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The Ayes have it!

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Abstract

This is my autoethnography about living with Facial Eye Disfigurement (FED). The purpose of this autoethnography is to answer the question, "What are the lived experiences of people living with FED?" There are wide and varying issues faced by people living with facial disfigurement (FD), for example, dealing with psychosocial and psychological aspects, the lived experiences and voices of persons with FED are nowhere in the research literature. The themes presented here are not unique to FED but illustrate how far and wide the phenomenon occurs, themes such as, social isolation, bullying, gatekeepers, discrimination, and hope. The themes are woven into the vignettes presented; all are inextricably woven together like a finely crafted tapestry. In my discussion four foundation blocks are explored: forgiveness; active intentional decisions; healthy self-esteem; spirituality and resilience. These are seen to be the underlying contributors towards why I hold such a positive attitude towards life, despite the everyday grind of explaining myself. In conclusion, I found the voices of FED require assistance and active engagement within the FED/FD community as well as the general public to dismantle myths such as "the greater the disfigurement, the greater the distress." I founded Karibu Anawim in 2015 which endeavours to train, equip, and nurture people living with FED/FD and the general public.

Keywords

Face, Facial Disfigurement, Eye Disfigurement, Facial Eye Disfigurement, Facial Difference, Visible Difference, Autoethnography, Karibu Anawim, Faceism, Third Nerve Palsy, Palsy, Facial Palsy

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The Ayes have it!

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This is my autoethnography about living with Facial Eye Disfigurement (FED). The purpose of this autoethnography is to answer the question, "What are the lived experiences of people living with FED?" There are wide and varying issues faced by people living with facial disfigurement (FD), for example, dealing with psychosocial and psychological aspects, the lived experiences and voices of persons with FED are nowhere in the research literature. The themes presented here are not unique to FED but illustrate how far and wide the phenomenon occurs, themes such as, social isolation, bullying, gatekeepers, discrimination, and hope. The themes are woven into the vignettes presented; all are inextricably woven together like a finely crafted tapestry. In my discussion four foundation blocks are explored: forgiveness; active intentional decisions; healthy self-esteem; spirituality and resilience. These are seen to be the underlying contributors towards why I hold such a positive attitude towards life, despite the everyday grind of explaining myself. In conclusion, I found the voices of FED require assistance and active engagement within the FED/FD community as well as the general public to dismantle myths such as "the greater the disfigurement, the greater the distress." I founded Karibu Anawim in 2015 which endeavours to train, equip, and nurture people living with FED/FD and the general public. Keywords: Face, Facial Disfigurement, Eye Disfigurement, Facial Eye Disfigurement, Facial Difference, Visible Difference, Autoethnography, Karibu Anawim, Faceism, Third Nerve Palsy, Palsy, Facial Palsy

In the Beginning: My Story

From birth, I was prepared to survive. Not only to survive but to thrive—the world as I knew it was about to change. This changed my perspective on who I found myself to be and how the world would interact with me and my journey to find my place within it. From my Mother's 1977 calendar (giving away my age straight away) I was due 15th July. I was prepared to survive from birth. Every day a baby stays in the womb adds weight—I was about to use all the weight I gained. I was born 22nd July 1977, seven days late and subsequently heavier.

August 4th, 1977 there was a car accident involving my Mother, my Father, and myself. My Father was driving and not to blame for the accident. I am first born, all the dreams and hopes my young proud parents had for me were soon tested.

The ambulance came and according to my Mother's recollection, as the officers attended to Mum and Dad offhandedly they said, "Has this baby been in the accident too? Well she should come too, I suppose." They had not been concerned about my well-being. This nonchalant attitude changed drastically as we hit the hospital and the staff saw me. They brushed aside Mum and Dad, rushed to my side, shone lights into my eyes and they were not responding.

Something was wrong. The local hospital was ill equipped to deal with cases such as mine. I was immediately transferred from the local hospital to the Royal Children's Hospital in Melbourne without parents, without familiar smells and without supportive voices I knew. You see, I was born to survive.

According to medical records retrieved through Freedom of Information, I was admitted and held at the Royal Children's Hospital from 4th-17th August 1977. I spent the next 13 days in intensive care, away from familiar smells, voices and feelings of my clothes my family members had made, bought, or borrowed. The yellow two-door car was a write-off. My young parents visited often, staying at a friend's house in Geelong. I stayed at the Royal Children's in an isolette (which was repeatedly reported to be too hot) 4th-12th August and then in a cot 12th-17th August. I suffered convulsions during my stay in hospital and subsequently had bilateral subdural taps draining over 23mls with light bloodstain. Afterwards, I was released into my parents' watchful care. I wonder if I had acclimatised to the hospital noises, smells and constant prodding to make sure that I was conscious. Did I go through another "culture shock" upon return to my own cot?

I acquired a brain injury (ABI) resulting in partial third nerve palsy. In reports obtained from the Royal Children's and Mum's 1977-1982 calendars, I spent the next 3-4 years of my life in and out of offices being prodded, tested, and re-tested with reports written. A swag (Australian slang for many) of specialists, the likes of the family doctor, ophthalmologists, psychologists, and neurosurgeons discussed my physical brain and vision, right through to my cognitive ability reports stating my mental ability would "peak" at Year 10 or equivalent, my future prospects, and whether or not the partial nerve palsy was going to rectify itself or was surgery required.

Only one instant was recorded whereby my "cosmetic appearance" was mentioned linking my future prospective acceptance within the community (psychosocial) and how I would cope with such (psychological). Within all the barrage of medical personnel and psychologists I had, only once had they thought of the after effects of having Facial Eye Disfigurement (FED), something that is repeated frequently today. Before I went to kindergarten, I had cosmetic surgery to bring my right pupil around to the front of the eye instead of it resting on the bottom right-hand corner. Mum and Dad chose to keep my eyelid "drooped," the alternative at that stage of surgery was to attach the lid to the top of the eye rendering it unable to blink with the possibility of infection and I think, losing it. They chose to leave the lid alone and correct the pupil only.

Recently, I have had to go to the ophthalmologist again as I had unusual pain in the left eye—my "good" eye. After the tests showed that there were no nasties present, I asked about the advancement of surgery and what they could do for my right eye. They can put an implant into my lid now that will open it and allow it to blink fully; they can fixate the eye to the middle, so that I would lose all movement that exists in the eye if it were successful. Weighing up the pros and cons, the effects if it didn't work, the expectations if it did, and everything in between, I *think* I have come to the conclusion that it would not lead to any greater level of psychosocial psychological contentment or acceptance within the community; I will leave how I look as is!

