ARE YOU DISABLED? SOCIAL AND CULTURAL FACTORS IN UNDERSTANDING DISABILITY IN TRINIDAD AND TOBAGO

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ABSTRACT

This thesis is an analysis of the under-researched subject of disability in Trinidad and Tobago and presents an understanding of the concepts and contestations of disability as it is lived and experienced by disabled people in T&T. In it disability is explored in the context of identity construction, power relations and self-empowerment, and takes into account the ways in which that identity is shaped by historical events, cultural relations, social interactions and political structures.

It identifies the relationships between disability and local social issues through an analysis of the everyday cultural paradigms of religion, kinship, beliefs, rituals, customs and values of the people, and gives particular attention to discrimination within the context of heterogeneity, and the effects that has on disabled people's contribution to society. The possibilities and limits of claiming a disability identity, and the role of state policy in framing understandings of disability are also explored, as are some of the impacts of those policies on the lives of disabled people.

The research took a broadly qualitative approach, drawing on narrative, semi-structured and formal interviews, focus groups, observations and documentary analysis. The research findings and analysis add to the existing disability scholarship by exploring the cultural impositions and social structures that impact on disability experiences in a country of the Global South, and pinpoint some of the limitations present in hegemonic Western discourse when applied in these settings. It highlights the importance of the legacies of colonialism and challenges assumptions that systems of Western modernisation and development can be easily transferred to countries of the South without considering whether or not they are socially or culturally appropriate. The data results have illustrated that disability in T&T is a social construct which diverges in important ways from the dominant Westernised theorisations of disability and in particular, identifies the significance of religion and spirituality in shaping models of reality and value systems, which must be taken into account more fully in disability scholarship, activism and policy in the country.

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1.0 CHAPTER 1

Introduction

The original motivation for this study came while conducting research for my Master's dissertation on disabilities in the workplace in Trinidad and Tobago and realising that there was a need for broader understanding on the discourses, experiences and practices of disability. That need was highlighted on numerous occasions in different arenas, for example, at the Eighth Biennial Conference of Caribbean and International Social Work Educators when the then Chair of the Disabled Peoples' International Trinidad and Tobago Charter, Mr Daniel (deceased), lamented:

> There must be research to inform policy makers. If there is no information then nothing will be changed in the lives of persons with disabilities … There is grave importance for a more aggressive approach to ensuring a place for disability research in Trinidad and Tobago. (conference notes 2007).

I am mindful that this lack of research applies not only to Trinidad and Tobago (T&T) but also to the wider Caribbean, 'as in much of the developing world, detailed knowledge about causes of disability is limited'. (Dudzak, Elwan & Metts, 2002:16) and as such my hope is that some of the knowledge presented in this study will be useful throughout the region.

There has been a noted increase in public interest in disabilities which poses questions on the ways in which cultural connotations can affect the understanding and interpretations of the lives of disabled people (Hiranandani 2005). I set out on the path leading to this research project mainly because of that new-found interest which I shared and because of the invisibility of the Caribbean in disability scholarship. I also felt that it was

an important topic to tackle given that international disability statistics estimate that approximately 10% of the world's population, roughly 650 million people, live with a disability, with the number projected to increase over the coming years (http://www.disabled-world.com/disability/statistics).

The study sets out to provide a critical exploration of the lived experiences of disability in T&T, by contextualising the way disabled people make meaning of, and construct their identities within social, political and economic structures. To achieve this, a review of the scholarship was embarked upon, field visits made for purposes of data collection, and analysis of the data findings was undertaken.

While my focus is on Trinidad and Tobago, the thesis also attends to the ongoing relationship between the local and the global. In particular, the relationship with the 'West', i.e., those Western countries formally known as 'First World Countries' and more recently called the 'Global West' must be taken into account. I use the term to differentiate between wealthy dominant societies and the poorer societies, i.e. those who were controlled by restraints placed on them by the wealthier ones, for example, by colonialism, and consider how these unequal power relations continue to impact on disability issues in T&T. I also reference a number of significant historical processes that are relevant to the study, specifically colonialism, slavery and indentureship, because they are responsible for some of the social and cultural transformations which have emerged in T&T.

Until recently, throughout the Western world, the dominant disability discourse had been centered on the medical model and its concern with individual functional limitations or psychological losses, however that

approach has been challenged by alternative theoretical models. More recently the dominant discourse has drawn on the rights-based social model which decentres the physical body, placing the emphasis on society's disabling effects (Oliver 1990). Key to this paradigm shift has been the politicising of the disability movement and the increased analytical voices including those of disability academics like Tom Shakespeare and Mike Oliver, who sought ways to address the perceived shortcomings of the medical approach to disability. This study engages critically with both the medical model and the social model mode, drawing on the insight that disability is socio-culturally constructed because one's culture is intrinsic to the realities of one's life, and that it permeates all facets of the human condition (Ingstad and Reynolds-Whyte 1995). I also show how the rights-based social model in its conventional form is inadequate in its theorising of the embodied disability experiences in T&T, and that an adapted approach with a far more robust theorisation that incorporates the local way of life would be more suitable.

As very little is known about the ways in which disabled people in T&T construct their identities, this study seeks to redress this by identifying the dominant disability discourses and the mechanisms through which meaning is made of the day to day social interactions that underpin disabled identity. It should be noted that advocating the acceptance of cultural specificity based on the way in which disabled people make sense of their lived experiences does not mean denying the need for any guiding principles upon which to build the community. Instead I am supporting Esteva's argument that those principles be 'fully rooted in the perception and attitudes of daily life, instead of supplanting them with artificial constructs which are hypothetically universal and more or less ahistorical' (Esteva 1987:138).

The project, therefore, aims to address the following research questions:

- What are the determinants of disability as an identity in T&T?

- What are the existing local theoretical models, definitions and narratives of disability that prevail?

- What are the lived experiences of disabled individuals in T&T bearing in mind the existing notions and contestations of disability?

- What culturally implicit and culturally explicit social relations impact on the lives of local disabled people?

1.1   The Research Setting: Trinidad and Tobago

Population

The twin-island state of Trinidad and Tobago lies geographically within South America as it is located just five miles off the tip of Venezuela. It is the southernmost of the eastern Caribbean islands with a combined population of approximately 1.3 million people: Trinidad is the larger of the two islands, approximately 1,978 square miles, and Tobago has a population of approximately 50,000 in an area of 115 square miles.

Trinidad and Tobago is one of the most culturally varied countries in the Caribbean, with significant sociological diversity between the two islands (Johnson 1987). Tobago is much more homogenous with the vast majority of the population being of African descent whereas the heterogeneous population of Trinidad is a melting pot of many ethnic groups, including traces of the indigenous Caribs. When the Spanish arrived in 1498 for the most part they eliminated the indigenous Amerindian population through the

introduction of diseases for which they had no immunity (Kiple 1996). The Spanish were followed by the planters from French territories in the region who arrived from 1783 with their slaves. That was just before the country was conquered by the British in 1797 (MacDonald 1986) who imported more slaves from Africa into the islands. Those slaves kept some of their traditional beliefs and practices which are still apparent today. After emancipation of the slaves in 1838 caused a labour shortage workers from India and a few Chinese peasants were then recruited as indentured labourers by the British, and they too brought along their cultural influences (Khan 2004) thus changing the socio-political landscape of the country. The Syrian/Lebanese settlers were the last to arrive, in 1904, as fabric merchants and house-to-house peddlers. All of these ethnic populations have contributed to the diversity of the country by adding their own traditional and cultural ideals.

The cultural configuration and customs of Trinidad and Tobago have been described by Mendes (2003) as a mix of Western influences, African, East Indian, French-Creole, Middle Eastern, Chinese, and Portuguese among others. There are, however, unique cultural differences between the two main population groups, i.e., those of Indian descent and those of African descent, for example, their religious beliefs and ways of worship, their dietary components and family structures (Yelvington 1993). But there also exist a sub-group made up of a genetic mix of these two groups which is characterised as 'dougla'. The exact origin of that term is not known but it is believed to be derived from the term 'dogla' which was used in northern India to mean 'a person of impure breeding' and the illegitimate son of a prostitute; it is also rooted in negative connotations of being dark-skinned (Reddock 1994; Brereton 1974). All over India, even in the darker Dravidian

South, that skin tone bias with a predilection for lightness of skin is manifest in many ways. The skin colour hierarchy is even present in the religious literature which is suffused with a distinct disavowal of darkness.

Religion plays a powerful role in the lives of Trinidadians and Tobagonians, and they are more spiritually aware than other secular societies with the majority of the population belonging to a religious group (Henry 2001). Wide-ranging religions/beliefs are practised, including Catholicism, Hinduism, Islam, Anglicanism, Pentecostalism and Evangelism, Presbyterianism, Jehovah's Witness, African syncretism faiths - Spiritual Baptist and Orisha, Judaism, Ethiopian Orthodoxy-Rastafarianism, Baha'ism and Buddhism. These groups offer spiritual enlightenment and their strong religious influences are played out in every facet of life of the twin-island state, including the economic, social and political spheres. Former Prime Minister, Patrick Manning was very open about having consulted a prophetess/spiritual guide. Religion and spirituality also provide community structures where many people acquire a sense of belonging and identity, and where resolutions are provided to practical problems. Indo-Trinidadians who are particularly aware of the effects of religious and cultural deracination pay close attention to upholding their beliefs and rituals (Khan 2004).

Identity and the social organisation of the islands would have been resisted, restructured and renegotiated over time and space and that will no doubt have an impact on disability discourses and experiences.

Political and Economic Structure

Trinidad and Tobago gained independence from Britain in 1962 and became a unitary state with a parliamentary democracy based on the Westminster

model (National Archives 2010). However, in 1976, it became a republic and though it still follows the Westminster model there is also a ceremonial President in place. Apart from one attempt in 1990 to overthrow the government, it is a state that values democracy (National Archives 2010) in a multi-party system of governance dominated by two main political parties based on ethnic identity (La Guerre 1993), reflective of the social stratification along the divide of Africans and Indians. At present there is a coalition government led by a female Prime Minister comprising two primarily Indo-Trinidadian majority political parties, one Tobago political party, and two labour NGOs.

Even though the World Bank Report 2013 classifies T&T as a developing high-income country (http://data.worldbank.org/country/trinidad-and-tobago), there is an ongoing reliance on international support and humanitarianism as seen in this extract from a recent news report:

> the dispatch of a medical team of specialists from China upon receiving a request from Trinidad and Tobago ... aimed at improving the delivery of health services to the people of Trinidad and Tobago together with a $5billion loan (*Trinidad Express*, 6 March 2014).

A 2008 Organisation of American States (OAS) Report, on 'Institutionalisation of Social Policy in the Caribbean', found also that NGOs dominated service provision – a legacy arising from the times at the end of the Crown Colony System when missionaries and international voluntary organisations were a key instrument in the delivery of health services. Those services were based on a hegemonic health discourse, with the indigenous population being viewed as passive recipients of imperialist knowledge and power from the knowing West. Turshen, in his work on the effects of colonialisation in Tanzania, found that 'the rudiments of a system of public health and

medical services were transferred from Britain … during the period of colonial rule. [These were] determined and designed in the metropolis rather than the colony' (Turshen 1977:8). A similar situation applies to T&T. Post-colonial health human resources had been heavily influenced by the presence of 'British colonial professionals' who oversaw the training of medical, nursing and related professionals. However, the University of the West Indies claims to have carried out 'considerable curriculum policy reform to reflect a Caribbean reality' (Ramnath 1998:7), a point with which I engage in Chapter 7 when looking at the disability discourse in T&T academia.

The T&T economy was traditionally based on the export of agricultural produce, i.e., sugar, coffee, cocoa, and cotton which increased the economic vulnerability of individuals. Social values were placed on the ability to produce and to be an economic asset therefore for individuals with impairments the consequences were increased chances of poverty. Statistically 82% of disabled people in Latin America and the Caribbean live in poverty (World Bank, 2004:1) and in T&T they are among the loWest earners, with 72% either not working or not seeking employment (T&T Survey of Living Conditions, 2005).

For several decades T&T has no longer been heavily dependent on agricultural exports. That is because because after World War II the Americans built a military base in Trinidad using local manual labour and at that time the construction industry accounted for approximately 15–20% of local employment, which led to the decline in agricultural export. Hydrocarbons was also discovered around that time and that plunged the country into the throes of socio-economic turmoil with the resultant oil boom giving rise to industry and services of oil, construction and manufacturing

dominated by the presence of multinational corporations (CIA World Fact Sheet). The USA also had a strategic political influence on the T&T government after the islands' independence in 1962, and continues to have a significant impact on the economy through the importation of American goods and services.

More recently, between 1973 and 1982 T&T experienced a vast increase in its national income from a boom in the oil and natural gas industry resulting in a significant growth in public sector jobs and in the oil/gas industry. However that undermined employment in other sectors leading to immense disparities in earnings which has given rise to a substantial underclass in which disability is largely located. The ensuing decline in international oil prices caused a drastic reduction in national income which increased poverty and according to the 2013 CIA factsheet approximately 17% of the population is now living below the poverty line and half of that number are unable to afford basic food items (CIA 2013).

The economic decline also had a negative impact on the provision of basic health services with expenditure being 5.4% of G.D.P compared to Grenada where it was 6.4% or the UK where it was 9.4%. The reduction in spending has meant that resources were diverted away from the provision of quality care leading to poor/understaffing, inadequate support services, extensive queuing and long waits to receive services, scarcity in certain prescription medications, and insufficient treatment options – all of which will have a bearing on the quality of life of disabled people (World Bank 1995, CIA 2013).

Disability Profile

In the United Nations Development Programme 2012 Human Development Report, Trinidad and Tobago is classified as a high development country positioned at 67 out of 187 countries, but with a low satisfaction rating in relation to heath care quality. In the Gallup World Poll question, 'Do you have confidence in the healthcare or medical system', only 32% of respondents answered 'yes' (http://www.gallup.com/poll/world.aspx). The WHO 2007 Country Cooperation Strategy on T&T supports this claim of inadequate health care services concluding that:

> health sector development challenges identified are diverse, but the priority challenges are categorized by critical areas that include: planning and policy development - the regulatory framework; health information systems, epidemiological surveillance, data analysis, and the use of information for decision-making; human resources in the public and appropriate competencies; the development of the health system and services; and the coordination, follow-up and networking at the local level for regional and global commitments. A major challenge in the current health system includes not having a health workforce that corresponds in quantity, competency and quality to the current and projected health needs of the population, due to inadequate human resource planning (WHO 2007).

The findings of these reports are however based on hegemonic discourse that contextualises health care in a Eurocentric framework. That is not to say that they are inaccurate in relation to the way in which local people experience health care services, but that considerations of difference in interpretations, meaning, identity and aspirations ascribed to the lived experiences and lifestyles of people living in post-colonial T&T may have been ignored in its conclusion.

Disability service provision in T&T currently falls under the Social Welfare Division of the Ministry of the People and Social Development. This came

about as a result of the recommendations of the West India Royal Commission (chaired by Lord Moyne), under the auspices of the Colonial Development and Welfare Organisation in 1939 as a consequence of the labour disturbances that engulfed the region in the late 1930s. The Commission's terms of reference were to investigate social and economic conditions in Barbados, British Guiana, British Honduras, Jamaica, the Leeward Islands, Trinidad and Tobago, and the Windward Islands. Amongst other things it unearthed terrible conditions such as poor health provision and high infant mortality rates. It then recommended a number of reform measures with 'older persons; necessitous children; persons with disabilities; victims of natural disasters; and other needy persons' as beneficiaries (www.2mpds.gov.tt). In 1999, the then government set up a specific Disability Affairs Unit with the mandate to:

1. co-ordinate and monitor implementation of the National Policy on Persons with Disabilities;
2. provide technical support and referrals for persons with disabilities, their families and all other persons interested in learning about disabilities;
3. evaluate requests for assistance from non-governmental organisations (NGOs) and individuals;
4. network with pertinent NGOs, mass media and international organisations to collect information and increase public awareness of issues pertaining to persons with disabilities (http://www2.mpsd.gov.tt/content/disability-affairs-unit-)

In T&T, as in many other developing countries, it is difficult to gauge the full impact of disabilities mainly because of 'the inadequacies in the type and quantity of statistical data whether through censuses, investigations, or records' (IDB Seminar 2005). Not only are disabled people in T&T one of the largest uninvestigated minority groups, but there is no legislation that specifically protects their rights or their access to goods and services

(Torres 2008), with their rights being largely overlooked by the state and its legislators.

The country, in aspiring to achieve developed country status by 2020, did however sign the UN Convention on the Rights of Persons with Disabilities (UNCRPD) in September 2007, which means that it subscribes to the principles laid out for the human rights of disabled people. But closer examination of Article 8 of the Convention shows that the state and other public bodies are required to bring about a cultural change to facilitate social change in attitudes towards and expectations of disabled people: so having signed the convention with the expectation of ratification in the future, the state is signalling its commitment to the facilitation of that cultural change. In keeping with that pledge, it has initiated a National Policy on Persons with Disabilities which sets out the guiding principles and action plans that it proposed to embark upon in reforming the quality of life of disabled people. It outlines that:

> The Government of Trinidad and Tobago is committed to the full inclusion and holistic development of persons with disabilities. In the pursuit of developed country status by 2020, Government is steadfast in its resolve to address disability issues from a human rights perspective, which in essence is to view people with disabilities as holders of rights which are to be protected and enforced (National Policy 2008).

However, for that pledge to be achieved, a true picture of the complexities of disability in T&T, in conjunction with fundamental attitudinal changes, is required. But to get to that stage will involve consideration of the existing cultural perceptions of disabilities, the issues and challenges faced by the disabled population, the gaps in service delivery, and equally important

whether or not the principles in the Articles as set out in the Convention are relevant, acceptable and realistically transferable given the residual, deep-seated cultural prejudices that exist in T&T. However, the Convention should not be ignored in its entirety, for it is better to be aspirational in its outlook than to contend that innovative approaches are inapplicable or unattainable because of cultural prejudices.

Local Statistics

In 2000, the T&T government carried out a population and housing census with a section on disability. To gather the disability-related data the questionnaire employed an interpretation of disability in relation to eight impairment categories, namely: seeing, hearing, speaking, mobility, movement, gripping, learning, behaviour, and based on the question 'do you suffer from any longstanding disability that prevents him/her from performing an activity'. From the categorisations stated above the results showed that approximately 45,000 people out of a population of 1.31 million were disabled. But this emphasis on impairment categories ignored the multiplicity of social and environmental factors that could cause disablement such as those implied in the UNCRPD Preamble 2006 that disabled people may be 'subject to multiple or aggravated forms of discrimination on the basis of race, colour, sex, language, religion, political, or other opinion, national, ethnic, indigenous, or social origin, property, birth, age or other status'. Nor did it take into account the considerations mentioned in the World Bank Report (Mont 2007:31): 'environment (urban/rural), type of society (developed/less developed) and cultural and societal norms'.

The effect of the interpretational anomalies in the definition means an absence of reliable statistics, resulting in the quantification of the disabled

population being contested. The Analysis of the 2005 Survey of Living Conditions concluded that 'the percentage of the population with a disability reported here may be just the tip of the iceberg. Policy makers will have to anticipate under-reporting' (SLC 2005). This assumption of under-reporting is not only relevant to T&T, as Mont (2007) noted that many households in developing countries tend to deny the existence of disabled family members because of the shame, stigmatisation, and resilient cultural prejudices.

Analysis of the 2005 Survey of Living Conditions from a sample group of 609 disabled individuals found that on average 24% of disabilities were congenital with the tendency for the percentage to vary depending on socio-economic status. This is an important point for policy makers to take note of and use as the basis of further investigation to determine 'if interventions among the poor can reduce the probability of disability at birth' (SLC 2005). The report also highlighted the key issues affecting the disabled population to be health care, education, transport, employment, housing and recreation, with a lack of accessibility to appropriate education cited as a major factor given the role of education in employment prospects and income generation.

Disability, Gender and Ethnicity

Begum notes that 'although disability may be the predominant characteristic by which a disabled person is labelled, it is essential to recognise that gender influences play an important role in determining how that person's disability is perceived and reacted to' (Begum 1992:62). Driedger and Guy (1996) in their work on gender relations in the T&T Chapter of Disabled People International postulate that awareness and empowerment has led to women being more self assured of their own personal development. In 1992 the Disabled Women's Network of T&T (DAWN) was formed and that

provided a platform for disabled women to bring their concerns to the fore. Some of the issues identified were prevailing prejudice, neglect and lack of research into their concerns, which increase disabled womens' susceptiblity to exploitation, physical, sexual and emotional violence (Huggins 2003). Those findings are not unique to T&T as many researchers have concurred that on average disabled women are twice more likely to be assaulted, raped and abused than their non-disabled counterparts (Sobsey 1998; Simpson & Best 1991).

In looking at the statistical distribution of disability by gender, the 2000 Population and Housing Census found no significant difference, with the gender split being 51% female and 49% male. However, in relation to specific impairments, there were more visually impaired females than males and more males with behavioural disabilities than females.

TYPES OF DISABILITIES BY GENDER IN TRINIDAD AND TOBAGO 2000
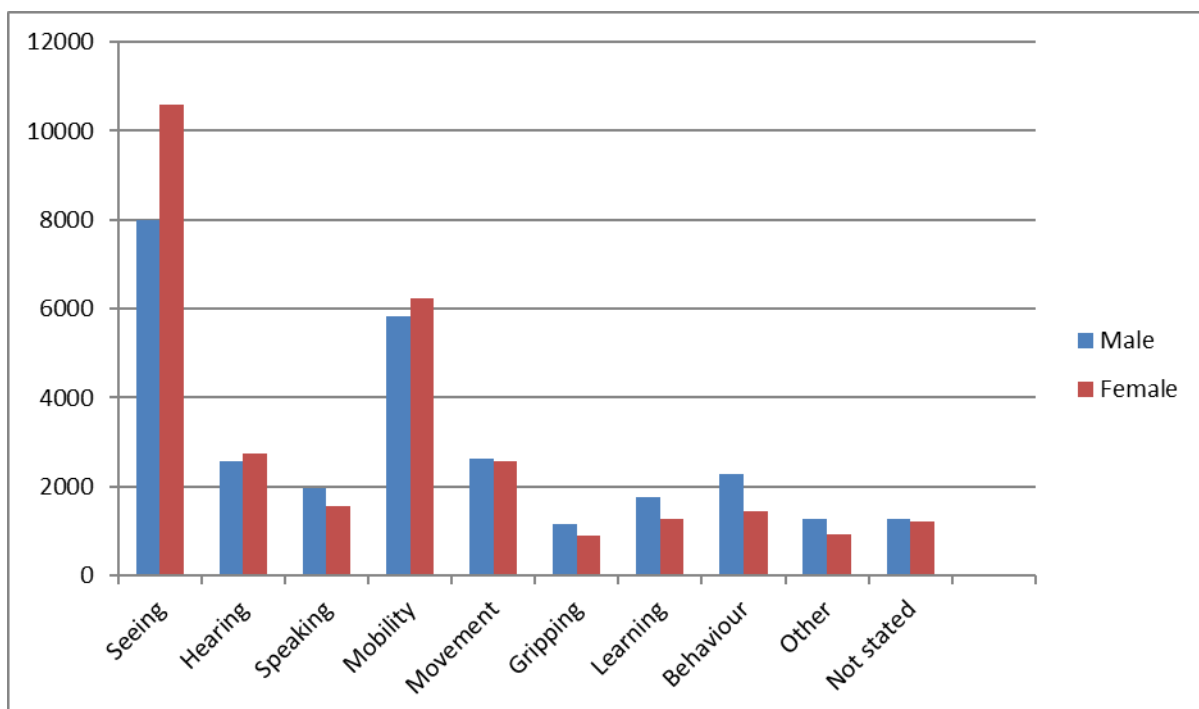
Source: Adapted from the 2000 Population and Housing Census

In relation to ethnicity the survey found that 41% were of Indian descent, 39% African descent and 18% mixed. This correlates roughly with the overall ethnic distribution of the population, as found in the Census Report of 2000.

Disability by Ethnicity

A bar chart titled "Disability by Ethnicity" with the y-axis ranging from 0 to 20000 in increments of 2000. The categories on the x-axis are African, Indian, Chinese, Syrian, White, Mixed, Other, and Not stated. African is approximately 18000, Indian approximately 18800, Chinese very low (near 100), Syrian negligible, White approximately 300, Mixed approximately 7900, Other near 100, and Not stated approximately 200.

Source: Adapted from the 2000 Population and Housing Census

1.2   Rationale for Study

Personal investment in a research project must be declared to avoid misconceptions between the individual's positioning and that of others (Said 1979). Therefore, it is important to say that I have a hidden disability, i.e., one that is not apparent to the unknowing observer, and I have also worked extensively in the field. One factor motivating this research occurred when I was asked by a family, who were aware of my previous research in T&T, to assist them with navigating the hurdles of acquiring health-care support and

dealing with the legal ramifications of a compensation case for their daughter who was involved in a vehicular accident. That experience shed considerable light on the organisational and infrastructural complexities of disability services in T&T, and because of my working and personal knowledge of disability in the UK at times I made subtle comparisons between both countries. I am aware of the problems arising from making universal judgements, especially as my own understanding and lived experience of disability is from a Westernised context grounded in my particular value system. I was therefore mindful not to impose on the family the common assumption that eurocentric knowledge and values are the answer to their problems. Conscious of the cosmopolitan ethnic diversity, the wide-ranging cultural ramifications and the void in disability-related research in T&T, I wanted to delve deeper into the contextualisations of disability and lived experiences of the disabled population. My aim was to understand disability in relation to the socio-historical cultural diversity of T&T and to ascertain the extent to which those influences had been considered in state policy, especially as the UNDP Report on Human Development guideline which states that:

> Development must be woven around people, not people around development ... and it should empower individuals and groups, rather than disempower them. (UNDP, 1993:1)

and also because one of the guiding principles of the UN Convention on the Rights of Persons with Disabilities, to which T&T is a signatory, states that:

> Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons ... To take all appropriate measures, including legislation, to modify

or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities (UNCRPD).

My view is that since little attempt had been made to examine the explanations, experiences and consequences of disability from the point of view of the disabled individual, it will be almost impossible for the state to adhere to those guidelines. For to do so will require clear cognisance of what it means to be disabled as experienced by those who are disabled, not only in relation to their impairments, but inclusive of the wide-ranging socio-cultural determinants existing in society.

This research is, therefore intended to disentangle and analyse the various constituents and contextual variables of the meanings ascribed to disability in order to build a more complete picture. To this end the study looks at the personal, social and environmental factors that shape and give meaning to the lives of disabled people. There is also a practical motivation: it is intended that the information provided be used as a framework to aid the formulation of culturally-sensitive, relevant and effective policies and services. It is hoped that the findings will go some way towards bridging the gap between policy rhetoric and disability provisions, with the explicit outcome of realistic and achievable outputs in line with Montes and Massiah's (2003:3) position that:

> Without reliable, comprehensive data on disabilities, an opportunity is missed to gather data on the changing dynamics among people with disabilities. This in turn limits the development of effective programmes of inclusion and restricts efforts to develop and monitor appropriate public policies.

1.3   Contribution to Knowledge

The primary reason for undertaking the research is to identify how the lives of disabled people in T&T are shaped by their individual, social, political and cultural circumstances and events, and to use this information to inform existing knowledge and practice. Barille (2000:209) makes the point that:

> Throughout history there has always been cultural and regional inequity in understanding and treating people with disabilities. Inequity occurs when the social structures and spaces, social norms, culture and the tools of social interaction are constructed without taking differences, and therefore, equity into account.

Many researchers have argued for disability research to move towards a deeper theorisation that delves into local and regional complexities. However, Marfo (1993) makes a valid point that such research should not only be fixated on the 'traditional' attitudes to disability, as evident in much research on African communities, because to do so can be counter-productive. Instead it should be widened to include the contextualisation of political, social, historical and economic factors. In view of this, together with Douglas's (1971:3) statement that 'the only way to understand the social meanings of social actions is by an analysis of everyday life', and that of Fernando who states that 'the more we know about systems of healing that are serving people in different parts of the world, the better prepared are we to think about and plan services that are culturally consistent with the needs and wishes of communities the world over' (Fernando 2014:xvi) the study intends to challenge mainstream assumptions by looking into the actuality of the lived experiences by attending to the emic and etic specificities of disabilities in T&T. The emic perspective relates to meanings, fears, beliefs and values of the individuals being studied, and the etic refers to the external factors that influence the individuals and wider society, for example,

political, economic and environmental factors. The research therefore takes account of the historical, cultural, social, political, sexual and other implications that account for differences in disability in T&T.

There are known tensions between the way in which disabled people view themselves and experience their disability, and the way in which the state structures its service provision, so it is hoped that in presenting the experiences of disabled people as relayed by themselves, in conjunction with the way in which they are received and perceived in terms of psychological, functional and social domains it will alleviate some of those tensions. Especially as this type of in-depth research is what was being asked for by Morabito & Bennett (2008) in their study on 'Policing People with Mental Illness in Trinidad and Tobago' who state that 'further research could profitably investigate not only officers' attitudes towards persons with mental illness, but also access to viable services, organisational structure and culture, and the relationship between police and mental health services personnel'. That need to bridge the research gap is also mentioned in the National Policy which states that:

> There is a critical need to undertake studies focusing on issues, which affect the lives of persons with disabilities and their families. Best practice and innovation in service provision (including inclusive education, mainstream vocational training, career guidance and employment services) are possible areas of research (National Policy 2008).

It is anticipated that the conclusions arising from the data analysis of this research will be beneficial to the state through the provision of a holistic understanding of the way in which disabled people construct their world. It will also enable those responsible for planning services and allocating

resources to be more aware of, and alert to the way that environmental, political, and social factors impact on the experiences of disability. Medical practitioners and officials providing services to disabled people will also be enlightened on the local meanings ascribed to disability, and its social, emotional and psychological effects. This knowledge can therefore be used to transform and adapt services in keeping with the fundamental social needs of the population they are intended for.

The research positions itself within the growing body of scholarship on disability by contributing to existing theories and empirical research on the subject. It contributes to a paradigm shift in understanding disabilities by moving away from the usual epidemiological studies which do not reflect the experiences of disability from the perspective of the local population, to one which identifies and explores the experiential realities of disabilities from a socio-political and culturally specific standpoint in relation to the heterogeneity of T&T. It offers a new body of knowledge on those intellectual and philosophical realities of life for disabled people and takes a multi-dimensional view that not only challenges assumptions, but sets those experiences in their historical, social, political and cultural contexts. In doing so, it is providing a perspective which is not reliant on the uncritical transfer of knowledge, skills or studies from a developed Western world universalised discourse, but instead presents disability as seen through the eyes of the person with the impairment.

1.4   Overview of the Thesis

Chapter 2. Theorising Disability

This chapter provides a review and critical discussion of previous literature relating to the theoretical frameworks of disability. It examines and debates the different theoretical and policy approaches to disability in the scholarship. I present a critique of the WHO ICF definition of disability because of its international use as the foundation for policy development and service delivery. The individual model and the rights-based model are interrogated, and analysis undertaken of the globalisation of disability and its relevance to the disability experience in T&T.

Chapter 3. Methodology

This chapter sets out the methodological rationale, techniques, components and data sources used in the study, by discussing the philosophy and theoretical decisions behind the approach taken with particular reference to Denzin's (1989) interpretative interactionism and to the debates around power, ethics and methodology. A pilot study was undertaken and the findings from that experience are discussed together with the rationale behind the reframing of the research. The method through which research participants were identified and recruited, my position as the researcher, and the ethical procedures employed are presented in the chapter. It also describes challenges encountered, the research design together with the specific data collection instruments used, and the processes by which the data collection was undertaken, prepared and analysed and the coding system used to analyse the information.

Chapter 4. The Place of Religion, Spirituality and Cultural Traditions in Experiences of Disability

This chapter is the first on the research findings and presents an insight into the way in which religion and spiritual/traditional thoughts, processes and beliefs are incorporated, and impact the way of life and notions of disability in T&T. I discuss how the socio-cultural factors of belief, religion, faith, superstition and myths all influence the way in which disability is lived and experienced.

Chapter 5. Everyday Discrimination

In this chapter, I further explore the factors which negatively influence the perceptions of and everyday lived experiences of disability in T&T. I discuss the social expectations and societal attitudes to disabled people, as well as their experiences of discrimination, stigma and shame. In addition taboo issues, such as sexuality are positioned in the mix as influencers of discriminatory behaviours towards disabled people.

Chapter 6. Identity

This chapter considers data conveying what it is like to live as a person with a disabled identity in T&T. I explore the possibilities and constraints involved in claiming disability as a collective or political identity in a context where deep-seated prejudices co-exist with an emerging disability rights movement. I discuss those factors which are important to claiming and owning a disability identity including group identity politics and asserting a political disability identity.

Chapter 7. Policy and State

In this chapter an analysis of the rationale and philosophy of state policy and service provision is presented. This is not done as a way of highlighting their appropriateness or shortcomings, but to explore how their concepts impact on the notions of disability and the existential experiences of disabled people.

Chapter 8. Conclusion

This concluding chapter is a summary of the results as they relate to the research questions. The principal arguments of the thesis are presented through a synopsis of the contributions of the participants. It suggests a possible way forward for future strategic disability development in T&T and makes recommendations for further research advancement that can improve service delivery. It is hoped that the new knowledge presented in this study will be extrapolated and used to influence policy and service delivery as it provides a much needed comprehensive assessment of disability in T&T.

2.0   THEORETICAL AND POLICY APPROACHES TO DISABILITY

Introduction

In this section of the thesis a critical review of theoretical and policy scholarship is undertaken to introduce conceptual frameworks of disability. I begin by offering an analysis of the WHO International Classification of Functioning, Disability and Health (ICF) definition, which is used as the guiding principal in the management and development of services for disabled people throughout the world. I believe that an examination of the definition and a critique of its limitations in theorising the disability experience in T&T is pertinent to this thesis given its use as a global benchmark in relation to 'intervention studies; environment factors; research; economic analysis; and policy development' (WHO 2002:7). It is also interrogated because although definitions differ globally across cultures they play a major role in both theoretical and policy-oriented disability studies (Liggett 1997).

I then engage with the two dominant perspectives of disability found in the literature i.e. the individual and rights-based models because of their significance in policy and service development and implementation. The review presented engages with the characteristic strengths of the models but at the same time questions their philosophy and efficacy in light of the fluidity and subjectivity of disability experiences. I then consider how disability identity is theorised in the literature.

In the final section of this chapter, I explore the issue of globalised disability frameworks, conventions and treaties for example the WHO toolkits, and how they may or may not be relevant to T&T on account of the peculiarities

rooted in its history of colonialism and its diverse population group. This examination is undertaken because anthropological studies show that disability is perceived and defined according to the dominant values of the specific society in which it is experienced (Ingstad and Whyte 1995). It is also true that it is through the use of the ever emerging toolkits that Western discourse continues to significantly influence the developing world and though they are designed for the common good of the populations they serve they are not necessarily contextually appropriate to the country in which they are being used, which in this case is T&T.

The number of papers and studies addressing sociological understandings of disability is evidence of its complexity and the multiplicity of conceptualisations and constructs. However, it is not my intention to provide a comprehensive literature review of the various theorisations of disability and their ramifications for service delivery. Instead as my aim is to facilitate an understanding of the conceptualisation of the disability experience in T&T and the normative principles by which disability is located in policy and service delivery, this chapter primarily summarises the two principal tenets and philosophical foundations together with the debates that have emerged within scholarship relevant to that experience. My position is that those two dominant perspectives and ideologies are contextually important, but in their present form do not adequately represent the lived realities of disability experiences. As such, I present an argument for a more culturally specific approach and draw on the social relational perspective advocated by Thomas and Corker (2002). I believe that a refined social and cultural approach will enrich the understanding of disability in non-Western society, and provide a more realistic insight into disability through placing the impaired body within its specific history, politics, culture and meanings

relevant to the circumstances, time and space in which it is being experienced.

2.1 ICF Definition

Rationale

The ICF definition is an international framework designed to standardise the description and measuring of health and disability functionality at an individual, institutional and social level based on 'the perspective that disability arises when barriers exist to participation' (WHO & World Bank 2011:5). The previous WHO International Classification of Impairment, Disabilities and Handicap (ICIDH) which was published by the WHO in May 1976 was developed with the intention of presenting a non-medical conceptualisation of disability. However, it faced much criticism for its reductionist approach and was subsequently revised to the present ICF definition. This new definition has also been evolving over time in response to ongoing arguments regarding its effectiveness.

According to the un.org website, in the ICF, disability is seen as a result of an interaction between a person (with a health condition) and that person's contextual circumstances (environmental and personal). It does not consider disability to be an intrinsic feature of the individual but rather a result of their interaction in an environment, covering a spectrum of various levels of functioning at body level, person level and societal level:

    (a) impairments in body structure and functions

    (b) limitations in activity

    (c) restrictions in participation

Figure 3 below shows these interactions between the body structure and functions, activity and participation and the contextual factors.
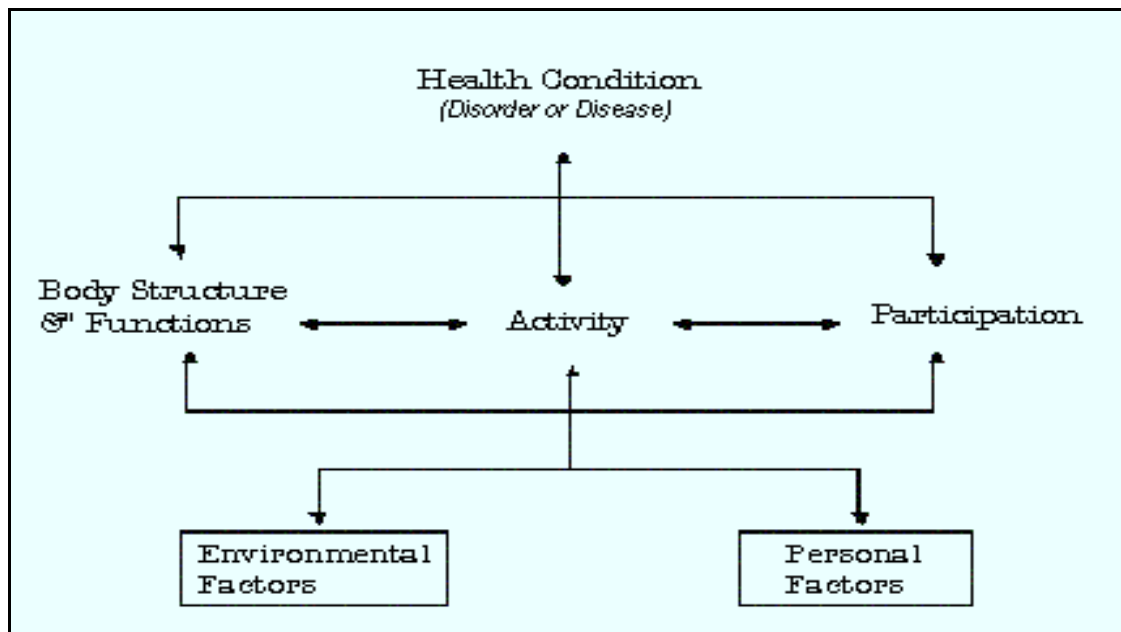
Figure 3. ICF definition interactions (WHO 2002)

Here functioning and disability refers to body functions and structures i.e. the actual anatomy and physiology/psychology of the human body. The activity and participation is about the person's functional status for example communication, mobility, interpersonal interactions, self-care, learning, or applying knowledge. The contextual factors are those environmental factors which are not within the person's control, such as family, work, laws, government agencies, cultural beliefs, and personal factors, for example race, gender, age, educational level, or coping style. The personal factors are not coded because they vary among cultures (WHO 2002).

This much welcomed revision of the definition was conducted in acknowledgement of the growing number of debates demonstrating that disability is a 'complex dialectic of biological, psychological, cultural and

socio-political factors' (Shakespeare & Watson 2002:22) in contrast to the ICIDH definition, which fixated on functional limitations as the key determinant of disability (Imrie 2004). Disabled activists and members of the Union of the Physically Impaired Against Segregation (UPIAS) were strongly against the ICIDH definition not only because of the semantics, but also because of the effects of the language used in shaping meaning and creating realities. In particular it was felt that impairment should refer to bodily limitations, and disability to the societal constraints and restrictions placed upon the individual with impairments. Those criticisms have been taken into account and consequently the revised IFC places the emphasis on the dynamic interaction between biological/impairment limitations, psychological factors such as the personal experiences that contribute to the person's disablement, and the wider social environment. In essence, disability is an issue requiring attitudinal and ideological social change and political will, with impairments being evaluative judgments of deviations in cognitive, physiological and anatomical functions (Albrecht 2006).

Impairments

Despite the amendments, Imrie (2004) argues that situating the ICF within the myriad of competing disability discourses will continue to be fraught with difficulty because of the disparity in the discourses which range from the bio-medical model in which disability is understood to be a biological malfunctioning of the body, to social perspectives that see disability as the result of social oppression. The ICF does in fact distance itself from both the bio-medical model and also from the social theory of disablement and instead locates disability within a bio-psychosocial construct intersecting biological, psychological and sociological perspectives. As previously stated, in the ICF, disability is 'the negative aspects of the interactions between an

individual with a health condition and that individual's contextual factors (environmental and personal factors' (2001:221) which is focused on bodily function and institutional structural barriers to participation, implying that restrictions of activity are imposed on a body which lacks the anatomical characteristics that make up human functionality and health.

On account of the anomalies in the ICF, Thomas advocates for a redefinition of disability along the lines of 'a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-social wellbeing' (Thomas 1999:60). This, Thomas argues, is a more realistic definition because it accounts for the relationship between impairment and disability and includes the likelihood of impairments leading to functional limitations.

Universalisation

The changes introduced in the definitional progression from the ICIDH to the ICF have been welcomed by disability scholars and activists, but its theoretical soundness is still underdeveloped. From both an academic and politicised standpoint it is regrettable that the universalisation of guiding principles which set out to address disabilities globally has not adequately accounted for the experiential realities and cultural specificities of non-Western post-colonial contexts. It is evident that insufficient attention has been given to the harsh realities that disabled people who have had to negotiate colonialism are faced with, their social, cultural and economic marginalisation, and the fact that they are less politicised and less empowered. What is missing from discussions is the unique embodied subjectivity of the disabled experience and the social dimensions that impact upon an individual's ability to participate in the wider society. It is those

unique socio-cultural meanings that define and situate the functional limitations of impairment and disability and construct the inclusionary or exclusionary social responses to it. The evidence to support this is there as many disability theorists have shown that disability is constructed differently in diverse countries and that history and culture play a significant part in the way in which it is experienced (Stone 1984, Groce 1999, Albrecht 1992).

The ICF as a universalised Western framework lacks analysis of the complexity of diversity especially in populations who have experienced diminished cultural capital often by virtue of their race and who have had to rely on their recollection of the skills, knowledge and practices that they bought with them from other parts of the world in particular from Africa and India. One reason for the ICF's, and even wider reaching lack of attention on disability in a post-colonial context is because the majority of critical disability studies are focussed on 'white bodies' often undertaken by white scholars and activists (Bell 2011) who do not necessarily appreciate the full significance of history, society and culture in the shaping of disability. Anita Ghai a leading advocate of disability rights in India, postulates that 'impairment like disability should be a signifier of not just society's response to impaired bodies but also to illustrate how these bodies are shaped materially and culturally' (Ghai 2006:129). Therefore ignoring diversity has compounded the knowledge deficit regarding non-white non-Western disabled bodies and that will undoubtedly create inaccurate hypotheses on the lived experiences of disability in contemporary society.

Another anomaly of the ICF is that it inadequately acknowledges disabled people's subjective experience of the meaning of participation in a life situation, which it defines as 'observed performance' (WHO 2001:229). It

presumes observed participation to be the same as involvement in so far as it is proposed that involvement is taking part, being included or being engaged in a situation, i.e. performing. However, the assumption of involvement tends to be based on an external point of reference that neglects the exclusive motivations, habits and the meanings ascribed to free will, quality of life, and the role of satisfaction and happiness, and the salience of the local culture in fulfilling those experiences (Wade & Halligan 2003). By excluding those subjective experiences, the autonomy of the individual and their self determination to choose what they participate in and how they do so is undermined.

There are also a number of other fundamental issues that are inadequately accounted for in the ICF definition. It is said that impairment, disability and poverty are 'linked in a deadly mutual embrace' (Albert et al, 2004:13) a point supported in the World Bank Report on Disability and Poverty (2009) which concludes that poverty causes disability, deplorable living conditions and social isolation. Other reports also show this direct relationship between poverty, ill health and disability which are due to the effects of social exclusion, marginalisation, vulnerability, powerlessness and isolation. Grech (2011) on his work on disability and poverty reiterates the significance of this point and cites Marks 1999 statement that:

> the body, the repository of the personal and the social and of pain, becomes hard to ignore in contexts of extreme poverty where livelihoods (and indeed most activities) are predicated on physical strength and when health care is often absent of at best fragmented. (Marks 1999:129).

Poverty in this context is not simply having inadequate income for basic subsistence needs, but is a symptom of imbedded structural imbalances that impact on the economic, political, social and cultural domains of an

individual's life (Poverty Assessment Study Report 1995). It is therefore perplexing why these wider topics are still so often neglected in disability conversations.

The various shortcomings of the ICF have been recognised and discussed by the WHO Chief Medical Officer who argued that it suffers from a quasi-total absence of references to some of the large-scale daily experiences of disabled people in real life: extreme poverty, abuse, neglect, substance abuse, exploitation, lack of security, imprisonment, non-application of human rights. This reflects the lack of experience among the ICF's authors and the domination by expertise from the rich countries. The WHO Chief Medical Officer concludes that 'the WHO needs to seriously contemplate the future viability of the ICF' (Helander 2003).

Codification and Classification

The ICF approach despite its attempts to consider both individual impairment and social/environmental factors is essentially a health status classification mechanism (Bury 2000) used by states to aid in the identification of individuals in governing the population; and according to Foucault (1977) this practice of scientifically individualising people is a way to achieve social control. The categories used to classify individuals are developed through the implementation of social processes that determine what features or malfunctions are medically defined as abnormalities requiring treatment (Barnes, Mercer & Shakespeare 2005). It is no wonder that Imrie (2004:297) considers the ICF to be reinforcing traditional biological reductionist medicine, because it is constructing a subjective interpretation of the reality of those with particular personal or behavioural traits, and creating and foisting upon them medicalised labels and classifications. Simon Brisenden, a

disabled independent living pioneer, argues that those categorisations and labels are 'nothing more than terminological rubbish bins into which all the important things about us as people get thrown away' (Brisenden 1986:21).

The practice of codification and classification, like colonisation, projects the unequal assimilation of people into wider society based on notions of difference. In short, it places individuals into a social stratification system that privileges and endorses particular forms of behaviour, functioning and appearance and oppresses specific characteristics not present in the dominant group. Adversarial relations then develop through the disparate distribution of power and resources. In addition, this reductionist approach which constructs a theory around a perceived normal body assumes an objective state of normality is to be achieved which in itself perpetuates the predominant fundamental philosophies of natural physical superiority, that the disabled body is inferior, and broken (Thomson 1997).

Developing a unified model of disability that embraces bodily subjectivity, individual experiences and social interactions is, of course, always going to be difficult and this is especially true when considering the contextual complexity of disability in contemporary society. But, too often assumptions are made that the codification processes are universally transferable without due regard to cultural distinctions.

Bio-psychosocial Context

Little is also known of the conceptual origins or the operational and practical uses of the bio-psychosocial model championed in the ICF which aims to 'achieve a synthesis thereby providing a coherent view of different dimensions of health at biological, individual and social levels' (WHO

2001:20); nor are its theoretical origins adequately specified or justified (Imrie 2004). Despite it being designed to locate disability in relation to the interconnections between physical, mental and social environments, there is some confusion with interpreting that concept as it is not explicit in the ICF. This lack of clarity of its multifaceted components has led to interpretational diversity. Imrie notes that it is not always possible to differentiate between:

> The variation of human functioning caused by ... the loss or abnormality of a body part i.e. impairment; difficulties an individual may have in executing activities i.e. activity limitations; and/or problems an individual may experience in involvement in life situations i.e. participation restrictions (Imrie 2004:290).

For example, an environmental barrier that hinders participation may at the same time be a facilitator to participation in an alternate set of circumstances. Also, extraordinary manifestations of bodily or cognitive functionality may be considered to be anomalous within a particular society, and a social norm in another. The point being made is that what is missing is a clear understanding of disability contextualisation in relation to the intrinsic (impairment) and extrinsic (social, cultural, physical, environmental) factors which cause even people with the same impairment to experience disability differently.

One of the objectives of the ICF is 'to permit comparison of data across countries, health care disciplines, services and time' and another is 'to provide a systematic coding scheme for health information system' (WHO 2001:5) but there are references in the literature showing that interpretational difficulties makes these very problematic. Diverse interpretations will invariably cause differing countries to develop divergent measurement standards and this has been noted by researchers who demonstrate that disability as a category within survey instruments has been

constructed rather arbitrarily resulting in statistical anomalies and empirical weaknesses (Shakespeare 1996). Robson and Evans in their review of international data on children with disabilities note that:

> Good data sets do not currently exist. Existing data sets are fragmentary and inconsistent in their definitions of disability. They provide little basis of meaningful international comparisons and, with some exceptions, are of unknown reliability and validity (Robson & Evans 2005:35).

Overview

There are critics who believe that using the ICF in its current form is difficult and unlikely to aid in the enrichment of disabled people's lives (Oliver, Sapey & Thomas 2006). However, even with its shortcomings and theoretical limitations, the ICF should be recognised for the role it has played in moving the disability agenda forward from one that was fundamentally medical disease-orientated to a more holistic concept where biological, social and cultural boundaries traverse and meet. There is also something to be said for its powers in offering an interpretation of disability which has at its core the insistence on the reduction of barriers and the creation of a more inclusive society.

