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**Towards Inclusion: Influences of  
Culture and Internationalisation on  
Personhood, Educational Access,  
Policy and Provision for Students  
with Autism in Ghana**

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Submitted for the Degree of Doctor of Philosophy  
University of Sussex

December 2009

I hereby declare that this thesis has not been and will not be, submitted in whole or in part, to another University for the award of any other degree.

Signature: \_\_\_\_\_

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## List of Acronyms

AACT	Autism Awareness Care and Training Centre
ADD	Attention Deficit Disorder
ADHD	Attention Deficit Hyperactivity Disorder
ASD	Autism Spectrum Disorder
EFA	Education for All
CBR	Community Based Rehabilitation
CRPD	Convention on the Rights of Persons with Disabilities
DPO	Disabled Persons Organisation
DSM-IV-TR	Diagnostic and Statistical Manual, Fourth Edition, Text Revision
DSW	Department of Social Welfare
EQUALL	Education Quality for All Project, USAID
ESP	Education Strategic Plan
FCUBE	Free and Compulsory Universal Basic Education
GES	Ghana Education Service
GSS	Ghana Statistical Service
ICD-10	International Classification of Diseases, 10th Edition
ICF	International Classification of Functioning
IE	Inclusive Education
IEP	Individualised Education Plan
MDG	Millennium Development Goals
MH	‘Mental Handicap’/ ‘Mentally Handicapped’
MoESS	Ministry of Education, Sports and Science
MoESW	Ministry of Employment and Social Welfare
NCPD	National Council on Persons with Disabilities
PECS	Picture Exchange Communication Systems
PDD	Pervasive Developmental Disorders
PLA	Participatory Learning and Action
SEN	Special Educational Needs
SEO	Special Education Officer
SES	Socioeconomic Status
SpEd	Special Education Division (of the Ghana Education Service)
SSI	Semi-Structured Interview
TICCS	Tamale Institute for Cross-Cultural Studies
ToM	Theory of Mind
TT	Teacher Training
UN	United Nations
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNDP	United Nations Development Programme
UPIAS	Union of the Physically Impaired Against Segregation
UPE	Universal Primary Education
USAID	United States Agency for International Development
VI	Vision Impairment
WHO	World Health Organization

University of Sussex

Jane Anthony, Doctor of Philosophy

***Towards Inclusion: Influences of Culture and Internationalisation on Personhood,  
Educational Access, Policy and Provision for Students with Autism in Ghana***

## **Summary**

This research explores the ways in which local knowledge, attitudes and beliefs surrounding disability influence the socially constructed experience of autism in Ghana. It further explores the impact of these beliefs on educational access, policy and provision as well as on inclusion in wider society for both children with autism and their families. It is argued throughout that conceptualisations of both autism and disability are subtly, and at times unconsciously, shaped by cultural influences as well as individual experiences.

Using semi-structured interviews, participatory methods and text analysis, this thesis first examines internationally accepted diagnostic criteria for cultural relevancy and concludes that while ‘autism’ does indeed transcend cultural barriers, its presentation is nonetheless culturally bound. The presentation of each of autism’s ‘triad of impairments’ is explored in Ghana, namely communication and socialisation impairments alongside a restricted range of interests and repetitive behaviour patterns. Significantly, the experience of autism demonstrated in this thesis, at both a personal and familial level, is linked to, and negotiated through, cultural belief systems. A relatively shared ‘worldview’, understood as the culturally mediated lens through which autism and impairment are understood and managed in Ghanaian society, is outlined. Traditional values, a deep sense of spirituality and communal kinship responsibilities are highlighted. Next, an exploration of causal attributions, valued and de-valued personhood traits and the expected role of an adult in society each highlights significant influences on the perception and management of autism in Ghana. Throughout, this thesis focuses on the impact of autism, as constructed and understood in urban Ghana, on the individual, one’s kin and broader society.

The second half of this thesis focuses on educational access, policy and provision with particular attention to Ghana’s burgeoning inclusive education efforts. Conceptualisations of disability and difference, as negotiated through Ghanaian culture, norms and history are explored alongside the implications of these beliefs in designing educational provision for students with autism as well as the socio-political pressures to adhere to large scale international movements such as Education for All (EFA). In particular, tensions between local and international conceptualisations of ‘disability’ and ‘inclusion’ are highlighted and it is concluded that adoption of international declarations into local policy, and subsequently into local practice, needs to be better negotiated alongside culturally relevant systems and beliefs. International declarations, rooted in a social model of disability, are found to clash with local conceptualisations of disability rooted in an often intuitive understanding of disability consistent with an individual model. However, consistency with an individual model did not equate to biomedical understandings of disability, which was instead mediated through a lens of social-relational causation and management more consistent with religious or cultural models of disability. It is concluded that acknowledging and respecting Ghanaian understandings of disability is a prerequisite to ensuring inclusion of children with autism, both in education and their community. Adoption of laudable rights based international declarations must also ensure adaptation to local culture and context. Conclusions and recommendations for synergy between advocacy for, and education of, students with autism in Ghana are proffered.

# Chapter 1

## Context and Background

### Introduction

As I was walking home one day, in Ghana's capital city Accra, I heard a gentle voice from behind me say bluntly, "I am sorry for your soul". I was inclined to keep walking and ignore this man all together, but something about him compelled me to stop. His voice was full of sorrow and tenderness; it was not at all mean, threatening or preachy. He was an older man with gentle eyes, someone you might cast as a wise elderly grandfather in a movie. The conversation that followed went mostly like this:

**Man:** I am sorry for your soul.

**Jane:** Why is that?

**Man:** Someone as beautiful as you should be allowed into heaven on Judgment Day.

**Jane:** And why will I be rejected?

**Man:** Jane<sup>1</sup>, you know it, God can never accept someone who speaks to the devil through his children.

**Jane:** I feel that I can help these children, I can teach them.

**Man:** The devil has taken them; you cannot help.

**Jane:** I feel I have to try.

**Man:** It will cost you your soul.

I decided to move on then, even without an explanation of autism and the typical advocacy that often leaps from my mouth. Somehow, in that moment, there was no need. Nothing I could have said would have changed his mind. I didn't have the answer; he was not even asking a question. He was a kind man with no apparent agenda; he genuinely felt sorry for me and simply thought that I had lost my way. This man, and so many other Ghanaians I met, shaped my passion for educating children with autism into a clear path of disability and special education work in international development. It, and so many experiences like it, have contributed to my quest for an answer to give; they have impacted both the desire and design behind my career and the current research.

---

<sup>1</sup> The use of my name took me by surprise, as I had never met this man before. It is likely that he was aware of me and my work with children with autism from a recent media advocacy campaign which included television interviews.

## **1.1 Rationale and Research Questions**

Many researchers have pointed to the need to understand the relevant historical, social and cultural background to disability in any given country as a precursor to successful policy and programme development (Groce, 1999a, 2000; Ingstad, 1999; Ingstad & Whyte, 1995; Kidd, 1970; Koistinen, 2006; Lamorey, 2002; Miles, M., 1992; Miles, S., 2000a; Patel et al., 1995; Peters, 1993; Serpell, 1993a, 1999; Stone, D., 2000; Stone, E., 1999a, 1999c, 2001; Stubbs, 1994). Others have recognised that disability is primarily a social construct whereby the need arises for a conceptually valid appreciation of indigenous knowledge, beliefs and interpretations of disability rather than mere uncritical transplantation of ‘outsider’ conceptualisations (Albert & Harrison, 2006; Coleridge, 1993; Miles, M., 1999; Stone, 1999a; Stubbs, 1999).

Given the paucity of available information on perceptions of disability or autism in Ghana, the collection of background information seemed a necessary precursory step to the creation of culturally sensitive or sustainable programmes. Exploratory research, which sought to identify and highlight the underlying social and cultural reasons behind the exclusion of children with autism from primary education in Ghana, was the goal of this research. Table one details the research questions.

**Table 1: Research Questions**

<p>What are the cultural beliefs surrounding autism in Ghanaian Society?</p> <ul style="list-style-type: none"> <li>✓ How do these beliefs influence societal and familial relationships?</li> <li>✓ What factors (if any) in society reinforce and perpetuate negative stereotypes and perceptions?</li> <li>✓ How do religious and spiritual beliefs affect perceptions and treatment of children with autism?</li> </ul>
<p>What causal explanations are invoked to describe the occurrence of autism by different stakeholders?</p> <ul style="list-style-type: none"> <li>✓ Do the explanations invoked serve a purpose and if so what are they?</li> <li>✓ Have the explanations invoked to explain the autism of a specific child changed over time by those who know him/her? If so, what brought about change?</li> <li>✓ Do causal explanations differ significantly by stakeholder groups?</li> </ul>
<p>What characteristics /attributes of ‘personhood’ (individual identity) are most important in Ghanaian society?</p> <ul style="list-style-type: none"> <li>✓ What traits are valued in society? Which are seen detrimental or are the most ‘disabling’?</li> <li>✓ How are impairments of the mind and body understood and responded to?</li> <li>✓ How is an individual’s culturally defined identity as a person affected by a social disability in a relatively collective society?</li> </ul>
<p>What do different stakeholder groups want in the way of services?</p> <ul style="list-style-type: none"> <li>✓ Do stakeholders actually want inclusive education for children with autism or is this an imposed mandate? What, if any, alternatives are available, desired and feasible in Ghanaian society?</li> <li>✓ What factors influence education choices families make for their child with autism?</li> <li>✓ What do different stakeholders perceive to be the best way to educate children with autism in Ghana? Why?</li> </ul>

## **1.2 International Context**

### ***1.2.1 Disability Policy***

Dating back to the 1948 United Nation’s (UN) Universal Declaration of Human Rights, access to basic education has long been recognised as a fundamental human right for all children (UN, 1948). Despite this long history, the first comparable international call for equitable treatment of persons with disabilities was not expressly stated until 1975 in the UN ‘Declaration on the Rights of Disabled Persons’. The International Year of Disabled Persons in 1981, followed by the UN Decade for Disabled Persons (1983-

1992), marked the beginning of international recognition of individuals with disabilities as a marginalised group. The Universal Declaration on Human Rights was eventually expanded to include people with disabilities in 1985, over 35 years after its original declaration. Equal human rights for people with disabilities have been reaffirmed numerous times since, most recently at the Convention on the Rights of Persons with Disabilities (CRPD) (UN, 2006).

The international community has also shown an increasing dedication to a *rights* based case for universal education in recent years. The World Conference on ‘Education for All’ (EFA) in Jomtien (1990) focused on the right to basic education for all marginalised groups, including students with disabilities (UNESCO et al., 1990). Here, for the first time, the international community formally recognised disability in their commitment to EFA by acknowledging

The learning needs of the disabled demand special attention. Steps need to be taken to provide equal access to education to every category of disabled persons as an integral part of the education system (UNESCO et al., 1990, Article III).

This proclamation of dedication to the education of children with disabilities has been echoed by international governments and aid agencies. The UN ‘Standard Rules on the Equalization of Opportunities for Persons with Disabilities’ (UN, 1994), the Salamanca Statement (UNESCO, 1994), the Dakar Framework for Action (UNESCO, 2000), the Millennium Development Goals (MDG’s), the EFA Flagship on Education and Disability (2004) and the Convention on the Rights of Persons with Disabilities (2006) all express a commitment and responsibility to ensuring the right to equitable education for children with disabilities. Importantly, Article 24 of the CRPD mandates the right to *inclusive* education in international law. The 2009 Salamanca Conference Resolution entitled ‘Initiative 24’ reaffirms commitments to the Salamanca Statement (1994) and attempts to better define inclusive education (Inclusion International, 2009b).

Striving towards a goal of EFA dictates a commitment to increase participation and improve equity across *all* underserved populations historically denied access to quality education, including students with disabilities (Inclusion International, 2009a; McLaughlin & Ruedel, 2005; Rieser, 2008). Unfortunately, while the EFA movement has lead to many forms of identity-based exclusion (gender, poverty, religion, ethnicity,

etc.) receiving large amounts of attention and funding, policy makers and researchers alike continue to consistently overlook the needs of children with disabilities (Coleridge, 1993; McLaughlin & Ruedel, 2005). Often ignored in international discussions of EFA, children with disabilities represent a vastly underserved and excluded group of students whose education must be given increasing priority if EFA and MDG goals are to be realised by the year 2015 (Coleridge, 1993; McLaughlin & Ruedel, 2005; UNESCO, 2009). At a particular disadvantage are those with intellectual disabilities, where intervention programs may be even less straightforward (Inclusion International, 2009a). In fact, a USAID Issues Brief acknowledges that:

Students with the most involved intellectual and developmental disabilities, such as cerebral palsy and autism, are frequently not considered within the parameters of education programs supported by USAID and other international donors (McLaughlin & Ruedel, 2005, pg 1).

### ***1.2.2 Inclusive Education***

An inclusive approach to education has been widely embraced as a laudable means to reaching EFA goals, simultaneously upholding and advancing the ideology of fundamental human rights (Hegarty, 2003; Inclusion International, 2009a; Miles, S., 2000a; Peters et al., 2005; Rieser, 2007; Tilstone et al., 1998).

The Salamanca Statement on Principles, Policy and Practice in Special Education (1994) defines inclusive education (IE) as:

The fundamental principle of the inclusive school is that all children should learn together, wherever possible, regardless of any difficulties or differences they may have. Inclusive schools must recognise and respond to the diverse needs of students, accommodating both different styles and rates of learning and ensuring quality education to all through appropriate curricula, organizational arrangements, teaching strategies, resource use and partnerships with their communities (UNESCO, 1994, pp. 11).

Notably, this conceptualisation of IE is not limited in scope to a discussion surrounding the physical location in which teaching takes place. Instead, it recognises the centrality of curricular, pedagogic, economic, logistic and knowledge constraints on effective education. What is uncertain is whether this larger conceptualisation of IE is shared by the myriad of organisations and countries in which it is advocated, and whether and how this concept is translated into local policy and practice, issues which this thesis will seek to address in relation to Ghana.

Proponents of inclusion view it as an approach which aims to transform repressive societies and educational systems through its foundation on values such as tolerance, respect, dignity and celebration of diversity. IE's touted philosophy of human rights, equalisation of opportunities and removal of barriers is appealing and can hardly be challenged as a utopian ideal. This has led to the seemingly universal acceptance and unwavering support for IE in international discourse and policy. Claims of IE's effectiveness have become incontestable, as has its ability to change discriminatory attitudes. However, Kavale & Mostert (2003) argue that "the ideology of full inclusion has influenced policy and practice disproportionately to its claims of efficacy," citing both an overall lack of research as well as ambiguous results of the research that has been conducted (pp. 191). Similarly, in reviewing studies and meta-analyses on the effectiveness of IE, Lindsay (2003) concludes:

These overviews, reviews and meta-analyses fail to provide clear evidence for the benefits of inclusion.... Do these analyses provide support for inclusion as a policy? At best, the support is weak. It is not at the level implied in the Salamanca Statement (Lindsay, 2003, pp. 6).

It appears then that IE is being encouraged despite a lack of supporting evidence as to its effectiveness, which creates the potential for uncritical importation of IE policies and practice throughout the developing world (Peters et al., 2005). In addition, movement towards IE tacitly assumes a universal acceptance of, and homogeneity in, 'fundamental' human rights.

The idea of human rights has gained a great deal of ground in recent years and it has acquired something of an official status in international discourse... Certainly the *rhetoric* of human rights is much more widely accepted today- indeed much more frequently invoked- than it has ever been in the past (Sen, 1999, pp. 227, original emphasis).

What should be deemed a human right is contentious at the very least and likely to be culturally bound (Norwich, 2008a). As Ainscow (1998) reminds us "schooling is so closely tied into local conditions and cultures that the importation of practices from elsewhere is fraught with difficulties" (pp. 3). In a country with scarce resources, parents are often forced to reconcile a child's right to education with their right to health, food and clothing or with the same rights of others in the family. Furthermore, there are potential conflicts between different rights, even within declarations. For example, the Salamanca Statement promotes *inclusive* education but also guarantees a parent's right to choice regarding educational programmes for their child (UNESCO, 1994). When



given a choice, Gaad (2004) found that some parents (in England) preferred segregated education arrangements over IE as they felt their child would receive services better tailored to his/her needs. Which then is the higher right, choice or IE? It is argued that the answer to this question is culturally bound and situationally dependant.

Steadfast claims of IE's efficacy, cost-effectiveness and ability to uphold human rights across various cultures are not assured. Each of these claims deserves further examination and this will be a central theme of this thesis, as will Ghanaian understandings of inclusive policy and pedagogy.

## **1.3 Ghanaian Context**

Ghana is a relatively small coastal country in West Africa, bordered by Togo to the east, Cote d'Ivoire to the west and Burkina Faso to the north. A former British Colony, it was the first Black African nation to gain independence on the 6<sup>th</sup> of March 1957 and recently celebrated 50 years of independence. In 1992, Ghana established itself as a stable constitutional democracy and has maintained free and fair presidential elections since. Major tribes include the Akan group (44%), Moshi-Dagomba (16 %), Ewe (13%) and Ga (8%), among numerous others. While each group has its own cultural heritage, history and language, today very little of Ghana can be seen as ethnically homogeneous. Ghana's official language is English though tribal languages are still the first language of most children.

### **1.3.1 Religion**

There are three major religions practiced in Ghana, an understanding of which will be crucial to this research. Christianity is predominantly practiced in the south, Islam in the north and followers of traditional African religions are spread throughout the country. Tolerance of religious difference is widespread and supported by the government through guarantees of religious freedom in the Constitution and in the recognition of both Christian and Islamic holy days as national holidays (Salm & Falola, 2002). In contrast, atheist and agnostic beliefs are essentially unprecedented (Utley, 2009). Census data detailed in

Table 2 demonstrates a shift in faith over time; an increasing number of people are professing Christianity and Islam as their primary religion with a corresponding decrease in the number of people who claim to follow indigenous religious practices.