In the Present: Myself the Researcher

My right eye is blind from this incident that happened to me as a newborn. Upon first glance, you notice my right eyelid is drooped. This could be because I had a lazy eye, some disease is attached to it ("Why isn't it patched, for Gawd's sake patch it, it could be contagious, don't you know, tsk"), or, could it be that I am in the heat of some domestic violence issue ("Please don't involve me," I hear you say) or that I have just plainly had a mosquito bite me and it is inflamed. Internal dialogue begins and is automatic—dare I say learnt; responses are enacted without the chance to be questioned or even brought to light.

Eyes are an important key to communication, they are where you look, a point of reference and where much of our "attractiveness" centres upon according to today's media

which loves to highlight many different formulas to slow down the aging process, especially around the face. McGrouther (1997) who puts it another way states that

Image and beauty are marketing tools portraying a particular “supermodel” as the desired “look” diminishing the value of individuals who deviate from the face or norm of the moment. (McGrouther, 1997, p. 991)

I invite you to journey with me through my autoethnographic testimony of experiences, peppered with academic studies that clarify and sort my shared experience. These studies will give weight and answer the “so what” question (Ellis, Adams, & Bochner, 2011) to help triangulate my experiences building the trustworthiness aspect of writing my autoethnography which is “an approach to research and writing that seeks to describe and systematically analyse (graphy) personal experience (auto) in order to understand cultural experience (ethno).”

Writing autoethnography varies in rationale from writing for catharsis, trying to make sense of all or parts of our journeys, or to give a voice to those who have not within a specific phenomenon been studied (de Bruin, 2016; Ellis, 2011; Ellis & Patti, 2014; Nethsinghe, 2012; Sutherland, 2015). It is my hope that in writing this, I can challenge and educate: challenge automatic reactions to people who are visibly different by raising awareness and through personal reflection help change the culture wherein I currently live regardless of want or desire.

Autoethnographies should use narrative tools such as character, scene and plot in a well-written story progression whether it is chronological or fragmented, meaning each chapter has its own beginning, middle, and end (Ellis & Bochner, 2006; Ellis et al., 2011). Autoethnography engages the reader in thick description, makes personal experience meaningful, cultural experience engaging, and brings the readers into the scene—particularly into thoughts, emotions, and actions in order to become actively involved within the narrative.

My FED defines where I fit in society regardless of where I want to or think I would like to. It also affects what jobs I am likely to gain or not (Stevenage & McKay, 1999; Stone & Wright, 2013) despite my skillset and education. FED is not something I dwell on but affects me on a daily basis from where I am “socially accepted” to just doing daily life such as grocery shopping. Some days I turn a “blind eye” (slang for not caring, showing that things do not hurt or are unseen when they actually have been recognized) to the stares (Worthington, 1974) and avoidance (Haloua, Williams, Murray, Skalko, & Vogelsong, 2011), strategies the general public have learnt. I believe the general public genuinely feels safer and honestly thinks that they are servicing me in the most polite way, after all, staring and avoidance are culturally acceptable—until now! Most of the time, I educate the “starebears” which is Australian slang for a person who stares at someone, usually unintentionally, because there is something noticeably different about the person. More often than not, it generally makes the person being stared at feel angry/irritated and uncomfortable. I challenge the avoidance of others by explaining to them that approaching and asking politely is much better than staring/avoiding. I do this to dismantle societal fear, which is the reason for avoidance and staring strategies so common within our culture of viewing people with visible difference.

The purpose of this article is to give a personal face and voice to people living with FED. This is an area in which there is a “departure from the literature” or a “gap in knowledge.” An autoethnography of my own experiences past, present, and prospective future explores experiences of living with FED in a world whereby attractiveness is “seen” through having “symmetry of body or facial form implies attractiveness” (McGrouther, 1997, p. 991). My research asks the question, “What are the lived experiences of a person with FED who does not match up to the modern form of attractiveness?” This research will add towards the available body of knowledge by describing what it is like living day-to-day and the issues that come from my lived experience. I believe I will add credibility to prior studies and offer an in-

depth view of the issues. I already know who the benefactors would be from my research (Creswell, 2015). They are those people within the FED community, medical and allied health professionals, and fellow researchers. Firstly, counsellors and medical personnel who work with FED clients will gain a personal insight into the internal workings through shared stories. Secondly, in this study I will validate and begin to vocalise FED stories as part of the FD community who do not have well-publicised networks like burn and cancer patients. Lastly, this will allow discussion to take place, so appropriate proactive measures and assessment tools can be created through a new level of understanding gained because it is the FED voice. It is the beginning of advocating for this marginalised and I believe, under-studied group. Clarke, Rumsey, Collin, and Wyn-Williams (2003) agree: "Very little is known about the psychological impact of an unusual appearance in visible eye conditions, which is surprising, given the central role of the eyes in both communication and perceived physical attractiveness that is part of the FD community" (p. 35).

It is currently estimated that one in five people have a disfigurement resulting from trauma/congenital condition or surgery. Between 34-51% of those affected experience significant psychosocial difficulties (Rumsey, 2008). It has been suggested that one in five people have a skin condition and Changing Faces (a non-profit organisation specialising in head, neck, and facial disfigurement) estimated that 500,000 people in Britain have a visible disfigurement (Harcourt & Rumsey, 2008). To demonstrate prevalence of FD in Australia, craniofacial conditions affect approximately 1 in 500 Australians with approximately 1 in 580 children being born with a cleft lip and/or palate (Roberts & Mathias, 2012). In Australia, general practitioners rarely treat patients with FD (about 2-3 per practice) and even fewer with FED (about 0-1 per practice; Clarke, 1999). There is an interest and thirst for information about the psychosocial and psychological effects of living with FED/FD.