As suggested by many scholars, Westernised frameworks need to move towards a deeper theoretical understanding of disability as it is experienced in non-Western societies. It is therefore anticipated that as the debates continue, and limitations and anomalies with the theoretical base of the ICF are unearthed, it will evolve over time to take account of the social spaces within which disability is located, as well as the individualisation of the lived experiences of those with impairment limitations. Disability scholars do however understand that this is by no means an easy task to accomplish not only because of the language and science behind it, but also because

of the politics and culture (Oliver 1996). In spite of that, revisions are unquestionably required because in its present form the imposition of a universalised framework grounded in a discourse of normalisation will more likely favour dominant groups as the actual lived experiences of disabled people continues to be systematically excluded.

2.2   Individual Models

This section covers a range of models of disability relevant to this study that share a common focus on the individual.

Religious/Moral Model

Even though the religious/moral model is historically the first implicit disability conceptualisation, and the religious command that 'Thou shalt not curse the deaf nor put a stumbling block before the blind, nor maketh the blind to wander out of the path' (Leviticus 19:14) is thought to be the first attempt at disability legislation (Daniels 1997 in Braddock & Parish 2001:11), Western debaters do not consciously consider disability in the context of religion (Miles 1995). However, it is unwise to ignore the role of religion because in many non-Western societies religious doctrine is the main means of legitimising attitudes and behaviours and of measuring social norms (Barnes & Mercer 2005).

Religion has historically been the 'all-embracing way of life' as opposed to the modern Westernised concept of 'individual sets of beliefs and values amongst a minority within a secular state' (Miles 1995), and for societies attempting to reclaim an identity which is separate and distinct from the one imposed during colonisation, many have found solace and fulfilment in their historical religious/spiritual beliefs. This reclaiming of cultural capital, the

embracing of rituals and ceremonial practices and spiritual habits, and strong beliefs has an extensive role in the pursuit of meaning and the way life is experienced (Henry 2001)

In undertaking a perusal of religious text I came upon a vast number of references to the body and disability, with the body conceptualised as the mandatory path to higher spirituality (Shildrick 1997). In the texts bodily difference is interpreted according to stated theological references underpinned by cultural values rather than a scientifically proven knowledge. The beliefs and values of disability are often referenced in affiliation with sin, shame, punishment, good or evil, and in many societies those religious judgements of what is good and bad/evil are instilled as a moral compass governing individual behaviours in relation to social and spiritual lives and relationships. For example in the Holy Qur'an a Prophet was reprimanded for neglecting to attend to a blind man who sought his assistance (Miles 1995) and this is translated into everyday Islamic life that the needs of those less fortunate in society should not be ignored. In the Christian text of Leviticus the impaired person is defective, with the impairment being a legitimate reason for discrimination and ostracism: 'the leprous person who has the disease shall wear torn clothes, and let the hair of his head hang loose, and he shall cover his upper lip and cry out 'unclean unclean'. He shall remain unclean as long as he has the disease. He is unclean. He shall live alone. His dwelling shall be outside the camp' (King James Bible Leviticus 13 45:46). Having said that, there is diversity in religious interpretations and that social deviance perspective is not present in all texts. In the Holy Qur'an there are scripts which concentrate on the notion of disadvantage that is created by society and imposed on those individuals who may not possess the social, economic or physical

attributes that people happen to value at a certain time and place (Bazna & Hatab 2005:5).

There are a variety of theological viewpoints and in some societies these have become enmeshed in indigenous beliefs, with many traditional/folk medical practices and healing rituals providing meaning to the experience and offering a sense of purpose and direction. For non-Western societies those belief systems are important in contextualising the perceptions, the causes ascribed, and the required responses to disability.

Obeah which originated in West Africa is one such enmeshed practice which is associated with religion, folk magic, and mysticism similar to Voodoo and Wicca. Its underlying principles are positioned within a system of forces/powers which for the unbelieving and those unfamiliar with its cultural context raises questions of logic and reasoning. McCartney (1976) in his research on Obeah in the Bahamas noted that for many it is looked upon seriously and offers a causation and response to disablement. For those who believe, Obeah like other traditional folk practices evokes positive emotions which afford respite and relief from daily struggles, giving a sense of connectedness, behavioural structure and guidance (Koenig 2001).

McCartney explains that a faith healer, who may be solely a religious healer or an Obeah practitioner or a combination of both, often interprets disability as being the result of a spell or hex in which an evil or bad spirit causes a mental or physical impairment. Thus religious healing and/or Obeah rituals will be used to repel the evil manifestation. That notion of evil manifestations is prevalent amongst many Latin American countries with evil eye or 'malojo' being thought to be responsible for 'general wasting and debility' (McCartney

1976:7). In societies where religion, spiritual and magical ways of thinking are dominant it stands to reason that disability will more likely be perceived as the result of witchcraft or punishment by Gods for moral imperfections or sin (Oliver 1990).

Disability can also be conceptualised as part of a learning process in religious models:

> one of the basic principles of Islam is to believe in the wisdom of the Allah in what He creates and commands, and in what He wills and decrees, in the sense that He does not create anything in vain and He does not decree anything in which there is not some benefit ... He created his slaves with differences in their bodies and minds, and in their strengths ... When the believer sees disabled people he recognises the blessing that Allah has bestowed upon him, so he gives thanks for His blessing (MDAA Ethnicity and Disability Factsheet undated).

A similar lesson is also evident in the notions of Karma in Hinduism which is based on the premise that the way this life unfolds is a direct retributive consequence of the way previous incarnations were lived. Therefore, disability may be punishment for past misdeeds or it could be a rehabilitative experience to overcome past life arrogance (Miles 1995).

Alternatively, disablement may also be a reflection of Christ's suffering and could be explained as an angelic or miraculous intervention designed to challenge chosen people (Ingstad 1997) as in noted in John 9:1:3: 'It was not that this man sinned, or his parents, but that the works of God might be displayed in him'. In such situations, disablement is positively accepted however the idea of not seeking to remedy impairment may be uncomfortable for those in the West especially because the dominant

discourse medicalises impairments and seeks a status of physical normality (Miles 1995).

For those disablements which are not considered as blessings or angelic miracles there are shared explanatory narratives that legitimise the use of prayer, exorcism, sacrifice, and rituals as coping mechanisms. These narratives have deep social and moral implications, particularly when derived from religious scriptures, such as:

> Every bodily infirmities, unless very grievous, should not keep us from public worship on Sabbath days. This woman came to Christ to be taught and to get good to her soul, and then he relieved her bodily infirmity (Luke 13:18).

Here, disability is interpreted as a characteristic of the individual to be endured.

Curiosity around the intertwining of religion and disability has led to some research in the area with one such study which was done by Idler and Kasl (1997) concluding that belief in religion is in some way attributable to improved health outcomes and changes in perceived levels of disablement. Given those findings there is surely something to be said for the role and importance of priests, imams, Pundits, evangelists, Obeah practitioners, shamans, shango priests, and witchdoctors in the medico-cultural spectrum of human existence of which disability is a part (McCarthey 1976). Miles makes a pertinent argument that in developing global efforts to improve the situation for disabled people it is unwise to maintain a Eurocentric outlook that neglects the historical beliefs and attitudes inherited from the world's major non-Christian religions. Although some of the religious/magico beliefs and practices may seem bizarre they all have their own socio-cultural logic

that can be enlightening challenges to Western discourse and practices (Miles 1995:62).

Disability models have often been founded on situational contextualisation, and as stated previously, in societies with strong theological Christian doctrines, the cultural responses of the religious/moral model of disability are quite dominant. The synergising of scientific bio-medical health approaches with religion and spirituality is evident in the refusal of Jehovah's Witnesses to accept medical interventions in the form of blood products; instead relying on their religion conviction because giving in and accepting treatment will indicate a lack of faith (Barnes et al. 2000).

Belief systems which seem unconventional to the Western norm have often been overlooked in disability debates and theorisation especially where it is constructed through the eyes of a sceptical critic who will undoubtedly ignore the strong cultural blending of spiritual/traditional and bio-medical explanations as practiced in some societies. This is despite research showing that as far back as the fourteenth century, doctors/healers were 'priests of the Gods, lawgivers, magicians, mediums, barber-pharmacists or scientific advisers' (Illich 1976) which is reflective of a blended religious/magico-biomedical approach to disablement. A study undertaken by Harvey and Silverman (2007) also shows how that blending of conscious and unconscious cultural structures including those of spirituality and religion play a key role in making meaning of lived experiences of disability.

Disability is referenced in Islamic scripture from a socially inclusive standpoint. One such example is when a blind man said to the Apostle of Allah (PBOH) 'I have no one to guide me to the mosque' and asked

permission to say prayer at his house. Permission was granted and the Holy Prophet asked 'Do you hear the call to prayer?' the blind man said 'yes' to which the Holy Prophet said 'respond to it' (IslamKotob 1990 Prayers 4:1373). Fundamentally, in most religious teachings there is a responsibility to protect vulnerable people.

That compassionate approach to disability is also evident in Hinduism, Christianity and Islamic tests with charity being a fundamental part of their teachings. One of the 'Five Pillars of Islam' is for mandatory alms giving:

> Alms are for the poor and the needy, and those employed to administer the (funds); for those whose hearts have been (recently) reconciled (to Truth); for those in bondage and in debt; in the cause of Allah; and for the wayfarer: (thus is it) ordained by Allah (PBOH) (Holy Qu'ran The Repentance 9:60).

However this emphasis on hand-outs perpetuates the pity/needy perception that many consider to be disempowering to disabled people. It is also at odds with rights-based activists even though it has shown to create a steady source of income for disabled South Asians (Whyte & Ingstad 1995).

Tragedy/Charity Model

The tragedy/charity model which emerged along the lines of the religious/moral model is an ideological construct based on the premise that disability is 'a tragedy or a loss causing suffering and blighting lives' (French & Swain 2004). The moralistic assertion is that disablement is a dilemma resulting from bodily failure and that disabled people are the victims of circumstances, thereby requiring pity as an appropriate emotional response to their impairment. The end result is the devaluing of disabled people and the reinforcing of stereotypes that they are incapable, incompetent and in need of charity (Coloridge 1993).

The application of the tragedy/charity theory to disabled people also presumes that they are dependent, unable to enjoy economic wellbeing, and that they want and need society to support them as they strive to attain able-bodiedness (Fulcher 1989). Jenny Morris, a disabled feminist and author, summarises her experience as follows:

> Our disability frightens people. They don't want to think that this is something that might happen to them. So we become separated from common humanity, treated as fundamentally different and alien. Having put up clear barriers between us and them, non-disabled people further hide their fear and discomfort by turning us into objects of pity, comforting themselves by their own kindness and generosity (Morris 1991:192).

Disability is problematised and the 'otherness' of disabled people is what causes their categorisation as suffering, broken or imperfect and in need of fixing, and it is that which perpetuates the ideology of normality. The personal tragedy discourse is so often seen in the media, particularly where emotive advertising and stigmatised representations of disabled people can be used for financial gain in the guise of a charitable cause. Unfortunately, impassioned disability representations are often accompanied by euphemistic labels, and insulting and demeaning imagery with the expressed purpose to communicate the message that disabled people are unfortunate victims of a personal tragedy that necessitates eradication or normalisation by any possible means (French & Swain 2004). Moreover, it reinforces the idea that disabled people are all striving for normality and able-bodiedness. The assumption that disabled people are in need of and desire fixing sustains a dominant role in the discourse for medical professionals who seek to remedy and correct what they perceive to be bio-psychological abnormalities. This expectation of requiring physical and psychological interventions to achieve normality is itself a cultural representation of the medicalisation of disability.

Medical Model

The medical model of disability has held a significant role in the conceptualisation of disability and has its roots in the ideology of determining physical difference and perceived bodily abnormality, as well as the recognition of functional limitations or psychological losses caused by impairments. It has been suggested that it emerged in line with the professional and technical advancement in Western medicine during the nineteenth century (Drake 1999), having evolved from a disease model to one of medical functionality that incorporates the belief that those with impairments are judged on what they cannot do and that they are malleable, and therefore they should be treated (Barnes & Oliver 1993).

The model which is defined as a contrast to the charity model's moralistic view of disability has as its main motivator the fixing of biological defects and bodily failures to achieve a state of normality (Price & Shildrick 2002), as opposed to the idea of victimhood and pity. However, both the charity model and the medical model focus on individual impairment and they invoke fear because of the assumptions that a pre-requisite to being assimilated into what is deemed to be 'normal' society is for any impairments to be mended at all costs. But how is this concept of normal society being defined? Does 'normalcy' in a Western context have the same conceptual meaning to individuals in a post-colonial state when considering what the loss of agency means, and what the dominant minoritising discourse is in such a state?

The main focus within the medical model, which Oliver refers to as 'the ideology of normality', emerges because of the way in which normality is constructed; it distorts human relationships to establish the concept that it is

the biological body which shapes and informs human existence (Drake 1999). Imrie notes that:

> The dominant way of thinking about disabled people is related to the functional limitations paradigm, which asserts that the most significant difficulty with disability is the loss of physical or occupational capability. This perspective argues that the disability resides exclusively with (in) the individual that is reducible to the nature of the impairment and is treatable much as a doctor would attempt to cure a patient's disease. A range of research shows the medicalisation of disability as a significant factor in society's treatment of disability issues (Imrie 1997:264).

This medicalisation is also suggested in Safilious-Rothschild's (1970) functionalist rehabilitation role approach, which has as its theoretical base the notion that when an individual becomes aware that they have an impairment, they must learn to accept their disability and seek to maximise their abilities with the help of professionals. Proposing that although the political, social and economic needs of disabled people have not been factored, they are still expected to come to terms with their disability and conform to the social norms of their contemporary society. Basically, they are expected to mirror normal functionality as much as possible as the assumption is that disabled people wish to strive towards 'able-bodiedness' so that they can emulate and conform to social norms. What this does, is that it reinforces a dependency upon health professionals, who will be required to provide and deliver rehabilitation services, and although most disabled people will not question the desire to receive medical attention if and when required, the work of the medical professions feeds into the societal expectation of normality. This preoccupation with 'fixing disabled people' is evident in the training of medical professionals and their socialised understanding as being experts in 'normalising' people (Oliver 1990). Illich

shows how medicine as a social institution is responsible for creating additional burdens of illness and disability in society, noting that:

> children learn to be exposed to technicians who in his presence, use a foreign language in which they make judgements about his body; he learns that his body will be invaded by strangers for reasons they alone know; and he is made to feel proud to live in a country where social security pays for such a medical initiation into the reality of life (Illich 1976:9).

Indeed, disabled individuals are expected to endure psychological or physiological interventions as they endeavour to cure, heal, correct or halt any impairment as long as the end result is the achievement of able-bodiedness. This determinist expectation encourages behaviours and attitudes that are in keeping with the medical profession's perception of reality. But such concepts have profound implications as they subliminally educate the population that what is required for those with impairments is professional help in order to come to terms with and where possible seek treatment for their 'lack of normality' (Oliver & Sapey 1999). This was evident in the ICIDH which emphasised the classification of health components and the implementation of interventions.

Over time medical practices have become so professionally organised that they undermine (whether consciously or not) the ability and freedom of disabled individuals to face up to their lived realities, to express their own morals and values, and to accept their impairment and pain. This is particularly so because disabled individuals have an emotionally vested trust in those they recognise as having legitimate power over them. If one is to consider the medical professionals' dominant role in the matrix and their emphasis on returning the body to 'normality', it is clear that there is often very little scope for disabled people, families and their carers to fully

participate in the decision making processes which affect their life outcomes. This is because the authority of professional dominance afforded to medical professionals enables them to exercise power and control over the population, in part due to the superiority that comes with such social positioning. This is especially relevant in T&T given the imperial processes of post-colonialism and other societal prejudices through which agency has been denied to particular groups.

The professional power can often be seen in the development and implementation of bureaucratic state structures, which according to Foucault:

> categorises the individual, marks him, by his own individuality, attaches him to his own identity, imposes a law of truth on him which he must recognise and which others must recognise in him. It is a form of power that makes individuals subjects, as a form of power which subjects and makes subjects to.. The State's power… is both an individualizing and a totalizing form of power (1992:212-3).

Evidence of this is in the state processes of labelling and categorisation and its construction of an individual's identity as 'officially disabled' by medical professionals who have attributed their own interpretation of a pathology and identity, taking away the individual's autonomy. With this state defined identity also comes an artificial dependency on the state in terms of social welfare and care, the recognition of the entitlement to certain rights, and the acceptance of social stigma and economic exploitation.

Critiques of the Medical Model

The medical model of disability has been debated extensively and heavily criticised. Its functionalist theory has been challenged by Oliver (1996), who argues that it is inadequate, lacking acknowledgement of the socio-political and economic factors, as well as the actual experiences and subjective

interpretations of disability and that it is the medical professionals' judgements of what are positive behaviours and attitudes that are used as a yardstick. Oliver is also against the notion of an overarching medical model of disability and instead considers it to be an individual model, of which medicalisation is a significant component of a 'bio-physiological abnormality'.

Other disabled critics have also successfully argued that the medicalisation of disability which aims to return the individual to 'normality' represents a subjective positioning embodied in the construction of difference, Brisenden notes that:

> Medical people tend to see all difficulties from the perspective of proposed treatments for a patient, without recognising that the individual has to weigh up whether this treatment fits into the overall economy of their life (Brisenden 1986:16).

In essence what is created by the model is a preoccupation with treatments and cures, which displaces the disabled individual from their social context and excludes them from key decision making processes.

It is clear that these conceptualisations do not recognise or accept that the quality of life of the disabled person depends on them achieving the lifestyle of their choice in relation to their own cultural context. We should be clear that this does not mean that disabled critics are saying that there should be any denial of the positive influences of medicine and charity on the lives of disabled people or denial of the physical pain or otherwise discerning effects of impairments, or that medical intervention should cease. Thomas notes that 'The potential for impairment to limit activities is not denied, but such restrictions do not constitute disability' (Thomas 2004:43). In fact, Jenny Morris and Liz Crow, both disabled writers, demand an acknowledgement of

the pain, tiredness, and physical or intellectual limitations that affect disabled individuals. Instead, what is being championed is a new disability paradigm that shifts attention away from overcoming and removing the impairment through the rehabilitation of the body to normality and takes account of the complexities and contradictions that create the experiences of being disabled. Crow postulates that:

> What we need is to find a way to integrate impairment into our whole experience and sense of ourselves for the sake of our own physical and emotional well-being, and, subsequently, for our individual and collective capacity to work against disability (Crow 1996:60).

Another important element missing from the medical approach is that in contemporary society conventional medical interventions are so often intertwined with other therapeutic systems. As discussed earlier, research shows that where faith, spirituality and traditional folk medicines are combined with conventional medical practices, they collectively affect impairment interpretations and experiences. For example Livingston (2006), in her research on an African History of Disability, notes that:

> Other therapeutic systems have produced knowledge that reveals our notion of individually bounded bodies to be yet another folk tradition, while also producing different idioms and networks through which stigma and power operate (Livingston 2006:117).

Medical Model and the State

The individualisation of disability that places pressure on disabled people to conform to perceived social norms has proven to be economically and politically beneficial to the state. This is because it encourages and has enabled the development of related industries ranging from bio-medical services to technological services, as well as services related to political human rights movements. This is exemplified by Albrecht (1992:28), who

notes that 'selected sets of social relationships are judged undesirable, dysfunctional or deviant and are targeted for interventions', leading to the profitability of the rehabilitation industry. This profitability has promoted the mushrooming of the numbers of disability related charitable organisations and rehabilitation services such as speech therapists and physiotherapists, who owe their livelihoods to the concept of having to 'medically' fix disabilities (Gusfield 1989).

State policy development and service delivery is grounded in the misconception that disabled people belong to a homogeneous group and the premise of the functional limitations paradigm that individuals should achieve an objective state of normalcy. Thus creating an environment where the focus of attention is on biological determinism and the assumption that the issues faced by disabled people can be resolved simply by applying a bio-medical solution of intervention, treatment or rehabilitation. This is done to the detriment of those who celebrate their difference, but have an imposed presupposition of diminished personhood foisted unto them, taking away their individual autonomy. In effect, through its function and structures the state reinforces the incorporated construct of disability as an unfortunate individual attribute caused by impairment.

To summarise, the individual model of disability distinguishes the bio-medical differences between individuals with impairments and the rest of society, with their quality of life and life outcomes measured according to the functional limitations of their impairment. As this largely ignores the other socio-cultural factors, what is being advocated is an approach that upholds the relationship between the individual and society; one in which interventions are guided by an understanding of the bigger picture and recognises the

social norms in the contemporary society in which disability is being lived and experienced.

2.3   Rights-based Model

Alternative views to the individual models of disability have always been present amongst disabled people (Scotch 2002), but in recent years the emergence of further research into their personal experiences, strong campaigning by the disability rights movement, and the evolution of disability studies as a discipline in its own right has led to a fundamental reconceptualisation of disability. A group of disabled scholars and activists came together in the 1970s under the banner of the Union of the Physically Impaired against Segregation (UPIAS) and developed a counter discourse to the individual model that revolutionised the understanding of disability internationally (Goodley 2011).

The resolve of the redefinition was to 'break the link between our bodies and our social situations, and to focus attention on the real cause of disability i.e. discrimination and prejudice' (Shakespeare 1992:40). The desired outcome was a major shift from the individual model of corporeal deficit, to one that situates disability within the wider social environment. This expanded view of disability which factored in the processes of inequalities, social oppression and exclusion was enthusiastically supported by many disabled people as the 'new orthodoxy' in conceptualising disabilities (Oliver 1996; Priestley 1999). As such the reconfigured model has been embraced across the international disability community as an instrument for removing societal barriers of discrimination, oppression and environmental obstacles, with Bengt Lindqvist the UN Special Rapporteur of the Sub-Commission on Prevention of Discrimination and Protection of Minorities affirming that:

Disability is a human rights issue. So long as Persons with Disabilities are denied the opportunity to participate fully in society, no one can claim that the objectives of the Universal Declaration of Human Rights has been achieved (DFID 2000:5).

However, notwithstanding those advancements that shifted the emphasis away from impairment and towards social environment, questions have arisen regarding who is privileged by this model; how is this rights-based model able to help the most disadvantaged in society, especially those who are less able or have the capacity to come together to assert their rights; and how does the notion of rights translate to post-colonial societies where rights have historically been devalued and the concept of equal rights may appear as a foreign concept? Borsay (1986) speculates that it is the most disadvantaged who are the least likely to be able to assert their rights, and that it is those in the upper classes who stand to benefit the most from this positioning. It is also the case that those with wealth will evidently have different experiences of impairments and disability in comparison to the disadvantaged, particularly those who rely on state social welfare. Moreover, the imposition of Western notions of empowerment and rights are not easily transferrable to cultures structured along religion and/or communal decision-making processes.

Social Model

Activism amongst the disabled people's movement and the redefinition of disability in the 1980s gave rise to a contrasting ideology which challenged the hegemony of the individualised model. This created a new paradigm which became known as the 'social model' of disability, a term credited to disabled scholar Michael Oliver (1996). In presenting a picture of the way in which disability has been socially produced, it sought to shift the focus away

from the functionalist individualised bio-medical paradigm to one centred on the relationship between individuals with impairments, social obstacles and barriers. Patterson explains that:

> Disability is not the outcome of bodily pathology, but of social organisation: it is socially produced by systematic patterns of exclusion that were -- quite literally – built into the fabric of society (Hughes & Patterson 1997:328).

Oliver in coming up with a reconfigured definition of disability, asserted that there should be 'A presence of an impairment; the experience of externally imposed restrictions; and self-identification as a disabled person (Oliver 1996:5).

Vik Finkelstein, a disabled psychologist and activist has argued that disability is a paradox involving the disabled individual and societal restrictions rooted in industrialisation (Barnes & Oliver 1993). A central tenet of his model is that individuals with impairments were redefined as disabled by the capitalist system, which was the reason for them experiencing social oppression and discrimination. He postulates that their autonomy and personhood was undermined by the personal tragedy assumptions which relegated disabled people to a subordinate role requiring care, help and special treatment. But this context not only ignores the complexities of post-colonial societies with a history of cultural, economic and political oppression and the resultant privileging and loss of agency that are part of the colonising of indigenous cultures, and it also neglects to take account of the other frameworks within which prejudice exists for example race, gender and social status.

There is no denying that the social model has played a significant role in politicising the discourse moving the discussion away from disability as a

property of the body to one which encapsulates social and cultural processes. Shakespeare (2006), a disabled scholar, is one of a growing number who have highlighted its shortcomings and he argues for what he defines as a critical realist approach to the model. His point is that those activists who stick rigidly to the social model in its current form are denying the relevance of the body and ignoring impairments because disability is experienced in a very complex way. This argument is supported by others who question the validity of underplaying the significance of impairments and the danger of devoiding the embodied experiences of disabled individuals for whom it forms a major part of their identity (Morris 1991; Crow 1996).

It is because of these oversights that Thomas and Shakespeare call for a re-examination of the social model with Shakespeare noting that, for many, 'behind closed doors they talk of aches, pains and urinary tract infections' (Shakespeare 2006:52). This point is reiterated by Chapelle et al. (2001) noting that the model does not account for differences in, for example, individuals with intellectual disabilities for whom the physical environment may not be disabling. Oliver does however present counter arguments to many of the debates on the lack of emphasis on impairment by claiming that the social model is not based on the personal experience of impairment, but rather on the collective experience of disablement, because impairment is just a descriptor of the physical body (Oliver 1996)

Lived Experiences

There is no doubt that the social model has had a profound impact on the promotion of values and self-worth for many disabled people as it has helped them to adjust to the psychological aspects of their lived experiences. Crow (1996:1) states that the model has impacted positively on her and that

'discovering this way of thinking about my experiences was the proverbial raft in the stormy seas. It gave me an understanding of my life, shared with thousands, even millions of other people around the world'. However, she too is aware of its shortcomings:

> So how is it that, suddenly, to me, for all its strengths and relevance, the social model doesn't seem so water-tight anymore? It is with trepidation that I criticise it. However, when personal experience no longer matches current explanations, then it is time to question afresh (Crow 1996:56).

It has even been criticised by Vic Finkelstein, who is one of its founding fathers. He has questioned its ability to fully explain the social position of disabled people in modern society (Oliver 1996), as well as the issues of historical specificity and socio-economic status. These are important points especially when trying to figure out how its application might influence professional practice and shape political action (Oliver 1996). It is therefore apparent that in its present form it lacks a thorough consideration of the life experiences of disabled people. Abberley (1987) for example, highlights its failure to consider the internalised oppression and social exclusion created by the individual's inability to fulfil societal standards due to the existing ideology of 'able-bodiedness' and 'normality'.

Some argue that the social model presents disability as a homogenous unitary concept; disabled people are portrayed as victims; and in issues relating to the cultural politics of their other intersectionalities of gender, race, age, sexuality, the experience of being disabled are underplayed (Riddell & Watson 2003; Shakespeare et al. 1996). It is this simplification of what is in effect a complex social identity into a 'straightforward, uncomplicated manner', that convinces 'a very sceptical world that disability can be reduced or eliminated by changing society, rather than by attempting

to change disabled people themselves' (French 1993:24). There are those like Miles (1995) who reject outright the social model as a theoretical grounding for disability in developing countries and while there is some validity that it is dangerous to take theories developed in the West and impost them on to non-Western societies it does not seem realistic to refute the idea that a social definition of disability cannot exist in non-Western countries.

Oliver (1996) is of the view that these issues arise because interpretations of the social model are often taken too rigidly, and it is that which creates the oversimplifications of the realities of disability. Finkelstein does acknowledge that there has been misuse of the model: 'sadly a lot of people have come to think of the social model of disability as if it were an explanation, definition, or theory and many people use the model in a rather sterile formalistic way' (Finkelstein 2001:6). Suggesting that the problems are not within the model *per se*, but in the way in which it is used. In this regard Thomas (1999) proposes a revised definition in which disability is not entirely focussed on the restrictions of activity as a form of social oppression but encapsulates the social reactions that oppress disabled people as well as the psycho-social realities of their experiences. She has created a redefinition of disability as 'a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional wellbeing' (Thomas 1999:60).

Corker (1999:627) also advocates a similar approach that addresses the gaps relating to meaning, difference and agency and pays attention to the 'relational, mediatory, and performative role of discourse [...] and the increasing importance of local knowledge in shaping the social and political

world'. This is supported by Abberley's position that the notion of a barrier-free utopia is not a viable option and that the historical experiences of disability must be factored in to the social model. He contests that consideration must be given to the economic and social exclusion and issues around sociology of sex and race. Abberley notes the model's inadequacy to include the 'historical biological component' of oppression, for example the internalised oppression brought on by an individual's inability to fulfil societal standards due to existing ideologies of 'able-bodiedness' and 'normality' and the way in which biological differences influence acts of oppression. These are all very pertinent points in relation to populations who have endured the legacies of colonialism and its influences on the privileging and marginalisation of individuals based on biological determinisms.

Implicit in the criticisms of the model is that to make sense of disability and the Western concept of equal rights in collective cultures, particularly where there are culturally orchestrated dynamics around subordination and entrapment, would require deeper understanding of the social and political structures. For example amongst Indian communities oppression is experienced because of the socially defined rules which then create lack of support and opportunities, ostracism and disownment (Sonuga-Barke, Mistry, Qureshi 1998). This especially happens to individuals who choose to marry outside of their caste, religion, or race as such socially contradictory actions are considered to be damageing to family reputations.

Amongst collective cultures there are very complex power relations, for example the honour system with its engendered undermining of particular individuals and where excessive control is exercised over women, their sexuality and body. It is the case in some Indian communities that the

societal power of the in-laws is such that they exercise subordination over married women (Lindisfarne 1998). Gilbert (2002) also examines how in collective cultures emotions such as shame not only manifest themselves in the individual's behaviour because of their negative self-perceptions or concern about the way that others view them, but also significantly affect the rest of the family and in some instances the community as a whole. A critical look at oppression and prejudice in post-colonial countries will also unearth issues on the hierarchies of colour and skin tone bias and how that can affect the social and economic positioning of individuals. This skin colour stratification which according to Hunter (2002) is attributed to 'internalised colonialism' continues to exist in some countries in the form of white/light skin privilege.

Situations like these show that the rights-based model cannot be viewed in isolation but that some reconfiguration would be required that provides a critical analysis of the social relational experiences of disability in contemporary society. This is supported by Corker who considers that the 'current approaches to theorising disability as a form of social oppression and their relationship to disabled people's experiences are hampered by a modernist conceptual framework, which is increasingly at odds with the contemporary social world and with developments of theory making as a whole' (Corker 1999:627).

The social model which has become the dominant approach, has undoubtedly been a force for change in the disability arena and there is no denying it has revolutionised the way in which disability is considered, particularly in the West. It has been responsible for politicising the way in which disability is perceived and understood, and has been the instrument

through which a great deal of positive activity has occurred in relation to policy development.

2.4 Summary

Given the criticisms of the medical and social model, my view is that the emphasis should not be placed on a singular approach because although there is a contrast between the individual model and the rights-based model, they are not mutually exclusive and as such can co-exist and overlap. A reconceptualisation of existing theories embracing various schools of thought will create a much more appropriate social relational model of disability that addresses the global experience of disability. That is because the contradictory cultural constructs are too complex to be rendered within one unitary model or set of ideas. Firstly, there are a wide range of impairments which are positioned under the disability umbrella, from physical impairments to psychosocial, intellectual and learning disabilities, and they all have distinctly different effects on the lived experiences of individuals over their lifetime. Another dimension is the intersection of disability with other axes of inequality, for example race, religion and gender, and the way in which those social positions are privileged in specific social and cultural systems. In addition, there is also the challenge of impairment in relation to notions of embodiment, and the differentiation of bodily functioning is socially construed as normal/abnormal. All of these would be better understood through a social relational theoretical approach.

2.5   Disability Identity

Disability identity is a complex construct influenced by the social processes of power, identity politics, societal disablement and cultural representations.

These complexities are all part of the contemporary debates which has led Shakespeare to come up with three categories of disability identity – the personal, cultural and political (1996).

Disability as a Personal Identity

It is apparent that the contested meaning of disability is an epistemological mine-field as there is no homogeneous identity for disabled people. A review of the literature shows that disability identity is often considered a personal construct: a way of creating meaning for the impaired self in the world (Johnstone 2004). Ultimately, the forming and claiming of identities is about categorisations, preferentiality and the discursive construction of corporeal differences, i.e. the self being aligned with something else and those differences being identified. Phenomenological and symbolic interactionist approaches to identity suggest that disabled people identify themselves using multiple descriptors related to the subjective meanings used to construct their everyday lives. Cultural belief systems, social expectations and economic demands of a society, determine whether a particular bodily or cognitive anomaly will be considered to have a disabling effect and whether or not the individual will experience social exclusion or inclusion (Groce 1999). Therefore the body becomes the site through which meaning is evolved subject to cultural expressions and prevailing ideologies:

> The body constitutes the visible representation of the individual. Its shape, size, colour, presence, functionality and degree of physical intactness, find a resonance in prevailing trends, attitudes and concepts of able-bodiedness and disable-bodiedness (Fawcett 2000:114:115).

Meaning is then created, interpreted and acted upon through interactions with others; Blumer explains that 'these meanings are handled in, and

modified through, an interpretative process used by the person in dealing with the things he encounters' (Blumer 1986:2).

However attempting to self-identify as a disabled person is not always easy for example, individuals with intellectual impairments may not possess the ability or capacity to self-identify. There is also the external attribution of identity which occurs when the definition of self is provided by an authoritative figure. This is apparent in disability identity discourse influenced by professionals using medicalised descriptors to define individuals. Many scholars are against this external attribution of identity, and believe that claiming membership of disability and its related cultures, should not be up to the professionals. Disability identity already comes with its own set of societal stigmas, which cause undue hardship and suffering, therefore individuals should have the option to choose, accept, deny or reject a disability identity. By denying and rejecting disability identity they are then given the opportunity to divert attention away from their impairment. Brisenden makes the point that:

> It is important that we do not allow ourselves to be dismissed as if we all come under this one great metaphysical category 'the disabled'. The effect of this is a depersonalisation, a sweeping dismissal of our individuality, and a denial of our rights to be seen as people with our own uniqueness, rather than as the anonymous constituents of a category or group (Brisenden 1986:21).

Disability theory often disregards that individualised identities are also construed according to experiences and intersections with other characteristics, for example race, gender, class and age (Barnes & Mercer 1997).

Disability and Ageing

In the elderly, disability and the impairments of ageing take on different meanings according to the culture in which they are being experienced. Notions of vulnerability, normality, and dependence inform interpretations of impairments in the elderly, and these differ in contemporary society. But, Western based universalised frameworks continue to place overwhelming emphasis on independence as being the most desirable bio-social state thus overlooking the discourses of social citizenship and the historically important aspects of self-identity e.g. kinship, interdependency, ancestral relationships and the significance of ageing (Livingston (2006). In collective cultures such as in South Asia, family structures are often extended multi-generational units with unique power relations, for example it is not uncommon for new wives to take care of the in-laws (Sonuga-Barke, Mistry & Qureshi 1998). This not only relates to the issue of ageing, but also the intersection of gender. However these relationships are often overlooked within the discourse in regards to disability and ageing.

Gender and Disability

Though both disabled men and women endure the negative effects of disability their experiences are often different with women further undermined by their gender status. For example disabled women are often thought of as 'cute, but not sexy; always the cared for, never the caring' (Blackwell-Stratton et al 1988:307). Gerrschick (2000) noted that disabled men were more likely to be physically abused, and disabled women were more likely to be victims of sexual assaults. Furthermore, even if the disabilities are similar between the genders the experiences are different with disabled women being economically, socially and psychologically worse off (Barnes 1999:87). These may be due to culturally orchestrated dynamics, for example a study

undertaken by Atkin & Hussain (2003) on Muslim, Hindu and Sikh families in the UK found that disabled males were afforded more freedom and privilege while their female counterparts with similar disabilities were overprotected. Examples of this gendered difference are found in studies on the Songye women of Zaire where it is an imperative way of life for the women to undertake tasks such as fetching water, cutting wood and washing clothes, so having an impairment that will restrict those activities will negatively impact on their chances of marriage and family life (Devlieger 1995).

This is not to say that the experience of disabled men is not equally important. Often masculinity is diminished from the male disabled body as it is no longer seen as strong, able-bodied and independent (Morris 1993), also the way in which disabled men determine their self-worth particularly in the context of their bodies, physicality and their sexual orientation is regularly undermined by cultural beliefs and value systems.

Disabled Sexual identity

The elephant in the room is the topic of disability and sexuality as it is rarely discussed. Shildrick 2009 makes the point that attention is rarely given to the sexual pleasures and sexual desires of disabled people except around containing or controlling those sexual expressions. That silence encourages common misconceptions that disabled people, in particular those with physically impaired bodies are asexual and that they are not capable of experiencing life as sexual beings or conversely that those with intellectual disabilities are hypersexual, resulting in either the denial of their sexual desires and pleasure or them being fetishised. (Engwall 2000 In Malmberg 2009, Shakespeare et al 1996, Sildrick 2009). Those fallacies make sexual self-validation difficult especially when disabled sexuality is omitted from

social policy and law because 'clearly some forms of corporeality exceed the limits of what is thinkable' (Shildrick 2009:60).

There is no denying that sexual identity may be difficult for individuals where their cognitive impairments affect their self-concept, however for many that point is irrelevant. But there are accounts in the scholarship of caregivers and parents who possess negative attitudes towards the sexuality of disabled individuals and as such they choose to shy away from the topic, which merely creates a gap in the sexual knowledge of their disabled family members (McCabe 1993).

Sexuality as a cultural construct is further problematised in the context of religion with its defined moral codes that guide sexual perceptions and practices, for example on issues such as homosexuality, fornication and masturbation. There are also religious scripts in which sex is explained as a mechanism for reproduction, so for those disabled people who do not fit that norm of procreative sex they are expected to endure the values of sexual conservatism that tells them that they are meant to be asexual beings:

> a focus on practices, ordered positively and negatively, promoted an economy of sex where expression of sexual desire deemed superfluous to the project of reproduction and mastery of desire, were considered wasteful both in moral and physiological sense (Hawkes 1996:49).

Sexual identity therefore becomes the domain of those who are physically fit and well and who possess bodily perfection, thus positioning disabled people as unsuitable candidates for reproductive sex or sex for pleasure which no

doubt hampers their ability to experience full personhood and sexual citizenship (Tepper 2000).

In societies with strong religious values on procreative sex, the negative attitudes of sex for pleasure, i.e. 'sinful pleasures of the flesh', will undoubtedly affect the intersections between disability and sexuality. Tepper (2000) notes that there are instances where the desire for sex for pleasure i.e. non reproductive sex, is deemed to be a sign of mental illness. It is therefore apparent that where these religious belief systems and creeds are established and projected, vital complexities in the claiming of disability identity will be forfeited, but too often in contextualising the experiences of embodiment, sexuality is neglected although, according to Tepper (2000) sexual pleasure is a powerful antidote to physical and emotional pain.

Disability as a political identity

There has been a noticeable shift away from some of the delimiting notions of disability, as disabled people have begun to actively reclaim their bodies and celebrate disability as a valued identity with a sense of pride and personal enrichment (Fleisher & Zames 2001). This is in part due to the work of the disability movement and the social model approach to countering oppression (Shakespeare (2000).

Reclaiming disability as an empowering identity with its political overtones has been gaining increased momentum with the rise of social model disability discourse. The disability movement has been responsible for creating an environment of disability politics that challenges the concept of disabled people as powerless and passive (Shakespeare 1996). This has strengthened the confidence of individuals to be able to claim a socio-

political disability identity along with the power to inspire and motivate themselves and others, the ability to share power with others, and an opportunity to gain internal strength and self-esteem (Rolands (1995). This politicised identity means that disabled people are able to define themselves as a legitimate group asserting their rights through the establishment of a coalition of a mutual culture that engenders a sense of unity, camaraderie and common purpose. The collective movement also provides a platform for the building of social relationships and friendships, and a place where consciousness is raised as members mobilise to regain control of their actions. In identifying with the collective, individuals are then able to 'reclaim the right to define themselves against the criteria of identification determined by an anonymous power and systems of regulation that penetrate the area of internal nature' (Melucci in Shakespeare 1996:8). This sense of commonality creates a common language, charts the shared experiences of disabled people; uses a collective voice to address disabling barriers, and is described as disability culture, which Barnes and Mercer (2001:525) refer to as 'membership of an oppressed or marginalised group extolling its virtues'.

One of the benefits of having a political identity is that it enables disabled people to challenge the notions that they are lacking or incapable of addressing the issues which affect them. It affords them the opportunity to be the experts on disability creating definitions based on their experiences, rather than the traditional method of professional dominance. However power dynamics are ever present, so personal life expertise is not always acknowledged for the benefit it provides.

The paradox of theorising disability identity is the tendency to ignore the multiple identities that disabled people belong to, and the mistaken belief

that claiming a political identity assumes that disability is a fixed characteristic and not a fluid concept. Political mobilisation also falls victim to this notion of a homogenous disability identity and the misguided impression that the values, experiences and interests of all disabled people will be similar. It stands to reason that assumptions of disability as a static identity will conflict with other intersectional identities and affect the politics that relate to the marginalisation and vulnerabilities of other identities as 'Disabled people as a group, are made up of black people, women, gay men and lesbians as well as white people, men and heterosexuals' (Morris 1991:180).

Shakespeare (1996) uses disability and ageing as one of the intersectional identities often neglected. He notes that those with impairments associated with ageing are not adequately represented in the disability movement, thereby distancing them from sources of collective support and strength. Morris using her personal experience noted that it is 'difficult for us to recognise and challenge the values and judgements that are applied to us and our lives' (Morris in Shakespeare 1996:104).

So if the notion of a collective disability identity is such a powerful and empowering experience, why then do so many people with impairments choose not to identify as such (Galvin 2003). One answer could be that there is the tendency for the work within the movement to be based on the notion of 'wounded identities', which does not actually challenge the biological essentialist assumptions and exclusionary discourses (Davis 1998)

What is clear is that there are several layers to the decision-making process in claiming a politicised disability identity, and given the social relationships

individuals encounter it is possible to manoeuvre between multiple identities. The politics of personal identity and that of collective group identity means that one can have a visible/public or invisible/private identity. It needs to be remembered that disability identity is not only associated with feelings of community spirit and pride, but also with 'feelings of difference, exclusion and shame' (Sherry 2007:10). Those emotions are part of the individualised mode of thought that disabled people are unfortunate victims, and influences the decision whether or not to reject a group identity. Many theorists have discussed the paradox resulting from the desire to have a unified fixed identity in an environment where identity is fluid derived from thoughts, words, deeds, experiences and society's reactions to them (Markell 2003).

Disability as a Cultural Identity

Disability scholars postulate that to understand the processes of the construction and representation of disability, its cultural values and meanings have to be placed within the context of social organisation, but this is often overlooked and is the basis of one of Shakespeare's criticisms of the social model. According to Scheer and Groce:

> A single personal characteristic, such as a physical impairment, does not generalise to define one's total social identity. In complex societies, however social relationships and contexts are more impersonal and task specific, and individuals are not related to each other in varied contexts. Accordingly, visible physical characteristics are commonly used to classify and socially notate the individual's identity (Scheer & Groce 1988:31:32)

But social model proponents argue that disabled people should develop a shared culture to address the issues of oppression on the understanding that sub-cultures are able to challenge dominant cultures (Riddell & Watson 2003).

Because disability experiences differ across cultures, Eddey and Robey (2005) advise of the relevance of including the values, beliefs, and also the needs of the wider network of individuals who are integral to the cultural context of the disabled person such as parents, spouses, partners, caregivers, siblings, children, and advocates. For in many societies, a person's worth is not only measured by their individual abilities and achievements, but their relationships with others are equally important. There are those for whom being an individual and a member of a family and community are considered to be equally or more important than physical appearance or having the capacity to work; however, the challenge is in understanding how disabling characteristics impact on achievements and relationships within a particular cultural context (Whyte & Ingstad 1995). For example dependency and interdependency of disability in old age have different implications in contemporary society, where status and identity is not measured by the physical/cognitive ability of the elderly person, but by their social positioning.

2.6   Globalisation of Disability

The work of a number of global transnational institutions emanating out of the West, for example the World Bank and the United Nations Convention on the Rights of Persons with Disabilities is about development and in that context they have set out to create mandates, treaties and frameworks with the intention of streamlining and regularising policies and practices globally. But the message underlying those systems is that for developing countries to resolve their issues they need to assimilate to Western strategies (Esteva 1992). Crush observes that 'development is fundamentally about mapping and making, about the spatial reach of power and the control and management of other peoples, territories, environments and places (Crush 1995:7) and this

is seen in the global institutions, with their focus on universalising responses to disability which are for the most part exerting their power and legitimacy by deciding how nations across the globe should develop and implement practices and to a large extent they also have a say in how resources are allocated. However, in the process of doing so they ignore the fact that cultural, economic and social interpretations of impairments, as well as the availability of resources, are some of the reasons why impairments are understood and experienced differently in various parts of the world (Barile 2000).

In some respects because this thrust towards universalisation is deficient in its attention to bodily interactions and embodied subjectivity, activists and researchers continue to highlight that the present attempts at implementing global disability frameworks do not sufficiently acknowledge the culturally specific sense of self and others, as being part of how disability is negotiated and experienced.

Globalised processes have reduced commonalities to equivalence, ignoring that cultural diversity such as the specific economic, ideological and political forces and the local beliefs, values, practices and attitudes are part of the dynamic that gives meaning to the experiential realities of disability. For example in developing countries the characteristics of the local economy affect the way in which particular disabilities are privileged over others. There are also cultural specificities regarding impairments that are acquired through the process of ageing later on in life and the socio-cultural values associated with elders in the community.

By ignoring those specificities, the international structures run the risk of drowning out traditional ways of life in less powerful countries by creating ambivalence and uncertainty in the population, and reinforcing the belief that cultural practices that differ from the West are to be scorned and derided which propagates the demeaning of developing world cultures. Coleridge rightly states that 'Development activities which ignore culture as the sum total of people's political, economic, social and spiritual aspirations will inevitably lead to alienation, exclusion and loss of identity as well as loss of sense of identity (Coleridge 2000:24).

The UNCRPD does claim to recognise that disabled people experience discrimination due to a multiplicity of social factors "on the basis of race, colour, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age, or other status" (UN 2006: Preamble). However, even though these factors have been noted, the imposed classification systems assume that impairments are objective, trans-historical and trans-cultural, and that disabled people have universally identical realities. Goodley citing Hardt and Negri, argues that 'empire is conceived of as a postcolonial and post-modern process in which knowledge, partly from the Global North, spreads across the globe in ways that are, potentially imposed upon, taken up or resisted by citizens in local contexts' (Goodley 2011:164). This is the case even when it is apparent that the legacies of colonialism, missionary influences, industrialisation and globalisation all impact on the ways in which agency is exercised and disablement experienced. In her research on disability in India, Ghai explains how despite the changes in terminology being undertaken in congruence with the international standards stipulated by the UN and WHO, the social and cultural perceptions were not altered and instead the predominant responses

of charity and philanthropy endured and continued to be reflected in state policies (Ghai 2002).

More recently it is the rights-based ideology that has been touted internationally, with countries being actively encouraged to sign up to and ratify the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The Convention is grounded in the rights-based social model theory and Thomas (2007) observes that 'although the social model is now hotly debated and contested – a consequence of theoretical diversification – it remains the central theme around which disciplinary adherents coalesce'. The Convention itself states that:

> Recognising that the United Nations, in the Universal Declaration of Human Rights and in the International Covenants on Human Rights, has proclaimed and agreed that everyone is entitled to all the rights and freedoms set forth therein, without distinction of any kind.

Furthermore, one of the obligations is:

> To take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities (un.org.disabilities).

But it is clear that the language of this human rights declaration is the domain of Western dominated establishments, demonstrating their notions that Western-based concepts of individual rights are transferable to developing countries (Uvin 2002). For example, Goodley describes how 'the UN Convention on the Rights of Children aims to extend children's welfare, cultural and political rights, but also instils a culturally specific notion of idealised child subjects and family form' (Goodley 2007:165). But different societal ideologies have profound implications for the human rights of a

population, and that point is overlooked in the human rights model because it assumes that the acceptance of an individual rights-based model is universally transferrable.

Human rights in this context assumes legalised reasoning using legislation, however according to Ashcroft et al what is missing is an acknowledgement of the links between disability and a post-colonial context which 'covers all the culture affected by the imperial process from the moment of colonisation to the present day. This is because there is a continuity of preoccupations throughout the historical process initiated by European imperial aggression' (Ashcroft, Griffiths and Tiffin in Sherry 2007:10). Miles (2002; 2006) also expresses concern about the proliferation of disability discourse originating in the West and its notions of rights, independence and individualism being applied in post-colonial contexts, and he also mentions the dangers of recreating colonialist processes.

The aggressive cultural penetration of the internationally imposed guidelines and the urgent drive by developing countries to enact national legislation in line with various conventions continues to ignore particular specificities. The effect of this is seen in Mikkelsen (2005) who noted that even though many organisations claim to have adopted the rights-based approach, their methodologies and practices do not reflect such claims. For many countries upholding the recommended protocols will continue to prove to be problematic, especially in societies where individual rights are secondary to collective group consultation in the decision-making processes for individuals. This is particularly relevant where the social norm is governed by theological and traditional beliefs that are considered to have greater implications and influences on the way in which life is experienced.

But there is an incentive for countries to buy into the concept of human rights. Uvin (2004:4) notes that not only do they 'benefit from the moral authority and political appeal of the human rights discourse', but there is an additional inducement in that it enables countries to attract international donor funding with the proviso that the funds are used to contribute to development initiatives in adherence with the universalised guidelines.