**Table 2: Census Data on Religion in Ghana**

	<b>1960 Census</b>	<b>2000 Census</b>
<b>Christianity</b>	42.8%	69%
<b>Islam/Muslim</b>	12%	15.6%
<b>Traditional African</b>	38.2%	8.5%
<b>Other</b>	7%	6.9%

(Kuada & Chachah, 1999)

(Central Intelligence Agency, 2009; GhanaWeb, n.d.)

The degree to which these numbers represent a real change in religious beliefs or a reporting bias is unclear. People may well be underreporting their actual traditional faith as claiming traditional beliefs or practices can be stigmatising. Despite this, traditional belief systems likely still permeate much of Ghanaian society.

Although the population census suggests a decline in indigenous religious practices, few people have dismissed traditional beliefs entirely. Christians and Muslims more often reconcile some indigenous beliefs and practices with the Christian and Islamic views (Salm & Falola, 2002, pp. 34)

Furthermore,

The success of Christianity and Islam on a national level does not mean that the importance of indigenous religion is waning. It continues to influence the way in which people see the world and their place within it. Almost all Ghanaians, regardless of class or education, are affected by indigenous religion, consciously and unconsciously (Salm & Falola, 2002, pp. 45).

Religious and spiritual beliefs in Ghana, whether traditional, Christian, Muslim or a combination of the three, are complex. Spiritual beliefs and practices which focus on supernatural forces are multifaceted, operate in many different forms and differ across region, tribe and even family. These beliefs and practices will be explored in more detail in chapter four.

Traditional ceremonies and festivals symbolise the religious, political and cultural values of Ghanaian society. Lavish ceremony and ritual mark important occasions in an individual's life such as birth, puberty and death, as well as honour certain gods such as

the god of hunting, war or drumming. While these rituals vary by tribe and location, common underlying features include paying homage to gods and ancestors, purifying society and asking for continued protection and prosperity (Salm & Falola, 2002).

Despite variations in belief systems, a hierarchical power structure is found in some form across differing beliefs. This hierarchy consists of the High God, the small gods, ancestors, witchcraft, oracles, magic and sorcery (Kuada & Chachah, 1999; Nukunya, 2003; Salm & Falola, 2002). A brief description of this traditional hierarchy of power is necessary to understand spirituality in Ghana.

### **The Hierarchy**

The Supreme Being or 'High God' goes by many names, amongst others He<sup>2</sup> is known to the Akans as *Nyame*, to the Ewe as *Mawu* and the Ga call Him *Nyonmo* (Nukunya, 2003). He is thought to be the creator and ruler of all things (Nukunya, 2003; Salm & Falola, 2002; TICCS, n.d.). Ghanaian legends describe how the High God used to be very close to the earthly world but human demands and nuisance forced him to distance Himself to the heavens. So as not to abandon His people, the High God sent down the small gods (Kirby, 2006; Nukunya, 2003) to act as his 'deputies' (Kuada & Chachah, 1999).

There are countless small 'earthly' gods or *abosom* (to the Akan). These gods have different functions and are typically specific to a community, village, household or even an individual (Kuada & Chachah, 1999). There is a strict hierarchy of gods; the greater the sphere of influence, the greater his/her power such that a regional god holds greater sway than a village god who is superior to a household god (ibid). Of course, the Supreme Being is the apex of this hierarchy with all lesser gods created, controlled and powered by Him (Nukunya, 2003; TICCS, n.d.). Most of the lesser gods are associated with objects of nature such as rivers, rocks, forests or animals (Nukunya, 2003; Salm & Falola, 2002) and their function varies by the needs of the community; there are gods of war, harvest, hunting, earth, fishing and so on.

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<sup>2</sup> The choice to refer to the High God in male form should in no way be taken to represent an endorsement of a gendered God. Male pronouns are commonly used in Ghanaian conversation and literature when referring to the High God and as discussions centre on the Ghanaian context that practice will be followed here.

The overriding purpose [of the small gods] is to help people to live in harmony with nature, the spiritual world in general, and with each other (Kuada & Chachah, 1999, pp. 38).

To this end, the gods are thought to give warnings when harmony is out of balance, through thunder, earthquakes and to some, by individual misfortune such as disability. Despite this, the gods are not thought to be malicious, rather they are deemed impartial in their judgment; once a warning is heeded and harmony restored the gods will once again watch over and protect the offender (Kuada & Chachah, 1999).

In effect, the relationship between human beings and their earthly gods is basically pragmatic and reciprocal. Ghanaians serve their gods and submit to their guidance; in return they demand protection, peace, happiness, and long life as their reward (Kuada & Chachah, 1999, pp. 38).

Ancestors represent another significant tier on the hierarchy of Ghanaian spiritual belief systems. Traditionally, many Ghanaians believe in the ‘eternity of life’; it is thought that when someone dies their spirit journeys to, and lives within, the ‘spirit world’ (Kuada & Chachah, 1999; Nukunya, 2003). Ancestors are the souls of the departed who reached a certain status and reverence amongst their communities and families during their lifetime. They are highly revered across all regions and it is in their honour that Ghanaians can often be observed dropping the first bite of food or splash of drink on the ground (Nukunya, 2003). Both gods and ancestors are thought to be responsible for mediating disputes between the physical and spiritual worlds (Kuada & Chachah, 1999) and are able to dispense punishment for misdeeds or rewards for worthy behaviour (Lewis, I.M., 1985; Nukunya, 2003). As such they are thought to be both defenders and guardians of the ‘moral code’ in Ghanaian society (Kuada & Chachah, 1999), a belief which will greatly influence causal attributions of autism as discussed in chapter five.

Many Ghanaians also believe in magical forces as part of their spirituality hierarchy. Human actors who call upon spiritual forces can take many forms including witches, juju men, oracles and medicine men. Magical beliefs and practices in Ghana are varied and complex. Understanding these belief systems, and their impact on behaviour, will prove critical in the exploration of the experience of autism in Ghanaian society (see chapters five and six).

### **1.3.2 Kinship Structures**

In Ghana, there is no more important social structure than that of kinship and familial ties (Kuada & Chachah, 1999; Mallory et al., 1993; Nukunya, 2003; Utley, 2009).

[Kinship] determines the rules, duties and obligations of individuals and groups in all aspects of life in which these individuals and groups interact (Nukunya, 2003, pp. 17).

In Western societies, ‘family’ is often thought of as a small core unit of individuals which may be limited to a set of parents and their children. In Ghana however, the notion of family is vast and cannot be understood without recognition of the importance, distinction and interplay between clans, tribes and lineage groups.

A ‘tribe’ is described by Nukunya (2003), as a group which shares the same language and culture such as (but certainly not limited to) the Akan, Ewe or Ga. A ‘clan’ is defined as a subsection of a tribe comprising a group who have descended through a common ancestral line, either male or female depending on the tribe (ibid.). It is at the level of a clan where many spiritual associations, such as totems and taboos are determined. ‘Lineage groups’ are further familial subdivisions of a clan. Significantly, lineage systems “define the nature of communal identity” where individuals are connected by social obligations and benefits (Salm & Falola, 2002, pp. 125). This lineage group has a leader who is responsible for governing the family, making important social decisions and for the management of economic resources. The significance of this leader and his role for the purposes of educational reform in the country cannot be understated. This leader will typically determine which children in the family attend school, whether and how money is distributed for resources those children might need and what responsibilities children are given. For a child with autism this could mean the difference between attending a boarding special school, an inclusive day school, a private programme or no formal schooling at all. A lineage leader will also influence other significant factors such as how the child is viewed and treated by the family, whether and what treatments are sought and as an adult, whether they will be allowed to work and if and to whom they can marry.

Traditional kinship relationships, while slowly changing as a result of urbanisation, migration and globalisation, are nonetheless still responsible for the economic and political organisation of the group, family obligations, ancestor worship and determine

social etiquette (Kuada & Chachah, 1999; Salm & Falola, 2002). As such, kinship structures will play a significant role in the Ghanaian ‘worldview’ unpacked in chapter four and the experience of autism in Ghana as discussed in chapters five and six.

## **1.4 Education in Ghana**

The current education system in Ghana is rooted in its colonial past. The government has shown commitment to Universal Primary Education (UPE) since 1945, while ‘fee-free’ primary years schooling was introduced in 1960 and further supported by the 1961 Education Act (Akyeampong, K., 2008; Akyeampong, K. et al., 2007). The 1992 constitution reaffirmed this commitment to ‘Free Compulsory Universal Basic Education’ (FCUBE).

The Ghana Population Project, based on the Ghana Census 2000, estimated Ghana’s total population at 19.4 million (Thormann, 2003) while estimates as of July 2009 bring the population up to 23,832,495 (CIA Factbook, 2009). In 2001, the total school-aged population (from preschool through Senior Secondary School) was 6.7 million (Thormann, 2003). Ghana has 16,028 primary schools, 8,423 junior secondary schools, 485 senior secondary schools, 40 teacher training colleges, 23 technical institutions and 19 universities<sup>3</sup> to serve this population. In contrast, at the time of independence in 1957 Ghana had only one university and a handful of primary and secondary schools (GhanaWeb, n.d.).

Ghana’s education system is coordinated at the national level and divided into 10 regions which are further subdivided into 170 districts. Districts are then divided even further into ‘circuits’, each containing around 10-15 government schools. Schools are assigned to a circuit based on their location and distances between them. There are four main government bodies with responsibility for various aspects of educational services for children with disabilities in Ghana:

1. Ghana Education Service (GES): The implementing agency of which the Special Education Division (SpEd) is a part.

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<sup>3</sup> All numbers listed account for registered public and private institutions as reported by the Ghana Education Service in 2006.

2. Ministry of Education, Sports and Science (MoESS): The ministry in charge of creating and revising policy regarding education.
3. Department of Social Welfare (DSW): The DSW is responsible for individuals with disabilities once they have reached adulthood. The DSW also runs rehabilitation centres (1 per region), is responsible for the registration of all children with disabilities into schools, acts as a referral point for parents and is responsible for policy specific to disability.
4. Assessment Centres: Four assessment centres throughout Ghana report to GES. Currently, assessment services concentrate almost entirely on identifying hearing impairment (MoESS, 2008).

Government special educational needs (SEN) services take three main forms: segregated 'special schools', segregated 'units' contained onsite with mainstream schools and what is termed 'inclusive education' (IE). SEN programmes are typically offered under the groupings of 'vision impairment' (VI), 'hearing impairment' (HI) and 'mental handicap' (MH). Government SEN services are largely concentrated on primary years education (Anthony & Kwadade, 2006) and in southern (MoESS, 2008) and urban areas (Avoke, M, 2001). Typically offered through local or international non-governmental organisations, private services are not thought to represent the typical provision offered within Ghana and the discussion that follows will therefore concentrate primarily on government services.

Despite burgeoning IE efforts, segregated services for students with disabilities are on the rise, as detailed in Table 3. An increase in enrolment of 51% was reported across special schools between 2001-2007 (MoESS, 2007) with a corresponding increase for students with 'MH' (7.2% in units and 5% in vocational institutions) for 2003-2005 (MoESS, 2005). However, all figures should be interpreted with caution as reports from the government are inconsistent as to provision available, sometimes even within the same document<sup>4</sup>.

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<sup>4</sup> The 2008 report indicates the numbers reported in Table 3 (12 schools, 23 units) in its text but a chart on the next page reports different figures: 7 schools and 27 units for the 'mentally disabled'. The 2005 MoESS report indicates there were 7 special schools for the mentally disabled in 2003-4 whereas the 2008 report reports 8 schools were in operation during that same period. These are just a couple examples, many more exist.

**Table 3: Government Educational Provision for Intellectual Disability ('Mental Disability')**

	<b>MH Special Schools</b>	<b>MH Units</b>	<b>IE all 'non-severe' disabilities</b>	<b>Source</b>
2004	7	3	35	MoESS, 2005
2006	9	5	Not Reported	Anthony & Kwadade, 2006
2008	12	23	129	MoESS, 2008

Even with an increasing number of facilities, there are still not enough spaces to accommodate even the most conservative of disability prevalence estimates. UNESCO reports that only 1-2% of children with disabilities living in developing countries receive a basic primary education (DFID, 2000). Reports indicating the number of children with SEN who are able to access education in Ghana range from 0.6% (UNESCO, n.d.) to 44% (Annor, 2002). The Ghanaian government estimates over 800,000 of people with disabilities are school aged but reported a total enrolment in all special education schools of only 5,654 for the 2007-2008 academic year (MoESS, 2008), less than 1% of those estimated to need services. There may also be over a million students currently enrolled in primary schools across Ghana with unidentified learning difficulties (Anthony & Kwadade, 2006).

#### ***1.4.1 History of Special Education in Ghana***

In detailing the history of special education in any developing nation, it is important to avoid the all too common hubristic assumption that history began with missionaries and colonisation. Stubbs (1994) reminds us that a superficial scratch beneath the surface of this assumption reveals many examples of pre-colonial, often ingenious, attempts to educate children with disabilities. Despite this, the first recorded attempt in Ghana to provide education for children with disabilities was undertaken by missionaries in 1936 (Anthony & Kwadade, 2006; Avoke, M, 2001). In 1964, parents of children with intellectual disabilities (ID) formed an association called the 'Society of Friends of the Mentally Retarded' whose extraordinary advocacy led to the establishment of the first 'home for the mentally handicapped' in 1966 (GES, 2005). The National Education Act (1961), saw the Ghanaian government assume responsibility for the education of children with disabilities (Anthony & Kwadade, 2006). This, coupled with increasing international influence, led the 'home' to become the first '*school* for the mentally handicapped' in 1970 (Avoke, M, 2001). The 1970-80's saw rapid growth in the



number of segregated special schools across Ghana. Increasing national recognition of the need for additional services led to the formation of the Special Education Division (SpEd) within GES in 1985 (GES, 2005).

### **1.4.2 Special Education Policy**

Recent international influence affirming IE has informed Ghanaian special education policy. Currently, SpEd is piloting IE in a number of districts with a proclaimed emphasis on identifying disabilities, increasing enrolment of students with SEN and providing adequate support and teacher training (TT). The stated goal of the MoESS is 100% enrolment of students with ‘non-severe’ SEN into mainstream schools by 2015 (MoESS, 2008; Republic of Ghana, 2003b). Ghana has ratified all international treaties on the rights of people with disabilities and has made domestic constitutional provisions for their education (GES, 2005). The following key documents give direction to educational provision for individuals with disabilities in Ghana:

1. **The 1992 Constitution:** provides for the protection of people with disabilities from discrimination and abusive treatment (Article 29), mandates the legislature to enact appropriate laws (Article 37) and requires access to FCUBE (Article 38) (Parliament of the Republic of Ghana, 1992).
2. **National Disability Policy, June 2000:** legislation which secures the rights of people with disabilities with regards to education, transportation, community acceptance, housing and employment (MoESW, 2000).
3. **Education Strategic Plan (ESP) 2003-2015:** echoes the Ghanaian government’s commitment to EFA and dictates that all schools within Ghana become inclusive environments for children with ‘non-severe’ disabilities by the year 2015 (Republic of Ghana, 2003a, 2003b).
4. **Special Educational Needs Policy Framework (2005):** based on key policy objectives indicated in the ESP, this framework addresses the challenges of marginalisation, segregation and inequality which have historically constituted barriers to the education of children with disabilities and students with SEN. (Ghana Education Service (GES), 2005).
5. **Persons with Disability Act, June 2006:** ‘Act #715’ fulfils Ghanaian constitutional requirements and incorporates suggestions from ratified human rights conferences (Parliament of the Republic of Ghana, 2006).

The above policies share common commitments and goals including the provision of additional SEN services and resources, improving the quality of available services, expanding IE, training additional teachers, improving infrastructure, collecting

incidence data and combating discriminatory attitudes. The extent to which each of these objectives has been implemented varies and will be explored throughout this thesis.

Today, despite laudable progress, Ghana's education system is still plagued by familiar barriers to actualising UPE and EFA goals, especially as pertains to students with impairments and SEN. Low quality schooling, a lack of qualified teachers, economic costs, difficult access and low expected returns are current challenges within the Ghanaian education system (Akyeampong, K. et al., 2007). Teacher shortages, especially in rural areas, coupled with poor teacher motivation and attendance, are significant barriers to EFA, especially as pertains to IE for students with autism.

## **1.5 Disability in Ghana**

### ***1.5.1 Prevalence and Incidence***

There is very limited information about the incidence of children with special needs around the country (MoESS, 2008, pp. 55)

Global *estimates* of disability prevalence and incidence vary widely. The UN estimates an often invoked rate of 10% while the United Nations Development Programme (UNDP) estimates a more conservative 5% global average. Based on these, and with a current population of just over 23 million, Ghana has an estimated total disabled population of 1.15-2.3 million. The World Bank acknowledges that there are currently 115 million school aged children out of school (Lawrence, 2004). Of those, 40 million (over 1/3) are estimated to have a disability, most of which are not visible or easy to diagnose (ibid.). Individuals with an intellectual disability make up an estimated 1-3% of the population according to UN figures (Inclusion International, 2005). Where known, the prevalence of autism also varies widely. Currently, the most widely accepted figure in the USA is 1 in every 150 people (CDC, 2007) though the latest surveys suggest this number may be as high as 1 in 91 (Kogan et al., 2009). As a guiding figure, the prevalence of autism can be extrapolated<sup>5</sup>, which gives us a figure of around 150,000 persons with autism in Ghana.