Research in this area is a relatively recent phenomenon. There was interest in body image in the 1920s, but it was seen to be much too frivolous to study (Perrin, 1921). Much research concerned with FD pertains to burns (Partridge, 2005), cancers (Meyerowitz, Kurita, & D'Orazio, 2008), and clefts (Pasoglou, Tebache, Rausin, Demarche, & Collignon, 2012). Medical research addressed the need to diagnose why people require cosmetic surgery (Harris & Carr, 2001b). The Derriford Appearance Scales (DAS 54) and the revised DAS 24 were specifically designed as assessment/diagnostic tools for the FD community and measure feelings and behaviour that reflect the degree of distress/dysfunction around appearance and identify key issues of adjustment: social avoidance, fear of negative evaluation, internalised shame, and externalised shame (Moss & Rosser, 2008). Psychosocial and psychological areas are addressed within several FD communities: adults within the cleft lip and palate community and (Mani, Reiser, Andlin-Sobocki, Skoog, & Holmström, 2013; Roberts & Mathias, 2012), children with oral facial conditions (Locker, Jokovic, & Tompson, 2005) through to the effects of parenting on mother-child interaction and the quality of life mothers experience having FD children (Gray, Cradock, Kapp-Simon, Collett, Pullmann, & Speltz, 2015; Weigl, Rudolph, Eysholdt, & Rosanowski, 2005).

In researching the psychological side of body image, Cash (2002) considered cultural socialization, interpersonal experiences, physical characteristics, and personality attributes. These blend with and affect each other on a continuous spectrum. Past experiences influence our present, and our future will be a mixture of our current/present experiences taking into consideration the culture that we inhabit (Cash, 2002). Persons with FD have identified that the intrusion of curious stares or rudeness of the general public are the hardest things to deal with (Harcourt & Rumsey, 2008; Kleve, Rumsey, Wyn-Williams, & White, 2002; Papadopoulos, Bor, & Legg, 1999). This can promote poor self-esteem, depression (Moss & Rosser, 2008; VanSwearingen, Brach, & Stratford, 1996), social anxiety and poor body image (Kellett & Gilbert, 2001; Papadopoulos et al., 1999; Partridge, 2006). Partridge (2006) never

thought that he would have a family or find work. Persons with FD may have a poor quality of life that includes difficulty forming relationships, people's lack of knowledge, fear, uncertainty of how to behave, and how to engage with attractive and unattractive people (De Sousa, 2010; Harcourt & Rumsey, 2008; Papadopoulos et al., 1999; Thompson & Kent, 2001). The greatest psychosocial challenge for patients who have acquired a FD is learning to cope with social response to their facial appearance (De Sousa, 2010). Sometimes it leads to social withdrawal with many limiting their range of social interactions. This may occur for different reasons.

Ptosis (drooping eyelid) impacts in ways that are not currently recognised (Richards, Jenkinson, Rumsey, & Harrad, 2014) and altered physical appearance and visible disfigurement such as a loss of an eye or eyelid have only received superficial attention (Clarke, 1999). The central part of the face, particularly the audio-visual function, when impaired was a most severe impairment (Dropkin, 1989). My research highlights FED in the hope that it will help society dismantle the myth that the greater the disfigurement, the greater the distress (Clarke, 1999; Rumsey, 2008). This myth implies that if the disfigurement is "minimal," and this resonates with Australian culture, wherein minimisation of one's self, feelings, and talents are the way to be socially accepted (Goddard, 2006). Colloquially, advice may be given: "Suck it up Mate, it ain't that bad, there are plenty more who are worse off than you!" This can be reduced.

Autoethnography: What Is It?

The word autoethnography is a compound word meaning auto (study of self/personal experience), ethno (study of a particular phenomenon/society), and graphy (ability to analyse and write; Ellis, 2004; Ellis et al., 2011; Holman Jones, 2005). Autoethnography was "birthed" in the 1980s because scholars became aware and began questioning the "truths" that were held through traditional forms of research. Every step in, research requires choices: what to include and exclude. A postmodernist approach challenges older forms of research that were traditionally viewed to be value-free even though they were not (Bochner, 1994; Ellis et al., 2011; Wall, 2006). Autoethnographic writers acknowledge and accommodate subjectivity, emotionality and researchers' influence on research transparency. By adopting this approach, I will be able to express myself or others in a unique and personalised manner. It is constructed from the tenets of autobiography and ethnography. Autoethnography is both process and product (Ellis et al., 2011). It is the platform whereby personal and cultural phenomena are able to be investigated through non-traditional forms of inquiry and approach.

Traditional ethnographers investigated and recorded culture/subculture generally as an outsider (person observing what is going on within the culture presenting their observations, field notes, having no affiliation or prior experience with the culture being studied; Hesse-Biber & Leavy, 2006; Wall, 2006). Autobiographers commonly use a narrative story-telling structure with a beginning, middle, and end, carefully sequenced, arranged in a readable manner (Kramp, 2004). Autoethnography differs because the researcher is an insider, and this enables her truth of the phenomena to be presented instead of being some "inspirational porn" subject. Inspiration porn (a term coined by the late Stella Young, an Australian disability activist [Young, 2012]) is viewed as sincere but offensive, irrelevant, or annoying comments regarding the disablement of the person. Able-bodied people appear to believe that they have "a right" to approve of what a person with a disability is doing. Approval that is not required nor warranted. Autoethnography allows me to voice my bias up front, own my story, and develop it within academic restraints. This autoethnography will enrich the known lived experiences of FED, adding to the known body of knowledge regarding this phenomenon (Chang, 2008; Ellis et al., 2011; Fung, 2014).

In a moment of personal revelation, I find it uncanny that I am choosing to employ a genre of academic writing that seems to have struggled to find its place within the academic world. The parallel here is I am not “disfigured enough” to fit into the world of disability/disfigurement and neither does the world of beauty, for want of another word, want me or accept me. I find myself to be either too disfigured or not disfigured enough. Why? I propose that it is related to societal perceptions, norms, and hidden mores of our society and raises questions about what is beautiful and what merits disfigurement, thus forming and confirming the societal myths of beauty (Rumsey & Harcourt, 2005), and the greater the disfigurement the greater the distress (Rumsey & Harcourt, 2012). I struggle to find a place where I am accepted for who I am without the constant need to address concerns and judgements of others. Generalisability or transferability is not required for this study, nor am I aiming for it (Creswell, 2015; Lincoln & Guba, 1986; Shenton, 2004). This study focuses on snapshots of my life, although they might be similar to others; I do not know this and cannot apply the rule of generalizability. Within my vignettes, I have not mentioned names or places whereby anyone else besides myself can be identified. I have kept family members out of my vignettes although I consulted with them to ensure my memories are as accurate as possible. Having taken all these precautions, I believe what I disclose about myself is free of causing any discomfort to anyone else, apart from myself. Having taken these steps, I decided that I had behaved ethically and did not require ethical permission to undertake this research. My supervisor agreed, and she is a long serving member of the university ethics oversight committee. The following are my vignettes and my thoughts presented thematically. After my vignettes I have summarised my themes in a table. I wrote many vignettes and read them repeatedly. As I read, I made marginal coding notes and found that particular themes emerged repeatedly (Reid, Flowers, & Larkin, 2005). Initially I saw the experiential themes appear that have framed my life: loneliness/isolation, gatekeepers, bullies, and discrimination. On reflection I began to see that as I got older, I became more resilient. I noted the presence of hope in my later vignettes and finally, my story was about defending myself and becoming proactive in the face of relentless discrimination. I have selected a few vignettes from across my lifespan that encapsulate my experiences. I have chosen to allow the reader to explore these before I offer my themes.