2.7   Conclusion

Given that T&T has such a rich mix of cultural, social and political diversity, there will undoubtedly be many challenges in relation to sociological analyses. With that in mind I have questioned the degree to which current disability theorisations can accommodate the politics of cultural specificity given the socio-historical context of the Caribbean region, and in particular in T&T.   This includes a broad spectrum of factors for example - values, belief systems, attitudes, and behaviours that impact on the actual experiences of disabled people. In reviewing the literature it is apparent that disability is a complex phenomenon and is one in which cultural specificity has been largely overlooked. This point is illustrated in Sherry's work on the relationship between disability and colonialism:

> Many epidemiological studies have produced reports of disability which are largely inconsistent with the ways in which the populations being studied understand their own experiences (Sherry 2007:17).

When cultural specificity is ignored, the outcome will be similar to that found by Lunt and Thornton (1997) in their research on disability employment policies in 18 countries (though none were in Latin America or the Caribbean) i.e. a lack of cohesion and interconnectedness amongst state

departments and service providers and a lack of mainstream knowledge and information on the ground.

In this chapter I have undertaken an examination of the ideologies and principles that underpin notions of disability and I have presented a descriptive summary and critique of the theoretical and policy approaches to disability, emphasising the implications of adopting those models in T&T. The various models are all useful in identifying some of the disabling factors endured by those with impairments, but their shortcomings have also been critiqued. In reviewing the models it is apparent that they are not mutually exclusive and instead there is some interconnectedness in the constructs. Indeed, a number of contextual dilemmas have also been highlighted, which will affect the development and implementation of policy and service delivery.

In conclusion, I advocate a culturally specific approach to disability rather than the universalised system promoted by the WHO (Whyte & Ingstad 1995). This is because 'to understand the social construction of disability in a particular socio-cultural context, it is necessary to examine the specific economic, ideological, institutional, political, military, ethnic, gender and age-related dynamics present in that society' (Sherry 2007:17). A social relational approach that will provide theorisation which acknowledges heterogeneity, locality and complexity and embraces multiple discourses that focus on the cultural constructions of the realities of having an impaired body will be more appropriate.

3.0   METHODOLOGY

Introduction

This chapter provides a rationale for the methodological approach adopted, and explains how it was used to aid in the exploration of the lived experiences of disability in T&T. It provides a description of the practicalities in undertaking the fieldwork bearing in mind the many debates around power, ethics and methods in disability research.

I have adopted a qualitative interpretative approach because it enables the researcher to 'study things in their natural settings attempting to make sense of or to interpret phenomena in terms of the meaning people bring to them' (Denzin & Lincoln 2002:3). I specifically employ Denzin's interpretative interactionist approach because of its focus on the dynamic sets of 'relationships between personal troubles and the public policies and public institutions that have been created to address those troubles' (Denzin 1989:2), and because it assumes every situation to be unique, shaped by an individual's experience and also makes meaning of problematic symbolic interactions (Denzin 1989:33). That is because people react to events and things depending on the meanings they attach to the situation which are constructed from day to day social interactions.

Consideration has been given to the concept of culture defined by Goodenough (197:258-259) as consisting of 'standards for deciding what is ... for deciding what can be ... for deciding how one feels about it ... for deciding what to do about it, and ... for deciding how to go about doing it'. It is the shared beliefs, norms and values that guide individuals' view of themselves and the world around them and how they react to their

experiences, and thus culture impacts significantly on the defining of lived disability experiences. In addition I have reflected on the conceptualising of relationships between the private lives of the participants, the public responses to their personal issues, and how these connect with service delivery, policy development and implementation.

3.1   Methodological Approach

It was felt that to undertake an exercise seeking to answer the question of 'how' disability is experienced, would require a qualitative methodological design that is interactional and biographical, allowing for the collection of personal experience stories and thick descriptions. The information gathered could then be unpicked to reveal the multi-layered subjective meanings that capture the internal - the perspective of the participants, and the external - the environmental, religious, socio-economic, political and cultural factors that represent the disability experience in T&T.

In order to examine and analyse the differing theoretical disability conceptions operating in T&T, a significant amount of reading was undertaken on research philosophy, and evaluations done of the various disability research methodologies and strategies to determine the most relevant process for this particular study.   Consideration was given to the objective of the research; the type of evidence that needed to be collected; the methods of collecting the evidence; and how the data collected would be analysed and interpreted in response to the research questions. In the end, an interpretivist methodology was decided upon as the most appropriate method to gain an understanding of the socially constructed world of human interests and behaviour that situates the lived experiences in their broader social and cultural context. Due attention was also given to the

emancipatory research methods advocated by Oliver in relation to 'changing the social relations in research production; the relationships between the researcher and the researched; and the links between research and policy initiatives' (Barnes & Mercer 1997:1).

Reading on interpretivism led me to Denzin (1989) who postulates that by using an interactionist interpretative approach, the lived experiences of the participants will emerge in relation to the positions of self, power, emotionality, ideology and sexuality, all of which are fundamental to this study. This approach then made it possible to locate assumptions which may differ between the disabled individuals, the policy makers, the medical professionals, and the general public through comparing and contrasting service user and public perspectives with that of the service providers.

By focusing on the analysis and interpretation of the participants' view of their own problematic lived experiences, it is possible to understand how meaning is constructed by way of their interactions between self and others, within a given space. This in itself raised questions as to the usefulness of the universal transferring of Western disability theories in a cultural context such as T&T. Notably, Western disability studies have tended to ignore the particularities around religion, superstition, folklore and myths and their impact on disability experiences in particular countries.

Contextualising the research questions

Denzin's (1989:56) interpretative interactionist approach identifies six research steps which were taken into account in this study:

　　1) Framing the research question to find out the 'how';

2) Deconstructing and critically analysing previous theories, and observations of the phenomenon;

3) Capturing the phenomenon, locating many cases and situating them in the natural social settings;

4) Bracketing, dissecting and inspecting the phenomenon to its essential elements to uncover its structures and features;

5) Constructing the phenomenon;

6) Contextualizing the phenomenon.

I achieved the six steps through:

1) Understanding how meanings of disability are framed by different social actions and experiences;

2) Critically examining existing literature for possible misconceptions and opposing theoretical perspectives;

3) Undertaking interviews in the participants' usual day to day environment; and carrying out direct observations during participants' regular activities;

4) Seeking out key phrases, meanings, themes and other relevant factors;

5) Re-assembling the constituent elements by comparing and synthesising the emerged themes for similarities and interrelatedness, and placing them into theoretical models;

6) Constructing a theoretical explanation and comparing and contrasting it with existing data and literature.

While classic ethnography has not been used in the sense of living in the field for an extended period of time, I have applied basic ethnographic methods. I have participated in the settings to capture the actions and activities of the existential lives of the participants in their natural environment, to better understand the meanings behind their behavior, and

that of others in the population group. I then analysed and situated the data from the fieldwork by re-presenting an interpretation and understanding of the 'native's point of view', their relation to life and their visions of their world (Malinowski 1922:25). This is in spite of the way that 'the native's point of view' is problematised given that in each culture there are different institutions in which individuals pursue their life-interests, different customs by which their aspirations are achieved, and different moral and ethnic codes which reward virtues or punish defections. (Malinowski 1922).

3.2   Research Design

Research methods are influenced by the social, cultural and political context of the research, and can affect the outcomes and integrity of the research process. Fortunately I took heed of Oppenheim's (1992:48) advice that 'it is dangerous to assume therefore when in doubt and especially when not in doubt, do a pilot run'. The original intention was to use a mixture of both quantitative and qualitative data, but the results of the exploratory activity led to a shift towards a much more qualitative approach which yielded sufficient data for an in-depth understanding of the social and human experiences of disability in T&T. The shift in the original data collection methodology was justified because of challenges encountered using quantitative data collection via questionnaires during the pilot study.

Ethics

Research ethics addresses the researcher's code of conduct throughout the process and in this project the guiding principle of ethical approval was ensuring that the aims and objectives of the study benefit society and minimise social harm. This was achieved by adhering to guidelines and processes governing the behaviour of myself as the researcher and my

interactions with the participants (EdQual 2008). This was in keeping with the project's ethics approval acquired in line with the London Metropolitan University Ethics Guidelines; the Statement of Ethical Practice for the British Sociological Association; and the Trinidad and Tobago Ministry of Health Ethics Committee.

In the project's conception stages, I met with key government policy officials and local academics in Trinidad and Tobago to discuss the research project. At the time I was given the go ahead – with most indicating great enthusiasm for the project. In July 2010 following a meeting with the Caribbean Health Research Council (CHRC) based in Trinidad it was brought to my attention that the project would require approval from the Trinidad and Tobago Ministry of Health Ethics Committee (TTMHEC). They were however unable to advise me of organisation's location or of the application process. In the ensuing months I contacted a number of local academics and key officials who advised that they were unaware of the existence of such an organisation even though a number of them had undertaken similar research. In January 2011 the information required to obtain the necessary approval from TTMHEC was received from CHRC, and an application submitted with approval obtained in May 2011.

Manson et al (1994) suggest that there are three ethical components that make up a valid consent that is – the person is informed; they are competent informants; and they are able to give their consent. However, the vulnerability of some of the participants within this study posed challenges in determining the competence of individuals and power relations where there was diminished responsibility. As a solution, proxy consent was accepted from parents/carers but during the interview particular attention was paid to

the individual and a decision taken as to their willingness to participate in the process.

Interview Guides and Permissions

An interview guide (appendix a) was developed outlining the key considerations to be addressed and as its intended purpose was as a prompt during the interview process I was mindful not to allow it to become a source of distraction of the participant's trend of thought. One of the stipulations of the Trinidad and Tobago Research Ethics Committee was the requirement to also develop and submit for approval a focus group interview guide (appendix b). Though the two guides were similar in content the focus group guide was structured to enable deeper probing of policy issues.

Consent and release forms (appendix c) were designed to address issues of confidentiality, security, ownership, disclosure and informed consent. It was clear from feedback of the pilot activity study (explained below) the importance of confidentiality and anonymity, so care was taken to make these very explicit. The consent form was discussed at each interview with clarifications given when required to ensure that participants or their representatives were aware of what they were committing themselves to. The vulnerability of some of the participants meant that extra time had to be expended explaining the contents in a format suitable to their needs.

Permissions were sought to record interviews for ease of transcription, and to have an accurate record of the encounters. However, many participants declined the use of the audio or video recorder because of the possibility of the recorder distracting, interrupting or inhibiting their responses. Some felt the use of a recorder would deduct from the informality of the occasion

while others were concerned about the recordings being uploaded to YouTube. Where the use of the recorder was declined verbatim notes were made and additional comments noted, capturing emotions, expressions and gestures. Where the interviews were recorded I corroborate with the findings of Booth & Booth (1994) in that some participants divulged sensitive information after the recording device had been switched off. For example Mrs Anthony indicated that 'what I am about to tell you is off the record so switch off the recorder for a while and I will tell you the true story about what happens in that family'.

Confidentiality

Tobago is a small island with approximately 50,000 inhabitants, so given its size, proximity and culture it is possible for individuals to be easily identified. There is a strong sense of community with many wanting to know what is happening and to whom it is happening which poses a privacy problem. On many occasions I was privy to conversations that started with 'So yuh ain't hear wah happen to she/he'. That sense of needing to know may be due to its historical beginnings and the idea that community comprises of informal family units. Tobagonian calypsonian Lord Nelson hints to this in his song.

> Mama tell me since a baby, Doh pass people just so when you in Tobago, Doh play proudy, tell dem howdy, Ah say, What's the reason Mammy? Is then she tell me. She say, All ah we is one family, all ah we is one family. You cyah doubt me, facts is history, Old time people will know how we come to be so bound together, one another, Nothing could separate we from since in slavery.

By virtue of the sensitivity of the subject being discussed, many voiced concerns about the repercussions of being identified, for example: losing their welfare grant or their job; being ridiculed or punished for speaking out against service providers; or for openly admitting to believing in the practice

of Obeah. Great attention was paid to ensure the anonymity of respondents and because of this I have taken the decision to avoid obvious distinctions between the responses received from participants in Tobago, and those from participants in Trinidad which means that the data specific to Tobago has become subsumed with that of Trinidad.

Every Tobago participant spoke about breaches of confidentiality, but ironically they were also willing to disclose private information about others. Many mentioned a community notice board in the village of Canaan which used to be updated on a weekly basis with local gossip. Given the gravity of the issue I have chosen to use pseudonyms to protect the identity of participants except where people have asked to be identified.

3.3   The Pilot Project and Reframing the Research

The pilot study unearthed some methodological challenges around the use of survey questionnaires. I fell into the trap of attempting to cut down on time by seeking to gather as much data as possible using a pre-conceived set of survey questions without giving adequate attention to local voices. Fortunately I noticed a problem arising and heeded the advice of Chambers to outsider researchers to 'step down off the pedestal, sit down, listen and learn' (Chambers 1983:101).

As the original intention was to employ the use of a significant amount of quantitative data I undertook a preliminary exercise using questionnaires with the expectation that they would yield sufficient statistical information that could be easily coded and analysed with the use of supported interview data. Erlandson et al (1993:58) does warn that 'it is the duty of the researcher to be ever mindful of threats to the quality of the research

through such issues as convenience becoming more important than the richness and appropriateness of the research setting'. This was a useful lesson I learnt at the exploratory stage which then allowed for a much more comprehensive, reliable and appropriate methodology to be eventually used.

For the pilot study a structured questionnaire checklist was designed as a vehicle to respond to the issues of:

- perceptions on what impairments were considered a disability
- perceptions on how widespread disability is within the society
- the experiences of disabled individuals
- attitudes towards disabled people
- barriers to integration

The questionnaires were then distributed to a number of key contacts in Trinidad and Tobago via email and hard copy. (appendix d). Fifty (50) participants completed the questionnaires, but more important to the process was the valuable feedback from the participants which influenced the eventual methodological approach. It became evident that the use of questionnaires was affecting the integrity of the study for a number of reasons:

- Where participants felt that their responses could be perceived as controversial, they did not reply according to their true feelings but according to what they considered to be the expected 'morally' appropriate answer. For example, pertaining to superstition or ethics where moral standings could be judged, questionnaire responses differed to the views participants shared when having direct one to one conversations

- The possibility of anonymity and confidentiality being compromised despite individuals not being asked to provide their name or address. Participants felt quite strongly about those issues to the extent that some refused to write their own responses but instead requested that I complete their form in my handwriting because of the possibility of being identified by their handwriting. This shows that the consent form explaining the research confidentiality clause did not of itself offer adequate reassurance.

- Literacy, grasping and understanding the nuances of the language, and clarity of the terminology in the questionnaires were raised especially by those with intellectual disabilities. A few participants indicated that in order to take part in the research process they would require someone to explain the questions. Some had not heard of particular words/terminology or did not understand the context within which they were being used. For others, the nature of their disability meant that they required assistance in completing the form but for confidentiality reasons did not want to rely on a family member or friend.

- The rigidity of the questionnaire limited the participants' ability to express themselves freely and spontaneously. For example it did not allow for responses that would be dependent on a particular time and space, or for possible conflicting responses.

It also became apparent from the feedback that in some communities one to one interviews would be more acceptable due to the trust they put in an individual from another country taking an interest in their life experiences. In other communities greater success would be achieved as a result of the

shared support and understanding of having a group discussion with a collective of like-minded individuals. To optimise the quality of the data collection process it was important to address the challenges and limitations of these cultural and social variables and to take on board the suggestions from the participants.

The exploratory pilot activity proved to be a powerful exercise in so far as it clarified the significance of the influences of notions around risk, power, determination, social standing, and beliefs, and the significance of these on the everyday lives of the disabled population. The results of the exercise led to a realisation that the definition of disability is still very much in flux in Trinidad and Tobago which meant taking a step back in order to get a sense of what 'disability' means in T&T. This required a revisiting and reframing of the research questions and reconsideration of the data collection instruments.

3.4   Data Collection

My aim was to understand 'how' disability is experienced, by contextualising the way that participants make sense of their social and cultural world and their own positioning within it. I was seeking to understand 'how they construct, what they construct, why and to what effect' (Weick 1995). As a result the questions are framed and data analysed with a view to understanding how communication, patterns, values, designs and beliefs which influence human consciousness are played out in the everyday lives of disabled people (Mills 1963). To get the data that will guide those responses and taking into account the lessons learnt from the pilot study where it was evident that the choice of data collection instrument can significantly impact on the outcomes of the research, I settled on the triangulation data

collection methodology suggested by Denzin (1989). I employed the use of incorporated interviews, focus groups, observations conducted within the participants' natural environment, and a critical examination of published and secondary sources of data; all of which enabled access to a range of scenarios that collectively provided a richness of information pertinent to the research. For example, I was able to extract valuable information on the way that culture is enacted by way of the personal stories, myths and folklores.

Using a plurality of data collection methods also allowed for a number of scenarios to be set up to capture information coming from many voices (some individual and some group) reflective of the diversity of the experiences of participants in relation to the complexities of their problematised lives. Sub-types of space, time, and person were achieved as the interviews, focus groups, and observations were conducted in a variety of geographic locations throughout both Trinidad and in Tobago in different physical spaces, for example in family homes, work places, offices, centres, places of worship, and shopping malls ensuring that the grassroots realities were also captured. Discussions were held at varying times throughout the day, evening and night with individuals and groups representative of diverse ages, ethnicities, religions, socio-economic backgrounds and family structures. A demographic data sheet was used to ensure the range of diversity (appendix e).

The contrasting of environments, time, space and circumstances meant that I was able to extract a particular wealth of information embodied in the range of experiences and opportunities. These variations were then accounted for in the deconstructing, comparing and reformulating of the data collected. For example, data gathered in relation to the National Policy during the

movement across time and place was valuable as it provided an opportunity to analyse the potential impact of the Policy before, during and after its official launch. The data showed that during the three stages the perceptions of the policy as seen through the eyes of disabled individuals remained consistent and constant. Another significant movement across time, space and person occurred at the time of the change of Government at the general election. I was able to get the views of participants before the election which was during the reign of the Peoples National Movement; during the campaigning period; and thereafter with the new Government (The People's Partnership) in power. I also interviewed a number of politicians and analysed the discussions from their position in the opposition, and later re-interviewed them as part of the ruling party.

Identifying participants

Sampling is an important aspect of this research project with Cohen et al (2000:92) advising that 'the quality of a piece of research not only stands or falls in the appropriateness of methodology and instrumentation but also by the suitability of the sampling strategy adopted'. This project employed the use of the Combination Sampling Method which according to Miller & Brewer (2003) is best suited to biographical narrative studies.

From the pilot study it became apparent that the research needed to have qualitative explorations as its core data collection source, and it was felt that the best way to go about this was to use a combination of sampling methods e.g. snowballing. Individuals where identified who had the potential to provide information relevant to the research questions, and who would know others either with a disability or with an interest in disability. During the process it became apparent that some of the key contacts had their

own ulterior motives when providing recommendations. For example, I was referred to an individual based on the assumption that I would influence the outcome of a political debate.

Discussions were also held with families and carers of disabled individuals with the majority indicating that it was a unique opportunity to share their caregiving experiences. Many welcomed the prospect of telling their stories, and referred me to other parents and carers so that they too could have a chance at sharing their experiences.

The study also involved a level of opportunistic sampling as I followed up on unexpected leads which arose during the field work process. For example, on seeing a newspaper appeal for assistance for a disabled individual I made contact and interviewed him, the outcome of which provided valuable data for the study. A critical factor in the process of gaining access to knowledge rich participants was to align myself with those who are well respected and highly regarded in the disability community, and as I had already established relationships with a number of key personnel during my MA research, I rekindled those contacts. Using this method of sampling not only generated valuable information relevant to the study, but those individuals also provided guidance on potential cultural barriers, and introductions to other key players in the local disability arena. Having some prior knowledge and the continued relationships proved to be useful in alleviating perceived obtrusiveness, by enabling familiarisation and a sense of what to expect, which increased both the effectiveness and efficiency of the process (Lincoln & Guba 1985).

In some instances individuals were either emailed and/or telephoned with a view to setting up appointments but for the most part this proved unsuccessful. Professor Samaroo, my external supervisor based at the University of Trinidad and Tobago, advised of a particular cultural challenge in T & T regarding timeliness which was particularly noticeable at statutory and public sector organisations. In one instance having waited an hour for a scheduled meeting, I was then informed that it was not unusual for the individual to arrive late even when they had appointments. Following Professor Samaroo's advice additional time was factored in for every activity e.g. allowing 2 weeks for appointment confirmations, and 3 hours for a 1 ½ hour interview.

The field work phase, which for the most part was conducted by 6 visits to T&T was completed in early 2012, however a sustained relationship has been maintained with many of the participants who continue to share what they consider to be 'useful information' or 'updates'. These usually take the form of an episode of perceived injustice or discrimination, or a newspaper article considered relevant to the research.

The following is a breakdown of the numbers of interviews conducted:
- Narrative interviews – 13 were conducted, of which 11 were with disabled individuals, 1 with a mother and her daughter who has an intellectual disability, and 1 with the grandmother of a disabled young man who could only communicate through blinking.
- Formal interviews – 8 were conducted with senior state officers in both Trinidad, and in Tobago.

- Semi structured interviews - 11 were undertaken representing academia, management of disabled people organisations, civil servants, medical practitioners.

- Focus groups – 4 comprising a total of 50 individuals made up of disabled students, carers, parents, teachers, activists

- Direct observations -7 were undertaken at a range of venues in which disabled people were present - A shopping expedition to a Mall, a book launch, a Christmas party, a conference, a support group meeting, and a vocational centre.

Positioning the researcher

The dilemmas and complexities faced by those undertaking disability research have been widely debated (Barnes 1992; Shakespeare 1996) and my aim here is to unveil and share some of the difficulties encountered in a country where I was told that research is not highly regarded. I experienced problems with the language and discourse of disability which became evident during the pilot study. In addition organisational politics, procedural policies and practices, power relations, and differences in value systems, beliefs and cultural norms also proved problematic.

Throughout the study I remained the sole data collection agent, conducting the fieldwork in an environment which threw up a number of conflicting social and cultural nuances, and because those can impact on the research dynamics, particular attention was paid to my position in relation to beliefs, assumptions, values and presuppositions, the setting aside of my own preconceptions and biases and my political and ethical stance in declaring my status as a disabled person.

Saunders et al (2003) note that the first few minutes of conversation and interaction can impact on the interview process and the credibility of the information provided, and Oliver (1992:105) argues that 'disabled people have come to see research as a violation of their experience, as irrelevant to their needs and as failing to improve their material circumstances and quality of life' hence it was imperative that I generated the right atmosphere from the onset. Denzin (1970:186) recommends striking a balance between viewing the interviewee as a research object and creating a comfortable environment that will generate 'rapport'. For example when addressing an autistic young man who showed discomfort in maintaining eye contact, I quickly diverted my eyes away from him and on to the notes I was taking.

There have been various debates on disability research methods with calls for a methodology that does not take place within oppressive social relations, that pays particular attention to the relationships between the researcher and disabled people, and does not reproduce oppressive theoretical paradigms (Zarb (1992; Stone & Priestley 1996). In considering the various views I settled for what Shakespeare (1996) refers to as a 'free spirit' approach that steps outside of the traditional research methods. When asked by disabled participants, I freely declared my status as a disabled person and I responded to questions when appropriate, enhancing the interview process and creating an atmosphere where the interviewees felt free to express their views and to divulge sensitive information without fear of judgement. Taking this stance meant that the participants showed increased interest in my role, understood why I would be interested in their stories and expressed that they/we were the experts by experience sharing membership of the same minority group being investigated. Though that shared experience did not eliminate the power divide it allowed the

participants to be connected to and invested in the project and its potential outcomes, with many remaining in contact after the interviews were completed, thus blurring the lines of traditional detachment interview techniques.

When interviewing state personnel I refrained from disclosing my status until towards the end of the interview and while that could be construed as manipulating the interview process I considered it to be advantageous to this research project as my intention was to get beyond the state rhetoric which I had received when I undertook my previous MA research. This shift in interview technique deviates from classic textbook interviewing ethics but by me initially using detachment methods many of the state interviewees spoke freely and fully, locating disability within people who are needy and ungrateful. However when my status was eventually disclosed the interview dynamics changed. Their contributions then drifted to more personal experiences of disability while also focussing on the state's aspirations for disabled people in line with the social model regarding the removal of disabling barriers. This unconventional method uncovered a wealth of information which may otherwise not have been shared, and also validated the data which could have been compromised had I only captured the original pre-disclosure discussions.

In carrying out the research I felt it was important to immerse myself within the discourse and language of the local population so that the findings would reflect a truer interpretation of the conversations and their meanings. However there were times when clarifications on the local dialect and linguistic variables (including the spelling and local interpretation) were needed. Throughout the study where direct quotes are cited I have actively

undertaken to ensure that the spelling is accurate, and that the interpretation of unfamiliar terminology is as intended. The use of the dialect may present some challenges for the reader and for that reason I have included explanations where it is considered that the meanings may not be immediately obvious. It is worth mentioning that there is a dialect difference between the two islands of Trinidad and Tobago with the Tobagonian accent being much stronger. Research participants were encouraged to challenge my interpretation of their discussions to ensure that the final analysis would be as true a reflection as possible of what was being relayed, and not reflective of my own interpretation. This meant at times having follow-up discussions with participants, and revisiting the transcripts in conjunction with the hand written jottings looking out for particular gestures or expressions that may have been used during the interview.

Maxwell (1996) argues that it is problematic to expect the researcher to be able to completely separate themselves from their own previous experience when interpreting the participant's perspective. However I have attempted as much as possible to minimise any impact my own experience as a disabled person coming from a Westernised Eurocentric background while at the same time refusing to give in to traditionally imposed passivity and detachment.

One way of levelling the power relationship between myself as the researcher and the research participants was to allow them to determine the flow of the interviews and to have the power and control over the direction and duration of the conversations even if it meant responding to questions if appropriate. The downside was that a number of participants veered completely off course and some interviews lasted in excess of 2 ½ hours.

The unexpected advantage of those long conversations was receiving the odd snippet of valuable detail that would otherwise have been missed.

I was also aware that personal appearances can adversely affect the outcome of the interview and the reliability of the information provided so having been advised in advance that my dreadlock hairstyle could cause negative presumptions by senior government officials and policy makers, I was mindful to have it tied up in a bun and dress according to their cultural expectations of a professional i.e. in a trouser suit. However, in spite of my best efforts I arrived for a prearranged interview with a service provider who outwardly expressed disappointment saying in a disheartening tone 'Oh, I thought you were white' and who then said that she had double booked and was no longer able to expend the time.

3.5 Field Work

The fieldwork commenced in July 2010 with the pilot project, and a number of additional field visits were made in relation to the revised research questions.

The research was conducted in as natural a setting as possible, including community collectives with participants in a physical space where social order had previously been imposed due to their shared identity e.g. the focus group of disabled young students held at their training institute. Some interviews were conducted at home, others were observations of interactions within day to day social settings with no specific reference to disability e.g. at a party and at a shopping mall.

Interview processes are generally categorised as either fully structured, semi-structured or unstructured interviews (Robson 2002). The fully structured interviews entailed asking the participants a pre-determined set of questions using ordered questioning as set out in the interview guides. Those allowed for an in-depth understanding of the topic as the process followed questioning based on specific themes enabling the interview to be guided in a suitably comfortable manner. In the semi-structured interviews the questions though pre-determined were more flexible and open to modification as the interview progressed and were more in keeping with day to day conversations as the lines of questioning were spontaneous. They were used because of the flexibility to probe responses for clarity, and to direct questions towards a particular theme. Narrative interviews with disabled participants were however used as the dominant data collection tool. The demographic data for this study was collected using a set of standardised factual structured questions.
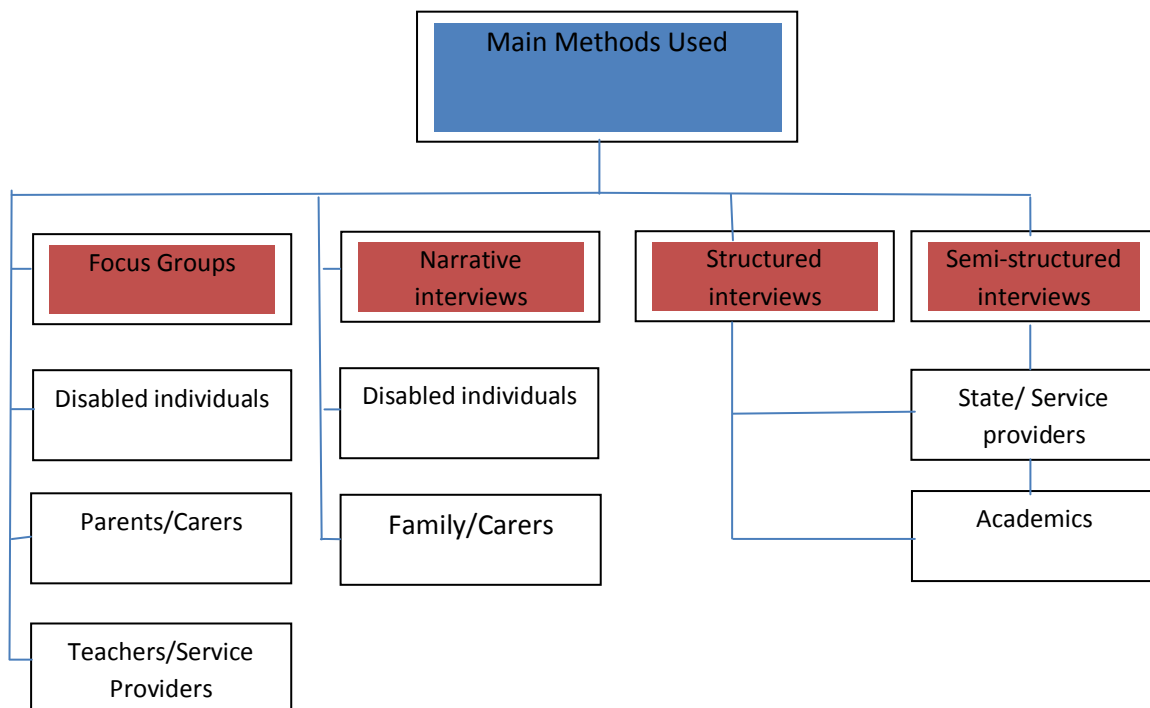
Figure 4. Main Data Collection Methods Used

Narrative interviews

Narratives were used as 'a window into the empirical realities' (Priestley & Shah 2001:44) to capture the unique experiences and the meanings constructed from them. Denzin (1989) maintains that it is the best method for the researcher to accurately capture and collect biographical stories from identified participants and Mitchell & Snyder (2006) embrace it as a tool in analysing disability as a phenomenological experience. There are many types of narratives and Denzin recommends that in undertaking interpretative research to collect the personal stories that embrace the teller's self with that of their previous life experiences.

A total of 13 narrative interviews were conducted with disabled individuals from diverse backgrounds and geographic locations from which a number of themes emerged. The stories shared were based on the thematic biography in relation to their disability, and not relayed as a chronological sequence of life events. That is to say, the participants related stories as they came to mind and not necessarily in the order in which they occurred. As the stories were being shared, connections were being made with other essential life events and those determined the direction of the narrative. The stories were given from the perspective of the interviewee at a particular place and time, but it is possible that the perspective would have changed had it been set in a different context.

The interviews were all carried out at a location, and time of day convenient to the interviewees. Some were undertaken within the participant's own home as their most natural environment allowing for comfort throughout the process. For example, during the interview with Nita (who has an intellectual

disability) and her mother, there were times when she interrupted the interview to have discussions with the family and little morsels of those conversations gave valuable insight into her life. Time limitations were not placed on the interviews because of the differing capabilities and abilities of the interviewees. The interviewees therefore had control over the interview process and went as fast or as slow as was suitable to them. On one occasion an interviewee became visibly tired and we both agreed to stop the interview. He acknowledged that he had gone off topic but was excited to be given the opportunity to chat to someone about his disability, and share his views on the politics of the country.

Structured interviews

Eight (8) structured interviews were held between me as the researcher and senior officials who were considered to be the State's gate-keepers, academics and service providers. For those interviews a questionnaire guide was employed to replicate the order of the discussions held, and to ensure that the same issues were covered with those key strategic individuals.

Semi-structured interviews

Eleven (11) semi-structured interviews or directed casual conversations were held. They followed an unbiased line of enquiry using an aide-memoire checklist which was discretely referred to ensuring that the direction of the conversation was based on the speciality of the person being interviewed. The prompt was used with service providers and policy makers as I was mindful of the need to capture particular information which they may or may not choose to discuss as there were instances when I was given what could be perceived as rhetorical political statements rather than existing reality.

Focus Groups

Four (4) focus groups, which are a form of group interview where participants with a shared interest can openly examine and express their views, were hosted. In the group of like-minded people sensitive issues were discussed with empathy, mutual support and understanding and in spite of the cultural issues of confidentiality and anonymity, sensitive and taboo topics were discussed openly with all participants at the focus groups actively contributing. The composition of the focus groups provided a holistic range of data as the groups were representative of differing positions in the disability community including those with mental and/or physical disabilities, carers/parents, policy makers, activists, social workers and special education teachers. The participants were also reflective of the diversity of genders, ethnicities/races, ages, and geographic locations e.g. Port of Spain - North, Chaguanas- Central , San Fernando – South, Tacarigua – East, and Tobago.

I did however encounter a challenge due to one group comprised of 26 attendees. Focus groups should be 'small enough for everyone to have an opportunity to share their insights, and yet large enough to provide diversity of perceptions' (Krueger 1994:27) and it was quite difficult to manage, engage, and monitor discussions in such a large group comprising of service providers, parents, teachers, social workers, and individuals with intellectual disabilities and/or physical disabilities. Some of the other issues encountered were:

- ensuring that everyone who expressed an interest in speaking was given an opportunity to share - including those who required additional time because of the nature of their impairment;
- participants with learning disabilities who required clarification were interrupted by others who attempted to speak over them;

- service providers using the opportunity to defend perceived slights;

- insufficient time and resources to complete demographic forms for all attendees
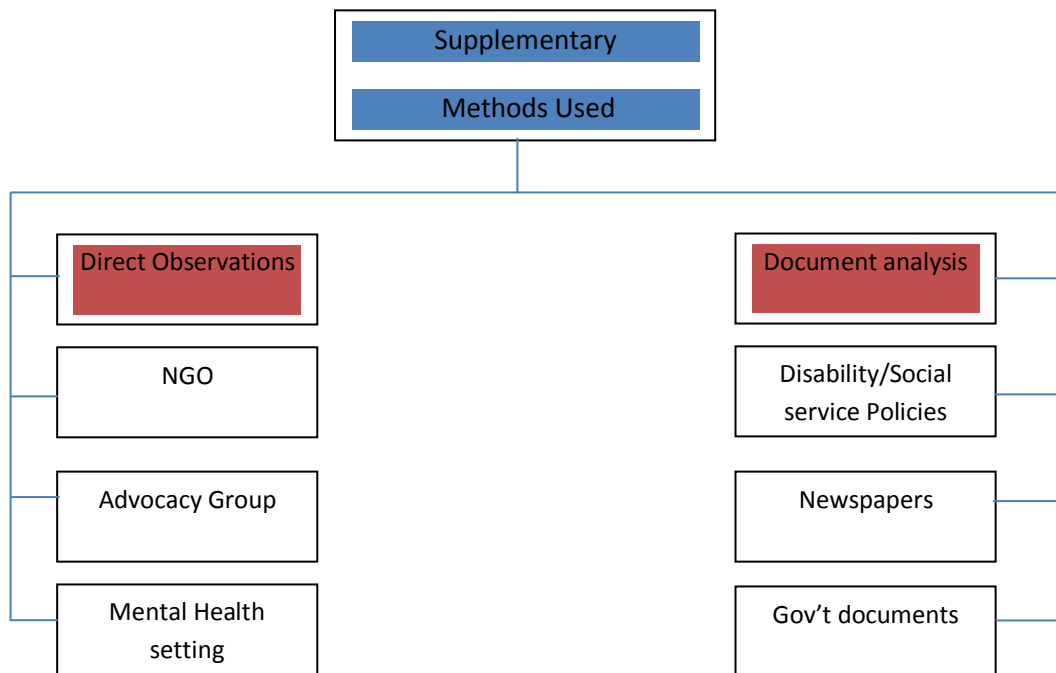
Figure 5. Supplementary Data Collection Methods

Direct Observations

Direct observation which is said to be an underused but valuable method of descriptive data collection (Taylor-Powell E & Steele S 1996) to document activities and behaviours about the physical and social environment was undertaken. I was able to use my senses to observe what people do, instead of what people say that they do (Gans 1999), and to capture the immediate reactions, patterns of behaviour and rituals to particular events and experiences in their natural setting. Having a stranger in the midst often creates some level of change in the dynamics of the group, if only to a very

small degree but this was minimised at the party where I was a 'passive observer' having integrated myself as a regular guest. There were however times when I was an 'active observer' mirroring the activities of the participants (Spradley (1980). Erlandson et al (1993) does however warn against the potential to over-identify with the participants leading to the undervaluing of information gained from having a shared outsider perspective. This was avoided by the process of passive observation, as I often opted to remain in the background, engageing in conversation only when approached.

Observations were undertaken in a range of settings: the social environments of a party, a book launch, and shopping trips; a formal school setting, and an international conference; and the semi-formal setting of a drop-in centre where the common thread was the nature of the impairment. The diversity of the settings made it possible for a range of interactions likely to happen at some time during the life of a disabled individual to be observed. These included dynamics where families and carers were present; where there were no strangers; where there were lots of visitors; and where there were different power scenarios at work e.g. parent/child; teacher/pupil; peer/peer; staff/client. In addition, by varying the times of the visits I witnessed participants at various stages of daily activities e.g. fresh and alert in the morning, interacting at meal times, attending the services of the drop in centre after being at work all day, and shopping at the mall on a busy weekend.

Recording the direct observations provided problematic especially in trying not to be obtrusive or to erode the quality of the observational experience. For example during the shopping trip I was invited by the participants as 'a

friend' and though they were aware of my role as a researcher the main reason for the shopping expedition was as a social event. However, there were a couple of noteworthy situations which arose when I took a decision to make very brief notes on my mobile phone. I also utilised the times when the participants nipped to the toilet or went into the changing rooms to make additional notes.

Supplementary Data

Supplementary analysis was accomplished by way of scrutiny of the 2000 Population and Housing census data, the Survey of Living Conditions 2005, and other relevant legislative and policy documentation e.g. the Equal Opportunity Act, the Mental Health Act, and the National Policy on Persons with Disabilities.

The field notes which are the written account of my observations as the event was occurring has been a very valuable tool in identifying emerging themes in the data analysis process. In addition to them a limited number of audio and visual recordings were undertaken and together these contained detailed 'thick' descriptions of interactions between participants, facial expressions, my own emotions, gestures and patterns of behaviour.

3.6 Data Analysis

The data analysis for this study was a continuous iterative triangulation process using the information from the pilot study, interviews, observations, and supplementary documentation including field-notes. The bulk of the field work was conducted using a longitudinal timeframe where the data was gathered having made six separate two week visits to T&T over a period of 18 months, while simultaneously carrying out supplementary data reviews.

Even though it is recommended by Gilham (2000) that recordings be transcribed immediately after interviews this was not always feasible, so the time consuming process of transcribing the bulk of the handwritten notes and voice recordings into the MS word programme was done over a 6 week period after the final field visit. In addition, the issue of linguistic variations meant that from time to time confirmations and clarifications had to be sought from the interviewees often causing delays because of the tardiness in receiving responses. Undertaking the transcription task in this time consuming manner did however mean that I was able to methodically immerse myself in the information, maintaining a closer eye on the data through continuous iteration which made it easier to observe the interactions between emerging themes.

Data condensation was undertaken i.e. selecting, focusing, simplifying, abstracting and transforming the data from all of the collection sources (Miles & Huberman 2014) from which emerging contexts, consistencies and themes were identified. As the focus became sharper and the themes developed the data from the various sources were cross checked for consistency and validity, for example connecting the lines of enquiry between statements made and the evidence presented in supplementary sources such as policy documents and newspaper articles. Additional appointments were set up to facilitate the gathering of further information, or to seek clarifications thereby reducing any interpretative errors or judgements and ensuring that the findings reflected the voice of the participant. For example initial analysis showed that 'traditional beliefs' was an emerging theme so appointments were subsequently made with a variety of religious/faith

leaders creating a broader understanding which warranted even deeper submersion into the topic for clarity and greater comprehension.

There were however instances where themes had emerged but it was not possible to delve deeper to the point of theoretical saturation because the vulnerability and safety of me as the researcher and of participants had to be protected at all times. For example the data threw up an interesting line of enquiry on traditional beliefs and psycho-social disabilities and it was suggested that I visit residents of the mental hospital who were institutionalised long term against their will. However, this was not pursued because of the lax security measures at the hospital.

Coding

The coding exercise which gives interpretative meaning to the data was undertaken in a number of stages as recommended by Miles, Huberman & Saldana (2004). An initial open coding exercise was carried out using coloured pens and coloured index tabs, with the transcripts being checked line by line, meanings of chunks of information given labels and patterns noted. The exercise used a number of coding methods:

- descriptive coding which unearthed many references to unfairness, discrimination, oppression;
- NVivo coding picking out recurring phrases within the local dialect e.g. Obeah;
- process coding which looked at how things emerged and evolved over time and space, for example the ways in which discussions on the National Policy either stayed the same or differed during the design, implementation and review stages;
- emotion coding which was mainly captured from the field jottings; and

- values coding around judgements, beliefs and interpretations of their social world.

The initial coding stage unearthed a wide range of topical themes which were then reconfigured into those with particular reference to the research questions. This was following by the focused pattern coding process of re-reading the transcripts and the initial coded categories for similarities and interrelationships appropriate to potential theoretical explanations and followed by a further narrowing of the list. The resultant pattern code cards were again refined looking for obvious links in the cards and the field jottings – for example distress was evident in the text 'it hurt so I was afraid to go to bed and I cry' and also in the notes I had made on participant's body language 'hands shaking and voice sounding like a quivering squeak'. It is from that final coding process that a list of four main thematic areas with their associated topics was identified i.e. religion, spirituality and cultural traditions; everyday oppression; identity; policy and the state. These are the themes that organise the next four chapters of the thesis.

4.0   THE PLACE OF RELIGION, SPIRITUALITY AND CULTURAL TRADITIONS IN EXPERIENCES OF DISABILITY

Introduction

This chapter begins the interpretative narrative of the research respondents which gave rise to a wealth of information and a richness of themes that fell both within, and beyond the scope of this research exercise. In it, I present the contested meanings of disability as told through the narratives and voices of the participants, as I explore the ways in which culture, attitudes and beliefs in religion, spirituality and traditional processes impact on the experiential realities of disability in T&T. This chapter expresses how culture with its shared value systems, beliefs and practices is passed on from generation to generation and influences the way in which individuals come to make meaning of who they are. In undertaking this research I discovered the strength of a range of disability interpretations tied to religion, spirituality and cultural traditions that are too often underplayed in the scholarly and theoretical explanations of disability and it is therefore impossible to contextualise disability experiences in T&T without understanding and considering those culturally specific underpinnings.

T&T's complex cultural configuration has its roots in the processes of colonialisation, and one of the questions that has been asked is how do people in an environment structured around dominance form a sense of identity (Roopnarin 2009)? To a large extent they resist the forces of domination and renegotiate their identity drawing on mixed but also fragmented cultural traditions. They often will reflect on what they can recall and use their imagination to provide an inner strength to assert their social

identity, but over the passage of time some of the stories being recalled will become based on legends, myths and superstitions.

Religious, spiritual and mystic explanations for impairments have existed in all cultures (Graystone P 1975 in Illich 1976) and traditional, cultural and indigenous healing practices have been part of the socio-cultural and geopolitical landscape of the Caribbean since the time of slavery and possibly before (Sutherland et al 2014). However, in disability theorisation the social and cultural relativities of religious and spiritual knowledge are more often than not neglected, underrepresented or misrepresented which is reiterated by Fernando who noted that 'Caribbean users of mental health services complain that Western systems of psychiatry and psychology lack spirituality in their treatments' (Fernando 2014).

Increasingly in recent times religion and spirituality in the context of mind-body-soul interactions has been a research subject (Kaye & Raghavan 2002), and that is mainly due to the abundance of holistic and alternative interpretations outside of the bio-medical sphere being sought for impairments and illnesses. In keeping with this emerging shift I present an argument for an interpretation of disability that embraces the religious (which may not necessarily be in the form of formalised modern day religion) and spiritual (directly linked to faith/religious practices, and ritualised processes) belief systems practiced by the population.

Research has shown that religion and belief systems are powerful cultural processes that have historically impacted profoundly on social relations and community developments. For example Coles (1990) and Douglas (1999) have identified that there are disabled people for whom their spiritual identity is

used to negotiate their interactions with others, shape their behaviour, and make sense of who they are. In addition, Serpell et al (1993) on researching families in Africa found many who believed disability to be the result of spiritual malevolence. Such beliefs have a strong effect on individual interpretations of ill health and impairments by reinforcing attitudes, and influencing coping mechanisms. In this regard a key issue relevant to the T&T situation is recognising that the African slaves and Indian indentured workers who arrived in T&T (these two ethnic groups are singled out as they represent the majority population) did so with their own historical and cultural representations of the notions of bodily perfection and disablement and because of the cultural resistance to colonial discourses many of those traditional expressions still persist. I therefore agree with Illich's (1976) argument for an approach that pays attention to the spiritual habits of the heart and strong cultural beliefs and recognises the roles they play in the pursuit of making meaning of life's experiences.

There is research to support the claim that disabled people contextualise their lived experiences i.e. hopes, fears, values, and customs in alliance with their belief systems, even if they are abstractions of forces/powers and not necessarily imbedded in absolute truth (Serpell et al, 1993). Where the meanings attached to the mind-body-soul interactions are at odds with Western belief systems the temptation is to demonise those cultures and consider them as backward or irrelevant. However for disabled people in T&T their experiential reality of disability is that it is equally influenced by religion/spiritual processes as it is by bio-medical concepts.

Bilby & Handler (2004) observed that in the Caribbean 'practices involving curing, divination, protection and negative or harmful objectives i.e. sorcery'

are carried out, and in contextualising disability experiences in T&T it is important to acknowledge Fanon's point that 'a national culture is not a folklore … A national culture is the whole body of efforts made by a people in the sphere of thought to describe, justify and praise the action through which that people has created itself and keeps itself in existence' (Fanon 1959 unnumbered). The message being conveyed here is that culture and all its components are integrated into the identity of the people and it is that which binds them together from generation to generation. Negotiating disability in T&T is a contextual interface with religion/spirituality and the data gathered from the participants goes some way in revealing how disability is defined in religion, how it contributes to, or demystifies disability, and the wider socio-political implications for disabled people in the context of religion/spirituality.

4.1   Bio-Medical and Spiritual Interactions

In T&T religion provides reassurance of hope, resignation and acceptance of situations and where disability is concerned it creates meaning for afflictions which can help to reduce any guilt and responsibility a person may be inclined to experience. Father Benedict, a disabled priest explained that many disabled people just 'want a spiritual meaning for their disability' and as such, they visit him for special prayers and to seek healing. Mother Bishop a prominent traditional healer and spiritual preacher whose clients range from senior politicians, members of T&T social elite, and grass roots individuals, said that for many, 'disability is not of man, it is of God' supporting the belief that the body is a gift from God, and therefore it is God who has the ultimate say (Harvey & Silverman 2007).

Mr Obasi an Orisha Babalawo (Priest) provided the following explanation for congenital disabilities:

> Orunbala – which is one of the names of the creator -- has the power to create the body how he chooses. So it is said that he creates the foetus in the womb how he chooses … so whether you are an albino, whether you have a physical disability, whether you are blind and the rest, you fall under that category because you were created right and the prerogative of that Orisha … the mere fact that you were born with these impediments is because of the will of Olamara.

Such thinking demonstrates that where the disablement is considered to be God's will a sense of acceptance is derived and with it displays of stoicism. That is not to say that bio-medical interventions are ignored and spirituality/religion considered as the ultimate response. There is no real emphasis on having medicalised diagnostic labels for impairments as they do not provide any real comfort, instead the emphasis is placed on finding a spiritual meaning for the occurrence of the impairment and appropriate treatment which may or may not be a medicalised intervention. As explained by Roy:

> when the doctor tell us that he will never walk again we take the medicine he give us but we still leave and went to Mother Bishop for her to come and smoke out the house (using incense and prayers) and find out where it is the curse did come from.

Dr Harry, a Psychiatrist and Pundit (Hindu Priest) is a proponent of medico-religious interventions and uses a mixture of pharmaceutical treatments, herbal remedies and prayers in his practice. He explains why the use of traditional/religious/spiritual interventions in isolation may not be adequate:

> The danger is if a person has depression, they will benefit temporarily from a charm, but then they can become suicidal. That is because the priest does not understand the nature of depression …

Someone who has an iron deficiency will be tired, but will be told that they are suffering from a spiritual illness.

He also explains that it is possible for those who use traditional practitioners to be exploited,

I am concerned about some naturalist and new wave healers because the system can be abused. They can exploit fears and superstition of people, so there is a challenge. The government can help here because people will always use folk medicines so when they drafting policies and legislation for people they must remember that.

What is being advocated is holistic medico-religious interventions that are available not only within private medical practice, or via traditional spiritual leaders but for a strategic approach to be taken that recognises and acknowledges the existing cultural hegemony and focuses attention on the strong religious cultural identification of the population.

The findings in this research show the extent to which the medicalisation of disability is enmeshed with spiritual concepts and traditional beliefs as many medical professionals such as Dr Harry actively practice a blended medico-religious approach in their interactions with patients. A number of interviewees made reference to an eminent psychiatrist who has been known to advise patients to 'seek help elsewhere, go and get some spiritual help'. He has often informed patients that their impairments are due to non-medical factors which require spiritual interventions.

