THE DISABLED IN THE CARIBBEAN

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Introduction

The literature has shown that in any given country, approximately 5% to 15% of the population is estimated to be living with a disability. According to Fremstad (2009), “disability is a complex and evolving concept.” To this end, definitions of disability may vary according to the policy or purpose for which it is being defined, or based on culture. Definitions of disability have evolved from looking at it solely in individual and medical terms as a problem intrinsic to the person with the disability to one where disability is seen “in dynamic social terms as a process that involves the interaction between people with health conditions and the environments in which they live and work.” In contemporary times the most broadly accepted framework for understanding disability is the International Classification of Functioning, Disability and Health (ICF).1

What then is it like to be disabled in the Caribbean? What is the lived experience of persons with disability? Is it different from persons living in the developed countries? Are there any similarities among the countries in the Caribbean region? How and by whom is disability defined in the Caribbean? This paper seeks to get an understanding of disability in the Caribbean using quantitative and qualitative data collected from interviews conducted with 1 student from each of the 3 campuses of the University of the West Indies located in Jamaica, Barbados and Trinidad and Tobago. Emphasis has been placed on experiences related to education, family support and social issues. It does not pretend to be representative of the disabled community but it is the belief that due to some of the consistencies identified it certainly can act as a catalyst for the start of a discourse on a Caribbean culture of disability.

Disability, Research and Public Policy in Caribbean

The literature on disability has revealed that there is a paucity of information about disability in developing countries. In the case of the Caribbean, little has been written although there is some change recently, but because of this it has been difficult to draw any conclusions on overall trends in disability in the region. The true extent of disability within the countries of the Caribbean is not known. The Population and

1According to the International Classification of Functioning, Disability and Health (ICF) manual (WHO 2001), disability begins as a health condition that creates impairments. The impairments result in restrictions and limitations on activity and participation within contextual factors. Contextual factors refer to environmental circumstances, such as social attitudes, legal systems, and physical barriers and personal circumstances, such as social background, gender and age.
Housing Census of 2000 indicated that there were 45,496 persons with disabilities living in Trinidad and Tobago. In the case of Jamaica, the 2001 census has shown that there were 162,859 persons with disabilities and in the case of Barbados, the Barbados Population and Housing Census of 2000 indicated that there were approximately 13,142 persons with disabilities.

Not only does this situation have serious consequences for the planning of appropriate programmes, political action, advocacy and improvements of services but for the general status of the disabled in these societies. Within the last decade though there have been concrete efforts by Caribbean governments to deal with the issue of disability within the region. In 2004, the CARICOM member states attended a regional Ministerial Conference on Disability issues with the understanding that there was a need to develop a coordinated approach to disability in the Caribbean region but also to ensure that disability issues became a permanent part of the CARICOM agenda. Due to the lack of information, in order to prepare for this conference it was proposed that a situational analysis had to be prepared on disability issues in the region reflecting country specific data.

In 2007, the governments of the three countries became signatories to the United Nations Convention on the Rights of Persons with Disabilities (2006)\(^2\) with Jamaica being the only one to ratify the convention thus far. This document speaks to the principles of:

- Respect for independence, dignity and individual autonomy of disabled persons
- Non-discrimination
- Equal participation and inclusion
- Respect for and acceptance of persons with disabilities as part of human diversity and humanity
- Access to equal opportunity
- Accessibility
- Equality between the sexes
- Respect for the development and identities of children with disabilities

What is notable is that the treaty assists the international community in pressuring governments to improve their policies regarding the disabled.

Though there may be noticeable ways in which the policies and programmes for persons with disabilities differ in each country there is agreement that historically, little attention has been paid to the disabled in terms of consistent and effective programme development as well as to a comprehensive legislative framework which incorporates their rights in all three countries. To date, the government of Trinidad and Tobago has enacted a national policy on persons with disabilities in 2005. However, there are no laws

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specifically protecting the disabled from discrimination (Schmid et al. 2008). Similarly in Barbados there are no laws except constitutional provisions asserting equality for all. The government has established a National Advisory Committee on the Rights of Persons with Disabilities with the mandate to coordinate government efforts to fully integrate persons with disabilities into society (ibid.). In Jamaica the National Disability Policy was enacted in 1999 which provides guidelines for cooperation between government and civil society in addressing the equalization of opportunities for persons with disabilities. At present work is being conducted on a National Disability Act (ibid.).

