

Review of: "The Plight of Rare Diseases in Southern Africa: Health and Social Services Policy Recommendations"

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Potential competing interests: No potential competing interests to declare.

This is an important contribution to the literature - thoughtful, well written and insightful, the proposal of collaboration across SSA around rare diseases is an important step forward. The combined expertise of a range of groups of researchers, service providers and advocates makes their arguments particularly compelling.

A few recommendations however:

> The term used here is 'Rare Diseases' - but there are a number of rare diseases and an entire group of diseases often considered under the term 'Neglected Tropical Diseases' - diseases like NOMA and Mycetoma, and also come to mind when the term 'rare diseases' is raised. What is being considered here are largely genetic diseases, with exceptions like multiple sclerosis, and Guillain Barre Syndrome. I think this call to action would be much clearer if some term like Rare Chronic and Genetic Diseases were used.

> I agree with all the points raised in the Recommendation section but these are all top down approaches focusing on clinicians, support providers, etc. . I'd add another Recommendations - development and support of self-help advocacy groups for people who have these diseases and their families, and links where appropriate with local, national and regional Organizations of Disabled People (ODPs) - who can provide information about the legal, economic and support supports needed for many people who live with these diseases, and who can collaborate with and help train health care providers to better understand what it is like to live with such diseases.