lesser extent the secondary care level CCRC, were capacitated by the GDoH for the additional clinical care of the MHCUs from LE. The District Health Services were not strengthened at all. However, the NGOs were dependent on District Health Services for general medical and multidisciplinary specialist psychiatric support. Oversight and administrative support of the NGOs are performed by the District health managers;

Over 200 patients were moved out of LE into the more restrictive and more highly specialised Weskoppies and Sterkfontein hospitals. The fact that this was planned early on in the LE Project with the necessary infrastructure preparations contradicts the plan to provide less restrictive, community based care. During the process of the LE Project progressively more MHCUs were added to the 217 in the specialist hospitals as NGOs were unable to deliver the care required;

The evidence from the investigation suggests that the GDoH had no plan to "upscale community health services" but simply to rapidly develop new NGOs in under-resourced districts;

To cut costs, save money and avoid problems with the Auditor General;

Firstly, the difficulties with the Auditor-General (AG) are not detailed in the GDoH report and the relevance to the care of MHCUs by LE is not explained. Secondly, there was no evidence prior to implementation that the care outside of LE Centres would in fact be cheaper;

At the start of the implementation period, a total of 358 patients were placed in Weskoppies and

Sterkfontein hospitals and the CCRC. Multiplying the number of MHCUs placed by the cost per day (Table 4, in Section 6 below) gives a figure of R 590 648 per day for 358 MHCUs, an amount that would care for 1477 patients per day if the LE costs were to increase to R 400 per day per MHCU;

The only means to cut costs in order to adjust to the high hospitalisation expenditure were to provide extremely cheap care to the majority of MHCUs. To expect that residential home CTR can be provided at just over R 112 per day indicates a lack of understanding of current costs of living and/or a disregard of the human right to dignity and quality care of these MHCUs.

**Summary 2:** To dissociate the decision-making process, the 'rushed and chaotic' execution that followed the decision, the human rights violations that unfolded and the conditions in the NGOs during this project from the deaths of the MCHUs, unearthed through the MAC, the Expert Panel, the OHSC Inspectors and the Ombud investigations, would not simply be preposterous but be also a denial of the worst type; the decision and the deaths are inextricable and closely linked;

 \* The word "decision" refers to the specific and precipitous decision to terminate the contract on the 31st of March 2016, as described in the GDoH "summary report on termination of contract relationship between GDoH and LE and upscaling community based mental health services."

The legal right of the GDoH to terminate the contract is not under discussion in the Expert Panel Report, but rather the decision that was made to enact this right and the consequences of that decision.

 The Ombud and Expert Panel supports the process of deinstitutionalisation and community based care for people with psychiatric disorders. However, in order for the human rights of the mentally ill to be preserved and for deinstitutionalisation to be successful, it must be preceded by the development of community psychiatry and primary mental health care according to the South African National Mental Health Policy Framework and Strategic Plan (MH Policy). The opinion of the Ombud and the Expert Panel regarding deinstitutionalisation is the same as that on page 23 of the MH Policy, i.e:

"These community mental health services will be developed before further downscaling of psychiatric hospitals can proceed. In accordance with the Mental Health Care Act (2002) NGOs, voluntary and consumer organisations will be eligible to provide and be funded for community programmes/facilities. This includes capacity development for users (service users, their families) to provide appropriate self-help and peer led services, for example as community health workers."

## THE FAILURE TO LISTEN

To MCHUs' relatives, professional experts and civil society; mental health staff members within the GDoH and NDoH (see Annexures 8a-b, 4a-b and 5):

- 'The MEC would not listen': Relatives of MCHUs;
- Voices and advice of reason not listened to; "difficult for us as "implementers", "it was tough" and 'very stressful': Mental Health Directorate;
- Many staff members felt 'powerless and having to implement and deliver the outcome of a project they 'did not believe in'; an outcome they thought impossible to achieve and an outcome not do-able 'within the short time frame' given. They did not 'shape the project's evolution' as they were 'not participants in the decision-making processes';
- Alternative approaches were not accepted: HoD and Project Manager;
- The Project Manager and HoD had 'listened' to relatives at meetings and the HoD was in constructive discussions with civil society, experts and the NDoH DG; all these engagements had changed his mind about the approach to the project. However, this changed status would not prevail, instead he 'felt sidelined';
- Failure to listen and take advice from repeated requests of: SASOP, SADAG, Section 27, Federation of Mental Health: presented in letters addressed to the MEC and copied to the HoD and Director of Mental Health;

- The GDoH is gripped with 'fear and disempowerment' of its staff and 'mental health champions'; fearful to name seniors or to question authority; Mental Health Directorate;
- The control of the free flow of information e.g. The Ombud requested information from the GMHRB. This request and response had to be vetted by the Director of Mental Health, Dr. Manamela; many relatives are still in the dark about their loved ones; senior staff has not discussed the issue of the deaths openly since it occurred: staff in the Directorate; many stakeholders commented about 'not seeing the project plan' despite requests and promises; Project Manager, SADAG, the NDoH;
- The GMRB was disempowered and had very minimal involvement in the project;
- Even some NGOs were 'fearful of someone above'.

Summary 3: 'ours not to reason why, but ours only to do and die' in Alfred Lord Tennyson's Charge of the Light Brigade. This overwhelming revelation of frustration and disempowerment came across all the sectors of the department during oral evidence below the Director's level. This finding is most troubling and a damning indictment on the leadership of the GDMH. Staff members could not exercise their fiduciary responsibility out of 'fear and disempowerment'. They became stressed and tensions mounted. Staff had no belief and ownership of what they were being asked to deliver. Some broke down during the interviews.

### PLANNING AND IMPLEMENTATION

#### The planning process

The planning process was largely limited to the government officials. Communities and civil society organisations were not involved in any credible manner. The evidence from the Expert Panel's investigation for this is as follows:

- The National Health Act of 2003 emphasises full community participation in many paragraphs. Furthermore, the Act provides for full community involvement through structures such as clinic committees, hospital boards, district health councils and provincial health councils. There was no mention of any of these structures in these planning documents;
- The groundswell of protest marches and court interdicts, described in the GDoH report as challenges, provide more evidence of a lack of proper and meaningful consultation with communities;
- The planning process should have aimed to place patients closer to their places, or places where they came from. The multiple transfers from NGO to NGO and to hospital and the evidence that many patients were transferred far from the homes indicates no or poor planning in this regard;
- The MOA between the GDoH and NGOs does not appear to be a document arising out of a consultative process. 10 The agreement is one-sided in the sense that it stipulates what the NGOs should satisfy, without commitment by the GDoH to provide the necessary resources. These would include infrastructure, specialist clinical support, managerial support and salaries to ensure stable and sustainable staff complements;

#### **Implementation**

The implementation of the LE Project was also unwisely performed, as evidenced by the following findings of the investigation:

The lack of data integrity and the absence of information;

The most notable **finding** of the investigation was the lack of data integrity and consistent information from GDoH regarding the numbers of patients moved from LE and the transfer processes that were followed. There was no patient register and no data base for the "LE Project". None of the figures between the GDoH, LE or the NGOs added up and it is still not known exactly how many patients were actually transferred from LE to the various facilities;

Regarding the deaths that occurred, the GDoH only listed 48 and 80 lately, (Dr. Manamela), 36, 37, 40 or 80 (Dr. Selebano) and 40 (MEC Qedani Mahlangu) depending on who one spoke to. Three senior officials of GDoH have no common total number of the deaths between October end and 29th November 2016 (when I last interviewed the MEC). However, the MAC had identified and confirmed at least 66 deaths by the middle of September 2016 and the OHSC inspectors identified and confirmed at least 73 deaths between the 1st April and the end of October 2016:

Around the 13th December 2016, 21 days after Dr. Selabano gave evidence to the Ombud, he did the following: i) a new list surfaced and was prepared through the offices of the HoD and the Director of Mental Health at 00:19hrs. This new list had the 'grand total' of 80 deaths for the first time. Neither the HoD nor the Director had provided this list nor this total during oral evidence to the Ombud. Instead both the HoD and Director were floundering giving contradictory responses; ii) surprisingly on the same date, the HoD sent another signed memo to the Ombud directly with a total death of 37. Surely these two totals could not be both true.

Of significance in this memo was Dr. Selebano's revelation and claim that the 'decision to start deinstitutionalization of mental health care users from LE was undertaken in the Office of the Premier of Gauteng, the Honourable David Makhura, together with the HoD'. It was in the Premier's Office and not by the Premier that the decision was taken. He later says 'there were simultaneous engagements by the MEC, Ms. Qedani Mahlangu, and the HoD with LE. The purpose of these engagements were to discuss the implications and process of the decision to terminate the contract'. During oral evidence Dr. Selebano would not reveal who 'stalled his alternative approach plans', who was giving him instructions or 'placed them under pressure'; iii) Finally, Dr. Selebano then proceeded to sign all the NGO licenses afresh that Dr. Manamela had initially signed. He signed them as 'licences and not as 'certificates' as he argued during oral evidence. He back-dated all the licenses to 1st April 2016, without indicating on which date he signed them.

This latest list of 80 deaths had the following; it excluded 5 deaths from Hephzibah Home and it had now reclassified all the 9 deaths from Siyabidinga into deaths at CCRC. The 9 deaths from Siyabadinga had been clarified to the Ombud by the Acting CEO of CCRC, Ms. Matilda Malaza early on in the investigation that they had not originated from LE;

In reconciling the various data sets from the OHSC inspectors, the Expert Panel, NGOs, emails received from families trying to trace 'lost' relatives, the GDoMH and from the MEC's last list, the Ombud identified 7 more unaccounted deceased. Some of these had died between April and July 2016. The Ombud, the Statistician-General and the Expert Panel have already commented upon the inconsistency and unreliability of data furnished by the GDoMH. The Ombud can only wonder how the GDoMH can provide quality service and care with such poor and unreliable data. 3 names of patients, 9 dates of death and 2 IDs had changed between the different data sets. It was not clear why GDoMH had not identified these 7 deceased earlier. However, the Ombud verified these 7 to bring the total death to 94.

One of the 7 above was Mr. Charity Ratsotso who died on 11th July 2016. The family was not notified until 20th/12/2016, when by sheer accident one relative paid a visit to CCRC. This is almost five months after the death. The deceased's body was still in the mortuary with other unidentified bodies. Such is the neglect and callousness of some of the GDoMH staff observed during this investigation. That there are still unidentified bodies should be of grave concern;

The reasons for these sudden changes were not clear. It would appear that by altering the cut-off dates and reclassifying the deceased one easily changed the total number of deaths! There appeared to be no respect for data accuracy. There also appeared to be a tendency to try keep the numbers low and away from the public or the media for allegedly 'political' reasons as both the MEC and HoD alluded in their evidence i.e. the death numbers have become a 'political game';

Furthermore, in the new list the GDoH claimed it could not trace the family member of Deputy Minister Bogopane-Zulu. 'All attempts to call the management of Takalani were fruitless'. The Ombud traced and verified the identity of the family member as Mr. Tlhapi Clerence Disene, who died at Takalani. This was done through the management of Takalani;

Two other LE-related transfer deaths had occurred: Sophia Molefe had died from allegedly 'overdose' while awaiting NGO placement which had been promised her mother and an Unknown elderly (81 yrs) male had died at Leratong Hospital. Apparently this 81-year old was transferred to Leratong during the 'rush' and was possibly missed by the GDMH team. All these added deaths brought the total death to 91;

The fact that there was no accurate documentation of the patients or the processes followed throughout the project was evidence of poor planning, chaotic implementation and a disregard for the human right of each patient to be accounted for;

#### Non-compliance with the MHCA

The MHCA of 2002 is designed to protect people with mental illness from overly restrictive care, inadequate CTR and from abuse by others. The category of Assisted MHCU indicates that the person is dependent on others for their mental health and wellbeing, due to a lack of capacity to assert themselves in an informed manner regarding mental health care decisions. It is for this reason that annual reports are made to the MHRB on a Form 13A as to the ongoing need to maintain Assisted MHCU status. Additionally, when a change in capacity and the person is discharged, the MHRB is informed with a Form 03 which also may serve as a referral letter for outpatient care;

Only one of the 38 patients was deemed clinically appropriate for discharge with a Form 03. None of the other patients may be considered as discharged. Although Form 03s were completed in 10 other patients, it should have been evident to the MHRB from the previous MHCA Forms that it was not possible for their mental capacity to have improved due to the irreversible nature of their diagnoses. The continued MHCA status as Assisted MHCU after transfer was evident by the Form 13A accompanying 9 of the patients with Form 03s to the NGOs. Furthermore, those Form 03s which were undated are invalid:

The non-compliance with the MHCA is more significant than just the chaotic manner in which forms were completed or not completed. It indicates a lack of appreciation for the responsibility of the Department of Health towards an extremely vulnerable group of people.

