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Submission in respect of the third cycle Universal Periodic Review of South Africa on the status of disability rights in South Africa

Submitted by organisations reflected in Section A of this report loosely referred to as the Disability UPR Reporting Coalition – South Africa for the purposes of this report.

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Disability UPR Reporting Coalition – South Africa is a coalition developed in 2016 for the joint stakeholders' submission for the third cycle of the Universal Periodic Review of South Africa. It is made up of seven organisations that work to promote disability rights or within the disability sector.

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I. Introduction

The Legal Resources Centre (LRC) is a national public interest, non-profit law clinic in South Africa that was founded in 1979. The LRC has since its inception shown a commitment to work towards a fully democratic society underpinned by respect for the rule of law and constitutional democracy. The LRC, through its Equality and Non-Discrimination project, focuses on empowering marginalised and vulnerable groups by utilising creative and effective solutions to achieve its aims. These include using a range of strategies including impact litigation, law reform initiatives, participation in development processes, education and networking within and outside of South Africa.

During November 2015, the LRC hosted a conference on disability rights titled '*Women and Persons with Disabilities: Marginalisation in Participating in Socio-Economic Activities for their Benefit*' in Durban, South Africa. Various community based organisations working in the disability sector attended and participated in panels addressing the rights of persons with disabilities over two days. There, collaboration on a submission for South Africa's next Universal Periodic Review (UPR) was discussed and, in July 2016, an invitation to collaborate was extended to the conference participants as well as other NGOs working in the disability sector nationwide.

a) Contributing Organisations

Community Based Rehabilitation Education and Training for Empowerment (CREATE) operates mainly in the province of KwaZulu-Natal, working with youth and adults with all types of impairments, as well as with disabled persons' organisations and organisations of parents with children with disabilities. Part of their work is on disability rights and advocacy training.

DeafSA is an organisation representing deaf and hard-of-hearing persons in South Africa. The National Deaf Woman chairperson represents the interests of deaf women at national level, as well as supports the women representatives in the country by providing workshops and developing capacity building activities.

Parents for Children with Special Education Needs (PACSEN) is the largest parents' association for parents of children with special education needs in South Africa. The parents monitor schools and PACSEN provides a channel for them to approach the various departments of education.

Pathways – Kloof is a centre that provides education, therapies, interventions and stimulation for 52 children and young adults with severe disabilities. There are four other Pathways centres around the country and a fifth in development.

South African Disability Alliance (SADA) is an umbrella body of 16 disability organisations that promotes collaboration between role players in the disability sector.

South African Federation for Mental Health (SAFMH) is the largest mental health organisation in South Africa, constituted by 17 mental health societies and 107 member organisations. SAFMH coordinates, monitors and promotes services to persons with intellectual and psychosocial disabilities, as well as promotes good mental health and wellbeing to society at large.

b) Sources of information

This submission has been compiled using information from a range of sources, including: first-hand experiences, field research and policy monitoring.

Two organisations, SADA and CREATE, submitted reports of research they had conducted. With support from Disability Rights Promotion International (DRPI), SADA coordinated research and put together a report on disability rights in South Africa using DRPI methodologies: (1) individual interviews providing evidence-based information identifying key issues that persons with disabilities identify as important to them; (2) systemic monitoring of laws, policies and programmes; and (3) media analysis of public perception of disability using the Disability Rights Media Monitoring Strategy (DRMMS), which makes use of textual analysis, coding, and qualitative critical reading. With regards to the interviews, it is noted that the small sample size (100 interviewees) and the research design limit what general conclusions can be drawn; however, a high degree of repetition makes the findings statistically relevant.

From 2012, CREATE has conducted research and advocacy training focusing on traditional leaders, including two workshops with human rights activists in 2011 and 2012 and advocacy engagements in 2013 and 2015.