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<sup>5</sup> By applying the most widely accepted prevalence rate (1:150) from the USA to the population of Ghana

The latest Ghana Education Service enrolment figures specific to ID<sup>6</sup> (2005), reveal a total of 955 students (M 598, F 357) enrolled in government run ‘Special Schools for the Mentally Handicapped<sup>7</sup>’ (MoESS, 2005). However, reports by GES only account for students who are enrolled in schools, which may greatly underestimate the actual number of children with disabilities across Ghana. It should be noted that GES has a recent policy objective to “determine the prevalence rates of different disabilities and SEN in Ghana” (GES, 2005, pp. 11) but little evidence of this has occurred to date.

Very few relevant studies provide some indication of the prevalence of ID in Ghana. During a recent external epidemiological survey of SEN, a ‘screener’ was administered to caregivers, siblings and teachers of children<sup>8</sup> throughout Ghana (total N= 551). When asked “do you recognise any of the following labels as being associated with the child” 3.1% of respondents indicated yes to the label ‘developmental delay or autism’ and 3.9% responded yes to the label ‘mental retardation or mental handicap’ (Boro et al., 2006).

Assessment figures reported by Ghana’s MoESS (2008) report that of 14,596 students screened for impairment, 101 were ‘clinically assessed’ as having ID. Annor (2002) estimates that 5% of the Ghanaian population has a disability but that social stigma is responsible for the underreporting of prevalence, especially in rural areas. In line with World Health Organization (WHO) recommendations, Ghana Statistical Service recently conducted a survey aiming to identify *functional* impairments (GSS, 2006). Results indicate that 16% of children in Ghana between the ages of 2-9 may have at least one functional impairment. Reported indicators which resonate with the challenges of autism are listed in Table 4:

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<sup>6</sup> There is no separate category for ‘autism’ in Government reports and as demonstrated in chapter 7, students with autism are typically included in the categories ‘ID’ or ‘MH’ for educational purposes.

<sup>7</sup> This figure includes government run special schools, units attached to mainstream schools, one psychiatric hospital and one privately run institution.

<sup>8</sup> A total of 1,236 children (642 M, 591 F) both in and out of school and between the ages of 6-14 years were assessed using a variety of measures. Unfortunately, funding for the SEN component of the EQUALL project was unexpectedly cut and no further analysis of child assessment results was completed.

**Table 4: GSS Functional Impairment Survey Results**

<b>Type of Disability</b>	<b>Average % of children 2-9 years old (obtained through caregiver report)</b>
“Not learning to do things like other children his/her age”	2.1%
“Appears mentally backward, dull, or slow”	3.4%
“No speaking/ cannot be understood in words”	2.6%
“No understanding of instructions”	4.1%

(GSS, 2006)

The studies cited above are intended only to give a possible indication of the prevalence of autism and ID in Ghana and should in no way be interpreted as conclusive. In addition, all of the above figures must be interpreted with extreme caution as it is exceedingly difficult to generate prevalence rates which are internationally comprehensible and comparable given variations in definitions, data collection methodologies and the quality of research or reporting (Eide & Loeb, 2005; Mont, 2007). The only thing that is clear is that insufficient data exists, especially as pertains to specific disabilities such as autism. An extensive database search revealed no available prevalence or incidence data specific to autism in Ghana<sup>9</sup>.

### ***1.5.2 Understandings of Disability in Ghana***

A Ghanaian herself, the recently retired head of the Special Education Division, Mrs. Doris Dinah Kwadade, said the following with regards to treatment of individuals with disabilities in Ghana:

In tracing the history of the treatment of individuals with disabilities in Ghana, one is confronted with the total neglect, cruelty, and degradation meted out to such populations. In past years, children with disabilities were either killed at birth, starved to death, thrown into rivers, abandoned in the woods to die, or looked on as imbeciles to be pitied

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<sup>9</sup> An extensive database search for data and statistics specific to the prevalence of autism in Ghana included the following sources: UNESCO Institute for Statistics, UNESCO World Data on Education, UN Statistics Division, World Bank Education Statistics, United Nations Disability Statistics Database (DISTAT), Washington City Group on Disability Statistics, World Health Organisation (WHO), US Census Bureau: International Data Base (IDB), CIA World Factbook, Global Education Digest, Education Policy and Data Center (EPDC), Southern and Eastern Africa Consortium for Monitoring Educational Quality (SACMEQ), Ghana Multiple Indicator Cluster Survey (MICS), Ghana EMIS data, Ghana Statistical Service (GSS), Ghana Health Service (GHS), Ghana Education Service (GES), Ghana Web, Institute of Statistical Social and Economic research (ISSER) at the University of Ghana, Cape Coast University Library, University of Ghana Legon Library, University of Education Winneba, Healthlink Worldwide, Enabling Education Network (EENET), International Autism Epidemiology Network, Source: Disability & Statistics, Measure DHS: Demographic and Health Surveys, Eldis, ERIC, PsychInfo

and protected without any rights...The conditions of persons with disabilities in Ghana have improved considerably throughout history but there are still cases of neglect, abuse, and exclusion even today. Superstitions – including beliefs in evil spirits – and deep-rooted negative attitudes about the strengths and capabilities of persons with disabilities have hindered the education, training, and social and economic integration of this population into mainstream society (Anthony & Kwadade, 2006, pp. 6-7).

The attitudes surrounding disability and autism in Ghana are complex, varied and dynamic. An analysis of these views, and their impact on the experience of autism, is a central theme of this thesis in later chapters.

## **1.6 Conceptualising Disability**

### ***1.6.1 Understanding Autism***

Autism is caused by a dysfunction of the central nervous system which leads to disordered development (Cohen & Volkmar, 1997; Volkmar et al., 2005). It is a lifelong neuro-developmental disorder with no clear aetiology or cure to date (Iovannone et al., 2003; Pellicano, 2007). It is evident before three years of age, though autism is often diagnosed much later when a child fails to reach developmental milestones as expected. As a developmental disability, children with autism do not develop in the expected way; they do not reach the same milestones as other children at the age appropriate time. While not specific or universal to autism, 50-75% of children with autism do exhibit lower than average intellectual abilities (APA, 2000; Pellicano, 2007).

Autism is a spectrum disorder with symptoms that range in severity and vary from child to child. Despite this range, autism is characterised by concurrent qualitative impairments in social interaction, social communication and a restricted repertoire of interests and activities, together known as the ‘triad of impairments’ (Wing & Gould, 1979). While all children with autism will demonstrate the triad of impairments, the severity of each impairment and the interaction between these impairments will present in a highly individualistic manner, which is likely to vary over time within a given individual. Autism typically affects the most fundamental aspects of quality of life such as the ability to understand what others feel and think, the ability to communicate your

basic needs or socialise with those around you and the necessary understanding to process and make sense of emotions (Iovannone et al., 2003; Jordan, 1997, 2005). A greater understanding of autism, its characteristics and the portrait of those characteristics in Ghanaian society will be the focus of chapter three.

### **Educational Needs of Students with Autism**

It is important to acknowledge that traditional impairment groupings (such as autism) may not always hold utility for educational purposes with regards to issues of placement, pedagogy, curriculum and teacher training (Florian & McLaughlin, 2008; Hardman & McDonnell, 2008; Lewis, A. & Norwich, 2005; Nagle & Thurlow, 2008; Norwich, 2008b; Wedell, 2008). As the educational needs of children with autism may vary from those with other impairments on the spectrum or included in the category ‘pervasive developmental disorders’, this section will focus on children with ‘Autistic Disorder’ as diagnosed using the DSM-IV-TR criteria (see chapter three) and should not be thought to generalise to higher functioning children on the spectrum (such as those with Asperger’s Disorder).

Classifications systems can generally be described as rooted in two overarching systems, those based on impairment groupings (such as in the USA) and those which are performance based (such as in the UK); neither system is ideal and both can result in marginalisation of students with SEN (Dyson & Kozleski, 2008). An exploration of the validity of categorisation for educational purposes, and the myriad of different possible classification schemes, is a complex and lengthy digression which regrettably, space constraints do not allow here (for further exploration of these issues see Florian & McLaughlin, 2008). However, in light of EFA and IE movements it is important to explore the degree to which educating students with autism does or does not present distinctive challenges and whether these challenges can be accommodated under inclusive systems.

The education of children with autism presents unique challenges  
(Iovannone et al., 2003).

This widespread view has contributed to a propensity towards individualised learning programmes for students with autism and an advocacy for specialised teaching methodologies. However, copious amounts of research on educational interventions for

students with autism has, as of yet, failed to identify a single strategy superior to its alternatives or one equally effective for all children across the autism spectrum (Dawson & Osterling, 1997; Iovannone et al., 2003; Jordan & Jones, 1999).

Just as these students have no natural intuitive ways to understand their teachers, teachers in turn, have no natural intuitive way of understanding a student with ASD (Jordan, 2008, pp. 13).

What is shared or unique about educating students with autism is much more difficult to conceptualise than is first apparent. The universal presentation of the triad of impairments may intuitively suggest shared educational needs. On the other hand, the heterogeneous presentation of these impairments implies the need for unique educational strategies tailored not to the larger group, but specific to the individual. In other words, if no two children with autism have the same combination of traits or educational needs, how can provision which is appropriate and common to the group be identified? Despite this theoretical paradox, as an educator of students with autism for over ten years, I feel strongly that there is an ‘autism-ness’ which is shared by the majority of students with autism and which, if understood, can be used as a tool in predicting a student’s challenges and educational needs. Jordan (1997, 2005) contends that this distinctiveness of autism can be found in the psychology of an individual, that it is:

...how the individual is feeling, thinking, perceiving, attending, learning, memorizing and making sense of his or her environment- that [is where] the ‘autism’ is really located and this is the level of understanding that has to underlie the ‘special’ practice needed for work with those with ASD’s (Jordan, 2005, pp. 111).

Many experts are in agreement with Jordan that the fundamental impairment for children with autism rests in higher order cognitive functioning and information processing, though theories regarding the severity and nature of that impairment vary (Bailey et al., 1996; Baron-Cohen, 1995; Baron-Cohen et al., 1994; Cohen & Volkmar, 1997; Edelson, 2008; Grinker, 2008b; Happé, 1994; Hobson, 1993; Pellicano, 2007; Volkmar et al., 2005). In attempting to explain the underlying features of autism, three information processing cognitive theories have dominated the literature: an underdeveloped or absent ‘theory of mind’ (difficulties with social and emotional inter-relatedness), challenges with ‘executive control’ (a set of behaviours needed for flexibility and planning) and weak ‘central coherence’ (the ability to process information in context) (Pellicano, 2007). However, no one theory can adequately explain all the features of autism and researchers have recently begun to suspect that

there are several underlying deficits which co-exist. (Bailey et al., 1996; Pellicano, 2007). While the theory of mind hypothesis accounts for the challenges children with autism experience in the areas of joint attention, imagination and social-emotional relatedness, it fails to explain other co-occurring features such as a resistance to change, repetitive behaviours and a restricted range of interests, which are better accounted for by theories of executive functioning (Pellicano, 2007).

Critically, for educational purposes, understanding this higher order difficulty in information processing is likely to be the essential knowledge required in providing meaningful learning opportunities for students with autism. For example, a demonstrated lack of eye-contact by a student with autism may be interpreted as a performance difficulty, a sign of disrespect or stubborn behaviour but may instead represent a fundamental information processing difficulty in grasping communicative intent and theory of mind. Pragmatically, a student with autism who fails to use eye-contact is unlikely to benefit from an intervention, even one which specifically attempts to teach eye-contact, unless that intervention begins with the fundamental understanding of what eye-contact is used for and how it can be of use to the student (Jordan, 1997). Conceptualising autism, and thereby the educational needs of a student with autism, based on each of the triad of impairments in isolation from each other, or in isolation from information processing challenges, can result in an incomplete picture and inappropriate educational services (Dawson & Osterling, 1997; Jordan, 2005). For example, the communication difficulties of a student with ASD may vary dramatically depending on the conversation topic (factual vs. imaginative), mode of communication (visual vs. auditory), nature of communication required (receptive vs. expressive), conversation partner (adult vs. peer, teacher vs. parent), communicative intent (initiation vs. response) or location (home vs. school vs. community). The range of possible intervention strategies for each of these distinct combinations of challenging interactions is potentially overwhelming, especially when considered alongside parallel challenges in socialisation and flexibility in thinking. Social rules and patterns of behaviour, such as eye contact, conversation turn taking, appropriate topics of conversation and how to initiate interaction with a friend will all need to be explicitly taught before additional learning that requires the use of these skills can take place.



It seems that a teacher must understand the *shared features* of autism in order to properly respond to, and provide for, the *individual needs* of that student. Following Lewis and Norwich's (2005) unique differences versus general differences framework Jordan (2005) concludes:

...there are few special educational needs that are uniform across the ASD group (and distinct from those without an ASD) and none that can be considered out of the context of the individual's pattern of strengths and weaknesses...It is an argument for individual (unique) learning needs, but only as interpreted within the understanding of group attributes (Jordan, 2005, pp. 112).

The educational needs of students with autism and Ghana's capacity to meet these needs will be further explored in chapter eight.

### **1.6.2 Labelling**

Labels, defined as a "brief description given for purposes of identification" (WordWeb Dictionary) are a natural consequence of the complexities of human perception and the language used to express such ideas. They are a necessary shortcut in the processing of huge amounts of complex information and can act as heuristic tools, allowing us to order and make sense of the world we live in. However, some labels are imbued with negative connotations, and as such, are potentially detrimental to those they encapsulate. The very notion that disabilities are given labels at all is a result of their salience, recognition and stigmatisation (Saul & Phillips, 1999). Labels are not only in line with a culture's dominant ideology, they can also serve to produce and preserve stereotypes. It may be however, that it is not necessarily the label attributed to a disability which is problematic, but rather society's reaction to it (Agbenyega, 2003). The meaning a culture attributes to a label is likely to be situated in a tension between language use and the understanding of disability in any given society (Whyte, 1995).

Labels both change over time and are culturally bound. For example, 'person first' terminology (person *with* a disability, child *with* autism) is currently preferred in the USA where it is believed that the individual is the primary consideration and that disability is only one secondary trait. Much as a person is one with blue eyes or black hair, they are a person with a disability. In the UK however, an understanding of disability through the social model (see below) results in the preferred terminology 'disabled person' as it is felt individuals are 'disabled' by societal attitudes and barriers.

In Ghana, labels are used inconsistently and can serve to marginalise, silence and subjugate (Agbenyega, 2003). Terms used to describe people with ‘mental retardation’ (MR) in Ghana, when translated from their local language, paint a troubling picture. ‘Asotowo’ from the Ewe language can be translated to mean ‘idiot’ or ‘fool’, ‘buluus’ in Ga translates to ‘reduced intellectual abilities’, while ‘nea wanyin agya n’adwene ho’ from the Akan language means ‘feeble-minded’ (Agbenyega, 2003). While Patel (1995) cautions that mere translation is insufficient without an understanding of the meaning a culture ascribes to the terminology, it seems logical that such derogatory terms, and the practice of labelling in and of itself, serve to marginalise students with disabilities in Ghana.

This assumption however, rests on the premise that negative connotations ascribed to translated labels such as ‘idiot’ or ‘fool’ are in fact shared perceptions. The term ‘feeble-minded’ was in official use in the United Kingdom until the 1960’s and did not carry the same negative connotations or social stigma that it does today. It is also possible that some labels such as ‘reduced intellectual abilities’ merely serve as descriptive labels. For example, Agbenyega (2003) suggests that the label used to describe epilepsy, which translates literally to ‘falling down sickness’, constitutes “derogatory tribal language” (pp. 4). The label appears however, to be factually descriptive of the condition and would likely be immune from negative connotations without the deeper meaning Agbenyega ascribes to the label. Agbenyega (2003) also argues that the names given to special schools throughout Ghana such as ‘X school for the Mentally Handicapped’ attach negative labels to the children who attend such schools. I would argue however, that this negative interpretation is again a result of the meaning Ghanaians ascribe to such a label, which in and of itself is merely descriptive. The school is one for students with a mental handicap just as ‘X Junior Secondary School’ is one for students of a certain age. On the other hand, the labelling of segregated schools as ‘special’ can connote a degree of distance and possible disdain while the location of special schools on the outskirts of towns and their residential nature is perhaps more ‘othering’ than the label of the school itself.

As will be demonstrated in chapter five, labels such as ‘useless’ and ‘possessed’ are commonly associated with children with autistic traits and serve to marginalise not only them, but their entire family unit. Furthermore, teachers were found to use pejorative terms such as ‘lazy’ or ‘stupid’ to label students (Agbenyega, 2003). It will be suggested that introduction of the concept and label ‘autism’ may actually alleviate some of the negative cultural ascriptions to these children by providing a medicalised alternative to current perceptions.

### **1.6.3 Traditional Disability Models**

#### **The Medical Model**

*Mmere dana a, yedane yen ho bi*  
*If times change, we change ourselves too*  
*(interpreted as: you must adapt yourself to circumstances as they are)<sup>10</sup>.*  
 (Appiah et al., 2007, pp. 28: 343)

Historically, definitions of disabilities have been largely influenced by ‘medical models’ in which a person with a disability is seen as ‘abnormal’ in some way (Coleridge, 1993; Miles, M., 1999; Oliver, 1996; Rieser, 2008). Critically, the organising concept for the medical model is that disability is fundamentally located within the individual themselves (Low, 2001). Medical models categorise and label disorders using familiar terms such as ‘Down’s Syndrome’, ‘vision impairment’ and ‘autism’. Rehabilitation efforts aim to ‘fix’ the individual and restore functioning to an ‘acceptable’ or ‘normal’ level. This requires the individual to adapt to social and environmental structures around him in an effort to fit with the mainstream paradigm. While variations of the medical model have been proposed, they all stress intrinsic factors and minimise or outright ignore external environmental and social factors (Lindsay, 2003).

