



THE PRESIDENCY
REPUBLIC OF SOUTH AFRICA

Addressing Inequity In Childhood Cancer Control In South Africa: A Civil Society Perspective

**The First Lady of the Republic of South Africa
Madam Tobeka Madiba Zuma**

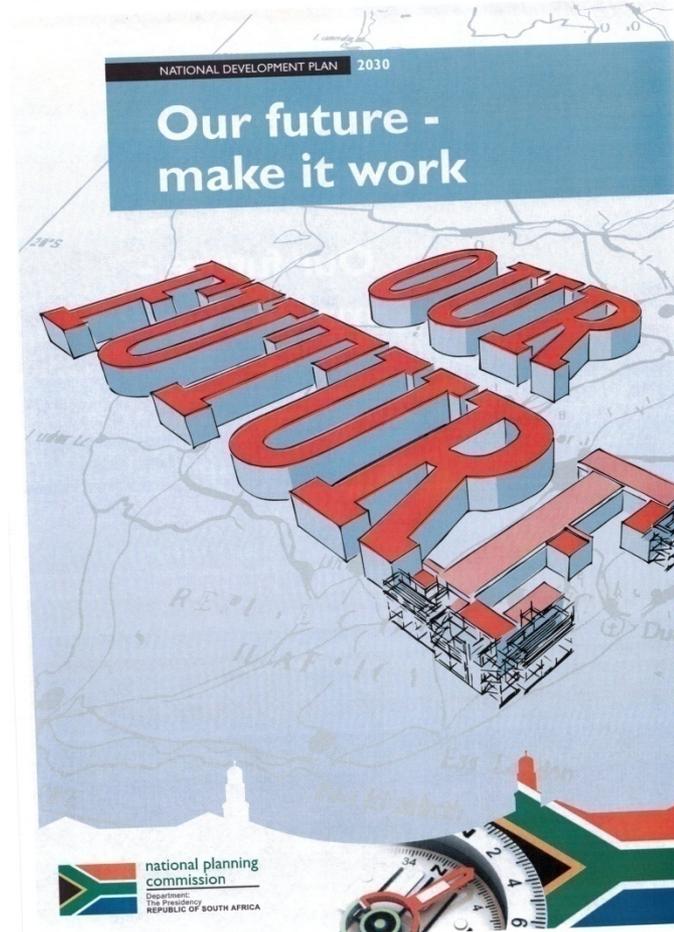
CONTENT

- What defines a civil society perspective on inequity and health.
- What is the status of childhood cancer in South Africa?
- What can be done to change the situation?
- Child with cancer and schooling
- Conclusion

The National Development Plan 2030

“Our future – make it work.”

- South Africa belongs to all its people and the future of our country is our collective responsibility.
- All South Africans seek a better future for themselves and their children.
- Plan to eliminate poverty and reduce inequality by 2030 through uniting South Africans”
- “Provide affordable access to quality health” recalling the need for person and community centered health care
- Universal health coverage will be achieved through the National Health Insurance and by legislating Standards Compliance



Observing inequities in health

- Target communities are vulnerable and therefore at high risk, including rural communities, older persons, persons with disabilities and children.
- Children with non-communicable diseases have been observed to “fall through the cracks” and fail to benefit equally as children with communicable diseases.
- Long term care of children incurs out of pocket expenses , also often demanding a parent who could be economically productive to take full time care of the child who is ill.
- Families with children who are ill remain in spirals of poverty and under-development.
- Inequality in outcomes is unacceptable and a matter of the right to health and social justice for children.

Informing the situation through evidence

- The SA National Children's Tumour Registry founded in 1987 is the only dedicated children's cancer registry in Africa and is partly funded by the CHOC Childhood Cancer Foundation
- The South African Children's Cancer Study Group (SACCSG) analyses trends, inform research and modifications to treatment protocols and provides data to the National Cancer Registry. However, more resources are required to increase reporting to both registries as current detection rates are still far from optimal.
- Data rates across the provinces are unequal. If the detection rate were the same across all provinces, the total number of cases reported annually would be three times higher.

WHAT IS THE STATUS OF CHILDHOOD CANCER?