#### Multiple transfers

Multiple transfers of numerous MHCUs occurred immediately prior to and during the "Project Period." Patients were transferred from the LE Witpoort centre to other LE centres in September, 2015. At least 40 were transferred from the LE Waverley centre to the Randfontein /Randwest complex before being moved to other facilities. An unknown number initially placed at CCRC were transferred to Siyabadinga, Anchor Centre and other NGOs. At least 20 were then moved from the Anchor Centre to Precious Angels. From the GDMH response to questions, there were numerous other transfers between NGOs and from NGO to hospital as facilities were relocated or closed;

The Expert Panel judged from the records that only 14 of the 38 MHCUs studied could have been regarded fit enough for transfer, if transferred with care to a facility with at least equivalent care to that at LE. The majority of patients were found to be not fit for even one transfer. Not only are the multiple transfers reflective of chaotic planning and implementation, they also reflect a lack of understanding of the clinical condition of the MHCUs, their vulnerability and their need for constant, stable health care.

**Summary 4:** The planning was poor or non-existent, implementation was chaotic, with no accurate, consistent data for decision-making, monitoring and evaluation; the implementation was non-compliant with the MCHA. Multiple transfers not only exacerbated the poor quality of data but added more anxiety and stress to the MCHUs.

# THE TRANSFER PROCESS: NUMBERS AND SPEED, RUSH AND CHAOS

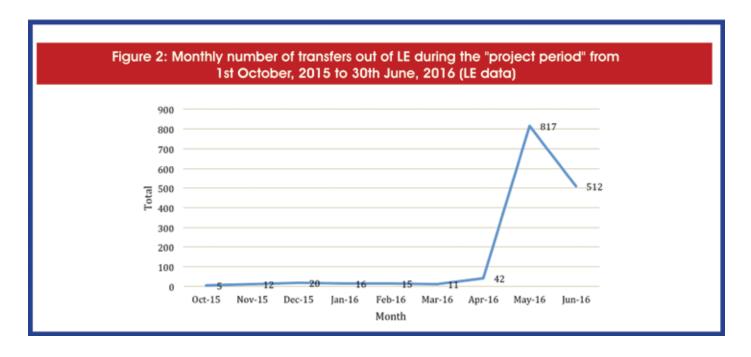
#### The transfer process

According to the GDoH summary, the LE bed capacity of 2260 had remained unchanged from 2008 to 2015. In September 2015, the Witpoort LE centre was closed and MHCUs were either discharged home or transferred to NGOs or to the other LE centres, and the bed capacity was reduced to 2060. The bed occupancy was reported as such that there were 1812 MHCUs at LE at the start of the "project period," with 295 of these being children and adolescents at the Baneng centre, for which the contract was continued.

However, only the placements of 1397 MHCUs transferred out of LE are accounted for in the GDoH summary report.

Of these, 217 were placed at the specialist academic psychiatric hospitals, Weskoppies and Sterkfontein. A further 141 were placed at the CCRC, a non-academic, district health care facility which provides long term primary and secondary level care for people with ID with 24-hour nursing. The remaining 1039 were placed at 27 different NGOs (Figure 1). The number of patients discharged home were not included in the report.

LE provided a data sheet of numbers of patients transferred out during the "project period." According to their statistics, a total of 1450 were transferred out between October, 2015 and June, 2016; with 817 transferred during the month of May (Figure 2).



Two lists were provided by LE of patients transferred out from the Randfontein/Randwest complex and the Waverley Care Centre respectively. The lists were compiled by the LE social workers according to patient name, address and date of birth and utilised placement information provided by the GDoH. These inventories accounted for the transfers out of 1345 patients, 794 from the Randfontein complex and 551 from Waverley. Transfers between LE Centres prior to NGO placement were documented as well as patients whose placement was not known to the LE staff. At least 20 patients were transferred from Waverley to Randfontein prior to NGO placement (the Waverley

list recorded 40, but only 20 of these were documented by the Randfontein social workers). Another 32 patients were transferred from Waverley to the Baneng Care Centre, 18 were discharged home from Waverley and 3 died at LE prior to transfer. The placement of 53 patients was not identified. From these two inventories, a total of 1239 LE patients were documented as being placed at NGOs or hospitals. However, the figures for some of the NGOs are not consistent with the data provided in the GDoH summary;

On interviewing selected NGO managers, three NGOs

reported receiving numbers of MHCUs which differed to both the GDoH report and the two lists from LE. These were Precious Angels, with 57 patients, Hephzibah with 30 patients and Takalani with 117. Siyabadinga, an NGO that was closed early in the LE Project due to alleged unlawful operation, received 73 patients as a subsequent transfer from the CCRC.

There were no formal patient registers available from the GDoH, LE or the NGOs from which to accurately ascertain initial placements and subsequent transfers, or the final number, of the MHCUs transferred out of LE.

## Chaotic Multiple Transfers and Interventions after initial placement at an NGOs or hospitals

As, after the initial placement of MHCUs from LE, some MHCUs were transferred either from one NGO to another NGO or from NGO to hospital, information was requested of the GDoH regarding these transfers as well as the closure of certain NGOs. The GDMH responded with the following information:

- 45 patients were transferred from one NGO to another after initial placement:
  - 4 from Elshadai to Bophelong, Mamelodi on 20/05/2016;
  - 1 from Elshadai to an old age home in Soweto at family's request on 16/07/2016;
  - 11 from Elshadai to Sebo Sa Rona on 20/08/2016;
  - 11 from Anchor Centre to Precious Angels on 20/06/2016;
  - 1 from Precious Angels to Sebo Sa Rona on 20/08/2016;
  - **8** from Sebo Sa Rona to Bophelong Suurman on 10/09/2016;
  - **3** from Ubuhle Benkosi to Rebafenyi on 22/07/2016
  - 12 from Anchor Centre to Precious Angels on 06/07/2016;
  - 4 from Shammah House to Bokang on 12/10/2016 (as reported by the GDMH, although Bokang was moved to Sterkfontein hospital on the 30/08/2016).
- Some NGOs were "moved", essentially relocated, into hospital wards in their entirety, i.e. the patients, carers, general workers and NGO managers were transferred to continue care within the hospital environment. In this situation, the hospital provided bed space and medical and psychiatric emergency cover; These NGOs were:
  - Bokang Moved on 30/08/2016 to Sterkfontein Hospital with all 23 male patients;
  - Siyabathanda Moved on 12/09/2016 to

- Sterkfontein Hospital with 10 female patients. Two patients were discharged home and one was placed in a general hospital;
- Precious Angels Closed by the MAC and moved on 19/09/2016 to Kalafong Hospital with 13 of their patients. Of their remaining patients; 10 were placed at Pretoria West Hospital, 10 at Weskoppies Hospital and 6 at Tshwane Hospital;
- Two NGOs were closed for renovation of the premises and the patients placed in those hospitals which had available space, as follows:
  - Bophelong Suurman closed for renovations on the 27/10/2016. Thirty patients were placed at Weskoppies hospital, 6 at Bokang and one at the CCRC. (As noted above, the NGO to placement at Bokang in view of the move of this Sterkfontein was not explained by the GDMH);
  - Anchor Centre closed on the 31st October on the recommendation of the OHSC Inspectors and Ombud and 27 patients were placed at CCRC:
- After the implementation period a total of 24 patients were admitted into acute psychiatric units due to a relapse of the mental illness. One of these was from Tshepong Centre. The other 23 were all from Rebafenyi in the Tshwane district and were admitted to Jubilee Hospital (N = 5), Kalafong Hospital (N = 5), Pretoria West Hospital (N = 2), Tshwane Hospital (N = 2) and Weskoppies hospital (N = 9);
- There were 5 types of transfers: i) the intra-LE transfers; ii the LE to NGO; iii) the LE to Psychiatry Hospitals; iv) the NGO to Psychiatry Hospitals and v) finally the inter NGO transfers. These transfers were complicated by two factors: the movement of some frail and sickly patients 2 or 3 times and the transfers occurring without the knowledge of or communication with patient's relatives;

Sterkfontein Psychiatry Hospital received 65 male patients directly from LE. These were patient deemed not fit for NGO placement by the doctors at LE. They were in good condition and none died. They were placed in Wards A and B which are normal wards.

Two NGOs, Bokang and Siyabathanda transferred 23 males and 18 females respectively to Sterkfontein Hospital. The females were provided clothing, linen and food. All treatment was started afresh. A further 10 patients from NGOs has arrived. In total Sterkfontein now houses 116 patients through the transfer;

**Weskoppies Psychiatry Hospital** received 72 and 62 patients directly from LE Waverley and Randfontein on  $5^{\text{th}}$ ,  $12^{\text{th}}$ ,  $24^{\text{th}}$  and  $31^{\text{st}}$  May and on  $2^{\text{nd}}$ ,  $7^{\text{th}}$ ,  $9^{\text{th}}$  and  $20^{\text{th}}$  June respectively;

**Four** NGOs, Tshepong, Precious Angels, Rebafenyi and Bophelong (Suurman) later sent 4, 8 10 and 29 patients respectively to Weskoppies Hospital. These were sent on the 29<sup>th</sup> of July 2016, 19<sup>th</sup> of September 2016, 6<sup>th</sup> of October 2016 and 27<sup>th</sup> of October 2016 respectively from the four NGOs;

In total, Weskoppies Hospital received 185 patients, 134 were direct transfer from LE and 51 were transfers from 4 NGOs. Two patients died;

The 134 direct transfer patients were identified 'as more suitable for hospital care and not NGO care by LE doctors;

The reasons for the inter-NGOs transfers were: 'patients relapsing on treatment' (Tshepong); 'NGO not suitable for placement, not and safe and patient's wellbeing at risk' (Precious Angels); 'Patients needing more clinical attention particularly with treatment that is not available at the NGO' (Rebafenyi); 'NGO not suitable for placement of patients' (Bophelong Suurman);

Other transfers discovered by the Panel and Ombud during the investigation, including that of an unknown number of patients initially placed at CCRC to other NGOs and of 20 patients from Anchor Centre to Precious Angels during September, 2016 were not accounted for in the response from the GDMH. **CCRC transferred** patients into Anchor, Siyabadinga and Precious Angels.

In addition, no rationale was provided in the response for either the transfers of patients or the relocation of NGOs.

