OTASA/POTS statement on the Esidimeni tragedy and the report by Health Ombud Professor Malegapuru Makgoba

“An event has happened, upon which it is difficult to speak, and impossible to be silent”.

(Edmund Burke, 18th century English statesman and philosopher)

“Our [professional] lives begin to end the day we become silent about things that matter”.

(with apologies to Martin Luther King)

The Occupational Therapy Association of South Africa (OTASA) and the Psychiatric Occupational Therapy Interest Group (POTS) note with grief and dismay the so-called Esidimeni tragedy. We deplore the needless and preventable deaths of vulnerable mental health care users, outlined vividly in the report of the Health Ombud, and note that the ramifications are likely to take years to play themselves out. While we are struck by the inexplicable omission of occupational therapists (OTs) from the Ombud’s panel of experts, we are pleased that OTs are included in the rectification process which is now underway for the Esidimeni survivors.

It is ironic that esidimeni means “place of dignity”, yet a precipitous, misguided and poorly managed deinstitutionalisation process robbed multiple patients and their families of dignity in a most profound way. OTASA also notes that the process disempowered health practitioners within Life Esidimeni, some of whom had cared for the patients for decades – they were unable to ensure that an appropriate and dignified relocation process took place. Instead, they found themselves caught up in an unseemly project, governed by financial rather than humanitarian principles. Even the NGOs which received the patients appear to have been treated with impunity by government, which botched the licensing process, did not carry out sufficient inspections, overloaded some facilities and failed to pay subsidies on time. This would have hamstrung the Non-governmental Organisations (NGOs) when it came to providing food, medication, bedlinen, heating and basic daily care – affecting not only those which had jumped on a seemingly lucrative bandwagon, but also those with a long track record of caring for people with disabilities. Precious Angels is a case in point – no mention has been made in the press or the Ombud’s report of what became of the disabled children who were already living there before that NGO collapsed under the abrupt arrival of numerous psychiatrically ill adults.

OTASA and POTS note that South Africa is a signatory to the UN General Assembly’s 2006 Convention on the Rights of Persons with Disabilities, which stresses the need to promote respect for such persons’ inherent dignity. Greater access to rehabilitation is a prerequisite for achieving the Sustainable Development Goal on health – indeed, the World Health Organization’s “Rehabilitation
2030: Call to Action” notes that it is negligent to deny people with disabilities the services they need to participate as fully as possible in the lives of their families and communities. Occupational therapists support the worldwide trend of deinstitutionalisation, which seeks to reintegrate psychiatric patients into the community and overcome the “human warehousing” which was so prevalent in the past. However, people with severe psychiatric conditions also have a high rate of medical problems and physical disabilities and their unique needs are poorly understood by society, so deinstitutionalisation must be carefully managed. In particular, they need living environments which ensure safety for themselves and others, allow them to function optimally and promote a reasonable quality of life. This was clearly expressed by Wits occupational therapy students in a January 2016 letter to the Gauteng Department of Health and National Department of Health, which has recently featured in the press. OTASA and POTS note that the burden their needs place on their loved ones (sometimes with deeply impoverishing and dangerous effects) can make it impossible or inappropriate for these patients to live in ordinary family homes. Those with severe behavioural and mental disturbances or mixed disabilities often need lifelong specialised residential care, with round-the-clock availability of professional staff. Some pose such high risks to themselves or others that they are placed in such care involuntarily, by order of the court – thus, the facilities where they live need to be secure enough to prevent them absconding yet open enough not to be prisons.

Our Mental Health Care Act (no. 17 of 2002) makes it mandatory for mental health care users to be provided with care, treatment and rehabilitation (CTR), and the Department of Health’s norms and guidelines specify that the mental health care team must contain occupational therapists and occupational therapy assistants and occupational therapy technicians (OTAs/OTTs) as well as psychiatrists, psychologists, nurses and social workers. Government, the key duty bearer in relation to the rights of mental health care users, has historically funded CTR programmes such as those run by Life Esidimeni. OTASA and POTS have been reliably informed that cost-cutting measures had already begun eroding Life Esidimeni’s Occupational Therapy programmes some years back, impacting not only on the patients but also on occupational therapy student training – however, those more minor measures have been entirely overshadowed by the 2015/2016 deinstitutionalisation process. This failed to address the patients’ individual functional needs and rehabilitation requirements, did not ensure the availability of curators to safeguard their rights, and blatantly disregarded how stressful an abrupt and haphazard relocation process would be – especially for those who lived at Life Esidimeni for decades. Some patients seem to have been sent home to their families regardless of whether someone was available to take care of them, while in other cases families were not given up-to-date information or were simply not contacted at all. In sum, the patients were treated like objects being moved from one cupboard to another, rather than human beings with rights. Given these realities, high levels of relapse and acute health problems were entirely predictable, even though no-one could foresee just how many deaths would occur. Distressingly, many patients’ hard-won rehabilitation gains (made over months, years or even decades at Life Esidimeni) would simply have been destroyed in one fell swoop, leaving them functionally much worse off than they were. The whole process went strikingly against local and international best practice, defying clinical evidence from a multitude of settings in which deinstitutionalisation has been carried out and even deviating markedly from the Department of Health’s existing plans and timeframes. It made a lie of the platitudes provided to patients’ families and other interested parties like Section 27 and the Esidimeni Campaign, and the alarm bells rung by numerous disciplines – including Occupational Therapy – were simply ignored. Most unfortunately, even our courts failed to appreciate the magnitude of the unfolding tragedy, striking from the roll (on grounds of non-urgency) the cases brought by Section 27 and others.

Going forward, OTASA and POTS call on government to learn deep lessons from this disaster. The patients and families impacted by the Esidimeni debacle should receive compensation where this is
due and administrative justice (including an inquest into each death) should proceed quickly – this will help the affected survivors and families achieve closure and move on. Government must ensure that all future deinstitutionalisation processes involve a proactive flow of resources into the community, to ensure the development of appropriate and well-capacitated mental health care facilities before the arrival of the patients. While highly cognisant of the financial factors at play in resource-constrained settings, OTASA and POTS assert that government cannot abdicate in relation to the provision of both hospital-based and community-based CTR. This requires the correct mix of professional expertise, including OTs and OTAs/OTTs, and our current inadequate staff:patient ratios imply a need to boost efforts to train and deploy practitioners. OTs’ role in developing and providing rehabilitation services and monitoring outcomes (both hospital-based and community-based) must be supported with adequate budgets. When it comes to subsidies paid to health facilities, government must ensure the highest degree of reliability and integrity – this will avoid situations where vulnerable patients suffer deprivations like hunger, thirst, cold or lack of medication, causing relapses, suffering and even death. Contracts must not be ended abruptly without good cause, and patients’ rights must take centre stage when programme changes occur. The national and provincial health departments must never again abandon their oversight functions and must strive to ensure that all mental health services comply with acceptable norms and do not violate patients’ rights. Finally, OTASA and POTS urge that appropriate sanctions be meted out to those health practitioners and bureaucrats who were directly responsible for what went wrong. Merely resigning from their posts is insufficient and they should feel the full might of the law, so as to deter anyone else who may be tempted to engage in similar conduct.

For their part, OTASA and POTS pledge to continue supporting Occupational Therapists and OTAs/OTTs to deliver high quality professional services in the mental health field. These structures also support individual practitioners in their advocacy roles in relation to disability rights in general and the rights of people with severe psychiatric conditions in particular.

February 2017

*Statement put forward jointly by the Occupational Therapy Association of South Africa (OTASA) and the Psychiatric OT Interest Group (POTS)*