- The most common cancers seen in children are leukaemia, lymphoma, brain tumours and neuroblastoma.
- Our children with cancer often remain undiagnosed, diagnosed late or un-referred.
- The rate of detection of childhood cancer is unacceptably low at approximately 40 per million, in contrast with an expected rate of 140 per million (Stefan & Stones).
- Our children with cancer die unnecessarily, with a dismal mortality rate of children with cancer at 50% (Stefan & Stones) in many centers.
- We are far from reaching the survival rate of children with cancer which should approach 75 – 80% with the available resources.

What needs to be done

- Urgency to strengthen prevention and early detection of cancer while complementing treatment offered and enhancing the quality of life of children, adolescents and adults with cancer and their
- cancer in children is rare and not preventable, it is income countries.
- In comparison with adults with cancer, children with cancer are relatively neglected in terms of awareness, funding and access to care.
- The financial burden of the treatment of childhood cancer is much less and there is generally good long term survival with acceptable quality of life.

Holistic care is more than medical care

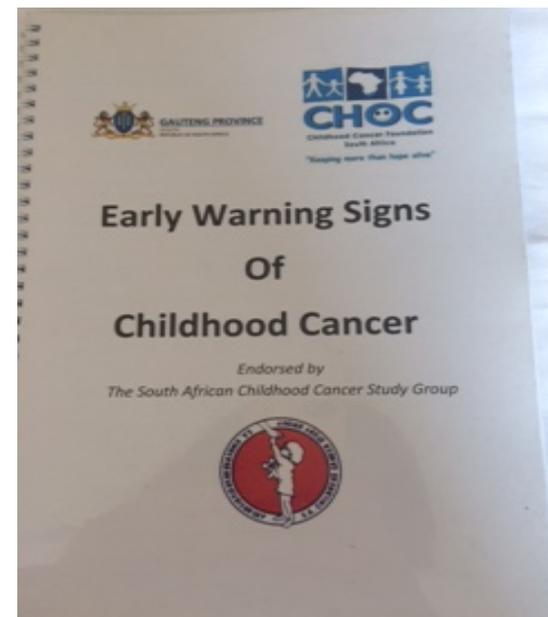
- Focussing on improving management of childhood cancer will thus have far-reaching effects, especially as the survivors of childhood cancer will have a contribution to workplace and GDP of the country as productive working members of society
- The child with cancer represents a perfect example of how multi-sectoral cooperation and integration including the child, parents and civil society can result in optimal outcomes.
- Holistic care incorporates not only early detection and comprehensive multi-disciplinary therapy but also education, community oriented care, rehabilitation, psycho-social care and comprehensive long term follow up.
- It has been shown in other settings that a focus on improving childhood cancer management has a positive ripple effect on a large part of a health care system

“Best Practice” on training

- All health care workers at primary care centres should be educated about the St

Siluan

which are designed to detect approximately 85% of childhood cancers.
which are designed to detect approximately 85% of childhood cancers.



- immediate referral
is mandatory if a childhood cancer is suspected.
- All children should be screened at every well baby visit for retinoblastoma with basic fundoscopy which can be performed by any health care worker with minimal training
 - Establish appropriate referral pathways to ensure that no child experiences delay in accessing appropriate care. Any child with proven or even suspected cancer should be able to be referred directly to a Paediatric Oncology Unit, without going through the usual channels of referral.

Specific issues relating to the child with cancer and schooling :

- Depending on age at time of diagnosis, developmental milestones are interrupted and the child may regress to a previous level of development if not managed well.
- Trauma of hospitalisation and treatment may impact on learning, hospital schooling is critical.
- Specific disabilities such as blindness, amputation and cognitive impairment may require a change in school or access to remedial services

•

CONCLUSION

- Inequities in childhood cancer control must be addressed within the broader health transformational framework which addresses:
 - Universal health coverage
 - National Health Insurance
 - Legislated Standards Compliance
- Achieving optimal health outcomes for all children must consider the social determinants of health.
- Optimal health outcomes requires a multi-sectoral approach
- Managing the child with cancer must consider the child and the family as central to all initiatives.