Despite these actions, the reality for persons with disability within the Caribbean region as it is worldwide is that stigmas and physical barriers to the inclusion of persons with disabilities are omnipresent. According to the IADB (2007):

Social exclusion in the Caribbean and Latin America affects predominately indigenous peoples, Afro-descendants, women, persons with disability, and those living with the stigma of HIV/AIDS, affecting their opportunity to access formal employment, credit, decent housing, adequate health care, quality education, safe and secure living conditions as well as their treatment by the legal and criminal justice systems.

According to the literature, the majority of people with disabilities find that their situation affects their chances of going to school, working for a living, enjoying family life, and participating as equals in social life. But one may beg the question of whether this is so within the Caribbean region?

Methodology

This paper examines the experiences of education, family and social life of three individuals who are differentiated by gender, age, country of birth, occupation and marital status. What they have in common though is that they all have been or are students of the University of the West Indies and they have experienced some form of disability. A brief biography of each of them follows.³

Karen John — Lives in Barbados. She grew up in an extended family household. She is a single, 35 year old female who became blind at the age of 5 years. She is a graduate of the UWI and is presently fully employed in a Non-Governmental Organization. She considers herself an advocate for persons with disabilities.

Linda Gale — Lives in Jamaica. She is a single mother (of 2 girls) who acquired a physical disability five years ago. She has a physical disability but is uncertain of the diagnosis of her condition since health care providers both locally and abroad have given her different diagnoses. She uses a wheelchair. She is a full time student of the UWI.

Kwesi Brown — Lives in Trinidad. He is a single young man, age 23 years, who lives with his mother and three siblings. He has Spina Bifida and uses a crutch. He is a final year student of the UWI.

³The names of these persons have been changed to protect their identity. Any similarity with other persons so named is purely coincidental.
Education

The literature has shown that persons with disabilities are less likely to attend school than their non-disabled counterparts. The educational opportunities for the disabled has evolved markedly over the last thirty or forty years within the region. It has moved from a period of “stay at home,” through special education to mainstreaming and most recently to inclusive education. Traditionally, special education has been dominated by the medical model of disability, primarily casting disability as a deficit inherent within an individual; a “problem” in need of scientific “examination,” “diagnosis,” and “treatment” (Berninger, Dunn, Lin, and Shimada 2004).

Inclusive educational practices are being endorsed internationally. This is evident in the wide attention and movement toward a more inclusive education system in almost every country in the region, inclusive of Jamaica, Barbados and Trinidad and Tobago.

Inclusive education, means more than simply placing a disabled young person in a mainstream school and providing extra support. Inclusion demands major changes within society itself and should not be viewed in a vacuum.

According to the Task Force report on the National Disability Policy (1997) of Barbados, “the emphasis in the pre 1970’s period was on the provision of basic education for specific categories of children with disabilities.” By the 1980s there was the acknowledgement and efforts to ensure access to education at all educational levels in an integrated setting wherever possible. In Trinidad and Tobago, the focus of special education had initially been on the one thousand or so children with physical and/or sensory impairments and children exhibiting behaviour problems who were placed in the country’s ten special schools. By the 1980s, there was the establishment of a Special Education Unit within the Ministry of Education to coordinate the delivery of special education and related services in the country. At this time there was the initiation to mainstream disabled students and this was dependent to a large extent on the benevolence of school principals.

According to a feature news article in The Jamaica Observer dated Sunday 12 December 2004, “the greatest strides in empowering persons with disabilities in Jamaica appear to have been made in education.” The history of the disability movement in Jamaica has shown that this situation was not only due to governmental efforts but on the relentless efforts of disabled persons themselves as they organized and advocated for their basic human rights beginning as early as the 1980s.