The four other contributors, SAFMH, PACSEN, Pathways – Kloof and DeafSA, submitted reports on their first-hand experiences. SAFMH, for instance, has a widespread national network of organisations and mental health care users who provide ongoing updates and information about developments and challenges, both from organisational and personal perspectives. It also works closely with the Departments of Health and Social Development and gathers information through members of the public who approach SAFMH for information. All information is analysed and management reports are produced on a quarterly basis. SAFMH uses a media monitoring service to keep abreast of content released via media. PACSEN, in turn, as an advocacy and lobby group, has first-hand knowledge and experience of anything that relates to education, health or social development of learners with disabilities, as does the smaller organisation Pathways – Kloof. DeafSA works with and represents persons with hearing impairments.

c) Aims and objectives of the document

The aims of this document are to monitor the implementation of the UNCRPD in South Africa and to hold the South African government to account in promoting and protecting the human rights of persons with disabilities.

The objectives of this document are to provide feedback from collaborating civil society organisations working in the disability sector on the implementation of recommendations made to South Africa since the second Universal Periodic Review held in 2012, as well as to provide comments on other emerging issues affecting the rights of persons with disabilities.

II. Feedback on recommendations issued at the second UPR in 2012

South Africa accepted three disability-related recommendations at the previous review in 2012.

1) Recommendation 124.112. Create a favourable environment for the effective enjoyment of the rights of persons with disabilities (Djibouti)

Not successfully implemented. The South African government has done much in terms of creating the legislative and policy framework for persons with disabilities to enjoy their rights, such as introducing the Promotion of Equality and Prevention of Unfair Discrimination Act (PEPUDA), the Employment Equity Act, the Mental Health Policy Framework and Strategic Action Plan 2013-2020 and the introduction of The White Paper on the Rights of Persons with Disabilities (WPRPD) in December 2015. The white paper does not replace any sectoral policies, but provides guidelines for the review of all existing and the development of new sectoral policies, programmes, budgets and reporting systems to bring these in line with Constitutional and international treaty obligations.

However, there is widely reported concern about the implementation and monitoring of these policies, as well as insufficient attention being paid to the ability of persons with disabilities to effectively enjoy those rights. For instance, non-conducive environments in psychiatric hospitals pose a serious concern for human rights. The failure to implement this recommendation is evident across five broad areas affecting the environment in which persons with disabilities are able to enjoy their rights:

a) Access to justice

Section 34 of the Constitution states that everyone has the right to have any dispute which can be resolved by the application of law decided in a fair public hearing before a court or another independent tribunal. Despite this, persons with disabilities face obstacles in their access to justice, especially in rural areas such as in KwaZulu-Natal province, where CREATE has conducted research.

Equality Courts. Despite the Promotion of Equality and Prevention of Unfair Discrimination Act¹ (PEPUDA) providing for the creation of Equality Courts, persons with disabilities continue to face a number of barriers. These include communication barriers, such as inadequate provision of sign language interpreters in courts or persons being undermined if they cannot speak with ease, as well as financial barriers. Many courts earmarked as Equality Courts do not function as such, forcing persons with disabilities and their assistants to travel great distances to access a court. One reason why the Equality Courts may not be functioning effectively is due to lack of use. However, the reasons behind the lack of use must be investigated as it may be due to communication and attitudinal barriers or to a lack of awareness of the provisions of PEPUDA in communities.

Traditional leaders. Customary law is recognised by the South African Constitution, and many rural areas are governed by traditional leadership in accordance with the customary law of a particular community. However traditional leadership tends to be based on patriarchal structures, and often the adjudicator or chief does not take into account human rights when

¹ The Promotion of Equality and Prevention of Unfair Discrimination Act 4 of 2000

making decisions. They often rely on practices and beliefs that can be discriminatory towards persons with disabilities. For example, persons with disabilities may not represent themselves in many traditional courts, even as adults.

Human rights training. Many traditional leaders, especially in the uThungulu District in KwaZulu-Natal, have not received training on the Bill of Rights or PEPUDA, or even received copies of the Act or the Constitution. This intersects with the issue of traditional leadership. A traditional leader who was a participant in CREATE's 2013 advocacy engagement in uThungulu commented about a human rights forum member: 'He came back with a lot of good information but as the leader I was offended because I was supposed to be the one that presents the information. In future the organisations need to train the leaders first.'

