Teetering on the Brink: Locating the Voices of Children Albinism in the Discourses of Disability and Albinism in Kenya

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List of Acronyms

CWAs   Children with albinism
KTN   Kenya Television Network
NCPWD   National Council for Persons with Disability
OHCHR   United Nations Office of the Commission on Human Rights
PWAs   People with albinism
PWDs   People with disabilities
UNCRC   United Nations Convention on the Rights of the Child

Abstract

Group identities are not sacred glue- nor are they corrosive to it. Instead, they are some of the material affording people a sense of self and purpose in and out of the process of shaping a collective future (Minow, 1997:146)

This qualitative study with an ethnographic orientation examines the discourses of disability in the context of albinism in Kenya by foregrounding children's voices in a highly politicised debate. By applying the concept of agency, the study considers how lived experiences of children with albinism reveal the desire for autonomy in spite of shared threats that call for solidarity among members of an oppressed group. While the dominant discourse presented at the macro level by adults is that of disability and a tenuous existence, to the contrary, this unification is contested. Children and their families present more nuanced narratives and counter narratives. These show diversity within the albinism community, but which are nevertheless muted because the group affiliations confer social, economic and political state benefits. Ultimately, findings show that group identity and that of the individual serve different but nevertheless important and mutually reinforcing purposes. This calls for re-defining children's contributions in the design of programs aimed at including marginalised groups in society- especially by civil society organisations.

Keywords

Albinism, ableism, disability, social exclusion, identity politics, occult economy, discourse.

Chapter 1 : Negotiating Ambiguities of albinism in Africa

"Children's bodies are the sites upon which terms of *the national future are being worked out*" (Woronov 2009:571)

Introduction

This research explores the contradictions that embody the existence of children with albinism in Kenya. It focuses attention on discursive differences between narratives by adults with albinism and contrasts them with the everyday experiences of children living with the condition. With the growing recognition for centrality of self-representation in social justice struggles, members of oppressed groups have taken up the fight for their rights against discrimination and societal injustices. Adults with albinism have used their distinct skin colour, characteristic low vision as well as fear for the occult that spread from Tanzania to construct themselves as disabled in political and legal terms in order to claim certain social, economic and political benefits. The process of entrenching this narrative of albinism was deliberate and well calculated, and succeeded in portraying a collective identity of a group of persons with disability at the risk of decimation, for which the state needed to take urgent corrective actions. However, personal accounts of children with albinism and their parents tell a more nuanced story, one that shows that this group identity is contested, and not every member of the group wishes to be identified in this manner which portrays them as "weak". I use a mixed methods approach to illustrate how children redefine who they are in settings where, challenging the adult-centred narratives especially on issues such as special needs education and the state-funded sunscreen program. This contest calls for more critical reflections among PWA activists, in spite of the progressive recognition of the rights of PWAs that has come about in areas such as health, employment and political representation.

In problematizing the research issue, I take a historical view, and use both primary and secondary empirical data to demonstrate evolution of the disability discourse to its present form in order to show the ways in which it espouses incompleteness by not taking to account children's views. In the research, two related concepts underpin the central place of children in society. One is childhood as a life phase and the other is children's agency which is elaborated in the background section together with the research context.

In this research, I use the term children with albinism or simply CWAs to refer to children born with a genetic condition where the pigment melanin is lacking, giving their hair, skin and eyes a pale white appearance (Lund and Taylor 2008). I also use the term people with albinism (PWAs) mainly to refer to adults with the condition The term CWAs is preferred over the term "albino" which in everyday use is considered derogatory (Salewi 2011).

Locating Children in the Social World

Almost all societies of the world consider and treat children as special, believing firmly that they encapsulate future aspirations of the nation. This futuristic perspective of childhood was most demonstrable in developing countries where, soon after independence, great efforts went into formal education in the hope that the young generation would be the sites upon which visions of the soon-to-be prosperous nation-states could be re-engineered and enacted (Hall and Midgley 2004, Valentin and Meinert 2009). Children's "physiological and psychological differ-

ences from those of adults" make childhood a distinct life phase, and consequently, have implications for children's positioning especially when we apply cultural interpretations to these differences (Qvortup 1994 in James 2011: 167). Thus, conceptualizing childhood as a social construct remains problematic, from a multi-cultural perspective (James 2007, Kelly 2005, Okwany et al. 2011), exposing the paradoxes and contradictions inherent in the framing of childhood experiences as well as the diversity in child care knowledge and practices (Okwany et al. 2011).

Similarly, not enough attention is paid to the dynamic variations that exist among children and their unique needs arising from the diverse contexts they grow up in, and related to this also their capacity to make choices and act on those choices within the social confines set by adults and society. Largely two models have shaped the current understanding about childhood and attitudes towards children. The protectionist model sees children as innocent and priceless (Roche 1999), but incomplete compared to adults, and socially incompetent and "inherently vulnerable" (Cheney 2013). Consequently, children need control and guidance as they gradually evolve from what Qvortrup calls "human becoming" to "human beings" (James 2011). Since parents/adults are presumed to know what is best for children, they speak and act on their behalf. This model's shortcomings are that it is "paternalistic, ignores the child's voice in decision making and has a tendency to understand children as a 'problematic population' in need of discipline and control" (Kelly 2005: 376).

The child rights model on the other hand is rooted in the 1989 Convention on the Rights on the Child (UNCRC). The UNCRC is informed by western ideals of childhood (James 2011, Kelly 2005, Cheney 2013, Okwany et al. 2011). In conferring upon children wide ranging rights based on the principles of best interest of the child, non-discrimination and consideration for children's opinion (Valentin and Meinert 2009), the model has "revisioned children as independent and autonomous beings with the right to express their views in relation to matters that affect their lives" (Kelly 2005:375). Though seemingly progressive, this model belies some of the deep contradictions in childhood studies today. First, it still has influences transposed from the protectionist model. Second, at its core, Eurocentric connotations of childhood are projected as the global standard hence it universalises childhood experiences (Arts 2010, Okwany et al. 2011).Third, and more disconcerting is the consequence of universalisation-the hegemonic silencing of the rich diversity of other childhood experiences occurring along other contours of life such as culture, gender, race, ethnicity, class, disability (Okwany 2011). Moreover, it further restricts children's lives from public spaces (especially the labour market) and into the private sphere of family (Cheney 2013) and other age-segregated child-institutions when age is used (below 18 years) as the defining feature of childhood (Hendrick 1997 in James 2011).

Consequently, such restrictions only entrench governance of children's lives and foster unequal power relations, contradicting the human rights approach that seeks to empower children to become active citizens. It lays a foundation for economic and social conditions that invariably make children dependent on adults. As a result, children cannot make direct demands on their rights. They require adult interlocutors to lay claims on their entitlements (Cheney 2013), but adults may not always accurately represent children's interests. A more nuanced multi-cultural and holistic approach to understanding childhood requires recognizing children are participants in their own development, albeit with constrained agency. Narvanen and Nasman (2004: 72) assert that children are "actors who interpret their own world, reflect and create meaning….. involved in constructing their own lives and influencing their own condition". Such an approach also allows a more honest interrogation of children's experiences that is cognisant of children's multiple relational and situational contexts such as spatial location (rural-urban), social class (rich-poor) or social functioning (disabled-abled) nexus. All the same, there is an imperative to recognise a child's evolving capacity through various ages.

Children and Agency

Redmond (2009: 544) defines agency as "the ability to act"). It is now widely recognised that children and young people have the capacity to act independently, but recognition is given for limitations to their capacity to make rational choices due to their power and positioning. Limitations to their agency is attributed to lack autonomy, and consequently, their choices occur in the context of interdependent relationships influenced by social-cultural and economic factors so that agency occurs in the nexus of "agency within structural constraints" (Ibid). This means that there are rules and regulations guiding individual actions. Accordingly, "some agency is sanctioned or positively encouraged, while some agency can be understood in terms of rebellion against adult and parental authority" (Redmond 2009: 545). Depending on their social environment, some young people may also show greater initiative in defining strategically adaptive strategies to overcome the barriers they face than others even though the options available may not necessarily be risk-free. In fact, some could in fact be self-excluding (Ibid).

Nevertheless, the concept of agency adds to the understanding of childhood because it moves away from protectionism to consider how children confront and negotiate their everyday social realities, which while similar in context, may vary in experience from one child to another (Huijsman 2011). That experience depends on a number of intersecting factors such as class, social skills, and ethnic background as examples. Further, through the agency lens, it becomes possible to evaluate effects of that agency, where some decisions may seem rational due to a child's situatedness, but not be in the child's "best interests, and may in fact potentially amount to reproducing highly problematic relations of inequality" (Ibid: 1317-8).

I apply the concept of agency to CWAs in order to explore how they individually experience albinism, how they develop unique ways of determining who they are and negotiating the adult and society-constructed identities in order to find their sense of belonging and self. In this way children challenge current thinking on issues affecting PWAs in Kenya. I will consider the role of three socially embedded institutions that include- civil society organisations (CSOs), the family and the school. The three are particularly useful in locating children in the social world, especially family and school, which exert the greatest influence on children in the formative years. Hence, they are vital in shaping, constructing, circulating and maintaining dominant narratives about CWAs, and how children negotiate through whatever knowledge society produces about them. By recognising children's capacities, I seek to foreground voices of the children, and in so doing, open space for reflections on how civil society organisations and activists can better appropriate children's voices to make claims on collective identities of oppressed groups in society of which children are an important part.

Research Relevance and Justification

In social justice struggles, civil society groups make attempts to represent a collective identity, often with an assumption that they speak for and represent the unified voices of the members they speak for. To the contrary, because of children's subordinated location, their voices may be muted, as adults assume to know what their needs are. Similarly, adults with albinism assume all PWAs including children want the same things, and for this reason fail to consider their unique needs in the fight against societal discrimination. The reality is that individuals in the group may show a lot more ambivalence as they struggle to balance between group and individual identities. On one hand, they may wish to be identified with the group because it defines part of who they are, and helps them find a sense of belonging, but at the same time they recognise who they are is beyond the group definitions (Minow 1997). This research attempts to demonstrate that children act in autonomous ways, making rational and deliberate choices even where those choices may not always work to their benefit. Nevertheless, they challenge adult beliefs, and calling for

re-examine the role of Civil Society organisations (CSOs) such as Non-governmental Organisations in struggles for justice especially where identity is an important part of framing the claims that will impact on the lives of children. In presenting their narratives and counter-narratives, I concur with Andrews et al. (2004: 112) who assert that counter-narratives offer alternative readings to situations by questioning commonly held views of well-known historical events against personal stories" to show great variability…"they challenge either implicitly or explicitly those master tales, revealing alternative versions of how those stories we know best might be retold". My approach does not deny the difference that exists between CWAs and other groups of children, and the genuine needs their condition creates. However, I question the incomplete picture painted when children's perspectives are ignored, and instead turn attention to their narratives in order to provide a new frame for understanding the diverse childhoods.