A recent news article entitled 'Yes, Jharay cured me' reported that 'Sprinkled across the country are men and women who cure snake bite and scorpion stings, jaundice, asthma, maljo (evil eye), headaches and a majority of illnesses through healing prayers called "Jharay"' (Jankie 2011). A traditional

spiritual healer shared that there are many occasions when patients are referred to him from doctors working in the general hospitals because 'they recognise that the illness of the patient does not fit into the category of a physical thing, [but rather] a spiritual thing'. Discussion with another traditional practitioner - who is also medically qualified – substantiated that assertion. He considers that medical interventions should embrace a more integrated approach that incorporates bio-psychosocial-spiritual interventions and that they should not only be targeted from a bio-medical perspective:

> People know how strong the power of prayer is and they have to believe in it ... for many people, they know and accept that their problem is because they not making the time to praise and thank the Lord, not being grateful for what he has done for them, and because they not remembering him so he give them a wakeup call.

A UK study found that nearly nine in ten (88%) adults trust doctors to tell the truth, making doctors the most trusted profession measured (Ipsos MORI 2011), and anecdotal evidence suggest that this is also reflective of doctors in T&T despite the issue of breaches of patient confidentiality. Given the hierarchy of credibility, the balance of power/knowledge will ultimately be in favour of the medical professional. In T&T the professional dominance of medical practitioners, the power that goes with their social standing, and the trust afforded to them means that 'esteemed' medical professionals have the ability to reinforce and legitimise the understanding of impairments and illnesses underpinned by spiritual philosophy. This is also equally true of religious leaders like Father Benedict who through consolation offered in worship provides spiritual meaning and affirmation of the social context to living with impairments. Such normative cultural values are part of a complexity of bio-medical and socio-ethnical-cultural approaches to impairments which are situated alongside each other and addressed on a

continuum. An example of this integrated approach was used by Mr Obasi - Orisha Babalawo:

> a couple of months ago I had a young lady who could hardly walk and they brought her by me, and upon instructions and certain things I do, when she left she was walking on her own, because the problem was a spiritual problem, but additionally, I also recognise that there were certain things that needed to be done medically for her, so I sent her to a herbalist and because of the family's trust in me they took my advice.

He went on to explain that there are also those individuals who seek a spiritual explanation for their disability when 'the problem is not a spiritual problem, sometimes it's a very physical problem which some persons or practitioners who understand it will be able to dispense the right kind of herbal or medical treatment to help that child or person'

For his clients who acquired their impairments he explains to them that:

> life is made up of three aspects – physical, emotional and the spiritual and each and all of them contribute to what your situation is so you need to understand yourself personally. You can rely on the medical practitioner but know that his knowledge in terms of his training has nothing to do with the physical, it has to do with the spiritual and we will tell you "I think you better try and look for some other help.

A major component of the two explanations given by Mr Obasi is the subtleties in differences in explanation of congenital and acquired disabilities and the notion that there is a degree of individual responsibility and self-regulation required.

In exploring Mary's story (mother of Nita, a 25 year old disabled woman) a picture emerged which unveiled the significant role of faith-based activities and rituals in the acceptance of, and coping with disability and how they affect decision making. Mary was advised by the Paediatrician that

'something wrong with the baby and she might not make it and I don't even know what to tell you … if she survives she will be blind, deaf and dumb'. Based on Nita's biological differences - she possessed body parts that appeared to work in opposition to the perceived norm, a medicalised reductionist assessment was made and she was labelled 'defective'. Mary and her family accepted the prognosis with fortitude and turned to their faith for answers. Mary advised 'we prayed that he - God would do what is best, and we left it up to Him' and it is that power of prayer which provided her and the wider family with consolation, comfort, acceptance and solidarity.

At the time of the interview Nita was 25 years old and though she has an intellectual disability the family expressed their thankfulness and gratefulness that through divine protection and intervention 'the Lord stepped in and saved the baby'. Nita is neither 'blind, deaf nor dumb' as the original medical prognosis suggested, and that has reinforced the family's belief in their faith. They continue to offer personal prayers for moral and spiritual direction in their daily lives including personal and relationship matters. Nita is now at the transitional early adulthood stage because of her delayed intellectual development, and it is that stage where most young people want to take control of their life and form adult relationships - Nita is no different. She has voiced her disappointment and unhappiness with her lack of a romantic relationship particularly because she identifies her position with that of her siblings who are of a similar age and have romantic relationships. The family response to the situation is with prayers because 'if it is the Lord's will then he will send a suitable boyfriend for Nita'. For them, the notion of miraculous efficacy is powerful and so they continue to make meaning of life experiences through a discourse that is dominated by their belief that God is omnipotent.

4.2   Disability as Punishment

Many interview participants hold steadfast in their belief that disability is a small price to pay for the greater good of an individual and/or the wider community. Mr Powers is a former serving politician and wheelchair user who acquired his disability later in life through hospital negligence. He maintains that 'you can't have something for nothing; you have to give up something in order to get what you want'. He explained the following scenario:

> An Orisha follower met me and said that he was not surprised that I became disabled because you have to sacrifice something in order to get something, you see I had spent time at the steps of the Hall of Justice – 40 days protesting national issues like corruption, so he said being disabled was expected. I don't buy into that thought that I am being punished for standing up for what is right.

The implication is that disability is a virtuous suffering to be endured in order for a benefit to be gained. Mr Powers had been told on many occasions that his disablement was a misfortune in reaction to his political stance but he did not share that view. Observers confronted with trying to make meaning of Mr Power's disability formulate explanations that place his identity as a politician at the forefront followed by the unusual circumstances that led to his injury. Those are then contextualised in relation to the spiritual beliefs of sacrifice in order to concoct a reason. This notion of political sacrifice is voiced in the statement by Martin Luther King Jr 'Human progress is neither automatic nor inevitable … Every step toward the goal of justice requires sacrifice, suffering, and struggle; the tireless exertions and passionate concern of dedicated individuals' (King 1958).

The virtues of sacrifice have been expressed by many from J M Barrie the author of Peter Pan who said that 'You can have anything in life if you will

sacrifice everything else for it' (Barrie 1911) to the holy texts 'For God so loved the world that he gave his one and only Son, that whoever believes in him shall not perish, but have eternal life' (John 3:16). It was also mentioned continually throughout the research process. A participant related a story he had heard in his village:

> I hear that the family wanted to build big house an ting, so they had prayers and make sacrifice to the devil and offer up the boy, and he come and make the boy a cripple, these tings does happen fuh true, no joke.

This is another dimension to the entanglement of the complex facets of disability. The cultural explanation implied in the example above is that the causation of disability is the retribution for sacrifices made either for personal or - in the case of Mr Powers - community gain.

In many societies including those in the West there are religious teachings and Holy texts that consider some disabilities to be the consequence of sin. In 1999, Glenn Hoddle the then England football coach was quoted as having said:

> You and I have been physically given two hands and two legs and half-decent brains. Some people have not been born like that for a reason. The karma is working from another lifetime. I have nothing to hide about that. It is not only people with disabilities. What you sow, you have to reap. (BBC News 1999)

Following a very public outcry he apologised for his statement citing his personal religious beliefs. During my research process, a participant had been advised that their disability was due to 'something one's parents have done' and that was supported by religious moral regulatory statement for example 'in the bible there is a scripture where they say the sins of the father falling on the generations'.

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On one of my field visits I was advised to interview the Carlton family, but was unable to do so for a number of reasons including the unavailability of the sign language interpreter. I did however speak to extended family members who shared the belief that the siblings of the family who were born with hearing and speech impairments were atoning for the sins of their father. The family are well known throughout the community where many believe that the impairments are directly related to the father's failure to abide to socially accepted codes of conduct. A neighbour said 'it's because their father when he was younger he used to catch birds and cut off their tongues'. The villagers affirmed this belief with such conviction. When asked if they believed that to be true the responses were unanimously:

> but of course, I know fuh sure dats the truth'; 'I ain't lying'; 'Girl, I telling you what I know and I know that's what happen to them'. One said 'ent all dumb people does be deaf too, but them not deaf, they just can't speak, so yuh see is God punish they ole man.

The judgement of the sins of the father falling on the next generation is legitimised by way of references to biblical text 'The Lord, the Lord God, … who forgives iniquity, transgression and sin; yet He will by no means leave the guilty unpunished, visiting the iniquity of fathers on the children and on the grandchildren to the third and fourth generations'. (Exodus 34: 6-7). But there are also contradictory scriptures e.g. 'The person who sins will die. The son will not bear the punishment for the father's iniquity, nor will the father bear the punishment for the son's iniquity; the righteousness of the righteous will be upon himself, and the wickedness of the wicked will be upon himself' (Ezekiel 18:20) In spite of knowledge of the contradictory text the reinforced collective community explanation is that the children were punished for the

sins of their father, with the story being communicated as an example of social and moral puritanical codes of conduct.

A taxi driver (unaware that I was a researcher, but knowing that I was from England) pointed to a man on the roadside and said 'yuh see dat man deh – Dummy, you know he, and his brother, and sister they dumb, you know is why? Is because deh fadda used to ketch bird and take out the tongue'. It was apparent that the taxi driver related the scenario to emphasise that punishment is inflicted on those who do not exercise sound moral judgement. As he was unaware of my research and because he emphasised 'he, and his brother, and sister they dumb', my assumption is that he was expecting a shocked reaction to the idea of three siblings in one family having speech and hearing impairments. The community holds very strong beliefs that disability is a punishment for transgressions and moral failures, and supported by theological texts they are used to reinforce a sense of community morality. However, the effect of such strongly held views is the enduring negative attitudes to disability which in this instance commits the siblings to a tainted cultural identity.

In T&T and beyond, Hansen's disease (Leprosy) is often cited as the retribution for sin because according to scripture 'God inflicted it upon mankind to punish sinners forcing the afflicted (including Kings) to be segregated from the rest of society (II Chronicles 26:21). Christian missionaries who are the originators of the care and welfare provided outside of state systems in T&T arrived at the end of the crown colony system because it was a requirement for countries who demanded independence to use missionaries to support their health care services (Lacey 1987). Upon their arrival the missionaries founded a segregated Leper

colony or Leper Island as it was then called situated just off the West coast of Trinidad and clearly visible from the mainland. Though Hansen's disease is no longer prevalent in T&T (according to Dr Sue, a specialist medical practitioner, there are on average only thirty new patients per year) the biblical connotations prevail and manifest themselves in people's attitudes. Father Benedict explained that 'from a spiritual point of view, in the old and new testament they speak about disabilities and leprosy as a curse from God. It is because of sin by self or a family sin'. Those beliefs continue to be intrinsic to the social production of notions of normality/abnormality and the resultant attitudes and discursive practices.

Patrick who has Hansen's disease is of the opinion that because 'in the Bible it say Leprosy is a curse for sin and people believe that', those with the disease continue to face undue discrimination, stigmatisation and ostracisation. Dr Sue also reiterated the point noting that 'the issue for them is Biblical. Leprosy is a curse from God and that is the problem that they have'. There appears to be no flexibility in the interpretations and Hansen's disease continues to be firmly located within religious thought. Negative beliefs and attitudes towards those with the disease are so prevalent that Patrick has chosen to hide the symptoms of his impairment except from immediate family, his medical doctor and nurse, a consequence of the unchallenged deep-seated religious association of the disease. Patrick justified his action stating that 'people don't really have a knowledge about the disease and ting. Remember in the Bible it say that it is a curse from God so if people know, well it will have stigma'. By keeping his impairment concealed Patrick is able to avoid a defective person classification and any judgements being made not only on his imperfect body part but on his entire being. Patrick did however insist on showing me the physical

symptoms of the disease because 'if you studying the ting, you should know what it look like and see why people does want to scorn we'. Raising his trouser leg, Patrick showed the scarring and said 'yuh see it ain't so bad'. It is clear that the negative attitudes and beliefs of society in relation to Hansen's disease causes Patrick some embarrassment and are behind his decision to avoid public acknowledgement of having the disease thereby denying himself a disabled identity.

Patrick's ability to hide his impairment and take on an outward normative appearance enables him to avoid the religious implications and conferred social status that accompanies perceptions of Hansen's disease. The negative preconceptions and hostility goes unchallenged because their value base is underpinned by theological scripture. That coupled with the ideology of the individual model which interprets disability as a personal tragedy causes those with the disease to endure social denigration, marginalisation and exclusion from mainstream social and economic life. Patrick considers himself fortunate in that he is able to avoid those negative experiences through the process of embodied 'normalisation' which deflects the chances of his bodily abnormality affecting his social normality.

4.3 Obeah and Jharay

On numerous occasions during the data collection process participants referenced the practice of Obeah, which is a folk religion/spiritual practice which had been brought to T&T from West Africa. It is associated with folk magic, and mysticism similar to Voodoo and Wicca and its underlying principles are positioned in spirituality – manipulating and controlling supernatural powers/forces of traditional African spirits through the use of material objects and recitation of spells; and natural herbs or 'bush

medicine' used predominantly for divination i.e. bringing about good fortune; finding out the causes of and treating illnesses; protection from harm; and avenging wrong doing (Bilby & Handler 2004). During post-emancipation the practice of Obeah was demonised by the colonial officials and became shrouded in a level of secrecy and eclecticism, and though it continues to be practiced and used both diagnostically and curatively with many expressing confidence in the efficacy of its rituals, there is some degree of stigma due to the then laws against it which were similar to those on the practice of witchcraft. Those who use the services of an Obeah practitioner do not do so overly publically.

Jharay which is a traditional Indian method of healing is performed by a Hindu Pundit in which there is gently stroking accompanied by the repeating of special pujas (prayers), offerings to respective deities, the use of herbal remedies and sometimes animated spirit manifestations (Winer 2009). Both Obeah and Jharay are accepted and embraced as a response to impairment and disability irrespective of social status, ethnicity and secular status. It is therefore not unusual for a non-Hindu to visit a Pundit for Jharay.

Spiritual/religious beliefs which do not fit the conventional concepts in the West remain rooted in the dominant disability discourse in T&T, because of the psycho-dynamics of supernatural powers that are embedded within the culture. A review of the data pointed to a number of widely held beliefs of disabilities that are directly linked to supernatural acts, for example those of spiritual interventions and Obeah. An Obeah (wo)man is considered an alternative therapy practitioner/healer, and many of them are also religious healers who offer holistic ritualistic treatment usually by way of exorcising

demons and offering herbal remedies. McCartney (1976) in his study of Obeah in the Bahamas mentions this fusion of medicine and spirituality:

> Healing or problems of physical and mental health are the most important aspects in the practice and art of Obeah … Being fixed ascribes the causation of a disease or disability, or mental condition, to the magical influence of Obeah (McCartney 1976 unnumbered).

In T&T 'maljo' (failure to thrive and develop because of an evil eye), 'going off' (mental illness) and 'malkadi' (unexplained fitting) are considered to be consequences of Obeah and are impairments to be viewed with suspicion and fear, the treatments for those are prayers, bush baths and retribution (Littlewood 1993). This linking of disability with spirituality, Obeah and Jharay is generally associated with sinful acts (though not necessarily by the afflicted), and carries with it a degree of shame, creating fear in the minds of people. The beliefs associated with these particular impairments are akin to that of Hansen's disease, and affect the way that people respond to individuals afflicted with them. Dr Maharajh, professor of psychiatry at the University of the West Indies, wrote in a newspaper article that 'demoniacal possession states were common in T&T with two-thirds of all patients presenting to a psychiatric clinic interpreting their symptoms as being caused by "spiritual wickedness from high places", Obeah or jadoo – a superstitious belief in the casting of spells on people, "spirit lash" or evil influences' (*Trinidad Newsday* 12 December 2010).

The synergising of bio-medicine and faith, religion and spirituality is a common concept, but there are disabled people who in choosing to locate their disability in the realms of bio-medicine, face resistance from family, friends and even strangers. Tony who has Systemic Lupus Erythematosus (Lupus) said his experience has been one where 'the first thing they like to

believe is somebody do something. They like to tell you that you need to get a bush bath[1] and that you need prayers so they want to pray with you'. Medical tests have shown him to have a conclusive diagnosis of Lupus yet his mother is steadfast that 'somebody do something to him'. Enormous social pressure had been placed upon him by his mother, the extended family and others who hold the belief that his impairment was due to the effects of Obeah, even though those pressures exacerbate his condition. 'They have their own notions of what it is and by they keep telling you somebody do you, they causing you stress. Stress flares up the disorder and superstition causes stress'. In spite of Tony's insight into his impairment, the family place considerable importance on the socio-religious cultural causation of his disablement and that takes precedence over somatic pathology with them believing that medical interventions would be inappropriate for his condition. Intertwined with the issue of the cultural discourse of disability, is that of family values and the role of mothers within the family structure in T&T. Tony indicated that 'but my mother is my mother, so how can I go against what she says? I can't argue with her'. The cultural norms around mother/child relationships can directly influence the choices made in relation to responding to disabilities.

Obeah has not only been used as aetiology of disablement, but is also used to inflict disablement on to others. Mother Bishop (a Spiritual Baptist Preacher, traditional healer and wheelchair user) explained that many visit her seeking to cause suffering unto others by rendering them disabled. 'It have a lot of people with vendettas, I will say over 50% of them have that evil possession of mind and they will come to me and say that they want

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[1] A ritual bath using a potion which usually contains herbs, roots, bark, leafs and limes taken to rid a person of evil influences (Aho W & Minott K 1977),

me to make somebody cripple'. In those instances disability is problematised, as it is being used in the context of causing undue suffering and hardship. Mother Bishop refuses to facilitate those requests and says that 'what goes around comes around, what you sow is what you reap, and I don't believe in that'.

Mother Bishop describes her 'spiritual powers' as being informed through her religious beliefs and not as 'acts of Obeah or superstition'. She uses those 'healing powers' to perform ritualised interventions for those with mental and physical impairments or those believed to have spirit possessions which is considered to be a real entity in which the body, soul and mind is taken over by supernatural forces. Exorcism through prayers, baths and herbal medicines are used as Mother Bishop's medium of healing coupled with acceptance, and submitting to God's omnipotence. Upon arrival to her home one cannot help but notice the presence of a large font where she performs ritualised bush baths and an open space laid out similar to that of a church. Though the setting exudes some sense of community collective it is in effect geared towards personal interests as visitors go there to seek specific individualised attention and personalised advice based on their symbolic needs.

Mother Bishop provided the following example of her work:

> There was a person who foot got taken off, but he was so abusive. His wife bring him to me to help him and I had to tell him that it is not man's work, it is God's work. He have to accept and be comfortable with what happened to him. I tell him he have to accept his disability. We prayed, and you know it worked! You see, if they sick they want healing, and it's prayers that give him that healing and comfort.

Her claim is that the man's mental health improved and he was no longer abusive. Her intervention also provided hope, not only to the afflicted, but to the rest of the family.

Mother Bishop professed to exorcise manifestations of evil spirits through the performance of rituals e.g. bush baths, prayers and the administering of homemade herbal potions.

> I can heal them ... I follow what the spirit reveals and then I tell the person what to do, sometimes it is to pray, or to take medicine, or to do other things. Sometimes they need a bath (bush bath). I take away the evil spirit that make them go mad.

The belief in Obeah is in direct contradiction to many mainstream faiths, and for that reason some of the participants were reluctant to openly acknowledge that they straddled both belief systems i.e. Obeah and mainstream organised religion. Mr Lindon a Christian was emphatic that the disability experiences endured by his family were the direct result of Obeah. He said that:

> The neighbours was jealous of we mother and they said that they go put ah spell so that all of my mother's sons go die. My two oldest brothers died under strange mysterious circumstances. They say that one get poison with dead bones from the cemetery, and the other one went to help somebody that had a car crash and on the way to taking the person to hospital he end up going over a precipice and he died. My other brother had a serious motorbike accident and end up with one long and short foot. They does call him hop and drop. After that my mother went up the Mount[2] and pray plenty and ask the Lord to take her life instead of her boy children and that is how I get away. I'd get chop on my neck and I lucky I survive but my mother come and die soon after. They say that she give her life to

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[2] Mt St Benedict Abbey where people from all religions go for healing and spiritual guidance often performed by the burning of a candle, blessings and prayers, and being sprinkled with holy water

save me and meh next brother. I lucky I only have a finny hand cause I fall down with a cutlass and cut a nerve and up to now my hand ain't good. But is jealousy that make them use Obeah that cause all these problems.

The problem of aetiology of impairment and death is attributed to a curse invoked on the family through Obeah by the neighbours.

In T&T spirituality and religion are embedded in all aspects of social life and the belief in the supernatural is ingrained in the culture and psyche of the people and is deeply fixed throughout all levels in the society (Beaubrun 1975; Gopie 2012).

4.4   Superstitions, Myths and Folklore

Ogechi & Ruto (2002:73) in their research on Africa found that 'modern African societies do not seriously uphold the traditional beliefs on the causes of disability. With the influence of Christianity, Western education and medicine, the traditional causes of disability are considered archaic and people no longer have any awe over the disabled people'. This is in direct contradiction to that of T&T which is a country rich in superstition. This incongruity with the findings of Ogechi & Ruto is based on the fact that during the research process all discussions on disability were entangled with complex and contradictory representations of traditional beliefs, superstitions and myths which were more in keeping with Davis (1997:76) findings that 'conspicuously abnormal persons were subjected to superstition, myth and fatalism. Their lives were seriously limited by widely held beliefs and superstitions that justified the pervasive prejudice and callous treatment'.

Forces that are perceived to be outside of the physical realm may not be easy to explain, but are the accepted cultural traditions upon which behaviours and values are based and continue to be passed on through the generations. Many embrace bio-medical explanations for disabling impairment but at the same time unwaveringly commit to socio-cultural beliefs, even when conflicts in understanding and logic arise. Dr Beaubrun, a Trinidad psychiatrist, observed that 'the populace is very superstitious at all social levels ... Trinidad culture is rich in superstition' (Beaubrun 1975:202-205) and my own research findings support his view.

It is widely believed that showing excessive admiration for a new baby is unacceptable because of the possibility of giving the baby 'maljo'. - an illness syndrome which happens when someone looks at another in excessive admiration and inadvertently causes harm. It can be debilitating and fatal if not treated, but it can be prevented by gently pinching the person who is being admired. In other words it is a sickness of looking (Graham 1985). A number of disabling conditions are attributed to 'maljo' and the strength of the belief is such that medical interventions are often delayed in children displaying mild symptoms of ill health in preference to spiritual/faith healing. The concept of 'maljo' is also identified in Talle's research on disability amongst the Kenya Maasai in which she talked of babies being particularly vulnerable to 'ilkonjek' people who admire particular parts of another person's body and either consciously or unconsciously cause them harm (Talle 1995).

Jo-anne who had recently given birth to her first child was told by her mother that the fretful crying baby had 'maljo' and advised her to make the sign of the cross on her baby's forehead with red lavender oil, place a

gaping pair of scissors on a bible opened to Psalm 23 in the baby's cot, and that the baby should wear a jet bracelet (a gold amulet with small black beads). Jo-anne duly followed her mother's instructions while stating that 'I don't believe in Obeah and thing, I ain't superstitious neither but I know for sure that the baby did get maljo'. Adherence to the dominant structured family hierarchy and the cultural norms around the mother/child relationship in T&T mean that Jo-anne is keenly aware of her expectations to heed her mother's instruction, and that her mother's opinion carries great weight and influence. The ritual discussed here was mentioned a number of times during the data collection process, and is an indication of a traditional ritualised diagnosis and treatment being accepted as a formalised intervention. It is interesting to note that Jo-anne considers maljo to be an authentic condition despite having stated emphatically that she was not superstitious.

Such rituals are also practiced as preventative measures 'just in case there is truth in the saying'. Respondent Phil explained that throughout his life he was led to believe that 'you shouldn't cut a boy child hair until he can speak because if you do that it can cause him to be dumb'. Phil has carried on the tradition with his own sons even though he has no evidence of such manifestation, but neither is he aware of any boys who have not been exposed to the ritual. This traditional cultural preventative practice has been produced, reinforced, legitimised and passed on through the generations without question.

The extract below is taken from a UK Daily Mail article (Nelson 2010) reporting on an incident in T&T of a community using both a medical and spiritual response to make meaning of a situation within a public environment i.e. a school setting:

Priests called in after 17 female school pupils are 'possessed by the devil'

A group of female school children who fell mysteriously ill and began rolling on the ground and talking in tongues were 'possessed by the devil'. Chaos broke out at Moruga Composite School in Trinidad and Tobago when 17 students began complaining of nausea and headaches before collapsing. Two of the students tried to throw themselves over a railing and had to be restrained, the Trinidad and Tobago Guardian reported.
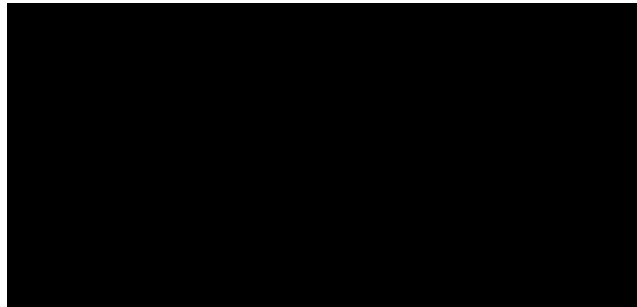
Pupils of the Moruga Composite School in Trinidad and Tobago wait for transportation after the incident

Fellow student Kerm Mollineau said: 'One girl was blabbering as if in a strange language. I would not understand what she was saying. 'It was sounding like "shebbaberbebeb shhhhee", they were unusually strong.' According to Mollineau the devil had possessed the girl. He said: 'I asked the devil what he wanted with the girls and the voice said he wanted a life. He kept saying to send the girls in the toilet and to leave them alone.'

Roman Catholic priests and pastors from nearby churches were called to the school and showered the children with holy water while reciting prayers. The students were hospitalised and pupils are set to receive counselling following the incident, which is reminiscent of scenes from Arthur Miller's The Crucible. The 1953 play dramatized the Salem witch trials of 1692.

Fire Officer Ramdeo Boodoo, who conducted safety tests in the school, said there was no evidence of anything that would have triggered the nausea or fainting spells. One teacher who did not want to be named, claimed the school had been visited a fortnight earlier by an Orisha woman who had had a dispute with a member of staff.

Orisha is an ancient religion with roots in voodoo. Another member of staff claimed the school had been built on burial site – but this was denied by residents living nearby. (UK Daily Mail Nov 17 2010).

Responses to the crisis draw on the combined cultural agencies of medicalisation and spirituality, with interventions from officers of the Student Support Services Division, the Ministry of Health's Mental Health Department, and a Pastor from the local church. The Pastor advised that

> they seem to be of a spiritual nature. It has nothing to do with food poisoning; it is something more. I came here to see what was going on'. He went on to say that 'he was blessed with the gift of deliverance and was able to detect the demonic presence. This school is a target. All of these children are not acting. It is not a health problem. It is spiritual warfare (Matroo 2010).

The engagement of spirituality to make sense of and manage the situation affirms how it is intricately woven into day to day life experiences and accounts for Pastor Daniel's offer of 'healing'. The notion of 'healing' is particularly prevalent amongst Pentecostal sects which have a 'Christian-based theology but is particularly reliant on vibrant preaching, manifestations of the Holy Spirit, including speaking in tongues and faith healing ... they hold strong beliefs in demon possession and faith healing' (Ward & Beaubrun 1980).

In negotiating the aetiology of impairment a number of people staunchly believe that arthritis is caused by 'catching a draught' or 'catching a cold in yuh hand' and it is often given as the reason for joint pains in advancing years. It is said to occur when an individual goes from a hot environment into cold e.g. ironing and then standing in front of an open refrigerator. Respondents shared the following explanations: 'Young people like to iron their clothes and then go out in the dew, but arthritis ain't go catch up with you now, is when you older and can't move your fingers that's the cause'; 'cooking over a hot stove and going in the fridge bound to give yuh arthritis'; 'I didn't used to listen to my mother when I was young and now I

paying the price because she used to tell me don't iron and drink cold water, but I didn't take her on and now I paying the price'.

The medical profession adds weight to the reproduction and legitimisation of many of the cultural attitudes and beliefs about health, health care, and impairments because they are also part of the community in which these cultural beliefs are practiced and have themselves adopted those beliefs as part of their own knowledge base. Mrs. Carter said 'the doctor told me so, he asked me if I used go from hot to cold and when I say yes, he tell me that I catch a cold in my hand'. Though the perceived cause of the ailment has a unique socio-cultural component and not one which is clearly defined by bio-medicine, the explanation is validated by a medical practitioner, therefore the concept of 'catching a cold in your hand because of extremes in temperature' is normalised as an absolute truth. The reinforcement of beliefs such as these will occur because of the positions of power and status that medical practitioners have in society, and the epistemology which creates an unequal power dynamic with a subordinate other (Illich 1976).

In examining the T&T folklore there were many representations of characters with physical impairments for example *douens* and *la diablesses* which for the most part are used to instil fear and act as deterrents for social wrongs, but that also fuel prejudice and discrimination against disabled people. *Douens* are characterised by their androgyny, short stature – no more than two to three feet in height -- deformed backward-facing feet and forward facing heels, and lack of facial features. They are explained as being the lost souls of children who died before baptism and therefore their spirits roam the earth forever (Besson 2007). According to informants *douens* attempt to lure other children who have not been baptised or christened into

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the forest, and they have also been known to visit homes making soft crying noises to get the attention of a mother's love.

Figure 7. *Douens* - Painted by Daniel O'Brien in Newsday 29:02:2012

A *La Diablesse* is a spurned woman who lures men with promises of sexual favours. She has a beautiful figure and poise, but is manifest as having one deformed cloven foot which she hides under a long dress reminiscent of the indigenous concepts in some African states that consider disabled people as between part animal and part human (Devlieger 1998). Participants have said that in order to avoid being lured under her spell unsuspecting men must take off their clothes, turn them inside out and put them on again.
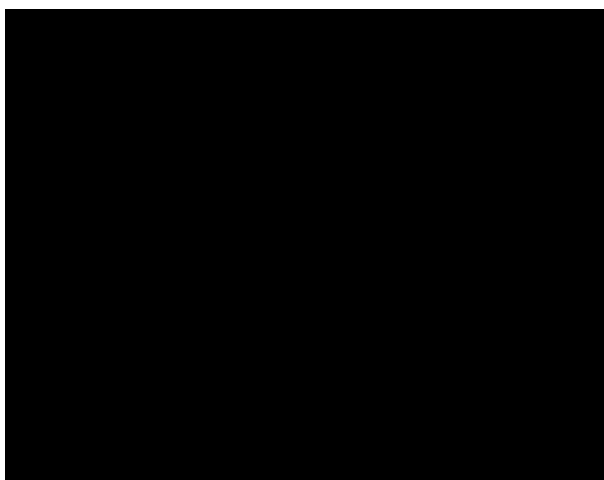
Figure 8. La Diablesse courtesy sadida25

The legends of the *dounes* represent the outcome of not fulfilling the religious sacrament of baptism and of *la diablesses* represent punishment for infidelity and betrayals. Both are used to intimidate others into adhering to socio-cultural norms and value based systems but there is also a subliminal message around depicting bodily imperfections in such a negative manner.

The disability studies programme at the UWI challenges some of the disability related socio-cultural myths and superstitions. The following examples were shared by students:

> Someone said that the child was born disabled because the mother saw a snake when she was pregnant. The child has cerebral palsy, but they believe that the child's jerking actions is because he is mimicking the snake his mother saw in pregnancy. They believe that you must never look at snakes when pregnant.

> When you do not satisfy pregnancy cravings they believe that facial disfigurements and scars are caused because the mother did not get what she craved. If she scratched her face while she had a craving then the baby will have a scar on their face in the shape of the thing that the mother was craving. What you supposed to do when you have pregnancy craving is to touch a part of your body like your behind so the scar on the baby will not be anywhere noticeable.

> If you look at a person with Down's syndrome when you are pregnant your baby will be Down's syndrome.

From these accounts one can see that the cultural responses to defining impairment are positioned in an outward projection of blame with the disability being attributed to external factors. The narrative explanations provided are framed in the context of presenting precautionary guidance against the possibility of 'catching the disability' thus giving rise to issues of the social positioning of those with disabilities. For example, the idea that an

individual with Down's syndrome should be shunned contributes immeasurably to generating fear, misconceptions and stereotyping, and results in the stigmatised social positioning and prejudicial attitudes they so often experience.

4.5   Spirits & Demons

In a country such as T&T where the social views and values of psychosocial illness are based on the notions of spirit possession, the cultural expectation is that exorcisms and sacrifices will be performed to expel the perceived evil. From my discussions with respondents it is apparent that spirituality plays a fundamental role in the representation and experiences of those seeking to enhance the quality of life of disabled people. It also shows that considerations of spirit possession are able to release responsibility and feelings of guilt. Doreen, a mother, shared with me the extent to which she was willing to go to make sense of, and negotiate her daughter's disability. The family were reluctant to accept the medical diagnosis of 'fits' (epilepsy) instead believing the daughter to be 'possessed'. Doreen said that she was advised to 'get help from a Pundit who could Jharay the child',[3] but 'even with the Hindi prayers she still have it [the epilepsy] so I still went to another religion to find out'. This trend of interpreting disablement as the consequence of supernatural forces even in the presence of a medical diagnosis is not uncommon.

The President of the Association of Mental Health Officers of T&T has condemned those strong cultural belief in spirit possession, noting that it contributes to the medical neglect of individuals. He observed that many failed to seek medical

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[3] A ritual performed using incense by a Pundit to ward off evil eye from babies and children.

treatments for their mental ill health instead favouring the culturally held beliefs of spiritual explanations:

> this thing about demons has informed and delayed the development of appropriate treatment methods … progress has been made, people still call the mentally ill, 'chupidee' or 'madman' regularly … History has stymied proper treatment, and even some medical practitioners do not accept mental illness as a disease. The stigma runs so deep that a family member's first line of response is that their loved one is demon possessed'. Many families hold steadfastly to Biblical stories of Jesus Christ casting out demons, although the family member may be ill. Another response has been that the mentally ill person is just "playing the fool. (Lara-Patterson 2011).

The President's comments were met with some criticism from Millie, a disabled Catholic Sunday School teacher, who advised of her continued believe in spirit possession and testified that spiritual interventions are ultimately more effective than medical treatments. She believes that 'at the end of the day it's God's will':

> I believe that it does exist … Like when I seeing a particular behaviour acting in a child and they were praying with this child and she started to vomit and speaking in this deep deep loud voice. You are dealing with supernatural forces and the prophecy came out that her grandmother offered her up to the devil … there was a lot of prayers, laying of hands and praying for the child and she was delivered not by the people, but by God.

It is often the case that mental illness is perceived as possession by evil spirits for which there is low tolerance and strong disfavour, and where 'evil' deeds are said to manifest as a mental or intellectual disability it carries with it a great deal of shame because it is viewed as an outward display and acknowledgement that the person and/or family are being punished for some sinful or immoral deed, or they are the recipient of someone's ill will towards them. The reaction to perceived spiritual possession is usually one of fear, misunderstanding and ignorance with the disabled person being the passive recipient of marginalisation, social segregation, care deficit and diminished productive potential and they are never

viewed as heroic or to be the recipients of empathy or pity. The responses to mental illness or evil spirit possession are invariably negative with blame apportioned as to its cause and divine intervention sought.

Spirituality can also be a catalyst for empowerment in the navigation of negative interactions with others. It provides an interpretative framework upon which to place the blame for the manifestation and absolve the individual from guilt by attributing their perceived negative behaviours and attitudes to the intrusion of the spirit. Spirituality also provides disabled individuals with emotional resilience needed to cope with the negative reactions they encounter. Ward & Beaubrun note from their research on demon possession that 'possession prone individuals are treated with deference and concern' (Ward & Beaubrun 1980:207). However in direct contradiction to the negativity meted out to those thought to be possessed by evil spirits are those instances where the possession is seen as an animated manifestation of the power of prayer. They are viewed differently and those possessed individuals who Milly referred to as 'catching the power' are actively encouraged to be a part of the church community and are 'accorded a sense of dignity and prestige in their sub-culture, and, even more importantly they may be given the affection and emotional support lacking in their daily lives (Ward & Beaubrun 1980:207).

4.6   Miracles

Father Benedict contextualises, interprets and responds to his disability as being God's way of testing his resolve, believing that despite having in the past asked himself 'why me', 'the Church's view of disability is that it is through a human condition, it's our faith being tested'. The 'why me' question is one that positions the individual in the realms of victimhood that interprets disability as a problem or failure through no fault of their own. But

having said that, there are contrasting responses to that 'why me' question. In most Western models of disability 'why me' is discouraged as people who do so are thought to be struggling to accept their disability. However it is encouraged within religion and spirituality because it stimulates thoughts and focuses attention on the purpose of life and existence. Wayne (quadriplegic) and his family were advised by an Orisha priest that Wayne's disablement was atonement for his father's wrongdoings. It was 'a message from on high to open the eyes of the problems in the family'. In this circumstance the response to the 'Why Me?' question was that his disability was to be the catalyst through which interpersonal structures could be negotiated to resolve the fractured social interactions, ill-conceived judgements and inappropriate behaviours of family members.

The practice of healing, curing and fixing as a way of dealing with illness, impairment and disability is a dominant feature of many of the religions practiced in T&T, for example the Pentecostal born-again faith. These medico-religion features are at odds with the rights-based social model approach because they identify impairment as the problem. The practice of seeking spiritual interventions by way of miracle cures and healing of inflictions and impairments is not uncommon and I received many testimonies from people who had attended religious services and deliverance crusades purporting to have been healed, cured and fixed through divine intervention. A respondent mentioned that in 2012 an evangelist from Bahrain visited Trinidad for four nights offering prayers and healing for the sick and infirmed. At a similar crusade the daughter of the Nigerian Ambassador testified that she was healed spiritually of her sickle cell anaemia (figure 9), and Evangelist Benny Hinn has purported to have 'cured

a lot of patients and chased away lots of ghosts and demons from Trinidad' and saved souls and healed attendees (Premaratne D 2001).

Envoy's daughter 'healed' at Benny Hinn crusade The daughter of the Nigerian ambassador to Trinidad and Tobago testified to being healed and began preaching at the opening of the three-day crusade. Philomena told the congregation of approximately 30,000 people that she felt a spiritual "touch" and was healed of sickle cell anemia. She fell to the ground, assisted by catchers, under the "anointing".

She then began exhorting the audience that God loved them all and they would be healed if they only believed, and they should read the Bible as it was the answer to all their problems. She was one of a small group of people testifying of their healings. A Presbyterian pastor, who said he was healed of a back condition, tore off his brace and walked around the platform. One elderly man said he was healed of walking with a limp and jumped and danced around the stage. Hinn took the old man's walking stick and threw it away, telling him he would not need it anymore.

Figure 9 (extract from *Trinidad Express* Newspaper 21 May 2006).

Unfortunately despite Benny Hinn's claims, one of his 'healed' congregants succumbed shortly afterwards to the ailment. The turn of events was responded to by the then acting Chief of Staff at the mental hospital who stated: 'the practice of casting out demons is taking the country back to the

15th century when mental disorders were perceived as the work of the devil and demons'. However those comments are at odds with the social reality in T&T as is clear from my findings that belief in spirit possession and the practice of exorcism still prevails. The President of the Association of Mental Health Officers of T&T spoke of the numbers of people who continue to delay getting treatment for mental illness because of their belief in demon possession and the references in biblical stories of Jesus Christ casting out demons. It is clear from the participants interviewed that religious thought permeates every aspect of the lives of many in T&T and is intrinsically intertwined with physical, mental and psychosocial disabilities.

The making meaning of experiences is not only about bodily expressions, as environmental positions constitute a major component in interpretations. For example individuals who display symptoms of convulsions, rambling speech, and are in a catatonic state receive diagnoses dependent upon the immediate environment in which those manifestations occur. If the event takes place in an environment of religious worship the interpretation will be one of having 'caught the power' (being possessed by the Holy Spirit and having purification of the soul), which is a sought after experience. If the incident is within a family setting the conclusion would be demon possession, and if it happens in a medicalised surrounding chances are it could be diagnosed as a 'nervous breakdown'. These show the flexibility in interpretation, and are evidence that disability theorisation is not negotiated in isolation, but in relation to the cultural, social, and environmental settings in which the impairment or abnormal functionality is experienced.

From the research findings disability perceptions were not dominated by one model or the other nor were there many specific references to the social

model approach that theorises disability as the effects of society's discriminatory and exclusionary factors. For the most part respondents contextualise disability in relation to their own impairment experiences, seeking individualised explanations, healing or cures and often hoping for miracles to ensure their best possible chances of overcoming the disablement, 'I believe that I will walk again ... God can work miracles, I have faith, I believe that I have faith' (Mr Powers).

From a social model standpoint, the miracle healing ideology can be seen as undervaluing the experiences of disablement, with its emphasis on eliminating impairments and the stigmatising of bodily difference. But, it is important to note that in T&T miracle healing tenets are a vital part of the socio-cultural context within which disability is experienced and that those beliefs affect entire decision-making processes, and peoples' approaches to help, guidance and support. They determine treatment plans, the expected and anticipated outcomes of inflictions and impairments, and the ways in which those outcomes are dealt with. In circumstances where guilt is being experienced those beliefs can go some way in alleviating the sense of responsibility by apportioning blame and shifting the focus onto external factors. With responsibility and blame deflected there are greater chances of empathy, understanding and support. For example, where impairments are deemed to be the consequence of devil possession it is the possessor of the body i.e. the 'evil spirit' that is responsible for any wrong doing that occurs because it has taken control of the person's mind and body.

Perceived misfortune and suffering is often attributed to a lack of spiritual or moral tenacity, blamed on the deeds of evil forces, or justified as being God's way of testing the faith of the individual. Because of that, the question

'why does God allow human suffering?' does not pose a challenge to those with strongly held spirituality, religion and traditional convictions nor does it appear to test the resolve of respondents. Mary explained that 'God don't give you more than you can handle ... I put the situation in God's hand because I have to believe he will do what's best for us'.

Disabilities interpreted as God's will are also used for deep soul searching. Wayne's aunt provides an example of this:

> My nephew is now a cripple, but when Papa (the Orisha Priest) came to see the family he said that there is a lot of negativity within the family and that the situation with my nephew is to make the family come together. It's not because my nephew do anything wrong but to let us realise that we need one another and we have to stop the back biting and fighting. There is a lot of evil doing in the family and everybody turning a blind eye, so the accident is our wakeup call.

Here the focus is on the emotional healing of the family, rather than the physical healing of the disabled individual, with the disabled nephew being the conduit through which resolution is placed for the moral failings and misconduct of the family.

4.7 Conclusion

Fundamentally in T&T faith, religion and spirituality strongly influence the course of an individual's life and are more often than not the basis for social or collective cultural explanations for impairments. Disabled people can either be blessed or cursed depending on the cultural context, and their impairments construed as punishment for sin or failure to abide by cultural norms, a result of lack or loss of faith, a source of virtuous suffering or lessons in humility, or a vehicle for promoting social justice and integration.

The underlying tenets of the messages conveyed either contribute to or debunk a number of disability myths or stereotypes.

In this study strong culturally traditional explanations were given for the causation of disability together with an intertwining of traditional and biomedical interventions. Though very trusting of medical professionals, alternatives to complement medicalised interactions are sought and it is apparent that non-medical practitioners (priests, evangelists, and faith healers) are considered to be as important as qualified medical professionals as they feature heavily in the medico-cultural dynamics. In addition, places of worship respond to the needs of disabled people not only through the provision of alms, charity and prayers, but they also offer a space for socialisation and community cohesion, and they strengthen resistance and resilience and play a key role in family relationships and social attitudes.

Superstitions and myths influence and compound negative attitudes of fear and prejudice, particularly in relation to mental and intellectual disabilities, but conversely, they also yield healing, hope and comfort for disabled individuals, their families, and carers. It is clear that superstitions and myths are the basis for many of the social and moral structures in T&T and although for those in the Western world or from differing cultural backgrounds they may be frowned upon, the traditional approaches discussed in this chapter do not mean that T&T is a primitive, feudal, backward or non-modern society.

The findings presented here are an indication that there is no true hegemonic disability discourse, but that a multi-layered approach to impairments is used to construct meaning of and to negotiate disability

experiences often through miraculous intercessions of the power of religion and spirituality, juxtaposed to and co-existing with scientific bio-medical interpretations.

5.0   EVERYDAY DISCRIMINATION

Introduction

'*To become an outcast in this country all you need is a disability, then you instantly become a second-class citizen*'. Joel Julien, *Trinidad Express*, 12th October 2013.

The previous chapter explored the complexities of religion, spirituality and cultural traditions for the roles they play in disability experiences in T&T. Following on, this chapter further develops those discussions by addressing some of the cultural notions and social relations (both implicit and explicit) which adversely disadvantage disabled people in T&T. The scope of the chapter does not do justice to the many examples of discrimination endured by the participants, but my aim was not to provide a long list of social slights but instead to present a critical examination of the most common socio-cultural norms that affect disability experiences.

Some of the narratives shared by the participants were of a taboo and personally sensitive nature and although there were concerns about confidentiality many welcomed the opportunity for openness and self-disclosure in a safe non-judgmental environment. The openness displayed is possibly because they viewed me as a learning outsider who may be able to encourage positive outcomes. Mr Mack advised that because I was somewhat unfamiliar with the 'local scene' he would 'teach me a thing or two about T&T culture'.

5.1 Difference

Disability constructs are embedded in cultural, social and psychological structures which vary between societies and create a number of notions and ideologies that affect attitudes and behaviours towards disabled people. Carlton (2000) posits that

> The modern world is composed of thousands of cultures, each with its own ways of thinking about other people, nature, family and community, social phenomena and so on. Culture is sustained through customs, rituals, mythology, signs, symbols and institutions such as religion and mass media. Each of these informs the beliefs and attitudes that contribute to disability oppression (Carlton 2000:25).

Throughout the research process it was apparent that disability was experienced as another dimension of difference, with individuals being differentiated, classified and ordered based on how they compare to the socially constructed norm.

A disabled participant in sharing what disability meant to him did the mind map below with the phrase 'not normal' being the first thing that came to his mind.
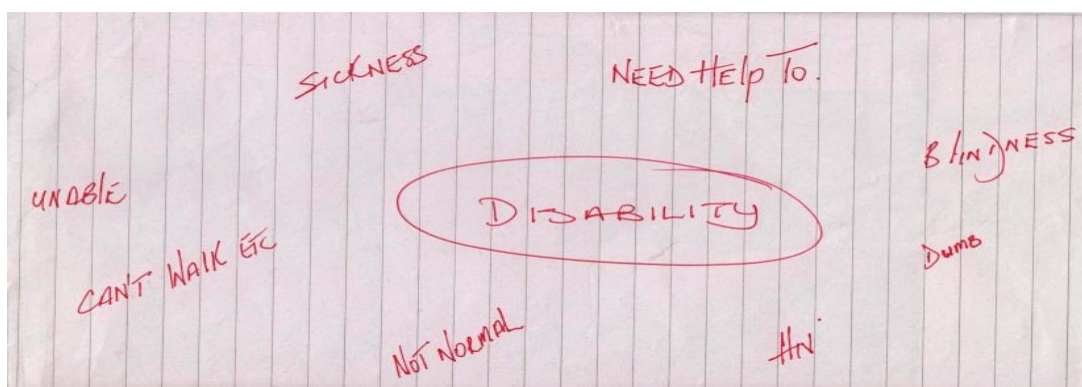
Figure 10. Participant's Mind map

Impairment identity which goes hand in hand with notions of normality/abnormality is often responsible for the negative attitudes and reactions to disabled people. Lord Melody, a T&T calypso artiste highlights attitudinal aversions to difference in his self-ridiculing calypso which references reactions to his distinctive facial characteristics. Mr Mack referred to Lord Melody as 'ugly ... his face looks disfigured'.

Mamma Look a Boo Boo by Lord Melody
I wonder why nobody don't like me, or is it de fact dat I'm ugly.
I wonder why nobody don't like me, or is it de fact dat I'm ugly.
I leave my whole house and home; my children don't want me no more
Bad talk inside the house they bring, and when I talk they start to sing
Mama look a boo boo they shout
Their mother tell them shut up your mout'
That is your daddy, Oh No my daddy can't be ugly so

Such distinctions are not necessarily indicators of discrimination but are representative of the socio-cultural attitudes that rely heavily on the acknowledgment of individual difference and deviations. While carrying out the field work I was often referred to as 'foreigner' or 'English' because of my accent and 'tall chick' because of my height.

Othering

The research data indicates that disability is constructed on the basis of the 'othering' where visible physical differences outside of the perceived ideal human body together with a level of incapacity become key markers. That process of othering is what leads to the denial of disabled people's bodies, lives and experiences especially where there is an obvious physical

incapacity. That physical impairment is then used to define the whole person; for example Peter has a physical impairment for which he uses crutches but the notion of functional incapacity is also extended to his intellectual capacities

> They assume that I am stupid because of my deformity .... they still have the crippled mentality based on perceptions, and these perceptions need to change.

body is deemed to be broken, faulty, or blemished because of visible physical or intellectual variances and it is those differences which lead to ridicule, mockery and discrimination. Dr Phillip explained that her clients endure unnecessary prejudice because of the physicality of Hansen's disease.

> Some of them have problems with their hands – they can become like claws, and with their feet because of the circulation, but because most people can't see it, they are not disabled. The older ones who got treatment in the late stages have more visible problems, so yes, people look at them funny, and they are disabled.

Those who display visible symptoms of the disease become subject to increased discrimination, and that prejudice is reinforced by the historical biblical narratives that present people inflicted with Hansen's disease as social outcasts.

The dominant cultural construct of disability focuses on the visible differentiations of physical and mental impairment manifestations, the severity of those impairments, and more importantly the degrees to which the impairments causes vulnerability and dependence are what determines whether an individual is considered disabled or not. Mrs English the grandmother of a quadriplegic questioned the legitimacy of a young man with cerebral palsy who self-identified as disabled.

He can hardly be considered disabled. I wouldn't even say he is disabled because all he has is a bit of a deformed hand, and a bit of a limp. That's hardly a disability. He hardly disabled.

