Author’s response to reviews

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

Authors:

Anita Franklin (anita.franklin@coventry.ac.uk)
Patria Lund (p.lund@coventry.ac.uk)
Caroline Bradbury-Jones (c.bradbury-jones@bham.ac.uk)
Julie Taylor (j.taylor.1@bham.ac.uk)

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Response to Reviewers

Children with Albinism in African Regions: Their rights to ‘being’ and ‘doing’.

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Authors:

Franklin, A.; Lund, P.; Bradbury-Jones, C., Taylor, J.

We thank the reviewers for their positive comments and having addressed the suggestions which were raised, we agree that this has now strengthened our paper considerably. The following provides detail on amendments, which are also highlighted in the paper:

Reviewer 1: The author could also usefully include discussion of the complaints mechanisms under the African Children's Charter and OP3-CRC as potential avenues for self advocacy in attempting to bring this human rights situation to the fore and pressure governments to take the appropriate actions to remedy human rights violations against this population and improve their rights situation more generally
Response: Reference has now been made to the complaints mechanism under the African Children’s Charter and new opportunities afforded to children under OP3 CRC, although we have referenced the latter mechanism’s limited use at present given the lack of ratification of this so far across African nations, Page 19 lines 389-398:

Accessing complaints, investigating and reporting mechanisms under the African Children’s Charter and the CRC could be, and has to some extent been, utilised as a potential avenue by advocacy groups to pressure governments and organisations to take human rights violations seriously and improve the human rights of children with albinism. If national legal systems do not provide a remedy for human rights violations, alternatives such as the Optional Protocol to the Convention on the Rights of the Child on a communications procedure (OP3 CRC) which came into force on 14 April 2014 [40], could also provide children themselves with the opportunity to access justice at an international level. However, children will only be able to use this complaints procedure if their States ratify OP3 CRC, and this is yet to happen across most of Africa.

Reviewer 1: There are a few points where there is some repetition in the paper and one point where the same lines are repeated i.e. lines 55-58 compare to lines 74 and few lines following. The authors should review the manuscript for the couple of occasions where there is repetition either exactly or by paraphrase and fix this

Response: The repetition in these lines (and elsewhere) has now been removed.

Reviewer 1: There is a section where violence against persons with albinism is linked allegedly to poverty-this is a very inflammatory statement and the countervailing view that such violence cannot be explained in this way should at least be mentioned.

Thank you for pointing this out. We have added a recent reference to this, softened the language, and included a countervailing view (lines 227-232):

There are strong arguments that it is poverty that drives the violence towards PWA [25] and this is specifically acknowledged by the United Nations as a key contributor to witchcraft related violence [26]. It is possible to make a direct link to the boom in mining and rapid social change and inequalities in Tanzanian society [24, 30] and though poverty in and of itself does not cause violence, in terms of PWA it seems to be a significant risk factor.
Reviewer 2: 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 kisswahili 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'.

Response: Reference has been made to the call by disabled people for the strengthening of the CRPD throughout. Lines 113-119:

Within the African context children with albinism not only have rights as disabled people under the UNCRPD; they are also afforded rights under the United Nations Convention on the Rights of the Child (UNCRC)[18] which has been signed and ratified across Africa. Additionally, the 1999 African Charter on the Rights and Welfare of the Child was created to provide additional rights to protection and outlines the rights that African countries must ensure for their child population [19].

P13 Table 1: Children with disabilities have equal rights to family life and to prevent concealment, abandonment, neglect and segregation (23)

Lines 402-404 Despite such obligations, politically active disabled people call repeatedly for the strengthening of human rights frameworks which recognise and address the barriers they face [41].

Lines 145 and 209 Alternative Brocco paper has now been cited.

Line 404 The work of Berghs has been referenced.
Reviewer 2: 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."

Response: We have specifically used both the CRC and CRPD because together they should afford disabled children and young people multiple avenues of protection and rights. We would argue that disabled children fall between the gaps of both conventions whereby disabled children are rarely mentioned within debates or reporting on the CRC, similarly disabled adults dominate discourse concerning the CRPD with often lip service given to the rights of disabled children within this. Thus bringing the two Conventions together offers an opportunity to examine the full rights of disabled children as both children and as disabled people.

Lines 415-419: The CRC and CRPD together provide a framework for children with albinism and their advocates to call governments and others accountable when their rights are not enacted and thus create, or permit the continuation of, barriers to ‘being’ and ‘doing’. Together these conventions should provide multiple avenues to facilitate the protection and rights of children with albinism.

Table 1: Reference to Article 23 has now been added. We do not think that the paper needs to be examined by a legal expert. The paper is not meant to be a full legal representation of the UN Conventions, but to stimulate debate and action.

Reviewer 2: 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?
Response: Really useful discussion, thank you. The conclusion has now been strengthened to further illustrate the practical uses of using this theoretical framework:

There is a severe lack of rigorous empirical research into understanding the lives of PWA, especially from their perspective and within a social-relational model of disability. Their voice concerning how their rights are being enacted or denied, the barriers they face and what might better support, empower and protect them has to date been denied. The limited available evidence on living with albinism has been predominately adult focused, with little attention being given to the unique experiences of children. Exploring what is known about children with albinism within an integrated disability and rights lens helps to identify and frame the barriers faced by this group and suggest possible ways to overcome them. The CRC and CRPD together provide a framework for children with albinism and their advocates to call governments and others accountable when their rights are not enacted and thus create, or permit the continuation of, barriers to ‘being’ and ‘doing’. Together these conventions should provide multiple avenues to facilitate the protection and rights of children with albinism.

In addition, our debate has illuminated the need to develop and enact a holistic concept of rights for PWA, which sees human rights as indivisible. Although little attention has been given to the issue, the evidence highlights that in trying to meet the fundamentally critical right to life and protection, other important rights are being denied. This debate has emphasized specific ways in which the lives of PWA could be improved by addressing the ‘barriers to being’ and ‘barriers to doing’. At its heart this requires both a shift in attitude and action to address discrimination among this group of people.

Reviewer 2: 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?

Thank you, we had not noticed how often we had repeated some words! We have amended throughout and undertaken a thorough proofread and definitional check. Line 109: The year is correct, according to the OHCRC website. http://www.ohchr.org/EN/Issues/Albinism/Pages/IEAlbinism.aspx
Reviewer 2: 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?

Response: We have checked throughout and amended. We have specified that it is children with albinism needing more attention, Line 38:

Significantly, the experiences and perspectives of children with albinism are underexplored and little is known about the psychosocial issues facing this group. Limited understanding of their lives in an African context and a lack of attention given to the particular needs of this group of children means that interventions to better support, empower and protect them remain elusive.

Reviewer 2: 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?

Response: Adequate standard of living has now been added, Line 99: These rights include a right to life, adequate standard of living and social protection, equality and non-discrimination, freedom from exploitation, violence and abuse, and a right to education, health, work and employment.

Reviewer 2: References: Please check formatting of reference 21 which seems copy pasted?

Corrected

We hope you agree the arguments in the paper are enhanced by addressing these comments.

Kind regards

The Authors