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Mainstreaming disability in education beyond 2015

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This article presents an exemplary case study of an Independent Business Owner (IBO) from multiple case studies on narratives of differently abled persons. The aim of this article is to illustrate mainstreaming disability through an exemplary case of the IBO. The article is informed by the imperatives of critical theory to understand mainstreaming disability. I examine mainstreaming disability in reference to inclusive education and sustainable development via hephapreneurship (later described in the text). The purposively selected sample of the study was (n=18) participants. The argument forwarded suggests hephapreneurship as one way of mainstreaming disability. Data were collected through interviews, observations and informal conversations. Results indicate the need to unlock entrepreneurial capacities of persons with disabilities such that they may contribute to sustainable development. The study concludes by showing that the participation of independent business owners in sustainable development activities could serve as an anchor for mainstreaming disability beyond 2015.

Keywords: actors in development; differently abled persons (DAPs); hephapreneurs; mainstreaming disability

Introduction

Clarion calls have reverberated through various discourses for inclusive education and participation of persons with disabilities in sustainable development. To this end, the term hephapreneurship is proposed, devised as a new concept that indicates change in the co-constructed perceptions about people with disabilities.

Premised on the fact that DAPs are generally not included in education, employment or training (NEET), subsistence entrepreneurship under the auspices of hephapreneurship attempts to mainstream them into the global market on an equal footing as every other entrepreneur (Higginbotham & Hughes, 2006). The phrase DAPs, indicates that people with disabilities have their own abilities and capabilities, and that they are able, only in different (non-normative) ways (Joshi, 2004). This term is used in place of disability here, which is deemed to carry more negative connotations. This argument espouses disability defined as a physical or mental condition that limits a person's movements, senses, or activities, curtailing participation in meaningful living. The thrust of subsistence entrepreneurship is a means of providing subsistence income in order to sustain the livelihoods and well-being of DAPs.

The definition of hephapreneurship forwarded here, is characterised by *transformative social justice*. Social justice is generally conceived as 'giving everyone their due'. The main aim of education when it comes to differently abled persons is the continuous struggle for social justice education that mainstreams disability (Francis & Le Roux, 2011). Education as a lifelong process emerges as a cornerstone in the mainstreaming of disability via other forms of education, such as entrepreneurship education, perceived as a precursor to hephapreneurship (Isaacs, Visser, Friedrich & Brijlal, 2007). Social justice is taken here as the mainstreaming of disability in all areas of human life. Social justice therefore may not be generally fair in relation to DAPs, because they are NEET (Higginbotham & Hughes, 2006:2).

The Aim and Context of the Study

The aim of this article is to present an exemplary case study extracted from the multiple case studies in a PhD study conducted by the author that would encourage participation in self-employment by DAPs. The study addressed the question of how understanding narratives of differently abled persons can inform career guidance policy. The context of the study was Lesotho, where the inquiry was conducted in the districts of Berea and Maseru, among institutions interested in disability, institutions of higher learning, relevant ministries as well as organisations of people with disabilities. Disability was not defined, but only classified into four categories of physical, auditory, intellectual and visual, as used in Lesotho at the time of research. According to Leshota (2013:2), "...the draft National Disability and Rehabilitation Policy of 2008 was made policy in 2011". This article addresses the global call to mainstream disability (Miller & Albert, 2005) as driven by the agenda for raising awareness for disability (Wunsch, 2010).

Mainstreaming Disability through Hephapreneurship

Mainstreaming disability in the development agenda renders itself to filling gaps in capacity building as one of the priority areas in addressing the situation of persons with disabilities (United Nations (UN), 2012). The call to mainstream disability was made by the disabled people from 20 countries at an international conference in London in November 2003 (Miller & Albert, 2005). The millennium development goals completely ignored the disability plight for inclusion, and none of the goals addressed disability directly. The United Nations Report of the Secretary-General is the driving force behind action towards a disability-inclusive post-2015 development framework (UN, 2012). Nonetheless, mainstreaming all aspects of disability may prove to be an insurmountable

task. It therefore may be prudent to focus on manageable areas of development, while working towards a holistic, all-inclusive approach. Consequently, particular attention is paid to economic inclusion through hephapreneurship. Mainstreaming receives initial attention.