#### MCHUs Transfer and Deaths without the 'knowledge of relatives':

- Ms. Virginia Gwen Machpela was moved around several times between NGOs; Virginia was transferred from LE to CCRC, to Anchor and finally to Precious Angels, where she died;
- Mr. ST Hlatswayo was moved between LE to Odirile back to LE and then to Anchor;
- Mr. Hendrik R Maboe was also moved around before finally moving to Bophelong Suurman;
- Mr. Alfred Sibiya was transferred from LE to Thuli Home and his date of death was 27th /07/2016, Home Affairs had been informed that the date of death was 15th/07/2016, this all happened without the knowledge of the relatives. All these are supported by signed affidavits;
- Mr. Sizwe Nkosi was transferred to CCRC. The family lives in Soweto.
- Mr. Charity Ratsotso was transferred from CCRC to Anchor Home without the knowledge of his family. He died on 11th July 2016 and his family only got notified on 20th/12/2016 by the GDoH The family is yet to receive a full report from the GDoH.

#### Patient transfer processes followed:

Clinical fitness to transfer – The underlying diagnosis of all patients included severe psychiatric diagnoses, such as schizophrenia and severe intellectual impairment. All patients were poorly functioning, with 17 of the 38 extremely poorly functioning;

Only 13 of the 38 could have been regarded fit enough for transfer, although remaining frail, if adequately cared for and transferred to an appropriate facility with high quality nursing care. The majority of patients were found not to be at all fit for transfer but there was no choice or alternative;

The lack of clinical fitness of the majority of patients to be transferred might have contributed significantly to the deaths of these patients;

The transfer or discharge of mentally ill is a regulated process (Regulation 43 of the Regulations to the Mental Health Act 2002; Mental Health Act 2002 Section 72; National Mental Health Policy Framework and Strategic Plan 2013-2020). The process is patients-based and patient-specific i.e. each patient must be individually assessed first and a suitable environment found for discharge, placement or transfer. This basic legislative requirement was not observed nor complied with in this project. Instead the transfers were random but importantly NGOs like in a 'cattle auction market picked and chose' which patient to accept and receive or not accept and reject;

The decision to move MCHUs around NGOs was the sole discretion of Dr. Manamela.

All the above are a reflection of poor planning, chaotic execution and poor data integrity to make correct decisions, monitor and evaluate a system. The various interventions not only illuminated the challenges but demonstrated the failure of this approach.

Summary 5: The transfer process was complex, characterized by high volume numbers of MCHUs in May and June and high speed. It was 'hurried, rushed and chaotic' as described by many; the accuracy and reliability of the numbers provided by DGMH are anyone's guess; the multiple transfers and the 5 types of transfers found illustrated the confusion that reigned and the added trauma to MCHUs during this period. The sudden closures and transfers of MCHUs from some NGOs back into hospitals asked deeper questions on the planning, proper preparation and the rationale for selecting and licensing some of these NGOs. Various forms of interventions compounded the challenges already faced in the Project and demonstrated the failures in this 'rushed' approach. Dr. Manamela was the central figure and must shoulder the accountability and responsibility for these activities.

## COST COMPARISON OF LE AND THE PLACEMENT FACILITIES

Costs of care per day per MHCU differed dramatically between the different facilities (**Table 4**). The costs at Weskoppies, Sterkfontein and the CCRC were obtained from the respective CEOs. That at LE was provided by the GDoH in their summary report and confirmed by Dr. Patel of LE. Neither the GDoH report, nor the Memorandum of

Agreement (MoA) between the GDoH and NGOs reflected the monthly subsidy per MHCU for NGOs. However, the NGOs reported receiving a subsidy of R 3 413 per month per MHCU as of October, 2016, which equated to approximately R 112 per MHCU per day.

Table 4. Average cost per day per MHCU by facility.

Health / NGO care facility	MHCUs placed (GDoH data)	Cost per day per MHCU	Cost per month (31 days) per MHCU
LE (2014/2015 budgeted cost)	2200	R 320	R 9920
Weskoppies Psychiatric Hospital (2016 budgeted cost)	140	R 1 960	R 60 760
Sterkfontein Psychiatric Hospital (2016 budgeted cost)	77	R 1 386	R 42 996
Cullinan Care and Rehabilitation Centre (2016 budgeted cost)	141	R 1 486	R 46 066
NGOs (2016 government subsidy, approximate cost)	1039	R 112	R 3472

MHCU = Mental Health Care User, NGO = Non-Governmental Organisation

**Summary 6:** If cost was the rationale for the termination of contract and transfer of MCHUs from LE to NGOs, see what the GDoH is paying now on Table 4; one has to ask what quality health care service can be delivered anywhere for an estimated cost of R112 per day. This surely must represent a serious form of neglect and denial of quality health care to one of the most vulnerable population of our society.

# 14 THE NGOs

The new NGOs were not only poorly prepared or ill prepared, but also lacked appropriate infrastructure, capacity and the basic competence in mental health care. There was a mismatch between the patients' requirements and the abilities of staff within the NGOs. Patients needed quality care while the NGOs saw the Gauteng Health Department Marathon Project as a 'business opportunity'.

In a letter dated 26/09/2016 addressed to Ms. HH Jacobus by Dr. Makgabo Manamela, Director of Mental Health in Gauteng stated 'Evaluation visits and follow ups made some improvements but there is much that needs to be improved.

I have noticed with serious concern that the status of the NGOs where we placed the Mental Health Users (MHCU) from LE leaves much to be desired'

Dr. Mataboge, a Specialist Psychiatrist in Tshwane made the following comments telephonically which she confirmed on record under oath: 'She and a team had inspected 9 new NGOs in the Tshwane Region. 8/9 could not function or barely functioned and only 1 functioned well. These NGOs were not properly prepared beforehand and the process of transfer was 'too quick'. It did not look like due process of assessment and the basic requirements for a facility of this type of care were followed and done. The selection and licensing was problematic for her. NGO staff were overwhelmed, were without skills and knowledge and did not know what was expected of them. Hospitals were given priority above the districts in preparation for the project and some districts were left out. As a result, the district clinics were also not ready or linked properly to the new NGOs. The team had to recommend or arrange for staff training and for better monitoring and evaluation systems. The MEC was concerned about 'patients' safety and security' as some patients 'were not stable and some were relapsing' One NGO, Bophelong (Suurman), it was recommended that 'all 33 patients be removed' and 14 patients from Rebafenyi were also moved into a hospital because of 'relapse'. Bophelong (Suurman) is the same NGO where 'Billy Moboe' was transferred to ('dumped' according his dad) and later died at Jubilee Hospital.

Dr. Mataboge's comments were echoed by Dr. Sokudela, Psychiatrist and Clinical Manager at Weskoppies Psychiatry Hospital: 'The reasons for the inter-NGOs transfers were: 'patients relapsing on treatment' (Tshepong); 'NGO not suitable for MCHUs placement, and not safe and patient's wellbeing at risk' (e.g. Precious Angels); 'Patients

needing more clinical attention particularly with treatment that is not available at the NGO' (e.g. Rebafenyi); 'NGO not suitable for placement of patients' (e.g. Bophelong Suurman)'. All these 4 NGOs had to transfer patients to Weskoppies Psychiatry Hospital

**NGO Capacity** – The investigation found a high degree of variability in the capacity of NGOs to provide the level of care required. It was also found that district health services had not been capacitated to support the NGOs.

Of great concern was that no training or qualifications of NGO staff was a **prerequisite for licensing**. Untrained or poorly trained staff would have been an additional factor contributing the deaths.

**Effects on the referral service system** – Referring back to the MH Policy and the need for bed capacity at medium to long stay hospital, as well as residential NGOs, raises the concern that there is now a completely inadequate bed capacity in Gauteng Province.

Immediate effects are that many more MHCUs than those transferred in the LE project will be affected, as the entire referral system is now even more poorly resourced than before.

#### Conditions and deaths at NGOs

The conditions to which MCHUs were subjected to during the period of transfer from LE and into the NGOS were negligent and devoid of respect for human dignity and rights. These conditions in many respects breached and violated the patient's Constitution Rights to Health and breached the NHA and the Mental Health Act 2002. These issues were pointed out to the GDoH before by a wide range of stakeholder.

The conditions were:

- The conditions in some of the NGOs are best described through the article on Mr. Collitz at Mosego on pages 12-13 and corroborated through other lines of evidence;
- transferring 'frail and sickly' assisted MCHUs from the 'structured environment' of LE of 24hrs non-stop competent health care with qualified medical,

nursing and social workers staff into the 'unstructured environment' of newly-established and illegally licensed NGOs, some of which, had no competent leadership, had no managerial capacity and had no qualified professional staff to take care of the specific health and medical care needs of the transferred MCHUs, these facts were established by the Expert Panel, the OHSC Inspectors, the Ombud during interrogations and the MAC;

- the NGOs staff were not trained nor the NGO prepared for the task at hand; the words 'rushed, unprepared, notice too short, we needed or training could have assisted' were often used by NGO managers during the Ombud interrogations,
- the NGO infrastructure not only 'left much to be desired' (Dr. Manamela) but was also unsuitable, unsafe and often insecure to host such high risk patients, evidence established by the Expert Panel, the OHSC Inspectors and the MAC;
- the NGOs did not have financial support for infrastructure, for food and for clothes and beddings during the cold winter to make them sustainable (Ombud, OHSC Inspectors and MAC);
- Overcrowding was commonly found in some NGOs;
- The OHSC inspectors found that 14 out of 25 NGOs inspected were non-compliant and some 'not fit for purpose' and recommended their closure.
- The MAC had closed one Precious Angels already and the Ombud had recommended the immediate closure of another, Anchor following OHSC Inspector's and Expert Panel recommendations;
- The GDMH also recommended the closure or transfer of 4 additional NGOs; NGOs which they themselves had just recently granted licenses. This say much for their licensing criteria;
- The transfer of patients without the knowledge of relatives; vi) the poor pre-selection and assessment that led to the transfer of some patients to several NGOs and some NGOs conducting inter-transfers to the detriment of the patients;

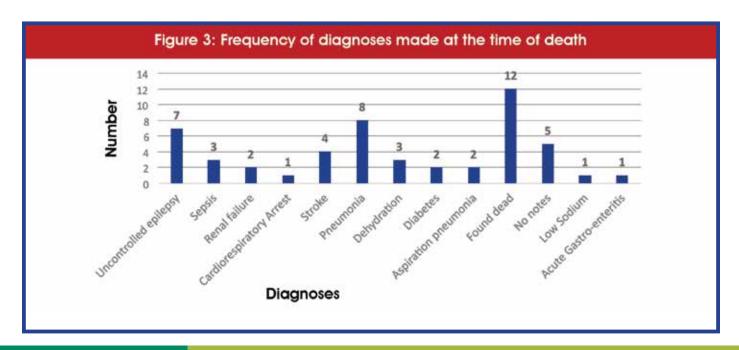
The failure to communicate and notify relatives timeously of adverse events such as death was devoid of respect for human dignity; viii) to transfer patients into an environment where food was scanty and there was no warmth infringed on patients' rights; ix) to transfer MCHUs to far away and unfamiliar communities seemed absurd considering the rationale for the 'closure'.

All the above activities bordered on the criminal for the following reasons:

- it is totally against the fundamental principle of health care practice to consciously remove a patient let alone a 'frail and sickly' patient from an environment of stable professional care to an insecure environment of less quality care or unpredictable and unprofessional care; this decision was made despite professional and expert advice and warnings;
- it went against the assurances provided to the court by the GDoH i.e. that the MHCU's health would not be compromised by the transfer to NGO's (Section 27 and LE Executive Summary);
- it went against the spirit of commitment given to relatives and the doctors at LE by the MEC.

Causes of death for the sample of 38 deaths – There was insufficient information to establish the cause of death in several patients. An immediate cause of death could only be identified in 21 of the 38 patients (Figure 3). The most common causes were community acquired pneumonia, followed by uncontrolled seizures. The former raises concern about the living conditions and infection control at the NGOs, while the latter raises concern that these patients did not receive medication for their epilepsy.