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<sup>10</sup> As described in chapter 2, proverbs are a valued source of data in this thesis and will be used throughout to highlight and reinforce traditional Ghanaian values and beliefs. The significance of proverbs in understanding Ghanaian culture is further detailed in chapter 4. Proverbs will always be presented in the current style for ease of recognition and any interpretation offered was generated by the relevant cited source, not by myself.

Low (2001) points out that the term ‘medical model’ is misleading as neither the characteristics inherent to the individual nor the treatments employed are necessarily medical in nature. For this reason some researchers prefer the term ‘individual’ (Low, 2001) or ‘individualistic’ model (Borsay, 1997). Use of this terminology serves to remind us that it is the individual and not necessarily the medical at the heart of this model and as such will be the preferred terminology here.

The individual model has recently come under criticism by people with disabilities for failing to connect to their lived experience of the world (Coleridge, 1993; Oliver, 1990, 1996; Riddell & Watson, 2003; Stone & Priestley, 1996). This has sparked a shift over the last 30 years away from medical/individual models of understanding and service provision towards a social model of disability (Lindsay, 2003).

### The Social Model

*Abasini twe adee bon mu na amma a, na emfiri ne nsa, na, mmom biribi ntira*  
*If a person with one arm amputated pulls something from a hole and it does not come,*  
*it is not because of his arm but because of something else*  
*(interpreted as: it is not always because of your shortcoming that you do not succeed).*  
 (Appiah et al., 2007, pp. 23: 240)

Disability, as interpreted by the social model, is caused by societal attitudes and environmental barriers arising from the discrimination, inequality and oppression of those with impairments in society. These social barriers can be physical, social, economic, political or cultural (Low, 2001), what is crucial is that they are external to the individual. According to the social model, it is these societal attitudes and environmental barriers, not intrinsic characteristics, which ‘disable’ the individual, preventing them from participating fully and meaningfully in society. In its extreme form, the social model denies that innate impairment has *any* casual relation to disability, which is viewed solely as social oppression (Oliver, 1990, 1996; Thomas, C., 2004b). It is this politically powerful and persuasive form which is typically postulated in contemporary advocacy arenas.

Emphasis is placed on the role of society in [disability’s] manufacture by directly causing physical and mental impairments, by applying pejorative labelling processes, and by operating economic, social and political institutions which are dead to the needs of disabled people (Borsay, 1997, pp 128).

Viewed through a social model lens, it is society and not the individual which must be 'fixed'. Societal and environmental structures should be adjusted to accommodate all individuals, including those with disability.

## **The Debate**

The social and individual models of disability are often represented as diametrically opposed with fervent advocates for either extreme. A major criticism of the individual model is that it maintains a status quo whereby 'normal' is not only a valid concept but is also attainable and desirable. The implication then, is that any deviation from this perceived normality is a tragic misfortune. Proponents of the social model argue that its superiority rests on a grounding in principles of equality and human rights whereas individual models perpetuate segregation and unequally distributed resources (Borsay, 1997). The social model was conceptualised and articulated by individuals with disabilities and as such should arguably hold greater sway than models and definitions which are produced by non-disabled thinkers (Finkelstein, 2001; Oliver, 1990, 1996; Priestley, 2001; Riddell & Watson, 2003; Shakespeare & Watson, 1997; Stone & Priestley, 1996). It is often suggested that advocates of an individual model, or even services grounded in one, are deliberately and wilfully acting against those who seek to liberate thinking around disability.

It should be remembered however, that historically, institutionalisation and charity based services born out of individual models were, at the time, hailed as a leap forward in human rights and development (Anthony & Kwadade, 2006; Borsay, 1997). It should also be acknowledged that an extreme individual model, one that attributes no role of impairment in disability, is largely a fallacy. Low (2001) suggests that a passionately articulated version of the individual model was constructed retrospectively by advocates of the social model as a way to juxtapose their own ideas. This opinion is supported more recently by Shakespeare (2006) who argues that the individual model functions as a catalyst for criticism of an 'antagonistic perspective' by proponents of the social model.

A major criticism of the social model is that it "tends to assume its own conclusion and make itself true by definition" (Low, 2001, pp 9). One must also consider the social

model's potential to amalgamate individuals with disabilities by attempting to fit them into one group, that of 'disabled people'. This fusing of potentially distinct groups may serve to ignore individuality, both within and across impairment specific groupings and tacitly implies that the experiences and challenges individuals with disabilities face are no longer distinct from those experienced by anyone else (Thomas, C., 1999).

Unfortunately, it seems that a model originally proposed to advance the disability rights movement and elevate the position of those with disabilities has fallen victim to extremisms within its own thinking (Shakespeare, 2006; Thomas, C., 1999, 2004b). The philosophical and moral appeal of rights based arguments have created a paradigm shift towards an exaggerated and often over simplified version of the social model in international development efforts, especially as pertains to policy.

In a kind of reductionism, 'not only individual' has become mistranslated as 'only social', and 'the individual is not everything' has become 'the social is everything' (Low, 2001, pp. 10).

An extreme view of the social model is dangerous and has the potential to reduce the complexities of disability in favour of a political agenda. While advocates of each model can at times be unbending in their support for either extreme position, no model of disability is so persuasive as to rule out the others and the individual and social models of disability need not be viewed as mutually exclusive (Lindsay, 2003; Low, 2001; Thomas, C., 2004a, 2004c).

Fortunately, there seems to be an emergence of ideas which see neither model as either theoretically or operationally sufficient on their own. Even Mike Oliver, who is widely credited with the creation of the social model, has himself questioned its widespread acceptance and acknowledges that its ability to connect with the personal experiences of those living with disability is not universal (Oliver, 1996). Similarly, Tom Shakespeare's earlier works (Shakespeare, 1997; Shakespeare & Watson, 1997) read as fervently persuasive promotions of a social model whereas writings that are more recent call for its complete abandonment (Kristiansen & Kermit, 2007; Shakespeare, 2006; Shakespeare & Watson, 2002). In moving away from extreme versions of either model, a number of authors have advocated for conceptualisations of disability which acknowledge the role of both intrinsic characteristics and extrinsic societal factors

(Borsay, 1997; Lindsay, 2003; Shakespeare, 2006; Terzi, 2005a, 2005b; Thomas, C., 2004a, 2004b).

Lindsay (2003) articulates a frustration with the social model of disability calling it ‘illogical and unhelpful’ in meeting the needs of children both in school and in the larger community (pp. 5). He proposes an alternative ‘interactive model’, whose conceptualisation he credits to Klaus Wedell. In this interactive model, disability is viewed as the interaction between a child’s inherent characteristics and external environmental factors, both of which can change over time. Social environmental factors are seen as supports *and* barriers to functioning. It is these more practical models which resonate with my experience as both a special needs teacher in diverse cultures and as a researcher in Ghana.

Surely, it is the interaction between skills a society values and an individual’s ability to achieve these skills, which is crucial. For example, dyslexia is not problematic unless literacy is widespread and valued in a society, and theoretically, not even then if sufficient supports are present. A vision impairment is arguably more disabling for a hunter who must see over great distances than for a farmer or artisan who can feel their work with their hands. In a hunting society, this individual would likely be more disabled by their VI than in one founded on agriculture. This interactive position is in fact similar to some descriptions of the social model, albeit in its less extreme forms. This is perhaps best evidenced in the WHO’s assertion that its International Classification of Functioning (ICF), which acknowledges the role of impairment, is based on a social model of disability. It is complications such as these which allow for the extreme view, that disability is ‘wholly and exclusively social’ (Oliver, 1990, pp. 41) to permeate development discourse (Shakespeare & Watson, 2002; Thomas, C., 2004b). Thomas offers a particularly enticing interactive model of disability as solution to this dilemma.

### **Furthering the Debate: a Social Relational Model of Disability**

Thomas (1999, 2004b) reminds us, that the social model, in its contemporary form, diverges from the original conceptualisation of disability on which it was based. Vic Finkelstein and Paul Hunt founded the Union of the Physically Impaired against

Segregation (UPIAS) from which the disabled people's movement, disability studies and Oliver's articulation of the social model grew. Finkelstein and Hunt initially acknowledged innate impairments and viewed them as prerequisites to 'disability':

Disability is something imposed on top of our impairments (The Union of the Physically Impaired Against Segregation (UPIAS) & The Disability Alliance, 1975)

To Finkelstein, disability is a result of societal injustices which compounded innate impairments and serve to exclude or marginalise individuals with disabilities, a view Thomas terms the 'social relational model' of disability (Finkelstein, 2001; Thomas, C., 2004a, 2004b). Importantly though, while Finkelstein acknowledges the role of impairments in restricting activities, in his (and Thomas') view, disability is not *caused* by those impairments but by social oppression (Thomas, C., 2004b).

The point here is that in this social relational proposition, disability and impairment are inextricably linked and interactive: disability is social exclusion on the grounds of impairment (Thomas, C., 2004a, pp. 43).

Thomas (1999) suggests that an extended, hybridised and unhelpful interpretation of the original UPIAS stance is now in common usage.

The social relational proposition that disability is the social imposition of restrictions of activity on impaired people has become the proposition that *all restrictions of activity experienced by people with impairment are caused by social barriers* (Thomas, C., 1999, pp. 42, original emphasis)

She argues that an overemphasis of this extreme view is an unfortunate result of confusion between not one but two interpretations of the social model which are highly conflated in the literature and used erratically even within the same text. The first definition, which she personally advocates, is the social relational model articulated above with roots based in UPIAS's original definition of disability. Thomas argues that this view can be contrasted with a second widely used version of the social model, one she terms the 'property approach'.

Disability is a *property of the person with impairment*... Disability [is] restrictions of activity experienced by people with impairment (Thomas, C., 1999, pp. 40-41, original emphasis).

It is this second view which, according to Thomas, obscured the 'social relational kernel' in Finkelstein's original definition which both laid the foundation for, and has since been obscured by, the social model in its contemporary form (2004a, 2004b, 2004c).



The social relational qualities of Finkelstein's and Hunt's understanding of disability were diluted, even lost, once its offspring- the social model of disability- came to the forefront (Thomas, C., 2004b, pp. 579).

Thomas argues that this conflation has led to the adoption of an extreme version of the social model by governments and international development agencies, which in turn has informed entitlement to assistance and services around the world. However, upon closer examination there is a challenge to the social relational model as defined above. Even if it were possible to eliminate the social imposition of restricted activity, an individual might nonetheless be restricted from that activity due to their still present intrinsic impairment. Thomas circumvents this challenge in her introduction of a concept she terms 'impairment effects'.

[Impairment effects are] the restrictions of activity which are associated with being impaired but which are not disabilities in the social relational sense (Thomas, C., 1999, pp. 43).

The introduction of these impairment effects allows Thomas to retain the ethical and rights based appeal of the social model while simultaneously acknowledging both the existence of innate impairments and their potential role in restricting activities. While initially quite alluring, upon closer inspection even this social relational model of disability has limited utility for understanding autism. It is to this dilemma that I now turn.

## **1.7 Limited Utility of Disability Models**

### ***1.7.1 A Challenge to Traditional Disability Models: Understanding Autism***

Unsatisfied with extreme versions of both the social and individual models of disability, and unwilling to accept the necessity of such a polarising divide, I too initially attempted to conceptualise disability as an interaction between intrinsic and external factors. I thought, like Thomas, that there must be a common ground whereby we can allow for the disabling nature of societal attitudes and environmental structures but also give weight to the internal characteristics of impairment and the role that impairment has on shaping identity and the lived experience of an individual. However, my initial thoughts, and Thomas' well articulated stance, both struggle to explain autism as a distinct disorder.

As shown above, autism is a disorder, for want of a better word, characterised by challenges in social relatedness. Where then can the line between a social impairment and a socially disabling societal barrier be drawn? Take for example a situation which I have observed many times, a student with autism playing alone during a ‘free play’ period in a preschool classroom. Is this student’s isolation due to a socialisation impairment, which drives her to prefer solitary play, or to a social barrier, perhaps resistance on the part of peers to play with the ‘odd’ student or a lack of skills by the teacher to fully include this student? In trying to determine whether this student is ‘impaired’ or ‘disabled’ the shared traits of autism as an overarching classification and the vast possible expressions of these shared traits (spectrum of abilities) must be considered for the individual student. Consideration of confounding factors such as the classroom environment is then needed. For example, possible sensory inputs in a loud and busy classroom may possibly distract the student. One must determine if this classroom environment is a social barrier for the particular student or a sensory processing inability to filter out background noises. On top of that, the interactive complexities of the *triad* of impairments must also be considered; is the social isolation of this student actually a result of co-morbid communication challenges? To that, the range of possible peer attitudes or varying levels of teacher knowledge and skills which could be ‘disabling’ the student (social barriers) must be added to the calculation. It is necessary to determine whether each of these aspects is an intrinsic trait or an environmental barrier. Only then can a judgement call be made about each aspect of the scenario, in isolation and in combination, in an attempt to determine what is responsible for restricting the activity of this student. Given the range of variables involved, it seems virtually impossible to determine where the student’s impairment begins and where that impairment might meld into disablism. Furthermore, this determination is essentially irrelevant to pragmatic education programmes which aim to maximise functioning for a student with autism.

What if a social relational model of disability, which allows for impairment ‘effects’, is instead used in our attempt to understand autism? Here, one must determine what the fundamental impairments of autism are, and by association, what their effects might be. One option would be to view the ‘triad of impairments’ as the fundamental underlying

impairments of autism. The consequences of these impairments then become impairment ‘effects’. In the case described above, socialisation would be the underlying impairment and the impairment effect then becomes isolated play in the classroom. However, Thomas defined ‘impairment effects’ as restrictions in activity caused as a direct result of innate impairment. If socialisation is viewed as the impairment and solitary play the impairment effect then it must be conceded that the student above is isolated as a result of intrinsic characteristics. This would mean denying that social attitudes or the classroom environment play any part in excluding this student from her peers. This conclusion is untenable. It is counterintuitive and does not connect with my experience as a teacher. Furthermore, it cannot account for the well documented tendency of children with autism to learn, and to interact with others, with greater success in structured and predictable environments (Grinker, 2008a; Iovannone et al., 2003; Jordan, 2005; Jordan & Jones, 1999).

The triad of impairments then do not appear to be the underlying impairments of autism, at least as understood by a social relational model of disability. What if the triad were instead viewed as ‘impairment effects’? There is increasing evidence of an as of yet unidentified biological aetiology to autism which may well represent the true fundamental impairment of ASD. In this case, the triad might be better described as a ‘triad of impairment effects’. Here too however, the ‘effects’ (for example socialisation challenges) are fundamentally a result of the underlying biological impairment and any role of social barriers in restricting the activity of an individual with autism must again be rejected. We are now back to essentially the same question we started with - where do we draw the line between an impairment (or impairment effect) of socialisation and a socially disabling societal barrier? Of course, this same argument could be repeated for the communication or imagination challenges of autism as well.

Even more importantly, how do these theoretical conceptualisations of disability translate to daily life for a student with autism? Take, for example, a teenage boy with extreme tactile defensiveness and sensory processing challenges such that he will not tolerate the feel of clothing against his skin. Forcing him to wear clothing causes extreme pain and results in unmanageable and lengthy tantrums which, to date, have kept him out of school. It could be argued that he is excluded from school due to

society's reaction to, and unwillingness to accept, nakedness. How then does one proceed? It is of course possible to theoretically conceive of a society which does not stigmatise nakedness. Note however, that the student cannot simply be moved to a remote society more accepting of his nakedness, the point of the social model of disability is to better include him in his own community. Instead, perhaps it would be possible to adapt society to be more tolerant of his needs. Perhaps it would be possible to remove modesty as a personality trait, eliminate the puritan values of some religions, set aside an entire fashion industry and remove concerns about hygiene in public places from the minds of consumers and health inspectors. Perhaps the small fact that this modification would in a sense be 'disabling' another group of individuals, namely the millions of people around the world who make a living in the production and sale of clothing, could be dismissed. However, it seems that the unfortunate but unavoidable reality of this situation is that it is the individual who must adapt to this society. For this student to be meaningfully included in educational opportunities and his community he must conform to an accepted cultural norm - he must learn to wear clothing. Whether this reality is just, whether it is a result of disabling societal structures and whether it is avoidable, all make for tantalising philosophical debate. They are however useless in mitigating the challenges this student, and his friends, family and educators for that matter, face in day to day life.

It is my position then, that addressing disability requires simultaneously directed efforts towards the removal of environmental and attitudinal barriers and to the rehabilitation of impairments. In fact, in an educational context at least, intrinsic and extrinsic barriers can be hard to differentiate, especially as pertains to autism. For example, the use of Picture Exchange Communication Systems (PECS) for children with autism would serve to remove an environmental barrier only if a student already had the ability to communicate but was not able to speak. On the other hand, pictures can also be useful pedagogic tools in teaching communication skills to a student with autism (Bondy & Frost, 1994), the majority of whom benefit from concrete visual instruction (Grinker, 2008a). In many instances, the use of PECS serves both as a communicative tool and instruction technique, thereby addressing both the social disability and bio-medical impairment. It seems then that current models of disability are not able to adequately conceptualise 'autism' as a disability. It is my contention that they are

similarly unable to account for cultural social-relational constructions of disability in disparate cultures, an argument to which I now turn.