Mrs English has constructed the meaning of disability through her personal interactions of caring for her grandson, and her interpretations of his normative functioning and ability. In her opinion the young man with cerebral palsy does not epitomise sufficient deficit or inability nor does he fit into her expectations of the personal tragedy model of disability she recognises.

5.2   Nicknames

Language is a powerful tool in the framing of disability and it impacts on disability constructs (Finkelstein 1991) with contestations and differences over its use being part of the process of forging identities. Throughout the data collection process, participants very seldom spoke of their disability using the biomedical terminology of symptoms and diagnosis. Instead terms such as 'he retarded' or 'I am wheelchair bound' or 'I can't walk', which are about the effects of having impairments, rather than specific medicalised diagnoses, were used. Those impairment related labels matter because they imply functional loss, reinforce lack of worth, and legitimise patronising behaviour (Barton 1996) especially in a society such as T&T where 'picong' (verbal teasing using satirical banter) is rife.

In T&T culture where the acknowledgement of difference is an important aspect of identification of individuals, reference to the nature of an embodied dissimilarity (behavioural, personality or physical) is the norm. Names are created that are derived from recognition of a constructed other and that becomes the individual's identifier. That is not unique to those with impairments but form part of the dominant system of classification, and

identification that uses characteristic differences to impose an identity by which a person becomes defined. Shaba explains, 'I got that name Shaba because people say I am ugly like Shaba Ranks, but that's no scene because he had plenty plenty woman'. Shaba rejects the 'ugly' identity, but accepts the name because of the redeeming suggestion of his namesake Shaba Ranks (Jamaican recording artiste) being a lothario. Such is his pride in being identified with the machismo sexual promiscuous culture in T&T.

The owner of a corner shop explained that he chose to call his business Stumpy's even though he initially rejected the nickname:

> It is the name that everybody does call me since I was a boy. People don't really know my real name but they know me as Stumpy or the man with the one foot … I didn't use to like it at all and I used to get vex when people call me that, but they still call me it, so I get used to it. When you think about it, I have a stump foot so they not lying.

The above is an example of the ethno-traditional cultural significance of nicknames which some may consider to be perceptibly derogatory and harsh, but are often used unreflectively as a term of endearment. However, what is so often disregarded is where the nicknames are crude, derogatory or have negative connotations they may adversely affect the individual's emotional wellbeing. Stumpy reluctantly accepts the nickname because his disability is now an integral part of his identity, but similarly there are others who are also disinclined to indicate displeasure with their nicknames for fear of reprisals. Terry explains that:

> In Trinidad and Tobago where if you complain that you don't like a nickname, it is then they will continue to use it and it will stick … sometimes it can be very hurtful but the person with the disabilities may not want to say so because they do not want to be teased more

Terms such as 'handicapped' in their crudest form can be tantamount to abuse. In this example it is used as a form of derision by a parent towards her non-disabled child and consequently it was used by the child's sibling to deride his brother.

> Parent: Yuh handicap of wha, eh, you stupid of wha, move your handicap backside before ah put ah slap on your damn duncy backside'.
> Sibling: Hahaha, mummy say you handicap and you duncy, hahaha. I will tell everybody, all yuh friends and them that you handicap, hahaha.
> Child: (sobbing) Mammy tell her to stop nah.

Often nicknames stick and they then become the sum total of the person's identity. Some participants voiced their disapproval where nicknames have become their social classifiers, effectively eroding their self-esteem and increasing their marginalisation particularly where it is used for verbal harassment.

> JaLisa: 'when somebody call me a nickname because of my disability I feel bad because I cry or go to my room. They should call me by my name because I have a name'.

> John: 'nicknames are part of the culture, but if you are educated you will see that nicknames are unacceptable'.

In some instances the nicknames do not merely emphasise embodied uniqueness but conjures up images of damaged bodies devoid of ideal physical or intellectual characteristics. David, a young man who has Down's syndrome is subjected to incessant teasing because of the social misconception that people with Down's syndrome are in a state of permanent childhood. He articulates feelings of dissatisfaction that most people refuse to address him by his name, and the assumptions made about his intellectual aptitude.

> I fed up ah people calling me dummy. I does cuss fuh so when people call meh that. That ain't meh name. I have a name, it's David,

so why the ass they can't call meh David. They feel ah dumb but ah smarter than all ah dem, I ain't chupid yuh know. I does bank meh money and they ketchin' they ass (laughing loudly) ... Children hear dey mammy and daddy call me dummy, so they grow up and call me dummy too. Next thing you know the children does want to fight me and all kinna thing so I does have to be careful whey ah going and thing.

In T&T terminology and meanings are ascribed to all types of human variations with colloquial terms focussing on the primacy of impairment commonly used, for example 'broko' and 'hop and drop'. The identifier of the disabled person is based on the use of a negative descriptor of their impairment. Hansen's disease/leprosy is most often referred to in the Caribbean as 'cocobay', which is a derogatory term used as a form of personal abuse to anyone with diseased or repulsive looking sores on their skin. For Indo-Caribbeans the term 'cocobay' can also be translated as an acute version of untouchability as associated with the Dalit communities in India. The name automatically results in stigmatisation with the individual being avoided at all costs.

The term has very strong negative connotations that are reinforced through its Biblical references and that fuses and perpetuates the myths and attitudes that stigmatise and immobilise those inflicted with the disease into shame and invisibility. It is fear of this stigmatisation that causes Patrick to reject a disabled identity and insulate himself from the possibility of being measured and discredited against a religious/spiritual standard of normality.

The colloquial language used to describe disabled people has been found to be quite derogatory, but often exists in the society's collective consciousness without disparageing intent. The social linguistic habit of using colloquial

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labels derived from physical differences or bodily imperfections is very much a part of the way that people are identified. But, whether the intention is to insult or not the veiled derogatory terms perpetuate the stigma against disabled people; labelling matters. Joan in her discussions with me used colloquial terminology to describe her son's impairment: 'My son had a terrible cokey-eye when he was born'. She does not intend to cause an affront but the description invokes a negative corporeality of her son's impairment through its discriminating connotations. The power of such words to cause internalised offence should not be underestimated because they are significant and they matter.

The following is a conversation that was overheard between friends:

> Person A 'Girl, but you know you have a wicked knock knee, you have a serious K foot'
> Person B 'Hahaha, but you now know that and is so long I know you'

Again one can assume that no insult was meant because of the social context in which these terms were used. However some individuals choose to deflect negativity as a way of taking control with pride while at the same time internalising the negative expressions of their impairment. Karen who has cerebral palsy said that:

> People don't know that their words have power and how they cut through me like a knife because you see, whenever people say something negative I put on a big smile, lift my shoulders up (well I mean as high as I can lift them because I need to use my hands to hold my crutches) and show them who is boss. I use my poetry to tell them that I don't care what they say and that I am proud of who I am. But between you and me, girl, it hurts plenty plenty because I know that deep down inside I will never walk without my crutches.

David also indicated his dissatisfaction with the negative implications and discriminatory names, and referenced his financial competence to disprove societal stereotyping judgments that he is 'dumb' (having low levels of intelligence). What is apparent is that the insensitivity towards disability is partly due to culturally learned behaviour, which allows individuals to react in negative, demeaning ways towards disabled people by using nicknames that identify and label them based on imperfections and impairments. Those labels matter because they reinforce negative stereotypes and attitudes that constitute harassment, bullying and abuse, and exacerbate the social exclusion of disabled individuals (Bruhns et at 1995).

People will usually react to bodily anomalies that deviate from supposed normal and acceptable physical images, but it is the negative perceptions which discredit the social identities of disabled people. Obvious physical/mental expressions of disability often create situations where disabled people encounter unfavourable comments and reactions directly related to those characteristics. Mrs. Persad expressed her frustration with the dominant normality ideal of bodily perfection that invalidates her physicality. 'While I was growing up I was ridiculed and mocked, called names like cripple, mongoloid, invalid, handicapped and so many others ... I felt worthless, but differently abled individuals are human beings and should not be stigmatised or called names'. Mrs Persad embraces her physical imperfections and identifies as someone who has been disabled by the negativity directed towards her. Because of her experiences she has taken a stance to immerse herself in the politicised movement, endeavouring to contribute to the resolution of the tensions in disability contestations in T&T. She advised that: 'people need to know that the differently abled are

affected by the things they say, and do to them. There needs to be more awareness to know how they affect our lives'.

5.3 Being a burden

The notion of being a burden materialises in the social space which constructs disability as neediness and incapacity and is described by Barron & Amerena (2007) as:

> where there is little perceived chance of meaningful change; dependency – with the individual needs to be looked after; passivity – the disabled person not being capable of self-determination.

Francioso a wheelchair user shared that:

> I can't do for myself so people see me as a burden, I have to get somebody to help me take care of myself, and sometimes they treat me like I am a burden to them ... I does use a wheelchair so I have to depend on people sometimes, and when people see the wheelchair they does treat me like I dotish.

Independence is a valued quality and impairments that limit or hamper activities and the ability to be independent affect personhood and autonomy. Francioso is imposed a dependent burdensome identity particularly by those who mistakenly assume he is also cognitively impaired.

Mark a wheelchair user is no longer considered a whole person, but instead he is thought of as needy/helpless and burdensome.

> Since my accident they don't see me as a person anymore, it's like they feel I have no feelings, but I am a person, a human being with feelings like everybody else. Not because I can't wipe my own ass it mean I am no longer a person with feelings. People only see how my body mash up, that's all they see.

The notion of impairments as burdensome was also evident in service delivery. Mr Powers relates his experience of attempting to claim state assistance:

> Here it is those who deliver state services, by reacting negatively to what is a rightful entitlement for disabled people are part of the disadvantageing factors. People's attitude is that helping disabled people is a real bother. There are services available and I think it is my right but they behave as though they are doing you a favour ... they give me the run around so I had to speak to somebody from my political contacts, but I should not have to do that.

There are however specific complexities in the cultural context of disability in T&T that are evident in the way that notions of encumbrance are contextualised. Impaired elders are not subject to the same marginalisation and stigmatisation because there are distinctions between disability and chronic illnesses in old age. The normative expectation is that the elderly will have diminishing bodies and with it comes increased frailty, vulnerability and dependency. These are all considered as part and parcel of what happens in 'old age', as such the term 'suffering from old age' is used as a blanket term to describe ailments endured by the elderly. In seeking clarity and a more specific diagnosis it was apparent that clinically medicalised labels are rejected in the elderly and phrases such as suffering from 'sugar' (diabetes); 'a bad heart'; 'pressure' are the norm. Ms Patsy speaks about her 80 year old mother:

> mammy not disabled she just gone senile and she have arthritis and sugar and thing. You see she can't really do anything for herself so I have to take care and look after her, sometimes she can be miserable and cantankerous but that is part of old age so I don't vex with her.

Ageing is part of being human and is inevitable within the life cycle so it is not necessary to compartmentalise or situate it into a disability

categorisation even though like disability it is expressed in terms of what the person is unable to do. Mr George, 83, expresses that:

> ah can't see too good, ah can't walk to far, meh wrist does hurt meh, and ah does pee down meh pants, but I know for sure I ain't wearing no pampers, that is fuh people who beh beh (severely intellectually disabled).

Mr George shows his own prejudice and derision against those with intellectual impairment.

William, a wheelchair user said that:

> I am the disabled one in the family, granny does suffer from arthritis bad bad and can hardly walk, and because of the diabetes she can't see too good, so I make joke an tell her how I going and get a wheelchair for her, girl, she start to cuss about how she ain't no cripple and wheelchair is for cripple and handicap people hahaha.

The elderly are able to retain their personhood because dependency in old age is normalised as increased frailty and weakened physical and mental abilities are expected as a matter of life's course. This disparity in responses towards gerontological disability is also due to the generational interdependence amongst families in T&T which is at odds with the Westernised model of autonomy and independence - a key factor in the social model's focus on person-centred independent living. In T&T family is a strong cultural value with roles and responsibilities taken seriously. The ideology of dependency/interdependency is rooted in the extended family structures that are common in Africa and India and where old age is considered as one of the socially significant stages within the life-cycle and with that status comes a high degree of respect. Dr Harry explained that 'we are ahead in that we do not put our old people in institutions but we look after them in the community'.

Western family norms are that upon becoming adults children leave the home and fend for themselves in the world. Whereas, in T&T, the family nucleus is an extended intergenerational family unit, and it is not unusual to have three or four generations living in the same household often in completely separate units within the same house as shown in figure 11 below. Note the steel columns on the roof which are positioned in anticipation of expansion upwards to facilitate the growing family.

Figure 11. A purpose built multifamily home

In T&T where religion and spirituality provide a moral compass it will no doubt influence the treatment of the elderly. The teaching in Exodus 20:12 is to 'Honor your father and your mother, that your days may be long in the land that the LORD your God is giving you', which many say they strive to adhere to.

5.4 Sexuality

In this section sexuality refers to sexual behaviours, identity, orientation, roles, feelings and attitudes expressed by way of intimacy, relationships, pleasure and eroticism that are influenced and moderated by a number of factors for example biological and psychological determinants, societal/cultural/religious norms, rules, values and ideals (Tarshi 2010).

Much of the literature on disability lacks content on sexuality and sexual reproductive health and one of the reasons for this lack of attention is the common misconception that disabled people are asexual beings, uninterested in sex or unable to participate in sexual acts (Anderson and Kitchin 2000). Quite often their differential embodiment (both of the physical body and the mind) is the basis upon which they are denied their sexual agency, and disqualified as sexual beings. For individuals with intellectual disabilities the problem is further compounded by assumptions that they are unable to be sexually responsible because of their social judgements deficit (De Loach 1994). These fallacies impinge on disabled people's abilities to enjoy sexual wellbeing and self-asserting sexuality and often it is not their impairment that restricts them from fully expressing their sexuality but the negative societal attitudes and lack of adequate social and health services (Tarshi 2010). They are also subject to the religious and spiritual moral codes on sexuality which influence perceptions, practices and activities and they also face challenges in relation to sexual morality and the cultural taboos on topics such as homosexuality and masturbation.

In a discussion on sexual intimacy Wendy (a participant) shared that during the Carnival season allowances are made for some level of sexual freedom and 'bad behaviour' including amongst disabled people. In the run up to, and

during the carnival season the display of extremes of behaviour often referred to as a 'bacchanal mentality' is prevalent. According to Wendy 'at carnival time anything goes, nobody cares how you look, you sure to get somebody to wine on you' (wining refers to a sexualised dance as depicted below).

Figure 12. Disabled reveller at Carnival

The cultural context of Carnival allows for particular interpersonal encounters to be played out with the usual social and cultural impediments to sexual embodiment and socio-sexual prudishness and isolation lessened during that period.

Nita, who was introduced in the chapter on traditional beliefs, is 25 and intellectually disabled. She expresses a desire to have a romantic relationship: 'mummy I want a boyfriend', but there are a number of obstacles which impede such an experience. The socio-physical barriers arising from the shortcomings in service delivery hamper her chances of social interconnectedness. Mary her mother explains:

> now that she has stopped going to school she has no friends, she always telling me that she has no boyfriend and no other friends ... she really wants a relationship and because she does not have friends that will not happen now. She needs a social life of her own ... there should be activities in each area of the country so that

people like Nita can go and make friends. This country is not ready and prepared for the needs of disabled people.

Friendships and relationships are an important part of expressive development and without them individuals experience an emotional embodied sense of isolation. Nita is no longer of school-age, and the lack of social support groups means that she is unable to meet potential friends or partners which causes her to miss out on an important life event of young adulthood.

Having a significant impairment calls into question the rights of disabled women to be wife, mother and lover (Morris 1992) and my research found a number of families actively aiming to restrict their disabled members from experiencing romantic relationships. Carol, an 18 year old with mild intellectual disabilities expressed a desire for 'a husband and children', but her father does not support those wishes and intends to suppress her sexuality.

> I worry a lot about her now because she is of age to want a boyfriend. I see her looking at boys with that look in her eyes, but as a father I worry. Men out there will want to take advantage of her, and use her and I can't stand for that. I rather she don't have no boyfriend at all but I know I getting old, and is only the two of us, so who go take care of she when I not there. I don't want her get pregnant so I going to do what I can to make sure she don't have no boyfriend.

His opinion is that Carol is incapable of being responsible for her physical and emotional sexual health, and carrying out the womanly role of motherhood. John infantilises her embodiment, questions her bodily integrity and concludes that Carol is unable to make informed decisions on her sexuality. Shildrick (2009:64) notes that 'the coming together of disability and

sexuality may signal a problem to be at least managed if not silenced altogether' and John takes that stance by renouncing the significance of a romantic relationship, sexual curiosity, a desire or attention and affection, and a satisfying sex life by imposing his values and power. He denies Carol the choice of independent thinking and to experience life the way she desires and is capable of experiencing, and he also foregoes her reproductive competence and freedom to establish a family of her own in the future and experience pregnancy, childbirth and motherhood. John's behaviour reproduces oppressive social relations but it is legitimised in the context of 'caring' and 'protection' as he is aware of the possibility that Carol's impairment may cause her to have compromised judgement and as such she could be used for sexual gratification by unscrupulous individuals. This is a real possibility as reports show that there are high rates of risky sexual behaviour among young people in the Caribbean (Douglas et al 2009).

John's actions emanate from a position of care and he displays a high level of commitment, compassion and concern for Carol's welfare but they also evidence his use of power over her vulnerability by the manner in which he infantilises her life experiences. She is denied the right to further emotional development derived through forming and experiencing a romantic relationship, and negotiating and developing sexual relations. Despite his good intentions she is being subject to his control, denied her independence, sexual maturity and identity which can cause a lack of confidence, loneliness and isolation.

Mary shared the following story:

> I recently heard about a teenager who got pregnant and couldn't look after the child because the mother was slow, so they take away the baby and put it in an orphanage. There should be some sort of

service or place where she could have gone to get help with minding the baby. Poor girl … Nita has developed physically like any other young lady … I don't worry about her getting pregnant or anything like that because she doesn't have anyone, but if that time comes I will deal with it when it happens.

There is an interesting component in this exchange because despite the potential risks Mary is unwilling to increase Nita's experiences of social exclusion and isolation because 'since she stopped going to school she has no friends'. She is determined that Nita maintain the same standards of normality as the rest of the family in spite of the socio-cultural processes that disengage her from finding a potential partner. John, however, takes a different position, and responds by restricting his daughter's chances of sexual relations and reproductive activities.

My findings show that very little or no consideration is being given to the sexual desires, intimacy, self-worth and pleasures of disabled individuals within local disability discourse. In the West the emergence of scholarship and activism on disability sex and sexuality is gaining momentum, and in India a few disability activists have been able to raise the topic of sexuality even though like in T&T it is a taboo subject. The Tarshi report (2010) on sexuality in India notes though that it is the issues of abuse, violence and negative consequences of sexuality that are more readily discussed publically, a point I too discovered in undertaking this research even though as stated at the beginning of this section, sexuality is much broader than those unwanted impositions.

The secrecy and silence on the issues of desires, intimacy and self-expression in relation to sexuality of disabled people increases their sexual vulnerability and reinforces mistaken beliefs that they are 'sick and sexless',

rather than individuals who are able to participate in sexual relationships (Lamb & Layzell 1994). In my research a significant number of disabled people bemoaned the fact that they were being prevented from forming fulfilling and sustaining romantic relationships so it is small wonder that Renu Addlakha, a disability rights researcher in India says that 'sexuality is an area of distress, exclusion and self-doubt for persons with disabilities' (Tarshi 2010).

Lisa a 30 years old research participant with a congenital spinal deformity expresses a yearning for love and the emotional and sexual expressions accompanying that love. She shares the following tale about her search for a long term relationship:

> I go on facebook and the internet to find good looking men and then track (flirt with) them. I was going an' get married to a small island man but it didn't work out. All the time we on the facebook he saying how he love me, and then he propose. He tell me to send him a ticket to come Trini and he go marry me, so I borrow money and send ah ticket. When he reach he tell me "girl plan the wedding" ... I even beg a friend to give him a job. He didn't use to take me out, so I used to ask him if he shame people see him with me and he say no, he don't care what people say. He used to tell me he love meh body, but you know what that stinking man do? When he get the job he leave and say he going to work and never come back. He telling people how I handicap, he didn't even like me and how he can't stand my body, and how it scornful and his family ask him what he doing with that cripple. He didn't have no problem when it come to sex though, and oh how we never used to do it. He lie!

Analysis of Lisa's experience highlights the cultural images of bodily imperfections and sexuality which are demonstrated by her fiancé's description of her body as 'scornful', and his family's repudiation of his choice of partner. It is the visible flaws that define her bodily difference that

creates an emotional conflict because she does not epitomise the cultural ideals of attractiveness, nor the social explanations of normative functionality, her agency is disregarded. This is one of the many socio-cultural processes in which disabled people are constructed as undesirable (Shuttleworth 2002). Critical evaluation of their appearances is undertaken and because of the social value system that is reliant on physicality any problems associated with their disability embodiment is exacerbated. Writers like Andreasen & Morris (1972) have also shown how society's values and emphasis on attractiveness and appearance causes women to disproportionately suffer psychological stresses so a disabled body in a cultural backdrop that is quite prejudiced will no doubt lead to increased distress and social avoidance.

Lisa acknowledges that her fiancé's rejection has caused her emotional pain but she remains intent on having a husband and family having reclaimed her sexual agency and now negotiating sexual intimacy on her terms:

> I fed up of this and want to get married and have children and I know I real good looking and can get any man I want. For now, I does sleep with whoever I feel for. I have about 10 boyfriends, and if I want something I know I could give them a little sweetness (sex) and I could get what I want. When I have to go somewhere I does call one of them up, and I does give them some of the money for the drop, and if I feel for sex sometimes I does give them that too.

The acceptable standard for sexuality in the West is a monogamous relationship between two adults, however Lisa deviates from this Western norm and conducts hers in accordance with the informal social standards in the Caribbean of multiple partners (Kempadoo, K: 2009). She is confident in her embodiment and acknowledges and celebrates her sexuality and initiates sexual intimacy on her terms.

My conversation with Lisa took place in the presence of two of her non-disabled friends and during the dialogue Ali interjected:

> don't bother with her, she don't have 10 boyfriends. Everyday she does come up with a new one. But Lisa why you like attention so girl you know you ain't have no man?

Lisa responded:

> but you know I look good, watch me (striking a model pose). Girl, real man (plenty men) want this, they just don't know what they missing.

Ali tuts disapprovingly, and Nekitia interjects half smiling, half frowning:
> Girl you real like yourself eh? Stop posing nah.

Lisa displays an outward confidence about her self-identity, her body, her sexuality and her desirability which may or may not be a normalising reaction to buffer the effects of eroded self-esteem, and the negative prejudices reinforced by the rejection from 'the small island man' and his family. As Ali and Nekitia walk away she remarks that:

> I had a boyfriend when I was in secondary school and after he, was the one who I was suppose to marry. People don't know nuh, but sometimes I does feel for sex, too, so I have 2 two friends with benefits that I does call. They don't charge me the whole price to drop me where I need to go, and sometimes when they bring me back home I does get fix up (smiling) ... I does be real lonely, not even my own mother want me. She tired tell me how she wish I wasn't born and how I make she shame.

There is a myth that disabled women should be grateful for sexual relationships (O'Tolle & Bregante 1992) and Lisa's exaggeration of the number of 'boyfriends' may be an attempt to live up to the cultural backdrop of having multiple partners. But whatever the reason, Lisa does not allow the social and cultural impediments towards sexuality to prevent her

from experiencing sexual intimacy and enjoyment on her terms. The ethno-traditional social attitude around sexual behaviour in T&T endorses a climate of male sexual promiscuity, but expects sexual prudery for women and disabled people. Lisa's actions go against this norm as she refuses to act in a sexually passive manner, instead resorting to initiating sexual interactions in an arrangement that suits her, and flaunting her self-expression as a sexual being. She controls the negotiating, and decision-making as far as her own sexual appetite is concerned by instigating sexual activity at a time and place of her choosing. She derives a sense of personal empowerment through the reclaiming of her sexual agency and the negotiating of sexual intimacy on her terms, but her behaviour can also be interpreted as transactional sex, with the sexual favours being the currency.

Lisa's fiancé displayed conflicting behaviours by wavered between intimate sexual contact, and feelings of revulsion alluding to his awareness of the role of sex in Lisa's embodiment. It could be that he obliged and consented to the sexual interactions in order to feed the illusion that they are in a harmonious relationship, or that there was a mutual desire devoid of any emotional considerations for Lisa.

His experience of sex in the relationship is located within the discourses of both pleasure and shame as he temporarily suspends his revulsion during the sexual encounter to enjoy the accompanying pleasure, but regains the disgust after the act, which is then accompanied by a degree of embarrassment. It is also possible that he genuinely possessed intimate feelings for her but was unwilling to publically acknowledge the relationship due to the adverse cultural socio-sexual ideologies around disability and

therefore the harsh words he used was directed specifically to her impairment and not to her whole person.

It is clear from the data that the sexual identity of disabled people is often denied which is in part due to society's sanctioned prudery in talking about issues of disability sex and sexuality. Negative perceptions and attitudes such as cultural notions of attractiveness and desirability, protective parenting, assumptions of normative functioning, poor body image, and unequal power relations all play a part in the socio-sexual isolation of disabled people (Shuttleworth 2002). These create obstacles to forming interpersonal and sexual relationships and invariably impact on the self-development, self-esteem, and sexual agency of disabled people.

5.5 Abuse and Violence

The abuse of disabled individuals was a worrying theme that emerged from the data analysis, and is indicative of the cultural resistance to attributing sexual agency to disabled people as a natural right. A significant number of participants shared stories of being violated with their bodies used as a practice ground for the sexual gratification of others. Betty, 32, who has a very mild intellectual disability said:

> My father used to abuse me from childhood but I did not know what he was doing was wrong because he is my father. I knew I didn't like what he was doing but I didn't know why … But no one in the family wants to talk about it.

In the West there have been many studies on the widespread prevalence of sexual assaults on disabled people (Shildrick 2009), and there is a general consensus among researchers that disabled women are assaulted, raped and abused twice as much as non-disabled women, and the more disabled the

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woman the greater her risk of being assaulted (Cusitar 1994, Simpson & Best 1991, Sobsey 1998). Research by Brown et al (1995) found that the major perpetrators of abuse were family members and other trusted adults such as carers, neighbours, institutional staff or health care workers, and a study published in the Lancet based on 18,000 children in the USA, UK, Sweden, Spain, Finland and Ireland claims that:

> one in four children with disabilities experiences some form of violence during their lifetime and that the risk of physical, sexual or emotional abuse or neglect for these children is nearly four times greater than for children who are not disabled (Diament 2012).

Given the international research findings it is no wonder that a significant number of participants shared experiences of being the victims of sexual abuse and violence but I was surprised by the lack of similar studies in relation to disabled people in T&T. My analysis anecdotally found that there were higher rates of abuse concentrated in two main geographical areas i.e. Tobago where the population is largely people of African origin, and in south/central Trinidad where the majority population is people of East Indian origin.

Sexual exploitation

This is a taboo subject shrouded in secrecy which makes it all the more difficult to address at a national level because of the silence and vulnerabilities of the victims. Research participants confided about those taboo subjects, and continued to do so long after the actual data collection phase of the study was complete. This was possibly because they considered me to be an enquiring outsider coming from a more liberal background and therefore unlikely to breach their confidentiality or make judgements about

their experiences. The participants were also afforded the time to discuss the topic for as long as they wanted to and in as much detail as they wanted.

Individuals with intellectual disabilities were less likely to resist and report abuse, and said that they were less likely to be believed because of their victim vocabulary or intellectual deficit in articulating the abuse, their lack of cognisance that what they endured was an act of abuse, or the unavailability of accessible information in a format equivalent to their level of understanding that explains how and where to report the abuse. Dr Bailey, an academic, Dr Harry, a Pundit and psychiatrist, and Dr Wilson, a psychiatrist based in Trinidad, concurred with my findings that sexual abuse of disabled people in T&T though prevalent is ignored and underreported.

> There is inadequate data but it exists. I know of a few families, but the topic is hush hush and not discussed. In one family the father was with more than one of his daughters, and it was exposed when one daughter realised what he was doing to her younger sister and she spoke out. (Dr Bailey)

Anecdotal evidence suggests that disabled people in T&T are so devalued that they are at a disproportionate risk of sexual violence and abuse, but that is an area beyond the scope of this study which requires much needed further research. Some perpetrators assume that victims do not understand what they are experiencing thus making it acceptable to treat them as sub-human and take away their rights.

Mother Bishop explained that:

> They feel that they could be going into people house and take advantage because the girls can't really help themselves. They disrespecting the disabled girls, but they forget that they could get disabled in the wink of an eye.

Mr Ali related an incident which occurred in his neighbourhood:

> the girl was brain damaged and mentally retarded, she slow and don't understand things properly and X (person identified by name) give she alcohol, get she drunk and rape she. She tell she mother and when the mother ask X he admit he do it and said how he go pay the mother some money. The mother refuse the money and went police station, but she say she know he go get away with it because who he rape is a helpless handicap girl. People behaving as if is no big thing just because the girl handicap, and he walking the road bold as brass. He lucky is not my daughter because I would ah deal with he ass.

Rape is one of the most pervasive and damageing forms of gender violence and carries with it a great degree of social stigma for the perpetrator, but in this instance X has not been ostracised. Because I was unable to interview the neighbours I could not ascertain the reasons behind their lack of public denouncement of X. But judging by Mr Ali's and the mother's comments the assumption is that societal prejudices and attitudinal aversion towards disabled people played a part in their silence. As the father of a young man who was left severely disabled after being hit by a drunk driver, Mr Ali is very clear in his condemnation which is influenced by his social conceptualisation of disability gained from the actuality of his son's lived experiences.

Gendering

The research highlighted a further dimension to the assumed gendered nature of sexual exploitation. The common perception is that the victims are almost always female; however this viewpoint is challenged by the numerous instances of male abuse.

Mr Mark shared one such incident:

> There was a retarded young man in town who was stupidy, and they say that he had a real big penis, and how the girls who used to work in a particular office used to buy him food so they could have sex with him, and bribe him that if he tell anybody they wouldn't give him money. They say that when he died the nurses cut off his penis and keep it in a bottle.

The behaviour of those who exploit the vulnerability of disabled individuals is influenced by a number of situational variables and in this account the suggestion is that the 'girls' exercised power over the victim and used their femininity as a way of achieving that control. The victim's intellectual vulnerability was the basis on which he encountered hostility, negative social responses, and the ridiculing and dehumanisation by others in the community.

> He used to beg and people used to tease him plenty about his big penis. I even know people who used to give him a couple of dollars to watch him play with himself (masturbate) and laugh at him (Mr Mark).

There is a clear gender bias in the acceptance of reports of sexual violation with the pervasive attitude that males should enjoy the sexual experiences and consider them a rite of passage. Sexual socialisation norms and processes influence sexual behaviour in boys in their transition to manhood and one way of negotiating and validating that transition is via sexual conquest and the sense of accomplishment which goes along with it. Mr Beard related that:

> This family up the hill have a disabled daughter, and the father does say to his young sons that is ok for them to have sex with their sister instead of the other girls in the village. The father say it ok for them to practice on their sister so when they come big man, women can't say they don't know how to sex good … this going on in plenty homes is just that people don't do nothing about it.

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Mrs Rose reiterated that:

> They does use the disabled child to practice their nastiness and I know some of them even let other boys in the village to have sex with a disabled boy. Is no use going to the police because they does chase you from the station.

And Mr Jack added to the discussion saying:

> Even if all of them is family I don't mind, but when is big big man who doing it then I have a problem with that. That is advantage!

In constructing their sexual development the boys are encouraged to experiment and practice on their disabled sister, thus sanctioning sexual activity with young girls as a rite of passage and at the same time sustaining and legitimising the machismo socio-cultural ideology of men in T&T as being sexually competent. The sexual activities exampled here are being negotiated and developed in an environment of secrecy, tensions, violence and misinformation as noted by Kempadoo's (2009) observations on Caribbean sexuality. Mr Jack's statement, in which he says that he does not have a problem with the act *per se*, but with the age of the perpetrator, gives the impression that he too identifies with the ethno-traditional culture on male sexuality.

Conceptualising the abuse and oppression of disabled people is challenging, especially because it relates to power and control in terms of domination, subordination, superiority and inferiority (Charlton 2003). The power relationship is also replicated between the abused victim and the state processes which inadequately protect them from imposed control and abuses. Those are indicative of the deficit embedded in the social values towards disabled people and the way that their rights to full citizenship are

denied. The high number of participants who shared experiences or knowledge of sexual exploitation leads one to conclude that sexual abuse/violence is normalised behaviour toward disabled individuals. But how much of it is because of the dependency notion that those with impaired bodies are incompetent, passive beings that things must be done for, and to, without any consideration given to their own decision-making processes? Carol's father buys into that dependency and in his role as having to care and protect her but as her body has undergone a number of physical changes in adolescence which has roused her relationship desires and sexual curiosity and desires he exerts his power and reinforces his parental beliefs and values which go unchallenged.

Joan, a social worker is aware that

> Overall incest is a serious problem in Tobago and in certain parts of Trinidad mainly south/central, and it has been happening for generations. Not only to disabled children, but all over. But it is often worse when there is a disabled child in the family ... it happens in poor families too.

My own findings strongly support Joan's observation.

Mr Mark is of the opinion that the lenient punishments are one of the explanations for the high numbers because 'people know they could get away with it so yes, they do it free sheet' because according to the CSO Report on Crime Statistics in T&T, incest involving minors (not specifically those with disabilities) is considered to be a minor crime in that it attracts a penalty of under five years imprisonment. Such lax punishment propagates the reluctance in reporting incidents of sexual abuse and violence, despite the laws, regulations, policies and repercussions. Many voiced an opinion that the law is not fit for purpose, and because it is not adequately enforced

wrongdoers go unpunished perpetuating the persistence of abuse. Mr Mark said that:

> The police they self know what is going on but they don't do a thing about it. They even chase you out of the station if you go to report a matter like that. People know they could get away with it so yes, they doing it free sheet.

Dehumanisation

In spite of the atmosphere of secrecy around sexually taboo topics, a rape scene which was televised caused a furore and there were extensive public debates on the ethics of airing such a programme.

> The host of a popular TV crime show in Trinidad has been arrested months after showing a video of the rape of a mentally impaired 13 year old girl in progress with her face clearly visible and her screams audible. Ian Alleyne was arrested as fans demanded he be freed. Alleyne aired the rape video three times on his show "Crime Watch" late last year, (foxnews.com April 2012).

The victim, an intellectually disabled minor could not have consented to the airing of the programme; however her mother who has been referred to as 'simple' provided the consent. Disability advocates have publically voiced that the airing of the programme in such an insensitive way has amplified the emotional degradation and humiliation of the victim:

> The airing of the video can be perceived as the exploitation of a rape victim to gain television ratings … and has serious repercussions for the victim's welfare (*Newsday* October 2011).

Advocates also pointed to the 'stigmatisation as a rape victim which is endemic in our society which could further traumatise the individual … the re-victimisation of any rape survivor viewing the video' (*Newsday*, October 2011).

Subsequent media coverage of the ensuing controversy furthered the dehumanisation and loss of personhood of the victim by those who referred to her as 'a case'. One commentator objected to this description saying:

> The victim of the attack is not a 'special needs case', she is a person ... Wouldn't it be more appropriate to refer to her as 'a child with special needs'? Is one of the reasons it was so easy for no one to think to block out her face because she was not seen as a person but a 'special needs case'? (*Newsday* online discussion forum October 2011)

The victim is degraded through the act of rape, the broadcasting of her face, her desperate cries for help and anguished screams of pain, by the voyeurism of the viewers, and classification as a 'special needs case', and though many viewers have voiced that 'the man (Mr Alleyne) takes advantage of the vulnerable to bolster his massive ego' he justified his actions by claiming that the programme was aired to seeking justice for the victim.

5.6 Family/Carer Experiences

As part of the process of gaining a wider understanding of the lived realities of disability I felt it important to gather narratives from families/carer experiences because the physical energies expended in coping with a disabled family member have been shown to have adverse effects on the quality of life, and health of the carer and the extended family (Jones & Vetter 1984). Here is an extract from an interview with Mrs English who helps care for her grandson Trevor, a quadriplegic and his sister Wendy:

> Poor girl (referring to Trevor's mother), I worry about her health because it is a strain taking care of Trevor. He is a big boy now and weighs a ton, and pushing him in the wheelchair not easy. I sure her health is worse because of all the stress, but her side of the family don't really help so she is doing it on her own. She has to get up in the night because he don't sleep for long, so of course she always tired. Poor girl, it ain't easy having to deal with that day

in day out nah. She can't work, don't have time for friends anymore, her liming (hanging out) days long over. You can see the stress in her face sometimes. I feel really sorry for her... Sometimes she want to take him out but she don't have the strength to push the wheelchair, and sometimes she has to stay up whole night with him.

Wendy interjects:

Mummy don't have no time for the rest of us. I know she has to look after Trevor but I find that she too selfish. I find that she does behave real selfish. You think I could go to her with a problem? No, she don't care. I feel she does use Trevor sometimes so people will feel sorry for her. I know she not well sometimes, but when she take in (has a health crisis) and she in hospital ent he does get looked after? I love my mother, but she never really was a caring mother, if you know what I mean? She forgets about the rest of us and behaves like she is not our mother too. I feel guilty sometimes for feeling this way ... When I ended up in hospital people feel is because I wanted to die. (The grandmother indicated that Wendy had taken an overdose). I was numb and wanted some attention and was feeling guilty for wanting it. People don't know what it is like since the accident nah, all of us suffering ... People look at us funny now and treat us different because of Trevor.

The narratives of Mrs English and Wendy, encapsulate the tensions and stresses of Trevor's disability in a society which places high values on family relationships. These raise a number of questions around what is a disability, and who really is disabled? Is it the individual with the impairment, in this case Trevor, or will it also include the family and carers? From the conversations above it is apparent that all the members of this family experience long-term disabling effects: psychological traumas that conduce, as in Wendy's case, to a sense of neglect, a craving for love and recognition as an individual, which is what ultimately led to her suicide attempt, and the discrimination endured by the other family members because of social responses to Trevor's disability. It is clear that caring for

Trevor has adversely affected the quality of his mother's life for example her heightened stress levels, declining health, and increased social isolation.

As Nita's mother was explaining the personal sacrifices she had to make in caring for her daughter the raw emotion was clear in her voice.

> hmm, this is my life. I have to make sure that Nita is safe all the time … she can't really take care of herself so I take her everywhere. She even goes to school with me and will sit in the class while I teaching … We go to the mall, shopping, everywhere together, that's my life. Everywhere I go Nita goes with me … So when she complains that she doesn't have a boyfriend I tell her that I don't have one either. Since my husband and I split up I have been on my own because I have to look after Nita so I don't have time to get a boyfriend and I doubt I will get one. I also look after my elderly mother.

It is apparent that 'the problem of disability is not a problem of the individual but rather a problem of the family' (Devlieger 1995) and the examples provided show how the families and carers make major alterations to the way they live their life, often to the detriment of the quality of their own existence. A parent summarised it as 'we have to put our own lives on hold and that is hard'. It is evident that disability impacts on the social and psychological interactions of the wider family and carers, but they are still expected to remain stoic.

5.7 Fear

The disabled physicality is at odds with the perfect bodily image that so many people strive for, and it is a reminder of one's own physical defencelessness and embodiment and that realisation is often accompanied by a heightened awareness of one's own mortality and feelings of fear (Stangor & Crandall 2000). Disability serves as a reminder of one's own vulnerability – a fearsome possibility and that fear represents tragedy, loss,

the dark, misfortune, and the unknown veiled with pity, charity and hostility. Ms Phillip who is disabled had been told: 'I don't know how you does live like that, me ah rather be dead than suffer', a statement that clearly shows the individual's sense of vulnerability and fear.

Patrick has chosen to normalise his appearance by covering up the disfiguring symptoms of Hansen's disease, but in spite of those efforts he has been the recipient of discriminatory practices by health care providers borne out of their fears and misplaced anxieties about contamination arising from the historical prejudices synonymous with Hansen's disease. His interactions with the health care workers have been a mix of compassion and empathy, and aversion and rejection.

> If people know you have leprosy they stigmatise you and thing, even the nurses, like they afraid that they will get it. Even up in the hospital the nurses afraid of you … But I don't feel a how because I have it, because that is how I go from being unemployed to getting a work here. One of the nurses told me about the job vacancy.

Often in disability scholarship, disproportionate emphasis is placed on the actions and effects of prejudice and discrimination, and less on the issues of fear and ignorance. But Patrick's experience illustrates how fear and ignorance implicitly influence the way in which services were delivered and in his particular situation the prejudice is reinforced by religious belief.

Below is an extract from a You-Tube video clip on Hansen's disease in T&T of an interviewee lamenting that:

> It suits them to keep people in this eternal fear, fear of Leprosy. The word rings a note like the days when you had to walk with a bell around your neck – Leper, Leper. Keep them in that life. So they would not like to release people from the stigma (Hansen's disease: a family Odyssey – Rudy63).

John P, the parent of a disabled son also noted that:

> A lot of people are afraid of the unknown. People don't know how to relate to blind people or somebody in a wheelchair.

Fear and avoidance is the default position where there is anticipation of a negative outcome. For example, Ann, a pregnant young mother, was advised that in order to negate any possibility of giving birth to a baby with Down's syndrome she must avoid any eye contact with anyone who has the condition, nor should she express any feelings of pity towards them. That contagious mysticism around the affliction encourages a pretence that people with Down's syndrome are invisible. Jenny Morris a UK based disability activist postulates that:

> It is fear and denial of the frailty, vulnerability, mortality and arbitrariness of human experience that deters us from confronting such realities. Fear and denial prompt the isolation of those who are disabled, ill or old as "other", as "not like us" (1991:85).

Dr Harry pointed out that the fear is often exploited and used to marginalise particular individuals. He exampled the situation endured by Ms Miller who had 'no prior accusations as to her mental health' but had 'an emotional outburst' at work which resulted in her supervisor immediately initiating a very public removal and sectioning of Ms Miller. In spite of Ms Miller's protestations on the interpretations of her behaviour she spent two weeks at the mental institution before being eventually diagnosed as not being mentally unwell.

Mental illness is very difficult to define because it is based on behaviours that deviate from the accepted psycho-social and bio-medical norms (Sengupta, 2008) and in T&T the socio-cultural ideologies around

psychosocial disabilities are grounded in superstition and myth, and shrouded in beliefs of spirit possession. This dominant interpretation of psychiatric impairments instils great fear and comments such as: 'I 'fraid mad people', 'I don't want to be near where it have mad people'. Paul Longmore, a US-based disability activist summarises that: 'what we fear, we often stigmatise and shun and sometimes seek to destroy' (1987:66). It is fear which was responsible for Ms Miller being stripped of her dignity and being dehumanised and disqualified as a person.

Primary and secondary data sources highlight the deep seated inherent fears around mental health disabilities and its emphasis on the dangerousness of those with psychosocial disabilities (Wilson & Beresford 2002). For example, the T&T Mental Health Act allows for the subjective judgement of those who 'look' mentally ill to be sectioned, and controlled.

5.8 Physical Barriers

In all societies there are individuals who are denied participation in that society making them strangers within their environmental settings (Bauman 1993) and in T&T many disabled people are denied access to participation by environmental barriers. Mr Powers noted that:

> it takes too long for disabled access. The Ministry of Works has no policy on roads. The culture says it is not important, but having to escape the prison of culture is a serious issue.

The lack of adequate infrastructure, transport, and accessible buildings hinders active participation in education, social and cultural activities, and employment which negatively impinges on a persons' right to full citizenship and the ability to live the life they desire for themselves.

Adaptive aids go some way in enriching the quality of live for disabled people but their effectiveness can be compromised by the disabling barriers. Father Benedict, a wheelchair user explains some of his accessibility struggles:

> There are building with ramps, but not enough and the ramps are too steep. Even if you have a care giver they can't push the wheelchair up the ramps … entrance to buildings don't have this kind of push button, you know where you push and the door open. I have to try and open the door and some doors not wide enough so you have to try and open the two doors and they go the wrong way. And people don't even try to help, they don't see me down here … I live on the 3rd floor here, with no lift.

Mr Jack another wheelchair user stated:

> The pavements are deplorable … they feel they putting in ramps for disabled people but they put it 3 three inches high instead of making it flush. So make sure when they put the ramp it don't have two steps before you put the ramp … there are ramps all over the place but we still have a big kerb wall to get up to the ramps. That don't make sense.

Kathleen, the grandmother of a disabled child, said:

> We try to take him out as often as we can, but I too weak to push the wheelchair up and down the pavements. One day we tried going for a walk just round the block but the pavement was so steep we had to turn back. Even his mother who stronger than me could not push him so we can't take him for walks. We want to but we can't. So you see why sometimes when people say how we lock away our disabled children is not because we want to do it, but because we have no choice. How am I supposed to take the child out when I don't have a car, and I can't push the wheelchair up the steep, steep pavements? What do they want us to do?

The dominant issue in the above quotations are that the well intentioned adaptations are not fit for purpose and the chances of disabled people being able to get out and about independently are affected which sustains

their social isolation. This also challenges the opinion that neglect and shame are the main reasons for the 'hiding away' of disabled people. The reality is that often the physical barriers, lack of accessibility and inadequate state structures leave few options for disabled people to get out and about even if the desire is to interact with wider society.

As previously mentioned Nita experiences similar disabling issues due to the environmental barriers and lack of support services which restricts her opportunities to meet and socialise with others. Mary explains:

> Nita sometimes used to miss the bus ... it is hard to get her ready in the morning and the bus used to come early so she missed the bus too many times ... The school in San Fernando is too far away for her to go, and there is nothing here in the east for her to go to. No centres, nothing, nowhere for her to go and make friends and to keep busy and active.

However, in keeping with T&T's commitment to developed country status by 2020 some work has been done to address the issues of disabling barriers, for example, the introduction of disabled parking spaces. Unfortunately, its implementation was not accompanied with awareness raising so the parking spaces have been a source of personal frustration. Mr Powers laments that:

> People in this country not sufficiently aware. In the supermarket there are a couple of disabled spaces but everybody uses it ... having marked spaces means nothing to the people, they have no respect and they do not care. It's form without substance ... there are no signs, and even though people see that it is a handicapped space they still use it and the security guards are not monitoring the spaces.

Figure 13. Parked vehicle using two disabled spaces.

The photo above was forwarded to me accompanied by the following comment:

> At Westmall HiLo, a woman park in a allocated parking spot for disable, she park in TWO PARKING area and refuse to move, even as the security ask her to move. Then a man with a blind woman, who was waiting to park, came to use the disable area.

Mr Powers inferred a lack of respect borne out of ignorance. He stated that the parking spaces were introduced without any awareness raising and many interpret the universal disability symbol of a blue space depicting a wheelchair (see below) to mean that the spaces are for the sole use of wheelchair users. Additionally, because wheelchair users are not often seen in supermarkets, there is an assumption that the designated spaces are a waste of a valuable resource.

Figure 14. Universal disability symbol

John (non-disabled) observed that:

> I never see nobody in a wheelchair in the grocery. You every see
> any? So what is the sense if nobody using it. Steups (kissing teeth).
> Ah go (I will) park where so ever I want until I see ah man or
> woman in a wheelchair in the shop.

The inaccessibility of the roads, transport and buildings no doubt reflects on the low numbers of disabled people being out and about. If they are unable to get to their destination or gain access to buildings they simply refrain from venturing out opting instead to remain at home, as acknowledged by Father Benedict:

> In the mall or grocery not even the washrooms have access, or they
> will put a sign on the door but you still can't get your wheelchair
> inside the washroom, so I rather stay home. It's a very very scary
> scenario to be in. I get frustrated trying to go about my business. If
> I stay at home I will be safe, but it is cutting yourself from life
> experience. Disabled people have to stay in homes shut away and
> their family care for them.

The rights of disabled people to full participation in society are affected by the environmental barriers, which makes them more likely to experience isolation and exclusion. Notwithstanding attempts by the state to change physical barriers, social and cultural assumptions remain unchanged and it is clear that the lack of access generates feelings of anger and resentment, which effect disabled people's mental health, self-esteem and confidence.

5.9 Institutional Discrimination

Social hostility, negative reactions, prejudice and discrimination are some of the ways in which disabled people experience the receipt of goods and services in T&T. The language used and the emotions expressed in the telling of the stories by participants paints a strong picture of pervasive insensitivity, personal prejudices and at times blatant discrimination. They

range from offensive name calling, lack of provision of adaptive aids, and barriers to accessing services embedded in discriminatory assumptions, and injustices, which threaten the self-esteem, trust and respect of those on the receiving end. Jo-ann explained:

> There is no grocery delivery service and you can't order your groceries on line like you all in London ... KFC does deliver, but if the person who comes to the door is disabled they turn away. They might find you taking too long to come to the door. Some of these places encourage their staff to treat us badly, so the problem is not only with the person serving you but with the company itself.

Online shopping is not an available option in T&T and participants spoke of the difficulties in getting to, and manoeuvring around the aisles in the supermarket. Jo-ann observes that recognition of her disability evokes a negative response in those making home delivery, which is manifested by their impatience, and at times refusal to render services to her. She notes that the prejudice does not stop with the delivery person, but permeates throughout the organisation by their failure to raise awareness amongst its employees.

> So what we suppose to do, how we suppose to live? You don't understand how frustrating it is for us when our own people don't even want to serve us. Companies need to take this thing seriously, and train the staff better and if they don't want to deal with us, then they could go and work elsewhere.

Independence is an important element to individual wellbeing, but the obstacles encountered by individuals in carrying out routine activities can be quite challenging and frustrating. Some are driven to take action, and challenge situations while others resign themselves to powerlessness and accept negative encounters. Suzi, the mother of a disabled child relates an incident of discrimination which occurred at a local bank:

How will you ensure that this person is not just an object but a person in society doing what they supposed to do in society at their level, whatever their limitation maybe … My friend daughter told the lady at the bank "Miss I can sign my name", but it takes a little time to sign her name so instead they tell her put a thumb print. My problem is that she can sign her name, so why they asking her for a thumb print. Her mother suppose to tell them no, you in the bank here to serve her, so if it takes 5 minutes for her to sign her name let her take 5 minutes. A thumb print can never be somebody's name.