Zombie, Zali

When I was in primary school I was teased, called horrible names like Cyclops, one-eyed willy, zombie which rhymed with Zali. That one encouraged conga lines of zombies to grab my shoulders and chant “Zali Zombie, Zali Zombie.” It would get rather long and many children would join the line laughing and giggling at my expense. A right royal circus it was. Back then I couldn’t run fast, but this was tested daily when lunchtime came round. I remember the stench of the toilets as I rounded the corner on the straight narrow (inside a tunnel) until I turned a sharp left and slid into the girls’ toilets with or without my lunch, as this was where I ate it most of the time. I was chased by kids, mostly boys, hitting and kicking me. I fell a lot. My lunch scattered to the four winds, other times at hands’ distance away, but having time to pick it up was another thing.

I was bullied on the way to school, at school, and on the way home from school—as the ringleader and his sidekick lived around the corner from me. I came home with black eyes, track marks up the back of my legs where they had ridden their bicycles on their back wheel and then dropped the front wheel down on me (known as “monos” as only one wheel is involved), and buttons off my uniform, which was optional at that time, not compulsory.

Looking at my school reports, I was a very good student, doing my work, being courteous and kind to others, however, I was making “progress with my peers,” never was it

mentioned that they were the issue, but rather I had issues fitting in with my peers. I was the one sent out for “help,” I was the one who was forced to sit in a room half-petitioned and half-glassed with a teacher in a room which faced onto the main indoor quadrangle made especially for winter so that school assemblies and sports could still be run. Tell me a story about this picture... the little girl by herself and the others not wanting to play with her... From a young age, I knew what they wanted to hear so I would imagine a wonderful story for them instead of giving them what they wanted, psychoanalyse that you mugs! ... or I would just sit there refusing because all their help didn't help, in fact made it worse for I have not got the gift of humour and fobbing kids off, the count to 10 slowly doesn't work, the go away and find a teacher doesn't work, the make friends with others and run away doesn't work when you sit in the girls' toilets eating your lunch or what is left from the journey. The teachers knew me to be a pleasant little girl in class, but I was the one who was wrong, that was the message. I want children like me to know that they are not the ones in the wrong and that even though children hurt that there are other ways of handling bullies.

In this vignette I explained what life was like during my primary years at school. It was full of bullying and the assumption I needed assistance in relating to my peers more appropriately. I explain that this “help” was not at all helpful. The irony was that I was a pleasant girl in class but was socially inept because I wasn't “fitting in” with my peers.

The “gatekeepers” in this vignette were the bullies who blocked other children playing with me. The teachers who understood I required help, placed me into positions that did not help me. They gave me strategies that proved to be unsuccessful. Ultimately, it was not I who needed to modify her behaviour.

A memory that contributed to my isolation apart from the taunts and chanting, was that I never had the opportunity to play with girls because of the severity and the grinding consistency of bullying. How could I make friends whilst confined on a daily basis to eat my lunch in the reeking girls' toilets? Discrimination began to raise its ugly head twofold. My peers saw me as easy pickings because I was visibly different and because I was the one sent out of class in order to be “helped.” There were no consequences for bullies even when I did dob (tell on them) or teachers could see I had been in a fight due to black eyes and other bruises. No matter what I did, the callous attacks never stopped.

Mirror, Mirror on the Wall, Who Is the Fairest of Them All?

Whilst waiting to be 18 before I was “allowed” to backpack around the world by myself, I found myself at the best college that prospective employers came to in order to find the best graduates for secretarial and receptionist work. During that year I was awarded the most industrious student award, just beaten by someone who was doing the Diploma course (I wasn't) for the best student of the year award. At the end of the year new heightened buzz was around at who would be the next person interviewed for a job.

The teachers put forward two or three candidates per job. My competitor for the best student of the year award was the first to get a job. There were a few others besides and then, I was being overlooked. Other people who didn't have my skill level or abilities suddenly were being put up for interviews, I was not. The students who were not achieving at my standard came back full of pride, glowing because they had obtained their first job that would be “well paid.” I, of course, was excited for them, but when the calibre of ability kept sliding and I was not given the opportunity to compete, I asked why. The response that the teachers gave me was that they didn't want to disappoint me nor hurt or lower my self-esteem because the employers wouldn't have hired me in the first place... upon what grounds might you ask, I asked ... they said, “you know,” I insisted I didn't, “your looks” they replied. This is yet another form of discrimination, being “helped.” These teachers also admitted that the school's reputation might

be “at risk because they fronted with a facially disfigured person whose intelligence could be called into question.” From that time, I asked questions such as what the “reality” was of me being “hired,” upon completion of courses I was interested in taking. There were quite a few areas from becoming an airhostess to being a travel agent that I didn’t take up because it was unlikely that I would obtain a job in the field. Reasons disclosed to me “off the record” were all about how I looked. I didn’t think that this would be the same in teaching.

Clearly discrimination threads through this vignette. This time discrimination occurred in the shape of “protection” for my emotional and psychological well-being. Was it truly “protecting” me from disappointment and hurt thus lowering my self-esteem because I might have been the unsuccessful candidate, or would I have been the successful candidate? It doesn’t matter what the outcome, I was not given the opportunity to interview, accept an offer, or handle rejection. This was the outcome of this form of “helpful” discrimination. I was not afforded normal experiences of job-hunting due to my FD! I was hopeful of being put forward for an interview. As soon as the ability of other candidates dropped below mine, I realised something was wrong. I survived because I employed proactive, assertive measures, asking why I was not being put up for interview. Again, this is where hope and survival dovetail together.