### **1.7.2 A Challenge to Traditional Disability Models: Limited Utility for Education**

A deep understanding of disability models is critical as differing conceptualisations suggest adoption of different educational programmes and policies (Borsay, 1997; Lindsay, 2003). A view of disability consistent with the social model requires the equalisation of educational arrangements and lends itself to inclusive education. Some argue that successful IE *requires* conceptualisation of disability to be based on a social model of disability (Avoke, M, 2001; Tilstone et al., 1998). Interestingly however, the converse, that conceptualisation of disability based on the social model *requires* IE, may not be true. Equating the equalisation of educational opportunity to an equalisation of physical environments is, at the very least, contentious (Norwich, 2008a). As shown above, respecting fundamental human rights has come to be equated with a conceptualisation of disability based on a social model, which in turn mandates IE, which has achieved an almost iconic status with development organisations.

Many authors agree that meaningful development for people with disabilities requires them to plan and implement solutions on their own; policy and programmes dictated by outsiders are inadequate (Coleridge, 1993; Riddell & Watson, 2003; Werner, 1987). As donors have moved towards redefinition of disability seen through a social model lens, both services and aid offered to developing countries have followed suit without critical examination of this model for cultural relevance in those countries. As will be shown in chapter seven, this has resulted in confused SEN definition, policy and practice in Ghana. It will be argued that the tacit assumption of shared values, rights and beliefs is hubristic and potentially detrimental to the aims of the very programmes which are meant to ensure these values are upheld.

### ***1.7.3 A Challenge to Traditional Disability Models: Understanding Culture***

The social construction of disability is a complex process, one which is invariably influenced by individual circumstance and cultural context (Peters et al., 2005). Research into medical systems in Nepal support the notion that ideas, beliefs and practices are deeply embedded into the traditions of religious and ethnic groups (Streefland, 1985). Recognising this, Coleridge (1993) adds a third model of disability termed the ‘traditional model’, to the more commonly recognised medical and social models. Defined as the “construct created by religion and culture in any society” he acknowledges that most religions and cultures, including Christianity, view disability as a punishment from ancestors or divinities (pg 71). Patel (1995) acknowledges that despite claiming Christianity as their main religion, many Zimbabweans continue to believe in witchcraft, the power of ancestral spirits and traditional cures. This thesis will demonstrate the same to be true, to varying degrees, in Ghana.

In addition to spiritual belief systems, in many African cultures, an individuals’ primary duty is to one’s kin (Miles, M., 1999). ‘Impairment’ is viewed as any threat to the fulfilment of familial responsibilities or obligations. Some of these threats, such as the inability to marry due to unattractive looks (Stone, 1999c) would not be identified as ‘impairments’ in the traditional sense but are arguably ‘disabling’ in a culture which holds beauty in esteem and views childbirth as compulsory for full membership in society. The individual, social and interactive models of disability are all concerned with the individual in question. Even the social model, which is concerned with disabling societal structures and attitudes, does not address how the individual impacts upon that same society. In relatively communal cultures, such as Ghana, this impact could be debilitating to other members of an individual’s family or community.

It seems then, that notions of disability are embedded in both culture and religion, which are in many cases, inseparable from each other as well as from conceptions of health and health services (Patel et al., 1995). To truly accept disability as a social construct, a deep appreciation for, and understanding of, each culture’s conceptualisation of disability is essential in the recognition of societal factors which contribute to exclusion. The social and individual models of disability do not easily

incorporate a spiritual worldview. They also struggle to account for the relatively communal nature of Ghanaian society. These issues will be explored in greater depth in chapter four.

## 1.8 Definitions

Given the complexity of terms associated with conceptualising disability it is important to outline their usage in this document. It appears there is no ‘safe’ terminology. Terms described above are loaded, subject to interpretation and used differently across (or even within) contexts. However, their use in a project such as this is unavoidable. In an attempt to clarify and simplify potentially loaded terminology, the definitions below will be adopted throughout this thesis. Consistency is the intended goal but the complexity of terminology and the topic as a whole may contribute to the occasional, and perhaps inevitable, discrepancy.

The terms ‘individual model’ or ‘social model’ will be used to connote their extreme forms whereas ‘interactive model’ or ‘social relational model’ will be used to describe more moderate views which allow for an interaction between intrinsic and social contributors to disability.

Autism will, somewhat regrettably, be referred to as a ‘disorder’ as this is the preferred terminology in internationally agreed definitions which place autism under an umbrella of ‘pervasive developmental disorders’. In speaking about an individual *with* autism however, I prefer the term ‘condition’ as it implies an element of dynamism to the experience of autism and recognises that autism for that individual is a state of being at a particular time.

I will adopt the World Health Organization’s (WHO) definition of ‘impairment’ to mean “an abnormality or loss of any physiological or anatomical structure or function” (in Scheer & Groce, 1988, pp. 23-25). This refers to entirely innate biological characteristics. An exception to this however, will come when discussing the ‘triad of impairments’ in autism, taken to mean the combination of socialisation and communication challenges alongside restrictive and repetitive interests or play. As

discussed above, these may not be true impairments according to the WHO definition but as the terminology ‘triad of impairments’ is well established in the literature its usage makes sense here. However, for the sake of clarity I will avoid talking about each component of the triad as an impairment when discussed separately and instead use ‘challenge’ as often as possible (which is preferred to the more commonly used ‘deficit’). So, I will typically speak of the ‘triad of impairments’ but ‘socialisation impairment’ will become ‘socialisation challenge’.

While it is enticing to adopt Thomas’s definition of disability as a form of social oppression, its limited understanding as such in academic discourse, international development or Ghanaian policy, as well as its limited utility for educational programmes, makes this definition impractical and untenable for this thesis. This is in some ways regrettable as I can identify with Thomas’ quest to completely redefine the concept of disability to one of social oppression. For clarity’s sake I will use Thomas’ term ‘disablism’ or ‘Disability’ (capital D) to connote disablement as the sole result of social oppression and will further this line of thinking wherever possible.

For the purposes of this discussion then I define ‘disability’ as:

The *experience*, at any given point in time, of being restricted from activities of daily living or from full membership in society due to *either* intrinsic impairment or society’s inability or unwillingness to accommodate this impairment (through inflexible beliefs, attitudes, actions and environmental structures) or most commonly, through the *interaction* of these two factors.

It is hoped that the use of the term ‘experience’ implies both an element of time and dynamism to this definition while also allowing for the psycho-social element of identity and personhood to play a role. Importantly, this identity or experience is not limited in scope to an individual one and can incorporate the more collective nature of Ghanaian society (see chapter four). For example, a mother with a child with autism, if excluded from meaningful activities or membership in her community through discriminatory attitudes, could be ‘disabled’ alongside her child.

Importantly, my definition of disability does not preclude the possibility of *supportive* environmental and social structures as those can easily be incorporated into the



experience of an individual. If these supports serve to include an individual such that they are no longer restricted from activities, by either social barriers or their impairment, then they would not be deemed disabled using this definition. While acknowledging that impairment on its own may limit functioning, it is a person's experience of this limited functioning which I view as a potential disability. A vision impairment may limit a person's ability to read printed text but it is her thoughts, feelings and reactions to this impairment, alongside cultural factors such as the perception of blindness or necessity for reading in her community, which could potentially restrict her ability to function and therefore become a disability. Critically, this experience is likely to be culturally bound and dynamic over time and circumstance. Beliefs in causal explanations, valued traits and social structures will all play a role in experience. It should also be noted that this experience need not be a wholly negative one and can incorporate feelings of empowerment or pride over one's condition such as is often found in the Deaf community or Disabled Persons Organisations (DPO's). I hope in this way to help redefine disability away from a pejorative term which invokes feelings of pity or disdain, to a term which is merely descriptive of a state of being at a particular point in time.

Most importantly, I also hope that this definition provides a pragmatic path forward in suggesting that the experience of disability can be mitigated by management which simultaneously attempts to address the impairment, social barriers and the interaction between the two. With regards to autism then it becomes less crucial to determine where impairment begins and where impairment may meld into disability; either or both can restrict activity and the alleviation of either or both can lessen the challenges an individual with autism has to face on a day to day basis.

## **1.9 Researcher Positionality**

Throughout this thesis, disability and autism are viewed as socially constructed phenomenon. I believe that understanding concepts such as health, impairment, disability, human rights, inclusion, autism and personhood, to name just a few, require continuous navigation of, and interpretation through, one's own culture (as defined in chapter 3), experiences and beliefs. The definition of disability offered above suggests

it is an 'experience'. To an individual without an impairment, 'disability' cannot be understood through lived experience and is instead constructed and understood through external influences, which continually shape an individual's knowledge of, beliefs about and responses to, disability.

At its epistemological core, constructivism affirms that because knowledge is constructed (made) rather than discovered (found), therefore all knowledge is inseparable from the individual learner's language, cultural values, experiences, and interests...In other words, constructivism embraces rather than denies the role of human consciousness and moral autonomy as integral to learning (Gallagher, 2004, section 4).

This constructed experience of disability and autism in particular, is a central focus of this thesis. In fact, the field of disability studies and the social model of disability can themselves be seen as a response to similarly constructed concepts such as 'normality' and 'disability' or 'insider' and 'outsider' (Gallagher, 2004). Understanding disability as a constructed experience is consistent with my leanings towards critical realism (see chapter two) as well as with the social model of disability and inclusive education (Peters et al., 2005), concepts which will be dealt with throughout this thesis. While not all disability theorists would concur, I agree with Gallagher's (2004) supposition that social constructivism is consistent with the field of disability studies ultimate aim, to confront disablism and empower people with disabilities to make their own decisions in life. Indeed, in this light, categorisation and labelling of impairments or disorders (including autism) is in itself a constructed understanding of normality.

This constructivist researcher positionality is apparent in my interpretation and understanding of concepts and research findings throughout this thesis. For example, chapter four attempts an understanding of Ghanaian culture; it is argued that culture is continually constructed and simultaneously influences constructions of disability, both of which necessarily differ depending on individual circumstance and position. Additionally, if all knowledge is constructed, then so too is any knowledge taught and gleaned in any classroom context (Kugelmass, 2007). This has implications for pedagogy of all learning (Gallagher, 2004), as well as for understandings of the social model and inclusive education evolving from the historical devaluation of individuals with disabilities (Kugelmass, 2007), topics which will be explored in more detail in chapters seven and eight.

In addition, a belief in social construction of knowledge has implications for the research process itself (Dunne et al., 2005). If disability is a social construction influenced by beliefs and experience, this construction will logically differ both between and within stakeholder participant groups. Interpretation of these constructions will once again be subject to my own constructions through the research process, particularly during the analysis and writing stages (Crewe & Harrison, 1999; Dunne et al., 2005). The degree to which this dictates a relative position of ‘insider’ or ‘outsider’ researcher differs across each unique situation and with each individual participant. For example, at times my gender and age created greater researcher distance in a culture where status and respect are afforded to elderly members of the male gender. My teaching background and previous volunteer work with some respondents afforded me an ‘inside’ look at times, while my identity as a non-disabled researcher created challenges in a field which often advocates for emancipatory research (Marfo, 1999; Priestley, 2001; Stone, 1999a; Stone & Priestley, 1996; Stubbs, 1999). In an attempt to mitigate situations in which my outsider positionality was dominant, attempts were made at participatory research (see chapter two and appendix two). Ghanaians were well represented as critical friends but the voices of both children and individuals with autism are largely, and regrettably, missing from this research. I feel that my previous experience living in Ghana also allowed me to lessen, to some degree, the effects of being a relative outsider at times.

Clearly, there are both advantages and disadvantages to each of these positions. As an outsider I am unlikely to be afforded the same intuitive understanding of the social and cultural context of my research as an ‘insider’ researcher (Le Gallais, 2003). In addition, even if done unconsciously, anticipating what one expects to find in researching any given topic is a challenge perhaps heightened by an ‘insider’ position (Smith, 1999); a degree of distance may have allowed me to mitigate this challenge, at least with regards to cultural constructions of disability. This distance from intuitive constructions allowed me a degree of objectivity. It may also have resulted in more detailed explanations on behalf of respondents, in an attempt to ensure I understood the point they were trying to convey, especially when it was perceived that I lacked a shared intuitive understanding. In addition, embracing my ‘outsider’ status at times allowed me to access and question figures of authority with relative impunity.

However, it must be acknowledged that as a social constructivist one can never be truly an ‘outsider’ researcher as this suggests ultimate objectivity and positivistic discovery of finite knowledge.

In my relatively outsider role then, I was continually mindful of the possible rhetoric of the expected response, or answers which are given because they are thought to be those the researcher wants to hear. On the other hand, it is possible, especially given the sensitive and at times taboo nature of the research topic, that respondents may have actually felt more comfortable with an outsider researcher. While another Ghanaian would certainly ‘speak the same language’, both figuratively and literally, it is possible when viewed as an outsider I was afforded a position of relative distance and objectivity, at least in the eyes of my participants, which may have invoked feelings of trust. For example, family members may have felt empowered to relay sensitive information without worry of judgement or consequence and with a greater degree of trust in the confidentiality I guaranteed. On the other hand, this outsider position meant the research journey toward understanding Ghanaian constructions of culture, disability and autism was, at times, a lengthy and difficult process. The experience and input of ‘critical friends’ was invaluable in managing this process (see chapter 2).

While remaining as objective as possible was a goal of this research, my constructivist positionality requires acknowledgment of the ultimate futility of this; knowledge and understanding were continually constructed throughout this research, both for participants and researcher alike. At the same time, as an outsider I was able confront norms and expectations, to ask the question ‘why’ and to challenge the status quo in ways which would have been difficult for a Ghanaian. The use of methodologies consistent with a social constructivist stance, such as semi-structured interviews and the trialling of participatory methods, was innovative in a research culture familiar primarily with questionnaires. It also seems fairly unlikely that an indigenous researcher would, at least today, even set out to explore constructions of autism in Ghana, as it is not yet well understood or recognised. The next chapter further details both the methods and methodological stance of this research.

## Chapter 2

### Methods and Methodology

#### 2.1 Methodology

##### *2.1.1 Researcher Identity*

For over twelve years, I have committed myself to the educational needs of young children with disabilities, with a focus on autism spectrum disorders. I hold a BA in Psychology, a M.Ed in Early Childhood Special Education, an early childhood teaching certificate and am a board certified Behaviour Analyst. My extensive formal training has been entirely comprised of Western notions, definitions and treatments of disability. My long-held passion for travel and cross-cultural studies however, drove me to work abroad and lends itself to an intense desire to learn more about children and autism through the eyes of other cultures. Principally however, I am a teacher and a teacher educator. I am not a development specialist, economist or disability theorist.

Prior to conducting this research I lived and worked in Accra for just over two years where I was involved in a variety of programmes and projects, all involving education of children with SEN, which informed both the desire and design behind the current project. Knowledge of the Ghanaian educational context, alongside a cursory understanding of the beliefs and attitudes associated with disability, was essential in gleaned the information contained within this thesis in the time available. Contacts within the education system, critical friends and an understanding of Ghanaian logistics were all invaluable. Despite this, I still identify myself, as an ‘outsider’ researcher. As a non-disabled American, I view and interact with the world from a privileged mentality and carried many of the somewhat unavoidable assumptions and beliefs which arise from this background with me throughout this research. The deep-rooted belief that children with autism have a fundamental right to participate in society with equal membership, and that when they are afforded appropriate support and educational services, they can and do participate meaningfully in any community, has undoubtedly guided my previous experiences and influenced the very selection of the research topic itself. However, I was also constantly aware of this potential biasing. I was challenged

throughout by my own preconceived notions that the perceptions and fear surrounding autism act as a major and ‘unacceptable’ barrier to EFA, and that any fear and exclusion of children with autism in Ghana is discriminatory and unjust. My background and Western mentality lends itself to a natural inclination to want to change those perceptions and beliefs, which I believe can segregate and dehumanise individuals with autism and their families. However, the hubris of this position is also recognised and despite my natural inclinations, it was very important to me to avoid conducting research within a stereotypical Western mentality of ‘change’. If disability is truly defined as an ‘experience’, shaped throughout by social construction, then one must try to be conscious of a variety of preconceived notions and truly be open to alternative constructions. I strived to achieve this to the greatest extent possible.

### ***2.1.2 Research Philosophy***

My research questions concern the beliefs, perceptions, attitudes and treatment of autism in Ghana. Given the inherent social nature of this research, notions of a value-free objective reality where factual knowledge can be obtained through the ideal research design were rejected. An empirical analytical position that allows for positivistic assumptions fails to address the complex and sometimes counterintuitive or inconsistent relationships between knowledge, beliefs, understanding and practice.

Quantitative methods, which prioritise gaining statistically reliable and valid results surrounding pre-determined hypotheses, did not meet the aims of the current research. Largely culturally bound to Western thought processes, I felt that appreciation of the intricacies of emotionally laden and culturally shaped beliefs, experiences and interactions would not be sufficiently gained through quantitative methods alone. Given research aims that are descriptive and explanatory, qualitative methodologies, which prioritise the meaning that individuals ascribe to experiences or events, were deemed more appropriate.

A theoretical framework incorporating clear ontological and epistemological positions is challenging given that *both* the process of the research being conducted, and the subject matter being studied, are highly socially constrained. Whilst I might subscribe

to a certain way of thought regarding the research process itself, the nature of the research questions may simultaneously ascribe a different set of epistemological views to the individuals being researched.