The research is also important because there is a paucity of empirical research on albinism in Kenya especially where it relates to the lived experience of children. Previous research work focused on harmful cultural beliefs and practices, discrimination, legal frameworks for protection of CWAs, medical care concerns and special needs education for CWAs (see Lund and Taylor 2008, Machoko 2013, Olagunju 2012, Thuku 2011, Cimpric and Unicef 2010, Salewi 2011, Braathen and Ingstad 2006, Gaigher et al. 2002, and Nzagi 2009). My study expands on the body of knowledge on albinism by adding voices of CWAs to raise new debates on how projecting albinism as a disability in Kenya impacts their lives.

I am inspired by critical disability studies and especially the works of Fiona Kumar Campbell which focus on narratives and technologies of "ableism" and how they are applied to in the "treatment" of those with the misfortune of having been born "incomplete" in an effort to bring them to an acceptable level of wholesomeness. I apply this critical approach to question underlying assumptions and principles that entrenched narratives on albinism as a disability in Kenya. It also suggests that depending on the eye of the beholder or whose gaze is cast, different perspectives of the problem are legitimated leading to crafting of policies that on the face value seem to aim for inclusion, but in the end may lead to consolidation of excluding practices or an adverse incorporation of CWAs.

Framing the Research: The Eternal Outsider

Undoubtedly, the element of 'difference' influences people's attitudes and behaviour towards others, especially those not fitting into prescribed normative categories. For years, race, gender, disability, and sexual identity have been sites for serious political contestation in the struggles for recognition, inclusion, and social justice, as they constitute the basis for most forms of discrimination (Crenshaw 1991). For CWAs, two elements of difference combine to generate risks that confound their existence-age and albinism though this does not certainly mean it is the case for all CWAs. The distinct pale appearance of their eyes and skin colour due to lack of the pigment melanin gives them a most dramatic appearance in non-Caucasian black populations in Africa. Consequently they experience this genetic condition very differently compared to children and adults with albinism in Caucasian settings (Braathen and Ingstad 2006). Unsurprisingly, an aura of mystery surrounds albinism in Sub-Saharan Africa where the condition is most prevalent but poorly understood. Numerous attempts to explain the skin colour difference have produced knowledge and belief systems that are culturally rooted in myths and witchcraft, often defying scientific knowledge. These beliefs have had a remarkable influence on the lives of people with albinism from childhood to adulthood in significant ways especially because of the ambiguities they generate both discursively and in everyday practices. Most significant were the recent developments in Tanzania where trafficking of PWAs as well as the murder and sale of their body parts had a domino effect in neighbouring countries and caused panic across the world (OHCHR 2013, Ross 2010, Thuku 2011).

Unfortunately, the challenges of living with albinism have existed in Africa for many years. The risks go much deeper and have a longer history so that what came into global focus only revealed the tip of the tenuous existence of people with albinism in Africa. Being neither black enough on the outside nor white enough on the inside, PWAs are confronted with the unstated question of belonging-whether they are Africans or white people (Machoko 2013). Besides, the contested identity means an ambivalent outlook by society which regards them with fear, while at the same time some people cherish them for their supposed economic and spiritual powers and the immortality they seem promise (Olagunju 2012). Attempts to harness their powers results in various forms of abuse and violation of their rights (*Ibid*, Machoko 2013, Thuku 2011), and unfortunately, the risks are initiated at birth and continue through the lifetime. Isaac Mwaura the MP with albinism sums up these life-long risks when he avers that the impact of skin color "must never be underestimated. It means that PWAs cannot hide even if they try,…… are exposed to unusual attention and all the associated discrimination and stigma wherever they go" (Mwaura 2014: 1).

Peter Ash a defender of the rights of persons with albinism (PWAs) in Tanzania contends that the birth of a child with Caucasian features to black African parents is quite problematic. It draws unnecessary attention and questions to the family, especially the mother who is suspected of adultery (Thuku 2011). Family members are also likely to reject the child for fear that such a child has evil spirits, or is cursed. Traditional societies sanctioned infanticide of CWAs in order to exorcize evil spirits from tormenting the family that brought forth such a child and the community at large (Machoko 2013). Unfortunately, the practice still exists covertly with a conspiracy of silent approval among family members guaranteeing its continuation. In August 2010, a Kenyan court sentenced one young mother of a CWA to a one-year jail term for murdering her baby. In her defence the mother told the court that she had been forced by her husband to kill little Esther Moraa to protect the family from evil spirits.

Perhaps the most controversial abuse relates to sex and commodification of bodies of persons with albinism. In South African there is a strong belief that sex with young virgins cures AIDs, so that a combination of youthfulness and albinism heightens the danger for CWAs to sexual violence and contracting HIV/AIDs with growing incidences of rape (*Ibid,* Salewi 2011). Other forms of abuse include forced attendance of political rallies for good luck and exclusion from marriage (Ibid); and participation in leadership (Olagunju 2012).

An intensification of the illicit trade in human body parts over the last 10 years indicates the depth of objectification and dehumanisation of PWAs which has fuelled the "occult economy". Comaroff and Comaroff (1999: 279) define the occult economy as "deployment, real or imagined of magical means for materials ends". The repugnant regional corporeal enterprise had Tanzania as the epicentre, with supply of coming from other parts of Eastern and Central Africa, and was premised on cultural beliefs and a system of knowledge based on myths that associate albinism with wealth, good health, power and luck. Black magic practices thus involve the use of PWAs' bodies and body parts such as fingers, nails, hair, crashed bones, blood or genitalia (Thuku 2011), hence murder and/or abstraction is necessary. A high market value for the body parts is ensured survival of the enterprise among communities that practice witchcraft, and where poverty incidences are relatively high. In the southern parts of Tanzania, the estimated cost of a full human body is US $250,000 (Ross 2010) while body parts such as arms and legs fetch between US $1000-3000 (Salewi 2011: 12, Thuku 2011, Nzagi 2009). There have been instances of parents and/or relatives conspiring with witchdoctors to sell their children (OHCHR 2013).

A plausible explanation that has emerged to explain the occultism is the failed aspirations of capitalism and globalization, which have spawned widespread poverty amidst an increased demand for sophisticated consumer goods and capital accumulation (Cimpric and UNICEF 2010, Comaroff and Comaroff 1999). Although this explanation seems far-fetched, it has gained currency in recent times in places like Zimbabwe where people have come to believe that "poverty,

unemployment and sickness can be solved on the occult market by magical powers of people with albinism" (Machoko 2013: 324). Strange as it seems, this might explain the sudden rise in commodification which seems unique to this region. In 2013 alone, the United Nations Commissioner for Human Rights (OHCHR) reported there were 72 killings of PWAs in Tanzania (OHCHR 2013). OCCHR believes there may be many more unreported attacks on children because they are particularly vulnerable due to their tender age and size, making them easier to capture, coerce or kidnap for dismemberment and murder, even where parents make efforts to protect their children from such attacks. Thuku (2011) reported that one Tanzanian grandfather was murdered while protecting his grandson with albinism from being mutilated.

Even where parents have not contemplated infanticide or the sale of their children, it does not automatically guarantee acceptance. CWAs may remain vulnerable to other forms of violence, cruelty and discrimination. Similarly, the community may reject them, manifesting it through social isolation, name-calling, open hostility and physical violence, neglect or denial of basic rights and failure to plan for their needs. There are high chances of missing out on educational opportunities, which condemns them to misery, and social and economic isolation (Olagunju 2012). Given the prevailing cultural attitudes, some parents may consider it safer to withhold their children from school. At the same time, the demand for special needs education may not be easily met because many special schools tend to be located in urban centres (Bines and Lei 2011), excluding majority of people in rural areas. Nevertheless, even the idea of enrolling CWAs in special schools may easily exclude and marginalise them further as observed among deaf children (Johnstone and Corce 2010), and may not necessarily be the ultimate solution. .

Unfortunately, the school system may also contribute to marginalisation. For instance, most public schools are not adequately equipped to deal with special needs education pedagogically as well as adequacy of the learning environment. Classrooms require special lighting, with daylight being carefully regulated (Lund and Taylor 2008), while some CWAs may need corrective devices for visual impairments. Adjustments to the normal short-sleeved light cotton shorts and shirts typical of the school uniform in tropical climates may be necessary. Lack of attention to these issues may impede optimal enjoyment of the learning experiences for CWAs (Nzagi 2009), and at worst are likely to prematurely push CWAs out of the school system. When it is also considered that CWAs have to use specialised skincare products to stave off skin cancer which reduces their life expectancy to about 30 years (Lund and Taylor 2008), skin related problems have consequences for career choices especially. The options shrink significantly, where better employment opportunities are not matched with higher educational attainment as well as quality education. Poor quality as well as limited educational attainment may even condemn people with albinism to outdoor work that increase their exposure to the sun, or to manual jobs which have low pay hence entrenching social-economic differences.

Fighting for rights or entrenching a dominant position for state benefits?

According to Mwaura (2014: 1-2), PWAs are "yet to be fully included in Kenyan society" a situation he says is unlikely to change soon because "there is a fundamental lack of understanding about albinism, and both occultism and prevailing cultural belief system create a context which can enhance vulnerabilities for CWAs, setting the stage for exclusion, discrimination and hegemonic ways of thinking about them. A discursive formation of PWAs is enabled through institutions such as civil society organisations, media, religion, politics and language, all of which could perpetuate difference and further alienate CWAs. Language is especially a powerful tool that society uses to conjure powerful imageries of the 'other' in order to sustain the binary group division. Naming also foments objectification of the "other", making maltreatment much more

possible to contemplate and condone, having distanced the person from the rest of humanity. Names such as *zeru zeru* meaning ghost*, nguruwe* (pig) and *mgodi* (literally meaning goldmine) are used to refer to PWAs in East Africa while among the Yoruba and Hausa of Nigeria they are referred to as *Afin* or *eni-orisa (one who belongs to the deity)* and *Bature-Ntuda* meaning fake white person respectively (Olagunju 2012). In addition, Campbell (2003) argues that able-bodied people consistently deploy non-integrative strategies to maintain a clear distinction between them and the 'patholigised other', a phenomenon she refers to as *'ableism'.* The word refers to a "network of beliefs, processes, and practices that produce a particular kind of self and body (corporeal standard) that is projected as the perfect species-typical and therefore essential and fully human" (Campbell 2001 in Campbell 2003: 94). In the end, the marking, ordering, and treatment of persons with disability as "corporeally intolerable or ambiguous" is considered a form of violence that is "epistemic, psychic, ontological and physical" *(Ibid: 23).* It is an affront to the rights of people with disability, but the attitudes are also firmly embedded in society.