Examining the immediate cause of death only provides a limited explanation of the circumstance. For example, the underlying frailty and co-morbid medical illnesses of most patients would have predisposed them to increased risk



of pneumonia, other infections and dehydration. A stable nursing environment was therefore needed for these patients. The rapid transition from a familiar, stable nursing environment to an insecure environment with untrained personnel, would have been a precipitating factor to the deaths. The higher calculated death rates and higher death percentages at the NGOs provided the close linkage and association of the observed deaths to some of the NGOs.

The MEC, HoD, the Director of Mental Health and Her team, the various directors of the 3 NGOs, Precious Angels, CCRC/Anchor/Siyabadinga, Mosego/Takalani and the other NGOs all knew they had no capacity, no competent and qualified professional staff to look after such patients. Vulnerable patients were thus placed into circumstances that could not preserve their lives.

#### The Licensing Process

The evidence for the irregular licensing process came from the various stakeholders including the NGOs during interrogations. This information was often volunteered.

- All the NGO licenses provided to the Ombud with the initial documentation were signed by Dr. M. Manamela and were effective on the 1st April 2016 to 31st March 2017. Dr. Manamela is not legally authorized nor has she the delegated authority to sign licenses. Dr. Manamela is fully aware she has no 'delegated authority to sign licenses' and confirmed this during oral evidence; the HoD is also aware of this irregularity and he confirmed this during oral evidence. The authority to sign licenses was raised sharply by senior staff of the NDoH as common practice dictated by Regulation 42 requires the Minister or DG in the National department or the MEC or HoD in the Provinces to be signatories to licences. The DG at NDoH had also emphasized this point in her evidence. In this Project licenses were issued and signed by a Director! This is very irregular;
- All licenses were issued for a year from April to March the following year, irrespective of when they were signed; in this scenario no one would know when the assessments were conducted and who conducted them; there were no clear criteria document available despite repeated requests from relatives and or families, from OHSC inspectors, from the Ombud and from some civil society organisations and staff of the NDoH, that were used in the process. These criteria had been requested by many stakeholders including the Ombud to no avail;
- However, some of these NGOs started receiving patients and operating even before they were issued with licenses (Ombud, OHSC report, SADAG, Relatives and staff voices within the GDoMH) e.g. Siyabadinga never had a license and never had an assessment for licensing but received 73 MCHUs from CCRC;

**Takalani** has no NPO license as it was deregistered, but is 'trading' and operating under Mosego's irregular license; Precious Angels was initially given a license for Kalafong Heights but the place issued for the license was not where patients were received and accommodated as they relocated without the knowledge of the department, implying patients were received into and some may have died in irregularly licensed premises, a very serious contravention of the MHCA; other NGOs were requested to increase capacity and promised licenses that have not materialized e.g. Mosego; again patients were received and some died during this period of 'promised licenses'; Mosego only received a legitimate license for 200 MCHUs the day after interrogation, this licence was signed by Dr. Manamela; other NGO licenses and SLAs issued and used did not often correspond with the NGO titles, some SLAs were not signed yet and yet others were used as cover to run other as yet unlicensed NGOs, the Mental Health Directorate had no legal contract with some of these NGOs (Ombud and OHSC Inspectors). Siyabadinga received 73 MCHUs from CCRC without a license and never had a license; 9 MCHUs died in this unlicensed NGO; Ubuhle Benkosi moved MCHUs from Pretoria North to Marabastad and then later to a place near Lanseria Airport without the knowledge of the department and without licenses and eventually to Centurion, one MCHU died. The monitoring and evaluating systems of the Directorate were dysfunctional and unable to detect such irregularities;

- All these irregular activities are serious contraventions
  of the law and rendered these NGOs illegal and
  the department liable. These activities took place
  under the watchful eye of Dr. Manamela, the
  Director of Mental Health. She provided legitimacy
  to these irregular and unlawful activities. Mentally
  ill patients were thus subjected to high risk through
  these illegal activities;
- There was no obvious template, criteria or processes that were used consistently to select or grant licenses to NGOs. The accreditation process was not documented nor legally authorised. It remained mysterious to most stakeholders who were interrogated. This was summed up by the following comment in an affidavit from an attendant at a meeting at Sterkfontein Hospital in November 2015, 'Even more disturbing was the fact that after the meeting licenses were issued to some of the attendees on the spot. I am not aware of any accreditation process which was followed before same were issued';
- The Ombud interviewed Dr. Manamela and Dr. Selebano separately on 23rd November 2016.
   Following this interview, Dr. Selebano went out to sign all the licences for the NGOs afresh. Effectively all NGOs to which patients were transferred have two licenses, one signed by Dr. Manamela provided and

confirmed during the investigation, the second signed by Dr. Selebano sometime after his interview. The effect of this action by Dr. Slebano are: it confirmed that the previous licences signed by Dr. Manamela were indeed invalid; all 27 NGOs to which patients were transferred from LE operated under licenses that were invalid; therefore, all patients who died in these NGOs during this period of transfer and investigation died under unlawful circumstances; Dr. Selebano undertook this action knowing he has given evidence to the Ombud; the ethics and seriousness of this finding cannot be underestimated;

- The main NGOs were Precious Angels, Mosego, Takalani, Anchor, Siyabadinga, Tshepong and Ubuhle Benkosi
- Appropriate remedial action must be taken against Dr. Selebano and Dr. Manamela.

#### Governance within the NGOs

The governance and management structures were often not dedicated, were confusing and contradictory to the licenses or the SLAs signed. Good corporate governance was non-existent in some NGOs. The examples of Anchor/CCRC/Love Disciples/Siyabadinga complex with seesaw relationships, operations and legal battles, despite these, Siyabadinga still received 73 patients from CCRC without a license; or Mosego/Takalani Homes governance and Rebafenyi with 3 different houses and 3 different managers come to mind; (the Ombud, OHSC Inspector's & MAC).

### NGO Capacity and access to health care

The capacity of the NGOs and the access to health care were not equivalent to that of LE with regards to the needs of these Assisted MHCUs with multi-morbidity and severe disability.

The standard required of the NGOs by the GDoH differed from that of LE, which provided 24-hour professional nursing, on-site medical and psychiatric care and transfer to general hospitals when needed. Feedback from the 2014/2015 LE audits by the GDMH included insufficient professional supervision of physiotherapy assistants, a lack of after-hours and weekend occupational therapy programmes, a need to improve the information handover at changes in nursing shifts and that more handwashing facilities for staff were required. By contrast,

besides the employment of a visiting nursing sister at R5 400 per month, the staff of NGOs were not required to have any experience or qualifications in mental health CTR. In addition, there was no indication of MHCA status for which the NGOs were licensed, and there was no commitment by the GDoH to provide social work, occupational therapy or physiotherapy to support rehabilitation programmes. The investigation however found a high degree of variability in the capacity of NGOs to provide the level of care required. Identified factors that positively influenced the capacity to provide appropriate care included;

- the years of operation and financial stability of the NGO
- the experience and insight of the NGO manager regarding the needs of MHCUs
- taking fewer patients from LE
- higher staff: patient ratios, with some experienced staff members to guide care-workers
- ready access to medical care.

Access to medical care appeared to be worst in Tshwane, where 52 of the 73 deaths occurred (excluding the 2 deaths at Weskoppies) and where none of the over 600 placed MHCUs had received a routine general medical examination. The high number of deaths at the NGOs (mainly Precious Angels) could reflect inexperience of the NGO staff in detecting medical problems in mentally disabled people and difficulty in obtaining timeous transport to hospital.

The inadequacy of certain NGOs to manage the MHCUs from LE is also reflected in the reaction by the GDoH to relocate or close these facilities.

Summary 7: Almost every National Health Norm and Standard (domains 1-7) was breached by the NGOs visited and inspected; there were several unlawful and irregular licenses issued to the NGOs by the Director of Mental Health; the conditions in some of the NGOs were found to be of such substandard that MCHUs placed there would be at higher risk than they would be at LE, as a consequence of the transfer into some of the NGOs, quality health care was withdrawn and substituted with sub-standard care; the critical comments made by Drs. Manamela, Mataboge and Sokudela above says it all about the unfolding chaos in the transfer process, the readiness, preparation, the sub-standard conditions and quality within the NGOs; the governance in some NGOs were of low quality and the capacity of NGOs was variable. In these circumstances quality health care of MCHUs was severely compromised.



## THE DEATHS, DATA INTEGRITY & MORTALITY ANALYSIS

**94**<sup>+</sup> mentally ill patients in total died in Gauteng Province and not 36 as earlier reported on 13th September 2016 by the MEC;

- The Ministerial Advisory Committee on Mental Health (MAC) identified and confirmed 66 deaths by 27<sup>th</sup> September 2016;
- The OHSC inspectors identified and confirmed 73 deaths after visiting 25 NGOs by 31st October vs 17 NGOs visited by the MAC;
- Only 4 MCHUs directly transferred from LE died in hospitals compared to 77 MCHUs deaths at NGOs directly transferred from LE; in absolute numbers for every 1 death at the hospitals there were 19 deaths at the NGOs however, correcting for the total base population the ratio is 1:7 This ratio is very high (see Tables 5a & 5b);
- 95.1% of MCHUs directly transferred from LE died at NGOs:
- It must be appreciated that the very ill MCHUs were directly transferred to hospital while the 'stable' MCHUs were transferred to NGOs. Thus death at NGOs is very telling and significant of the conditions there;
- 77 patients died before 13<sup>th</sup> September; this is the day the MEC made the public announcement of 36 deaths in the Gauteng Provincial Legislature.

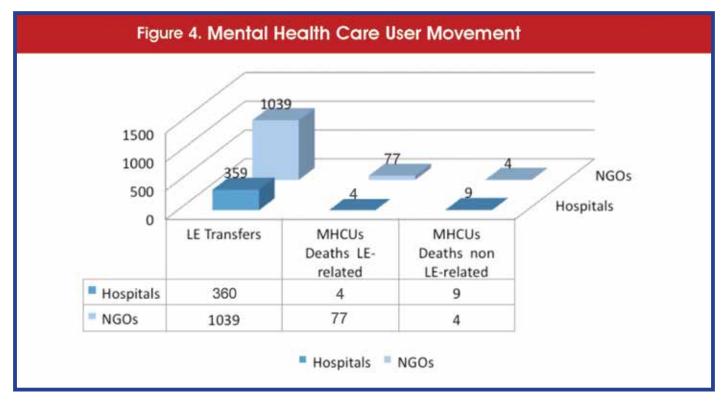
#### Why did the MEC not know this information then?

- 77 patients died within 5 months, (May 3, June 13, July 28, August 24 and September 9);
- 5 NGO/hospital complexes -(Precious Angels 20, CCRC/Siyabadinga/Anchor 25, Mosego/Takalani 15, Tshepong 10 and Hephzibah 5)- account for 75 deaths (79.78% of the total deaths);
- There were 11 NGOs with no deaths; 8 NGOs with average deaths; and 8 NGOs with 'higher or excess' deaths;
- However, only 48 patients were identified dead by the Gauteng Directorate of Mental Health (GDoMH) on 28th October and confirmed on 23rd November by Dr. Makgabo Manamela; it should be noted that this figure is 18 and 25 deaths less than the figures identified by the MAC on 27th September and the OHSC inspectors and Ombud on 31st October 2016;
- 81 deaths were LE-associated while 13 deaths were not;
- 8 of the (8.5%) deceased had come from the 'sick bay'; 7 of the 8 died at Precious Angels Home and 1 died at Weskoppies Psychiatry Hospital;
- Only 1 of the deceased died from alleged suicide!
- The average length of stay per patient was 57.2 days at the NGO for the 38 MCHUs analysed.