Mr Bishop via facebook relates his own interaction with another bank:

I signed up for Republic Online a little over two (2) months ago … This service is usually activated within five (5) days … After my mother made a few inquiries into why it is taking such a long time, the last excuse the personnel gave was that the bank usually equates thumb prints with illiteracy. Apparently, banking officials at Republic Bank have never heard of literate quadriplegics. I cannot hold a pen to write my name but I use special technology to access the computer. Republic Bank, we are in the year 2011 and it is time to update this archaic policy. Online banking would make my life a lot easier.

Father Benedict, a wheelchair user, is unable to reach the top of counters or tills without difficulty. He explains:

When I try to use my debit and credit card the bank clerk gets impatient with me. One time I made a mistake putting in the number but I couldn't see the thing properly because of the light. I make a mistake and the Clerk was agitated and it made me even more nervous. Her aggression antagonized the situation. Staff are unhelpful. In Mario's pizza the counter is too high … when I have to pay, the chip and pin machine is too high and the staff get vex. I order my pizza and then I ask for a drink and she put the drink on the counter with a straw, but I can't reach the counter. She could have put the straw in the drink and then handed it to me because I can't reach the top.

From a social model perspective the lack of social awareness, provision of assistive and adaptive aids and services all impose an unequal playing field

whether intentioned or not. The following comments were made at a focus group:

> They need subtitles and the media should use sign language. I know I can't get a job in government because they don't cater for my needs at all

> There is so much technology for persons with disabilities these days but here they still so backward that even if you want to work you can't.

A significant number of participants have been on the receiving end of poor customer service but that is not only unique to disabled people. I too experienced unacceptable service and as my own impairment is not visible it challenges some of the assumptions that the dismissive attitude of service personnel is based on impairment prejudice. On balance there seems to be a pervading undercurrent of poor customer service irrespective of the identifying characteristics of the individual seeking the service as experienced and discussed by Mr Wharwood.

> I can't be wrong when I say that we often get piss poor customer service in Trinidad and Tobago. From the KFC girl who might give you a serving of attitude along with the Cruncher combo you waited on, to the salesgirl in a clothes store who might rub you the wrong way or give you a 'yeah wha yuh want' look, these sorts of experiences are common for almost everyone. I'm sure that no business deliberately sets out with the goal of providing bad customer service, but that is what happens day in, day out. (J Wharwood BlogSpot).

The point I make is that there are instances where the inequality experienced by the participants are not exclusive to disabled people nor based on impairment prejudices.

Mr Tony a disabled journalist shared his experiences of workplace stigmatisation and discrimination.

> Employers are not sympathetic at all because sometimes its 3 days per week the patient will be off work for dialysis so you see the employers don't understand. Sometimes you can't turn up for work, sometimes you just can't even though you want to, but you can't make it and employers don't understand.

Socio-cultural interpretations have reinforced the stereotypical notions of disabled people as being needy, and incompetent that can lead to their exploitation. Dr Bailey, an academic explained that

> Disabled people often work for other people as a favour and so they get paid the minimum wage. They get exploited. They face a lot of discrimination.

Josh who has an intellectual disability explained his experience of work related exploitation:

> The boss where I used to wuk before didn't uses to pay me all the time. When is pay day he only short changing meh and he say that is how is because I ain't wuk hard enough. Buh other people tell me to lef the wuk. One day he come just so and hit meh ah lash and start laughing so I cuss he mother and lef the wuk.

The prevailing social conceptualisation that people with intellectual impairments are incompetent creates a power dynamic that denies them their autonomy, individuality and equity leaving them open to bullying and ridicule. Josh however challenged that hegemony of intellectual disabilities by asserting his agency and refusing to remain a passive recipient of bullying.

Police Services

The police service in T&T can be described as a disabling organisation due to the lax attitude in responding to crimes against disabled people, and the

negative actions towards, and harassment of disabled individuals by its employees. The job of a police officer offers a privileged position of social power and with the execution of that power goes dominance, force and abuse. The difficulty in maintaining good police/citizen relationships and the use of force is a vestige of the colonial security forces in the Caribbean which were subsequently transformation into law enforcement agencies (Harriott 2000). The newspaper article below reported on the high numbers of complaints of excessive force:

> The use-of-force policy of the Police Service is under review by acting Police Commissioner Stephen Williams. This is in the wake of a growing number of complaints against police officers by members of the public, the number of live matters before the authority stood at just over 350, of which 60 to 70 per cent to date were complaints about unnecessary use of force by police officers. (*Trinidad Guardian* Aug 2012)

In T&T because of the inadequacy of the mental health services it is the police who usually respond to people who display symptoms of mental ill health (Morabito & Bennett 2008). My own findings corroborate with that of Small (2005) and Hutchinson et al (1999) which points to a general dearth in police support for disabled individuals across the spectrum. Many officers will have deep seated prejudices in keeping with the culturally pervading beliefs that some disabilities, in particular psychosocial disabilities, are due to the individual's own misfortune, or spirit possession. There will also be those who lack general awareness and understanding of disabilities. Below is an extract from a conversation with Tasha a former journalist which captures the way that power, use of force and lack of awareness can affect disabled people:

> The police arrested a deaf man and they ended up beating him to death because he was refusing to do what they told him. They used too much force, and they beat him because they felt he was being

disobedient and defiant. But the poor man could not hear what they were telling him and because he could not speak he wasn't able to explain to them. The more he bawl is the more licks they give him, even after they arrest him and took him to the station they kept on beating him. Some police in this country are bullies and they feel good beating people but seriously, are you trying to tell me that they didn't realise that he could not hear. That just goes to show the lack of awareness.

Mr Mark provided another example:

This retarded young man in town who was stupidy also said that even the police used to harass him. If they see him they used to walk up to him and clout him just so. Hear nah, I telling you even the police and them does take advantage of these people, so it ain't have nobody you could trust to protect them, because the police who suppose to protect and serve advantageing people just so, and they get away with anything so you can't even take them to court.

Participants expressed their feelings of powerlessness at the hands of unscrupulous members of the protective services and explained how those power relational impediments negatively impact upon their day to day lives.

Productivity

The dominant social ideology in T&T is still based on productivity with work being a significant signifier of personhood, with the lives of those deemed to be unable to contribute productively being inevitably controlled by processes of exclusion and expulsion. The result is the creation of devalued others considered to be non-active members of the community because they cannot, or do not contribute to the social or economic capital but instead are seen as passive recipients of pity, help and hand-outs. John lamented that,

People see the wheelchair first, and think that I helpless. Nobody want to give me a job because they don't see pass the wheelchair.

Lisa explained that:

> People feel I can't work because I am a person with a disability ... I applied for a work that I know I could do easy easy, but when I [they] saw I wheelchair bound they say they can't give me the work, they didn't even give me a chance. I willing to do any work right about now but nobody giving me a chance.

Her physical impairment causes others to assume that she is incapable in all spheres of her life including her intellect. In attempting to mitigate those negative effects Lisa applied for a training programme, but was unsuccessful:

> I sign up for a course and they blank me, they say the tutor wouldn't want to teach me because of my disability. Steups, they feel I stupid or what.

The local biological reductionist ideology perceives the impaired body as one which is not capable of making an equal or valuable contribution to society, and this contributes to the social and economic polarisation of disabled people which results in increasing numbers living in poverty. International research shows that disabled people are disproportionately on the margins of the labour market and encounter economic, political and social inequalities (Barnes & Mercer 1997). My previous MA study found that the increasing poverty amongst disabled people in T&T was for the most part attributable to the difficulties experienced in accessing education, which in turn impacted on job prospects. The barriers to education ranged from inadequate infrastructure, lack of adaptive aids, physical inaccessibility, unavailable public transport, costs, and social attitudes. Ms Jordan, an academic explained:

> At the University not every lecturer is accepting of disabled students. They will still have classes on the first and second floor even though they have a physical disabled student in the class. The lecturers are sometimes the worse when it comes to accepting disabled students.

Lisa attests to such incidents by citing her own experience:

> I get accepted on a course and when I went to sign up I couldn't get upstairs and the building have no lift. I tell them before and even put on the form that I am wheelchair bound so they know that I can't go upstairs. I ask if the lady could come down and bring the forms for me to sign and after one set ah drama she finally come. She say that I can't do the course anyway because the tutor wouldn't want me in the class because of my disability – starts crying.

Many of the organisations interviewed at the time of my MA research which ranged from multinational organisations, state enterprises, and banks, to small independent businesses were forthright in attributing the lack of recruitment of disabled employees to inadequate disability awareness, apathy, insufficient interactions with disabled people, lack of resources, and business priorities: Organisations explained that:

> We are willing to recruit persons with disabilities but we really do not even know what we should be doing – (bank)

> If we hire a handicap person how will the other staff feel? They not going to like that at all at all – (state enterprise)

> Disabled people don't apply for the jobs though, so that's why we don't hire them – (private sector)

There is also a misconception that disabled people will be an economic and human resource liability to an organisation because of the notion that the presence of impairment equates to helplessness, dependency and a need for special assistance. The CEO of a company with over 50 employees said that 'Hiring a person with disabilities will cost my business place too much money'.

Joan, a disabled employee advocates for greater disability awareness and credits her manager's interactions with his disabled family member for his display of empathy and ultimately giving her the opportunity to prove that she was a suitable candidate for the job. She observed that:

> The employers who make you comfortable and listen to what you want to put in, is one who have a cousin, aunt or so, because he has that experience or exposure.

Close interactions with disabled people are therefore able to reverse some of the subjective perceptions which erode their agency.

5.10 Conclusion

The narratives shared by research participants provided an insight into their experiences of discrimination, and the impact on their lives, and the lives of their families. It highlighted the challenges endured, the levels of difficulty, and the unfairness experienced in their day to day lives due to stereotyping, prejudice, misconceptions, and lack of awareness. The information shared was an eye-opener in the sense that it was not possible to predict the extent of the hardships and adversity that disabled people in T&T experience in trying to live a reasonably contented life.

In attempting to negotiate independence, participants came up against many barriers - both physical and institutional - which compounded their marginalisation and isolation. They were also faced with material constraints imposed by relative poverty and a weak welfare infrastructure which failed to address their complex needs. Social undermining, social conflict and lack of or negative social support all have adverse bearings on the well-being of disabled people some of which may be so subtle that unless one is disabled

they will not be able to discern them, however, for the disabled person those become part of the daily life experiences they negotiate.

The information which emerged from the study is testament to the range of prejudice, exclusionary barriers and institutional discrimination experienced by disabled people in their minority group status in T&T, and the evidence in this chapter demonstrates that the oppression of disabled people occurs on many levels. The prejudice does not only occur 'because of a tyrannical power that coerces them, but because of the everyday practices of a well-intentioned liberal society' (Iris 1990:41). Because of that the daily life for disabled people is about constant negotiations 'not only with doorways or stairs but also with language, stares, assumptions and policies' (Holmes 2001:27).

6.   IDENTITY

Introduction

'It has actually been a blessing in my life because it has made me the man that I am ... it has made me very unique' Rajesh Durbal – Trinidad Express 18 July 2013

This interpretative chapter explores some of the complexities of disability as an identity, using the richness of the stories that disabled people tell of themselves, and their day-to-day experiences. It draws on the social model approach to explore the problematisation of disability as an identity, analyses the extent to which disability is claimed as a political and/or collective identity in T&T, and addresses questions around the discursive framings of disability that inhibit and/or allow such identity claims to be made. The chapter also considers how the deep prejudices which are part of the traditional approach to disability in T&T poses particular challenges in relation to the processes of claiming a political identity, and organising the recognition of one's rights.

It is evident from the data that there are a number of impediments to claiming disability as a positive identity which have not been adequately covered by the rights-based social model theory. Identities are complex instantiations constructed out of discourses and practices, with power relations determining the way in which people interpret who they are and their place in the world (Khan 2004). Identities are abstractions which are heavily influenced by historical processes that form part and parcel of the culture of a society:

> There is a considerable consensus, about the extent to which the process must be seen as a matter of a specifically historical entry into some specific historical figuration - an interweaving of personal and collective histories. In this sense identity formation en masse is seen as a historically located historical sequence (Abrams 1982:241).

With the thrust towards globalisation and the universalisation of the disability discourse, the tendency is towards the eventual use of Westernised culture and knowledge which will usurp indigenous approaches. According to Grech (2011) the exportation of Western epistemologies assumes that theoretical writing from the West is transferrable to the rest of the world. The data in this research highlights a number of key issues in implementing universalised frameworks in T&T around the shaping, reshaping and claiming of identities in view of the traditional socio-cultural approaches to disability.

6.1   Impairment Implications

It may seem odd to start a chapter which sets out to answer questions of identify by first speaking about the effects of having impairment but in the analysis of the data, what stood out the most were the parallels equating impairment limitations with disability, inferiority, incapability and helplessness. The starting point in the interview process was designed to gauge participant's interpretations of disability. Repeatedly, the language used was based on the 'ideology of normality' (Oliver 1996:104) with disability described in terms of biological determinism. Unusual physical embodiments were seen as the cause of problems that created vulnerability, dependency and practical incompetence. Such accounts paint a picture of a body and mind that is individualised, medicalised and socialised in the context of action and compliance located in the personal tragedy model. As substantiated by the following examples:

- Mr Patrick 'the first word that comes to my mind is helpless'.

- Mr Mack 'needing help to do things'

- Sandra 'when I think of disability I think can't do'.

- Karl 'to me disability is when you cannot do what people normally can do'.

In these examples disability is relational to functional ability and capability as a consequence of a deficient body that invariably encounters problems due to its biological structure. Mr Mack gave the example that: 'When you have a disability you not normal. It's not being able to express yourself like a normal person because of having a body that does not work properly'. Here the ideology of normality assumes that the lack of functionality is due to inherent bodily imperfections which are separate and apart from the societal barriers of discrimination, oppression and stigmatisation. Medical professionals, carers and disabled people themselves reiterate this discourse of disability as abnormality, with able-bodiedness being the preferential desired status which continues to be the culturally and socially embedded ideology.

It is therefore hardly surprising that participants spoke of their negative positionings due to beliefs that they are needy, poor, victims requiring help – of being devoid of agency. Dependence and pity then become significant components in the deficit conceptualisation, and it is that cultural representation of the personal tragedy model which influences the way disabled individuals and others in close interaction with them define their place in society. Where there is inferiority, incapability, and helplessness, there will be unequal power dynamics and the tendency is for wider society

to attempt to take charge of the structuring of the lived experiences of the disabled individuals, taking away their independence, agency and autonomy. Disabled people are then disempowered as they are afforded little control and influence over their own needs, values and opportunities.

Such occurrences are seen in the condescending assumptions of well-intentioned people who have been socially conditioned to believe that expressions of sympathy rather than empathy are acceptable, as well as intrusions in the guise of concern and welfare of disabled people even if unwelcomed. In relationships where pity is experienced, disempowerment and oppression gain strength; the self-perception and entire being of the disabled person is influenced by the social positioning of those who have power over them, including their families, community groups, and the society as a whole. An example of this was found when carrying out the documentation review of the T&T Mental Health Act (Amended 1999) which refers to 'a disorder requiring care, supervision, treatment and control'. Here social and political forces undermine the capacity of the individual, deny them their autonomy and forces them to accept care and control.

The notion of disabled people as helpless beings remained fairly constant in the research findings; Jo-anne and Mr Michael allude to this in their definitions. Jo-anne said that disabled means 'always depending on someone to help ... because of how their body is'. According to Mr Michael 'one tend to believe that there is something missing so to speak ... because of society, they will have to depend on somebody'. The interpretation is that disability is predicated on a relationship of dependency, between the impaired individual and the physical and social context in which they are located.

6.2   Claiming Disability Identity

Categorisations, preferentiality and discursive constructions of difference all influence identity claims. Stryker (2002:59) explains that 'one's self is the way one describes to himself, his relationship to others in a social process', meaning that identity which is part of the self, is developed in relation to the social settings and structured role and relationships that the individual participates in. Where inferiority is a signifier of the identity it is possible that as individuals try to fit in it can be given less emphasis. Father Benedict while embracing his disability identity refuses to let it dominate his life and that decision is based on the oppressive social responses to his impairments.

> I am not my disability, but that is what people see when they see me. They feel sorry for me, but I don't want their pity. Being disabled does not mean that I don't make a contribution ... People say to me "If I was like you I don't know how I will cope", or "I don't know how I will live day-to-day".

He receives sympathy and pity from those who assume that an intrinsic feature of disability is an inability to do things, dependency, and the enduring of perpetual adversity and in such situations the socially important role he performs as a priest becomes irrelevant, with the focus being on what it is presumed that he is unable to do.

In claiming his identity, Father Benedict emphasises 'I am a Catholic Priest first and foremost' which is a valued identity that he is committed to. His dominant identity is as a priest – a distinguished role that affords membership to a group that has a powerful social status. Because of that his communal relationships are often characterised by his faith, but he is also frequently assigned the identity of a disabled person belonging to a devalued group. He faces a challenge in having the freedom to choose who

he is and being able to publically claim and embrace that identity. Despite Father Benedict's best efforts it is the ideology of normality which continually impinges on his endeavour to define himself primarily as a priest, and with that is the continued reminder of his vulnerability.

In his vocation as a priest he has often asked himself 'Why me'? in order to undertake an evaluation of the spiritual meaning of his disability, seek self-improvement, and to distance himself from associating his impairment with victimhood. However, in spite of Father Benedict's notions of himself, the social norms, values and structures mean that he is subject to biological reductionist thinking. He contextualises his impairment as a source of spiritual development and self-empowerment and ignores the functional limitations caused by his physical imperfections. However artificial constraints and restrictions i.e. barriers to doing and barriers to being are imposed upon him by those who inaccurately judge his ability to fulfil tasks and transact his own self-care. Those erroneous assumptions then subject him to the personal tragedy construct in which his disability is viewed as 'a tragedy, or a loss causing suffering and blighting lives' (French & Swain 2004).

There are many complexities in claiming disability identity in T&T and Mrs Smith a mother of two disabled sons actively resists them being given that identity because of the negative connotations of belonging to a devalued group. The boys are officially categorised, labelled and provided with state services as disabled individuals but within the family circle the label does not define who they are.

> I have two sons and I don't ever classify them as disabled. He can do anything, he is artistic and anything you give Colin he can do it freely. The only thing is that he is physically um – he walks with a

stick, so I don't think of him as a disabled person. I think of him as a normal person, and he has the gift to do anything. I have two sons and I don't classify them as disabled … They go to a school for persons with disabilities but I don't classify them as disabled … When it comes to doing things with their brain they are good so I don't ever say I have disabled sons.

Ironically, both sons attend a segregated school for persons with disabilities which is in effect a public pronouncement and acknowledgement of their difference. Added to which, the ethos and practices at the institution mean that their day-to-day routines and social interactions are for the most part, rooted in the individual model of disability where the focus of attention is on the specificities of their physical and mental embodiment. But Mrs Smith is so acutely aware of the negative connotations of disability in T&T that she even hesitates when describing the nature of Colin's impairment to avoid using the word 'disabled'. She unconsciously begins to refer to him as being disabled, but then reconsiders, and given the point she is trying to get across she settles for 'he walks with a stick'.

The significance of his impairments is downplayed and within the family they are not considered a significant enough premise upon which to claim an identity. It is however difficult to completely avoid the disability identity because attending a segregated institute means that a large part of the boys' functions, behaviour, social relationships and interactions will act as constant reminders of their impairment limitations. In the examples given in this section it is easy to see that normative cultural values have deeply embedded parallels between impairment and incapability, and that socio-cultural norms create, reinforce and influence understandings of disability that ultimately shape the lived experiences of disabled people.

6.3   Disability as a Public Identity

Ms Brown is not disabled but is a teacher at an institute for disabled young people. Her interpretation of disability is: 'well I wouldn't go so far as to say they are helpless, they need help, and to be assisted. Being disabled or having a disability might not necessarily mean helpless, but it means that they would need some assistance or help'. She is reluctant to use the term 'helpless', but alludes to a level of powerlessness around ability, dependence and capability. That mode of thought invalidates disabled persons as agents in their own right, and undermines group collective identity.

In the hierarchy of identity salience which is the process of deciding what type of identity to publically claim (Stryker 2002), with disability identification an index of incapability as defined and conceptualised in the personal tragedy model, it will undoubtedly be low on the list. Oppressive social responses will cause individuals to shy away from claiming a public identity to devalued social groups. Mr Powers (wheelchair user) explained that disability group identity locks people into invalidity because society perceives them to be incapable and incompetent: it is 'about those poor people who need pity. That is the cultural sociological underpinning of the society'. Such opinions typify the disabled body in relation to the personal tragedy discourse and ignore embodied subjectivity but rather relegate disabled people to the needy role symbolic of requiring help/care and special treatment.

Mr Tony's construct of disability as a social identity is explained in this extract which highlights his experience of being held hostage during the 1990

aborted coup in T&T where insurgents stormed Parliament and the television station:

> Let me tell you, you see in this part of the world, disability is when you have a handicap. I remained captive for two days and the workers at the station negotiated with the kidnappers for them to release me because of my disability. When the men who took over the station see me they said "but I thought they say he sick, nothing wrong with him, he don't look sick". I didn't take my medication and was getting very sick, but if you don't look sick and mash up and you don't have a handicap they don't think you are disabled. But they don't know, they really don't know.

Mr Tony has systemic lupus erythematosus (lupus) causing him to experience severe joint pains, skin rashes, chronic tiredness and problems with his kidneys, heart and lining of the brain. At the time of the kidnapping he laid public claim to disability identity based upon the problematic realities of the biological limitations he experiences as a result of having lupus: 'We are disabled because patients at a late stage are diagnosed by doctors … I was having headaches, convulsions, my kidneys almost stopped working and I was eventually hospitalised', but his disabled identity was not sanctioned by the kidnappers nor did he benefit from sympathy or care and concern. At the time the physical manifestation of his disability and the painful experiential aspects of his impairment which continue to cause him anguish in his day to day life were not sufficiently noticeable and as such, he was denied a victim identity. He remains angered that because he does not have any outwardly distinguishable physical disfigurement the captors did not acknowledge his disability.

Milly who has the same medical condition as Mr Tony, chooses to individualise her experience of living with it and not attach a disabled identity to herself:

> I don't really consider myself to be disabled, not really, but I suppose in the truth of the sense, yes. But in my mind I don't think so, but yes because I can't be exposed to the sun like a regular person because of the consequences of that. But to me because I can be moving and doing regular stuff like any other person I am not disabled. I go out and talk to others with the condition, I am always out busy busy ... I suppose in theory I do have a disability and would be considered a person with a disability, but in my mind I can do everything like anyone else so I am not disabled.

Milly explained that her strategy is to downplay any impairment restrictions, and deny herself a sick role and victim label because she considers them to be distinct from her primary experiences as a person. She refuses to accept them as a sign of incapability and helplessness instead using her impairment for the promotion of self-determination and self-empowerment. She defines herself in terms of her interpersonal skills and social relationships, and ranks disability as a secondary feature of her identity: 'I see myself as helping people who have the same medical illness as me. I use my experience to talk to them about it. I visit them at home, hospital, anywhere. Once I hear that someone has it, I find a way to go and talk with them and pray with them. Well you know me, always busy, out and about helping people'.

Milly further explains that:

> I am forever in the hospital, I go clinic and next thing you know is that they ward me. I think I've been in hospital more often than Mr Tony ... I cannot work because of my condition, I used to work as a Nursery Nurse at a school for special children, but I then I got a really bad flair up and I had to quit my job. Mr Tony still has his job. I suppose you can say I still work, because I go around and talk

to others with the same condition especially those newly diagnosed ... But I still will not say I am disabled.

Milly acknowledges the significant impact impairments have on her life, and while she embraces those embodied limitations as being part of her day-to-day lived reality and endures the difficulties she encounters, she does not consider them sufficiently symbolic to her narrative of self. Mr Tony and Milly are friends with the same medical condition experiencing very similar symptoms but fundamentally their human identities are based upon the self-interpretations of their individual experiences, characteristics and social relationships. They conceptualise disability using the subjective interpretations of their encounters in their social world, together with the way they experience impairments within their own bodies, and the effects of those impairments on their social positioning.

Disability as a positive identity is not often valued and is seen as an unwarranted imposition therefore in situations where impairment is not immediately visible the easiest option will be to choose an invisible stance. Patrick who has Hansen's disease feels unable to claim a public identity because of the social exclusion, discrimination and injustice associated with the negative biblical identification of the disease. He made a decision to pass for normal by choosing concealment and opted to abstain from disclosing his medical condition to others and wears long trousers to hide the visible symptoms of the disease. At the interview he lifted up his trousers to reveal his disfigurement to me saying: 'I only have it on meh foot. Ah go show yuh! Yuh see it not bad, but I don't really wear shortpants and thing and nobody can't really see it so I don't get discrimination and thing'.

In T&T, individuals with visible signs of Hansen's disease or 'Cocobay' as it is called locally are 'scorned'. Through non-disclosure and the hiding of any visible symptoms of the impairment, Patrick is able to maintain his normalcy and social acceptance which negates any possibilities of him being judged as different or deviant. Through anonymity he is able to resist the imposition of a negative identity and weakened social position inherent in Hansen's disease:

> I only tell my family about it: my wife and children, my close family but other people don't know. Well I don't have any deformities except those on my leg so people can't really see that I have the disease ... well because people can't see that I have it, I wouldn't say that I have a disability. But it have others who hand and thing does show, they kind of crippled so they disabled. But for me nah, not really, I'm not disabled because people can't see it.

Patrick protects himself from discrimination through concealment and non-disclosure and is able to assimilate into mainstream society. His choice of invisibility is an individual survival strategy implemented to guard his social positioning and his normalisation and behavioural modification techniques enables him to assume that public non-disabled role, but that ambiguity brings with it a complex web of problems. An ambivalent state undermines any possibility of him pursuing collective claims, being part of the disability community, or claiming a political status.

Claiming disability as a public identity is fraught with complexities and difficulties due to the cultural variables and the social responses to them. The study found instances where anti-disability attitudes and sexist prejudicial behaviours converged. In 2012 'a female interior designer, an amputee' set out to provide role models from within the disability community by hosting a

Miss Differently-Abled Trinidad and Tobago Pageant. The aim was to 'motivate and lift the self-esteem of persons with disabilities' by reclaiming disability as a source of strength and pride and celebrating embodied differences. In so doing it aimed to reclaim feminine attractiveness from the impression that the impaired female form is ugly. Under normal circumstances a show based on attractiveness, appearance and the physical aesthetic of beauty will attract sexual adulation, but where the body deviates from the normative female ideal and impairments are placed in the forefront as the focus of attention the scenario was much different.

The aims of the pageant were stated as to: 'Emphasise appreciation by showcasing their true strength and beauty, and to sensitise the public to the prevalent fact that differently abled persons are beautiful. We are striving to increase integration in society at this level' (*Trinidad Guardian* Nov 11, 2012). But there are a number of valid questions to be asked in relation to judging of beauty, the hierarchies of measuring disability, the way that gender interacts with the concept of beauty, and the objectification of the disabled body. How do you judge a body that is placed outside of the established standard that lays down normative conditions and values and ranks people according to those values? The competition was designed with 'judging in the categories of congeniality, best evening gown, Miss Photogenic, as well as poise and intelligence' (*Trinidad Guardian* Nov 11, 2012). But what does this say about conditions of female beauty and intelligence, how disabled women are located in society, and where they locate themselves?

In attempting to claim a proud disability identity the pageant reinforces the concepts of difference with its demarcation and categorisation that separates and ranks individuals against each other and sets one impairment against

another. Measuring and objectifying bodily differences i.e. physical, anatomical and intellectual within a value system that is already riddled with stigmatisation is especially ironic where everyday socio-cultural processes create and reinforce stereotypical images of disabled people.

Given the deep social prejudices that exist in T&T and the fact that disability experiences are constantly being renegotiated how easy would it be for contestants to exist outside of the disability label or to reinscribe another identity after having taken part in a pageant that publicly acknowledges and celebrates a disabled identity? How do the contestants in a society such as T&T let go of the negative connotations attached to discursive disability identity as they journey to define themselves outside of that identity while working at the limits of themselves?

The show received mixed reviews which are not surprising as it was fundamentally about placing bodily imperfections on display within the constructions of beauty and attractiveness while ignoring all other social distinctions relevant to disability. Superficial judgements were made on the gendered imperfect physicality of individuals who struggle to maintain full citizenship in a prejudicial society. The gendering of disability in the context of a society where there are sexist prejudices and where gender exacerbates female disability experience is problematic. The contestants become objects and exhibits being graded and judged in relation to their mental and physical imperfections against a backdrop of stereotypes and imagery that others presume to be 'strength and beauty'. Because of the deep prejudices reflected in the local disability discourse a number of people felt that there was a strong possibility that the contest would further marginalise disabled individuals and subject them to ridicule. Ian (the parent of a disabled child)

alludes to the fetishised objectification and fantasies that can be associated with the exotic body. In a very animated voice he said:

> Who going at watch that shit? Nobody ain't going to that show, it go flop. Who want to see them girl and dem in bikini? Is only kinky man go get excited by that? Who paying money fuh dat shit? Nah nah that's shit. She gone in the papers begging for sponsor, for that? She shouldn't get a red cent. That's mocking people, man, like she telling people – all yuh come and laugh all yuh belly full at ah set ah disabled woman.

Ian's body language and choice of words reflected his strong opposition to the pageant but what was interesting is that when he was previously interviewed he was equally passionate for his disabled child to be able to have fuller participation in social activities stating:

> Trini ain't ready yet, disabled people does catch dey ass in this country. They does get small money from the government, yuh can't get a wheelchair, you does catch yuh ass to pass on the road with the up and down pavements, and people does treat disabled people like shit. But yuh see me, I ain't care a shit, I taking meh child anywhere – panyard, up the road, down the road, anywhere I feel, and who vex loss.

Here he alludes to the discrimination and oppression they face, and he is adamant in his resolve to challenge social barriers that exclude his child from fully participating in society. Given his passion for inclusion it is apparent that he does not recognise the pageant as a positive step in the right direction.

The pageant attracted some hostile negativity and the organiser explained that she had to 'put a man in his place after he posted derogatory comments on the pageant's FaceBook page'. Below are some of comments taken from a public discussion of the pageant:

Well yes, a contest for differently abled women.

What's next Miss K Foot T&T (knocked knees), or better yet Miss Current Roll (blemished) Leg T&T.

Would the women be placed into categories as cokey-eye (crossed eye) & one foot, douen like, hop and drop (walking with a limp), broko & blind … how would you select Miss Personality, the woman with the shortest flipper?

It is worth mentioning that the comments above were made by male contributors. The statements paint a picture of prejudice, anti-disability attitudes, and sexism which shows how gender presents an additional dimension to the oppression disabled women face. The sexist macho comments and the condemnation of the disabled contestants may be attributed to the construction of femininity where beauty and sexual attractiveness are important, and also that sees women as child bearers so consequently if they are deemed to be flawed they are therefore unsuitable and undesirable partners.

The pageant aimed to 'aid the social inclusion of disabled individuals and to motivate and lift the self-esteem of each person living with a disability giving them something in which they can identify with' but from the comments posted in the forum it is apparent that there is a disconnect between the intended outcomes of the pageant and what critical gender theory posits about the female body. Sexist societal standards and values attached to the way women should look, be and act have the effect of further disabling women (Wendell 1996) and in this situation it is compounded by taking the female disabled form and judging it in relation to a context which discounts femininity from the female disabled body. The outcome is that the

discussants conjured up monstrous images of grotesque women with severe physical deformities as being representative of the female disabled form.

The pageant also raises issues of definitions of disability and impairment hierarchy, with one forum discussant commenting:

> Imagine you broko (physically impaired) and yuh enter the Miss Differently-Abled and yuh come last, not only that but the girl who win look like a *douen*.

Another contributor questioned the selection criteria: 'There are too many variables, or are they selecting only those with at least one foot facing backwards?' Putting aside the crude derogatory language used those two statements rightly question the construction used in the identification and labelling of being differently-abled, and the criteria used by the judging panel to determine eligibility. There are a number of factors at play here especially because in T&T there are cultural contestations and differences in disability definitions, and tensions implicit in striving to claim a disabled identity. The oppressive social approaches and reactions to those with impairments (as evidenced in the disdainful comments exampled above) is a clear indication that claiming disability as a positive identity is fraught with long term social implications and therefore is not a decision taken lightly. It is for that reason that many like Patrick choose to disassociate themselves from a public disability identity.

There is certainly a paradox with a show to 'motivate and lift the self-esteem of persons with disabilities', while at the same time objectifying, judging and grading the contestant's impaired bodies based on the categories of strength, beauty and intelligence. The emerging picture is one in which contestants were paraded in front of a judging panel with their bodies and

minds scrutinised and assessed in comparison with an assumed 'normal', as understood and interpreted by the panel. The judges tasked with measuring and comparing human characteristic elements are themselves members of a society in which there is deep seated prejudice. By its very nature the pageant presumes that the judges will inevitably privilege particular impairment groups over another with lesser values being placed on the other impairment groups. For example, crowning a visually impaired contestant as the winner could convey preference over those who may have an intellectual disability especially as intelligence was one of the judging criteria.

There is a sense from the majority of the respondents who discussed the pageant that the negative connotations attached to the judging of 'handicapped women' and 'women with imperfect bodies' within the category of beauty will impact on the contestants rendering them objects of ridicule. While understanding the promoter's rationale of wishing to raise awareness within wider society, many of the research participants did not support the idea and could not see that 'it served any useful social purpose in its portrayal of disabled people'. It is worth mentioning though that a couple of those who were against the concept of the show said they would be tempted to enter in order to get the prize.

Lisa a pageant competitor said that by entering the pageant she was asserting her right to be proud of her difference despite it compounding the normality discourse. Lisa's point of view is that she does not seek a state of normalisation, but is proud to celebrate her disabled individualism:

> Even self I did not win I know I beautiful: girl I know I hot and spicy so I don't care wha' nobody say I hot hot hot. You see them people, they only jealous. What they saying is hurtful against persons with disabilities, and even though I wheelchair bound, and I can't walk I

know I sexy. The show was to show Trinidadians that us, persons with disabilities can do things like normal people, to stop discriminating and see that we have talent. Yeah I'm wheelchair bound, but I am proud of what I have achieved.

In this context her self-affirmation is that she is beautiful with her disability being part of her embodied reality and in spite of the disparageing comments posted on the forum she maintains that she is not ashamed of her impairment nor will she allow the comments to negatively influence her self-esteem. Instead taking part is validating her existence as a beautiful disabled woman and gain personal pleasure from it. Lisa describes herself as 'wheelchair bound' implying that though she is restricted by the wheelchair, it is an extension of her body, and it is that thinking which probably goes some way in validating the acceptance of her impairment.

The beauty pageant by its very nature is about making social comparisons of human characteristics even though the underlying philosophical understanding was to provide a space for participants to increase their self-esteem and sense of worth. Its shortcoming was that insufficient attention has been given to the way in which women are perceived in contemporary society and the unequal social relationship that goes with the gendered/sexist assumptions about what constitutes beauty, and women's availability for public scrutiny and judgement. Making appraisals in relation to bodily imperfections of those considered to be outside of the embodied norm is risky given the deep prejudices in T&T and the ongoing social undermining of disabled people. Attempts at embracing a public disability identity and positively celebrating a sense of self leaves contestants open to mockery, name calling, intolerance and patronage which many accepted with a sense of resignation to the embedded social and interactional conditioning

that is part and parcel of the disability experience in T&T. This demonstrates the limited space presently available for a positive embracing of a public identity as a disabled individual and particularly a disabled woman.

6.4   Group Identity Politics

The social model is a stepping stone in the development of a political strategy to address social change, remove oppressive barriers and empower disabled people. It provides a pathway to those choosing to claim a political/collective identity and gives prominence to a public acclamation of them owning, accepting and committing to that identity. However this is problematic in T&T as the local narrative is that they belong to a homogeneous collective of people who are incapable, incompetent and helpless because of impairment limitations. Nyrone explains: 'I am disabled because you are restricted from doing certain things. People who see me, see that I have physical challenges and think that I cannot function unaided'. He goes on to say that he prefers to emphasise the things that he is able to do, and actively makes claims to being a 'differently abled' person to highlight competence in other areas of his life. 'I use the term differently abled because I can do most of the things able-bodied people do, but differently … we do things differently, differently abled or not'.

Claiming agency in one's own right, and accepting and committing to a collective/political identity is fraught with challenges which undermine the giving of prominence to, and public acclamation of owning that identity. Lou-anna is committed to mobilising disabled people to become part of the local disability movement but encounters considerable apathy: 'The challenge is how do you connect with persons with disabilities who are not part of the movement so that they may come out and lend their support … people are

not willing to raise their heads above the parapet and fight for what is right because they don't feel they can contribute. They feel powerless'.

Societal prejudices including the dominance of religious and spiritual notions of disability discourage disabled people from having a collective identity, even though the aim of the politics of disability identity is to recognise and acknowledge impairment deviations, and engage with others who celebrate similar variations and share the commonality of oppression. But claiming positive identity is undercut by those attitudes of wider society that diminish the real life experiences of disabled people which means that they have to work that much harder to achieve their day- to-day desires leaving little time to actively engage in the political movement.

Despite the many challenges, the disability social movement in T&T has been slowly gaining momentum. The Consortium of Disability Organisations (CODO) a non-governmental organisation (NGO) was set up in 2001 is the umbrella body for all disability organisations in T&T. It includes people who are deaf, blind, paraplegic, autistic, dyslexic and people who have acquired disabilities due to ageing or various diseases such as cancer, heart disease, bipolar disorder, diabetes, Alzheimer's and Parkinson's (Ali 2013).

Not only are individuals becoming more enlightened to the virtues of self-empowerment and self-reliance, but they are also becoming more politically aware which is important for democracy. The movement has also enabled the forging of new friendships and relationships and these can only redound to the advantage of the disabled population.

HIV/AIDS as a disabled identity

There is resistance by HIV positive people in T&T to be defined as disabled which is due in part to the negative connotations of disability which tends to discredit agency and therefore discourages specific groups from choosing to claim a collective disability identity. Two HIV positive participants openly resisted any claims to disability identity. Angel was very animated in disclosing that: 'I do not have a disability. I am HIV positive that is all ... I can go about my business like everybody else and don't need help to do what I have to do. So you see for yourself I do not have a disability'.

I met Angel a few months after our initial interview and she shared an encounter with a consultant from the UK who she felt was quite insulting because of the consultant's continuous reference to individuals who are HIV positive as disabled. Angel believes the consultant may have been well intentioned but by insisting that her HIV status meant she was disabled she was being pressured into accepting a label she does not identify with. The consultant displayed a level of naivety in assuming a universalised categorisation of HIV as a disability, and ignoring Angel's right to construct her own identity. Angel rejects the consultant's ideological imposition of a disabled identity and counters that her experience is not one of being trapped within a flawed body: 'I don't want no label. I have a sickness but I get very good medicines for it and I can come and go as I please. I do not suffer because of it and I am not disabled, so nobody is going to tell me I have a disability: full stop'.

Angel demonstrates displeasure at having an identity imposed upon her based on someone else's interpretation of the disability construct and makes it quite clear that labels matter to her. Both disability and HIV/AIDS are

conceptually linked to forms of social deviance and stigmatisation so Angel's decision to deny herself a disability label 'may be a deliberate act to protect oneself from the loathing of society or may be an unchecked impulse spurred on by internalised self-loathing'. (Linton 1998:20). Angel does not define her sense of self within the disability category because as far as she is concerned, her health does not adversely affect the social order of her life, she does not have physical limitation and as such is not in need of fixing, nor does she require special assistance as she is able to respond to and engage with, environmental and social demands.

The participants at a HIV/AIDS focus group were unanimous in distancing themselves from the disabled identity, and when asked about their opinions on claiming the government disability grant a member said: 'That is the doing of the government and the policy makers but as far as I/we are concerned they did not ask HIV people if they consider themselves to be persons with disabilities. We have to apply to get the disability grant and to get our meds but we are not disabled'.

Another member of the group in discussing the loss of agency and imposition of identity said: 'We do not want to keep being referred to as people with HIV or HIV positive people or even more ridiculous as persons with disabilities. Our status does not define who we are as individuals. She also indicated that 'I know that some people will use this as a badge of honour to go to conferences, go on TV, and get benefits and perks that they would not get otherwise. A kind of celebrity thing'.

The group challenges the use of labels that are being imposed upon them as it was done without consultation, but there are instances where members

adopt and position themselves socially within a disabled role in order to achieve personal benefit.

The Political Movement

Throughout the Western world the disabled peoples' movement has been increasingly active in challenging traditional notions of disability. This is also true of T&T where a plethora of social interest groups are mushrooming and a local chapter of Disabled People's International has been formed. These groups are particularly important in that they provide a platform for disabled people to get involved, be empowered, and be able to construct a positive identity through collective strength and purpose (Paterson 2006). The domain in T&T is relatively new and many of the groups are working on the basis of the modernisation theory as a path to progression in the developing world. (Marshall 2003). The theory is based on:

- Helping establish business that can compete in Western market
- Providing access to capital
- Transforming the cultural, institutional and organisational features of poorer countries

In this quest for modernisation, disability groups actively recruit Western based professionals to undertake consultancy work in T&T which is a vestige of colonialism and perpetuates the application of Western based ideology. Ms Niles – the manager of a centre for disabled children spoke very proudly of her achievements in procuring the services of 'a lady who comes from the States (USA) to help us with our work ... She shows us what the latest techniques are that they are using up there'. That is not to say that local knowledge and expertise is not available because there are a multitude of parents and carers who have hands-on day-to-day experience of addressing the needs of their disabled family members from a traditional/cultural

perspective. But local knowledge is significantly underplayed and insufficiently appreciated in favour of social and political structures heavily influenced by Western models, mainly the USA and the UK. Historically, Crown Colony government was responsible for shaping the development of the country in the lead-up to independence (Marshall 2003), and the vestiges of colonialism when 'we were taught and believed that the best were English ideas, the best government was the English government and the best men were English men' still remain (Mandela 2002:53). To this day, the privileging of outside (foreign) influences continues with expertise from the West favoured over inside (local) influences as mentioned in a newspaper article. 'We still operate under a colonial mentality that white is right (Gopie 2012 in *Trinidad Express*)'.

This uncritical appropriation of knowledge socially situated in Western discourse and ideological assumptions excludes the actual lived experiences of disabled people in T&T. To understand the prevailing disability discourse in T&T requires it to be contextualised within the country's history, taking account of the value systems arising from Western colonisation and those from the African and Indian diaspora. This is particularly important in an environment where agency was denied to the society as a whole, and where conventions were that colonised people were infantile - requiring tutoring and therefore could only be appendages, and also because of the profound cultural dimensions which constitute the social organisation and the power relations of the African and Indian ideologies.

It is worth mentioning that modernisation and the appropriation of Western knowledge approach does not only occur within the disability movement, but is evident in the wider political sphere. On one of my visits to the Ministry

of the People and Social Development I was told: 'they brought in somebody from the States who is working on the disability legislation without consulting our own persons with disabilities' and that 'the Minister went to the States to look at disability good practice but I've heard that he has never even been to our own National Centre in South, and you know throughout the Caribbean it is considered a centre of excellence and good practice'.

The thrust towards modernisation represents a paradigm shift from traditional belief systems, cultural representations, values, and instead indigenous ways of working are being side-lined or reinterpreted in order to keep up with the modernisation ideology (Marshall 2003). The fall out is that the modernisation discourse marginalises communities and disadvantages people with its preoccupation and prevailing inclination that expertise must come from abroad, giving the impression that there is a lack of local knowledge and skills. Mr Small advised that

> You know how many times people come to me to help them get jobs. There are highly qualified and experienced Trinidadians and Tobagonians who can walk the walk and know how to talk the talk but can't get a break ... they have the knowledge but nobody will hire them and even if they hire them they will still bring in a white person or an expert from abroad.

He went on to lament that

> they don't even know what skills they have here. There is no register where you can find out who has what skills, and even if they had one, they will still go foreign because they believe that foreign is best, especially if the person is white and foreign ... Girl I sorry for you because you see all this work you doing, they not interested because, yes you foreign, but you not white and worse still you pushing a rass (referring to my dreadlock hairstyle).

There have been and continue to be a number of debates and discussions amongst disabled activists at grass roots levels actively challenging the

negative perceptions of disabled people, including the misconceptions that they are incapable and unproductive. This politicisation to defy discrimination is being achieved through the willingness, motivation and knowledge gained from their lived experiences as disabled people. Their impetus to challenge the inequality that disabled people encounter has led them come together as a unified body under the Consortium of Disability Organisations (CODO). By strengthening and fostering a collective community voice, the movement's intention is to jolt the state into acknowledging and taking heed of the valuable experiences of the group as a collective as well as its individual members and they have taken the first steps by making a public pronouncement for the social integration, and the recognition and enforcement of the human rights of the disabled population. Paul a disabled activist and member of CODO observes 'for years persons with disabilities have listened to the many promises of successive governments, now it's time to act'. The intention is that by taking a rights-based approach the movement will use their capacity to work with the state to alleviate some of the tensions evident in state processes and systems through legislation.

Relationship Tensions

The collective political identity which is being fostered through the formation of disability interest groups enables individuals to make sense of their lived experiences from a collective positioning and goes some way towards reversing the prevailing cultural hierarchy of values imposed on disabled people. As with most relationships, this collective gives rise to tensions, differences of opinion, manipulation, speculation, and in some instances the parting of ways. Father Benedict explains the reason behind his reluctance to be part of the collective: 'I am hesitant to be an advocate because I do not think I should use my vocation to raise the issue. The problem is, the

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creation of visible sensitivity motivates people to help, but the money may not get to the right place. It is immoral to exploit people's emotions nor should there be self-gain'.

The coming together as a united force creates an impression of a stable group but there is some level of 'them' and 'us' wrangling which is affecting the work of the collective. This is inevitable given the sheer numbers and types of different disabilities and intersectionalities which makes it difficult to have a narrow single interest vision. The movement's conceptual framework has at times proven to be inadequate in dealing with those shifting identities and interests which has resulted in polemical arguments amongst members who have moral and emotional connections with specific issues at a given point in time. Contradictions also arise between those premises grounded in Westernised universalised model of disability, and those based on lived reality with its myriad of social contextualisations and theories. A university lecturer noted that: 'We use the social model of disability on the course. We know that the textbooks are not really for Trinidad and Tobago culture, and some of the students have problems understanding some of what is in the books for that reason. But we use it'.

Issues also arise because there is no seamless category of disability; it is not one-dimensional and its meanings are ever changing, emerging, being reproduced and passed on depending on time and space. So though organisations within the movement share a common community and common culture and are ultimately working towards a common goal it is also possible for them to have a vested blinkered interest in a particular category of disability which may be because of personal experience and knowledge on a specific impairment. Group harmony may also be disrupted because the

diversity in the social relationships individuals encounter makes it possible to manoeuvre between multiple identities, or political causes.

There is considerable advocacy for social change and political reform but many advocates have shared that amongst other things, perceived governmental apathy and political corruption have stymied their advancement. Mr Weeks referred to the following newspaper extract to support his assertion: 'While the perception of corruption is already casting an embarrassing and gloomy outlook on T&T, the stench of nepotism is burning our noses'. (*Trinidad Guardian* 07 Dec 2011) and went on to give an example of a state official allegedly misappropriating funds for development work with disabled groups. Another reason is cited by Marshall who in discussing the delay in addressing the social ills in the Caribbean concludes that: 'the region has a culture of delaying action or subjecting everything to the bureaucratic trough and to look outside the region for assistance for its problems' Marshall (2003:158).

Tasha, a former journalist, concurs with the findings of Marshall but also points to the underlying assumption that the government is mired in corrupt practices:

> a government minister went to America under the pretence of looking at disability and health care good practice but didn't even bother to check out what best practice is happening right here in Trinidad and Tobago ... They love to travel, going all over on government money. They give grants to the groups they are in favour with or run by their family or partners (partners refer to friends).

The nepotism which is rife breeds cynicism about politics as an instrument of reform or change and the disability movement is affected by strained

relationships and a political system that is seen to perpetuate an environment of social inequalities. There is the belief that the political system reinforces a 'them and us' culture within a hierarchy of needs on one hand, and a lack of cohesion in the politics of coalition within the disability community and service providers, on the other. This is evidenced by the disenchantment expressed among the key players, disabled individuals and their carers. Carol B the mother of a disabled child said that 'there is too much fragmentation; disabled groups need to come together', thereby acknowledging the problems within the group, and the need for solidarity and cohesion within the movement. Other participants shared that 'those in government departments and in the public service like to power trip and abuse their position to intentionally demean the receiver of the service'; 'there is a lack of respect for persons with disabilities'; and 'Government needs to be held accountable'.

Mr South, a disability advocate is of the view that the government has not responded effectively to the disability movement, contending that there is a mismatch between the requirements of the disability community, and state rhetoric: 'If they (the Government) doing something for us they need to ask us. It's no use telling us that you doing something for us without asking us ... There are advocacy groups throughout the country and all they have to do is get together. We need to have a voice. The society needs discipline'.

Effective meaningful consultation that takes account of the experiential reality of disability remains a contentious issue with participants advocating for revised systems that take into account their descriptors of their experiences of living with disability as shaped by their bodily norms and social encounters. Ms Joseph, the mother of two autistic sons, pointed out that

there is a lack of knowledge and understanding in government departments that can be resolved in part by way of a collaborative approach:

> The government don't have a clue what is happening to you ... we need consultation with the authorities whatever that entails, because they will feel that they putting in a ramp for disabled persons, but they put it three inches high instead of making it flush. That is where they need consultation with the users of these facilities so that they get it right in the first place ... The government is essential.