In spite of the level of subornation, people make efforts to exercise agency in reaction to injustices. The killings in Tanzania triggered shifts in the social configuration and understanding of albinism in the Kenyan society at the peak of the occult economy. The formation of organisations by PWAs such as Albinism Society of Kenya (ASK) and the Albinism Foundation of East Africa (AFEA) evidences this claim. In addition, adult PWAs in influential public positions have used the space to question societal views and to lobby for inclusion of PWAs. Mumbi Ngugi, a renowned Kenyan judge with albinism vividly observes;

> ''we deal with a society that is largely silent about our plight, and a media that refuses to find a way of referring to us in ways that can bring to the fore our humanity rather than our genetic condition……….. In a world where colour has defined so much of people's fate from slavery to colonialism, we are in the unfortunate position of not having been born with any, or with very little and remain the eternal outsider" (Thuku 2011: 8-9).

Actions directed at PWAs that had previously been interpreted only through a cultural perspective (Thuku 2011, Olagunju 2012), had now been catapulted to the realm of an urgent human rights issues, requiring political and legal mediation. Although the Persons with Disability Act of 2003 did not explicitly define albinism as a disability, it did so implicitly. It created the possibility of considering it as a form of disability by defining it loosely as any

> "Physical, sensory, mental or other impairment, including *any visual,* hearing, learning or physical incapability, which impacts adversely on social, economic or environmental participation" (Article 2).

These legal bottlenecks have not been a hindrance. Instead, PWAs used the ambiguities in law to fight for recognition and their rights as citizens, pointing out that the state ought to recognise threats to their lives as an infringement of their rights and grant them protection (Mwaura 2014). PWAs successfully lobbied for a state-funded national sunscreen distribution programme for all registered PWAs in Kenya (personal communication with ASK officials in July 2014). This program's current success and future sustenance seems dependent on the presentation of albinism as a form of disability both in physiological as well as legal terms. Similarly, over time, PWAs have gained a sizeable representation in various echelons of government including the National Council for Persons with Disability (NCPWD) and in the legislature-thanks to 2010 Constitution that reserved 5% of all public slots for persons with disabilities, to be filled through nominations by political parties, proportionate to their numerical strength in the House. Isaac Mwaura was nominated by one of the major political parties because of crucial role is giving albinism a high profile.

Whereas I acknowledge that PWAs have unique needs and the state obligations to them, in stating the main problem of this study, I assert that adult PWAs enabled by ASK made a very deliberate, and calculated campaign that that was supported by a sympathetic the media, fear or

the occult economy and their political connections in order to secure material, economic and political benefits from the state. ASK was initially driven by genuine fear of the occult, and desperately needed an ideology that could yield more than just sympathy from the state because "without an ideology or a set of constituent ideas, a social movement is not possible" (Anspach 1979: 771). Disability provided just the right crutch on which their demands could stand on. With time the however, the dominant narrative took root, and with it PWAs gained access to powerful political spaces and decision making bodies within government, further entrenching their interests and making greater claims for material benefits for the group and individuals. The material benefits for the group did not however mean that the members of the group agreed with the narrative of disability.

Thus, the willingness of PWAs in Kenya to appropriate the label of disability while projected as dominant is in fact problematic especially for children with albinism as embraces the patholigised meaning of disability (Campbell 2004), bringing with it the burden of the subjectivities it embodies in the society. Along the same vein, the able-bodied persons are typically blamed for 'othering' or stigmatising those with disabilities (Ibid, Anspach 1979), but in the case of ASK it is PWAs themselves that authorize the discourse. By not questioning historical aspects of this identity, this position is likely entrench long standing forms of exclusions as well as open new avenues for limiting survival, social integration and education opportunities for CWAs. Yet, adults with albinism insist upon this label, disregarding its likely effects on children's' trajectory over the life course.

Explanation for the baffling position taken by PWAs in Kenya and its consequent politicization could be found in Kimberle Crenshaw's argument that "the most critical resistance strategy for disempowered groups is to occupy and defend a politics of social position rather to vacate and destroy it" (Ibid: 1297). In short, playing safe. However the strategy comes with challenges. On one hand there are dilemmas of striking a balance between using contested identities to lobby for justice by drawing attention to the unique needs of a social group, and maintaining aspirations of social justice where the "liberatory objective should be to empty such social categories of any social significance" (Crenshaw 1991: 1242). However, feminists refute the possible counter-dominance claims arguing that embracing such social frames of difference should not result in domination. Instead, it could provide greater freedom for defining groups from multiple locales, all of which contribute to the composite identity -for example, being female, and black, and unemployed (Ibid). Further, Anspach (1979: 771) writes of how disabled persons have overtime learnt to embrace and take pride in their negative identities, having come to the realisation that it is nothing to be ashamed of, and taking lessons from the gay and civil movements of the 1960s in America.

All the same, challenge remain on how genuine concerns of a subjugated social group should be made visible without accentuating the group's difference in ways that would increase their social distance from the rest of society? Does this then create the possibility of "self-othering", and even then, doe it only foresees it as a positive event? Does a re-definition have acceptance by all persons with albinism? So far, the disability narrative of PWAs has privileged adult's voices, while those of CWAs who constitute an integral part the community remain peripheral, yet they have genuine issues that they raise. Subordination of CWAs is likely to be more pronounced due to the unequal chid-adult relations. Since CWAs are not passive recipients, they develop unique coping strategies that need to be recognised. They may include acceptance, resistance, revision, or simply re-invention of the negative identities by deploying them in ways that are more beneficial. In that sense, attitudes toward albinism in Kenya are neither monolithic nor static. Rather, they vary, shifting significantly from time to time, affecting policies under the mediation of social institutions, such as CSOs, the school, and family as well as legislative and political influences.

Organisation of the paper

This paper is organised into five chapters. The first one elaborates on the historical and socio-cultural practices that have shaped understanding of albinism in Kenya. It problematized the adult-centric identity of albinism, arguing for a critical examination of the disability *viz-aviz* albinism discourse from the perspective of CWAs in order to gain a more nuanced understanding of how CWAs contend with their condition. Chapter 2 is an overview of the main research methods, and ethics that underpinned this research. Chapter 3 captures the essence of how children make sense of albinism, especially how the adult world perceives them with the aim of showing children's self-defining possibilities as actors in social spaces like the family and school. Chapter four discusses the contours of corporeal politics in Kenya seen through the eyes of the Albinism Society of Kenya (ASK), a civil society organisation that fights for the rights of PWAs. It points out the role of ASK in orchestrating production of a certain knowledge and understanding of albinism for the benefit of its individual members and the collective group through the disability discourses. The fifth chapter synthesises the empirical findings in light of implications of the discourses for activism around the rights of PWAs and children.

Chapter 2: Methodology and Research Ethics

An Overview on Site Selection

The research had a two pronged approach targeting both the macro-level as well as the micro-level which would allow me to examine the locales of the discourse on albinism and which spheres of the children's lives it influenced. At the micro level, the study drew on experiences of children from two primary and secondary schools in Thika Town. Thika is a main urban centre within Kiambu-one of the 47 counties in Kenya and is approximately 50 Kilometres from Nairobi the capital city. Historically, the town has the highest number of institutions for children with disabilities, and most of these are sponsored by religious organisations including the Salvation Army Church. Besides the two schools, there are three others and a vocational training centre for children and young people with special needs. Being the oldest and most established, the two schools serve as a catchment for visually impaired children from all parts of the country.

The Salvation Army Church set up the first institution in 1946 to assist blind Second World War veterans, but later turned it into a school for visually impaired children (Kiarie 2004). However, enrolment remained low since children with disabilities rarely got educated; often being neglect because their families had little utility for them, and the society even encouraged their murder (Scheerenberger 1982 and Devlieger 1989 in Kiarie 2004). Overtime this has changed and demand for special schools has also increased, but the Thika schools remain popular, leading to a high concentration of CWAs in the two schools. Both schools have a large alumnus of visually impaired persons in Kenya, most of who have made very successful careers, and a good number of them maintain contact with the schools as role models who inspire the current cohort. Since the population of CWAs is not evenly distributed, the schools were an ideal location for the research, giving me a sizeable group of subjects for a qualitative inquiry in a peri-urban area while also catering for the diversity due to their national reach.

At the macro-level I interviewed officers both the government and civil society organisations. Interviews with these adults were important to first of confirm what their narratives were, and to show the role they play in the knowledge production because of their positon, then to compare this with the children in order to identify similarities, areas of agreement as well as tensions.

Aim of the Research and Research Questions

The objective of this study was to critically examine both the narratives and counter narratives that define the lived experiences of CWAs. It explored how knowledge produced by adult PWAs defines CWAs as person with disability has been used in certain policies and practices and the ways in which it affect the lives of children with albinism.

Research Questions

1. What are the prevailing narratives on albinism in Kenya and how did they come about?
2. What are the children's experiences of albinism and how do they differ from those of adults?
3. What roles do social institutions like family, school and civil society organizations play in constructing and maintaining the prevailing narratives on albinism?

4. What implications do the counter-narratives have for the ways in which civil society engages in activism on albinism issues?

Design, Selection of participants and Data Collection techniques

The study took a qualitative approach with an ethnographic orientation that utilised stories of children with albinism. This approach allowed me to get as close as possible to understanding the lived experiences of children whom I interacted with within their school environment during their free time in the evenings and over the weekends. I interviewed 13 children between grades three and form two. Four were in Secondary school (2 girls and 2 boys aged between 15-17 years) and the rest were primary school pupils (3 boys and 6 girls between 11-14 years)*). For the secondary school pupils, the semi-structured interviews were longer, lasting between 45 minutes to one hour. I had more sessions with the primary school children and used a variety of data collection methods. First, to build rapport with them I first designed a short photography project that utilised manual cameras and required each of the children to take 5-7 photographs on any subject that was of interest to them after a short training session on how to use a manual camera. The photographs were then processed and used to facilitate semi-structured interviews with each of the children. A growing number of studies attest to the benefits of using photography and other forms of participatory techniques and expressions in research involving children (Huijsmans 2010, Wang et al. 2004, OH 2011).