The contemporary view on Special Education is one of Inclusion. That is, persons with special educational needs must be given the opportunity to participate fully in all of the educational, employment, consumer, recreational, community and domestic activities that typify everyday society. The three interviewees have been a part of the inclusive education drive which has its genesis in the UNESCO sponsored “Education For All” initiative which states that all children, including those with disabilities and other special needs, are entitled to equity of educational opportunity.

According to Porter (2001) the provision of education is challenging for the countries of the region. Challenges of establishing and maintaining a quality inclusive educational system not only requires well trained and motivated teachers and administrators but also the large infusion of money to keep the system up-to-date and relevant with rapidly changing societies and economies. The fact that educational reform and restructuring is on the public agenda but funding and progress are limited may point to the reality that education systems have remained reactive rather than proactive.

The issue of universal design which may be influenced by finance and attitudes was a fundamental issue for all three individuals. According to Ron Mace, “Universal design is the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design.” As the experiences of the interviewees will show in the main this was not the case at the mainstream institutional facilities.

Linda’s disability was acquired as an adult while she was already pursuing tertiary level education. According to her, becoming disabled while within the education system in Jamaica has not been very easy. While she did not face any real challenges in the early educational years, she has faced many challenges after she had acquired her disability. She related that: “Now that I have become disabled... the challenges I have, make me more aware of the challenges people face on a daily basis.”

In addition to trying to cope with the struggle of acquiring a confirmed diagnosis of her condition, she has to battle on a daily basis with the pathological issues surrounding her condition (having to be in and out of the hospital for treatment). To date she has had to take two leaves of absence from her studies and hence is taking a longer time to complete her programme. This delay has nothing to do with her intellectual capacity but rather with her health issues. She faces issues of mobility and states: “I have to use a wheelchair .... and depend on others to assist me get around because the campus is not so much accessible...”

Although there is a Centre which catered to the needs of students with disabilities on campus, she was unaware of it and was only recently informed by someone who shared her concerns for her education. Linda’s survival depends on the interventions made and assistance given by the Centre and the support of friends. Special arrangements to cater to her specific needs have been negotiated by the Centre with Lecturers and Department offices which assist by making adjustments without which “I could not manage” and which therefore makes her life at UWI much easier.

On the other hand, Karen acquired her disability at age 5 just as she was going to enter primary school. For her, school days at the School for the Blind were good days. According to her, entrance to secondary school was “with fanfare.” It was the first time that a totally blind child was entering secondary school. It was a national story. Even if there was the temptation to see this as a token affair, Karen went on to successfully complete secondary school and pursue the first of her certifications at tertiary level at the University of the West Indies. For

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her the university was accommodating. She operated under a system she terms “ask and have.” To this end the operations of the university at that time were reactive rather than proactive. However, the system though presenting a number of challenges worked for her and she successfully graduated from the university within the required time.

Kwesi’s experience has been different from the others since he came through the system attending a special school from preschool to primary school. These years he described as protected where he did not have to adapt to his surroundings; in fact the environment was designed to a great extent to be used by all. When he graduated to secondary school, the integration of students with disabilities into mainstream schools was more common. He describes this transition as:

...greatly different...at Princes Elizabeth, the environment was kinda conducive to you, you did not have to adapt to it. In Tranquil’ you had to adapt to the environment, teaching pace, the children....

Accommodations were made for Kwesi’s stay at school inclusive of keeping his classes on the ground floor during his five years at the school. The teachers appeared to have knowledge of working with persons with disabilities but for Kwesi, it seemed that

...for some reason like everybody, when they dealing with people with disabilities, they tend to feel they need to walk on egg shells, so they need to be on their best behaviour, mind what they say, won’t treat you like the rest of the class, won’t talk too loud...

However despite the good times, accommodations, the ability to make decisions about subjects for study and the success, he felt that: “...still I was not treated totally normal.” He goes on further to say that: “sometimes you use to feel like you never really fit in per se, it may be paranoia but you always feel some have a slight thing towards you – a negative attitude or something.” Kwesi found that his transition to the tertiary level of education was easier. He never had problems interacting with his peers and had made friends. However it was within this system that Kwesi believes that his disability did play a role in the type of experiences he had. To him it was now a matter of adapting to his surroundings and access was often achieved through accommodations. For example, he now had to move from class to class and because he was registered in 2 different Faculties he had a lot of walking to do across the campus. This affected his health and he had to miss classes for a while. He however depended on orthopaedics to correct his problem. This has delayed his completion time at the university. He pointed out though that he did not have it “as bad as” some students he knew. He would encourage other students with disabilities to attend the UWI but he advises “you must be willing to work hard to achieve what you want to achieve.”