Proposed recommendations:² (1) Equality Courts must be monitored and non-functional courts must be investigated and provided with the resources required in order to function more effectively. (2) Equality Courts should have a discretionary fund to pay transport costs for those who require it in order to access courts. (3) Traditional leaders administering justice in the traditional courts as well as persons with disabilities need to receive training on the Constitution, disability rights and PEPUDA.

b) Access to education

Despite the 2001 Education White Paper 6 promoting inclusive education, the Department of Education continues to exclude children with disabilities.³ This exclusion is apparent in a number of ways.

Waiting lists. Up to 600 000 children with disabilities are on waiting lists to be placed in a school or institution; yet, only one province has opened more schools to address this waiting list.

Barriers. Many children with disabilities have to attend special schools far away from their homes, creating exorbitant financial costs for their families. As a result, many disabled learners are not sent to school at all. In addition, schools and hostels do not always have safe conditions which are suitable for learners with disabilities. PACSEN reports that a number of children were lost in a hostel fire in 2015.

Resources. Children with barriers to learning may not receive resources to enable them to access an adequate education. For instance, blind children represented by PACSEN did not receive braille books for their school work. While PACSEN liaised with the Department of Education to come up with a resolution for the children they represent, the overarching problem of available resources remains.

Specialist staff. Schools continue to have a lack of adequate specialist and professional support staff, despite various policies setting out standards of support required. A school within the Umlazi

² For these recommendations, see Holness, W. and S. Rule. (2014). Barriers to Advocacy and Litigation in the Equality Courts for Persons with Disabilities. *Potchefstroom Electronic Law Journal* 17(5), pp. 1907-1963.

³ Ngwena, Charles (2013). Western Cape Forum for Intellectual Disability v Government of the Republic of South Africa in *The African Disability Rights Yearbook* (Chapter 7), pp. 139-164; Human Rights Watch (2015). *Complicit in Exclusion*; Section 27 (2015). *Left in the Dark*; Equal Education Law Centre (2016). *Inclusive Education: Learners with Learning Barriers – The Right to an Equal and Quality Education*.

district in Durban reported an incident of death of an epileptic learner at the hostel facility as there was no nurse on duty at the hostel at night.

Proposed recommendations: (1) The Department of Education must be required to invest necessary resources in improving data systems to ensure schools of all types account for numbers of children with disabilities in school, grade levels, progression and drop-outs. (2) Translate Education White Paper 6 into a comprehensive and realisable law binding national and provincial governments, ensuring it is in line with the United Nations Convention on the Rights of Persons with Disabilities. (3) Finalise and publish the 'National Learners Transport Policy', guaranteeing inclusion and subsidised transportation for learners with disabilities.⁴

c) Access to health care

Stock outs. Despite the Mental Health Policy Framework and Strategic Action Plan stating that medication should be available where required, this is not the case as there are frequent stock outs of psychiatric medication. The Stop Stock Outs Campaign found that 10% of reported stock outs between January and June 2015 were of psychiatric medications.

Community-based health care. There is a shortage of community-based health care facilities across South Africa, and a particular shortage of facilities for young persons with challenging behaviour. For instance, a large number of inquiries to SAFMH relate to people seeking residential facilities for persons with mental disabilities. The widely-opposed closure of Life Esidimeni facilities in Gauteng in 2016 left 2000 mental health care users displaced. This is despite SA's commitment to deinstitutionalisation, illustrating what is either a lack of understanding of what deinstitutionalisation entails or a disregard for the mental health care users, their families, and the NGOs having to come to the rescue with no additional funding and little notice.