Secondly, I also collected written stories from children, acting on the same convictions as Hammersley and Atkinson (2011) who argue that this is a non-invasive means of gaining personal insights that yields more specific and intimate information compared to face-to-face interviews or cross-sectional surveys. The written accounts focused on "growing up as a child with albinism" which children were free to write in the language of their choice. Although they had the option of writing in Kiswahili- the national language, all chose to write in English. The written accounts were triangulated through semi-structured interviews and group chats with the children, during which time we used Kiswahili language which the children readily used among themselves and were most comfortable conversing in. The mixed methods also aimed at minimising the power differential between the researchers as an adult by creating a variety of options for expression, which were also intended to reassure children that whatever they say is important because children are not used to being believed, by adults (Punch 2002, Thomas and O'kane 1998).

Finally, I also conducted in-depth interviews with adult key informants who included two schoolteachers (one was a PWA); Two current officials of the Albinism Society of Kenya (ASK); Two government officials of the National Council for Persons with Disability (one of whom is a former ASK official); and Two parents of children with CWAs. I also had informal chats at various points during my research with two other special education teachers (one was from the physically challenged school). These chats were particularly helpful for me to appreciate the challenges of special education in Kenya, the level of preparation teachers in special schools require and to elaborate on these teachers' scheme of service, which gave me a sense of their motivation as well.

I found these methods most suited for effective exploration of personal experiences of children living with albinism because they are less invasive. Since the occult economy emerged, safety concerns have made PWAs suspicious of strangers. I realised how suspicious PWAs had become during my first interview with LM. Our meeting was at the 'Bomb-Blast' memorial park in the heart of the bustling Nairobi city centre. Being within walking distance to several university campuses in the city, the park is popular with college students, hence is busy. During the interview I noticed how LM got uncomfortable whenever people approached our bench, and would stop talking altogether until the person(s) moved away or walked out of earshot.

This level of suspicion presented dilemmas of accessing CWAs who constituted the main research participants (and their parents). These uncomfortable encounters confirmed the need to rely on informal networks and contacts from my previous professional life which helped me build rapport quickly. In both schools, the teachers helped me in the selection of participants. The teachers advised against including students in the senior class were preparing for mock examinations at the end of the second school term in July. The selection was also base on informed consent with the understanding that this was a voluntary interview for those students who wished to willingly share their experiences purely for purposes of research.

I corroborated empirical data from the field with textual and documentary material from secondary sources of data on albinism in Kenya. These consisted of documentaries depicting everyday experiences of CWAs, parents of CWAs, as well as adult PWAs. I focused on two- *"In my Gene"* produced by Lupita Nyongo and *"Albinism: Prisoner of my own skin"* produced by Andrew Cowper and aired by Kenya Television Network (KTN) on 2nd July 2013 and a subsequent follow-up interview with Isaac Mwaura a Member of Parliament with albinism representing persons with disabilities and co-founder of ASK. I also reviewed a newspaper article by Mwaura, together with several journal articles on disability, the constitution of Kenya and the disability law of 2003. The combination of primary and secondary sources of data in ethnographic research allows the researcher to corroborate or challenge information received from one source with another (Hammersley and Atkinson 2007), greatly enriching the qualitative study. Because of his multiple roles Mwaura's written materials and recorded interviews helped to confirm the position of ASK and that of adult PWAs'

Analysis of Data

For analysis, I follow the three-level discourse analysis approach taken by (Campbell 2003) in order to examine and isolate the main narratives as well as the meanings inherent in those narratives that are represented in face-to- face dialogues as well as in the secondary materials. The first level is a textual assessment focusing on "what is said" which constitutes the narrative *(Ibid)*. Second level is discursive, inquiring into how something is said, and therefore "what is excluded, minimised, disqualified or considered marginalised". The final stage pays attention to the social context to discern any pattern of representation that indicates the influence of ideology and hegemonic technologies. I present the findings under two analytical categories of: CWAs search for personal identity and the role of family and school which is about adoptive technologies by children and; mobilising pity and corporeal politics of albinism in Kenya where the adult narrative is presented. Within each there are sub-themes which are discussed in details in the related chapters.

Reflexivity and Positionality

As a female researcher, from a middle class background and former NGO child rights activist, I straddled different identities, which bring about a subjective experience of the research process and hence have undeniable effects on it. I acknowledged these by being aware that my previous professional experiences, feelings, values, biases and perceptions could affect the research outcomes but sought to employ them in more positive ways through a reflexive process. Reflectivity "acknowledges that the orientation of researchers will be shaped by their socio-historical locations, including values and interests that these locations confer upon them" (Hammersley and Atkinson 2007:15). It became necessary to constantly carry out an in-depth interrogation of my personal experiences on a daily basis in order to distinguish my own interpretation of what I heard and saw against what the people I talked to said and projected through their body language. I achieved this by keeping a journal where I documented my reflections, which also pro-

vided additional insights through an introspective review. Reflexivity therefore served to simultaneously enrich and challenge my field experiences.

I was also aware that as a pigmented and non-disabled person I stood a chance of projecting power differentials on CWAs, and risked reinforcing the supremacy and overbearing attitude that abled persons show towards persons with disability (Campell 2011). I explained that as a child rights activist I interested to see that children's views are taken into consideration, and perhaps might influence future decisions affecting CWAs though I could not guarantee immediate changes. I also tried to ease my field entry by having a sponsor whose networks ensured that I got accepted by the school community without drawing too much attention to myself if I was treated as an outright stranger. In my initial contact visits to the schools, I introduced myself as a graduate student and former NGO worker, assuming this revelation would earn me early acceptance in the school environment and reduce any curiosity about myself and the research. In retrospect, I feel that the mention of my previous work somehow gave both advantages and disadvantages. It created some expectations but also allowed some interviewees to reveal interesting attitudes. I had to inform respondents that my research was mostly academic and had nothing to do with soliciting sponsorship of CWAs or solicitations from international donors. I was nevertheless surprised when the head teacher's comment revealed very early on the general attitude which casts them as poor and always in need of charity. He casually mentioned that many of the children enrolled in his school were in need of financial and material support from well-wishers, and invited me and my friend to come back at a later date so I could spend time with children and see that some were too poor to even afford shoes and went around their business in the school barefooted. He suggested that perhaps that would inspire us to make donations. This experience is not new to researchers as Abbot (2007) writes about the "what will you do for me" dilemma. Whereas research work on disability has also noted the material condition of persons with disability, I had not expected this to be projected so readily by people charged with the role of inspiring the young CWAS to make something of their lives.

For these reasons, henceforth and throughout the remaining part of my field work I kept my introduction simple, rarely mentioning the international nature of my studies in case it raised expectations for payments or favours that I was in no position to guarantee.

Chapter 3: Identity Struggles: Technologies of Self-Definition among Children with Albinism

Introduction

This chapter highlights how children with albinism individually and collectively view and define who they are, and the ways in which their definitions differ or converge with those of society in a variety of settings. The role of education/school and family as two institutions central in the lives of CWAs are especially considered in terms of the ways they may enable or limit opportunities for self-definitions. Some children accept the societal framing of who they are and express finding a sense of belonging in special schools because they feel understood, others reject the label of disability and want to be treated like other children in mainstream schools and yet others deploy means such as their religion to counter the dominant references. Counter- narratives are particularly useful in exposing alternative ways of interpreting the same historical events or phenomenon in ways that question the most dominant, popular or accepted perspectives to a reality (Andrews et al. 2004).

In his book, *Seeing Like a State* (Scott 1998) argues that many state-led social re-engineering projects fail on account of "an imperial or hegemonic planning mentality that excludes necessary local knowledge and know-how". Similarly, the stories children shared with me made me realise how the adult world consistently misreads children and their intentions. This misreading is a product of conflation of children into one category as well as an over-simplification of children's choices and actions when in fact their actions are far more complex and carefully considered as the stories from the children illustrate. The dissonance between what children and adults see constrains CWAs' desire for self-determination as they wish to live their lives without the daily reminder of being disabled even though they are in a special school which confirms how they are labelled by society.

Low vision presents learning difficulties for CWAs, with most being enrolled into special schools (Gaigher et al. 2002) where they are categorised along with the visually impaired or blind students. Indeed, the challenge can be serious as I witnessed with LM, who during the fieldwork explained to me that she often is late with her school assignments because it takes extremely long for her to read printed materials and the university she is attending does not have the course materials in braille or audio forms.

A view often expressed is that since CWAs are not legally blind, their visual challenge is not acute, it is recommended that they are enrolled in mainstream schools, but at the same time there is a counter argument for separation, with emphasis that children receive better attention in special schools where teachers and the facilities are geared towards meeting their unique needs (Gaigher et al. 2002). Still, others like Minou (2011) argue that as a general rule, severity of the disability should be the main determinant for placement of child either in special care institutions or mainstream schools, whilst ensuring adequate support by qualified personnel and related facilities.

The various conversations I had with CWAs indicated that they take their education seriously, understanding that a good education makes a big difference in life. Indeed, the 13 children and two parents I talked to represented mixed but genuine concerns for the type and quality of education. Their views indicate a concurrence with the emerging view that the growing recognition that education is a right has increased demand for quality education (Tomasevski 2006, Sayed and Soudien 2003). Particularly, it was useful to see that CWAs engaged in a debate on the differences between integrated schooling and special needs education.

Finding a sense of belonging and acceptance in special schools

For some CWAs, the special school is a lifeline. It is a vital channel that gives meaning to their lives as social beings who value human relationships. They find friendship and acceptance, as well as useful information about self-care practices in order to prevent cancer hence their survival. It is also a place for 'restoration'- an important site for re-defining the children's identity and restoring self-confidence affected by previously hostile school environments.

Out of the 13 children in the study, at least nine of the children had first enrolled in mainstream schools near their homes but by grade three or four (about ten years or so), they had serious visual problems and had to transfer to special schools. One 13 year old girl in primary school wrote in her essay;

> "When I grew up I (*first*) went to a nearby school in our village. There I started in lower primary school. In the school, the teacher could not get nearby me, and even the teacher could not mark my work. I was isolated and even did not have anybody to play with. So I was transferred to the other school (her current one) where I found other people like me and there I could cope with them because we socialised" (LW, 13 years).

Another 14-year-old boy in primary school wrote;

> "when I reached standard four, I joined this (*special needs*) school …and from here I started to know how to treat my body well" (*referring to the use of sunscreen and other self-care practices that he learnt in school*).

This boy also revealed to me that

> "*nikikuja hii shule nilikua na shida ya kusoma na kuandika sababu hiyo shule ingine niliku sioni ubao*" (by the time he joined the special school he did not know how to read and write because he could not see the chalk board well).