The Ugly Duckling

I was at University doing my undergraduate degree in Education. I had strategies in place for the children’s taunts and staring eyes. I had my lower, middle, and upper primary stories about my eye delving into as much detail as required for the cognitive ability of these age groups. I forgot about how adults are children in disguise. During my first teaching round, I was devastated and came home, crawling into a fetal position sobbing because whilst on “home time duty” my “antennae” shot up as groups of parents were giving me “the look,” glancing across their shoulder, trying to find their children. I knew that it was me that they were staring at. I didn’t know that I would have to educate the parents. I thought that the simple fact that university had accepted me would be “proof” enough that I had the intelligence and the wherewithal to be able to teach their children. I thought that this would be “enough” to quench the stigma—obviously I was wrong!

Within the same teaching practice experience, straight after the parental slap in the face, I had a smaller in stature male teacher rock up to me whilst traversing the quadrangle asking me whether or not teaching was the right profession for me to begin (Catholic school, mind you). “Why wouldn’t it be I asked?” ... “Because of your eye,” he said point blank, as matter-of-factly with chest out, because he thought he was onto something and could squash me right then and there. “No,” I replied and finished walking across with him rambling on about how I should rethink because of xyz and abc.

This wasn’t the only time during my 4 years teaching that teachers questioned my “ability to teach” purely because of “my eye.” In third year, I had a teacher who discussed with me her “growing concerns” about me being able to “see enough to be able to control the class.” I said that she was silly if she was going to write that on my report due to discrimination. She was going to write this into my end of teaching round assessment, but instead spoke to the appropriate university people who then came out and discussed it with me. University lecturers were “programmed” to come out on certain teaching rounds as a part of assessment, this was NOT one of those pre-planned, pre-warned rounds. I was angry at the fact that throughout my university degree my eye was the cause of many illegitimate “concerns” which were irrelevant to whether or not I could teach.

Within this vignette, I relayed my experiences whilst completing my undergraduate education degree to gain employment. Comments made from children, parents, and also

teachers were not stand-alone comments, rather a swag (Australian slang for a bunch) of them over the duration of the course. The comments illegitimately focused around whether or not I should become a teacher because of my eye or because of the “growing concern” pertaining to my ability to “see enough to be able to control the class.” My actual teaching skills were never called into question. In this vignette, I felt discrimination threefold from children, their parents, and teachers. Self-defense was the only way I combated these probing questions about my ability to teach. Being as assertive as I could, allowed them to articulate pointedly the issue revolving around my appearance rather than skill. I thought I had prepared myself for every point of entry whereby my facial appearance would be questioned. I was seriously mistaken perhaps because of the hope that I have and still have, but it quickly became a survival issue. This reinforces how these themes are inextricably linked.

The gatekeepers in this vignette are clearly the teachers. Whether or not they understood the gravity of their fears couched as “well-meaning concerns” it was perhaps because of my hope or survival techniques, employed over and over again, that allowed me to focus on completing rather than listening to the myriad of voices telling me that I was wrong.

I am proud of my efforts of “keeping it together,” and my professionalism when placed in these situations. The reality of other people’s bias hits hard when you are trying to gain an education in a field whereby you are passionate about.

Wheels on the Bus

I had just returned to the First World from volunteer teaching in a Third World country Kenya where no one had asked me what was wrong with my eye. It took a third trip (the same year) to figure out that the locals thought I had been cursed so therefore never bought it up. Prior to leaving Australia, I had booked a 50-day tour around Europe after my stint in Africa. The bus was nearly booked out and had either 2-3 seats left which were never filled, thus leaving a seat next to me vacant for the entire bus tour. The bus was filled with Australians, New Zealanders, and white South Africans. At the beginning of the trip, everyone went to the microphone, and introduced themselves. It would have been there that ordinarily I would have self-disclosed about my eye, however I plain and simply forgot because I hadn’t been asked or looked at differently for the past 6 months. In Kenya, I was getting attention because I was a *mzungu* (white person and supposedly a rich one to boot, considering Australia would *definitely* be paying me a wage whilst I volunteered my time and my own money to teach in a remote rural school whereby I was placed into the Special Unit with specially undiagnosed disabled children). I was not asked why my eye was the way it was, it was not mentioned. I think that this is the only time in my life, looking back, that I had completely forgot to explain my story.

I had introduced myself, explained that I was very proud of myself that I had been in Kenya teaching English for the past 6 months and said I was definitely not available as a sexual partner during the tour as I had a boyfriend in Kenya. As a result, I had a seat to myself, I was not asked to go to any parties, not accepted to “play” with anyone else. My tent buddy learnt about my eye because she asked nicely and had to share a tent with me for approximately 49 days. I asked her not to tell; she didn’t.

One day three quarters into the trip, a spokesperson on behalf of the entire bus (crew included) came to me. She introduced herself as the spokesperson, “Hi my name is Sandra” (not her real name for I cannot remember it), “I am a secondary school P. E. teacher. During my teaching I have had some experience with teaching children with disabilities, this is why the group thought I was the best qualified person for the job.” She continued with hands on hips, “We would like to know why you stand so close ... what is wrong with you?” Me, stand too close (I almost laughed; I think I scoffed)? We were in a bus! She demanded to know why

I stood too close to them and why I hadn't disclosed what was wrong with me before now, how come she had to come up to me, obviously something was vitally wrong with me if I couldn't have seen that people were uncomfortable and didn't like me. Despite that in Kenya, where I had just been, there was no such thing as personal space. Try hitching a fee-paying ride in a matatu! Chickens and arses, not to mention smelly pits in your face. I learnt to sit between two fat women otherwise I finished the trip with bruised hips.

Sandra kept on saying angrily that I was in their personal space. I mentioned that no one for the duration of the trip had actually sat next to me and apart from me sitting on the roof (highly illegal) that it was the largest amount of space they could possibly afford to give me. I was angry and buried my head in writing poetry, thinking, "Is this what First World is really like?" In my Master's degree, I found a study that actually demonstrated that people almost stand twice as far away from a facially disfigured person than they ordinarily do. This story just proves their conclusions were entirely correct (Rumsey, Bull, & Gahagan, 1982).

In this vignette I traversed around the world working/volunteering and for recreational pleasure and then I found myself on a bus with a handful of spare seats, no-one talking to me or inviting me to be a part of their friendship circle.