Mainstreaming is defined as the predecessor of inclusion (Graham & Slee, 2008). However, inclusion is regarded as implying a strategy used by others in view of including DAPs. This formulation conveys a sense of dependence on others, and therefore, an imbalance of power relations between “margin and centre” (Graham & Slee, 2008:279). Generally DAPs are marginalised in most societies. Being included seems to suggest that those who are included were not previously part of that into which they are now included, yet it is necessary to acknowledge that DAPs are a *de facto* part of society. Mainstreaming, on the other hand, implies an act by DAPs to enter voluntarily, and purposefully the centre stage of life, make themselves heard, seen and understood. Mainstreaming in this regard seems to suggest highlighting, expanding, enhancing and emphasising that DAPs are a legitimate part of human society, and require to be equally recognised as such. Mainstreaming implies a more deliberate act by DAPs in positively contributing to the development agenda, as active participants. Based on the philosophy of existentialism, mainstreaming encourages authentic living of DAPs (Schnell, 2010). As described by Hendriks (2009:5), “mainstreaming/inclusion [is] the process of integrating formerly segregated and/or stigmatised issues and people into ‘mainstream’ society and development programmes – and out of the welfare department.”

Disability is not, however, mainstreamed. In this study, mainstreaming abilities, competencies, gifts and any strong points are emphasised, despite the fact that disabilities may be conspicuously inherent to a DAPs’ life. In the spirit of promoting the good in a person, it may be necessary to promote that which advances the goodness in a person, instead of that which denies DAPs equal participation in all spheres of life. Lifelong career guidance can be instrumental in this regard (Pillay, 2012). Nonetheless, until disability has been replaced with a concept with greater efficacy, it suffices to mainstream it in so far as it is mainly used in ordinary discourse, perhaps for it to be better understood and acknowledged. The majority of people need to be orientated regarding disabilities in order for mainstreaming to become meaningful (Stone, 1994).

The various policy and development documents in the field make only fleeting mention of disability as a development issue worthy of mainstreaming in their discourse, rendering DAPs mainly invisible within mainstream programmes

(Kett, Lang & Trani, 2009). Even the millennium development goals failed to acknowledge and mention disability directly. This gap was glaring, and it led to the dawning of a new convention whose central theme became mainstreaming disability (Kett et al., 2009). Issues around mainstreaming might not be new *per se*; however, what emerges as a fresh approach is the creation of space for DAPs to take a legitimate existential space at the centre of development activities. A new paradigm is emerging, namely that of mainstreaming disability onto the global development agenda. Notably, research is extremely scarce on the lives of DAPs in relation to career choice and disability employment (Kett et al., 2009).

Through hephapreneurship, Sefotho (2013) attempts to foster positive and meaningful existence for DAPs, and any other underprivileged persons, aiming at transformative social justice and change. Putting disability at the centre of development would seem the right approach towards mainstreaming, provided that this process is also driven by the needs of DAPs. The aim of this would be to promote full and meaningful participation of DAPs in all spheres of life. Hephapreneurship encourages the acceptance and understanding of DAPs. It is held that through fully co-existing with them, society stands a better chance of facilitating meaningful existences for all. It is hoped that transformative social justice would bring about change so as to mainstream disability in meaningful ways. Notwithstanding, the urgency of participation in employment is crucial, especially through self-employment and promotion of entrepreneurial careers (Wilson, Kickul & Marlino, 2007).

Premised on the ethos of self-reliance, independence and self employment, hephapreneurship is underpinned by principles of entrepreneurship in general, and disability entrepreneurship in particular. Hephapreneurship emphasises abilities over disabilities, and the entrepreneurial propensity of DAPs to mainstream themselves (Langowitz & Minniti, 2007). Hephapreneurship seeks to unlock the entrepreneurial capacities of DAPs for mainstreaming towards sustainable development.

Conceptual Explanation

This section explains the central concept of the study, which may be unfamiliar to the reader. The concept hephapreneurship is a neologism coined in my doctoral (PhD) thesis.