This experience of coming from a mainstream school having completed more than four years of early childhood education and lower primary but not able to demonstrate the requisite competencies for the educational attainment show the level of neglect that CWAs suffer in such schools. I also noted that even though the boy was in grade six- by which time many children his age have formed a consistent and clear handwriting, his handwriting was somehow still difficult to decipher. This denotes that he may have missed foundational practices that are grounded in grade school-which I also noted with at least three other children's essays. This is not to stereotype but simply to show how mainstream schools can reject and fail to support learners with special needs. Thankfully, he also mentioned that he was able to catch up because he was given the support he needed in the new school including a hand-held magnifying glass available to most pupils in the school which he showed me with pride.

The reality of limited slots in special schools however presents new dynamics that CWAs and parents have to contend with. Many travels long distances from home and have to be way in boarding schools. Children are thus drawn away from their families at a tender age, something that parents of two CWAs found to be a painful experience (*Albinism: Prisoner of my Own Skin*). The tender age at which some of the CWAs join special schools is s concern. At least four CWAs I interviewed had enrolled directly as boarder in the special school at kindergarten, aged between four and half to five years. A parent also indicated she took her daughter to the school at around the same age. The primary school head teacher also confirmed this, adding that some of the children enrolled into pre-school early especially if their older siblings with the same condition are already in the school. Whereas parents of non-visually impaired children make boarding school a preferred choice in spite of other possibilities (and perhaps with less pressure), parents of CWAs feel that they do not have much choice if their children are to benefit from education especially when they have been pushed out of the mainstream education system.

Children are disconnected from emotional support that is needed in discovering answers to difficult questions as they discover self-identity, especially if they have faced previous rejection. The process of finding acceptance and coming to terms takes time. Betty a from one student for instance travels back and forth 600 kilometres at the start and end of three school terms in a year. In her early years of schooling, her parents enrolled her in a day primary school near her home. The head teacher in this school would not let her and her brother who also has albinism wear protective clothing considering the scotching sun that is characteristic of the coastal region where temperatures are as high as 38 degrees all year round. Eventually the siblings were forced to transfer to a more friendly mainstream school where more CWAs in the region enrolled and receive support (sunscreen supplies) from a Dutch NGO. She still had to transfer yet again to a special needs boarding school before later joining the secondary school for the blind. The numerous transitions through four schools can be unsettling for a teenager who has to also deal with the challenges that come with teenage-hood.

CWAs normalising the self through integrated schooling

CWAs were willing to challenge some notions of their schooling circumstances that adults tend to take as a given. For example adult PWAs like the ASK official believe that;

> "Special schools are better equipped to cater for CWAs because they are aware of their special or peculiar needs and interaction with other children with disabilities allows them to understand themselves better"

However, not all CWAs agree with this position, rather showing mixed views, pointing to a much-individualised process of experiencing albinism and the learning process. A few examples from those in primary schools tended to show an agreement with the adult position, expressing their satisfaction with special schools, secondary school CWAs showed preference for integrated schools. Perhaps because the secondary school was implementing the integration policy by admitting some sighted student whom CWAs had a chance to interact with, and due to age they may have greater self-awareness and therefore did not feel too threatened.[1]

One secondary school pupil (EKT) who was initially enrolled in a mainstream primary school in Eastern Province said

> "After I sat for class eight exams in 2009 and did not pass, my parents were advised to take me to Kitui Integrated School, which has a unit for visually impaired students. I had to repeat from class six and learn braille. My teacher (he fondly refers to her by name) was very nice because she taught me braille and also advised me on the kind of clothes to wear, and told me to apply sunscreen lotion".

EKT's local school could not support him to deal with the learning difficulties caused by low vision, and consequently he could not obtain the pass mark required to join secondary school and had to re-sit the same examinations three years later (2012) before proceeding to the special secondary school. Experiences like EKT's indicate that there may be massive wastage as they tend to be overlooked. Consequently, CWAs tend to be much older at a certain grade compared to their counterparts in the same grade in mainstream schools (Gaigher et al. 2002).

In spite of his initial tragic foray into mainstream schooling, EKT feels that because of his latter experience, he found great support in the integrated school, and thus turned out a more confi-

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[1] *This could be an area for further research with a larger sample.*

dent person for the interactions with non-visually impaired students. He went on to join an integrated secondary school and says

"Since I'm in the school with *"masighto"* (nickname for non-visual impaired classmates by CWAs) I don't feel very different from them, but when I was younger (in the other school), people treated me differently. For example, when I would play football with other children, they would not tackle me for the ball. They would call me names like *"kamzungu"* (little white person).

He emphasises that CWAs should not be isolated in special schools, pointing out that mixed schooling allows CWAs to interact with other children and boost their confidence comparing himself to those who have been in special need schools throughout he says

"najiona mimi siyo mnyonge sana lakini wale wako special school, wakona uwoga. Wako tofauti na wengine." (I do not consider myself weak but those (children) in special schools are fearful and not confident. They are very different from other children).

Noteworthy is the Kenyan government effort at adopting an integration policy based on recommendations of both the 1988 *Kamunge Report* on Education reforms as well as the 1999 *Koech Report on Totally Integrated Quality Education and Training*-TIQET (Government of Kenya 1999). Integration was aimed at ensuring children with special needs were adequately catered for in mainstream schools. The policy aim was to phase out stand-alone special education schools while ensuring children with special needs were adequately catered for in mainstream schools. By 1986 the Kenya Institute for Special Education (KISE) had started offering teacher's training diploma in pedagogy for special needs education (SNE), while a scheme of service that gave special education teachers higher salary grade. The difference in salary could be as high as Kenya shillings 10,000 (about Euros 90) for secondary schools but depends on years of service according to the two teacher with whom I had informal chats. They also explained that it is now mandatory for teachers in special schools to have completed a certificate course in SNE to qualify, which is the ministry's way of ensuring learners' needs are met, but the teacher has to self-finance the skills acquisition and present the certification to the employer.

Clearly, attaining aspirations of education for all (ALL) is still fraught with many challenges. Concerns for quality, quantity, relevance (adaptability) and inclusivity of education remain (Tomaevski 2006), with less than 10% of CWAs in Africa attending school (Bines and Lei 2011). In Kenya, a sizeable proportion of children with special needs still attend separate special schools. It is estimated that one special secondary school caters for a population of about 1500 visually impaired children (Kiarie 2004. Discrimination by teachers and peers, long distance to schools, limited capacity of the schools to cater for their needs, as well as instances of a hostile schooling environment eventually force some of them out and into special schools, where many say they find acceptance. To date, mixed views remain about whether integration is an effective strategy for meeting the educational needs of children with disabilities.

Unfortunately, not enough attention has been to this in the disability discourse especially efforts and resources for adapting the learning environment to the learner, and not the learner to the environment. I am in agreement with Bines and Lei (2011: 422) who criticise the minimalist reforms efforts in special education because they problematize the children, which "undermines efforts the need for wider institutional curricular and pedagogical changes to develop a more inclusive education"

Self-Definition through Denial and Religious beliefs

In some instances, children's self-definition manifested as a denial of difference; refusing to see themselves as any different from their siblings and peers. Denial allows children to project an image of self that is less stigmatising, allowing them to contest negative societal labels. Some of

these children found support for their position in religion. For example the community where Betty comes from a community with strong beliefs in witchcraft. Some people in her village accused her parents of having *"mashetani"* (evil spirits) or being be-witched. Here, she deploys the counter-narrative of Islamic faith to contest the stigma, observing;

> *"mimi siamini vile ambavyo watu wanasema, eti ni mashetani. Mungu ndiye aliniumba hivyo"* (personally I do not believe in what people say about evil spirits (It is God who created me this way).

Similarly, *MA, a* 17-year-old boy in secondary school whose seven siblings are also CWAs concurs by saying he did not experience any rejection from both the community and his peers, explaining that they understand his condition is

"the work of God and …… they are not afraid of you……I do not consider myself different because the things they can do, we can also do".

AM showed extensive knowledge about albinism which he attributed to his big brother in the university. AM and all his siblings were enrolled into the special school at kindergarten age, and similarly may have has a longer time to understand their condition.

Similar sentiments were expressed by RO who is also 17 and in secondary school. While in class five she developed eye problems and had to move a boarding special school. RO likes the special school mainly because she found other students with similar challenges like herself. She did not also need to walk in the sun every morning to get to school. She is the only one with albinism in her family but she does not feel different from because

"the Creator is one and all of us come from that one Maker who created us in His Image".

These examples reveal that children's spirituality was important in finding their self-definitions in more positive and empowering ways. This findings are consistent with those of Braathen and Ingstad (2006) who found that PWAs is Malawi explained their existence as being in God's will.

As part of developing positive self- image, I learnt that both schools had a strong role modelling culture. Almost all the children pointed out somebody with albinism they wanted to emulate- popular among those being Judge Mumbi Ngugi, Isaac Mwaura, popular Radio newscaster/broadcaster and a teacher with albinism. The school often invites adult PWAs with successful careers to the school for motivational and career talks. RO's role model is her teacher with albinism whom she admires because "she dresses well, has cool hair styles and takes care of her skin. She also helps us when we are in problems". CWAs see role models as an inspiring way to confront negative attitudes by society as they can point out successes of others like them.

Self-Definition through resistance and negotiation

Besides wanting to project a more acceptable image, some CWAs bargain for better positioning and refusal to conform. DI's mum narrated a conversation she had with her 13 year daughter regarding her secondary school preference. DI is in form one in a non-special needs public secondary school after completing her primary school education in a special school for the blind. Her daughter did not wish to continue her education in a special because she felt it might interfere with her career aspirations of becoming a lawyer. DI begged her mum to be allowed to go to a mainstream secondary *"najua nikienda Thika High School for the Blind sitaenda university sababu watanilazimisha kujifunza braille "* (if I go to Thika High they will force me to learn braille and I will never make it to the university). Often the practice is to allow pupils to make independent school selection with some guidance form parents/teachers, it sat that autonomy is not given to CWAs. They are restricted to special schools with teachers making efforts to ensure they select special schools. In any case, all children in the Salvation Army primary school have an

automatic admission to the adjacent high school for the blind. Parents are similarly advised as DI's mum quipped

"mwalimu alituandikia shule" (the teacher wrote the list of special schools for us)

Even though her daughter performed quite well and got admission to three special schools, she was adamant that her mother finds her a "normal" school. Reputable public secondary schools are few and entry is highly competitive. Finding a slot can be agonising for parents, yet DI's mum found one that was willing to admit DI after visiting at least three others. She says DI was elated about her new school, adding that "all the students and teachers love her".