Clinics and specialists. When it comes to mental health care, there are approximately 1.2 psychiatrists for every 100,000 people in public health nationwide. Private practitioners are too expensive for much of the population. This results in lack of or wrong diagnoses. Further, rural areas lack rehabilitation services to support persons with mental illnesses and their families. Rehabilitation services tend to be in hospitals, often far away, also losing opportunities to integrate psychosocial rehabilitation into existing community-based services.

d) Social inclusion and participation

There are reported positive accounts of the effects of disability grants on the lives of persons with disabilities; however, securing a disability grant is a difficult process that could be made easier. LRC paralegals often assist clients who report rejections of their application for a disability grant by the South African Social Security Agency (SASSA) due to administrative issues or narrow interpretations of medical reports being applied when assessing applications. The physical collection of the grant at designated pay points proves to be a further challenge, as persons with disabilities often have to pay double transport costs if using public transport or have to pay a fee to another person to collect the grant on their behalf.

⁴ Human Rights Watch (2015). *Complicit in Exclusion*.

e) Stigma and awareness of disability issues

Stigma and a lack of awareness of disability issues continue to permeate the South African environment, limiting the extent to which persons with disabilities can enjoy their rights. Mental health is particularly vulnerable to stigma and the resulting discrimination, as the disabilities are often referred to as 'invisible'. Stigma is pervasive across the country, in rural and even corporate settings.

Stigma may interact with other issues, such as by contributing to a lack of *access to justice*. For instance, a local 'induna' may deny knowing a person with disabilities, or frontline workers at courts, such as clerks and security guards, may have insensitive attitudes towards persons with disabilities, even at courts that are supposed to function as Equality Courts.⁵

With mental health care, stigma can be detrimental. For instance, stigma often results in people not using mental health facilities. Further, persons with disabilities may face discrimination or a lack of assistance with health conditions, such as being told that they should not become pregnant because they place additional burdens on their communities, or they face difficulties in accessing ARVs.

On a more positive note, the media analysis conducted by SADA with the DRPI found that 40% articles in the media are now framed in a human rights perspective, compared to practically none 10 years ago. The SAFMH is also embarking in a media empowerment drive to ensure that media recognises its role in sharing information and shaping perceptions.

Proposed recommendations: Awareness of disability issues and inclusion of persons with disabilities needs to be promoted within all sectors of society.

2) Recommendation 124.111 Strengthen its development policies in rural areas, with special emphasis on the access of children and persons with disabilities to services (Chile)

Not implemented. Rural areas are still hit hardest by the slow implementation of policies. Persons in rural areas, for instance, are often hardest hit with lack of specialist doctors or with medicine stock outs.

Rural Health Campaign. With regards to the implementation of the Mental Health Policy Framework and Strategic Action Plan, the Rural Health Campaign was initiated in 2011 to address the slow progress. SAFMH is a member of the Rural Health Campaign (RHC), which has provided a report with recommendations based on testimonies from mental health care users in rural Eastern Cape, KwaZulu-Natal, Limpopo and North West provinces.⁶

The RHC reports that there has never been a systematic tracking of expenditure on treating mental illness in public and private sectors and that it is difficult to obtain information or to determine how much is spent on mental health care services. This is largely due to an absence of a coordinated mental health strategy that is costed and fully funded, with clear strategies,

⁵ Holness, W. and S. Rule. (2014).

⁶ Rural Mental Health Campaign. (2015). *The Rural Mental Health Campaign Report: A Call to Action*.

activities, targets and budgets – this may be addressed if the Department of Health fully implements its National Mental Health Policy Framework.

Proposed recommendations: (1) Ensure that persons with disabilities in rural areas are provided with equitable access to basic services. This includes access to health care facilities, education and housing that accommodates their disability needs. (2) Provinces must ensure that the National Mental Health Policy Framework is translated into the provincial strategic and operational plans, explicitly addressing rural settings.⁷

3) Recommendation 124.26 Provide the Ministry and Department of Women, Children and People with Disabilities with the necessary powers to continue promoting the participation and contribution of these vulnerable groups to the development of the country (Chile)

Not implemented. There is no longer a Ministry and Department of Women, Children and People with Disabilities.

The Ministry was disbanded and the disability desk was merged into the Department of Social Development, despite much opposition in the disability sector. As a result, disability has become diluted amongst other priorities of the Department of Social Development. A direct plea was made to the President in 2016 at the Disability Summit to reinstate the disability desk, but as yet there has been no progress.