It is evident from the discussions that disabled people believe that their own voices are not given sufficient acknowledgement, and instead others arbitrarily assume the role of speaking on their behalf, thus excluding the subjective experience of disabled persons. In effect, they are challenging the notion that the professionals are the ones with all the knowledge, and are asking for a more level playing field with a shift in the balance of power and control. What they want is meaningful effective and efficient consultation and active involvement in the development, implementation and delivery of services so that those services respond to the actual needs of the people they are intended to service.

The newness of the disability movement together with concerns of corruption, create particular problems which can be potential threats to the movement's sustainability and viability. There is general feeling that members of community development groups will invariably represent the best interest of the community and grassroots, but issues of competitiveness and power relations have arisen. Mr Wilson observed that 'organisational competitiveness is hindering progress ... there needs to be cohesion within the various disability groups'. Where there are individuals or groups that possess resources of knowledge, culture and educational credentials, the individual/group uses said resources to maintain or enhance their position.

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Possessing the resources creates an uneven power relationship, and enables the individual/group to form another layer within class demarcations that distinguishes them as the dominant class (Bourdieu 1989 cited in Marshall 2003).

There is also concern that individuals purporting to speak out on behalf of disabled people are not necessarily the nominated voice of the people but are able to do so by virtue of social hierarchy, class and acquisition of personal capital. The data threw up marked differences in the way disability is experienced for those belonging to particular communities in T&T. For example class privilege was notably evident in the Syrian/Lebanese community where the majority of members belong to an upper/middle class social stratification with adequate financial security. Livi the mother of a disabled child stated:

> They don't understand what we does go through on a day to day basis. They can afford to send away for the best medical care, buy the best equipment, hire the best doctors, and have the best private tutors for their special needs children. We, well we can't do that. The little pittance we get from the government can't even pay transportation much less private lessons. They don't live like we live. You don't see them in the papers asking for assistance for their child. They keep everything hush hush and only send their children to the posh special schools. I bet you never see a Syrian child in Lady Hochoy? They talk their talk in the meetings but they don't know what it really like for us poor people who have to wait every month for a government cheque to take care of our special needs children.

In contrast, Tanya, a Syrian/Lebanese mother says: 'I stopped working when my son got in the accident and now my husband runs the family business … My son has everything he needs so sometimes I help raise funds for other charity case children'.

Though T&T is a multi-cultural society with its imagery of harmony and cohesion there is a pervasive undercurrent of tensions based on race, and social class.

The regularity with which issues of power and control were raised, as well as the influences particular individuals have both within the emerging movement and the state, reflects the tensions within the movement. Concerns were raised about members' views being representative of the wider disabled population and whether or not those views were in the context of a personal or political agenda. Jenny a disabled advocate noted that:

> Some people only in it to go to conferences overseas, get free flights and have a good time and they not doing anything for persons with disabilities at all. Some people in it because they have a big mouth and want everybody to listen to them … a kind of power thing nah, and then it have the ones who in it because their name is Mr So-and-So and they in it because of who they know, not how they can help. In T&T, some people apply for certain important jobs in the Ministry not because of their love or passion for the work, but how quick it helps their chances of getting promotion. So you will find people who not committed to what they say they are doing, but doing it for their own benefit and gain.

The mistrust no doubt affects the ongoing development of a harmonious collective. The movement is however well aware of the challenges it faces and some of those topics were openly discussed at a conference held in 2012 in Port of Spain at which I was present. As one conference participant said: 'the disability organisations need to look inward and ensure that it has leadership and succession planning so that the work of the movement can continue … be more radical in behaviour, be visible, be more aggressive'. The acknowledgement of the challenges is a step in the right direction towards changing social and political structures.

6.5   Collective Naming

Globalised disability standards and international frameworks have sought to standardise the use of disability terminology, language and names and though the ultimate intention is to overturn the use of euphemistic labels and stigmatising language there is still much debate and discussion around preferred terms.

Nyrone, a focus group participant with a politicised identification devotes a significant amount of his time to raising awareness and points out that he is so empowered by the term 'differently-abled' that he has set up a social networking forum page for 'differently-abled people'. In keeping with the politics of normalisation he claims an identity that distinguishes outside of the helpless, dependent paradigm: 'I use the term differently-abled because I can do most of the things able-bodied people do but differently … we do things differently (differently-abled or not)'. Another disabled individual queried Nyrone's use of the term to which Nyrone responded 'I don't think anyone should have a big problem with the phrase'. He makes the point that by identifying as 'differently-abled' increases his value as a person, and emphasises his ability and capability. It is clear that labels matter to Nyrone.

The suitability of the term 'differently-abled' is not shared by everyone as some accept that although it is a progression from the term 'handicapped', it still underpins an outlook that measures people against a competency standard.

> Danny: I don't like to use differently-abled because that is saying that we are different and that we have to do things different to do it right. I don't like that at all

> Camille: Come to think of it, everybody is differently-abled, so that is a stupid thing to say. I wonder who came up with that saying.

Throughout the research process the terminology varied widely and it was noticeable that at times younger people referred to 'special, and special needs' which reinforces difference and positions individuals into a separate distinctive 'out of the ordinary' classification. However, the vast majority of the older generation used the term 'handicapped', despite the implication with being recipients of alms and charity – 'cap in hand'. In many instances the word appears to be carried on from one generation to another even in households with disabled family members. This is likely to pose a challenge in view of the shifting political climate towards the use of Western models of disability, as there is not the same sense of discomfort and pressure to ensure that politically correct terminology is used and that is particularly evident amongst the older generation for whom the only real shared definition they are used to is 'handicapped'. A social activist seeking election as a local MP made the following statement on a public platform:

> Which Ministry is responsible for making sure that all public buildings are accessible by the elderly and the handicapped … I want to know who and what is the procedure to bring legal action against the state on behalf of the handicapped, infirm and the elderly.

Mr Powers, himself a disability activist from time to time referred to 'handicapped people' so in spite of the terminological transformations being undertaken globally the words used in T&T reflect the ingrained social ways of knowing without any thought given to actual meanings or implications of the words. As Mr Mack explained: 'we say handicapped because that is what we accustomed saying'.

Milly rejects a disabled identity because 'words have power' and are able to shape people's sense of reality, their view of the world and the way that they experience it. She is also not supportive of the word 'disability' because the negative connotations conjured up reinforce the cultural perceptions and stereotyping of disabled people as incapacitated victims and privilege the able-bodied.   Labels matter to Milly, and in constructing her identity she aims to assimilate into the dominant group and emphasises her similarities to that group. She explains that:

> in the minds of people it is a negative because it begins with the word DIS, you know DIS always has a negative sound like disadvantage ... that is why I know some other people prefer the word differently-challenged because it sounds better. But that still isn't good. I don't like those words at all, that's another reason why I don't say I have a disability. I can do most thinks that others can do.

This view has been referenced in Linton (2006) who postulates that the prefix 'dis' connotes separation and creates a barrier which cleaves ability and its absence, as polar opposites. Disability is therefore the denial of ability.

In labelling theory there is a power dynamic of who is labeled, who applies the label, why they do it, and the consequence of doing so. For example Longmore (1985) in his study on language and social identity of disabled people noted that those in the medical profession who view disabled people as objects who should surrender themselves for medical treatment are inclined to use medicalised labels, and those within the movement will use language that deflects euphemistic labels and is politicised and self-identifiable.

A review of official state documents found a mix of various terminologies being used interchangeably, for example:

> The Government of T&T is committed to the full inclusion and holistic development of persons with disabilities (National Policy on Persons with Disabilities)

> Government housing units will be allocated for ... persons who are physically challenged (Ministry of Housing and Environment Housing Policy)

> T&T Government calls for focus on special needs children (Government Information Service Bulletin)

> It provides assistance to parents who are unable to meet the financial cost of caring for a special child. (Ministry of the People and Social Development – Social Welfare Division Policy)

> To provide income support to the disabled, between ages 18 and less than 65, and who satisfy other criteria of income and residence (Ministry of the People and Social Development – Social Welfare Division Policy)

In carrying out the review of state documents the complexity of disability language was apparent. For example, the Trinidad and Tobago Survey of Living Conditions 2005 (SLC) asked: 'Do you have a disability – Yes/No. If yes, what kind: Seeing; hearing; speaking; mobility; body movements; gripping; learning; behavioural; confined to wheelchair'. 4% of the survey group identified as being disabled, while 59.1% indicated that they had a chronic illness under the categories of asthma, diabetes, arthritis, or mental disorder. Given the Western based constructs of disability which use those medicalised diagnoses of chronic illness as a disability marker, the figure could be skewed or distorted based on the perceptions of those being interviewed. It is therefore possible, that if the same survey was carried out

in the UK the numbers would have been significantly different based on interpretation of the language.

6.6   Conclusion

This chapter considered the liminal unstable abstractions of disability identity and the way in which participants use this fluidity of identity in order to make meaning of their lives. The data verifies that disability is not a homogenous group identity, and although disabled individuals share a range of common characteristics, just as there is commonality, there is difference. The identification of a collective of people using the label 'disability' categorises them on a shared feature, and imposes a fixed identity, but in so doing it discounts other identities and characteristics. It is somewhat ironic that disability is constructed on difference, but belonging to the collective implies sameness even though the embodied difference is what is central to the notion of a disabled identity.

Definitions and labels with their powerful implications remain a contentious issue amongst those who are subject to such cataloguing and labelling, and the individuals interviewed as part of this research process affirm their desire to seek an identity that expresses what matters most to them. Claiming a positive disability identity is not always been easy because of the cultural stereotypical representations of disabled people as flawed, broken, needy, and dependent. One of the ways that this cultural imagery manifests itself is through the use of negative euphemistic terminology and labels that reinforce that idea of incapacitation. Many disabled people accept the language in resignation to the embedded social conditionings, although doing so perpetuates the discrimination and loss of agency.

The disabled people's movement in T&T has been slowly gaining momentum as people embark on a journey to forging a positive political identity. In this regard the social movement is using a rights-based approach to champion for social transformation. However, they have encountered a number of obstacles and resistances to claiming that identity which are not helped by the fact that the state processes have been developed and implemented without meaningful and effective consultation with disabled people.

7.0   POLICY AND THE STATE

Introduction

The previous chapter explored the complexities of disability identity and the way that disabled people understand themselves in the context of claiming or rejecting a disabled identity. This final analysis chapter delves into the state's ideologies and interpositions by investigating the definitions that underpin government policy and legislation, their implications and ramifications on service delivery, together with their effects on the lived experiences of the disabled population.

This assessment has been done taking account of Oliver's 1990 assertion that 'Disability policies must also face the same rigorous analysis of their ideological underpinnings ... There is the need for the deconstruction and reconstruction of the ideological agendas by which policy produces the dominant concepts of disability' (Oliver 1990:2). In response the chapter presents an analysis of the relationships and social attitudes between the state, disabled individuals, and the wider disabled community. This was achieved through an interrogation of the language and communication used, and an analysis of the meanings ascribed by the state in framing and conceptualising disability across a range of legislation, policy, service delivery and political frameworks. The interrogation and analysis contextualised the parameters used by Government in the development of its legislation and policy, allocation of resources, and delivery of services for the disabled population.

Foucault contends that individuals are made subjects in part through state inspection and control, and individuals make themselves subjects by the way

in which they speak truth about themselves (Foucault 1982). In view of this, it is important to explore the ways in which political and institutional relations are engaged, how they influence public perception and opinion, and the impact they have on the lives of disabled individuals because 'political actions or inaction contributes to the disadvantaged position of disabled people (Hahn 1985:96). My focus here is not so much on critiquing the specific details of state policy but is an exercise in interrogating the discursive underpinnings of policy and the ways in which it impinges on the lives and experiences of the disabled population.

In T&T the state department with principal responsibility for disability is the Disability Affairs Unit situated within the Ministry of the People and Social Development. In Tobago, the Disability Affairs Unit is positioned in the Social Services Department of the Tobago House of Assembly (THA) which is the local government body responsible for the running of Tobago. The Ministry of Health covers mental health for both islands, and under the directive of the Ministry of Justice there is an Equal Opportunity Commission whose aim is to 'work towards the elimination of discrimination' (http://www.equalopportunity.gov.tt/about). There are also two other Ministries with mandated objectives that directly impact on the lives of disabled people, namely the Ministry of Community Development, responsible for 'people centred development, poverty eradication and social justice' (http://www.community.gov.tt/home/content/mission-vision), and the Ministry of Diversity and Social Integration, responsible for 'creating an inclusive and more equitable society through greater social justice and sustainable human development' (https://www.facebook.com/ministryofdiversitytt).

The Ministries above were contacted to determine their specific roles in the disability agenda - The Ministry of Community Development responded that 'we have nothing to do with disabilities, but I'm not really sure who you should really speak to'. At the Ministry of Diversity and Social Integration I was advised 'you come through to the wrong place, you need the Ministry of Health', and the Ministry of Health informed me 'not here, disability is not here. It's People and Social Development'. I then asked specifically about mental health and was told 'oh yeah, that's St Anns (referring to the St Anns Mental Hospital), yeah yeah that's under Health'. My interactions with the Ministries gave some indication of the absence of synchronisation of disability as a cross-cutting issue within the state.

7.1   State Documentation

In undertaking this research a number of state documents were scrutinised, namely:

- The Trinidad and Tobago National Policy on Persons with Disabilities (which lays out the Government's commitment to addressing the needs of the local disabled population);
- The Population and Housing Census 2000 (the most up-to-date population-wide statistical documentation available);
- The Survey of Living Conditions 2005;
- Equal Opportunity Act 2000; and
- Mental Health Act 1975.

All of these were considered important documents for analysis because of their role in framing the state's relationship with the disabled community. They are key to unveiling disability interpretations and frameworks used in government policy discourse because policy definitions have a strategic role in the social construct of disability (Oliver 1990). As stated above, my purpose in undertaking the analysis of the state documents is not so much to critique the specifics or to determine whether they stand up to scrutiny.

Instead, my intention is to understand and conceptualise their discursive framings of disability and the effects they have on the lives of disabled individuals.

The National Policy

The National Policy on Persons with Disabilities was approved by the Government of T&T in 2005, as part of the state's 'pursuit of developed country status by 2020, and its commitment to address disability issues from a human rights perspective' (National Policy 2005). The document 'serves to unify the many disparate guidelines and pieces of legislation that address persons with disabilities' and has been a significant initiative towards the achieving of equality of opportunity for the disabled population. However, the absence of enforceable legislation means that the Policy is for all intents and purposes a set of guiding principles and frameworks, rather than a state-imposed action plan because without legislation there are no sanctions for non-adherence. The lack of enforcement probably accounts for the reported slow piecemeal implementation of the Policy.

The policy contextualises disability using the WHO's International Classification of Functioning, Disability and Health definition, which is based on the understanding that disability is as a result of the interaction between individuals and their environment. The policy states that:

> In keeping with the International Classification of Functioning, Disability and Health (ICF) (WHO), disability is defined as an umbrella term for impairment, activity limitation and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and the individual's contextual factors (environmental and personal factors). Whilst it is recognised that it is difficult to have one generic definition of disability, the ICF's definition will be adhered to in this document (National Policy 2005:4).

By committing to the ICF definition, the state is making the claim that the local framework has been developed in keeping with a combination approach that bridges the gap between the medical and social model, and that the individual, institutional and societal factors which contribute to disability experiences will be accounted for in its work. However scrutiny of the policy did reveal inadequate representation of the social, institutional and cultural factors that impact on disability in the context of T&T. Having said that, the ICF definition has itself received ongoing criticism by international researchers for being too vague, for failing to capture the complex meanings of impairments (Snyder and Mitchell 2006), and for inadequately protecting the rights to privacy (Imrie R 2004), all of which are quite pertinent points in relation to the T&T cultural context.

Spirituality and Religion

In the Policy there is no evidence that many of the local ideologies underpinning impairment have been taken into consideration. The historical, economic, cultural and social factors relevant to the meanings that the local population attach to disability have been ignored, for example the complexities around the relationship between spirituality, religion, and disability which were previously presented in Chapter 4. Instead it replicates modern Westernised approaches although many of them are not representative of the dominant ideology in T&T disability culture where matters such as superstition, belief in forces, powers and spirits (for example, the African derived force of Orisha and Obeah and the Indian philosophy of Karma) shape disability experiences and explanations.

The intertwining of religious thought and notions of disability is prominently illustrated by the religious-based philanthropic organisations that are an important aspect of community services. A major component of their work is the personal development of disadvantaged people in society which goes hand in hand with their instilling of spiritual values. One such establishment is The Living Waters Catholic Ecclesial Community founded in response 'to a call from God to light a fire of love in the hearts of God's people for the poor in Trinidad – the physically and spiritually poor, e.g., the illiterate, hungry, homeless, disabled' (LWCC) and another is The Islamic Relief Centre which 'provides assistance by way of relief to the poor and destitute, and those individuals and families, in accordance with Islamic Principles' (http://www.Islamicreliefcentre.com). Organisations such as these are a valuable community resource that ought to have a more prominent role in the strategic planning processes of the state with due regard given to their values, interpretations and ways of working.

Cultural Specificity

The National policy is the structural framework upon which disability services are developed, initiated, and monitored, and in alluding to the ICF definition it is claiming to take account of the relationship between environmental factors, and personal circumstances and the way that they affect disability. But making such a claim is problematic because the policy has been initiated without due consideration to disability in the context of postcolonial T&T, and the cultural competence around the dominant indigenous ethos, for example the place of superstition, traditional beliefs, religion and myths, in day to day disability experiences.

Dr Burgess believes that the lack of cultural specificity in the Policy was because of the 'closed door process' taken during the developmental phase of the Policy. Dr Burgess advised that very little inclusive public consultation was held with the wider disabled community, and that many of the key advisors were not themselves disabled people, but individuals who either worked in the field or have an interest in disability issues and who took the role of acting for and on behalf of disabled people. The lack of alliance between the disabled population and the state professionals has consequently resulted in a document that inadequately reflects the lived realities of the population it is meant to serve.

The policy has also been affected by financial constraints in that at the time of its development Trinidad and Tobago was undergoing structural adjustments to correct its 'balance of payment problems' resulting in time, money and resources being cut back and those adjustments ultimately affected policy development and delivery of services for marginalised groups (Marshall 2003). There is no doubt that the mainstream political issues and the economic positioning of the state at the time had a direct impact on the development and rolling out of the National Policy.

Confidentiality

Privacy and confidentiality is insufficiently protected in the Caribbean (Amnesty International 2006) and Kelly & Bain, in their research on HIV in the Caribbean, noted that 'it is alleged that the majority of breaches (of confidentiality) occur at public health and social support institutions' (Kelly & Bain 2005:42). Throughout this research process it was an area of considerable concern and was cited as one of the reasons for the reluctance in consenting to recorded interviews.

Mrs. Mark said that 'people love to mind your business and gossip' and 'in Tobago there ain't no thing as a secret, people does spend they time talking people business'. A number of participants shared their experiences to support their reluctance in seeking medical treatment: Mrs. George shared that 'Ah went up the hospital for a test and before ah even reach home meh husband did done know whey wrong with meh, cause one ah dem fas nurses did done call she friend and tell she, and de friend call meh husband and tell he is whey wrong with meh'. Ms Joy explained 'I refuse to go to the clinic in my area because I know before I even leave the building the whole of town will know my business. People in this place like to maco (be excessively nosey) and mind your business too damn much'.

Participants shared a number of examples of breaches of confidentiality, believing it to be a cultural manifestation that permeates throughout the islands. It is clear from the research findings that respect for privacy and confidentiality is not embedded in the local culture and it is equally ignored by policy makers and health care service providers although it poses a barrier for people seeking health care services and also their family and carers.

> The question of confidentiality, especially in a small society like Tobago, ranks high among the issues that must be addressed in the drafting of any legislation which seeks to protect the rights of persons infected with HIV/AIDS ... HIV/AIDS patients in Tobago would have sought testing and then accessed treatment at facilities in Trinidad due to a perceived lack of confidentiality among health and other personnel in Tobago. (Cupid 2008)

Although this example is specific to Tobago, my findings suggest that it is equally relevant in Trinidad.

Normalisation

Further examination of the National Policy found that its premise is based on normalisation principles that place disability in the context of functional limitations. The references contained therein are derived from the medical model of disability and centred on preventative measures to eliminate the occurrences of impairments. For example, the action plan emphasises the need for:

- mandatory screening of all children from birth to 5 years to detect disabilities so that corrective action can be taken;

- the dissemination of information on issues such as genetic screening, counselling, effects of sexually transmitted diseases and the causes of disability to prevent such occurrences and facilitate early detection of impairment (National Policy 2005:24).

A significant part of the overall disability strategy is grounded in the medicalised construction that disability is an unwanted imposition upon the individual that places them within a 'sick role' with the obligations that comes with that role (Parsons 1975). The action plan replicates the medical model's functionalist approach equating impairments to defects with normalcy at its core. The action plan is unduly centred on impairment interventions through prevention, curing, correcting or rehabilitation with the explicit outcome of making the disabled individual, who is considered as biologically or psychologically damaged, broken and inferior, to be as normal as possible. Those action plan statements are about 'eliminating impairments and correcting disabilities', and highlight the economic and resource

shortcomings in disability-related service provision in so far as they are saying that the state is unable to adequately support those with disabilities who require assistance, and therefore those impairments must be prevented from occurring. The assertion is that disability is an unwelcome burden to be avoided, and that all disabled people should aspire to be cured, which of itself denies the agency of those individuals for whom their disability identity is a very important part of making meaning about themselves and the world as they know it. Nyron related the following statement to support his claim of a positive disability identity:

> I'm glad I was born differently abled because if I was born abled bodied, I would not have been who I am and who I am evolving into.

Population and Housing Census 2000 & Survey of Living Conditions

Different mapping systems extract diverse meanings because their language is interpreted in relation to the existing notions of disability within contemporary society. These divergent interpretations confuse the data gathered that is eventually used as the baseline in the design and implementation of policy and service delivery. For example, in T&T a range of instruments have been used to gather statistical data each having specific disability interpretations:

The Population and Housing Census 2000 uses the following defining question to capture disability data:

> do you suffer from any longstanding 'disability' that prevents him/her from performing an activity" based on the following categories – seeing; hearing; speaking; mobility; movement; gripping; learning; behaviour. (emphasis added)

In the Survey of Living Conditions 2005 the question is framed as:

> Do you have a disability – Yes/No. If yes, what kind: Seeing; hearing; speaking; mobility; body movements; gripping; learning; behavioural; confined to wheelchair.

The Population and Housing Census uses the emotive word - 'suffering' to define experiences in relation to performing particular functions which implies that the individual endures severe affliction that is 'bad and undesirable' (Nordenfelt 2007). In addition, the Census fails to contextualise the reason for the 'suffering' - for example if the suffering is due to chronic pain, social oppression, or lack of resources.

Both documents are based on the defining characterisations of impairment and ability/capability. In the Survey of Living Conditions, being 'confined to a wheelchair' is singled out as a type of disability, even though it is an adaptive aid that enables an individual to have the capacity to perform a particular function that he or she may otherwise be unable to accomplish. By isolating specific impairments the definition erodes the individual's sense of self, especially if he or she does not consider himself or herself to be disadvantaged by the impairment. I must make it clear that by questioning the notion of 'suffering' and singling out impairments I am in no way attempting to romanticise the embodied experience of disability. In fact, I acknowledge the effects and vulnerabilities that impairments can have on the quality of life of disabled individuals which have been highlighted by Crow & Morris in their critiques of the social model theory (Morris 1991; Crow 1996). The point I make is that these two documents i.e. the Population and Housing Census and the Survey of Living Conditions do not reference the other components that affect an individual's quality of life, and their ability to perform the activities specified, for example their intersectional

characteristics, personal resources, physical, social, economic, and political influences (Mitra S 2006).

In the extract below Narish explains the disabling effects of diminished resources:

> sometimes poverty is a problem and it causes people to suffer, it's not their disability per se that's the problem ... sometimes if the people get proper housing with water and lights, and they able to pay for medicine for whatever they sickness is they ain't going to suffer ... I not saying that rich people don't suffer eh, I just saying that when you ketching your tail to stretch what little money you have it bound to cause you stress and that stress is what does sometimes cause you to suffer and not your sickness ... Think about it, if you stressed out because you ain't really living in a proper place, and you don't have money, ent when your sickness acting up you will stay in your bed? You know what will happen? After a while you will only keep staying in your bed and next thing you know your body getting stiff stiff, and you can't really move about. You see what I saying? So is poverty that cause that, is not really the sickness.

The census and survey documents' line of questioning also poses a problem for those individuals who do not recognise themselves amongst the impairments listed. Milly has a chronic health problem but with none of the impairment characteristics listed; she has however been assessed, approved and is in receipt of the disability welfare grant because she has been categorised as disabled by the state even though in her social life she shuns the disabled identity. In a situation such as Milly's, completing the two survey documents will be dependent upon the classification most appropriate at that given time. Based on Milly's self-identity and the listed categorisations provided her response will be negative, but if she was defining herself in accordance with the state appointed medical officer's findings she will indicate a positive disabled identification. Angel, who is HIV positive, has a

similar experience in so far as she does not have any of the listed impairments, and is adamant that she does not wish to be categorised and singled out as being different. 'I do not want no label'. She embraces her embodied experience as non-disabled and rejects the group identity although she has been medically classified as disabled.

The Survey of Living Conditions states that 'Policy makers will have to anticipate under-reporting and examine the extent to which the various services provided are reaching the universe of clients, and just as importantly, the extent to which the society is organised to allow those with disabilities to achieve their fullest potential'. In view of this observation together with my own findings I question the validity and reliability of the raw data collected, and note that it will be difficult for statisticians and researchers to work effectively with that data. The potential impact is that disability will undoubtedly be misrepresented given the anomalies in terminology and definitions used in the process of collection and analysis of data and that will be problematic in the planning and development of services.

The complexities in interpretation are however not unique to T&T. The Review of Disability Policies, Statistics and Strategies in Latin America and the Caribbean Report cites the range of definition differences and interpretations:

> a visual disability category in one country may be classified as blindness in one or both eyes in a second country and may include another type of visual impairment in a third country

and recommend that 'the need to create a common language and methodology for collecting and analysing disability statistics should be emphasised' (Dudzik P *et al.* undated).

The Equal Opportunity Act

The Rights of Disabled People in T&T are protected under the Equal Opportunities Act 2000, which is:

> an Act to prohibit certain kinds of discrimination, to promote quality of opportunity between persons of different status i.e. – the sex; ethnicity; origin (including geographic origin); religion; marital status or disability of that person (EOA, 2000).

In the Equal Opportunity Act, disability is defined as:

- a total or partial loss of a bodily function
- a total or partial loss of a part of the body
- a malfunction of a part of the body including a mental or psychological disease or disorder
- malformation or disfigurement of part of the body (EOA, 2000)

This is at odds with the ICF model used in the T&T National Policy. The philosophical rationale that underpins the EOA places disability solely within the medical model, using the language of deficit with individuals being defined and characterised by their bodily functions or lack thereof. In its present state, the definition within the Act depoliticises the disability discourse and legitimises the symbolic perceptions of disability as being an individual functional deficit problem due to a bio-medical condition or impairment that needs to be fixed or overcome in order to conform to a perceived norm of bodily configurations. This language of deficit continued to present itself throughout the fieldwork process. For example Mr Mack describes a disabled person as:

> someone unable to function normally, so to speak ... One tend to believe that there is something missing so to speak

This reductionist language is also reflected in some of the local colloquialisms for disabilities, such as 'broko', which describes someone with a physical impairment, or 'gone off', for those with mental ill health.

The Mental Health Act 1975

The legal framework that addresses mental and psycho-social disabilities is the Mental Health Act of 1975, which aims to provide for the 'admission, care, and treatment of persons who are mentally ill', and contains the following descriptors:

- "mental disorder" means mental illness, arrested or incomplete development of mind and "mentally disordered" shall be construed accordingly;

- "mental illness" means the condition of mind of a mentally ill person;

- "mentally ill" or "mentally ill person" means a person who is suffering from such a disorder of mind that he requires care, supervision, treatment and control, or any of them, for his own protection or welfare or for the protection or welfare of others (Trinidad and Tobago Mental Health Act 1975)

Sengupta recognises that defining mental ill health is difficult as it is about behaviours that deviate from accepted norms which then get labelled as madness, lunacy, insanity, mental illness and mental disorders (Sengupta 2008). This language which is featured in the Act is based on a normative discourse that has artificial demarcations of ability versus inability, normal versus abnormal/subnormal and thus, diminishes the agency of those with psychosocial disabilities. In addition, here is a presumption of a desirable homogeneity in mental ability, which does not account for the cultural norms of human functioning, competence and intelligence. However focussing on changing the terminology and language used to describe mental ill health will be a futile exercise if the reasons behind the attitudes and the situation on the ground are not understood and addressed (Sengupta 2008).

- The Act defines those with mental and psycho-social disabilities in very problematic terms:"mentally subnormal" or "mentally subnormal person" means a person in whom there is a condition of arrested or incomplete development of mind, whether such condition arises from inherent causes or is induced by disease or injury before such person attains the age of eighteen years, and includes a person who requires care, supervision, treatment and control, or any of them, for his own protection or welfare or for the protection or welfare of others;

- "mental subnormality" means the condition of mind of a mentally subnormal person (Trinidad and Tobago Mental Health Act 1975);

The language is itself discriminatory and stigmatising and implies that the body/mind requires control, treatment and/or rehabilitation. This produces a 'Us' versus 'Them' power hierarchy where the 'us' is normal and in control, and the 'them' i.e. the people we are not are abnormal and portrayed as the 'other' requiring controlling. Nita's mother was of the opinion that 'people who are mad can damage themselves because they can't really take care of themselves'. Thinking such as this inculcates attitudes that enable those in power to ignore, devalue, depersonalise and socially distance disabled people to whom a mental ill health identity is ascribed.

In his work on stigma, Hunt (1966) notes that when people are distinguished as abnormal they are aligned to the challenges they are perceived to pose to societal values, and judging from definitions contained in the Act which place a great deal of emphasis on the need to control/contain such people for the benefit/protection of society and 'for their own good' it is clear that people with psychosocial impairments are considered to be objects requiring supervision and control and to whom things must be done. Maybe it is this

misplaced sense of power, control and protection that causes the street dwellers - 'vagrants' in T&T -- to be rounded up from time to time and placed in the St Anns Mental Hospital without effective assessments or adequate follow up services provided:

> At least part of the ongoing problem with the earnest hand wringing over the homeless in Trinidad and Tobago is the persistent misunderstanding that there is one solution to people who have ended up on the streets from various paths in life ... Lumping all these people together under one rubric and attempting to implement a single action to "process" them is a cruel mistake ... What's been consistently missing is the kind of social services support and humane administration that makes sense of dozens of different life stories and attempts to chart a course that compassionately sorts them out. (*Trinidad Guardian* 29 November 2010)

The street dwellers are denied their social rights and obligations although many may not necessarily be experiencing mental ill health but may be experiencing the effects of poverty and destitution bought on by drug use, HIV positive status, physical impairments. Some are known to be deportees from countries such as the United States and Canada where they may have lived most of their lives but because they have no place else to go when they are forcibly sent back to T&T they end up on the streets.

The descriptions used in the Act define disabled people and position them in a hierarchy of superiority using the baseline of normality. Those with mental and psycho-social disabilities are judged within a framework of being 'subnormal' which stigmatises and discriminates against their lived experiences. Then by virtue of being classed as incapable, invalid and not a

worthwhile contributor to society, they then become objects of the law instead of subjects within the law. This dehumanisation of individuals with mental and psychosocial disabilities is very explicit in the language used in the Act so I asked a medical practitioner to clarify what non-judgemental scientific measure was used to categorise a person as being 'subnormal' in accordance to the Act, to which he responded that it was dependent upon perceptions and interpretations of the person's behaviour. 'If they act out of the ordinary, like if they dotish and can't understand what it is that does be going on around them then yes. Mostly we say then that they behaving abnormal'

According to the Mental Health Act the initial contact for a situation involving an individual with a psychosocial disability ought to be trained mental health nurses, however the lack of adequate resources means that it is law enforcement officers who ultimately end up handling the situation. WPC Dean said 'mad people should not be roaming the road they should be locked up in St Anns but you ever see inside that place, it's a disgrace. Mad people, vagrant, everybody could just walk in and out ah that place so you don't know who is who'. Morabito & Bennett in their research on policing and mental health in T&T questioned whether police officers' reactions to those with mental ill health were due to their 'beliefs about the human condition with either a cynical or tragic perspective of human behavior' (Morabito & Bennett 2008:193). Their findings found that officers' were reluctant to refer people to the mental health services mainly due to past experiences in their interactions with the system, which the officers deem a 'useless endeavor'. But they did not find a clear-cut signifier for officers' personal refusal to assist people with a psychosocial disability, however my

own research found many officers shared an opinion similar to PC Frankie that:

> mad people really need to be put away somewhere, locked up in St Anns but we does feel sorry for them, hear what eh, at the end of the day we does be doing we job and if they can't get the priest, Pundit or who so ever to sort them out then is St Anns for them and is there they should stay and keep away from people

a view that nullifies the social relevance of disabled people, but is also reflective of the officers disenchanted with the mental health services. In the Moribito & Bennett study, the authors were unable to explain the reason for the officers' behavior and suggest that the topic be further investigated. They did however make mention of the socio-cultural specificities with regard to policing in T&T, stating that 'postcolonial Caribbean nations like Trinidad and Tobago had difficulty in transforming the police from a colonial security force to a law enforcement agency' (Moribito & Bennett 2008).

The findings from my discussions with law enforcement officers indicate that behavior and attitudes of officers towards disabled people are influenced by their individual belief systems and previous interactions. They function using the dualistic view of mankind, i.e. there are good people (themselves) and there are bad people (those they encounter who display a behavior that is different from the socially accepted norm) and they react according to those judgments.

According to Castillo there have been increased numbers of people with psychosocial disabilities which is described as an emerging crisis (Castillo 2007 in Morabito & Bennett 2008). However, I question the accuracy of this observation in view of issues discussed on identity and the number of variables that come into play. For example, is the number of individuals self-identifying as having psychosocial disabilities increasing or is it the case that

they no longer remain hidden away, 'locked up' from society and as such their presence is much more visible or is it because the dominant discourse around mental health which has often excluded the specificities of the setting and the culture of postcolonial T&T is being challenged. I make that last point because social theorising has often excluded the realities of the historic struggles around the acquiring of authenticity of agency in postcolonial societies and as such certain behaviours are misconstrued as offensive and become categorised as symptoms of mental ill health.

Academic Discourses

In undertaking the research I observed another definitional model at work being used by The University of the West Indies (UWI) and though not directly situated within the state, it is a public actor that speaks to the state. The UWI has initiated a significant shift in the disability paradigm by implementing the Westernised social model conceptual framework within the Disability Studies Programme syllabus. The model, as explained previously in the literature review, is motivated by a political and research strategy that strives to combat socio-economic oppression by redressing issues of marginalisation and social exclusion of disabled people (Devva & Shuttleworth 2003). It addresses the interaction between the individual with the impairment and the environmental and attitudinal barriers which they face (Barron T & Amerena P 2007), with the aim being a 'barrier free utopia' (Shakespeare T 2006), but there are a number of relevant criticisms of the model and in this case my concern is about its lack of consideration for ethnic and cultural specificities.

Local academia in attempting to keep up with evolving global Westernised developments has neglected the accounts of the experiential dimension of

life of the local disabled population. Those experiences are heavily influenced by Indian and African diaspora cultural narratives and traditions, as seen in the folklore. In addition the belief persists that competent, capable local knowledge is often side-lined in favour of Western trained professionals who are more desirable and preferred (Kalyanpur 1996). Although I highlight the shortcomings of using the social model in academia I also acknowledge that the social model paradigm is a useful mechanism in getting conversations started as it offers a radical and politicised way of locating disability through its grounding of the problem within the wider society rather than placing it with the individual. The politicised premise upon which the social model is founded creates opportunities for wide-reaching debates.

The use of the social model in local academia is but an additional strand in the mixed web of contradictory conceptualisations of disability within the state, which is not entirely surprising as many international disability scholars recognise that there is no specific single model that can explain disability (Pfeiffer 2001), but that there are many theoretical models with operational definitions applicable in diverse situations (Altman 2001).

7.2 Policy applications

The data analysis revealed a myriad of differing notions of disability in state policy and systems, and showed how the state's power to define disability overrides (or undervalues) the experiences of disabled individuals by its mismatch between the state's definitions and the experiences of disabled individuals. Below is an extract from a conversation with Professor Augustine, who has some responsibility for the provision of special assistance to students at an institute of higher education. He explains that since there are no specific guidelines on determining who is disabled, he is often

suspicious of requests for special assistance by students with hidden/non visual impairments:

> Is there a way you can measure an intellectual disability … Sometimes students say they have an intellectual or mental disability and they need additional student support for their studies but what do we use to measure this? It is subjective and we have to believe the student if they bring in a doctor's note. Sometimes they have a doctor note but we know that there is nothing wrong with them, they just want extra time to do the exam.

Discussions with Professor Augustine revealed his conceptualisation of a disability identity is limited to those with a diagnostic label of a significant physical functional deficit or social incapacitation. He is therefore wary of students who identify themselves as disabled based on their need for special adaptive measures at a particular time and space. In some instances students had been assessed by a medical professional with a conclusion that the student has a 'medical condition' requiring special assistance, others had chosen to go down the route of self-identification to avoid paying the costs of the medical examination, and there are others who self-identify to enable them to benefit from the special measures and boost their chances at the exams. Professor Augustine considered those who seek special assistance via self-identification as cheats. He however neglects the important point that disability identity is often accompanied by stigmatisation and discrimination and it is not a decision that many students will take lightly or be willing to put themselves into. Professor Augustine's uninformed stance is again an example of the medical model insistence on the power of the medical professional to measure, classify and define what constitutes disability. In addition, his powerful position in determining who qualifies for special assistance means that it is possible for him to undermine an individual's identity status and deny them their personhood and agency.

7.3   Legal Processes

The apparent rise in service organisations for disabled people can give the impression that as a disadvantaged group they have more rights than are actually present in State Law. There is currently no specific legislation that confers and recognises their rights and that creates a wide gap between their legal enfranchisement and their status as a marginalised group. Mr Powers, a former government minister, is of the opinion that the lack of legislation influences the way that others interact with disabled people, and the power differentials discerned:

> People treat disabled people as charity cases and commit violations against them but there are no penalties.

Mr Powers advised that because many disabled people face economic hardship and poverty, and have been disadvantaged by some of the recent political reforms, he has been in continuous dialogue with state departments lobbying for the human rights of disabled people to be put on the political agenda. But he also advised that one of the shortcomings in state services is that individuals who experience injustice are unsure of the support available or the processes for redress, and as such injustice often goes unchallenged. However those who accept the wrongdoing and oppression without seeking to draw attention to the problem or to seek justice are themselves complicit in reinforcing the existing dominant structures. Many participants shared experiences of been 'discriminated against', their 'rights infringed' or their 'status as people been undermined' but the lack of adequate legislative structures negates any real judicial recourse. Mr Powers noted that 'the Equal Opportunities Legislation does not properly cover disabled people and nobody really cares about it'. From the findings one can deduce that the justice system as it currently stands is weighted against

disabled people and that is illustrated not only by the absence of specific legislation to protect their rights, but also because of the physical inaccessibility of judiciary buildings. Mr Lal, a disability advocate, said that:

> up to now they have not sanctioned the legal order in regards to providing proper access to the Hall of Justice for persons with disabilities … that shows how serious they deal with the problems faced by persons with disabilities. The Ministries could have worked together to sort it out quickly.

> Mr Ali said 'yuh can't even get into the Halls of Justice or some of the other court houses because deh have no ramp for wheelchair. In the court house by me, it have endless stairs to climb and the lift always breaking down'.

From the field notes I was able to garner a picture which reveals a significant amount of socio-cultural laxness as it pertains to respect for disabled people, and it gives the impression that even if legislation were to be enacted the law will not be obeyed nor will it be enforced. Mr Mack:

> People over here doh care about laws, they does disobey them free sheet. Law or no law ain't go make a difference nah. Trini's love to break de law. Who yuh go call when somebody harass a disabled chile – the Police? Yuh must be joking, because they does break the law too. Look even the government does be breaking the law.

Young (1990:41) makes the point that social injustices against disabled people are often a result of 'unconscious assumptions and reactions of well-meaning people in ordinary interactions.' However, it is evident that justice will not be redressed by simply enacting equality legislation to deal with subjective vulnerability but that it will also require non-disabled individuals to address their own discriminatory attitudes towards disability (Markell 2003).

At each focus group, participants spoke of the accessibility issues endured by Mr George Daniel and Mr Lincoln Myers, both wheelchair users who experienced difficulty and loss of dignity in accessing the judiciary buildings. The late Mr George Daniel, a well-known disability activist, won a case in 2007 with the Judge ruling that the state's failure to provide wheelchair access to the Hall of Justice was in violation of the right to freedom for disabled people. The state was then ordered with immediate effect to put the necessary measures in place to ensure direct wheelchair access to the court but despite the ruling in 2007, former Government Minister Mr Myers had to be lifted in and out of the Hall of Justice in 2011 because the building was still inaccessible (*Trinidad Guardian* Feb 2010). Instances like this not only call into question the state's commitment to the human rights of disabled people but support the claim by participants that even if legislation were to be enacted there is a strong possibility that it will be flouted. Ben a group participant lamented that:

> even relatively new government buildings are not accessible. This has been discussed for years and in 2012 it is still being discussed.

This extract from a newspaper article of May 2013 was sent by a research participant who felt quite strongly about the state's neglect of disabled people:

> T&T President Anthony Carmona recalled that a week after becoming president and after the appointment of temporary Independent Senator Hugh Russel Ian Roach, who is disabled, he was scheduled to meet with Roach but "was embarrassed to learn and to have to inform Mr Roach that I could not meet with him at his official office on the second floor because it was not wheelchair-accessible." He said the first-floor offices also were not wheelchair-accessible because there was no ramp. He said to facilitate the meeting on the first floor, "the Presidency had to have a ramp built over the weekend" (Donta 2013).

Articles such as this go some way in showing the social and political neglect of the rights of disabled people.

7.4 Equal Opportunity

The government's disability policies and systems are situated in the mode of thought that considers the disabled body to be flawed, and that impairments are undesirable and therefore they should be prevented. That way of thinking then compounds situations that make disabled people subject to rehabilitative interventions to get them to achieve maximum functionality or for measures to be taken to avoid impairments occurring in the first instance. That is not to say that I am against preventative measures being undertaken, but when there is such a strong emphasis on fixing and preventing disabilities it reinforces social prejudices against those with impaired bodies, gives the idea that they are societal liabilities and undermines their basis human rights. Abberley (1987) and Morris (1991) both point out that state policies that are aimed only at preventing impairments impinge upon the rights of disabled people, which ultimately has an impact on society as a whole and its value system. Abberley also postulates that:

> the key distinction that must be made is between the prevention of impairment, on the one hand, and attitudes to and treatment of people who are already impaired on the other.

At present the Equal Opportunity Commission (EOC), which is a state organisation within the Ministry of Justice, is the mechanism for citizens to challenge instances of discrimination and injustice. Its aims are listed as:

- Work towards the elimination of discrimination.
- Promote equality of opportunity and good relations between persons of different ethnic and religious backgrounds.

- Receive, investigate and as far as possible, conciliate allegations of discrimination.
- Develop, conduct and foster research and education programmes and other programmes for the purpose of eliminating discrimination and promoting equality of opportunity and good relations between persons of different races, ethnicities, religions, geographical origins, marital status, gender or physical disabilities.
- Prepare and publish appropriate guidelines for the avoidance of discrimination (www.equalopportunity.gov.tt).

In spite of the stated aims of the organisation the reality is that in its working mandate there is an absence of developmental activities and initiatives for marginalised groups. Instead the day to day activities are concentrated on addressing infringement of employment rights complaints.

A focus group participant expressed that in their opinion the existing structure of the EOC was discriminatory because there was no disabled employee working for the organisation, nor was there an employee with specialised knowledge to assist in cases of disability inequalities. She commented:

> How they going to deal with we case when they don't know anything about disability and what we go through? What if the person is mentally challenged eh, who is there to help to explain things to that person using words that the man on the street can understand and not the big big words these people like to use? Imagine if you didn't go school or you went to a special needs school you would not know what it is these people saying to you.

Another participant in attempting to quell the concern, advised that one of the Commissioners is the Chief Executive Officer of a disability rehabilitation organisation, and though the C.E.O is not disabled, nor has an active case-related role within the E.O.C disabled people should be 'grateful' for her representation in the E.O.C Board. To which another responded:

imagine it takes a person without a disability to be the voice of the persons with disabilities in the Commission.

In May 2008 the UN Convention of the Rights of Persons with Disabilities came into force, with the aim 'to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity' (CRPD Article 1). T&T is a signatory to the convention, but the lack of ratification has been a contentious issue for a number of local disability advocates because they view ratification as the mechanism through which the state will be forced to address the human rights of disabled people. A focus group participant involved in the development of policies shared his frustration about the 'way the Government is dragging its feet on carrying out ratification … the overseers are severely lacking, they need more co-ordination so that the CRPD can be ratified, they are not serious at all at all'.

Another participant from a different focus group shared that frustration with the delay:

> they need to get to ratify the convention. Other countries in the region already ratified, but in T&T we 'fraid, they ain't really want to do it because it will give persons with disabilities rights. We need to ratify the Convention, that's what we need to do. But I can tell you what happened to me when I start telling them about ratifying, they don't treat you fair.

Mr Jason Clarke who heads the Disability Affairs Unit in Tobago referred me to his report entitled 'Disability Rights Violation - Is this Discrimination against a Person with Disabilities?' An extract is given below:

Right to contribute to the Convention negotiations initially DENIED!

The saga began with a decision by Mr. Aldington Spencer, Secretary of Health and Social Services in the Tobago House of Assembly (THA) to deny funding to Mr. Jason Clarke to attend the Eighth Session of the United Nations Ad Hoc Committee negotiating the International Convention on the Rights of Persons with Disabilities (ICRPD) from August 14-25, 2006. Mr. Clarke is a person with disabilities who the Government of Trinidad and Tobago appointed as its representative to the Ad Hoc Committee (AHC) negotiations in 2004. He is under contract with the Disability Affairs Unit, Tobago House of Assembly as a Social Services Officer. Mr. Clarke had attended the preceding 5 Sessions.

A number of participants were of the opinion that the delay in ratification should not only be blamed on the state's lack of drive and determination, but also the lack of 'passion in the disability movement' and the movement not being 'sufficiently proactive'. According to Mrs James:

we need to stop complaining, and organisations for and of the disabled should come together to advocate for the ratification.

While another indicated:

stop turning the other cheek and encourage media support for the ratification.

Mr John was of the opinion that the delay is intentional because ratification will assist in harmonising the movement because the groups will be working towards a clearer agenda, and as a collective the group will be able to take the state to task for any failings or shortcomings.

It is indeed the case that the desire for the early ratification of the UNCRPD is a response to the inequalities experienced by disabled people and where they are preoccupied with daily survival, fighting for equality of opportunity, and challenging discrimination such treaties appear to be the utopian answer. However, though the convention has been signed judging by the comments shared about the socio-cultural attitudes towards legal processes it is not

surprising that it has done little in the way of changing the landscape regarding the rights of disabled people. Given the questions that have arisen on the universal applicability of UNCRPD ratification does not mean that ingrained social perceptions and attitudes will be seamlessly altered. Ratification of any UN convention in itself is rarely a sufficient step to changing social attitudes and as such the UNCRPD should be seen as only one part of a much larger process of social change.

7.5 The Welfare State

At the Caribbean Conference on Horizontal Co-operation in Social Protection, held in September 2008, it was noted that the approach to disability policy by the T&T Government was fragmented, and that:

- there is a distinctly social welfarist approach to social policy
- there are increasing tendencies to a more developmental environment to social policy
- there is a disconnect between the main line social ministry and other public goods ministries
- there are fragmented approaches as they relate to policies
- inter-agency co-operation is bureaucratic and time-consuming (www.news.gov.tt)

These statements imply that there is a need for greater coordination and a more harmonious relationship between ordinary disabled citizens and the state. A senior government officer shed some light on the apparent lack of co-ordination and integration:

> I do not really think the general population is concerned about disability, because when people were asked about their issues and concerns, disability was not top of their considerations. It is not considered important from an everyday point of view; they are more concerned about housing, access to medical care, etc.

There is some uncertainty as to whether this is the general opinion amongst state officials, but there is a sense that the population is apathetic to disability reform so it is no surprise that 'there is a disconnect between the government and the actual needs of the people'. What is being requested is for the state to effectively 'engage with disabled people' (conference participants).

When interviewed, strategic informants in various government agencies tended to paint a positive picture of a consensual partnership with unity and cohesion existing among themselves, the key disability related organisations, and disabled individuals. Many senior officials placed considerable value on their provision of financial support to groups that work with and for disabled people (which was described by a participant as 'piecemeal, insufficient, scraping the bottom of the barrel sums of money that you have to beg for and be grateful if you get it on time), and much less importance was given to addressing the wider social issues arising from the complexity of disability. A senior employee at Ministry of the People said:

> we work with the NGOs and support them ... they get a lot of grants. You will find that some of them will complain but I can tell you that they do get a lot of grants from the Government. We have a book with a list of NGOs that we help.

Other employees gave a less rosy view of the experiences of policy development and service delivery, with many supporting the need for more collaboration between the various Ministries, NGOs, disabled individuals and service providers. Below are some quotes from government employees of varying levels of seniority outlining some of the issues requiring state attention.

education is an area of concern especially around accessible classrooms;

disaster preparedness needs to be given serious consideration especially for disabled persons;

workplace employment still needs addressing;

HIV/AIDS issues for disabled people are not being considered at all;

while there are some strides and progress made regarding transportation, accessible transport is still a problem.