Hephapreneurship

Hephapreneurship is a neology introduced to fill the gap - there are no models regarding DAPs that represent abilities, work, participation in education and contribution to development. Greek mythology

includes the story of Hephaestus, a Greek god with a physical disability (Dolmage, 2006), who is espoused to symbolise craftsmanship, invention and technology (Bazopoulou-Kyrkanidou, 1997). This depiction of Hephaestus was coopted as representative of entrepreneurship, and resonating with possibilities for artisanal education and self-employment of DAPs. As it was used in the thesis, hephapreneurship is described as, “a process of fostering positive and meaningful existence anchored on subsistence entrepreneurship of differently abled persons and underprivileged persons, which is founded on the ethos of career choice/construction, towards transformative social justice and change” (Sefotho, 2014:306).

Methods

This article is based on a qualitative research methodology, which was guided by an emancipatory paradigm with a socio-political concern for mainstreaming the experiences of DAPs (Barnes, 2003). The sample was purposively chosen (Babbie, 2008), and the study utilised face to face interviews conducted over a period of three months from June to August of 2009. The sampling bias (Leedy & Ormrod, 2005) through a focus on “fitness of purpose” (Cohen, Manion & Morrison, 2007:262) was taken into account, where however, because of the uniqueness of the participants to provide required information, it was found to be the most suitable.

Research Design

This study used multiple case studies (Thomas, 2011). The interview proved to be the central method, underpinned by the concept of reflexivity as a method of social science research (Pillow, 2003), which is considered a process of ensuring qualitative validity (McCabe & Holmes, 2009). I was aided by cognitively and philosophically guided methods and attitudes in my reflection (Van Manen, 1990). Here reflexivity is only reviewed as it relates to relevant experiences of in-depth thinking about mainstreaming disability. The researcher “engage[d] in explicit self-aware meta-analysis” in co-creating the story of the IBO (Finlay, 2002:209), considering four generally used strategies of enquiry, namely: reflexivity as recognition of self; reflexivity as recognition of other; reflexivity as truth; and reflexivity as transcendence (Pillow, 2003). Since the study followed a multiple case study design, it allowed me significant opportunities of reflection on the case of the IBO in particular as an exemplary case.

The ability to relate strongly to so many of the experiences of the IBO informed the research directly. The majority of her experiences of poverty, hunger, stress, frustration and resilience in the face of adversity were very close to my own (Ebersöhn, 2010). Due to a close intersubjectivity

with many DAPs, the research was conducted with self-awareness and “empathic sensitivity” (Warin, 2011:810).

Seeing oneself in “the other” paradoxically becomes recognition of “the other” in a “self-Other” connectivity (Warin, 2011:811). This is the form of reflection that allowed a better understanding of the IBO (Pillow, 2003). On one level, research can be equated with translating “the other” so as to understand them better. However, as a deeply subjective technique, reflection can lull the researcher into being subsumed by the research process (McCabe & Holmes, 2009). It is therefore prudent to always be alert, not to be consumed by the reflexive moments. If there is such a thing as meta-reflection, one ought to also consider reflecting on one’s reflection as a measure of self-check.

The technique described in what follows concerns reflexivity as truth. In my reflection, I always have to be wary of whether it is my own truth, or the co-constructed truth that comes to the fore.

Reflexivity as truth is directly challenged by a post-modern worldview. Where truth is subjective, and what the researcher may consider as true may not be shared by the IBO, thus situating the debate in “a double hermeneutic” (Warin, 2011:811). Wary of the danger of self-indulgence, pains were taken to engage in on-going reflexivity and prolonged self-examination (Bishop & Shepherd, 2011). This process necessitates careful consideration of the truth as it is perceived on both sides of the interview, where it remains important for the researcher to acknowledge the truth as it is construed by “the other” and not to impose the researcher’s truth. Here, ethical reflexivity becomes crucial as a yardstick for the researcher’s ethical and political beliefs (Gewirtz & Cribb, 2006); it was always necessary to recede and let the IBO’s truth find voice.