Budget cuts. Budgets to local and provincial departments have been cut. With respect to mental health, there is a disparity in funding across provinces and an almost nationwide reduction of funding and subsidies for mental health care services at the community level.

Reduced funding. NGOs that provide fundamental services such as training on human rights issues, schooling for children with disabilities, or other supportive work within the disability sector, receive little or no funding from the government, despite undertaking work that would otherwise fall upon the State in its implementation of disability policies.

Proposed recommendations: (1) NGO's require greater support from government in terms of resources and funding in order to continue to provide services for persons with disabilities, particularly in the rural areas. (2) There needs to be consistency in the ministry that is delegated to assist persons with disabilities, and that is accountable and accessible to communities. (3) The Department of Social Development should be given necessary powers to promote the participation and contribution of persons with disabilities to the development of the country.

III. Other emerging issues

Two additional issues emerge from the experiences and work of the collaborators for this submission: potential human rights infringements with respect to involuntary admissions and criminal justice, and a need to update certain policies.

⁷ This recommendation can be found in *The Rural Mental Health Campaign Report (2015)*.

a) Potential human rights infringements

Involuntary admission. The topic of involuntary admissions of persons with mental health conditions to a hospital or institution is currently being debated globally. SAFMH gathered the views of mental health care users with regards to such a practice, finding that a majority thought it was necessary and were in favour of it. Many reported a sense of security in knowing that involuntary admission is in place if they were to experience a relapse and pose a threat to themselves, although many of those that had been involuntarily admitted also reported that they would have, in most instances, agreed voluntarily if they had been consulted – but they were not. Nevertheless, there is debate about whether involuntary admission is in fact against the human rights of persons with disabilities. At the very least, the Mental Health Care Act 17 of 2002 does have safeguards in place to protect persons from the abuse of the involuntary admissions system, but this requires that Mental Health Review Boards in all nine provinces be functional. This is not always the case.

Women, children and crime. Women and children with disabilities who are victims of criminal activities are often faced with barriers when attempting to report these incidents or if they require a medico-legal examination. There is a general lack of information about women with disabilities and crime, which is itself a threat to the successful implementation of the UNCRPD. Research by the Centre for Disability Law and Policy in three provinces confirms that gender-based violence against women with intellectual and psychosocial disabilities is underreported and that there are significant barriers to accessing justice.

Proposed recommendations: (1) Ensure that Mental Health Review Boards are functional. (2) Pay special attention to the safety and security of women and children with disabilities within the criminal justice system and provide additional mechanisms to assist vulnerable groups who are victims of criminal activities to report crimes, as well as provide assistance and support during prosecution of offenders.

b) Policy-related issues

Definitions. A variety of definitions are used across policies, some still based on the medical model of disability.

Absence in policies. In relevant policies related to situations of risk and humanitarian disasters, there is no mention of the protection of the safety of persons with disabilities, despite their distinct needs.

Barriers in policies. Barriers in the Electoral Act exclude persons with intellectual and psychosocial disabilities from voting, democracy training, and standing for Public Office.

Lack of unity. Lack of intersectoral engagement among government departments, resulting in, for instance, most departments not seeing mental health services as their mandate.

Mainstreaming. Disability is being mainstreamed in law, policies and programmes; however the allocation of resources does not correspond with the policy direction. The government must be cognisant that mainstreaming is not always ideal in every circumstance. For example severely under-resourced mainstream schools do not always have the capacity or expertise to provide adequate education to learners with disabilities.

*Proposed recommendations:*⁸ (1) Attend to the different definitions of disability and how this is being adjudicated upon in various forums. (2) Amend any and all discriminatory laws, regulations and practices. (3) NGOs and government to combine to resolve issues associated with mainstreaming.

⁸ These recommendations can be found in SADA and DRPI (2015). *Monitoring the Human Rights of Persons with Disabilities in South Africa: Holistic Report.*