Reviewer's report

Title: Children with Albinism in African Regions: Their rights to 'being' and 'doing'

Version: 0 Date: 18 Sep 2017

Reviewer: Maria Berghs

Reviewer's report:

I thought this was a really interesting paper and obviously written by people who have a lot of expertise working with PWAs. It also follows in the line of some recent scholarly work where politically and socially active disabled people have requested a strengthening and innovation of human rights frameworks, such as the CRPD, using the social model (Berghs 2016, 2017). It speaks to those urgent concerns people have about legal instruments such as conventions becoming soft and how to ensure they are being enforced. I did have some questions and suggestions on how to improve the paper.

Firstly, the main body of the text argues that there is growing recognition and acceptance on the African continent that PWAs should be considered disabled or persons with disabilities? I think this is a more nuanced argument in that those are global discourses affecting creation of adult subjectivities but we don't actually know what children want (you also state this). Similarly, in your article there is a lot of mention of elite PWAs but very little of voluntary organisations run by PWAs? Most of the support cited for disability framework and labels is also institutional? You mention Brocco (2015) but in that paper he mentions how albinism is perceived as both good and bad in the African context. Even in kiswahili there are differences between dili and zeruzeru no? There is considerable heterogeneity in Africa but in specific countries like Tanzania, human rights abuses and deaths are occurring. You are correct in making connections between rising inequalities and these killings. I think perhaps Brocco (2016) is a stronger paper to cite, because he examines how and why PWAs now adhere to local and global discourses on disability in Tanzania. There is also a tension in adopting the disability framework and gaining legal and other entitlements and issues with increasing stigma and countering discourses of 'normality'.

Secondly, what is useful about the paper is that it illustrates how legal conventions can work in tandem using Thomas' social-relational model and you present a kind of middle road to those tensions. Conventions can strengthen each other. However, the CRPD is a very innovative legal instrument and it is based on the social model. Disability is also an evolving and dynamic concept as the preamble states. There is also a kind of flow in the Articles from individual to social to environment to structural and it is inclusive of Article 7 about Children with Disabilities. A legal practitioner might question why the need to have the CRC instead of the CRPD for children with disabilities? I would also suggest you give Table 1 and 2 to a legal
practitioner to check. For example, I was surprised to see Article 23 on respect for home and family life missing when you examined impact on family life and friendships? If you look at that Article in more detail you will see that it also states, "3. States Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realizing these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families."

Thirdly, I felt the conclusion was a bit weak. What are the practical consequences of linking two conventions with each other and focusing on barriers to doing and being? In terms of translation to PWAs and empowering children's voices what does this approach do and how could it work in practice? In terms of ensuring legal empowerment, working across national and international agencies, NGOs and institutions? Think of why Carol Thomas in her work is now linking intersectionality to psycho-emotional disablism? People always have issues in the field in terms of understanding 'rights' (CRC and CRPD) and resistance to rights of children but they might have less issues with understanding barriers to doing and being? One of the reasons that the social model was so successful was because it was conceptually simple. Could you work with PWAs or children to translate this in the field with them or check in with them?

Please check you are using the correct human rights and social model definitions on pages 5 and 6. Just quote those. Page 5: when listing rights included in the CRPD maybe adequate standard of living and social protection (Article 28) might be important to state? Especially with your argument on page 7, line 150?

Please check the text and proofread because there were some typos (Pg. 6, line 109) where the year is incorrect and there are several points during the text where there was some repetition for example, variations of the word 'highlight'. See page 14. Or 'It is important to note' on page 9?

There are some heavy generalisations. Be careful of these: For example, Pg.3, line 37. It is not true to state that there has been a paucity of research on psychosocial aspects of albinism. See Ezeilo (1989) onwards and Phatoli et al. (2015) where issues like stigma, internalised ableism etc. are discussed? Do you want to say that psychosocial aspects of children with albinism need more attention?

References: Please check formatting of reference 21 which seems copy pasted?
Are the methods appropriate and well described?
If not, please specify what is required in your comments to the authors.

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