The current research is guided by the tradition of critical realism which holds that an independent objective reality exists, but is essentially unobtainable, as each individual views 'reality' through a potentially different lens. It is more important to understand how individuals and cultures make sense of 'reality' than to aim for a relatively meaningless objective truth. This epistemological view is clearly evident in the working definition of disability as both an 'experience' and a 'condition'. Moreover, the purpose of critical research "to uncover non-explicit processes and relations...and communicate those to people so they may act upon them in order to improve society", is highly consistent with the personal aims of the project (Scheyvens & Storey, 2003, pp. 21).

According to critical realists, reality is both highly subjective and fluid (Dunne et al., 2005; Miles, M. & Huberman, 1994). While the reality of natural science can be empirically examined and understood, studying the social necessarily requires that an individual's uniquely constructed reality is examined through conversation.

Information collected through conversation is subsequently subjectively interpreted by the researcher (Willig, 2001). In the current research, immanent interpretation occurs at two distinct levels, first in the way that research participants interpret their own views surrounding disability and again as I interpreted this information through my own culturally constructed lens and role as a researcher. As a previously quantitative researcher, my natural inclination and past experience was to want to minimise researcher effect, to be concerned with issues of reliability and validity and to engage in empirical experimental research with a positivistic mentality. However, while it is sometimes tempting to think subjective interpretation can be avoided, the premise of this research was that culturally constructed, perhaps implicit, unintentional and unrecognised negative perceptions of disabilities can fundamentally contribute to inequitable treatment of students with autism. It therefore seems inconsistent and hubristic to maintain that I am not subject to similar unacknowledged assumptions from my own cultural, moral and educational background as is being ascribed to research

participants. The research questions I was interested in lead me to the inevitable use of unfamiliar and unnerving research methods, data interpretation and epistemological and ontological views.

A critical realist view of knowledge as fluid allows for an epistemological constructivist model of the social which asserts that knowledge is dependent on human perception and social experiences (Dunne et al., 2005; Scheyvens & Storey, 2003). Social constructivism suggests that experience and reality are constructed through language and context, not through an objective reality (Willig, 2001). This is consistent with the research premise that disability, specifically autism, is a socially constructed phenomenon. This research presupposed that perceptions of disability are continually *constructed* from knowledge and experience gained from tradition, education, religion, values and culturally bound norms. Constructionists view social context and environment as crucial to the construction of knowledge, which is consistent with the critical realist supposition that knowledge is not finite but fluid. If knowledge can be reconstructed in light of changing circumstances (additional knowledge, education, societal pressures, international influences, etc), then research participants (and indeed the researcher) maintain agency over their own actions and potential for future betterment of their own society. This constructionist perspective is consistent with my poststructuralist leanings in understanding culture, as discussed in chapter four (Dunne et al., 2005). My research was also founded on a desire to honour collaborative and emancipatory approaches, most obviously in the use of ‘critical friends’ to inform research procedures, as described below.

Traditional models of disability are imbued with tacit assumptions about a person's methodological leanings. For example, Shakespeare (2006) questions the tautological circle of the social model in its implicit assumption that the social is ontologically authentic whereas the physical and biological are not. Similarly, the individual model, in denying the lived experience and social influences on disability, can be seen as requiring an extreme positivist stance (Kristiansen & Kermit, 2007). Given my own epistemological and ontological leanings towards critical realism, it is no wonder that I fail to connect with either the traditional social or individual model dichotomy.



Proponents of either extreme model position themselves as offering the one true understanding of disability, a position which critical realism rejects.

A strong movement in recent disability studies calls for emancipatory research, defined as research that involves those with disabilities at all levels such that they are in control of their own fate and progress (Priestley, 2001; Stone, 1999a, 1999c). However, proponents of this type of research rarely account for the fact that many individuals with disabilities may not want to, or may not always have the ability to, participate. Individuals with disabilities in the developing world may be more concerned with the day to day tasks of life (Miles, M., 1999) than they are with participating in research or political advocacy. Those that do choose to participate may not represent the individuals in greatest need of a voice, such as those with a severe intellectual impairment. Given the aim of uncovering perceptions surrounding young children with autism, two qualities which make participation difficult and subjugation in research likely, true emancipatory research was regrettably inappropriate and unfeasible. A desire behind, and initial attempts to, engage both parties (i.e. children with autism and DPO's) were unsuccessful. The participation of key stakeholders concerned with the rights and education of young children with autism as critical friends was the best alternative to truly emancipatory disability research.

### **Critical Friends**

Having previously spent a significant period of time in Ghana, I was in the unusual and fortunate position of having established relationships which afforded me the trust of a number of extremely knowledgeable and dedicated individuals. These individuals, in the spirit of emancipatory research, became 'critical friends' (Stubbs, 1999). The six 'critical friends' included: a mother of an adult son with autism, a teacher working in an autism classroom, a speech and language pathologist, a paediatrician, the Head of a private preschool and a former Director of the Special Education Division within GES. It should be noted that in the spirit of emancipatory research a highly accomplished Deaf individual in the education sector was invited to act as a critical friend but declined to do so. It is unfortunate that in keeping their identities confidential I cannot accurately recognise the contribution and invaluable assistance, especially in the research conceptualisation phase, of critical friends. In addition to advice regarding

data collection methods, critical friends afforded me the collaborative discourse required to maintain as much research objectivity as possible. Due to voluntary participation in the research, those selected as critical friends were only expected to participate to the extent they were willing, and were therefore thought of as guides throughout the research process.

The engagement of Ghanaians was firmly rooted in the belief that they have just as much, if not more, information, knowledge and skills to impart as they do to gain. The conviction that lasting change or ‘development’ can only occur with the empowerment and commitment of stakeholders at the local level should be evident from the methodological underpinnings of the research, and is highly consistent with the decision to involve and gain from the experience of local stakeholders.

While not a conscious part of the research design, other Ghanaian contacts have also been instrumental in furthering my ideas during the analysis and writing stages. University of Sussex links with Ghanaian universities and researchers have provided a unique opportunity for collaborative discourse throughout. Full time PhD students and visiting researchers, all with considerable experience in the Ghanaian education system, have provided hours of stimulating conversation regarding some of the complexities of the information reported in the subsequent chapters. Perhaps most valuable were reassurances that I was on the right track and that I was ‘understanding Ghana well’, which provided both the motivation and confidence to carry on during some of the more challenging moments.

## **2.2 Methods**

### ***2.2.1 Research Location***

Given practicalities, logistics and the researcher’s familiarity with the city, Accra served as the primary research location. As the capital city and epicentre of resources, Accra is also where any services in the country that are specific to autism do exist, and where I worked in various programmes for two years prior to commencing research. As such, it was felt that focusing research on Accra would allow me greater access to families of

children with autism (as they would potentially be seeking services in Accra) as well as professionals within the MoESS and GES at the national level. The exploratory nature of the research, as well as initial personal contacts, made ‘snowball’ sampling a desirable and valid technique. Given potential disparities in urban and rural beliefs, it was hoped that the use of snowball sampling would lead me into truly rural settings. However, as quickly became apparent during pilot data collection, the nature of the research topic itself made this unfeasible during the time allotted. The trust afforded to the researcher through previous relationships was essential in gaining meaningful information. Longer term ethnographic research would have been necessary to gain this trust and address my research questions in remote rural settings.

While the majority of data was obtained in Accra, attempts were made to gather information from additional regional locations including Cape Coast in the Central Region, Ho in the Volta Region, Koforidua in the Eastern Region and Winneba in the Greater Accra Region. While these locations are still prominent cities within their regions and cannot be said to represent rural villages, they are nonetheless somewhat removed from the modernisation and globalisation of the capital city. Unfortunately, time constraints, travel logistics and snowball sampling methods used did not allow for data collection in the Northern Regions of Ghana, an area consistently identified by participants as being more traditional in their beliefs and practices as compared to the rest of the country.

Despite a lack of travel to many of regions of the country, diversity within Accra allowed me to speak with a wide range of participants, many of whom identified themselves as being from the Northern or Eastern regions. Four distinct tribes were represented although the majority of participants identified themselves as Ga or Ashanti. However, the gathering of information across four regions, diverse participant characteristics and analysis of nationally relevant education policy and provision allowed for later data analysis and reporting of information using ‘Ghana’ as the prominent level of analysis (as compared to Accra or Sub-Saharan or West Africa).

### **2.2.2 Procedures**

Fieldwork was conducted over nine months during the period between October 2006 and December 2007. Two trips were undertaken, the first, which served as a pilot stage, lasted three months; the second was 6 months in duration.

#### **Pilot Stage**

Given the exploratory aims of my research and an awareness of the potential complexities in speaking about a fairly taboo topic, the pilot stage was aimed at finalising research methodology for later stages of the project.

#### **Focus Group**

An initial ‘focus group’ meeting was organised with critical friends during the first week of fieldwork. This meeting was intended to allow me to reconnect with old contacts and to gain their insights in finalising the methods to be used during data collection. Critical friends’ participation in the focus group meeting was entirely voluntary, the meeting lasted two and a half hours and drinks and snacks were provided. All participants were thanked for their attendance with a small token, as is customary in Ghanaian culture. This gift was given at the beginning of this first meeting such that it was not contingent on participation during any research stage.

During the meeting we discussed a range of possible previously identified data collection techniques, a number of which were participatory activities, as well as draft interview questions. Critical friends also participated in a ‘word picture’ activity which was intended to generate terms which could be used to describe autism when speaking to respondents who were unfamiliar with this term. The activity involved brainstorming, grouping and ranking generated terms which were commonly associated with autism in Ghana. The terms generated, while useful in understanding autism, were ultimately deemed inappropriate for their intended usage. The activity however was a rich source of data which is reported throughout and detailed in appendix one.

### **2.2.3 The Plan**

The focus group meeting with critical friends was undertaken in the spirit of emancipatory research to ensure participation of local stakeholders in the research process. It was intended to make the research more participatory. Instead, it called into question the degree to which 'Participatory Learning and Action' (PLA) methods were appropriate. On the advice of critical friends, most if not all PLA methods previously identified would have been discarded. The belief that critical friends have both more knowledge of, and experience with, autism in the Ghanaian culture conflicted with my own belief in participatory research and triangulation of multiple methods. Attitudes of critical friends were understandable, I was however resistant to discount methods simply because they were new and unfamiliar to critical friends. It was believed that since critical friends had no experience with such PLA methods they would not be able to accurately predict their success or failure. On the other hand, it was felt that the reactions of educated critical friends were likely to be mirrored by participants when faced with these same methods in the field.

A main premise of the upcoming research was a commitment to value local knowledge and to the empowerment of Ghanaian stakeholders, i.e. critical friends. I felt the need to respect and honour their contribution; why else had I called them all together for a focus group meeting if not to listen to their experience and advice? On the other hand, my commitment to this research was drawn out of a desire to break the traditional mould, to gather valuable information and to conduct novel and groundbreaking research thereby exposing stakeholders to new ideas, methodologies and ways of collecting information.

Given the success of participatory methods in countless contexts (Chambers, 2002; Maguire, 1987; Mukherjee, 2002; Nelson & Wright, 1995; Pretty et al., 1995), I made the difficult decision to go forward with the pilot testing of various PLA methods despite the reservations of critical friends. I did however, decide against the use of free and interpretive drawings on their advice and continued insistence that asking literate adults to draw a picture could be considered juvenile and insulting. Other drawing, mapping and ranking activities were pilot tested. A description of the methods trialled

during pilot testing but not subsequently used in the main data collection phase of my research can be found in appendix two.

### **2.2.4 The Reality**

#### **Informed Consent**

While informed consent was a critical aspect of the research process it did call into question the necessity of *written* consent procedures. Like researchers before me I was initially perplexed by considerations of what ‘consent’ truly means in developing or oral cultures (Barata et al., 2006; Boschma et al., 2003; Koistinen, 2006; Miller & Boulton, 2007; Newton & Appiah-Poku, 2007). To me, written consent in Ghana, a primarily oral culture, seemed inappropriate despite commitments to the principles of informed consent. I had the opportunity to interview very senior professionals (such as ministers, directors, etc.) who, given an underlying culture of political diplomacy and potential culpability, may have found signing their name to any document to be quite threatening. I felt respondents would be inclined to change their responses if they felt the interview was quite a formal process in the way that a signed consent form would make it appear. Critical friends confirmed this assumption and strongly advised against written consent procedures with senior professionals. Other respondents were not literate and would potentially be embarrassed if they were not able to read a consent form, or even perhaps to sign their name to it. While this would only be the case for some participants, it was not always easy to tell who was and who was not, literate. Finally, in an oral culture such as Ghana very little is written down on a daily basis and therefore using such a tool seems only to widen the gap between researcher and participant in a situation in which I was already quite conscious of potential power dynamics. For the above reasons, I felt that a signed consent form was inappropriate and had the potential to cause more harm than good by unsettling my research participants. An oral consent procedure was devised.

During initial contact (either in person or on the phone), I gave a brief description of my research, told them I was interested in talking with them for about one hour and arranged a meeting at their preferred location. At the very beginning of that meeting, I remind participants about my research aims, going into a bit more detail. I informed

them of the procedure, highlighted voluntary participation and their right to skip any question or stop at any time and finally asked them if they would still like to talk with me. This oral procedure also allowed me to vary my tone and language used for explanation to my audience and their education level to ensure full understanding by each participant. A written form was also produced and provided when deemed appropriate (see appendix three). The occasional usage of this form reinforced notions of its inappropriateness. As one participant said best:

*You said his parents wouldn't know I was speaking to you, how can it be [anonymous] if I sign my name here. You don't know my [sur]name but if I sign it, you will know. You see? –Anonymous*

## Respondents

Research participants were selected in an effort to include as many key stakeholders as possible. Participants from three key stakeholder groups were recruited for participation: 'family members', 'professionals' and 'community members'. These three groups were broadly defined and represented varied interests, needs and involvement in the education of children with autism.

1. **Family Members:** For the purposes of this research, 'family' was defined liberally to account for a more inclusive notion of family among Ghanaians than typical of the West. This group included parents, siblings, extended blood relations and 'aunties' or 'uncles', i.e., anyone with a vested interest in the well-being of the identified child and who shares in household knowledge and responsibilities. Of critical importance is whether the child and his/her parents viewed the individual as 'family'.
2. **Professionals:** this diverse group was defined as anyone who had a professional stake in either education or autism and represents a broad range of knowledge and experience. This group includes teachers, assistants for individual children, Heads of schools, Ministry officials, officers within the various divisions of the Ghana Education Service, doctors and medical health professionals. Professionals were included from various levels within the education system including classroom, school, district, regional and national levels.
3. **Community Members:** This group is comprised of anyone who did not have a direct connection with, or responsibility to, an individual with autism. Of particular interest were those who had little to no knowledge about autism and related disabilities as I wanted to understand commonly held beliefs and attitudes towards autistic traits.

### **2.2.5 Second Fieldwork Stage**

An initial meeting with Ato Essuman, the Chief Director of the Ministry of Education, Science and Sports, resulted in a letter of introduction and support for the current research project. This letter of introduction, which is standard practice in Ghana, opened avenues for greater snowball sampling and allowed for interviews of many key informants holding senior positions within the national education system. Over the next six months, the following procedures were utilised:

#### **Interviews**

Semi-structured interviews (SSI) were the main method of data collection. Using SSI procedures it was not necessary to design specific interview questions ahead of time, instead a checklist of information and general lines of enquiry guided the interview process (Bryman, 2004; Kvale, 1996). In this way, no two interviews were the same and took their own shape based on the directions participants chose and their responses. The open-ended, exploratory and participatory nature of semi-structured interviews was seen as more appropriate in meeting the aims of the proposed research than rigid fixed question interviews. I attempted to ask open-ended, probing, non-directive and non-judgemental questions. Critical friends assisted in the identification of possible interview topics by commenting on suggested draft questions given to them during the initial focus group session. They were able to inform me of the level of appropriateness of certain subjects and alert me to potentially taboo lines of inquiry. Of particular concern were the ethical implications, and validity concerns, of questions surrounding highly sensitive information in a society in which questioning one another is not the norm (Stubbs, 1999). Considerations of interview procedures, location, setting, seating arrangements, timing and interviewer body language were all structured in an effort to value the knowledge of the interviewee and minimise the danger of a potentially hierarchical didactic interview. In seeking to conduct truly participatory semi-structured interviews, respondents were encouraged and empowered to ask questions of the interviewer themselves. Thirty interviews were conducted across the three key stakeholder participant groups. An example of a typical interview can be read in appendix four.



**Table 5: Stakeholder Interviews**

	Semi-Structured Interview
Professionals	13
Family Members	9
Community Members	8
TOTAL	30

All interviews occurred on an individual basis with the exception of two teachers who preferred to be interviewed together. Given the language limitations of the researcher, interviews were conducted in English. In one instance however, snowball sampling led to a situation in which the researcher was faced with an interviewee with limited English language skills. In this instance, the language restricted interview was conducted in Fanti with the regional director, who set up the interview, present as an interpreter.

Interviews with family members began by asking them to relate a narrative of their ‘life-history’ as relevant to their child with autism. They were encouraged to tell their story, in their own words and without interruption. Family members were encouraged to share their moments of hardship and joy and to describe how these have impacted upon the life of their child and their family. Semi-structured interview themes were explored, and probing follow-up questions asked, of family members to gain additional information not related during the telling of their oral-life history.

In response to advice from critical friends, and with their assistance, a fictional ‘story’ about a Ghanaian child named Kofi, who exhibited characteristics of autism, was written. Interviews with most community members, who were chosen as they had little or no direct experience of autism, began with a reading (either by me or by them as they preferred) of the Kofi story. It was then possible to ask questions about ‘Kofi’ during the interview rather than using the term ‘autism’ (which was not mentioned in the story). The Kofi story can be read in appendix five.