#### \* Table 5a & 5b

		Values	
MHCU movement	Hospitals	NGOs	Grand Total
LE Transfers	359	1039	1398
MHCUs Deaths LE-related	4	77	81
MHCUs Deaths non LE-related	9	4	13

\* A patient's point of entry or registration into the health system remains their permanent home. When patients left LE they were either discharged home, transferred to hospitals or NGOs. These became their registered homes within the health system irrespective of their movements or place of death. This is standard practice in health care and formed the basis of the analysis.



- The very ill MCHUs were transferred to hospitals directly; some of the 'frail but stable' went to NGOs.
   Still 7x more deaths occurred at these NGOs;
- The number 48 reported by the GDMH Director is not only low but also came as a surprise, but illustrated clearly the essence and the critical nature of data integrity in implementing, monitoring and evaluating a complex system and strategy such as in Mental Health Care in a Province or country; inconsistent and inaccurate data may lead to misinformation and wrong decision-making such as was the case in this investigation;
- However, even more startling is the fact that the HoD and MEC were aware of the MAC investigation, briefed the MAC and visited with some of the MAC teams to the various NGOs and still the HoD signed for the figure of 48 furnished by the Director of GDMH at the end of October but contradicted this figure in his oral evidence;
- In his evidence the HoD cited a figure of slightly above 36 for the number of deaths and later slightly above 40 deaths within the same interview; the MEC cited a figure of 40. That 3 senior officials of the GDoH could cite different figures in such a serious matter begs many fundamental leadership and governance questions;
- The scale and speed of transfer within 3 months, to new poorly prepared, not ready and not professionally staffed NGOs without a military-style type plan and execution led to total chaos and disaster in this project; staff in the GDoH reported severe levels of stress and several 'broke down' during the interrogations;

 The MEC's office provided the Ombud's office in total a list of twenty-seven NGOs that had been identified, 'licensed' and used. These together with the files of 36 patients became the focus of our investigation.

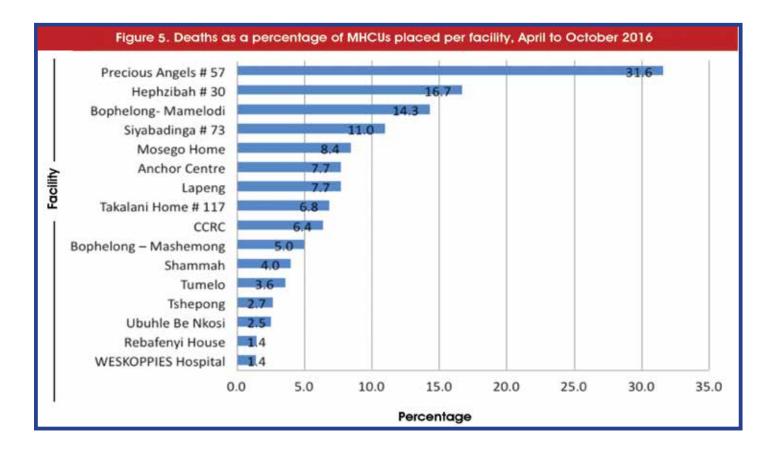
#### **Summary 8:** 94 patients died (verified)

- 77 patients died within 5 months (May September)
- 77 patients died before 13th September 2016
- 75 deaths occurred in 5 NGOs/Hospital complexes
- 11 NGOs had no deaths recorded

#### Mortality data

The total numbers of deaths at the placement facilities varied according to different sources. The OHSC inspectors identified a total of 75 deaths which occurred between the 1<sup>st</sup> of April (the start of the "implementation period") and the 31st October, 2016 (the cut-off date for the Expert Panel investigation). These were recorded per facility and per month. Of these 75 deaths, 73 occurred amongst MHCUs who had been placed at NGOs and CCRC. Figure 5 depicts the deaths per facility, according to the OHSC findings, as a percentage of the number of people placed. The # denotes the number of MHCUs placed according to the NGO reports rather than the GDMH report. These are used as there were no figures for Siyabadinga and a figure of only one MHCU for Hephzibah from the GDMH. Note the higher percentage at Bophelong – Mamelodi is related to the low number of MHCUs rather than a high number of deaths.

In consultation with StatsSA, the number of deaths at the NGOs and CCRC was compared to those occurring at LE over the same period of time in the previous two years.



This was done in order to establish whether or not the mortality rate was in excess of that anticipated had the patients remained at LE. The official figure from the GDoH of 1180 MHCUs was used as a denominator for those placed at NGOs and CCRC. This was adjusted for the deaths that occurred per month, but not for the numbers of MHCUs transferred into hospitals, or NGOs which were closed. Data from LE reflected a total of 54 deaths in 2015 and 78 in 2014 from April to October of each year, however the denominator does not change as it reflects the average bed occupancy.

Below is a comment by Dr. Pail Lehotla, the Statistician-General:

This investigation highlights the importance of proper administrative record management across all institutions. The presence of such is an enabler to comprehensive analysis and monitoring of issues. In the present case, the

data gaps that resulted as a consequence of inadequate record keeping have limited the kind of analysis that could have been made and thus enabled comparison of mortality levels across time and between institutions.'

Notwithstanding this issue, and using the information available from LE and the GDMH, table 5c shows the number of deaths, the underlying populations and the derived death rates by type of institution. If the information as provided is indeed used to make the comparison between deaths that occurred at LE and those at NGOs, one would have to conclude that, on the basis of this information, the 2016 NGO death rate of 0.07 is higher than the death rate at LE of 0.04 and 0.03 for 2014 and 2015 respectively. In other words, the information provided suggests that, 7 out of every 100 patients in the NGO facilities died in 2016. The corresponding figures for LE facilities are: 4 deaths out of every 100 patients in 2014; and 3 deaths out of every 100 patients in 2015.

**Table 5c**: Number of deaths per institution

2016 MHCUs in NGOs and CCRC	Apr	May	June	July	Aug	Sept	Oct	TOTAL
MHCUs died		3	11	25	22	8	4	73
Total	1180	1177	1166	1141	1119	1111	1007	1075
Death Rate	0,000	0,003	0,009	0,021	0,020	0,007	0,004	0,07
2015 LE	Apr	May	June	July	Aug	Sept	Oct	TOTAL
MHCUs died	4	6	13	15	9	6	1	54
Total	1805	1805	1805	1805	1805	1805	1805	1805
Death Rate	0,002	0,003	0,007	0,008	0,005	0,003	0,001	0,03
2014 LE	Apr	May	June	July	Aug	Sept	Oct	TOTAL
MHCUs died	8	8	17	16	7	11	11	78
Total	1962	1962	1962	1962	1962	1962	1962	1962
Death Rate	0,004	0,004	0,009	0,008	0,004	0,006	0,006	0,04

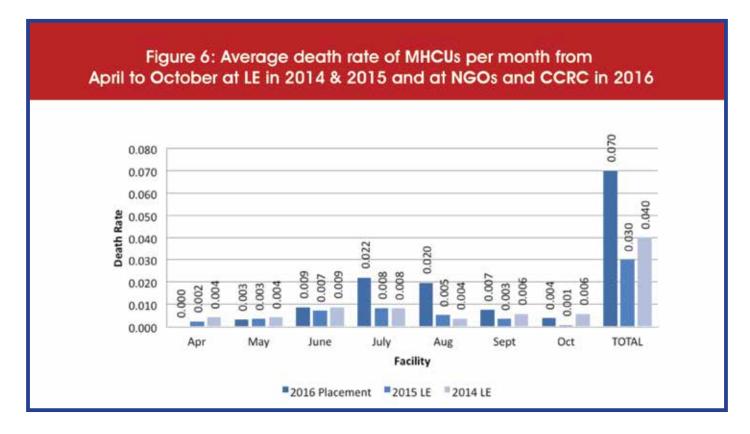
It is therefore Stats SA's position that death rates and comparative analysis thereof is difficult to undertake short of accessing raw data about base population at each point in time for those who died and those who survived. An effort should be undertaken to reconstruct such records by whatever means possible including associated contractual arrangements between LE and NGOs. Stats SA could put its resources to bear to undertake such a reconstruction'.

Using the figures in the table 5c, the percentage of people who died at the NGOs and CCRC peaked in July and August, 2016 and was in excess of the increase during the winter months at LE in 2014 and 2015 (Figure 6). The peak at LE occurred in July only in both years. The pattern of deaths at the NGOs appeared different from the pattern of death at LE. The per facility death percentages were even more striking.

The GDMH sought to explain and absolve or distance itself from the linkage to the 36 deaths (May-August 2016) by using the following argument: the causes of death were natural and 37 patients had died in 2010 (April-June) at LE, therefore this current figure of 36 deaths at NGOs was consistent and comparable with what took place at LE. Both reasons are false, lack statistical rigour and should be eschewed and rejected off-hand for the following reasons:

- The GDMH was aware that 12 cases were already reported to the SAPS for forensic pathology investigations by the MEC, a position the Ombud strongly supports;
- 8 relatives assisted through Section 27 and led by

- Christine Theresa Nxumalo had applied for judicial inquest of 8 residents who died at at Precious Angels;
- Several deceased had died from illnesses that questioned the conditions/circumstances under which and the quality of care patients received at NGOs e.g. fits, dehydration, aspiration pneumonia, acquired pneumonia, cardiac arrest, 'being found dead in the morning without night observations' etc. (Ombud, Expert Panel and MAC);
- So in short, nothing could be that simply 'natural'; the conditions and circumstances at NGOs made these deaths other than 'natural';
- The exercise of just picking up an absolute death figure of your choice without controlling for the total population under study, as the GDMH did in the analysis is statistically flawed. Deaths rates or even percentages are recognised as statistically better indicators;
- Finally, 'I received a file from the department of Health analysing the 'Deaths of 36 Mentally ill patients'. The statistical method and analysis done by the department appears flawed. Firstly, they choose a period in 2010 in one cohort and a period in 2016 for the alleged patients. The numbers are the same and they draw comparisons and conclusions from this; secondly the total population in the two cohorts is different; the cohort in the 2010 is in one place and the cohort in the 2016 is located in 6 places'. Dr. Christine Khoza, StatsSA.
- It seemed statistically and logically absurd that the cold winter of 2016 in Gauteng had only selected 5 NGO/hospital complexes out 27 NGOs.



Regarding the sample population of 38 patients, the NGO placement, date and place of death are indicated in Table 6. The date of death was ascertained in most cases by the NGO clinical records. In four patients it was taken from the OHSC inspector reports. Of the 38, one person died in May, five in June, sixteen in July, fourteen in August and two in September. Fifteen of the 38 deaths occurred at the NGOs, two arrived dead at hospital from the NGO and the remainder died in a general hospital.

