



Public Hearings

UN Convention on the Rights of Persons with Disabilities

to the

**Portfolio Committee on Women, Youth, Children and People with
Disabilities**

Day 2: Thursday, 26 July 2012

Venue: V454, Old Assembly, Parliament

**Presented in honour of all people with dementia and their families
And carers who struggle with the challenges of dementia
(including Alzheimer's disease)**

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Internationally, the rights of persons with disabilities are inalienable, interdependent and indivisible and this is reflected in the Convention. It can be argued that older persons, like persons with disabilities, are such a vulnerable group who, as a result of historical and systemic disadvantage as a group, are not in a position to equally realize and enjoy their human rights. So too then are those who are left vulnerable as a result of a diagnosis of dementia – including Alzheimer’s disease.

A UN Convention will lay foundation for enhancing the rights of older persons and create a blueprint for potential legislation, policies, practices to Member States and Regional Bodies.

“Human rights violations range from age discrimination which often has a clear gender dimension, abuse and violence in both domestic and institutional settings which disproportionately affect older women, lack of participation in matters affecting the elderly and a failure to discharge the various social and economic rights to which they are entitled including the right to health care, work, education, social security, food and adequate nutrition. The HIV/AIDS pandemic has also meant that older persons carry a disproportionate burden of family responsibility.

While in traditional African societies older persons were generally supported and cared for by their children or extended family, the changing societal dynamic brought about by among other factors, globalisation, urbanisation and the HIV/AIDS pandemic has impacted negatively on the cohesion of the family and its ability to create a nurturing and enabling environment for the protection of older persons. Under these circumstances there is clearly a need for increased state intervention in support of the elderly based on universal human rights norms and standards. While the African Charter provides a broad normative rights framework, there may be merit in developing a specific treaty that articulates both clear and concise human rights standards for older persons and provides a mechanism for implementation and accountability, both of which are currently lacking.”

Judge Jodi Kollapen - 2008, *Report on Older Persons in South Africa*

Older persons can be considered a vulnerable group and we need to recognize that many vulnerable groups may and often do overlap. Some older persons may belong to the group of persons with disabilities; some may belong to indigenous peoples while a substantial amount of older persons, are women. Most importantly it needs to be recognized that persons with disabilities will ultimately join the older persons sector and thus the struggle to promote rights of this sector will ultimately benefit all.

Another compelling consideration for strong legal protection of both sectors is the issue of participation and inclusion – the issue of having a voice. Like persons with dementia, older persons often do not have a public space to articulate their concerns or claim their rights. These rights therefore need to be formally recognized. Without clear legal norms older persons may have difficulties in challenging stereotypes of them being a burden on society or as being weak and passive individuals. The existence of international and regional legally binding instruments such as a Protocol or Convention can facilitate the realization of their rights in practice making it a society for all ages and not just an aspiration.

So what is Dementia and why could it be considered a disability?

The term 'dementia' refers to a degenerative brain syndrome involving gradual deterioration in multiple areas of a person's brain giving rise to a progressive loss of cognitive functioning. Progressive meaning that it gets worse over time. Cognition is the mental process of *knowing*, including awareness, perception, reasoning, insight, understanding and judgment. Cognitive functioning is a conscious intellectual activity and controls memory, emotion, behaviour and the ability to make decisions. Dementia damages brain cells, or the connections between brain cells, and impairs an individual's ability to communicate, behave, and make decisions.

Dementia is chronic, progressive and terminal. Dementia is the umbrella term for a number of conditions such as Alzheimer's Disease, vascular conditions, dementia with Lewy Bodies, Frontotemporal dementia, Korsakoff's syndrome (alcohol related dementia), over 100 different types of dementia. It may also be associated with HIV/AIDS. A study done at University of Cape Town indicate that 1:3 (one in three) people with HIV/AIDS will develop HIV/AIDS DEMENTIA COMPLEX – a very scary statistic and one which needs to be taken seriously especially with the high incidence of HIV/AIDS in South Africa.

Dementia is an epidemic sweeping the entire world. In 2010, an estimated 35.6 million people worldwide were living with dementia. This figure is projected to increase to 115.4 million by the year 2050 and 71% of those with dementia will live in low and middle income countries.¹ It knows no social, economic, ethnic or geographical boundaries and affects people throughout the world.²

The number of dementia cases in South Africa is unknown due to lack of research, inadequate diagnosis, lack of training and no public awareness and education.⁽³⁾ Accurate figures for the cost or burden of dementia in South Africa simply do not exist. Research on virtually every aspect of dementia is lacking in South Africa.