Reflexivity as transcendence allows “the other” to occupy the centre stage, so that social justice is done in giving witness. The voice of the IBO and those of other participants were prioritised (Bishop & Shepherd, 2011). Beyond simply writing about their stories, whenever an opportunity arose, each one of the participants was invited to mainstream their own narrative on and in their own terms.

Participants

The multiple cases (n=18) sample of participants were purposively selected, with (n=6) persons representing types of disabilities in Lesotho and additional (n=12) representatives of education institutions (n=3), associations of disability (n=3), a rehabilitation centre (n=1), the corporate world (n=1) and government ministries (n=4). All participants were selected because they were

deemed suitable to provide valuable information in this inquiry.

Data were collected through semi-structured interviews and narrative interviewing. I utilised a set of semi-structured questions to guide the narrative interviews, which I audio and video-recorded. I also used field notes to record observations made during field work. The data analysis commenced with general inductive analysis as an overarching analytic approach (Thomas, 2011), which was then fused to aspects of analytical strategies from Thomas, Yin and Carney. The following aspects were specially selected: Thomas' (2006) general inductive analysis, Yin's (2009) cross-case analysis and Carney's (in Miles & Huberman, 1994) construction of explanatory framework for formation of themes. I then used word clouds to enhance the process of analysis (Thomas, 2011), allowing for cross-case synthesis in order to "identify common issues in each case and interconnecting themes between them" (Simons, 2009:164). I used selective coding (Flick, 2009) and key-words-in-context (KWIC) (Ryan & Bernard, 2003); and through this, two main themes emerged. Here, two categories of the themes are presented, namely: life choices and empowerment of DAPs.

Ethical Considerations

Prior to data collection, formal application was made to the department of educational psychology's ethics committee. Ethical approval to conduct the study was gained and consent forms duly signed by all parties concerned in Lesotho at the site of data collection. Particular attention towards participants in order "to preserve their psychological well-being and dignity" (Willig, 2013:19). Prior to engagement in the study, in-depth discussions with the participants were conducted, explaining ethical implications of the study, as well as its benefits for them (Flick, 2009). Since no apparent or remote harm was evident, all participants signed the consent forms and data collection commenced therewith.

Results

The presentation of the results is preceded by the case of an independent business owner. This is an intrinsic case study that was carefully selected from the multiple case studies, and makes no attempt to generalise (Thomas, 2011), although it has far-reaching implications (Silverman, 2010). For purposes of entrepreneurship, I found the case of an independent business owner to be exemplary, significant and revelatory (Yin, 2009).

The case of the IBO, as presented below, epitomises unlocking of entrepreneurial capacities. The IBO is self-reliant, independent, self-employed and also employs other women as a measure of contributing towards sustainable development,

signifying "...ongoing economic growth and enhanced well-being" (Trudell, 2009:74). Indeed, the subject presents herself by mainstreaming her experience, where she depicts herself as the only narrator of such meaningful existence.

The Case of an Independent Business Owner

The IBO featured in this study grew up in the rural areas of Lesotho. This was before the advent and advancement of technology, especially in remote areas of 'least-developed' countries like Lesotho. Like most children with disabilities, she was not exposed to school early enough. She was concealed from the public eye. For the most part, she was alone with her mother, and the father was working in the mines in South Africa, only coming home occasionally after extended periods of time away. This meant that the predicament of her disability was largely a circumstance for her and her mother to deal with.

It was not long after this that the father was retrenched from the mines in South Africa. He returned to his home village to eke out a living, where a sound livelihood that provides one with the means to meet basic needs is extremely difficult. The IBO was two years of age when her father returned. The mother was not working either, as most women would wait whilst rearing their children for their husbands to return with remittances from the mines in South Africa. It was at this time that the mother decided to save her family by selling food around the village. She also started selling boiled sheep heads, popularly known as a "smiley" among the youth. This type of meat is a treat for people who scarcely have any meat on their plate. It is also famous among those who pass their days drinking liquor. For some reason, smiley is best enjoyed with the local beer; so many people would buy it, especially in winter. The smiley business is seasonal, as the cold winters of Lesotho help preserve the meat. In order to assist his wife, the IBO's father also started working as a builder of local houses in the surrounding communities. However, with increasing retrenchment in the South African mines at the time, not many locals, who had likewise been working on the mines, could afford to build houses as had been able to before, so the market for this kind of work was becoming more infrequent.