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6 Princess Elizabeth School for the Physically Handicapped, Trinidad and Tobago, is a facility for special education.

7 Tranquility Secondary School, Port of Spain Trinidad, is a mainstream secondary school.
Family Support

To what extent does family support affect the quality of life that a person with disabilities would experience? There is much diversity and complexity in Caribbean families because of their multiple races, traditions, and structures. Do these families deal with the issue of disability any different from families for example in the USA or Europe? The literature has shown that children with disabilities have higher emotional, economic, physical and social needs and this can put additional stress on parents. Further to this a disability can profoundly affect family dynamics when roles are altered; there is a disruption to family routines and parents may perceive the disability as an extension of themselves and feel shame, social rejection and embarrassment, which ultimately will influence the type of life that the person with the disability has. In most cases the disability may affect much more than the individual with the disorder.

Karen grew up with her mother who was a single parent, her father having died before she was born. They lived in an extended family household. She felt that her life was “normal.” She was involved in all the activities that her family members were involved in, went the same places and to her the onset of her disability only meant there was now a physical impairment but life was the same. She distinctly remembers her mother almost apologising for not being a good mother because she felt that she had treated her “too normal.” Karen would not have it any other way since she felt that is what has shaped her into the person she is today, one who is able to make a productive contribution to the society just like any other citizen.

Linda on the other hand acquired her disability when she was already a parent to daughters aged 15 and 9 years and hence her experience has been different within the context of her family to that of Karen and Kwesi. The dynamics in her family changed with the onset of her disability. Not only were roles altered but also the rules which governed family behaviour and interaction. Linda stated that, “I don’t think I was accepting what was happening to me..., I stopped concentrating on my family, work and everything... all I thought about was getting well.” Her perceived preoccupation with her disability over the past five years has resulted in her having to deal with the anger, disappointment, resentment and the subsequent deviant behaviour of one of her daughters as they tried to come to terms with the great changes that had taken place in the household. According to her, because they were not accustomed, “I have found out that my disability affects them (her daughters) in a different way it affects me.”

Kwesi however was disabled from birth. He has indicated that he got special treatment “... here and there, it wasn’t like (how) people would be ashamed of you, they were very supportive.” His siblings would question why they had to do chores and he was not given more to do, to which the mother would reply “because I said so.” The question of his disability never came to the fore. His parents treated him as an equal to his other siblings allowing him to make choices in areas that affected his life whether it was recreation, education or even making mends. So confident were they that at age eleven just before his father died, he asked him to take care of the family. This has inspired and motivated him to do well and hence pursue higher education since he saw this as the only way to get a proper paying job that will enable him to take care of his family. He is the only one in his family to attend university. However, he remembers that the decision to be placed in institutional care at the special school in his early years was not his to make but according to his parents it was done
“for your own good.” Research has also alluded to the fact that siblings tend to adopt the attitudes of their parents towards the child with the disability. This may be the reason why he had great relationships with his siblings and the case of exclusion did not involve him on the receiving end but rather he and his elder brother excluded their younger sibling from their social outings because of his age.

Social Issues

“I do not manage in general.” These are the words of Linda as she describes her life after the onset of her disability. Linda remembers that she was what you would call a “tomboy” while growing up and she led a normal life. She was very active and as a single mother she was very independent conducting chores which society would normally label as the work of a man. She was gainfully employed and was a student of the university at the time. However the onset of her disability relegated her to a state of depression, dependence on others because of low mobility and the inability to manage her daily affairs.