The spokesperson for the bus became the gatekeeper. She had the opportunity to report back to the bus about my self-disclosure, she chose not to understand my story holding onto her feelings of discomfort and anger at the fact that their suspicions were entirely well-founded and need not change. I was discriminated against in two ways. In Kenya I experienced discrimination/assumption of being a rich, cursed white woman. On the bus, I experienced a spokesperson on behalf of the entire bus qualifying herself to be to be the best advocate because of her experience teaching disabled children in a secondary school environment. This discrimination was shown in an act of aggressiveness because they had been uninformed about my FED thus felt a sense of invasion/discomfort due to my non-disclosure. The Wheels on the Bus episode has different facets of hope and survival.

I hoped that by self-disclosing my fellow travellers would change their attitude towards me, sadly they didn't. I remained socially isolated. I sat alone. I had no invitations to parties. Reading and re-reading my vignettes as interpreter/observer (Fung, 2014), I found some rather alarming themes I already subconsciously knew lurked within my experiences but when confronted with, found myself procrastinating from writing. The main themes that appeared were gatekeepers, isolation, discrimination, hope versus survival, and self-defense versus preparedness and invisibility.

Throughout the four vignettes one of the most influential themes was the presence of gatekeepers. Gatekeepers shaped my life teaching me strategies in order to survive. My colleague posed these as self-defense mechanisms, but I prefer preparedness. Gatekeepers are people in life who either open or close doors (Creswell, 2015; Dowling & Brown, 2010). Within my vignettes there are several people from bullies to teachers and professionals who have influenced my life opportunities. All themes interweave and mesh together, there is no clear first, second, and third, or this theme began the domino effect; rather they are inextricably linked. To summarise, I have created Table 1. It is clear to see which themes are prevalent within the vignettes and which have their own set of differences.

Table 1: Vignette Pictorial of Themes – Chronological order

	Zali Zombie (Primary school years)	Mirror, mirror on the wall who is the fairest of them all? (Secondary School Years)	Wheels on the bus (Holidaying/volunteer working)	Ugly duckling (Tertiary School Years)
Gatekeepers	Yes	Yes	Yes	Yes
Discrimination	Yes	Yes	Yes	Yes
Survival	Yes	Yes	Yes	Yes
Isolation	Yes	Yes	Yes	Yes
Bullies	Yes	Yes	Yes	Yes
Hope		Yes	Yes	Yes
Self-defense Preparedness				Yes

Although in all four vignettes I am seen by many, often I get the “blind eye treatment.” Blind eye treatment means people see the person but actively avoid them, thus the slang “turning a blind eye.” I was “made invisible” to several people/groups within each vignette. I realise that I was always made invisible to potential friends in Kenya, Australia, Europe; employers; teachers; parents.

Discussion

I found issues pertaining to those who are ostracised from society. The themes found are not new, neither do I profess that they are unique to people living with FED. What my autoethnography does is raise them within the lived experience of FED. This is what is new, this is what needs addressing. As with other issues for which there is raised awareness and education, I hopefully suggest there needs to be a shift in social perceptions of people living with FED. If this was to occur, I would hope that the long road to social acceptance and inclusion could begin.

Well-known issues such as cancer and burns have well-established foundations of support. Within Australia, there are no *known* support groups or established advocacy groups for people with acquired FD let alone people who live with FED. Australia is lagging behind the UK and Canada in this respect. About Face is a Canadian organisation that supports people with “facial difference.” Changing Faces UK uses the word disfigurement and is in the process of advocating for people with facial, neck, and hand injuries. Changing Faces is person-centred offering counselling and educating the person through to influencing governmental decisions beginning to impact the way that media portray people with FD.

Research has found that people who live with FD are seen to be less attractive, intelligent, dateable, likeable, successful, capable, popular, optimistic, effective, and to have difficulties in obtaining employment and career progression (Bullock, Warwar, Beinenfeld, Marcinişzyn, & Markert, 2001; Mojon-Azzi, Potnik, & Mojon, 2008; Stone & Wright, 2013) and poorer communication skills (Bullock et al., 2001; Olitsky, Sudesh, Graziano, Hamblen, Brooks, & Saha, 1999). This autoethnography supports these findings in various ways. In the vignettes, I definitely had difficulties in obtaining employment and career progression (Mirror, Mirror on the wall). I was less likeable, successful, dateable, attractive, and deemed to be of lesser intelligence in the Wheels on the Bus vignette.

This paper adds to the well-documented and known issues pertaining to people living with FD. Past literature highlighted what “society” thinks of people who have FD (Borwick & Ferrett, 2010; Halioua et al., 2011), that is, the psychological and psychosocial issues (Harris & Carr, 2001a; Harcourt & Rumsey, 2008; Kellett & Gilbert, 2001; Kent & Keohane, 2001; Kleve et al., 2002; Moss & Rosser, 2008; Murray & Rhodes, 2005; Papadopoulos, 2010; Papadopoulos et al., 1999; Stone & Wright, 2012, 2013; VanSwearingen et al., 1996), and some have even suggested ways in which to help (Clarke, 1999; Kent, 2000). This paper delves deeper into the issues and highlights themes that literature has not shed any light on before, within the FED population. I am not generalising here, and neither can I for this paper, this is the experience of one; however, the themes found are not unique to FD. The themes were bullying, isolation, discrimination, gatekeepers, invisibility, self-defense or preparedness, and hope and survival.

The following list is of marginalized groups from prisoners through to people dealing with tongue trauma who often find themselves isolated, discriminated, have gatekeepers make decisions for them without their approval, not to mention feeling invisible. This list is not exhaustive by any means; however, it demonstrates the many marginalized groups within our society at large which rarely receive any recognition:

- Prisoners (Ireland & Qualter, 2008)
- HIV patients (Cline, 1990)
- Cerebral Palsy (Lindsay & McPherson, 2012)
- Neuro-developmental disorders (Jawaid, Riby, Owens, White, Tarar, & Schulz, 2012)
- Autism (Hsiao, Tseng, Huang, & Gau, 2013)
- Physical disabilities and brain injury (Hawthorne, Gruen, & Kaye, 2009; Person, Addiss, Bartholomew, Meijer, Pou, Gonzalvez, & Borne, 2008; Rokach, Lechcier-Kimel, & Safarov, 2006)
- Leprosy (Barrett, 2005; Thilakavathi, Manichkam, & Mehendale, 2012)
- Tongue trauma (Sieminska, 2006)
- Obesity (Puhl, Luedicke, & Depierre, 2013; Robinson, 2006)
- Cancer and arthritis (Adsett, 1963; Bejoy, NanaMohan, Madvan, & Pandey, 2011; Bonanno, Esmaeli, Fingeret, Nelson, & Webber, 2010; Bowers, 2008;