In addition, teachers in both schools feel that the automatic admission to the special secondary is a great advantage as it guarantees educational continuity for CWAs. Moreover, in a school where they can learn/use braille, sitting for Kenya Secondary School Certificate Examination (KCSE) confers advantage to their learners because they gain entry to the university with slightly lower points (a grade of C+ where a B- (minus) is expected of other students), which is an affirmative action policy by the government. At least secondary school students reported feeling pressured to learn braille, which takes a while if you did not learn it at primary level, losing valuable secondary school time. Mwaura (2014:2) confirms that indeed there is some coercion highlighting that low vision leads to "an assumption that they (CWAs) are all blind …are forced to learn in special schools for the blind and use braille which affects their employability". Notwithstanding this criticism, I noted from children stories that in their journey to SN, in nearly all the 13 cases teachers played a role in early detection, assessment or alternative placement, an observation that was also similarly noted by Kiarie (2004).

Ultimately, it is useful to recognise not all children are happy with automatic admission to special schools or having to learn braille. One teacher said that;

"Children with visual impairment (but not blind) resist braille saying they are not blind and many insist on using print even when it causes a lot of difficulties for the child. But the few who take it we encourage them because they be advantaged"

Whether this is out of resistance against being labelled as disabled or simply that they genuinely feel they can cope without that kind of support is a much personalised experience for each child. For example in total contrast to DI, EKT from Eastern Kenya was elated to have been called to the Thika School which boasts diverse alumnus of very accomplished PWAs-it represented the birthing of a cherished dream. Children's stories therefore demonstrate capacity to understand and make choices in quite complex situations.

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The Family and community as sites for negotiating Identity

There is evidence to show that a sizeable number of CWAs experience abuse and rejection within their own families, which may also extend to society (Kiarie 2004, Thuku 2011, Olagunju 2012). However, there is some evidence to the contrary. Braathen and Ingstad (2006) found that stigma and marginalisation are not universal for PWAs, and that most found the greatest acceptance within their families and their immediate community because in this settings people's appreciation for others was not conditional upon appearances but emphasised the individuality of each person "as a whole person and kinship and personal characteristics become more important than the looks" (Ibid: 600). At least 10 of the children's experiences seemed to concur with this position, pointing out that their parents loved and supported them, and went to great

lengths to meet their needs including purchasing sunscreen lotion, taking them for frequent eye check-ups, and enrolling them into school. The youngest respondent (an 11-year-old boy) wrote

> "I am happy because my mother loves me so much more. Sometimes my father takes me to see wild animals. I love my parents and also I love my teachers so much".

Only two girls explicitly said they felt that the parents did not love them. One of them expressed this in the essay by writing;

> "Sometimes when my parents left me home alone I could always think they did not love me".

In contrast though, rejection seems to be still pervasive in the community, and quite a number of CWAs felt the same unconditional acceptance in their community and extended family. One primary school girl said that during school holidays she preferred to stay indoors because her cousins would tease and bully her. Yet another said that people in her church took long to accept her and her mother, accusing the mother of adultery. All the 13 also reported being teased especially by other children in the neighbourhood and being called "names you cannot imagine" as one of them put it. Another 13 year old told me;

> "I understand my condition so even though they usually call me many names, nothing will happen because I am very proud of myself now".

From an early age, CWAs learn to manage their anger over the teasing as one 15 year old boy explained saying "I used to get very angry before, but since I came to this school I have learnt how to live". Only one child- the youngest in the group said that he would usually seek the intervention of his parents to stop the bullying.

CWAs are blamed for family break-ups. In the KTN documentary, a grandmother who is raising a granddaughter with albinism said her daughter rejected the child at birth saying she did not give birth to a child, it was a doll, and refused to breastfeed the infant. When the grandmother decided to raise the infant, she was roundly condemned and endured verbal abuse from her own daughter, her other children and some members of the community who said she had brought *"ghasia* (rubbish)"* into the home. Her daughter has since left home. In the same documentary, a couple from Rift Valley (Hellen and Silvester) separated following the after the birth of their firstborn child who has albinism but Hellen's parents forced her to reconcile with her husband upon which they had a second child with the same condition before they accepted the two children saying "we realised this must be God's plan" and resolved to live together'

While confirming that birth of CWAS may cause family break-ups, LM blames father saying that that most cannot handle the stigma associated with the condition;

> "the minute a CWA is born, many fathers walk out…………or chase away the mother with her child because. The first reaction is *kwetu hakuna watu kama hawa"* (we don't have people like this in my family).

The attitude that CWAs are a problem for the family is also recognised widely within the disability discourse in the community. I encountered this attitude quite early in my research when teachers observed that most children enrolled in their special schools were also very poor. The Head teacher explained to me that their poverty situation was also linked to family background, with children of single parents being considered more vulnerable compared with those with both parents, which ties with LM's assertions that

> "fathers walk out……… something that even Mwaura experienced……….. his mother and grandmother raised him……mothers are forced to bring the child up alone……..she probably is without a stable source of income………….. But even when both parents accept their child, they are still confronted with the dilemma of how to handle the general societal rejection

………. there are questions like *"watu watasema nini?? "tutapitia wapi?"* (What will people say? How do we live in this community?"

Parents Love and Dedication

Some children talked about the love and devotion of their parents which was often demonstrated through the pursuits that ensure the child's survival, especially by seeking information and treatment for some of the complications associated with albinism CM a 12 year old boy in Class seven (7) wrote in his personal account a story of perhaps what he has been told by his parents or siblings about his birth, and also his later life encounters;

> "when I was born in 2002, my mother took me to a hospital and she was explained my albinism condition. She brought me the lotions but it was quite late. The spots had already grown in my face"

 Another 12 year old girl also in the same school wrote

> "when I was born people were shocked and surprised. They were saying a lot of things about me and my mother, and calling me many names that came from nowhere.......................... My mother did not give up. She cared for me very well during my childhood till I grew to go to school. She took me to different hospitals for checking because of my eyes and after all that I came to this school".

Difficult as the birth of a CWA may be, some parents genuinely want to love their children but are confronted with societal prejudices which cause them distress, with some blame going to medical staff and how they handle the birth. PM a farmer from Central Kenya and a father of twins with albinism narrated to me how nurses handled the birth of his twins with albinism who were born in a government hospital. When he asked to see the babies, the nurse asked him to first go to her office whereupon she interrogated him the family's history with albinism. She tried to prepare him for the reality of having twins who both had albinism. Whereas this would be considered invasive, this father says he appreciated the information provided. It was helpful in accepting the children and knowing how to care for them. In other instances the medical staff runs away one mother explained in the KTN documentary.

The stories of both the grandmother raising the CWA rejected by her daughter, and the experience of PM are important in refuting claims that generally children with albinism are out rightly rejected. The two together with the children's stories of love reinforce the alternative narrative that some researchers into African childhoods found to be true; the belief that the birth of any child, even one with disability is truly a cherished experience, much preferred to not having, which more stigmatising. It represented continuity of the family lineage, and positively alters the parents' social status in the community (Okwany 2011:86).

Chapter Summary

Through the rich stories that the children told, the chapter examines agency among CWAs as they confront who they are as well as what society says they are especially in spaces where children are most visible- the school, family and community. CWAs particularly pay attention to their educational needs and this is where the greatest contestation of the disability label becomes apparent. Some of the children value the 'disability' framing by expressing their satisfaction with special schools. The attitude being that of being finally in a school that understands their needs and equips them for life as PWAs. Some of the children place greater value on integrated education and shun the 'weaknesses that special education represents. At the same time, on the family front, children prove that contract to the dominant view that most CWAs are rejected, there is

also acceptance and belonging that family and community show, affirming the view that the joy of parenthood is far more pervasive than the fear of having a child with disability.

Chapter 4: Corporeal Politics in Kenya: Examining Emergence of the Albinism-Disability Discourse

"Denying a person with albinism sunscreen is like denying somebody the right to food-in both cases they will all die with time" (LM July 2014).

Introduction

This chapter focuses on how knowledge on albinism and the identity of PWAs has come to be redefined as disability through the actions of the Albinism Society of Kenya (ASK). I show how ASK strategically used various means to bring albinism into the political, legal and policy spheres of Kenyan life for material benefits: through political connection and therefore a voice in the legislature; through representation on the NCPWD; through media (both the widely publicized news reports of occult killings) and two documentaries that are widely used as promotional campaign materials. The aim is to expose the intricate contour of corporeal politics in Kenya, showing how organised groups make claims on their rights, what messages are enacted and privileged, what is silenced and at whose/what expense; and finally how these affect the people they represent. Evidence points to a level of incompatibility between the collective goals of social justice struggles that require a unified representation of group identity and those of the individual members-in this case CWAs.

I used material from interviews conducted with three ASK co-founders (LM and AM) two of who are also linked to NCPWD, and one staff (DN)[2]. Secondary materials including the two documentaries and a 15 minutes TV interview with MP Mwaura by KTN after it aired the documentary are also included.[3]

Albinism Redefined: Pity Politics and the beginnings of a new Identity

ASK was registered in 2006 by PWAs in Kenya to fight for the rights of PWAs, motivated by the need to pressure the state to act in order to save PWAs from becoming "an endangered group" (LM). ASK effectively mobilised both political power and the social capital of PWAs using pity. The trigger for public action was a joint campaign by ASK and a Kenyan film actor/producer Lupita Nyong'o[4]. One of the campaign materials was the powerful documentary by Lupita *In my gene,* produced to educate the public on albinism and lobby policy makers to make sunscreen affordable. According to both LM and AM, the time sunscreen was considered a cosmetic product and was heavily taxed. By 2009 the producer's father was the cabinet minister in charge of the Ministry of Medical Services (Now Ministry of Health) which bolstered the campaign, as AM notes;

> "Lupita was very strategic……….she put a copy of it in the pigeonholes of all Members of parliament …….she had political access because her father was the then minister for Medical Service"

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[2] *The filed interviews were carried out between 15-21ˢᵗ July 2014,only initials are used to identify respondents.*

[3] *Mwaura's interview with KTN aired on 2ⁿᵈ July 2013 and can be found on:*
http://www.standardmedia.co.ke/ktn/video/watch/2000066799/albinism-in-kenya-a-prisoner-of-my-skin

[4] *The producer is the 2014 Oscar Award winner for her role in the movie 12 years a Slave*

The political connections proved useful for ASK, providing it an opportunity to present a petition to parliament that demanded protection of PWAS. This came by way of a private members motion that was sponsored by an MP who later became the minister in charge of justice and constitutional affairs. On the floor of parliament the motion found ready acceptance but encountered opposition at the final approval stage by the parliamentary committee on budgets. For this, ASK, and the MPs mobilised pity as AM points out;