Dementia SA is currently engaged in discussions with a team of specialist academics, to partner with us to embark on crucial and much needed research on dementia / Alzheimer's disease in South Africa. The research will use globally accepted research criteria, protocols, assessment tools, and methods and will therefore be accepted by the international

¹ Alzheimer's Disease International *World Alzheimer Report 2009* (2009), at: <http://www.alz.co.uk/research/world-report>.

² Dementia SA, *Media Quick Facts About Dementia* (2010), at: <http://www.dementiasa.org/downloads/MEDIA%20FACTS%202010%20%20WAD%20SEPT%202010.pdf>.

³ Awareness is especially poor amongst older persons themselves as over three-quarters claim no familiarity with the terms 'dementia' or 'Alzheimer's'. Community Agency for Social Enquiry *The Status of Older Persons in South Africa, A National Study on the Needs and Access to Services of Older Persons* Research commissioned by the national Department of Social Development (2009).

community. This type of research has never been undertaken in South Africa before. The study is estimated to cost R4,5million – we need the support of Government to assist with this initial study – and make a difference to the way we understand the silent epidemic which is dementia.

Dementia is not a normal part of ageing. However, the primary risk factor for dementia is advancing age. Most cases of dementia occur in persons over the age of 65 but dementia may manifest in younger persons.

Persons with dementia eventually need supervision and assistance not only with important financial and legal matters but also with basic activities of daily self-care such as eating, toileting and hygiene, dressing, taking medications, and mobility in the home environment.

There is no reason to believe that South Africa will fare differently than any other country regarding the projected sharp rise in dementia incidence by 2050. And while the HIV/AIDS epidemic is slowing growth in both life expectancy and population growth, South Africa is nevertheless expected to experience a 52 percent increase in the number of persons age 60 and older by the year 2050.⁴ A larger population of older persons in South Africa brings an increased incidence of age-related diseases such as dementia.

Dementia is a global issue of epidemic proportions, capable of dramatically impacting families, communities and governmental economies. Older persons with physical and/or mental health issues (and who become dependent on others) are particularly vulnerable to abuse, especially persons with impaired cognitive abilities due to dementia. Some communities or cultures in South Africa, dementia symptoms may be linked to witchcraft and result in violence against sufferers. Early detection and diagnosis of dementia is important for many reasons, one being the ability of persons with dementia (and their families) to plan and put steps in place to help avoid abuse. These steps include arrangements for care, advance health care directives, estate planning documents, and durable financial powers of attorney. Unfortunately, South Africa does not allow financial powers of attorney to be durable and that this forces families to be subjected to the cost of court administered curatorships. **Dementia SA** supports the valuable work of the SA Law Reform Commission (SALRC) *Project 122 on Assisted-Decision Making*. It has been re-aligned to integrate and include the UNCRPD and this law reform is crucial for the protection of people who require assisted decision making and we look forward to the support of Parliament to accept the suggestions of the SALRC. The abuse of older persons, and especially those with dementia, is often perpetrated by family caregivers who may be suffering isolation, burn out, lack of support, respite care and knowledge about the disease. Furthermore, a caregiver of a person with dementia can become the victim of verbal and

⁴ Alzheimer's Disease International *World Alzheimer Report 2009* (2009) at <http://www.alz.co.uk/research/world-report>

physical abuse in those cases where, in some cases, dementia may causes personality and behavioural changes in its sufferers. The rights and protection of older persons with impaired capacity and of elder abuse are inadequately covered in existing human rights mechanisms, and **Dementia SA** would support a human rights treaty that specifically addresses the situation of older persons with dementia.

Older persons are a vulnerable population group in South Africa. Older persons with dementia (and persons of any age with dementia, for that matter) are amongst the most vulnerable, subject to financial exploitation, abuse and neglect by family members and caregivers. South Africa's transforming health and social care system has no chance of attaining the equity it aspires to, if persons with dementia and older persons are not specifically included. We need to promote a social conscience around ageing in South Africa so we can debunk the myths that older persons are a burden but also acknowledge the vulnerabilities of ageing with disease, especially dementia which robs them of their former selves.

The human race is biologically wired to care for helpless babies and ensure their survival. The human race lacks the same genetic and societal motivation to care for helpless adults. It is often said that the true measure of any society is how it treats its most vulnerable members and this includes older persons and those with life altering diseases.

Persons with dementia cannot advocate for themselves. We need to be their advocates.

Thank you for this valuable opportunity to address you and to give a voice to those who have lost theirs through the progression of a cruel and insidious disease, Dementia/Alzheimer's disease.

We appreciate the opportunity afforded us and respectfully submit this report as our written report and a transcript of our verbal report given to the Portfolio Committee of the Department of Women, Children and people with Disabilities on Thursday 26 July 2012 at the Public Hearings on the UN Convention on the Rights of Persons with Disabilities.

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