**Table 6.** Date and place of death of the sample population

Patient No.	Date of death	NGO placement	Place of death
1	25/05/2016	Takalani Home	СНВН
2	06/06/2016	Takalani Home	Bheki Mlangeni Hospital
3	12/06/2016	Mosego Home	NGO
4	22/06/2016	Mosego Home	Leratong Hospital
5	25/06/2016	Rebafenyi	Kalafong Hospital
6	27/06/2016	Mosego Home	NGO
7	01/07/2016	Takalani Home	NGO
8	03/07/2016	Precious Angels	NGO
9	05/07/2016	Precious Angels	NGO
10	06/07/2016	Precious Angels	Kalafong Hospital
11	08/07/2016	Takalani Home	Bheki Mlangeni Hospital
12	17/07/2016	Precious Angels	NGO
13	18/07/2016	Precious Angels	Pretoria West Hospital
14	18/07/2016	Takalani Home	NGO
15	18/07/2016	Tshepong Centre	Hospice

**Table 6.** Date and place of death of the sample population (Continued)

Patient No.	Date of death	NGO placement	Place of death
16	18/07/2016	Precious Angels	Kalafong Hospital
17	22/07/2016	Bophelong, Mashemong	Jubilee Hospital
18	22/07/2016	Tshepong Centre	NGO
19	22/07/2016	Precious Angels	DOA Pretoria West Hospital
20	24/07/2016	Anchor Home	NGO
21	24/07/2016	Precious Angels	NGO
22	27/07/2016	Mosego Home	NGO
23	01/08/2016	Precious Angels	NGO
24	02/08/2016	Mosego Home	Leratong Hospital
25	03/08/2016	Mosego Home	Yusuf Dadoo Hospital
26	04/08/2016	Precious Angels	NGO
27	06/08/2016	Precious Angels	NGO
28	08/08/2016	Precious Angels	Pretoria West Hospital
29	15/08/2016	Precious Angels	Pretoria West Hospital
30	15/08/2016	Precious Angels	NGO
31	16/08/2016	Anchor Home	Mamelodi Hospital
32	23/08/2016	Bophelong, Mamelodi	Mamelodi Hospital
33	23/08/2016	Takalani Home	СНВН
34	26/08/2016	Precious Angels	Kalafong Hospital
35	29/08/2016	Mosego Home	НЈН
36	31/08/2016	Tshepong care centre	Kalafong Hospital
37	01/09/2016	Precious Angels	Kalafong Hospital
38	03/09/2016	Precious Angels	DOA Pretoria West Hospital

Most of the total deaths occurred in July and August (Figure 4). For the sample of 38, it was found that the average length of stay at the final NGO placement was 57.2 days before dying. Of the 38 patients, 25 (66%) died within 2 months of their final transfer to an NGO (**Table 7**).

Table 7. Duration in days between transfer and death by NGO placement

NGO	Nu	mber of day	/s between	transfer to N	IGO and de	ath
NGO	≤ 14	15 – 30	31 - 60	61 - 90	≥ 91	Total
Precious Angels	3	4	7	2	1	17
Mosego Home	0	1	2	3	1	7
Takalani Home	1	2	1	1	1	6
Tshepong Centre	0	0	1	1	1	3
Anchor Home	0	0	1	1	0	2
Bophelong Mamelodi	0	0	0	1	0	1
Bophelong Mashemong	0	1	0	0	0	1
Rebafenyi	1	0	0	0	0	1
Total	5	8	12	9	4	38

Of the 25 who died within 2 months of transfer to an NGO, only 7 were deemed fit for transfer by the Expert Panel (Table 8). Regarding site of death, 11 died at the NGO and one arrived at the hospital dead. Of note, 14 of the 25 were placed at Precious Angels. It was not known how many of these patients had had two or more transfers before being placed at Precious Angels. Over half of the 25 (14 patients) were assessed by the Expert Panel as having had an extremely poor level of functioning.

Table 8. NGO placement, site of death and fitness for transfer of the 25 who died within 60 days

NGO Placement	Patient No.	Duration of stay (days)	Site of death	Fitness for transfer	Level of functioning
Anchor Home	3	48	Hospital	Yes	Poor
Bophelong - Mashemong	17	22	Hospital	Insufficient information	Poor
Mosego Home	3	34	NGO	No	Extremely poor
Mosego Home	4	47	Hospital	Yes	Unknown
Mosego Home	6	24	NGO	No	Extremely poor
Precious Angels	8	10	NGO	No	Unknown
Precious Angels	9	12	NGO	No	Extremely poor
Precious Angels	10	7	Hospital	Insufficient information	Unknown
Precious Angels	12	18	NGO	Insufficient information	Extremely poor
Precious Angels	13	20	Hospital	Yes	Unknown
Precious Angels	16	19	Hospital	No	Extremely poor
Precious Angels	19	23	DOA - Hospital	No	Extremely poor
Precious Angels	21	31	NGO	No	Extremely poor
Precious Angels	23	39	NGO	Insufficient information	Extremely poor
Precious Angels	26	36	NGO	Insufficient information	Extremely poor
Precious Angels	27	44	NGO	Yes	Poor
Precious Angels	28	46	Hospital	Yes	Very poor
Precious Angels	29	53	Hospital	No	Extremely poor
Precious Angels	30	47	NGO	No	Very poor
Rebafenyi	5	8	Hospital	Insufficient information	Unknown
Takalani	1	12	Hospital	Yes	Extremely poor
Takalani	2	24	Hospital	No	Extremely poor
Takalani	7	50	NGO	No	Extremely poor
Takalani	11	29	Hospital	Yes	Very poor
Tshepong Centre	15	53	Hospital	No	Extremely poor

Five main characteristics of the NGOs were identified that could have contributed to the deaths of the 38 patients. These were as follows:

- Lack of skills and experience of NGO staff;
- The type of patients selected for the NGOs and lack of preparation of the NGOs;
- Lack of suitable infrastructure in the NGO;
- Programmes for rehabilitation and occupational therapy; and;
- Financial sustainability.

The Panel examined each of these factors in turn:

#### Lack of skills and experience of NGO Staff:

More than half of the patients that died were in newly established NGOs without the necessary managerial experience. The Precious Angels NGO illustrates all the above four factors very well, as delays in financial support from the GDOH could have precipitated the deaths of 18 patients;

#### The type of patients selected:

There was no evidence that patients were selected according to the skills and experience of the NGO staff with respect to the diagnostic categories and severity of disability. However, it appeared that the established NGOs or those with more experienced staff, e.g. Hephzibah and Tshepong, were better able to identify and request the patients that they believed they could manage;

#### Lack of suitable infrastructure:

The best NGOs that were visited had solid infrastructure and adequate facilities. San Michele illustrated this point very well; it was formerly a high school on a site area of 40,000 square meters with ample accommodation and usable space, although they were still in need of 30 beds. In contrast, Precious Angels, which tried to house 57 patients in two ordinary houses on a site area of about 1,500 square meters;

#### Programmes for rehabilitation and occupational therapy:

The best programmes were in the form of workshops for the different gender groups of mental patients (in San Michele), and the products of patients' work were marketed to raise funding for the NGO. Another example is Shammah House where patients were seen in groups walking to the nearby shopping centre as part of rehabilitation. This NGO was established in 2010 and the manager did not have special skills in psychiatry. It was merely the passion, experience and understanding of mental illness of the manager which contributed to the patients' welfare. On the other hand, the manager of Precious Angels had plenty of passion for the work, but her lack of experience and understanding of mental illness was evident in her being totally out of her depth in managing adult mental patients;

Another NGO, Mosego House in Krugersdorp, received regular structured support from the Occupational Therapists at the nearby specialised psychiatric hospital, Sterkfontein. Takalani also expressed an appreciation of the close proximity of one of the Soweto Clinics, which meant easier access to medical care. However, the lack of staffing of the clinic and the district hospital meant that a nurse from the home would be absent for the whole day, or several days, accompanying a patient to the clinic and hospital;

#### Financial sustainability:

The best illustration here is from San Michele in Brakpan, where one was greeted by a demonstration cheque of **R58,000** displayed on the wall from a South African bank. At this NGO, all the staff were paid salaries and not stipends. Other NGOs with additional independent funding were Dolphin Acres and Shammah House. This financial stability contributed to greater staff satisfaction which in turn benefited the resident patients. The financial stability of these NGOs enabled them to withstand external factors such as the very unfavourable state of the patients on arrival from LE and delays in financial support from the Gauteng Department of Health;

A general comment from the other NGOs was that the stipends were not adequate for the demanding nature of the work, resulting in a high turnover of staff and burnout. The manager at Tshepong Centre reported waiting for 4 months for the subsidy to be paid, Precious Angels reported a 3-month wait; Lapeng, a more established NGO, also reported a frustration with delays in the subsidy, and inconsistent payment once it came through. These managers all reported borrowing money on a personal basis in order to keep the NGOs functioning. Even with the subsidy, the Tshepong Centre manager had been unable to pay herself back. She expressed a concern that, even when paid the subsidy of R3 413 per month per user, it is insufficient for the NGO to be sustainable, given the level of care required by the MHCUs.

### Causes of the excess mortality of transferred MHCUs

From the sample of 38 patients, severe neuropsychiatric disorders ("organic" mental illness) were highly prevalent amongst the MHCUs resident at LE. This subpopulation group are characterised by a higher premature mortality than the general population, even in highly resourced countries and more so in low and middle income countries. 1, 7-9 The risk of death is highest in the immediate months following hospital discharge but also increased in the first 1 – 2 years after the transition from institutionalisation to community based care. The causes of death are most commonly medical rather than suicide due to the mental illness. Community based close medical and psychiatric follow up during these transitional periods is imperative in order to avoid an acute excess in mortality.

Where they could be established, the immediate causes of death were consistent with those anticipated for this subpopulation, i.e. uncontrolled seizures, community acquired pneumonia, stroke and cardiovascular disease. However, dehydration, renal insufficiency and septic bedsores were also documented, and reflect inadequate nursing care of severely disabled people. The immediate cause of death was not evident in almost half (45%) of the 38 patients. The fact that there were no notes available at all for 5 patients and that a further 12 had been "found dead" indicates not only severely deficient nursing and medical care, but also a lack of dignity afforded to these individuals.

Hospital care was also inadequate in some cases. One patient from Mosego Home was discharged after one night's admission to die the next day at the NGO. The patient who died from Bophelong – Mamelodi was sent to hospital with a detailed referral letter by the NGO manager, however the hospital notes were very scanty and provided no information regarding the cause of death. The patient from Lapeng, who died from gastrointestinal bleeding, had been discharged after a blood transfusion pending an outpatient gastroscope.

The MHCUs transferred from LE to NGOs and CCRC were done so in an abrupt manner, en masse with over 817 transferred in May and 512 in June, with multiple transfers in some cases. NGOs lacked the required skills to provide daily care, even to provide adequate hydration and food in some cases. Interruptions in the regular administration of medicines were inevitable. In addition, transport to get patients to health care facilities was not readily available. District health services were not strengthened to provide the close integrated follow up health care required for people with such severe disability. The 'higher' or the excess mortality is attributed to these combined factors, all of which were precipitated by the decision to terminate the contract with LE.

Summary 9: 94 MCHUs died in Gauteng Province during the period of investigation; this total number is that minimum that could be verified with certainty; the nature of the relationship of the GDoMH with NGOs, the information control and fear factor existent made it difficult to be confident that 'all is being revealed' about deaths as these numbers kept changing and being being kept low; higher percentage or excess deaths occurred in 8 out of 27 NGOs, average percentage occurred in 8 and no deaths or occurred in 11 NGOs; the NGOs where excess death occurred were largely new, without experience, skill, qualified professional staff and knowledge and some operated with irregular licenses; the Expert Panel and OHSC Inspectors independently identified 5 critical features of success for NGOs pp 46-47; some of the newer NGOs were poorly or mysteriously selected and were not adequately prepared or funded; notwithstanding the data gaps identified in the numbers during the study, deaths were 'higher or in excess' at some of the NGOs than at LE; 7x MCHUs deaths occurred at NGOs compared to deaths at hospitals.

As some of the deceased had been reported to the SAPS by the MEC and some relatives had requested judicial inquests through Section 27 and the circumstance of some of the deaths identified by the Expert Panel, the Ombud and the MAC were questionable, the cause of death recorded as 'natural' must remain pending until the judicial inquests and full forensic pathology investigations have been undertaken and concluded. However, that the 3 most senior officials in GDoH still cited different total **deaths figures**, made the Ombud wonder as to the goings on, on a matter so serious.