- Dropkin, 1989; Elmir, Jackson, Beale, & Schmied, 2010; Hagedoorn & Molleman, 2006; Pan, Fei, Zhang, Fan, & Fan, 2014; Tighe, Lolassiotis, Morris, & Richardson, 2011; Tong, Jones, Craig, & Singh-Grewal, 2012)
- Burns and skin conditions (Burr & Gradwell, 1996; Konigova, 2010; Lewis-Jones, 2006; Nitescu, Calota, Stancioiu, Marinescu, Fluescu, & Lascar, 2012; Porter, Beuf, Lerner, & Nordlund, 1987; Ravindran, Rempel, & Ogilvie, 2013; Solomon, 1981; Strittmatter & Drepper, 1984)
 - Face neck and hand disfigurements including cleft (Bonanno, et al., 2010; Eliason, 1991; Gamba, Romano, Grosso, Tamburini, Cantu, Molinari, & Ventafridda, 1992; Gupta, Bansal, & Tyagi, 2010; Hearst, 2007; Newell & Marks, 2000; Rafique & Hunt, 2015; Rumsey & Harcourt, 2007; Sarwer, Bartlett, Whitaker, Paige, Pertschuk, & Wadden, 1999).

I started this to take a step back and critically reflect upon my life with regards to FED with the view to begin discussion on the lived experiences of FED. In my autoethnography I have been able to do this. I write in the role of Interpreter and Observer to make sure that I interrogate and bring about the implications in a way that is meaningful and easy to read/comprehend (Fung, 2014).

All the themes that are evident within my vignettes are similar to the experiences of a hoard of “social misfits” already documented and addressed. After living through these experiences, I question what drives me and why am I still as outgoing and as “well adjusted.” Why haven’t I...

- Attempted suicide (Duberstein, Conwell, Conner, Eberly, & Evinger, 2004; Lueck, Kearl, Lam, & Claudius, 2015; Robinson, 2006; Roxborough, Hewitt, Kaldas, Fleet, Caelian, Sherry, & Sherry, 2012)?
 - Did you know even in suicide, women will not disfigure their face? Women suicide through overdose, gassing, slitting wrists ... even when using a firearm will not disfigure their face (Callanan & Davis, 2011).
- Become depressed and anxious (Kaltiala-Heino, Frojd, & Marttunen, 2010; Levinson, Langer, & Rodebaugh, 2013; Undheim, Wallander, & Sund, 2016)?
- Dropped out of school or done poorly academically (Al-Saadoon, Al-Farsi, Rizvi, Al-Sharbati, Al-Jabri, Almamari, Al-Baluki, & Al-Adawi, 2014)?
- Placed myself into social isolation/loneliness (Krieg & Dickie, 2013; Leone, Ray, & Evans, 2013; Rokach et al., 2006; Soler, Forns, Kichner, & Segura, 2015) because it hurts too much to go out and brave the world?
- Developed what is called Demoralisation Syndrome in which everything becomes too much coupled with a sense of helplessness and perception of being a burden (Kissane, Clarke, & Street, 2001)?
- Decided work and or higher education isn’t for me because of the bullying and gatekeeper issues (Cacciaccaro & Bonnie, 2006; Hawthorne, Gruen, & Kaye, 2009; Johnson, 2011; Rodwell, Brunetto, Shacklock, & Farr-Warton, 2014)?

Why is it that I think I have a pretty good self-worth/self-esteem, body image, social life, and that I can cope with stressful situations? All these are issues that can be “damaged” throughout life.

The point of this autoethnography was to raise awareness of the issues pertaining to FED. I do not think for one moment that the issues that I face are unique to myself. My lived experiences are unique to me. I have revealed my themes and now attend to the question: “Why do I think that I am the person who I am today with strong self-esteem?” I have arrived at this conclusion: There are four key foundation blocks that have given me the ability to be who I am today.

These are in no particular order: active intentional decision-making (glass half full, a common phrase for seeing things in a positive light), healthy self-esteem based on personal belief system, forgiveness, and resilience.

These are the foundation blocks on which I have been able to “survive” the deluge of issues I combat throughout my life because of an unfortunate car accident which left my face disfigured. Without these personal foundation blocks, I do not think that I would be in the space whereby I am able to have the privilege of pioneering with this autoethnography into the world of FED, story-telling, and advocating. I have given a pictorial representation of these four foundational blocks in Figure 1.

Figure 1: Foundational Blocks

Forgiveness has shown to be not only good for the short-term but also the long-term well-being of a person (Grant, 2008; Macaskill, 2012; Macaskill, Maltby, & Day, 2002; Maltby, Day, & Barber, 2005). Forgiveness towards self and others has been studied (Macaskill, 2012; Wohl, DeShea, & Wahkinney, 2008) and shown that when there is forgiveness (forgiveness means letting go of the anger and vengeance towards the other person for intentionally or unintentionally hurting you) there is a greater life satisfaction and happiness. Harboursing unforgiveness is seen to be unhealthy (Greenberg, Warwar, & Malcolm, 2010; Zechmeister, Garcia, Romero, & Vas, 2004). There is a strong emphasis for leaders, medical, and allied health practitioners to know and have the skills to ready clients to forgive which lead to a more positive lifestyle of gratitude and life satisfaction (Balkin, Freeman, & Lymann, 2009; Baskin & Enright, 2004; Butler, Dahlin, & Fife, 2002; Hartwig Moorhead, Gill, Barrio Minton, & Myers, 2012; Kelley & Waldron, 2005; Toussaint & Friedman, 2009; Tripp, Bies, & Aquino, 2007).

As the literature suggests, forgiveness is a very good foundational block on which I build. This does not mean that once forgiven I forget, which is a popular aphorism, but in my experience untrue. I do not forgive the perpetrators in order to forget the ordeal/s. I forgive them so that I do not ruminate, want vengeance or retribution because all this makes for seeds of bitterness to grow. I actively choose to forgive, and that happens on many layers as different levels of healing take place. This is a key in the healing process to free myself from the events that have happened to me. It frees me to become who I want to be, after all most of the time the bullies have forgotten about what they have inflicted or at the very least don't care, so why should I hold onto the hurt? This allows the hurt to be healed so that my scars can be my stars. I choose to forgive. For me, forgiveness acts as a release to be able to live life without burden and bitterness. It is an active intentional decision—obviously, I do not forget.