She has been in the health care system in Jamaica and has sought medical attention abroad. However she is still unsure of her diagnosis since there is a difference in opinion between doctors abroad and doctors in her homeland. She also feels that there is no recourse as she continues to grapple with the uncertainty of her diagnosis and her inability to deal with the changes she is undergoing on a daily basis. According to Linda, her depressed state was also because, “I didn’t think I was accepting what was happening to me...I could not perform at the standard I should and I held on to the notion that I could still walk.” It took some time for her to come to the realization that she could not go on this way and that she had to do something with her life. She felt that the only way to do this was through the completion of the education process which she knew was very important for employment and a good standard of living. She therefore returned to the university after her second leave of absence.

She is able to cope financially because of her forward planning while she was employed. Added to this she has income from her medical insurance, pension and from relatives from abroad who help from time to time. However her disability has certainly added to her cost of living in terms of health care, purchasing of meals on a regular basis, paying others to perform duties that she would otherwise have done for example, transportation.

Linda had dreams of being a lawyer but was dissuaded by her parents due to their religious beliefs. The challenges which she has experienced as a person living with a disability have increased her interest in human rights and her passion for those whom she considers to be vulnerable and in need of representation within the society in which they live. She has decided that it is not too late for her to follow her dream career path.

Karen, has always been in the eyes of the society in which she lives and has been acknowledged on a national level on several occasions. Today she is employed and works in the field of disability or as she describes it, “working within her own world.” Karen believes that there are less employment opportunities for persons with disabilities despite their qualifications. She has the experience of applying for jobs on the open market but had only gone for 2 interviews, neither of which she got. When she compares her economic status with that of her non-disabled friends the reality is that some are working for 2 and 3 times what she works
for. Of note is the fact that she is employed with a non-governmental organisation which history will show is generally low-wage work. For her the cost of living with a disability is high as one seeks to acquire the much needed aids and devices (for example, specialized software for the computer, Braille paper, transportation) which will enable inclusive and independent living for the person with the disability.

Kwesi has indicated that he really did not have many challenges and believes that he has had a normal life as is possible thus far. He has a social life, engages in recreational activities and has a lot of friends. There have been times when situations made him wish that he did not have a disability but according to him “…when you come back to your normal senses you then say I will keep it.” In terms of employment, he has worked for the four summer vacation periods since starting his studies both in the private and public sector. He describes himself as short sighted in that he does not have a vision of his work life but is concentrating at one “task” at a time. He is therefore concentrating on his plans to pursue his Masters degree and his aim at this time is to get a job in order to save money to pay for his education. For him the sky is the limit.

He speaks of his experience in the public space nonchalantly. He was happy to take public transport after years of car pooling since he felt that he was “allowed the freedom to do as you want.” Public transportation proved challenging in as much as you understood that “people would push you down” despite your disability so that he coped by waiting until the right time to attempt boarding any vehicle. In terms of public response to persons with disabilities, he felt that it was not totally correct to say that people “stared him down,” but his personal belief is that people will naturally look at him because he was walking differently to them. He is comfortable with this rationale and perhaps this has made living easier. He would like to see changes within the society for persons with disabilities and cites accessibility as a major issue.

Conclusion

Although the experiences of both Linda and Karen have geared them towards being advocates for persons with disabilities, Kwesi has not yet gotten to that level and seems to be interested in his self development not so much as a person with a disability but as a productive citizen in general. He however believes that more needs to be done for persons with disabilities and this is based more on the experiences of others than on his experiences.

The data from the interviews have reflected some similarities in lived experiences among persons from the three countries. It is seen that persons with disability are indeed being included into the wider or mainstream society on particular levels like education, work, and the social environment. They have success like other persons within the society but there is definitely room for improvement in the overall policy making, programme development and the society’s attitudinal changes for their status to be improved within our societies. It is probably the time for countries to follow in the footsteps of Jamaica and not only sign but ratify the United Nations Convention on the Rights of Persons with Disabilities. They also need to understand their responsibility to create a comprehensive approach to disability in their individual countries as well as within the context of CARICOM. Governments’ policies must be proactive and not reactive. In order to move forward, it is imperative that information about disability must be available and hence there must be an aggressive campaign to start proper data.
collection on the prevalence and epidemiology of disability in the region. To this end we will see an era of non-discrimination, equal recognition before the law, liberty, security, accessibility, mobility, independent living, health, employment, education and participation in political and cultural life for the disabled.
References


Interviews

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