> "we brought people with smelly wounds to the meeting-they had skin cancer at an advanced stage. The idea was to shock the MP into realising how serious the problem was. ………
> The MPs could not stand the sight of the smelly wounds so they approved our budget request immediately………..we wanted four things in our petition. ……we wanted sunscreen to be zero-rated……the counting of PWAs ……we were worried about the killings ……and wanted protection……… for the law on disability to out rightly recognise albinism as a disability. Finally, we wanted a clear government commitment to stop the killings and threats on the lives of PWAs in Kenya"

Parliamentary approval was a milestone for ASK and PWAs in their rights struggles regardless of how it was secured- which is a moral issue. Notably, the strategy used validates Fortman (2006) views that realising aspirations of human rights as a framing for social justice is a performative function, and that in an attempt to realise people's rights, it is not the rights in and of themselves that ought to be claimed but rather the "resources necessary to acquire what people need" (Fortman 2006: 34). ASK thus had a clear focus mostly on the immediate material needs, and made concerted efforts to gain recognition. Though I concur with Fortman , I also uphold similar views as both (Anspach 1979) and Minow (1997) who argue that such a process can be fraught with challenges and may in fact accentuate the inequalities that such struggles attempt to correct. In her work on identity politics *Not only for Myself* Minow (Ibid: 9) expounds on the need for striking a balance between equally important but opposed choices, observing that "Using policies to remedy group based harms makes the group identities seem all the more real and entrenched, but denying significance of group based experiences leaves legacies of harm and stereotyping in place". In short, there are trade-offs and consequences to choices. Crenshaw (1991) supports this view, albeit with greater caution not to privilege one group over another as it could raise new exclusions.

For ASK, the delicate balance meant taking the risk of wearing the disability in spite all the notions that *"ableism" (*Campbell 2000) projects on persons with disability. Given the material benefits in question which were essential for survival of PWAs, the options were limited. The definition took on urgency when vulnerability was couched in the language extreme deprivation and poverty, lifelong financial burdens, as well as a threat to survival, where sunscreen was equated to food. LM painted the picture for me saying;

> "Denying a person with albinism sunscreen is like denying somebody the right to food-in both cases they will all die with time…..sunscreen is life to us. You can imagine in my case I budget for Kshs.2500-3000 (Kenya shillings-equivalent to euros 20-27) per month for sun screen alone, and I have to use it for the rest of my life"

For AM, the matter transcends materials needs, making it a human rights issue, arguing that;

> "At the very least, PWAs have a right to live like other people………reducing cancer risks means that PWAs have to use sunscreen lotions throughout …….. from time the child begins crawling and getting exposed….until the day the person dies".

Keeping in mind that evidence shows a causal association between poverty and disability (Rust and Metts 2007, Campbell 2000, Bines and Lei 2011), the above issues were legitimate concerns that could not be ignored, especially in the context of limited economic opportunities for PWAs. And

thus the definition of albinism as a disability began to take root with all these as well as the occult killings being cited to show vulnerability.

For DN of ASK disability means;

> "Something that makes you not work optimally. For example, PWAs cannot work in the Jua kali sector (loosely translates to "hot sun")5 due to their sensitive skin. They cannot engage in farming, nor become secretaries or typists, because of visual issues …… albinism ought to be treated as a disability because of these restrictions"

LM explains that in particular, it is the low vision that makes albinism a form of disability. However, even among its own members, ASK gets challenged on its stand as LM pointed out;

> "when we go for awareness campaigns for our members, the question they keep asking us is
>
> *sisi tunaona, kwanini tunaambiwa tuko na disability?"*(We are not blind, we can see, why are we always being told we have a disability?).

This stance by ASK adds to the ambiguities surrounding albinism. Given how pity was mobilised for parliamentary approval, it may imply agreement with the Campbell (2004:443) critical interpretation of forms of disability as "a personal medical tragedy", where deformities require medical solutions to expunge the monstrosities or least manage them in ways that would bring about more acceptable normative corporeal standards (*Ibid*). Yet, the whole idea of propping up albinism through the discourse of disability is not entirely new in Africa. Braathen and Ingstad (2006) showed that in Malawi PWAs consider themselves disabled for social welfare and economic benefits. However, drawing on experiences of social movements, Anspach (1979:765) sees the motivation going beyond the instrumental value to focus on intrinsic and structural concerns of attitudes and "societal conceptions". ASK made attempts to do both- meet material needs for members, and also change public perceptions. However, because of the strategies it used, ASK ended up re-defining its members through a reconstruction of their identity as disabled in a context where a hegemonic view of disability is associated with stigma and shame. It would be safe to assume the logical explanation for this situation was that though ASK was driven by fear of the occult, it desperately needed an ideology that could yield more than just sympathy from the state because "without an ideology or a set of constituent ideas, a social movement is not possible" (Anspach 1979:771). Disability provided just the right crutch on which PWAs' demands could stand on.

Authorizing the Discourse and Legalising albinism as a Disability

Having gained attention and sympathy, legal means were necessary to entrench what had been secured politically using power in a literal as well as a Foucauldian sense. Mills (2003:67) points out that Foucault's power/knowledge concept

> "emphasises the way that knowledge is not dispassionate but rather an integral part of the struggles over power, but it also draws attention to the way that in producing knowledge, one is also making claims to power".

In this case, to create a collective identity of PWAs, ASK used its political connections, and gained access to spaces that most marginalised groups may never access. Once established, ASK was also able to gain power to further influence and entrench itself, bringing about new understanding of albinism. However, this is a negotiation process signalling how contextual and transi-

ent societal identity constructs and epistemologies can be. Having understood this, ASK had to legalise the new identity in order to entrench it firmly.

As a signatory to the Rights of Persons with Disabilities (UNCRPD), Kenya gave it effect through the 2010 constitution (mainly articles 54), guaranteeing a wide-range of rights to various groups of people including PWD. These were further enacted in the Persons with Disability Act of 2003. Even without the explicit mention of albinism, ASK has invoked all the above laws, especially the recognition of visual impairments to try and fit into the disability definition, but found itself caught up in a contentious legal debate with mainstream groups of persons with disability (PWD). The groups consider themselves to have more recognised forms of disabilities (like physical handicaps and blindness), and argue that albinism is not in law and is

> "just about skin color and PWAs should therefore not make claims to any benefits that the 2003 confers on PWD law guarantees" (AM).

Indeed a comparison of article two of PWD Act of 2003 against article 260 of the constitution, shows deliberate vagueness especially in article 260 (Onyango 2012). It states;

> "Disability includes any physical, sensory, mental psychological or other impairment, condition or illness that has or is perceived by **significant sectors of the community** *to* have , a substantial or long term effect on an individual's ability to carry out ordinary day-to-day activities" (Constitution of Kenya 2010).

Article 2 defines disability as "a physical, sensory, mental or other impairments, including **any visual**, hearing or physical incapability which impact adversely on social, economic or environmental participation".

According to Onyango (2012), such latitude in definitions within law allows for inclusion of unforeseen circumstances, making it a matter of interpretation for various users in the future-which is where power becomes crucial. It has both merits and de-merits, giving room for PWAs to bargain for their identity, but also opening space for subjective interpretations that could also shut PWAs out depending on who wields greater political influence. At the moment, ASK has political influence which has been significant in authorising its version of the disability discourse. Representation within the National Council for Persons with Disability (NCPWD) and in the National Assembly (through the representation by MP Isaac Mwaura) allows for this influence. NCPWD was created under the PWD Act of 2003 to ensure integration of PWDs in all aspects of development and Kenyan life. So in spite the opposition, ASK has used the vagueness in law to establish the National Albinism Sunscreen Lotion and Support Program with state funding of Kenya shillings 100million annually, and which was launched in 2014. But even then, ASK feels the need to secure its place through law. This is one of the reasons why ASK is pushing for a distinct law on albinism. An attempt to amend the existing law by inserting the term "albinism" was met with stiff resistance from the mainstream disability community in 2010 (Onyango 2012). In the interview with KTN, Mwaura said ASK will continue to agitate for such legislation because currently "albinism is moralised through soft law. We want it in hard law so our protection can be certain". Given ASK has access to the legislature, the possibility of such a law becoming reality cannot be underestimated, and ASK remain adamant that it must happen.

For whom is the State sunscreen lotion anyway?

There is no doubt that the free sunscreen program has changed people's lives, despite its sustainability hanging desperately on the balance of the albinism-disability contestations. Most PWAs see this is as a ground breaking policy intervention (which it is if you disregard the debate on transformative changes that should occur alongside it). But CWAs have a different interpretation of both the program, the identity it created and affirmed, as well as what it means to grow up with albinism. From their shared experiences, CWAs value quality skin and eye care services

but they also want to be seen not as a collective group but as individuals. The situation is aggravated when adults in CSOs presume to speak for children but fail to account for how their actions affect children's lives.

Certainly, in my discussions with some of the 13 CWAs, many categorically stated they are not different from other children. The experiences of RO and JM capture the ambivalence among some CWAs on the sunscreen program, and raise fundamental question of who ASK actually represents. RO who is in form two for example has decided not to use the government supplied sunscreen lotion because of its lower sun protection factor (SPF) of less than 30 saying that it will not adequately protect her skin from cancer. She says she has never had a skin problem because she uses lotions with SPF 50 for maximum protection, and which her parents buy for her. She has a good understanding of the important self-care practices observing that;

> "………my parents always buy me the right kind of sunscreen I need so I don't use the one we get from the government hospital even though its free *sababu iko maji maji sana*" it is too light/dilute).

AM who is in charge of the sunscreen program at NCPWD he readily admitted there were there were some problem saying,

> "Though some public hospitals are reported to have limited supplies that are not the main issue. The lotions were procured at inflated prices, effectively reducing the number of beneficiaries".

ASK vigorously protested the breach of government procurement processes through a street protest by PWAs on 3rd July 2013 in Nairobi, the media, and also instituted court proceedings against the leadership of NCPWD at the time leading to dissolution of the previous board and reconstitution of the current one (KTN News Hour 2013). He also clarified that lower SPF lotions could still be used, but have lower protective compared to SPF 50 lotion which provides longer protection and does not need frequent re-application. CWAs seemed quite aware of this fact-one that is critical for the tropical climates where exposure to sunlight is all year round. Moreover, in a resource poor environment where one bottle of SPF 50 equals more than a full month's wages, it leaves the poor with little or no alternative options but to use what is available, with likely increased risks to cancer. Whatever the real reasons, the children's concern is for protection from cancer, and that the quality of government lotions should not be poor even though it is free. Importantly, RO's rational choice shows that CWAs experience albinism differently, and income plays a useful role in widening options.