I believe people are intentional with what they want to accomplish.

For example, when I was about 5 or 6 years old, my IQ was tested. There was an expectation that I had been cognitively impaired and the lower my IQ, the more financial compensation I might receive. It was predicted that I would not be able to complete Year 10 at school. In one way, this was correct, I did not complete Year 10 in Australia. Instead, I decided that I would like to be an exchange student in Denmark. I had an idea that I wanted to be Scandinavian. I intentionally sought out an exchange program whereby I had a host family for the entire year. I completed Year 10 in Denmark in Danish. I passed my exams in Danish, English, Mathematics, Science, and Physical Education. These were two of my active and intentional decisions I had made when choosing an exchange program.

I can decide to let the bullies and the gatekeepers found in these vignettes and indeed the quick example I have mentioned to “get me down” (slang for crush and hold you down for another's own benefit or personal gain), “knock the stuffing out of me” (slang for crush you emotionally and physically), or I can decide to forgive, carry on, and continue the hope that I have that people will inevitably treat me better and more “human” than my experience so far.

Studies on resilience have demonstrated that a healthy self-esteem, positive feedback, ability to be self-disciplined, and spiritual belief are linked to increased resilience (Benard, 1995; Brooks, 1994). Benard (1995) suggests that there are three “protective measures” that to help build resilience: caring and supportive relationships, positive and high expectations, and opportunities for meaningful participation. According to Benard (1995) I have a strong sense of autonomy, and it has helped me maintain a positive outlook in life. Rather than looking at what I cannot or what society does not “allow” me to do, I have disciplined myself in order to become the person who I am today. My personal faith and spirituality have been big factors in providing me with the three “protective measures.” When caring and supportive relationships have failed I have had my faith to help me maintain who my God sees me to be as opposed to how others see me. I find that I have positive and high expectations built within my relationship

with my God, and I am involved in meaningful interactions between myself and my relationship with Him and also others.

Through my vignettes, the need for education about FD is clearly evident, as throughout each one, each different group—whether it were teachers, acquaintances, complete strangers who stare, prospective employers, potential friends, and bullies all require education to better include people like me who have a FD. I have found study after study in which the medical and allied health professionals need to be educated (Bonanno et al., 2010; Bowers, 2008; Eliason, 1991; Elmir et al., 2010; Pan et al., 2014; Rumsey & Harcourt, 2007). Constable and Bernstein (1979) found professional reactions of medical staff to people with FD interfere with the rehabilitation process and it concludes that medical staff require education in how to better engage and be aware of their own automatic responses such as fear, rejection, alarm, and withdrawal. In my experience as an educator and counsellor, I have found that education goes a long way in addressing people's preconceptions and behaviours.

I foresaw the need for medical practitioners but clearly didn't see the "elephant in the room," my fellow teachers in my chosen profession. My own experience throughout primary, secondary, and also tertiary education, clearly requires educators to be educated. Teachers' perceptions matter. There is research that shows that if a teacher perceives a child to have a "severe" FD they interpret this as having lesser intelligence. In contrast the more "normal" looking a FD child appeared, teachers over-estimated the child's intelligence (Richman, 1978). From personal experience, it is evident that this has not changed. The need for creating inclusive school communities is vital if children are to have a different experience than I. Frances (2004) confirms that there are probably 1-3 children FD affected within a secondary school environment in which 94% of "regular" teenagers between 11-16 years had appearance concerns. Further 51% specifically cited fear of teasing/bullying about appearance; 31% lacked confidence about appearance affecting academic work and 20% 13-14 years skipped school because of appearance concerns (Lovegrove, 2002). Clearly there is a growing need to educate teachers not only for the few FD children within the school environment but also because it is a widespread phenomenon.

In 2015, I founded a company called Karibu Anawim "Welcome to The Way of Victory" (for further information see www.karibuanawim.com or www.karibuanawim.com.au). Karibu is Swahili for welcome. Anawim is a Latinised Hebraic word. Hebraic words generally have more than one meaning, anawim means either the downtrodden and outcast of society or the victorious so it seemed to me to be an apt choice. I set this up because there is a need for people who live with FD within Australia to access current research, be advocated for, educate the public, counsel, train, gain strategies combatting negative attitudes and stigmas which revolve around FD, and be nurtured. This can be done! Karibu Anawim is the first organisation outside major craniofacial organisations and hospital settings within Australia whereby people can seek and gain understanding/empathy. Through Karibu Anawim, I and others hope to raise the FD/FED profile within the general public. Changing culture begins with awareness, exposure and education in order to challenge ingrained thoughts, beliefs, and attitudes of society.

Conclusion

I set out to examine the lived experiences of FED in order to begin to tell the stories and create awareness about this community in Australia. Overarching themes such as bullying, social isolation, gatekeepers, discrimination, hope, survival, invisibility were brought to light. Upon reflection, I cannot identify a parent, teacher, family friend or anyone in authority who came to my aid. Underpinning these, at least for me, are my own values and tools within my toolkit called my foundation blocks:

- Active intentional decision making (the decision to be positive, persist, press on, prove wrong, educate)
- Hope (people's attitudes can change, or be affected by my reactions to their actions)
- Resilience (based upon my sense of self-autonomy)
- Forgiveness (ability to not harbour resentment which leads to bitterness that outworks in body or mind dysfunction)
- Personal belief system (spiritual awareness and connectedness with someone outside time and space).

My hypothesis was right, as the general public, medical and allied health practitioners (including counsellors as well as the people living with FED) will all benefit from research such as mine. The findings suggest that teachers and the education sector require education. This of course was an unexpected but pleasing addition to my findings. What was revealing was that the literature indicates that my issues are not unique (phew), neither are they something to get over (Hallelujah) nor are they something that I made up because I was the ONLY one who had these issues.

I could have personally laid down, wallowed and hid myself, decreeing "I hate this world because this world hates me!" or I, through the aforementioned underlying values and building blocks within my toolkit, could decide to "pack up my troubles in the old kit bag and smile, smile, smile." I have always been a do-er and now with the advent of Karibu Anawim, I hope to create spaces and educate people in order for the facial eye disfigured children of tomorrow to grow in a world who will see them first as a person, rather than first seeing their disfigurement.

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