### **Other Verbal Methods**

As part of SSI sessions, some respondents, as time allowed, were asked to relate proverbs they might have heard regarding disability. Some researchers have examined

the linguistic properties, structure and meaning behind language and proverbs (Agbenyega, 2003; Appiah et al., 2007; Devlieger, 1999; Kisanji, 1995) while others have attempted to interpret and analyse Ghanaian culture through the analysis of oral traditions, myths, proverbs, religion and philosophies (Akyeampong, E. & Obeng, 1995; Appiah et al., 2007; Cottrell, 2007). Enticed by methods employed by Kisanji (1995) when studying disability in Tanzania I asked some participants to generate proverbs associated with health or impairment. If they struggled to come up with any they were asked instead to interpret up to five common West African proverbs which had been previously identified in consultation with critical friends and narrative texts. During the fieldwork process, it became apparent that proverbs were potentially more powerful for advocacy purposes than descriptive purposes. Some participants in the later stages of data collection were therefore asked to generate proverbs which could be used to counter negative stereotypes. These are detailed in appendix six.

### **Visual PLA Methods**

Visual methods, largely taken from a catalogue of participatory methods have been shown to be a highly successful mode of collecting information when researching a sensitive or taboo topic (Chambers, 1997, 2002; Mukherjee, 2002). Their use was intended as a secondary data source to add to the breadth of overall information collected and an attempt to bypass the rhetoric of the expected response. Additionally, in the spirit of participatory and emancipatory research, visual methods would allow for the participation of respondents who were non-literate (from rural communities, children, individuals with disabilities, etc.) as methods involved the use of diagrams and pictures (Stubbs, 1999). Selection of PLA techniques occurred in consultation with critical friends but unfortunately, subsequent pilot testing did not glean the depth or breadth of desired information (see Appendix 2 for additional details).

### **Ranking and Scoring**

Ranking and scoring techniques are of particular significance to the current research as they act as tools for the analysis of difference in unequal relationships by assessing people's expectations, beliefs and attitudes (Mikkelsen & Dillon, 2006). In an initial meeting with critical friends, possible ranking and scoring techniques were offered for consideration. The one they felt had the most potential for future advocacy and policy

initiatives was that of an adapted well-being ranking procedure. Well-being ranking is generally used to contribute to an analysis of difference between members of a community as well as to illuminate which characteristics of personhood are valued above others in a society. It was decided that a disability ranking exercise in which participants ranked and commented on different disabilities would reveal some of this information. Given the specific labels used to talk about different disabilities this ranking activity was given to participants during an in-service inclusion training for mainstream GES teachers who would shortly be faced with inclusive classrooms. The ten disabilities and labels used for this ranking procedure were duplicated from training materials and presented in the same order as in the training manual. Participants were asked to rank the disabilities in order from those with the best ‘prospect for a successful life’ to those with the ‘least prospect for a successful life’. A total of 23 participants from the professional stakeholder group chose to complete this voluntary individual activity at two separate in-service trainings.

Given methodological concerns about the applicability of Western disability labels, a second ranking exercise was created in which traits of autism were listed. The format was mimicked from the first ranking exercise but no mention of the label autism was used. Thirteen different participants at one in-service training participated in this ranking activity.

Additionally, on the recommendation of critical friends, the word-picture brainstorm and ranking activity was duplicated with approximately 20 parents at a parent advocacy group meeting and seminar organised by a local paediatrician.

### **Diagramming and Visualisation Methods**

Upon the advice of critical friends and pilot testing results, drawing and mapping exercises were not used. Picture and video interpretation was conducted with five community member respondents but did not prove a fruitful source of data. For additional information see Appendix 2.

## Text Analysis

For the purposes of this research ‘text analysis’ is defined as the examination of any *locally* gathered or written secondary source of information. In this way, a distinction is drawn between knowledge gained locally through cultural texts and viewed as data, and the ongoing literature review of publicly available information which informs the research process. The analysis of local texts, particularly myths, proverbs and folklore, assisted in understandings of the rich history of Ghanaian culture, a history, it is proposed, which is the foundation on which cultural constructions of disability and autism are formed. Miles (1999) proposes that the history of a culture, sometimes forgotten and invisible, forms the very ‘cultural bedrock’ upon which all future knowledge is built. He further suggests that the analysis of cultural texts, far too often overlooked by Western researchers as a key source of relevant information, has the potential to reveal ways in which international development programs can fit within the relevant cultural context, thereby increasing the likelihood of success. While many researchers in the past have attempted to explore indigenous knowledge through fieldwork, few have started with the analysis of local information through textual or pictorial sources (Stubbs, 1999). The current research was informed by information from relevant sources including:

1. Political Documents: Government policy surrounding education and disability from relevant Ministries and the Ghana Education Service
2. Unpublished national or regional statistics, where available
3. Curriculum Documents
4. Media: newspaper articles, journal or magazine articles and radio and television broadcasts
5. Folklore: proverbs, mythology and folktales
6. Art: paintings, drama and Adinkra symbols

**Table 6: Number of Research Participants**

	SSI	Word Picture Activity	Kofi Story Interpretation	Disability Ranking	Trait Ranking	Proverb Interpretation
Professionals	13	18	14	26	11	20
Family Members	9	20	0	0	0	0
Community Members	8		3			5
TOTAL	30	44	17	26	11	25

### **2.2.6 Data Analysis**

Given the constructivist methodological stance and hermeneutic research aims of the current project, the use of Qualitative Content Analysis was apposite. Initially, interviews were transcribed and subsequently coded using ‘Thematic Coding’ guidelines developed by Flick (2006). Thematic coding is used when comparison of information across groups or themes identified prior to data collection and derived from the research questions, is desired. Thematic coding is of particular relevance when research questions concern the “social distribution of perspectives on a phenomenon or a process” in which differing beliefs or viewpoints are expected (Flick, 2006 pp. 307). Coding was a fluid process, initial codes were developed prior to data collection, were likely revised in my mind throughout the interview process and were adapted throughout as data analysis and writing progressed. While the major themes remained consistent, specific codes were revised and regrouped throughout. The qualitative data management programme Nvivo was used as an organisational tool in this process.

Given the exploratory nature of the research, data from as many different sources, gathered in as many different ways as possible, was thought to provide the richest information (Mukherjee, 2002; Stubbs, 1999). Triangulation, simply defined as “looking at things from different points of view” (Mikkelsen & Dillon, 2006) was the intended goal. I intended to gather data from each of three strategies, namely visual PLA methods, verbal ‘listening’ methods and text analysis to add to the overall breadth information collected. While many methods were pilot tested, and some utilised further during the second fieldwork phase, none gleaned the depth or breadth of information which was conveyed during semi-structured interviews. For this reason, interview data comprises the majority of information reported in this thesis. Alternative methods will be used as secondary sources and referred to when appropriate.

### **2.2.7 The Writing**

This thesis is an attempt at multidisciplinary research. I have accessed, incorporated and been influenced by background literature from various fields including education, disability studies, anthropology, sociology, philosophy, psychology, economics and international development. While I have attempted to draw on and integrate a wide

range of diverse theories, this may lead to inconsistencies which fail to fit squarely within the traditions and accepted norms of any one discipline. My justification for these potential disparities is that ideas as overarching as ‘culture’ and ‘personhood’ are dynamic, inconsistent and cross disciplinary; adhering to the norms of any one discipline would ignore what others have to offer and place this study amongst the many others which fail to collaborate and draw on the strengths of diverse ideas.

After wrestling with concerns about egocentrism I have ultimately succumbed to the realisation that this work has been a largely self serving intellectual journey and that the views represented here are mine alone. It is for this reason that I have chosen to write in the first person. Academic distance would suggest an air of objectivity which I can neither guarantee nor subscribe to; the view that there is one ultimate truth is inconsistent with the methodological stance above.

In order to respect the authenticity of interview responses I have decided to leave quotes largely untouched. This means that in many instances grammatical errors such as inconsistent pronoun usage (i.e. switching 'he' for 'she') have not been corrected. I felt the reader would be able to adequately unpack the message of these quotes and that frequent interruption with the expression [sic.] would disrupt the flow of participant's ideas. Unfortunately, due to space constraints, I have at times needed to shorten often powerful sentiments in participant responses. I have used three dots (...) to indicate the removal of a sentence or less and four dots (....) to indicate the removal of more than a sentence. In some instances, I have added clarification words or phrases to these quotes and have used square brackets to indicate this. To protect patient confidentiality and anonymity any and all names of children or respondents used throughout this thesis are pseudonyms.

Finally, to respect participant confidentiality and guarantee anonymity it has often been necessary to obscure potentially important and revealing information about respondents. I was fortunate to speak with many high level government officials and while it has been tempting at times to reveal their position alongside certain quotes to afford those ideas additional weight, it would be unethical to do so. For consistency

sake then I have used the following labels in indicating the ‘author’ of cited interview responses

**Table 7: Interview Respondent Descriptions**

<b>Stakeholder Group</b>	<b>Description</b>	<b>‘Label’ used in Thesis</b>
<b>Family Member</b>	Of the 9 family members I spoke with 3 were fathers, 5 were mothers and 1 was a grandmother who was the child’s primary caregiver and guardian. For simplicity’s sake, these family members will all be referred to as parents. Some are also given pseudonyms in chapter six where I discuss their experiences in greater depth	<i>Parent</i>
<b>Community Members</b>	I interviewed 8 community members, 4 of whom were males and 4 females. All could be considered relatively young adults (approximately 20-40 years of age) although exact ages were not obtained. Street vendors, a media reporter, neighbours and friends from previous experiences in Ghana are all examples of the type of community member who participated in this research.	<i>Community Member</i>
<b>Professionals</b>	This group was diverse as described above. The 13 professionals I interviewed will be grouped under three headings: teacher, professional and senior professional. Senior professionals are national level professionals holding top positions within the MoESS or GES, teachers are those working at a classroom level and professionals are those not better included in the previous two categories.	<i>Professional</i> <i>Senior Professional</i> <i>Teacher</i>

## Chapter 3

### Discovering Autism in Ghana

#### Introduction

The term Autism comes from the Greek word *autos*, meaning ‘self’ (Happé, 1994). Working independently, both Leo Kanner and Hans Asperger published papers first identifying and describing the disorder of autism in 1943 and 1944 respectively (Asperger & Frith, 1991; Kanner, 1943). The definition of autism provided by Hans Asperger was far broader than that described by Kanner and included higher-functioning children with intact linguistic abilities. Today, the term ‘Asperger’s Disorder’ is used to describe someone who resembles an individual with autism in many ways, but who has attained relatively normal intelligence levels and intact language abilities. Kanner’s initial description is more in line with the current diagnostic criteria for autism. However, current thinking recognises the complexity of the disorder and the multitude of different presentations identified to date has sparked momentum towards the redefinition of autism as part of a ‘spectrum’.

Prevalence estimates of autism vary and have ranged from the accepted and widely stated figure of 1 in every 150 people in the USA (Centers for Disease Control and Prevention, 2007) to the highest reported estimates claiming that up to half of the population fall on the autism spectrum (Edelson, 2008). A large gender difference in prevalence of the disorder exists, with four to five times as many males diagnosed with autism as females (Bailey et al., 1996; First, 2008). While the exact cause has baffled researchers for years, there is increasing evidence of a genetic predisposition coupled with an environmental trigger which activates the relevant but as of yet undiscovered gene(s) (Daley, 2002; Dyches et al., 2004; Pellicano, 2007). The majority of researchers agree that there is a biological aetiology to autism with some authors suggesting this is evidenced by its universality across cultures. (Cuccaro et al., 1996; Daley, 2002).



### 3.1 Diagnostic Criteria for Autism

A brief description of the clinical labels will assist further discussion. Clinical diagnostic criteria for a range of disorders is outlined in two main documents, the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, Text Revision (DSM IV-TR) and the International Classification of Diseases, 10<sup>th</sup> Edition (ICD-10). The DSM is traditionally used in the USA where it was developed, however it informs the ICD-10 criteria and has recently been taken up for use by a number of additional countries. The ICD was developed by the World Health Organization and is the most widely used diagnostic criteria around the world. The DSM IV-TR label of ‘Autistic Disorder’ is generally accepted to be equivalent to the ICD-10’s ‘Childhood Autism’ (Wing, 2008) and sits with other disorders (such as Asperger’s) under the larger clinical category of ‘Pervasive Developmental Disorders’ (PDD). Other disorders such as Tourette’s Syndrome and Attention Deficit or Attention Deficit Hyperactive Disorder (ADD/ADHD) are often confused with ASD; these disorders can occur alongside autism within a child but are not considered to be on the autistic spectrum when they occur in isolation (Wing, 2008). The two manuals use slightly different terminology and diagnostic criteria for autism; labels are detailed in Table 8.

**Table 8: Pervasive Developmental Disorders**

<b>DSM-IV-TR</b>	<b>ICD-10</b>
Autistic Disorder	Childhood Autism
Asperger Disorder	Asperger Syndrome
Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)	Atypical Autism
Rett’s Disorder	Rett’s Syndrome
Childhood Disintegrative Disorder	Other Childhood Disintegrative Disorder

(Wing, 2008)

Despite clearly defined diagnostic criteria, conceptualisation of autism has been a fluid process evolving and changing dramatically since its original definition (Daley & Sigman, 2002; Dyches et al., 2004; Pellicano, 2007). This has resulted in confusion over, and revision of, diagnostic criteria over time. Perhaps Dyches et. al (2004) illuminate the situation best when they state:

The professional literature is replete with controversy, and even hostility, in the exploration of ways to define, assess, and diagnose the disorder (pp. 212).

Movement from practitioners towards the term ‘autism spectrum disorder’ (ASD) has further complicated research and literature, as ASD is not a clinical diagnosis to date though it is roughly analogous to the clinical category ‘Pervasive Developmental Disorders’ of which autism is a part (Wing, 2008). Revision of the diagnostic label to ‘autism spectrum disorders’ is widely predicted for inclusion in the DSM-V, expected in 2011. Application of diagnostic criteria by clinicians is likely to vary considerably across cultures (Daley, 2002; Daley & Sigman, 2002), is of questionable relevance to developing countries (Fryers, 1986) and may have limited utility for educational purposes (Grinker, 2008a; Jordan, 1997).

### **3.2 Autism across Cultures**

There is a scarcity of research into autism in non-western cultures and even less which examines autism through a cross-cultural perspective (Daley, 2002; Daley & Sigman, 2002; Dyches et al., 2004; Fryers, 1986; Ingstad & Whyte, 1995). Despite this, the Autism Society of America state on their website that:

Autism knows no racial, ethnic, or social boundaries. Family income, lifestyle, and educational levels do not affect the chance of autism’s occurrence (www.autism-society.org, 2009).

A quick Google search finds this phrase replicated on countless international autism information websites. While there may be a political justification for this claim, likely aimed at ensuring equitable service provision in the USA, the notion of a universality to ASD seems to be unproblematically accepted in international discussions of aetiology, assessment and service provision.

The cultural research which does exist generally takes the form of unpublished dissertations or case studies and largely minimises discussions of cultural factors (Daley, 2002). Extensive literature review revealed only one study examining cultural influences on autism as a specific disorder in an African context. In an effort to question the universality of autism well before its time, Lotter (1978) attempted to compare the prevalence of autism across 6 African countries (including Ghana) with rates found in Britain. Lotter (1978) concluded “some of the behavioural symptoms which define the syndrome childhood autism do occur amongst children in developing countries in Africa”, although at rates less common than in Britain (pg 239). Lotter

(1978) concedes however, that it is not possible to determine whether the lower prevalence rates were a result of lower incidence of the disorder in African populations or less common expression of the symptoms of autism across Africa. A third possibility is that the symptoms which were viewed as autistic through the eyes of Lotter (1978) and his team of British researchers were not culturally relevant and therefore not as salient to African clinicians. Unfortunately, dramatic changes in understandings of autism since Lotter conducted his study make generalisation of his findings difficult and very little research has followed in his footsteps since.

Limited research does tend to support a relatively stable picture of the expression and prevalence of autism across cultures or ethnicity (Cuccaro et al., 1996; Daley, 2002). However, these studies largely detail ‘developed’ European or Asian countries. Cohen and Volkmar (1997) use the inclusion of chapters from international perspectives in their Handbook of Autism to claim a ‘nearly universal acceptance’ of the diagnostic criteria of autism but they fail to acknowledge that these countries represent a small subset of the world which comprises only relatively ‘developed’ countries. Notably, African nations are not represented. Unfortunately, the latest edition of this Handbook includes only one broad chapter on ‘international perspectives’ (Volkmar et al., 2005). Conclusions such as “it is readily apparent that autism varies little across culture, ethnic group membership, and [socioeconomic status] SES” (Cuccaro et al., 1996, pp. 462) seem premature based on the research available.

As of 2009 however, a database maintained by ‘Action for Autism<sup>11</sup>’ lists national autism organisations in over 100 countries around the globe, many of which are African or from other ‘developing’ nations. This suggests that, at the very least, the terminology ‘autism’, and possibly the diagnostic category, has become a truly international concept (Daley, 2002). Autistic-like features occur in non-clinical populations and it has been suggested that the autism spectrum exists on a continuum with normal behaviour (Brown-Wright & Gumley, 2007). However, throughout the history of autism the core characteristic of social and communication difficulties along with limited interests and repetitive behaviour patterns, have remained constant and when found together, still define the disorder today (Dyches et al., 2004). It is this triad

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<sup>11</sup> <http://www.autism-india.org/worldorgs.html>, accessed 05 September 2009

of impairments which will be examined for cultural consistency and relevance in Ghana. The remainder of this chapter will examine the diagnostic criteria for autism, attempting to verify these traits in stakeholder accounts of autism in Ghana.