Dr Burgess, a researcher, noted that some progress has been made and the state is slowly intensifying its attention on disabilities. That is partly due to the politicising of disability which has resulted in the growth of state involvement in a number of projects and them working on a number of public pronouncements around alleviating discrimination, hardship and disadvantage experienced by disabled individuals. Dr Burgess also noted that with politicisation there has been a proliferation of new 'organisations of and for persons with disabilities' and those have impacted positively on the local disability movement and by extension on the lives of disabled people.

Several influential disabled individuals also mentioned this intensified interest in disabilities by the state, noting that the Minister of People and Social Development has from time to time issued a number of press releases as seen below:

Cabinet has approved $30,000 to the Cerebral Palsy Society of Trinidad and Tobago (CPSTT) to buy much needed equipment and material; (LaRose 2012)

Minister of the People and Social Development Dr Glenn Ramadharsingh said Cabinet had given approval for $74,850 to be

released to cerebral palsy associations to assist with workshops and activities. (Clyne 2013)

A review of the Minister's press releases showed disproportionate attention has been given to cerebral palsy which highlights the complexities of the hierarchies of impairment. Garvin a focus group participant noted that 'the difference between services promised and services delivered is low … they only concentrate on the groups they are in special favour with'

The prevalent imagery in the many press releases of the Ministry of the People and Social Development reemphasises the social identity of disability as tragic/charity/needy by its portrayal of disabled individuals as being less than whole, helpless, and victims in need of pity and hand-outs. The messages portrayed use patronising headlines and language and are fundamentally charity-driven. They are also often accompanied by a photograph of the Minister handing over an object of goodwill, for example a wheelchair, hamper or cheque to a needy person, which is also a way of using the disadvantaged in society to raise his political profile. A research participant asked 'is it necessary to publish all those photographs of hamper recipients?' which is ironic because he is reporter working for one of the newspapers that printed the press release. He further advised that although he was against the manner in which disabled people are often portrayed in the newspapers he does not feel he can challenge the use of the imagery because 'the politicians control a lot of what we can put in the papers'.

Mr Lalla voiced his scepticism at the motives behind the Minister's numerous press releases saying that 'it's political … it is just a pappyshow to fool people to get their vote … make people believe he really interested in their problems'. Mr Lalla's mistrust over the political rhetoric is however not unique

to T&T experiences. Oliver & Barnes (2006) in their work on charities in the UK, found that the rhetoric of the government in addressing disabilities was often more about their self-preservation and doing what is politically expedient to retain their position as the government in power.

The Minister also released the following statement:

> The worst disease that I have seen in my life is cerebral palsy and I am committed to doing something about it ... If I can do something about this, then I would feel as if I have done something in social development. (Kissoon 2010)

which is a clear example of what is referred to by Paterson (2006) as the patronising discourse used by politicians when discussing disability. The Minister has contextualised disability within a normative able-bodiedness discourse that denies agency to those with cerebral palsy. The language used valorises the need to eradicate and overcome disability in line with the functionalist medical model and gives no acknowledgement to the social, psychological, cultural or political experiences that provide meaning to disability identity. Dr Burgess who drew my attention to the article commented: 'that just goes to show the ignorance of those in positions of power and how little they know or even understanding persons with disabilities. He don't even know how much he insult those people'.

The number of press releases issued is a testament that disability is on the Minister's radar, which of itself is a positive step towards addressing disability-related socio-economic reforms. But although the work he has illustrated in the press releases are given as examples of good governance and social reforms they are counter-productive, in that they reinforce negative stereotyping of disabled people. For example, the Minister's reference to cerebral palsy as 'the worst disease that I have seen in my life'

conjures up negative imagery, justifies the notions of abnormalcy, and ignores disability as a valid human characteristic with scant credence given to the values of those who positively identify with that disability. Alan embraces his cerebral palsy and was slighted by the Minister's statement: 'he don't know wha' he talking about, I wouldn't change my life at all'.

In addition, the Minister's focus on the construction of an impairment-specific institution positions disability in the medicalised model of rehabilitation that concentrates on the provision of services for disabled people in a segregated environment. Those types of segregated institutions strengthen traditional dependency conceptions and increase the marginalisation of disabled people, at a time when disabled people and the movement are championing for their integration into mainstream services.

7.6 Disability Welfare and Governmentality

The system of governmentality and the way that the power of governance and subjectification are developed is evident in the state disability welfare system with its process of identification, classification, and division. Medical officers are required to make a determination on the percentage of disability the claimant experiences through the use of:

> techniques of an observing hierarchy and those of a normalising judgement. It is a normalising gaze, a surveillance that makes it possible to qualify, to classify and to punish. It establishes over individuals a visibility through which one differentiates them and judges them. (Foucault 1977:184)

The state has the responsibility for ordering the lives of the population, and for the economy of the country and these two converge through governmentality and its regulatory systems that objectify and classify the body. As the custodian of the welfare purse the state controls who has

access to its welfare system, but given a situation of limited resources, unfair distribution will be systemic. So how do individuals including medical officers realistically navigate the myriad of experiences, definitions and interpretations, to determine the degree, and extent of the functional deficit that constitutes disability? Are factors such as economic circumstances, environment, family, gender, age, and beliefs taken into consideration as recommended in the ICF definition? Or is it measured based on a reductive understanding of the body that judges anatomical characteristics to define functionality and health? These are all important questions bearing in mind that these are used to determine who can and cannot qualify for a portion of the limited state resources.

Mr Copper requires the use of glasses for full vision, but does not know how much vision loss will categorise his impairment as a disability, nor is he sure whether his socio-economic status (he is financially very wealthy) will be taken into consideration. He was also unsure if the state will categorise him as disabled, because when he uses his glasses he is able to achieve full sight. Carole and Mary have differing views on whether their mutual friend, who had been previously diagnosed with mental ill health, should be considered disabled:

> Mary 'A mental health problem is a disability. I say so because they do not have a clear understanding of what they are doing';
>
> Carol 'I think a person with a mental problem can be a stable normal person. With medication they can be classified as a stable normal person so I would not classify them as a disabled person'.

These statements challenge the social and cultural perceptions of disability construction and the questions 'who is disabled and what constitutes disability'? Baker (1999:94) cautions that 'this treatment of definitional issues

assumes, however that one already knows what constitutes a biological impairment, that one can see'. The reality is that disability is a fluid construct and is not a fixed state of being and therefore incredibly difficult to define.

Claiming Disability Grant

Eligibility for the welfare grant requires the individual to be subject to a medical assessment administered by a state appointed medical officer (figure 15) and is a discretionary and assumption-based assessment process.

SOCIAL WELFARE DIVISION

MEDICAL OFFICER'S REPORT

Local Board ....

Address ....

Date ....

THE DISTRICT MEDICAL OFFICER

CLINIC/HEALTH CENTRE ....

Kindly provide a Medical Report for the purpose of Public Assistance.

....
Social Welfare Adviser

Name .... P.A. File No. ....

Occupation....................................... I.D. No. ....

Address ....

Nature of illness or injury ....

Whether disabled from earning .... Percentage of disability ....

Probable duration of disability ....

....
Date

....
Medical Officer

(*Kindly affix your office stamp*)

Note to Medical Officer—The object of the report is to assist the Local Board in determining what assistance may be given to the applicant.

G.P., TR./To.—O 3072—40,000—2/99

Figure 15. Medical Officer's Report

The process legitimises the universal medicalisation of disability by making assumptions based on prevailing medical guidelines that cause individuals to lose their autonomy and instead acquire a label, categorisation and identity based on the interpretations of the medical professional. The professional's position of power gives them unchecked sovereignty in identifying needs (in relation to health and social care requirements), judging the capabilities of the disabled person (based on their individual conceptualisation of impairment and disability), and prescribing what he/she deems to be an appropriate solution, i.e. whether or not the individual qualifies for economic or supportive assistance. Feedback from focus groups showed that lack of awareness, education and know-how means that patients, parents, and care givers experience difficulty with instructions, but are reluctant to ask appropriate questions and too embarrassed to seek clarifications from professionals because of the prestige attached to medical professionals, that deems them to be 'demi-Gods' with an unquestionable acceptance of their decisions. Below are some comments from the focus group participants:

> 'I just do whatever the doctor say because is he that went to school and study and qualify'
> 'How you expect somebody like me to argue with the doctors and them, not me I know my place'
> 'sometimes you ask them questions and they does buff yuh (telling off) and talk to yuh like you 'chupid so you see me, I does but meh tail between meh leg and do what they say yes'

Illich (1976:3) noted that:

> the medical profession is a manifestation in one particular sector of the control over the structure of class power that university trained elites have acquired. Only doctors now "know" what constitutes sickness, who is sick, and what shall be done to the sick and to those they consider at a special risk.

The welfare grant application is therefore mainly engaged with scientism that ignores the socio-cultural determinants of illness, impairment and care. Here the medical professionals are the gatekeepers to the state's resources and they have control over who qualifies for assistance or not, thereby creating a client dependency relationship. This unequal power relationship with a subordinate other is further reinforced by a system that does not provide prior knowledge of the specific impairment, medical condition or socio-cultural factors that determine disability in the welfare system. Determination is made by a subjective assessment process wherein individuals are diagnosed, pathologised, and labelled. Having spoken to Ms Roopnarine soon after she was discharged from St Anns Mental Hospital, her confusion with the state definitional system was evident. In spite of having lifelong mental ill health, she remains unsure of her qualification for the grant mainly because it is the side effects of medication that make her tired, sleepy and unable to concentrate and it is those symptoms that negatively affect her quality of life and render her unable to work.

The assessment process makes a number of assumptions about the functional abilities an individual needs in order to be able to live the quality of life they desire, and those assumptions though not reflective of the lived reality of the disabled individual become taken for granted by professionals and are naturalised as the measure of functionality. In addition, screening individuals to determine the severity of their impairment means that it is those with worst-case scenarios who will have better prospects of being successful and as such individuals become creative actors in order to increase their chances of receiving support and assistance.

The state recognises the social and economic hardships associated with disability, but at the same time its system increases disabling prejudices by drawing attention to the othering of individuals. Disability identity is generated in the state by pointing the finger to an innate biological imperfection garnered through examinations for physical symptoms of bio-medical difference. The diagnosis, assessment and treatment determination that is made negates interpretation of the individual's socio-cultural and economic conditions and the social processes of impairment classification that are grounded in the medicalised model inadvertently amplify aspects of oppression that disabled people then encounter.

Mr South, a local activist said that there are 'lots of hurdles and intentional red-tape to frustrate people so that less people would apply for help and get the grant. They doing that to ease up the treasury'. Many view the claiming of state welfare in T&T with trepidation not only because of the 'endless red tape' involved in the application process, but because its structure creates an automatic power divide with disabled people regarded as being needy and worthy of pity which can be quite stigmatising. Its authority of professional dominance makes for an unequal power dynamic that can adversely affect the self-concept of disabled people. Mrs Mack explained that:

> persons with disabilities have to depend on people who are not like us, people without disabilities so that we can have a good life and enjoy the things in life that we want to enjoy and experience. Sometimes I feel like they don't think we have the willpower to achieve what we want to in life so we fail before we even start.

The opinion of others that perceives disabled people as non-achievers affects the way that they judge themselves and their ability to overcome

obstacles to success. The negativity and low expectations around them can bring on feelings of social inadequacy and inferiority

The welfare process is entangled with peculiarities for example those individuals who do not self-identify as disabled but are in receipt of the grant. Mr Narine, who is HIV positive was adamant that individuals with HIV are not disabled: 'people with HIV live good lives, and we do not suffer, we are not disabled'. This is a clear indication that individual's lived experience is not what defines them as being disabled, but instead it is the state medicalised welfare benefit framework. The HIV positive participants are subject to assessment by a government medical officer and once their HIV status is confirmed it is determined their physical and/or psycho-emotional embodiment renders them 'permanently disabled' even if that positive HIV status does not affect their day to day activities. To be successfully awarded the disability grant applicants have to convincingly show that they experience permanent bodily inadequacies which render them disabled and for people like Angel, Milly and Patrick they become actors assuming an imposed role. In accordance with the application guidelines, they would need to act out an 'enacted fantasised versions of impairments' (Shildrick 2009, Tremain 2006) to portray inadequacy, incompetence and helplessness. Their existential experiences of impairment will therefore be disguised and instead the persona of a disabled person who complies with the state's definition of disability is taken on, but that begs the question, what would an acceptable 'permanently disabled' performance look like?

The state's definition of 'permanently disabled' suggests perpetually belonging to a fixed homogenous group identity, however, the data in this study shows that not only is disability very complex but that it is not a fixed absolute. It

is a fluid state of being. This is evidenced by Patrick, Milly and the others are able to dip in and out of the disability identity, by assuming the role only when required by the state to convincingly 'prove' that they are 'permanently disabled'. That is not to say that they do not experience disabling societal barriers and oppressions but rather that they distance themselves from disability as their absolute identity and choose not to correlate it to their embodied reality.

The irregularities highlighted present a strong case for the reconfiguration of the welfare grant processes to one that takes account of disability as it is actually experienced by those with impairments.

Measuring disability

The current system of 'objective criteria' is open to exploitation, especially in determining levels of incapacity, so understanding the mechanism used to measure the 'percentage of disability' as required on the state's application form was relevant to this research process. I also explored the avenues taken by the state to ensure that the distribution of its limited resources is done in a fair and systematic manner.

Professor Augustine's discussion explained the impact that limited financial and human resources has in honouring requests for special adaptive aids and how that disproportionately affects the support provided to students with hidden disabilities.

Ms Jack was unsuccessful in getting the welfare grant for her daughter who is a quadriplegic:

the officer told me that I don't look like I need help for my daughter, and because I have been coping in the past I can continue doing what I been doing to survive ... I went to them for help because I needed help, but they turn me away even though all the medical reports say that my daughter is disabled. They turn me away because the way I dress they say the family have money, that's why.

The inexactness of the welfare process creates a web that many disabled people find difficult to manoeuvre and untangle, not only in relation to determining entitlements (who qualifies for specific services; what they get; when they get it; and how they get it), but also in the way that state employees' conceptualise disabled individuals. The data revealed interfaces between disabled and those working in the sector in which the employees by virtue of their occupation appear to have empathy and concern but instead hold negative prejudicial views of their disabled customers. A participant shared the story of a visually impaired woman who had accidentally dropped her purse while in the queue waiting to submit a claim for the disability grant. However because she was able to pick up the purse her application was declined as the worker had wrongfully assumed that the applicant was insufficiently impaired when in fact she was able to retrieve her purse from the sound it made when it fell. The worker's lack of understanding of the complexities of disability has disenfranchised that applicant causing her unnecessary hardship.

Research participants felt strongly that there is a need to 'educate the government themselves' and 'social workers need more training', especially because the professionals have the power to decide who gets what services, how and where they are delivered and by whom. Disabled claimants are vulnerable, and as Oliver (1996) points out, that vulnerability is not only related to their impairment limitations, but also to the social, cultural,

environmental and political structures in which the disabled person exists. The local cultural norms and values impact upon the attitudes and notions of disability in much the same way as the bio-medical pathologies of impairment/bodily imperfections/chronic illnesses.

The call for awareness raising is specially needed at this time as there has been a mushrooming of pseudo-professionals and the expansion of 'disability business' which has fuelled economic and financial growth in the health and social care industry, and also for others working outside of that remit, e.g. human rights experts and activists. Sheldon points out that 'disability in the majority world is big business' (Sheldon 2005:115), and T&T has seen the growth of an industry of medical professionals who are benefitting from the bodily differences of the subjects they assess, for example speech therapy, occupational therapy, and clinical psychology who use their specific skill sets and knowledge to identify bodily imperfections, organise interventions on disabled people, with the aim of restoring them to normality (Oliver 1996). The escalating of private health care facilities offering diagnostic and therapeutic services has been observed over the period of this study, with 6 new private clinics opening on one street.

7.7 CONCLUSION

This chapter highlighted the definitions and interpretations of disability underpinning social policies and legislation, and their impact on the lives of local disabled people. It found that although the National Policy purports to be based on the ICF, it is situated in the medicalised model of disability and the politics of normalisation. The health and social care frameworks and press releases also draw on the charity model with the focus on pity, victimhood and welfare. Local academics, in keeping with globalised

developments, are using social model theory in their teaching, which in some respects is being taken up by the disability movement who are basing their fight on a rights-based model. These all create a disjuncture between the various models operating at the individual/state/academia level especially when one considers the persistent intertwining of religion, spirituality, and superstition in the lived experiences of disability and the fact that many disabled people contextualise their bodily experiences in line with biblical/spiritual teachings.

Examination of the Equal Opportunity Act and the Mental Health Act which are the only legislative structures in place to support disabled people found that they are designed in such a way that denies human agency and autonomy, and in addition the language used has patronising overtones, and encourages stigmatising labelling. The lack of adequate legislation and the delay in ratifying the CRPD is interpreted as reluctance on the part of the state to acknowledge the rights of the disabled population. But a core group of advocates is emerging who have reclaimed their identity, are using their collective voices to fight for additional powers to be devolved to civil society, NGOs and community groups, with the intension of empowering them to effect positive change within their marginalised community. That political movement is growing and where once individuals were more accepting and grateful for whatever state assistance they received, there is now a collective voice coming together with the aim of bringing about positive social change.

State documents were found to be contradictory and confusing, lacking co-ordinated strategising and mainstreaming amongst the key players. Ineffective consultation also means that policies and strategies are not reflective of the informed perspective of those who are in the know, based on their life

experiences. A salient point omitted in the state processes is that disability is not homogenous in its identity, and that there is no such thing as a single disability identity. Disability is multi-dimensional with multiple identities within the domain (Skelton & Valentine 2003).

8.0   CONCLUSION

Introduction

The original aim of this study has been to expand upon existing knowledge on the constructs of disability in T&T by critically examining current disability theorisations and the extent to which they provide an understanding and interpretation of the lived realities of disabled people in T&T. In this concluding chapter I revisit the research findings and present a synthesis of the most salient discussions relevant to the conceptualisation of disability and its experiences in T&T. With the original research questions in mind I present responses to them by way of a summary of the findings, facts and main themes that have emerged during the research process, together with a general conclusion to the thesis with recommendations.

It is clear that there is a need for culturally specific theorisation which recognises the realities of disability in the environment in which it is being experienced. In that regard I hope that this thesis will provide for a better understanding of disability experiences in T&T and I also believe that there is considerable scope for it to be used as a baseline for further critical reflection amongst researchers, practitioners and advocates.

8.1   Implications and limitations

The information in this thesis will add to existing knowledge by the accounts of local perceptions of embodiment, historical legacies, and state ideologies and how they relate to existing disability theorisations within academic scholarship. I explain the ways that the indigenous disabled population constructs their meanings given the cultural conflicts. I also present an

exploration and analysis of state policies and systems, that can be a source of reflection for policy makers in terms of the effects of power imbalances and subject positioning constructed through its processes and practices. For disabled people, lobbying groups, and those in the disability movement the discussions presented can be used to highlight potential areas of conflict in identity politics and how they may be resolved to achieve their ultimate goal of enhancing the quality of life of disabled people.

Sheldon (2005) made a strong point that 'indigenous beliefs and attitudes, when described and interpreted by Western/Western trained researchers often illuminate more about Western prejudices and belief systems than they do about the societies of which they claim to be gaining an understanding' (Sheldon 2005 in Barnes & Mercer 2005). With that in mind I have attempted as much as possible to present the data using the language and expressions as they were relayed to me. I am however aware that in some instances the true nature of the conversations and nuances may be lost in translation, as it is not only the words that may differ but also the meanings. I am however mindful of my own limitations given the cultural context in which the situations were being experienced by the participants, and the time and space of the occurrence of events. In relaying the stories there may have been a multitude of realities, the interpretations for which will be dependent upon the individuals' positioning at any given time. However despite these limitations, the discourse analysis and the interpretations of the data have provided answers to the research questions posed. In the following sections, I return to those original research questions to consider how they are reflected in my findings.

8.2   Determinants of Disability as an Identity in T&T

Claiming disability as a positive identity in T&T is fraught with difficulties especially in a population where historically the social structures have been centred around dominance and oppression. This is then further compounded by the notion of disability as being defined by incapacity, helplessness and incompetence. Perceptions of embodiment and unusual physical manifestations, historical and cultural antecedents, and state ideology all impact on individuals' choices to resist or claim disability identity.

T&T is a country with deep seated prejudice so labels which denote devalued characteristics matter to people's social agency. Profoundly negative comments based on differences in biological determinism as exampled in the discussions on the beauty pageant significantly influence claims to a disabled identity. However, negotiating a disabled identity is not just about impairment characteristics, it is also dependent on time, space and circumstances, for example the state processes that impose a disabled identity upon HIV positive individuals in order to manage its welfare systems and requiring them from time to time to assume a victim role of undue hardship. Additionally, having gerontological impairments does not fit into a disabled identity because ageing is considered to be a natural inevitable life event.

The research found that claims to a politicised group identity and the fight for recognition of rights are hampered by socio-cultural marginalisation and poverty. Struggles with getting by from day to day mean that political involvement is a low priority even though the lack of political will and empowerment perpetuates disabling experiences. In the political movement there is an uncritical appropriation of Western disability discourse which

disregards historical processes of privileging the West and affects power relations, for example issues of class, social status and ethnicity in relation to the Syrian/Lebanese community. All of those important determinants outlined above are neglected in state processes.

8.3   Theoretical models, definitions and narratives of Disability

As the chapters developed it became apparent that there are many theoretical models of disability operating simultaneously. In the policy arena, the individual medicalised model prevails, while in relation to social care, the tragedy/charity model is more prominent. The social model has purchase in academic circles, while the rights-based model is drawn on in activism. In the sense-making processes of disabled individuals, the individual religious/moral framework remains very powerful.

Where impairment and medicalisation approaches were the most significant components, disability was viewed as a problem located within the individual irrespective of other socio-cultural interactions.   Where the rights-based model was deployed, there was a slight shift from concepts of dependence to independence with disability situated in the realms of socio-political discourse and focused on entitlement to equality of opportunity, justice, and human/civil rights. Further analysis of these two approaches reveals how religious/moral, tragedy/charity, medical and social models of thought are referenced, utilised and incorporated into all aspects of disability identity and its experiences.

Religion is the key determinant in the benchmarking of social norms and values and it 'provides people with a model of reality – a worldview, and a model for reality – an ethos that guides people in their social life' (Geertz

1973 in Forde et al 2009). It is core to the culture providing meaning to life and enabling a population who are coming to terms with the effects of colonialisation to reclaim their cultural capital through the practice of their traditional African/Indian/Indigenous religions. Scriptures and religious texts and spiritual/magico-religious concepts are systematically used in conjunction with medicalised orthodoxy to legitimise responses to impairments and attitudes towards disabled people.

Media portrayal of disabled people were as victims requiring pity or as disabled heroes to be celebrated if considered to have overcome perceived bodily adversity through determination. The Minister of the People and Social Development described a triple amputee as 'an icon of strength, conviction, determination and a symbol that impossible is nothing' (*Trinidad Express* 18 July 1013) thus creating a false impression that regardless of social, economic, physical resources or family structures it is possible for disabled people to overcome their difficulties through sheer will and determination. It also reinforces the idea that disabled people are incompetent, with success at carrying out otherwise ordinary tasks being equated to overcoming an undesirable burden.

The use of emotive advertising which depicts disabled people as requiring charity and handouts allows the privileged to demonstrate their empathy while maintaining their positions of power, but there is some degree of attachment by disabled people to the notion of the tragedy model as it offers them outpourings of alms, sympathy, and encouragement.

State documentation and systems are based on medicalised orthodoxy emphasising diagnosis, assessment, labelling and treatment with a view to

normalisation, prevention and rehabilitation. Policies, action plans, welfare application processes, ministerial utterances and legislation see impairments as unwanted defects on a body which is broken, damaged or inferior thus locating disability as an individual problem to be avoided at all costs, and that the individual should aspire to be cured and healed to conform to the perceived embodied norm. This has led to a proliferation of professionals from medicine and allied disciplines.

The state has however given a commitment to work towards international treaties and guidelines which are based on the rights-based model that separates corporeal deficit from the notions of disability. This is not yet evident because its processes continue to be based on the medical functional deficit model. The University of the West Indies does however speak to the rights-based social model in its Disabilities Studies syllabus and challenges some of the barriers to inclusion and discriminatory cultural practices.

According to the National Policy, the state adheres to the ICF classification but because it is so broad the state uses only its definitional aspect which is too vague because it does not account for the complexities of impairments, for example psycho-emotional/psycho-social wellbeing. When conducting the interviews the participants described themselves in relation to their wellbeing i.e. the severity of their impairments, their experiences of pain (physical and emotional), their functional deficit, level of dependence with hardly any mention of their diagnostic terminological classification.

The research found many interpretational anomalies in the state processes which affect data collection and the efficiency of policy and service delivery.

For example, the Survey of Living Conditions distinguishes between chronic ill health and disability even though qualification for disability welfare is measured by the effects of chronic ill health. The Population and Housing Census refers to disabled people as 'suffering' from a number of functional deficiencies thus disregarding the cultural, political, economic, social and spiritual aspirations that make up the lived experiences of disability. This deficit language is also evident in legislation and the Mental Health Act uses the language of deviance for example 'sub-normal', thus imposing a forceful objectification that psycho-social impairments fall outside the bounds of normality – a view which is held by wider society and strengthened by religious/spiritual modes of thought. Other terminology such as persons with disabilities; persons who are physically challenged; special needs were also evident in state documentation.

Terms such as 'handicapped' continue to be used widely by the population and even though Western discourse has moved on from such terminology it did not present the same sense of discomfort amongst the participants. It was noted that some of the younger people referred to 'special needs' a term that positions the individual into an 'out of the ordinary' classification.

Much of the legitimised cultural vernacular of terms, concepts and symbolisms and myths used creates unintentional discrimination, stigmatisation and oppression. For example crude names such as 'broko' and 'cokey eye' which make distinctions of and emphasise visible embodied differences, perpetuate the devaluing of the physicality of impaired bodies. It is clear that many of the definitions and labels that are used to identify people based on their embodied differences are a result of insensitive learned behavior.

8.4   The Lived Experiences of Disabled People in T&T

Religion/spirituality, superstitions, supernatural acts, and mysticism e.g. Obeah and Jharay bought from Africa and India are powerful processes in negotiating lived experiences and are retained because historically they are what held them together as displaced people. However the very thing that they hold on to is also what prejudices them. Within those cultural traditions disability is interpreted as virtuousness, retribution for sin, or evil spirit manifestations and these traditions are relied upon to diagnose, cure, heal, protect, punish, demystify, and contextualise disablement, even when there are conflicts in logic and interpretation.

Environmental factors also play a part in contextualising experiences, for example convulsions and slurred speech can be categorised as virtuous suffering if they occur within a spiritual setting and deemed to be 'catching the power of the holy spirit', a health crisis if they occur in a medical environment, or demon possession if happening at home. In that case fear and ignorance then leads to social segregation, care deficit and diminished productive potential.

In negotiating their independence disabled people are faced with physical and institutional barriers for example inaccessible buildings, poorly trained police officers; poverty. Weak welfare infrastructure such as the subjective application procedure, and flawed social processes undermine their quality of life. Not only are they faced with restricted employment opportunities and diminished personhood including the denial of sexual agency but they are also subject to inappropriate sympathy, unwanted interference, interjections of pity and condescension, imposition of power and in some instances are

expected to act out a fantasied version of disability by heightening their vulnerability, functional deficit and helplessness.

As individual lives are guided by their self-directing skills, including sense of self efficacy, self-world relationships, active planfulness, and supports and threats, and are influenced by social and cultural factors and personal experiences (Tyler 2002), cultural experiences and meanings should not be disaggregated from disability experiences. The research showed their power in determining who is considered disabled, who is not, and the social responses to those identified as disabled.

8.5 Social Relations that Impact on the Lives of Disabled People in T&T

Individuals

Disability experiences are about how individuals feel and live their lives hence it is not only the external factors that disadvantage them but more intimate sets of circumstances such as family, reproduction, and sexuality, but those are often overlooked. Another factor which is often sidelined is the personal and psychological tensions and stresses which are experienced by the extended family and carers. They too face discrimination and increased isolation and the personal sacrifices they make in caring for their disabled family members sometimes requires them to make significant alternations in their way of life.

Theocratic and spiritual spaces are revealed as important features in determining interactions. They identify those impairments to be feared and avoided and legitimises attitudes and behaviours such as the stoical acceptance of ones circumstances. They also provide treatments and protection by way of ritualised interventions and offer social assistance

through community gatherings and the material support of alms and charity. Folk legends also play a role in disability experiences with disabled characters e.g. *Douens* and *La Diablesses* used as deterrents for social wrongs by inducing feelings of fear through the projection that disablement, fragility and death are real possibilities.

The movement

The lack of cohesion in the movement, the social hierarchy, the propensity for competitiveness, personal benefit and capital all impact on its viability and sustainability. There are instances where professional and academic dominance takes precedence over expert knowledge based in experience, thus widening the power divide. The movement is however working towards a rights-based approach but lacks focus on one of the main tenets of that approach which is personal autonomy and the freedom to independently define and experience oneself within existing political institutions and social structures.

The state

The researched showed that the state did not take account of individuality - what the population desire for themselves, their expectations and goals, and how they go about making meaning of their lived experiences. A number of issues that directly impact on disability experiences were noticed in state systems e.g. apathy, political corruption, reliance on Western knowledge and discourse, economic constraints, inadequate legal processes, bureaucracy, and a lack of equality of opportunity. But these can be addressed through political reform, social transformation and sustained communication between the state, the disabled population, the movement and academia if the

ultimate goal is for disability to be accepted as an ordinary characteristic of human existence.

There is disconnect and contradiction in the relationship between the state, the movement and the disabled population. The state is focused on using Western discourse in its management and control of the population, while the movement concentrates on what it means to claim a public identity and the power struggles within, and the disabled population who are less politicised and less empowered get by on a day to day basis through the community strengths of religion/spirituality and kinships.

8.6   Challenges and the Way Forward

This study has highlighted the ways in which cultural impositions and social structures shape individual understandings (Thompson 1998) and how they account for the vast differences in disability studies in non-Western societies (Talle 1990). It also shows how local indigenous knowledge embedded in language, folklore and cultural experiences has been ignored in professional discourse and in the development and implementation of state strategies. However for there to be effective and efficient disability policy and practices there needs to be an acknowledgement of the local culture, social and psychological structures. Such an approach would need to be grounded in the cultural traditional responses for example the strong religious/spiritual and bio-medical constructs that give rise to medico-religious interventions. For it is the non-medical healers – priests, spiritual leaders, evangelists, and Obeah practitioners that people with impairments turn to for advice, guidance, to make meaning of their experiences, and for social and material assistance. The challenge however is how to embrace the work of the non-

medical healers but defy the underlying prejudices evident in some of their practices.

Coming out of the study is the way in which secrecy and silence perpetuates sexual vulnerability. The deafening silence on sexuality of disabled people is accompanied by a huge gap in policy, service interventions and implementation. However, 'if we accept that sexual expression is a natural and important part of human life, then perceptions that deny sexuality for disabled people deny a basic human right of expression' (Donta 2010:29). Therefore, one of the first steps in addressing the rights to sexual citizenship of disabled people would be an understanding of the needs, concerns, desires and the issues they come up against in manageing their sexual and reproductive health. These are urgently needed and will go some way in safeguarding disabled people against the prevalence of sexual abuse and sexual violence, and will alleviate some of the concerns that deny them their sexual agency and reproductive competence.

The use of inappropriate language, terminology and definitions in day to day interactions, in policy, legislation and systems can be addressed through public awareness programmes done in collaboration with disabled people – not just those belonging to organisations of and for disabled people, but those grassroots individuals who do not usually get their voices heard even though they are often the ones who endure disproportionate prejudice. The study highlighted how notions of helplessness and dependency are key to the feelings of inadequacy experienced by disabled people so challenging the technocratic hierarchical approach taken by some of the workers in the various state departments and service sector, and their general attitudes and

behavior towards disabled people is critical to the process of social change, inclusion and empowerment.

Disabled people are neglected in the constitution of T&T as there is no legislation with the exception of the Mental Health Act (MHA) to protect them as a specific minority group. However the manner in which their identities are treated in the language of the MHA diminishes their personhood, right to autonomy and full citizenship. In addition, though the National Policy offers some degree of redress, in a country where there is an underlying culture of deep seated prejudice the policy will be more effective if it is reinforced by legislation. The legislation will then compel those mandated with disability agendas to implement processes that effectively attend to the welfare of disabled people, for example health and social care services, access to education, infrastructural barriers and equality of opportunity. That is not to say that there will not be those who will violate the legislation but at least then those violations will be illegal.

Despite the statements that the National Policy was developed with input from disabled people, evidence suggests that it was done without proper inclusive, transparent, robust consultation that has their voices at the core. The research shows that disabled people are not a homogeneous group but a heterogeneous entity with a range of differing needs, wants, hopes, aspirations so the idea of a one size fits all approach will invariably be flawed. What disabled people ask for is the opportunity to have a 'real and meaningful' say in the shaping of their future, and for greater participatory approaches to development and implementation that reflect their lived realities.

The universal applicability of the principal tenets of the international frameworks have been questioned by disability theorists, but in T&T the dominant cultural ethos is that Western knowledge is best which is a direct consequence of the processes of colonialisation – slavery, indentureship and missionaries. The Western development discourse marginalises the local disability community and perpetuates the illusion that it is possible to have a seamless transfer of the Western treaties and conventions. That is not to say that development, modernisation or globalisation are necessarily an unwelcome imposition because there is definitely a space for them but they need to be understood and contextualised alongside the cultural and conceptual histories of the country. It should be possible to draw on the best principles of the global disability agenda while also taking account of the existing socio-cultural, political and economic conditions, and of local/traditional ways of thinking and customs.

8.7   Key Policy and Practice Recommendations

In this section I take the liberty to present a number of specific recommendations arising from the data:

- Wider inclusion and participation in legislation, policy and service design and development. This can be achieved through active and meaningful consultation exercises that are committed to capturing not only the voices of those within the movement, but also those who are not usually included in such processes. For those with intellectual disabilities e.g. those with intellectual or psycho-social disabilities information should be available in alternative formats such as easy read. For faith/religious practitioners consultation exercises should be held within their places of worship. For individuals living in remote

areas of both islands outreach activities should be provided in local shops and community centres.

- Increased use of research and data emanating from the Global South to inform decision making processes

- Revisiting of the National Policy and Action Plans to bring them in line with local contestations of disability e.g. recognising the significance of medico-religion interventions

- Inbuilt accountability processes within state systems that enable monitoring, complaints and feedback to be presented without fear of recrimination, and the data captured to be used to improve services

- To establish culturally appropriate criteria or definition of disability as the current ICF definition is interpreted too broadly by the state but is too narrow for the population

- Public campaigns to increase the awareness and understanding of disability and mental health that are interactive and inclusive, with specific compulsory training for employees in the state sector

- Multi-partnership safeguarding programmes with key stakeholders e.g. protective services, health care providers, educators, researchers, civil society organisations, etc. to address the high incidence of sexual violations and abuse of disabled people

- Targetted sexual and reproduction health outreach programmes including those specifically designed for individuals with intellectual disabilities

- Adopting a rights-based approach to new initiatives that promotes respect and protects the inherent dignity of disabled people

- Capacity building and capacity development initiatives for civil society organisations that work for and with disabled people

The findings and recommendations I have presented in this study are by no means the end of the road regarding the ways in which disability is contextualised in T&T and I hope that they will raise interest amongst theorists, practitioners and activists and enlighten and inform further work. Essentially, the information contained in this thesis which has been derived from my analysis of the voices of disabled people in T&T has made a significant contribution to existing knowledge because it presents a picture of their actual lived realities.

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APPENDIX 1

GUIDE FOR DISABLED INDIVIDUALS:

Greetings and explanation of the research project including confidentiality issues and consent forms.

Introduction to interview: *I am interested in knowing about your experience as a disabled person but first I'd like to get a better understanding of what disability means to you.*

- Can you tell me what words immediately come to your mind when I say "disability".

- Can you tell me a bit more about these words and why you choose them?

- Would you consider some with a mental health problem to be disabled?

- If someone was to describe you (in regards to your disability) what do you think they will say?

- Have you ever experienced discrimination/prejudice due to your disability?

- Who helps to take care of you?

- Have you ever used any folk medicines, alternative therapies, special prayers, offerings, sacrifices to treat your condition.

- Have you ever visited a spiritual healer or church leader about your disability?

- Do you know about the T & T National Policy for Disabled People?

- What is your experience of services for disabled people in T & T.

- Open   for   discussion................

GENERAL PUBLIC

Greeting and brief explanation of research project including confidentiality issues:

Introduction to interview: *I am interested in getting a better understanding of what disability means to you.*

- When you think of a disabled person what is the first image that comes to your mind?

- Why do you think that image came to you?

I'm going to set a scene for you. Imagine that you became disabled:

- Can you tell me what words immediately come to your mind.

- Can you tell me a bit more about these words and why you choose them?

- Who or where would you go for help/healing?

- Would you visit a spiritual healer/church leader?

- Would you use folk medicines/alternative therapies/special prayers/offerings/sacrifices?

- Would you consider some with a mental health problem to be disabled?

- How have you heard people describe disabled people

- Do you know about the T & T National Policy for disabled people?

- What is your opinion of the services provided for disabled people in T & T?

- Open for discussion....................

GOVERNMENT/POLICY MAKERS

Greeting:

Brief explanation of research project :

Introduction to interview: *I am interested in getting a better understanding of what disability means to your organisation and the impact your organisation has on disabled individuals.*

- When you think of disabled people what immediately comes to your mind?

- Why do you think that image came to you?

- Would you categorise mental health as a disability?

- How has your organisation contributed to positive change on the perceptions of disabilities?

- How has your organisation contributed to positive change on the experiences of disabled people?

- What are your perceptions of service provision for disabled people?

- Do you think the National Policy is adequate to ensure equality of opportunity for disabled people?

- Open for discussion ....

SPIRITUALISTS/ RELIGIOUS LEADERS ETC

Greeting:

Brief explanation of research project :

Introduction to interview: *I am interested in getting a better understanding of what disability means to you, and the services you offer disabled people.*

- When you think of a disabled person what is the first image that comes to your mind?

- Why do you think that image came to you?

- Do you think of someone with mental health problems as being disabled?

- Can you tell me some stories of the experiences of disabled people who have come to your for healing or advice?

- Open for discussion ....

NGO'S / ACTIVISTS

Greeting:

Brief explanation of research project :

Introduction to interview: *I am interested in getting a better understanding of what disability means to your organisation.*

- When you think of a disabled person what is the first image that comes to your mind?

- Why do you think that image came to you?

- Do you think of someone with a mental health problem as being disabled?

- What is your organisations' role within the disability agenda?

- Can you tell me your views on services provided for disabled people

- What needs to be changed for it to be better?

- What areas of government policy creates the most challenges or needs further work?

- Has disability stigma changed since the implementation of the National Policy.

- Can you tell me some recent successes for your organisation.

- Open for discussion ....

CARERS/ FAMILY MEMBERS

Greeting:

Brief explanation of research project :

Introduction to interview: *I am interested in knowing about your experience in caring for a disabled person but first I'd like to get a better understanding of what disability means to you.*

- Can you tell me what words immediately come to your mind when I say "disability"

- Can you tell me a bit more about these words and why you choose them?

- Would you consider some with a mental health problem to be disabled?

- How will others describe the person's disability?

- Have you ever suggested that they use folk medicines, alternative therapies, special prayers, offerings, sacrifices or visited a spiritual healer or church leader about their disability?

- Do you know about the T & T National Policy for Disabled People?

- What do you think of service provision for disabled people in T & T.

- Open for discussion ....

Collect demographic data sheets at the end.

APPENDIX B

FOCUS GROUP GUIDE

Greetings and explanation of the research project including confidentiality issues and consent forms

The same questions are being asked at each focus group:

- Can you tell me what words immediately come to your mind when I say "disability"

- Can you tell me a bit more about these words and why you choose them?

- Would you consider someone with a mental health problem to be disabled? Why?

- What traditional customs or beliefs (including special prayers) do you know of that are used by disabled individuals….

  if these are mentioned then prompt for further information …. Witchcraft; bad blood; God's will, evil spirits; genetics;

- What do you think about people having nicknames based on their disability

- How you think being male or female, whether you are rich or poor, or whether you have an education or not, and where you live makes a difference to the quality of life of a disabled person

- If there is one thing you would like to see in a Trinidad and Tobago Disability Policy, what would it be?

APPENDIX C

RESEARCH BACKGROUND AND CONSENT FORM

LONDON metropolitan university

Title: An investigation into the social and cultural factors that impact upon understanding of disabilities in Trinidad and Tobago

Background: I am a PhD student at London Metropolitan University with an interest in disability equality having worked in the field for a number of years. This research is an expansion of previous MA research investigating the reasons why physically disabled people were not clearly visible in the workplace in Trinidad and Tobago.

Aims: The research seeks to identify and evaluate how the lives of disabled people in Trinidad and Tobago are shaped by their individual social and cultural circumstances.

It will investigate the intersections between disability with ethnicity, social status, gender, sexuality, religion, and age in the shaping of experiences, and the specificities of culture and location as they impact on the lives of local disabled people.

Participant Interactions: Individuals representative of the diverse composition of the population, are being invited to take part in semi-structured interviews. These may be recorded and will last approximately forty five minutes. Direct observations are also being undertaken within specific settings.

Ethics Approval: This study conforms to the British Sociological Association Ethical Guidelines and is approved by the London Metropolitan University Ethics Committee.

Confidentiality and Security:
- All interviews will require the consent of the interviewee
- All interviews will be anonymised and personal details will be removed if appropriate
- The interviewee will have the right to refuse an interview or reject a previously consented interview at any time up to publication
- All interviews will be kept strictly confidential unless permission has been given by the interviewee
- Any information that I am privy to will be treated confidentially and sensitively
- The transcripts will be analysed and the data used in writing up the final research thesis. These will then be securely stored at the London Metropolitan University where it will only be accessed by myself or my supervisors.

There is a possibility that the findings from the research may be published either in the form of an article, journal or book, and for this purpose I would like to retain the research material for a period of five years, subject to participants' approval. However in publishing the findings I will ensure the anonymity of the participants except in instances where the participants have given prior permission to be identified as being a part of the research process. The findings will then be in the public domain.

If you have questions or concerns about this research or the process, please contact: Yansie Rolston or Supervisors: Dr Irene Gedalof at i.gedalof@londonmet.ac.uk or Dr Clem Seecharan at c.seecharan@londonmet.ac.uk or Professor Brinsley Samaroo at samar@tstt.net.tt or 365-8475

RESEARCH CONSENT AND RELEASE FORM

**LONDON
metropolitan
university**

Title : An investigation into the social and cultural factors that impact upon the lives of disabled people in Trinidad and Tobago

Reference Number:........................

Please tick to confirm

I confirm that I have read and understand the information sheet attached for the above research project.   •

I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.   •

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.   •

I agree to the use of recording equipment in this interview   •

I understand that after recordings/observations are made they will be transcribed and all personal details will be changed to ensure anonymity   •

I agree that any words spoken by me can be quoted and attributed to me   •

I agree to take part in the above research study.   •

I understand that by signing this form the interviewer agrees to keep the contents of the interview confidential   •

I understand that if I have any concerns about the nature of the study or conduct of the researcher, I can contact any of the supervisors   •

_____   _____   _____
Participant   Date   Signature

_____   _____   _____
Researcher or Name of Person   Date   Signature
taking consent

APPENDIX D

QUESTIONNAIRE

Understanding disability equality: an investigation into the social and cultural factors that impact upon the lives of disabled people in Trinidad and Tobago

I would be grateful if you would take a little time to complete and return this questionnaire.
This is a **CONFIDENTIAL** study and your name is not required and will not appear anywhere in the study and it will not be possible for you to be identified.

Please take your time and answer the questions as honestly as you can and remember that there are no right or wrong answers.

ABOUT DISABILITY
Please say if you agree or disagree that the following are considered a disability
Please use the following codes and put a tick in the corresponding box

SD = strongly disagree
D = disagree
N = neither agree nor disagree
A = agree
SA = strongly agree

Statement	SD	D	N	A	SA
Cancer					
Diabetes					
Chronic heart disease					
asthma					
HIV/AIDS					
Difficulty using arms or loss of arm/s					
Mobility issues which means using wheelchair or crutches					
Blindness					
Deafness					
Epilepsy					
Clinical depression					
senility					
schizophrenia					
Madness					
Downs syndrome					
Dyslexia					
Autism					

Please say if you agree or disagree with these statements, by using the following codes and putting a tick in the corresponding box

SD = strongly disagree
D = disagree
N = neither agree nor disagree
A = agree
SA = strongly agree

Statement	SD	D	N	A	SA
1-5% of the population of Trinidad and Tobago has a disability					
6-10% of the population of Trinidad and Tobago has a disability					
11-15% of the population of Trinidad and Tobago has a disability					
Over 20% of the population of Trinidad and Tobago has a disability					

Statement	SD	D	N	A	SA
I am disabled					
A member of my family is disabled					
A friend is disabled					
A neighbour is disabled					
A co-worker is disabled					
A customer/client is disabled					
A fellow student is disabled					
I do not know anyone who is disabled					

EXPERIENCES AND ATTITUDES

Please say if you agree or disagree with these statements, by using the following codes and putting a tick in the corresponding box

SD = strongly disagree
D = disagree
N = neither agree nor disagree
A = agree
SA = strongly agree

Statement	SD	D	N	A	SA
Disabilities can be a repayment for sinful deeds					
Disabilities can be because someone put the person so (put an Obeah spell on the person)					
Disabilities can be a punishment from God					
When I see a disabled person they make me feel scornful					
I feel pity for disabled people					
I feel uncomfortable being around a disabled person					

	SD	D	N	A	SA
Disabled people are not as dedicated and hard working as other staff					
Mentally disabled people should be kept in a hospital or institute					
Disabled children should attend regular schools					
Disabled people should be more involved in society					
Disabled people should be treated just like everybody else					
It will be helpful if I had more general information on disabilities					

Can you name a T & T disabled artiste e.g a calypsonian, singer, musician, dancer, or artist

…………………………………………………………………………

Thinking of the person that you have named above, please say if you agree or disagree with these statements by using the following codes and putting a tick in the corresponding box

SD = strongly disagree
D = disagree
N = neither agree nor disagree
A = agree
SA = strongly agree

Statement	SD	D	N	A	SA
He/She are a positive role model					
He/She should not be seen in public					
Their disability is punishment from God					
He/She is disabled because somebody put them so (put an Obeah spell on them)					
He/She has not let their disability stop them from achieving					
You do not think about their disability when you see them perform					
He/She uses their disability to get attention					

SUPPORT NEEDS
Thinking about disabled people who need help in looking after themselves, please say if you agree or disagree with these statements using the codes and putting a tick in the corresponding box

SD = strongly disagree

D = disagree

N = neither agree nor disagree

A = agree

SA = strongly agree

Statement	SD	D	N	A	SA
Disabled people should live on their own and provided with someone to look after them					
Disabled people should live with family or friends					
Disabled people should live in residential homes e.g. Lady Hochoy					
Disabled people should live in hospitals					

Do you think the health service should pay for and provide the following services for disabled people

Statement	SD	D	N	A	SA
Help with personal care					
Transport					
Help with housework					
Help in looking after their families i.e their children					
Help them to get a job					

Do you think NGO's/charities should pay for and provide the following services for disabled people

Statement	SD	D	N	A	SA
Help with personal care					
Transport					
Help with housework					
Help in looking after their families					
Help them to get a job					

Do you think the families of disabled people should pay for and provide the following services

Statement	SD	D	N	A	SA
Help with personal care					
Transport					
Help with housework					
Help in looking after their families					
Help them to get a job					

Do you think disabled people should pay and seek assistance for these services themselves

Statement	SD	D	N	A	SA

Help with personal care					
Transport					
Help with housework					
Help with getting a job					

THE ENVIRONMENT
Please say if you agree or disagree with these statements, by using the following codes and putting a tick in the corresponding box

SD = strongly disagree
D = disagree
N = neither agree nor disagree
A = agree
SA = strongly agree

Statement	SD	D	N	A	SA
Disabled people should be able to use public transport					
Disabled children should only attend special schools					
Disabled children should attend regular schools					
Disabled people should be able to get regular jobs					
Disabled people should be able to go to the cinema/ restaurant/ bars/ pubs					
Disabled people should be able to participate in sports/games					
Disabled people should be able to attend sporting events					
Disabled people should be able to participate in cultural shows					
Disabled people should be able to attend cultural shows					
Disabled people should be able to go shopping					

Please make any further comments that may be useful to this study

……………………………………………………………………………………………………
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ABOUT YOU

We need some background information in order to classify your responses to the previous questions. I remind you that all information that you provide is confidential and you will not be identified.

Are you: Male •   Female • **How old are you**: ....

Race: African •   Indian •   Chinese •   White •   Syrian •   Carib   Mixed or Other • explain ……………………………………………….…

Marital status: Single •   Married •   Divorced •   Separated   Widowed •   Common law •

Sexuality: Hetrosexual/Straight   •   Lesbian •   Gay •   Bisexual   •

Religion/Faith: Catholic •   Anglican •   Hindu •   Muslim •   Adventist •   Jewish •   Jehovah Witness •   Spiritual Baptist •   Rastafarian •   Other • (explain)………………………………………………

In what area of the country do you live (**eg Arima**) …………………

Have you attended school Yes •   No •

What is the highest level of schooling you have reached: Primary   • Secondary •   Vocational/Technical •   University •

Employment Working full time   • Working part time   • Unemployed due to disability • Unemployed other • Unpaid work • Retired • Student • Self employed   • Other (explain) . . . .

Employment category: Managerial • Clerical • Sales • Agricultural • I.T • Craft • Labourer • Hospitality • Voluntary • Professional • Finance • other(specify): . . . . •

This is the end of the questionnaire. I thank you for your cooperation and remind you that all responses will be treated confidentially. If the survey findings are published in any form, you will never be mentioned by name.