Unfortunately, 12-year-old JM has very little choice but to use the government-supplied lotion. Her parents are divorced and she lives with her mother who is an informal trader in the urban centre near her home. She said she depends on the lotion she gets either through the school when they get donations from time to time or government hospital l where the school facilitated her registration. She readily admitted that she depends on it and uses it sparingly because;

> "I feel bad when I see other children are playing in the sun outside, but I cannot go out to play because of the sun because sometimes there is a shortage of sun-screen. So I cannot go out to play if I have not applied the lotion".

Similarly, other care practices such as frequent ophthalmological assessments depend on families having resources. RO fortunate to have had an eye operation four years ago which she feels expanded her career option. Every three months her parents also take her for eye check-ups as well to prevent deterioration of her vision. Failure to detect and deal with some of the challenges early enough compromises both visions and longevity which averages about 30 year (Hong et al. 2006). RO can read braille as well as print, but prefers print which she is more comfortable with, believing that with print, it will be easier to pursue her career in legal studies at the university. In any case, the use of braille would be an admission to being disabled

These experiences by children should invite an honest re-examination of approaches CSOs use fight for rights and social justice of disadvantaged groups, with the aim of making them inclusive. This could be achieved by ASK embracing a cultural model that is also advocated for by Devlieger (2005) as opposed to the medical or social models that ASK seems to waver between. The social model argues that disability is socially constructed by society, placing limitations on the disabled person-less due to their impairment and more because of prevailing social attitudes (Ibid). The clinical/medical model on the other hand serves a functional purpose by promoting medical interventions as the panacea for disability, and through medicine brings deformed human bodies to normative corporeal standards (Campbell 2011). ASK is caught between the two. Devlieger (2005) argues that a more adaptive cultural model to understanding disability allows for the co-existence of multiple disability models that acknowledge individual experiences hence a nuanced approach can be arrived at for dealing with challenges involving disability.

Chapter Summary

This chapter sought to examine the genesis and entrenching of the dominant albinism narrative by adult PWAs and their institutions using ASK as the example. The discussions show the success of ASK in shaping the disability discourse in spite of contestation from mainstream disability groups and ambiguities in the law, utilising political connections. However, it also revealed the failure to represent other voices particularly those of children and parents of CWAs in determining the disability identity and interrogating its impact on the lives of CWAs, as the arena for participation was accessible mostly to a small but well connected group of PWAs. Personal experiences of CWAs and their families show the tension between the collective identity and dominant narrative that ASK has variously project in order to ensure state support, and the aspirations for individuality and self-determination by CWAs whilst not denying group benefits.

Chapter 5: Summary of Key Findings and Conclusion

Childhood is one of the most intensively governed sectors of personal existence" (Kelly 2005:377)

Introduction

This study set out to answer four research questions focusing on the dominant narratives of albinism in Kenya and how they emerged; children's perspectives on living with albinism in contrast to the views of adults; the role that various institutions play in foregrounding the dominant discourse and finally; what these discourses mean for the lives of CWAs as well a civil society organisations working to secure the rights of people with albinism in Kenya.

Overview on findings

Evidence presented through this research has shown that there was a deliberate, and strategically orchestrated campaign by ASK to re-engineer albinism and present it as a disability. Using political means, it succeeded to insert albinism into the current disability discourse for material, economic and political benefits of PWAs. Poverty, pity, and fears rooted in historical and cultural practices that also drive the occult economy were important in this process-enabled by media. The consequence is a dominant view of albinism as a disability permeating the political and legal arenas. However, despite the image created, this view is actually contested, and not enough attention has been paid to those contestations especially by CWAs and their parents. The findings show that children with albinism exercise their agency in family, community and school settings where children are most visible in order to contend with what and how society has constructed them. Through the children's voices, I demonstrate that children are aware of the dominant narratives, and react to them in different ways such acceptance, denial, re-negotiation or resistance. The failure to account for children's voices in particular leads to a reading of only half of the story, which could miss out important aspects for policy and programming.

Whereas these results are not generalizable to the entire population, the rich experiences of children with albinism, taken together with the results of the advocacy work by ASK at the macro level provides interesting insights for thinking about representation (identity), participation and interventions targeted at disadvantaged groups in policy-making and programming.

Findings of this study show that the process of politicization of albinism in Kenya shifted significantly following emergence of the occult economy about 10 years ago. The corporeal enterprise created fear and panic, providing the impetus for PWAs in Kenya to organise and react to the threats on their lives. It also offered an opportunity to politically confront long held prejudices and derogatory practises against people with albinism that had mostly been backgrounded as retrogressive cultural practices, and thus not challenged much prior to the killings. Need for an ideological basis for making claims beyond the subjective media reports saw adoption and insertion of disability into in the definition of albinism. The insertion was enabled by building on an ambiguous legal environment that left the definition of disability to multiple interpretations. Although in political, legal and policy formulation terms, albinism is now viewed as a form of disability; this collective identity is not fully embraced even within the PWA community, but remains useful for gaining material benefits from state such as free sun-screen lotion, tax exemptions for corrective devices, and political representation in public spaces which guarantees PWAs a voice.

However, the personal accounts of CWAs reveal an individualised experience of albinism from one CWAs to another, but in all cases children have shown great capacity to make rational choices in spite of a constrained agency. Some choices depend on their economic background, amount of information available to them as well as family support.. The social location presents greater choices for determining whether one uses the government lotion which has lower protective factors. To access the product, one has to be registered as a PWA. Inherent in this situation is the possibility that perhaps ASK does not represent the middle class fully. However, the middle class also recognise vulnerabilities their condition carries, and hence cannot fully disassociate from the group, so they register. For CWAs, as well, a supportive family environment allows children to discuss present and future educational and career possibilities. This was demonstrated by the case of one child opting to go to a mainstream secondary school which the parent readily supported. In addition, CWAs adopted a variety of ways to self-define who they were. Some children accept the societal framing of who they are and find a sense of belonging in special schools where they feel understood, others reject the label of disability and want to be treated like other children in mainstream schools, and yet others deploy means such as their religion to counter the dominant references.

Implications of the findings

According to Fraser (2000), social justice causes have to be framed in three dimensions- economic, cultural and political, with the aim of bringing about parity so that people can equally participate in their community. Related to the three are the expected aspirations ones the barriers are lifted which include distribution of economic resources, recognition of cultural diversity and political representation allowing people to participate in decision making. Ultimately the aim is to break down barriers that deny some people the opportunity to participate (Ibid) These understand is important in considering how ASK went about realising its agenda, in which the identity of disability was first appropriated. Identity remains central to ASK's social justice cause, and ensures continuity of the benefits so far secured. What seems to be a challenge however was ASK's inability to confront deeper societal concerns that create disadvantages for PWAs, some of which the foundation is laid in childhood- for example through the quality of health care and education provided to CWAs.

Special Needs education

NGOs for instance those dealing with orphans and vulnerable children are often accused of not doing enough to challenge and deal with the real reasons that perpetuate deprivation of their clients, and that the failure arises from not " depoliticising the structural roots cause of poverty"(Cheney 2012:104). In the case of ASK, it succeeded in hyper-politicizing albinism and gained the recognition necessary, but this had a very narrow scope. It reduced issues of PWAs to threats to life, the need for skin protection and to some degree confronting myths. With the kind of political connections ASK could marshal, it had a chance to do more for example lobbying for more resources towards special needs education in order to ensure the integration policy was achieved, which would give CWAs favouring such schools an opportunity to learn in an environment that accommodates them. CWAs education concerns arise from the low vision and the poor quality education that was historically availed to people with disabilities, laying a foundation for future exclusions. PWAs are disproportionately more affected by poverty than other groups of socially disadvantaged groups due to historical exclusion (Bines and Lei 2011). These social disadvantages open trajectories for progressive exclusion (Kabeer 2000). Depending on the terms of provision and quality, education could reduce the disadvantages or extend them. In the findings, CWAs have shown great propensity to interpret this in their lives and some have acted in attempts to change that situation either by not learning braille of opting to go to a different school in the belief that being in such an environment is better for their career plans. This reso-

nates with fears that were already expressed by adult PWAs, who say opportunities to earn are also limited due to the constrained career choices hence there is a constant struggle to balance between purchasing the lotion and meeting other basic survival needs. LM believes that education is the most useful gift that parents and society can bequeath CWAs because;

> "there are jobs that one has to also decline ……….I have missed three job opportunities in North Eastern Kenya (where temperatures reach 40 degrees). ….it is risky for me even with protection…………I could go but unapata kazi mwaka mmoja alafu unakuja kulala kitandani the rest of your life?" (What is the point of getting a good job for one year then you are bed-ridden the rest of your life?).

According to the primary school head teacher, the capitation of free primary education per child is the same for mainstream and special needs schools, yet learning needs of SNE learners are higher. For instance, the cost of translating one textbook to braille is almost 3-4 time that of printing. The school provide stylus and special braille paper which is also quite costly compared to ordinary paper. There is no evidence that ASK has raised any challenges to the state on education provision for CWAs or other PWD in spite of having a strategic political platform to do so.

Preference for a medical model over a cultural model

The fact that the national sunscreen program is coordinated by the Ministry of Health can be interpreted to mean that not only is albinism a disability, but is also medicalized, which begins to treat CWAs as sickness people, resulting in what has come to be referred as "patientization of the population" (Taylor 1997 cited in Campbell 2004:443). In fact, part of the future plans by ASK include a skin cancer treatment centre. While recognising that cancer prevention is an imperative, I question the approach for failing to recognise that experiences of living with albinism also go beyond this, and one size –fits all interventions do not work for every CWA hence it calls for a cultural model. This model takes account of diversity and unique needs of each individual. It also allows for a variety of approaches to be applied to the same challenges.

Conclusion

This study sought to answer four research questions examining the current disability discourse, what the discourse means for children; the role of social institutions in maintain the discourse and implications of the discourse on CSO work and CWAs' lives. Personal experiences of CWAs and their families show the tensions between the collective identity and dominant narrative that ASK has variously project in order to ensure state support and the individual CWAs who wish to be defined in ways that go beyond the albinism condition. This findings call for a honest reflections among the PWA activists; perhaps more honest recognition of whom they represent and whom they do not represent. Wider consultations with children on the policy proposals could be pursued as they hold promise, and children have shown ability to make rational choices in spite the recognised constrain on their agency.

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