To dissociate the decision-making process, the 'rushed and chaotic' execution, the human rights violations and the conditions in the NGOs during this project from the deaths of the MCHUs is not simply preposterous but also a denial of the worst type; this decision and these deaths are inextricable and closely linked;

### NEGLIGENT/RECKLESS DECISIONS/ACTIONS

The decision to transfer patients to:

- Overcrowded NGOs which are more restrictive, is contrary to the deinstitutionalization policy of the MHCA and MH Strategy and Policy.
- Transfer patients to far-away places from their communities, is contrary to the policy of deinstitutionalization.
- Transfer patients to NGOs that were 'not ready', that were 'not prepared properly for the task'.
- NGOs without qualified staff and skills to care for the special requirements of the patients.
- NGOs without appropriate infrastructure and not adequately financially resourced.
- NGOs without safety and security.
- NGOs without proper heating during winter, some were described as 'cold'.
- NGOs without food and water, where patients became emaciated and some died of 'dehydration'.
- Grant and sign licences without legal or delegated authority.
- 27 NGOs operating under invalid licences.
- Transfer patients without the knowledge of their families or relatives.
- Change the pre-selected placements of patients into NGOs, thus transporting patients to several NGOs.
- Transporting patients particularly 'frail and sickly' patients in inappropriate vehicles.
- To transfer patients from the 'structured environment

- of 24-hours non-stop professional care' in a licensed institution to an environment of 'overcrowded, non-structured, unpredictable substandard or no care at the NGOs with invalid licences.
- To transfer any patient from a place of care to one of substandard or no care runs against the fundamental philosophy and principle of health care i.e. the promotion of well-being and life; this contravenes the Constitution.
- To transfer 'precipitously and chaotically' without a well thought-out plan and against the advice of experts and professional practitioners of psychiatry and mental health.
- To have made promises to families and the court that were not borne out by evidence i.e. that patients' care will not be compromised and patients will be transferred to places that are equivalent to LE.
- The manner, the rate, the scale and the speed of transferring such large numbers of patients were reckless.

The above decisions/actions as supported by evidence in the Report and taken by the 3 decision-makers and implementers were negligent/reckless. These contravened the Constitution, NHA and the MHCA.

### VIOLATIONS OF ACTS: CONSTITUTION, NHA, MHCA

#### (a) Constitution and the Bill of Rights

- In light of the factual findings made in this report, several human rights violations that are protected under the Constitution and further recognized under international human rights treaties to which South Africa is a party have occurred;
- Article 25 of the Universal Declaration of Human Rights recognises the right of everyone to an "adequate standard of living for the health and well-being of himself and of his family including medical care.";
- Furthermore, Article 12 of the International Covenant on Economic, Social and Cultural Rights provides for the "enjoyment of the highest attainable standard of physical and mental health conducive to living a life of dignity." This right to health care includes the obligation on States to refrain from denying or limiting access to health care services to any individual; health care services should be available to all on a nondiscriminatory basis; and to ensure that privatisation does not constitute a threat to the availability, acceptability and quality of services provided;
- In this case, the transfer of MHCUs to facilities that could not take care of their health needs resulted in the denial and limitation of health care services which was discriminatory and resulted in the unavailability and reduction in the quality of healthcare services offered to the MHCUs in accordance with international norms and standards;
- Within the region, Article 16 of the African Charter on Human and People's Rights also recognises the right of individuals to enjoy the best attainable state of physical and mental health and further enjoins State parties to take the necessary steps to protect the health of their people and to ensure that they receive medical attention when they are sick;
- Persons with disabilities are some of South Africa's most vulnerable citizens. Studies suggests that persons with disabilities are economically disadvantaged and carry vulnerable characteristics associated with poverty. In addition, persons with mental and psychosocial

- disabilities often face stigma and discrimination, as well as experience high levels of physical abuse, which can occur in a range of settings, including healthcare facilities and homes. The vulnerability of a person with a disability is heightened when he or she is dependent upon a caregiver, which is often the case for people with mental and psychosocial disabilities;
- In terms of the Convention on the Rights of People with Disability (CRPD), to which South Africa is a party, all persons with disability are entitled to all fundamental rights. In particular, persons with intellectual disabilities and psychosocial disabilities are entitled to liberty and security in terms of article 14 of the Convention. The limitation of these rights therefore must be approached with due caution to ensure limitations are justifiable and rights are not negated completely. It is therefore incumbent on States to protect the security and personal integrity of persons with disabilities. As conceded by the parties and given the vulnerability of the MHCUs, this level of care was not evident in this matter:
- At the domestic level, section 27 of the Constitution recognises the right of everyone to have access to health care services which should not be hindered by limited available resources. Given the interrelated nature of rights, the protection of the right to health is central to the protection of the right to life. To achieve these protections, a range of responsibilities arise to protect other related rights such as the right to an environment that is conducive to health and wellbeing, right to food and nutrition, as well as the right to freedom and security of people;
- The evidence provided in this case indicates that a number of the NGOs and other healthcare facilities that accepted the transferred MHCUs did not have the capacity to provide the necessary healthy environment as well as adequate food and nutrition for the MHCUs. The right to adequate, nutritious food is recognised under South African and international human right law. The right to food is linked to the right to life and dignity and requires that food be available, accessible and adequate for everyone without discrimination. The evidence suggests that this was violated in this case, particularly, with the GDoH's

failure to adequately fund and pay certain NGOs to provide the healthcare for the MHCUs. Arising from the recorded submissions on the issue of food, it is of paramount importance that this often neglected right is appropriately planned for, resourced, and monitored and evaluated to avoid the indignity of hunger, malnutrition and other adverse impacts to health;

- Other administrative rights which would have secured the protection of the above mentioned rights were also violated during the "chaotic" transfer process. This includes the right of access to information by the MHCUs as well as their family members. The notion of the right of the affected people to free, prior and informed consent in a participatory process of consultation before the policy decisions for transfers were taken was violated at different stages of the implementation process by the GDoH. The basket of administrative rights also provides that States must ensure accurate and accessible information is provided about service options and that non-medical approaches are made available while preventing abuses by non-state actors, such as the NGOs in this case;
- The robust health care legislative framework of South Africa is specifically designed to protect the constitutional rights to health care including the right to participate in decisions regarding one's health protected under section 8 of the National Health Care Act of 2002:
- The Act specifically requires the provision of health care services be made available to the population equitably and efficiently. The protection, promotion and respect for this right is not only a duty to progressively realise the constitutional right to health care but also requires the application of a minimum standard of care, which was denied to the MHCUs transferred out of LE. The standard of care envisaged in the domestic framework is aligned to the international standard envisaged in the CRPD;
- In light of these international recognitions and protections as well as constitutional and domestic protection of healthcare rights, in 2009, the South African Human Rights Commission (SAHRC) instituted

- a public inquiry into the state of access to healthcare services in South Africa. The SAHRC found that poverty is a major cause of ill-health and a barrier to access health care services. This finding recognises and is premised on the fact that poverty creates a heightened dependency on the public health care services, and illustrates a need for the state to prioritise accordingly. Decisions, both at the level of policy development and implementation, should envisage the exercise of a greater duty of care for the protection of poor people, particularly, the rights of vulnerable people which includes elderly people and people with disabilities affected in the LE transfers;
- Consequently, public health care remains a critical public service that is central to the protection of human rights in South Africa. The unfortunate deaths that occurred after the rushed transfers of MHCUs from LE to ill-equipped NGOs and other health care facilities demonstrates a failure in the adequate implementation and monitoring of national and provincial health care policies with direct implications on the violation of the various interrelated human rights;
- Stiama and discrimination around mental illness and psychosocial impairments is pervasive, subsequently leading to severe forms of inhumane and degrading treatment, creating barriers to the enjoyment of numerous human rights. Adequate healthcare and de-institutionalisation programmes potentially contribute to the improved quality of life for MHCUs, enabling them to participate in all spheres of life, thus limiting social exclusion and dependency. The guarantee of the right to health and to adequate healthcare is therefore an effective way of promoting principles of autonomy, equality, and promotes an improved standard of living for persons with mental disability. It is a fundamental part of our understanding of a life of dignity and is essential in promoting respect for the rights of vulnerable groups, including persons with mental illness and psychosocial impairments;
- Poor planning and implementation, including the methods and degree of consultation, access to information, transportation, general treatment (etc.) of both the persons being moved from LE as well as the family members resulted in egregious violations

to the right of persons to be treated humanely and with dignity. In as much as budget considerations fundamentally impacts planning, implementation and delivery, the adequacy of resources within the GDoH, cannot justify the rash implementation of decisions leading to the inhumane and degrading treatment of patients as well as their loved ones;

- This case also illustrates the responsibility of private actors in the protection of human rights. Section 8 of the Constitution recognizes that both the State as well as private persons and bodies bear responsibilities to respect human rights. The United Nations Guiding Principles on Business and Human Rights ("the Ruggie Principles") together with section 8 of the Constitution recognise that both the State as well as private persons and bodies bear responsibilities to respect and protect human rights. While often overlapping, these responsibilities are also distinct. The outsourcing of healthcare services by the State to a private entity does not, however, absolve it from its responsibilities to promote and protect the fundamental rights of persons under its care, including MHCUs. Likewise, private persons and entities also bear responsibilities beyond specific contractual terms and timelines to ensure that the level of care provided is compliant with human rights standards, which includes, amongst other things, sufficient food and nutrition as well as continuity of care. In addition to the State's responsibility to provide sufficient oversight, monitoring and resourcing to ensure the adequate protection of the rights of patients transferred to NGOs, these organisations, too, held a direct responsibility to ensure compliance with adequate standards of treatment and the protection of the fundamental rights of persons within their care. This includes a duty to protect persons within its jurisdiction against human rights abuses by third parties, including private enterprises. On the facts of this case, no entity is completely absolved of responsibility towards the MHCU, however, it is accepted that the primary responsibility for the provision of healthcare services resides with the State, carrying with it a clear responsibility for the protection of persons under its care and authority. This duty extends to protections from human rights violations by third parties including private enterprises;
- On a final note, the adequate functioning of the health care system depends on good budgeting, rational expenditure, planning, oversight and accountability. These core actions must be embedded in the context of the respect for the basic rights and dignity of MHCUs. The Office of the High Commission on Human Rights emphasises how human rights standards can provide valuable guidance to policymakers and

legislators when weighing competing demands on limited resources, and that a rights-based approach to budgeting can assist in ensuring, for example that "budget allocations are prioritized towards the most marginalized or discriminated against; provision is made for essential minimal levels for all rights; there is progressive improvement in human rights realization; and particular rights are not deliberately realized at the cost of others." Decisions around budgeting and implementation of plans for MHCUs by the GDOH appear to have paid scant regard to the rights based approach advocated in our Constitution. The Mental Health Care Act provides that the person, human dignity and privacy of every mental health care user must be respected and that every mental care user must be provided with care, treatment and rehabilitation services that improve the mental capacity of the user to develop to full potential and to facilitate his or her integration into community life (section 8);

- The neglected state of the MHCUs observed by the NGOs on their arrival from LE, suggests that there was a significant lack of care once the implementation period had started, even whilst still in LE between LE transfers and awaiting transfer to an NGO. This was a joint project between LE and the GDoH;
- The mass transfers of patients and the terminology used in the GDoH summary report of "transportation" of MHCUs in "batches" indicates a complete lack of respect for their human dignity;
- The non-compliance with the MHCA of 2002, legislation designed to protect the human rights of such individuals. This includes the placement of Assisted MHCUs in facilities and districts without the resources to provide the appropriate standard of care for such patients;
- The number of patients with no identified cause of death indicates a lack of respect for the individual in their final hours.
- Finally, the lack of data integrity and record keeping reflects a lack of responsibility towards individuals who are completely dependent on the health care system for their wellbeing.

#### (b) Fiduciary duty

Ineffective leadership and direction was lacking in the process of transfer as monitoring and control occurred post the events and there was poor response towards further occurrence of deaths. Mission contained in the GPH project plan failed to include aspects related to implementation of the process (planning, monitoring, and timeframes). The plan itself was unsigned therefore not approved by relevant authority.