Even though initially the IBO was hidden from the public, she had to find a place to go when her mother went out selling her wares, so that the family could survive. The only place for her to go was a nearby school. She started late, but was encouraged by the principal of the school, who saw potential in her. She finished primary school with the assistance of the principal. While in school, the IBO started making and selling sweets, dressing the hair of other girls for a small fee, and doing other menial chores that would earn her some money. As

part of her savings from this, she was saving some money to pay for her education after primary school. She joined a vocational training school and tried her hand at several trades, eventually specialising in sewing.

At the time of the interview, the IBO welcomed me to conduct the interview in her rented business location. The business was strategically located, and she had many people coming by for one thing or another, particularly for items she was sewing for them. The IBO declares her love for self-employment. She recalled seeing her mother with those “smiley” carried on her head, her father with a leather bag containing tools, both going out to work and coming back home to continue a life that was fulfilling for them. She admits that a seed was then sown, and she duly followed in her parents’ entrepreneurial footsteps.

The IBO prides herself in being self-employed and in employing other women. She warns however, that in order for her to be counted amongst business owners, and to be mainstreamed, she has to work hard. While admitting that it is sometimes difficult because of her failing health, she relies on her employees to run the business. The IBO acknowledges that many DAPs are from poor backgrounds, without education, and therefore not employable. She therefore strongly encouraged other DAPs to work for themselves and own their own businesses, as, critically, she regards them as capable. The results below ought to be read in light of the case of the IBO presented. The two key issues presented below, though not isolated from the results of the larger research, are closely representative of the story of the IBO.

Training in Entrepreneurship Skills

It emerged from the study that the need to identify talents of differently abled children should be the first step towards training in entrepreneurship skills later in life. One representative of an association of DAPs expressed the need in the following words: “we want first to have a centre in which we will train youth and parents in entrepreneurial skills, together with income generating skills.” The need for training occupied centre stage, as evident in the report by a representative of one vocational training institute, that: “we are taking [sic] them [differently abled trainees] to courses [mostly] related to bookkeeping.” Most differently-abled participants generally expressed the need for: “training in business development”. A representative from an association of DAPs supported training in entrepreneurial skills, pointing out the need to: “train them [differently abled trainees] to identify projects they can do”. There was also an interesting observation from most participants that: “training offered in vocational schools is limited to manual work.” Related to training in entrepreneurial skills, a representative of the corporate sector provided

the following encouragement: “vocational training will enable them after their training to be self-reliant”.

Training for Empowering Entrepreneurial Careers

Differently abled participants had similar needs with regard to training for empowering entrepreneurial careers as an alternative to formal employment, which is mostly unattainable for many. These participants emphasised training in entrepreneurship skills as a tool for empowering entrepreneurship careers. As one of the Ministry representatives exhorted: “empower these children with career guidance!” A representative from the Ministry of Finance elaborated on this through the following anecdote:

We need to empower them, let them go into the world, let them think. One of the biggest problems is that they had never got [sic] the idea that they are also participants, they have already developed the mentality that they are dependants; so I think until we get to the level of empowering them, letting them know they are part of the world, making [sic] them be independent, then they can do a lot.

Another representative of an institution of higher learning endorsed entrepreneurship by declaring: “I can [confirm that] people who are differently abled can [indeed] enter into entrepreneurship and they can run their own businesses, even though our policies do not [currently] cater for them.” In the same vein, a differently abled participant acknowledged:

I like the idea of entrepreneurship. I overcame my fear about careers and work. I had to go out to work, but I wished I was trained in something from the word go [sic], because I could think of something I could do even where I was, but I had no training [to support my entrepreneurial ideas].

Discussion

This discussion section commences by providing definitions and examples of both hephapreneurial careers and hephapreneurial skills. Hephapreneurial careers are pro-disability careers characterised by flexibility and boundarylessness and are constructed to suit lifelong learning and work needs of differently abled and any other marginalised persons. These careers are constructed on the bases of abilities of differently abled persons regardless of their disabilities. Hephapreneurial careers mainstream the abilities of DAPs. For example a career as a radio announcer who cannot stand or walk, can empower a DAP to, through broadcasting, reach out, as well as serve to motivate the broader public. Motivational speaking, as a protean hephapreneurial career can change its form according to context and need: for example, career coaching, life coaching or even business training. Hephapreneurial skills are career management skills, which can be categorised as the hard skills needed to perform any kind of job,

without jeopardising the life of differently abled workers. Soft hephapreneurial skills include social adaptability, communication, interpersonal skills, positive attitude building, a stable work ethic, and ability for lifelong learning. Given the discrimination and stigma that surround differently abled persons, especially in the world of work, social adaptability becomes crucial if mainstreaming is to be truly the aim of all development programmes beyond 2015.

Given the scarcity of employment opportunities for DAPs, training in hephapreneurial skills supports the enhancement of chances for active participation in development. Hephapreneurial skills imply a mix of functional skills tailor made towards self-sustainability. While acknowledging the need for their own training, DAPs also indicate the necessity to train those who help them, especially their parents. This finding supports that of the broader literature on training parents of differently abled children. While this inclusion of parents in training might seem to undermine individual independence, it equally serves as reinforcement of support networks. If disability is to be mainstreamed, DAPs need not face the task of mainstreaming alone, but ought to do so together with those who form the fibre of their support systems.

Training in hephapreneurial skills implies a repertoire of variable skills according to individual needs. However, results in this study emphasise more generic skills such as income-generation, business development, running their own business and book keeping. These are, traditionally, skills reviewed in literature, which seem to address training needs on a larger scale. Nonetheless, it remains clear that there are likely additional skills required to venture into the complex world of entrepreneurship. Development economics and entrepreneurship training currently discusses these while omitting specific training needs for DAPs. Therefore, the results suggest more comprehensive training packages are required, tailor-made to cater to the needs of differently abled entrepreneurs. It is equally important to note that more informal forms of entrepreneurship might equally play a crucial role in setting beginner entrepreneurs on the road to the acquisition of the requisite combination of skills. Training in hephapreneurial skills implies that hephapreneurs must be lifelong learners; an area widely discussed in career guidance literature. In this way, they are likely to acquire the necessary repertoire of skills.

Although results indicate a slew of vocational training systems emphasising manual skills, it can be inferred that DAPs need not be confined only to manual or 'basic' labour. Since the world of work is changing so rapidly, it is evident that skills that

are required to carry out work in the 21st century are changing accordingly. Literature on skills development emphasises the need to acquire new skills central to employability. Equally, development discourses seem to strongly promote hephapreneurship among DAPs. The results of this study point towards a much more active promotion of hephapreneurship. If DAPs participate in hephapreneurship, for example, they will be obliged to develop 'people skills', perhaps 'green skills' and technological skills, to align themselves with current shifts and tendencies in the world of work and self-employment. Thus, participation in productive activities would mainstream disability.

Training for empowering hephapreneurial careers emerges as paving the way towards mainstreaming disability. Entrepreneurial careers could be used as a platform for the inclusion of differently abled hephapreneurs into the mainstream of development. The endorsement to empower DAPs enables them to feel unrestricted in participating meaningfully in development, as reflected in the case of the IBO cited here. The conceptual formulation of hephapreneurship extends the current theoretical base in disability entrepreneurship in particular, and entrepreneurship in general. The findings of the study further point towards the possibilities of mainstreaming disability through finding viable alternative ways of employment for DAPs.

Conclusion

Drawing from the case of the IBO, it was established throughout this article that there is a need to mainstream disability in education beyond 2015 through participation in sustainable development activities such as hephapreneurship. In order to mainstream disability, the need for training in hephapreneurial skills was established, as well as the need to empower hephapreneurial careers. The major strength of mainstreaming lies in the central placement of disability in education in the broader framework of global development. This article contributes to developing an alternative in mainstreaming disability through practical action that is based on the experiences of DAPs. This may form the basis of a comprehensive disability policy approach, while focusing on inclusive education/employment of DAPs and support in self-employment.

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