#### (c) Health laws and regulations

- Direct provisions of the NHA on consent and discharge of patients;
- Indirect provisions in the NHA that link to other laws e.g. (NHAA) and policy (NCS);
- Regulations to the Mental Health Care Act R17-23 on patient movement processes;
- Regulation 43 (2) on conditions of license;
- The National Core Standards-domains 1 -7 on aspects of rights, safety, care management and accommodation.

#### (d) License procedure

- No screening criteria nor conditions service were stipulated as is in common practice;
- Manner of issue was unscrupulous e.g. License criteria was based only on NPO;

 Certificates-experience and other credentials were not taken into consideration.

#### (e) Contract law and procedure

Requirements for validity not adhered to e.g. no signatures in other contracts and entered into after service provider has started to operate meaning they operate without agreed service levels.

Selection Criteria for entering into the contract was based only on mental health license irrespective of suitability or lack thereof.

Provisions of the SLA (service conditions) were found to be against the principles of good values and were de-humanising e.g. one nutritious meal a day, other meals are additional; access to a medical doctor once a year.

**Summary 10:** The Expert Panel, the OHSC Inspectors, the Ombud and the MAC found several contraventions of the Constitution especially the Bill of Rights, the NHA and NHAA and certain sections of the MHCA; contract and Fiduciary Responsibilities. The accountabilities and responsibilities vested in all these Acts and codes must be followed and acted upon expeditiously following recommendations.

# FUTURE EFFECTS ON THE MENTAL HEALTH SERVICE SYSTEM

There is now no medium to long stay beds in Gauteng with 24-hour nursing designed for Assisted MHCUs requiring such care. There has been upscaling of CMHS and no increase in the numbers of general hospital acute psychiatric beds.

The immediate effect is that the entire referral system is now even more poorly resourced than before the "LE Project." Many more MHCUs than those transferred in the LE project will be affected.

**Summary 11:** This was one of the predictions of the experts. That it has come true is a measure of the quality of the expertise we have. We must trust and learn to listen to professional experts a bit!

Summary 12: If MEC Mahlangu, Dr Selebano and Dr. Manamela did not know how many patients had died by the 29th November 2016 as confirmed in their evidence, in a matter that has caused so much 'pain and anguish' in families and has attracted so much national and international interest, then one must wonder what else they do not know in the system they preside over.

Summary 13: A combination of negligent/reckless decisions/actions (page 48) with 'appalling conditions' in some of the NGOs as revealed through the evidence of different stakeholders and the findings of the Expert Panel, the OHSC Inspectors, and the MAC, led to the 'excess' and unnecessary deaths of some of the innocent mentally ill patients.

### **RECOMMENDATIONS**

- 1. The Gauteng Mental Health Marathon Project must be de-established.
- 2. The Premier of the Gauteng Province must, in the light of the findings herein, consider the suitability of MEC Qedani Dorothy Mahlangu to continue in her current role as MEC for Health;
- 3. Disciplinary proceedings must be instituted against Dr Tiego Ephraim Selebano for gross misconduct and/ or incompetence in compliance with the Disciplinary Code and Procedure applicable to SMS members in the Public Service. In the light of Dr Selebano's conduct during the course of the investigation, which includes tampering with evidence, it is recommended that the Premier should consider suspending him pending his disciplinary hearing, subject to compliance with the Disciplinary Code and Procedure applicable to SMS members in the Public Service.
- 4. Disciplinary proceedings must be instituted against Dr Makgabo Manamela for gross misconduct and/ or incompetence in compliance with Disciplinary Code and Procedure applicable to SMS members in the public service. In the light of Dr Makgabo Manamela's conduct during the course of the investigation, which includes tampering with evidence, it is recommended that consideration be given to suspending her pending her disciplinary hearing, subject to compliance with the Disciplinary Code and Procedure applicable to SMS members in the public service.
- 5. The findings against Drs. M Manamela and TE Selebano must be reported to their respective professional bodies for appropriate remedial action with regard professional and ethical conduct.
- 6. Corrective disciplinary action must be taken against members of the GDoMH: Ms. \$ Mashile (Deputy Director); Mr. F Thobane (Deputy Director); Ms. H Jacobus (Deputy Director); Ms. \$ Sennelo (Deputy Director); Dr. \$ Lenkwane, (Deputy Director); Mr. M Pitsi (Chief Director); Ms. D Masondo (Chair MHRB), Ms. M Nyatlo (CEO of CCRC), Ms. M Malaza (Acting CEO of CCRC) in compliance with the Disciplinary Code and Procedures applicable to them, for failing to exercise their Fiduciary duties and responsibilities. They allowed fear to cloud and override their fiduciary responsibilities and thus failed to report this matter earlier to relevant authorities. Fiduciary responsibility is essential for good corporate governance;

- 7. All the remedial actions recommended above must be instituted within 45 days and progress be reported to the Chief Executive Officer of the Office of Health Standards Compliance within 90 days.
- 3. The Ombud fully supports the ongoing SAPS and Forensic investigations underway. The findings and outcomes of these investigations must be shared with appropriate agencies so that appropriate action where deemed justified can be taken.
- The National Minister of Health should request the SAHRC to undertake a systematic and systemic review of human rights compliance and possible violations nationally related to Mental Health.
- Appropriate legal proceedings should be instituted or administrative action taken against the NGOs that were found to have been operating unlawfully and where MCHUs died.
- 11. In light of the findings in the report, the NDoH must review all 27 NGOs involved in the Gauteng Marathon project; those that do not meet health care standards should be de-registered, closed down and their licenses revoked in compliance with the law.
- 12. The National Minister of Health must with immediate effect appoint a task team to review the licensing regulations and procedures to ensure they comply with the National Health Act, the Mental Health Care Act 2002 and Norms and Standards. The newly established process must ensure that NGO certification is done through the OHSC. This newly established licensing process should form the first line of protection for the mentally ill. Currently, this does not seem to be the case.
- 13. All patients from LE currently placed in unlawful NGOs, must be urgently removed and placed in appropriate Health Establishments within the Province where competencies to take care of their specialized needs are constantly available, this must be done within 45 days to reduce risk and save life; simultaneously, a full assessment and costing must be undertaken.
- 14. There is an urgent need to review the NHA 2003 and the MCHA 2002 to harmonise and bring alignment to different spheres of government. Centralisation of certain functions and powers of the MHCA must revert back to the National Health Minister, While Schedule 4, Part A of the Constitution and Sections 3 subsection 2; section 21, subsection I, section 25, subsection

1 and 2, sections 48 and 49 and section 90 of the National Health Act. No. 61, 2003, recognize and define Health as a concurrent competence between the National and Provincial government spheres the findings and lessons of this investigation merits such a review. Furthermore, projects of high impact on the quality and reputation of the national health system and whose outcomes undermine human dignity, human well-being and human life must not be permitted nor be undertaken without the expressed permission of the National Health Minister or his/her nominee.

- 15. Projects such as the GMMP must not in future be undertaken without a clear policy framework, without guidelines and without oversight mechanisms and permission from the National Health Minister; where such policy framework exists the National Health Minister must ensure proper oversight and compliance.
- 16. This investigation has clearly shown that for deinstitutionalisation to be undertaken properly, the primary and specialist multidisciplinary teams that are community based mental health care services must be focused upon, must be resourced and must be developed before the process is started. It will most probably require more financial and human resource investment initially for deinstitutionalisation to take root. Sufficient budget should be allocated for the implementation.
- 17. The National Minister of Health must lead and facilitate a process jointly with the Premier of the Province to contact all affected individuals and families and enter into an Alternative Dispute Resolution process. This recommendation is based on the 'low trust', anger, frustration, loss of confidence' in the current leadership of the GDoH by many stakeholders. The National Department of Health must respond humanely and in the best interest of affected individuals, families, relatives and the nation. The process must incorporate and respect the diverse cultures and traditions of those concerned. The response must include an unconditional apology to families and relatives of deceased and live patients who were subjected to this avoidable trauma; and as a result of the emotional and psychological trauma the relatives have endured, psychological counselling and support must be provided immediately. The

- outcome of such process should determine the way forward such as mechanisms of redress and compensation. A credible prominent South African with an established track record should lead such a process.
- 18. The Gauteng Mental Health Review Board was found to be moribund, ineffective and without authority and without independence. As a structure its terms of reference must be clearly defined and strengthened in line with the National Health Act and the Mental Health Care Act 2002 and its independence and authority re-established.

#### Recommendations to the GDoH:

- The development of information systems with patient registers and a data base by which to make evidence-based decisions, monitor and evaluate health care delivery must be a priority for the GDoH; this recommendation is strongly endorsed by StatsSA;
- Exemplary adherence to the MHCA and its related regulations by the GDoH and the MHRB;
- District health services must be capacitated to ensure adherence to regulations and to provide clinical and rehabilitative support to the NGOs in each district. The strengthening of Primary Health Care Services and District Hospitals;
- If deinstitutionalisation of MHCUs is to be implemented in South Africa, it has to be done with the provision of structured community mental health care services, as recommended by the MH Policy and articulated by Prof Freeman's document, with the adequate planning and allocation of designated resources;
- Specialist run community/ psychiatric services, as described in the MH Policy, must be included in the proposed NHI structure and funding in order to address the needs of people with severe psychiatric disability/ who require specialist level care close to their homes;
- GDoH must develop a capacity programme for all newly established NGOs within 45 days (submit such to the OHSC within 90 days).

### **REFERENCES**

- 1. Charlson FJ, Baxter AJ, Dua T, Degenhardt L, Whiteford HA, Vos T. Excess Mortality from Mental, Neurological, and Substance Use Disorders in the Global Burden of Disease Study 2010. In: Patel V, Chisholm D, Dua T, Lax minarayan R, Medina-Mora ME, editors. Mental, Neurological, and Substance Use Disorders: Disease Control Priorities, Third Edition (Volume 4). Washington (DC)2016.
- 2. Gauteng Department of Health. Summary Report on Termination of Contract Relationship between Gauteng Deaprtment of Health and Life Esidimeni and Upscaling Community Based Mental Health Services. Report compiled by the Gauteng Directorate of Mental Health; October, 2016.
- 3. Government of South Africa, National Health Amendment Act No. 12 of 2013. Pretoria: Government Gazette.
- 4. Government of South Africa. National Health Act 61 of 2003. Pretoria: Government Gazette; 2004.
- 5. Government of South Africa. Mental Health Care Act No.17 of 2002. Pretoria: Government Gazette; 2004.
- 6. National Department of Health. National Mental Health Policy Framework and Strategic Plan 2013 2020. Pretoria: Government of South Africa; 2012.
- 7. Sohlman B, Lehtinen V. Mortality among Discharged Psychiatric Patients in Finland. Acta Psychiatr Scand. 1999;99(2):102-9.
- 8. Shavelle R, Strauss D, Day S. Deinstitutionalization in California: Mortality of Persons with Developmental Disabilities after Transfer into Community Care, 1997-1999. Journal of Data Science. 2005;3.
- 9. Meloni D, Miccinesi G, Bencini A, Conte M, Crocetti E, Zappa M, et al. Mortality among Discharged Psychiatric Patients in Florence, Italy. Psychiatr Serv. 2006;57(10):1474-81.
- 10. Gauteng Department of Health. Memorandum of Agreement Entered into by and between the Gauteng Provincial Government Acting through Its Department of Health and a Non-Profit Organisation. Johannesburg: Document printed by the GDoH; Undated.
- 11. Petersen T., 'South Africa: UN experts shocked by death of at least 37 people in flawed relocation process from psychiatric hospitals'. News 24 03/12/2016)
- 12. Jadoo Y., 'UN slams 'flawed' handling of psychiatric patients saga. National 9/12/2016)
- 13. "United Nations. Conference of States Parties to the Convention on the Rights of Persons with Disabilities. CRPD/CSP/2015/2".









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