### **3.3 Autism's Triad of Impairments in Ghana**

In an effort to identify those characteristics that are specific and universal to the disorder, Wing and Gould (1979) outlined the now widely accepted 'triad of impairments'. Despite different manifestations of these impairments, all children with autism (or on the autism spectrum) will demonstrate impairment in the areas of *socialisation, communication and imagination*<sup>12</sup>.

#### **3.3.1 Socialisation**

Difficulty with socialisation is a fundamental trait of autism, but this difficulty can present itself in diverse ways, hence there is no universal presentation of the socialisation challenges experienced by children with autism. Wing and Gould (1979) proposed three sub-classifications of autism, that of the 'aloof child', the 'passive child' and the 'active but odd child'. The classically 'aloof child' may present (perhaps deceptively so) as unfriendly and detached whereas the 'active but odd' child will likely seek out interaction but does not always know how to utilise socially appropriate ways of engaging others. The 'passive child' typically responds to the social approaches of others but may fail to initiate interactions with others on their own. Perhaps the most commonly recognised description of autism is one of complete avoidance of social contact or 'autistic aloneness', a term first coined by Kanner (1943). 'Autistic aloneness' is used to describe the profound aloofness of a small minority of individuals with autism who appear to retreat into a world of comfort within themselves, blocking out the external world. However, autism is far more typically associated with milder social anxiety, awkward social or play skills, avoidance of eye-contact and socially inappropriate behaviour.

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<sup>12</sup> For reviews of autism and its characteristics and symptomology presentation see: (Bailey et al., 1996; Cohen & Volkmar, 1997; Edelson, 2008; Grinker, 2008a; Happé, 1994; Jordan, 1997; Volkmar, 2005; Volkmar et al., 2005; Wolf-Schein, 1996)

The pattern of social challenges described above has been consistently recorded across cultures which recognise and diagnose autism. It is how however, critical to first establish whether this same pattern of socialisation challenges can be found in Ghanaian children who are considered to have autism. Interviews did support this consistency and revealed remarkably similar social challenges in students with autism in Ghana. Some participants identified ‘aloof’ individuals who do not appear to wish to, or do not seem to know how to, integrate with others:

*You see them they are different, they are different [than] those that they are playing with...they like to play alone. And if you watch them if you sit at the back and watch them you see that the person, the way she is behaving or he is behaving, is not normal. –Teacher*

*They play alone, they don't play with any of the children, they just play alone. If you ask them anything, they won't talk. They won't answer. –Teacher*

Other comments suggest a presentation of socialisation challenges similar to the ‘passive child’:

*The peers, you know some peers when you try to make this kid f, if for instance...I might like to walk with you to [meet] my friends, you can even stand there and be flat like that by not talking not doing any action but we ff would talk. –Community Member*

Still other participants described what could be termed the ‘active but odd’ social presentation of autism. One parent spoke at length about her son being mocked at school.

*When he is at school students are always taking advantage of him, they mock him. –Parent*

Observation of this student revealed that the ‘odd’ behaviours his peers were mocking were often attempts to communicate or join in with his peers such as waving to them with slightly awkward but excited arm movements.

Socialisation challenges of autism also involve difficulty in understanding expected but often unstated rules of social behaviour:

*Well sometimes it is hard because he doesn't always know, if someone enters [the bus] and there is a space next to him he won't just shift over, they have to ask him to shift. –Parent*

In addition to more global social challenges, respondents also described specific challenges often associated with autism, such as an avoidance of eye-contact.

*But you know he can't, he doesn't like eye contact. –Parent*

Children with autism often demonstrate sensitivity to sensory stimulation, which can further complicate their socialisation challenges. An aversion to touch may cause them to resist physical contact which, in the extreme, can produce a pattern known as ‘tactile defensiveness’. Similarly, they may also suffer a sensory overload from auditory or visual input. High pitched or repetitious noises can cause extreme discomfort for some children with autism, as can bright lights or certain colours. Unlike adults and typically developing children, children with autism appear unable to habituate to these inputs, which to them seem intolerable. Evidence of these same tendencies was found in children with autism in Ghana:

*Some [students] will be crying, they like to close their ears, cover them tight. I didn't know why they do this and one day I asked Mr. [teacher] and he just said it is because they can hear noises so much from everywhere, even out there on the street, the noises you can't hear right now, they can hear them. –Teacher*

Given the interdependence of communication and socialisation skills it is often difficult to determine where challenges with one meld into the other. In Ghana, challenges with social communication, both in understanding and in expression, were also evident in interview responses.

### **3.3.2 Communication**

The second universal characteristic of autism is found in difficulties with communication but, as with socialisation, the range of possible communication challenges experienced by a child with autism can be vast. Even so, whether the child with autism is completely mute, speaks with odd accompanying gestures or simply mimics what others say, impairment in communication is by definition universal to all children with autism. Communication skills can be broken down into those which are expressive (an output of communication) and those that are receptive (the ability to understand and process communication inputs). Children with autism will nearly always demonstrate challenges with both receptive and expressive aspects of communication, as they did in Ghana.

#### **Expressive Communication**

Expressive communication refers to the full range of strategies used to convey one's beliefs or desires, whether those are verbal or non-verbal and whether they are initiated or in response to others. Children with autism may have challenges in any or all of

these skills. Some children with autism are completely non-verbal while others may have limited verbal abilities or unclear speech due to oral motor difficulties. Other children may demonstrate fluid speech but lack non-verbal communication skills such as the appropriate use of gestures or facial expressions. It is important to differentiate between expressive communication, taken to mean the complete set of behaviours and rules of language used to express oneself, from speech, a *verbal* production of that language. All children on the autism spectrum will have communication challenges, though those with high functioning autism or Asperger's Syndrome will, by definition, present with fluid speech. Challenges with expressive communication, including speech production, were evident in interviews:

*At the time, you might even be surprised of the way they speak to other people; do you understand [them]? - Community Member*

*He has delayed speech. Which means that, well it covers so many things, which mean that you ask him anything he can't tell you anything but he understands everything – Parent*

*But he can't speak, he can't, he doesn't know how to say, you know, even though he might think you are sweet but he wouldn't have the courage [ability] to tell you. – Community Member*

*When he needs something he will come and hold you [pull you to it], what of the speech? -Parent*

*Like they are just delayed or the time for them to talk has been delayed. –Teacher*

*But I have heard the attendant [at school] teaching him 'ah', 'apple' and now he can pronounce those things. But you see the only problem is that he on his own will not take maybe apple and say 'apple'. Or he will not see you and call you 'daddy' but when you say it, he will say it [back]. Or if you say, who is this? He hasn't gotten to that stage. -Parent*

Another common portrait of expressive communication challenges in children with autism is echolalia, a term used to describe the tendency to repeat back, or 'echo', others' speech. This behaviour, in children with autism, often continues well past when it would be considered typical of language development. Some echolalia serves no apparent purpose for the child, suggesting minimal mental processing. In other cases, echolalia is actively used to communicate and may become a response to others. For example, a parent may ask their child if they would like a drink. Rather than responding "yes", the child with echolalia will respond "drink" to communicate their desire. Phrases or entire sentences may be repeated, apparently at random. Echolalia, while not always termed as such, was reported by multiple respondents when describing the behaviour of children with autism:

*But [he is] listening, because now he has been reciting some of these... British [television] adverts, he recites them, yes he has got all of the short ones. -Parent*

*And also, when they are verbal it is always echolalic. When you say 'what is your name' this boy [points to a student in distance] will say 'what is your name, [boy's name]' -Teacher*

*They realised that when they mentioned a word he repeats the same thing. -Parent*

Pronoun reversal, or the tendency to reverse appropriate pronouns in speech, is also commonly associated with autism. This, paired with echolalia, will often lead a child with autism to repeat questions they have heard before as a way of conveying a desire. For example, a child with autism who says 'do you want a drink?' may really mean, 'I want a drink'. Pronoun reversal also includes speaking in the third person rather than using the pronoun 'I', such that a child may say 'Eric want to play' in place of 'I want to play'. In discussing the cross-cultural representation of ASD, Daley (2002) wonders how this idiosyncrasy translates to cultures whose language does not contain pronouns. In Ghana, pronoun reversal was observed to be quite common in everyday speech. When speaking in English, Ghanaians would often use 'you' or 'we' in place of 'I' and tended to refer to both males and females as 'he'. In attempting to determine if and how Ghanaian local languages used pronouns, and how they were then subsequently translated into English, a conversation with a Ghanaian colleague revealed the following:

*We do, we do use the pronouns [in local languages], but you see it is depending on who you are talking to. You would express yourself in different ways.*

It seems then that the added complexity of social rules in the use of language, such as speaking with respect to an elder, may influence the ways pronouns are used in Ghanaian languages. In response to the observation that 'you' is often substituted for 'I' as in, for example, 'you go to the market and they just try and cheat you', my colleague remarked:

*Maybe it is a way of distancing oneself. You see, people wouldn't want to own up, when I am not sure, not close to you, they are not sure whether people see it in the same way. If you don't have the courage to stand alone you just construct it in a way to include those who you are talk to hoping they will see the 'I' in 'you'.*

This suggestion would seem to suggest an outlook rooted in the collective nature of society and a tendency to maintain the status quo, issues which will be explored further in the next chapter. Interestingly, in the preponderance of interview quotes throughout this thesis, respondents tended to speak in terms of 'we' rather than I. While a complete linguistic examination of Ghanaian languages is beyond the scope of this thesis, it is



worth highlighting the cultural relativity of some autistic traits. Differences in the way pronouns are used in local languages and subsequently translated into English suggest it may be inappropriate to judge pronoun reversal as evidence of impaired communication in a Ghanaian child with autism. It is also noteworthy that research in the USA indicates that communication delays can be compounded by the use of multiple languages in the home (Kremer-Sadlik, 2005). If this pattern holds, it follows that children with autism in Ghana would be hindered by the commonplace usage of multiple languages, including during instruction in educational settings. However, research undertaken on an Indian sample of students with ASD revealed multilingual abilities in children with ASD, one of whom was fluent in five languages (Daley, 2002). In addition, Kremer-Sadlik (2005) highlights the potential exclusion which can occur when a child is not taught the dominant language of their home and community. It is clear that additional research is needed on the impact of multilingualism for communication abilities in students with autism in Ghana.

## **Receptive Communication**

Children with autism will almost certainly have challenges with receptive communication alongside their expressive communication difficulties. Children with severe delays may only understand very short or even single word utterances. Long complex instructions such as ‘it is time to leave, go and get your coat and put it on’, may only be understood if shortened considerably to ‘put coat on’, ‘get coat’ or even just ‘coat’. Interestingly in Ghana, difficulties in receptive understanding, coupled with a tendency for adults to speak to children only when instructive, resulted in the manifestation of receptive language challenges largely as a failure to comply with directions. Given the status and role of a child in Ghanaian society, it seems that the inability to follow directions can be particularly stigmatising and was typically interpreted as ‘bad’ or ‘stubborn’ behaviour.

*Yes. And with the behaviours, they [parents] tell you ‘this child is too stubborn, he wouldn’t hear’. They’ll tell us our children are very stubborn. So... they don’t really know what is wrong with the[ir] child -Teacher*

*Yeah, when you come to the autism, many people do not know they are children with disabilities. They just think they are some normal children who are very hard, [they don’t come when you] call, and [not] listening to stuff. For that children, until I talked with this special education thing [training], I didn’t know that such behaviours were part of disabilities. So we generally will tend [to think] those children, like he is very stubborn. -Professional*

*... they will [think what they] have is a stubborn boy, like maybe back at home the mother will always beat him because he is very stubborn, [she says] don't do this, he keeps doing it. Or at school, the teacher will always give him some lashes because he is stubborn, [the teacher] keeps repeating things that he not [doing but] is supposed to do [and he doesn't listen]. -Professional*

Serpell (1993) discusses research by Dasen and colleagues which examines notions of intelligence among the Baoulé tribe, a subdivision of the Akan ethnic group. One of the most important aspects of intelligence was found to be that of 'servability', someone who is obliging, always ready to be accommodating. Combined with *agnyhie*, roughly analogous to 'respect, obedience and politeness', it comprises the 'most important concept of intelligence among the Baoulé. While never explicitly discussed, parents did subtly indicate the importance of 'servability' in Ghanaian society.

*Sometimes I send him, take the cup, go and give it to Momma. He will stand there look at you. Or sometimes he will even leave it there and he doesn't want to go and sometimes you send him, go and put this at the kitchen he will be there you will hear 'thump thump', [he] just go and throw it out and come back. [Laughs] -Parent*

*Now, he listens to instructions. Previously, when you tell, give him instructions he wouldn't obey you. But now, the lights, 'go and put the lights' he knows that. -Parent*

A child's expected role in Ghanaian society will have further implications for the inclusion, or lack thereof, in education and society. I will explore these issues further in chapter five.

### **3.3.3 Imagination**

The last universal impairment identified by Wing and Gould (1979) was termed 'imagination' but is somewhat easier to understand as an 'insistence on sameness' or 'resistance to change'. Jordan (1997) describes these imagination difficulties as "flexibility impairments" in "both thinking and behaviour" (pg 11). While challenges with 'imagination' must occur alongside communication and socialisation challenges for autism to be present, they represent many of the quintessential 'autistic' behaviours in mainstream understandings of the disorder.

The DSM-IV criterion for 'autistic disorder' defines this trait as "restricted, repetitive, and stereotyped patterns of behavior, interest, and activities". These behaviours can be divided into two subcategories, insistence on sameness and repetitive motor behaviours. Recent discussions on the revision of diagnostic criteria for the DSM-V have suggested

splitting these two facets as they might have different implications with regards to both presentation and treatment of the disability (First, 2008).

### **Insistence on Sameness**

Insistence on sameness in rituals, fixed or limited interests and topical compulsions are all common presentations of the imagination challenges experienced by many children with autism. This may manifest itself as a preference for learning rote facts about seemingly mundane (but concrete) topics such as memorising the name for every type of bird imaginable or a fascination with the inner workings of plane engines. Concrete topics appear to be preferred to more typical (social and imaginative) activities like telling stories or enacting in imaginative scenes with props (Grinker, 2008a).

Compulsive interests were evident in children in Ghana as evidenced by interview responses as well as observational sessions.

*He is always bringing things back [to the house], electrical things, remnants of old TV sets and things, he is leaving them around everywhere....There is one person in town who always gives him the parts I am talking about. But he has so many, they are always lying around and he gets very upset if I try and remove [them]. –Parent*

*He is obsessed with water. He would like to sit in the bath for hours, will watch it from the tap, the garden hose. He makes a mess all over the house, in the kitchen and the bath. The teacher has complained he is always making a mess at school too, when he goes to wash his hands. –Parent*

### **Repetitive Behaviours**

A focus on concrete topics often leads to very limited, unimaginative and at times, inappropriate play. Play with toys is, for example, often repetitive and the function of the toy misunderstood or ignored. A child with autism might sit with a toy car and spin the wheel repeatedly while staring at it in an almost hypnotic trance, rather than “drive” the car around the room. Some behaviours seem to mimic obsessive-compulsive behaviour such as lining up toys in perfect rows or moving items from one side of the room to another repeatedly. Other repetitive behaviours do not entail the use of objects but involve sensory motor sensations such as toe walking, rocking back and forth, hand flapping, head banging or repetitive oral noises.

These self-stimulatory behaviours are often displayed by children with autism and are best understood as a fascination by the movement or the sensation produced by the behaviour. At times, this appears to be a security measure, something controllable and

familiar in unpredictable situations. Stereotyped and repetitive motor movements were evident in descriptions of children with autism in Ghana and were frequently observed in students at schools I visited throughout fieldwork.

*Many of them are always looking at their hands, doing like this [placed hands in front of eyes with fingers spread apart, turned head to one side to look at hand out of corner of eye]. They will always be laughing or shouting, making loud noises. – Teacher*

*This one [pointing] he likes to spin and jump, always spinning and jumping and making these noises, and [he likes] swinging too. - Teacher*

Overall then, children with autism in Ghana shared the typical ‘imagination’ challenges as expected, including repetitive and restricted play, insistence on sameness and repetitive utterances and motor behaviours.

### **3.3.4 Putting the Triad of Impairments Together:**

It is important to remind ourselves that what is unique about autism is the *combination* of these three fundamental challenges. Communication and socialisation challenges alongside restricted interests, while universal to autism, are only unique to the disorder when presented in combination. Happé notes that a ‘qualitative shift’ occurs when all three impairments present together making it less likely that an individual can compensate for challenges in other domains (in First, 2008). For example, an impairment in socialisation may cause the child to shut out, and hence not attend to, the outside world. This child therefore does not naturally learn vocabulary, communication or normative rules of behaviours through interaction with his environment, as typical development would occur. Thus, a socialisation challenge causes a delay in language and communication, and this in turn further inhibits social interaction. This cycle continues throughout development, leaving the child with autism far behind his or her typically developing peers. These impairments are then potentially confounded even further by societal attitudes and structures, creating disability.

*And some [peers] too, after realising you are not responding to whatever they are saying to you, they will just ignore, and they will not come close to you [again] - Teacher*

This quote also hints at the additional impact social barriers (i.e. Disability) can have on a student with autism. Without the necessary prerequisite knowledge or compassion, peers may exclude the student further, creating a societal barrier to the full inclusion of this student.

*Interviewer: If you could fix just one thing to improve their day to day lives in society here in Ghana what would it be?*

*Respondent: Probably socialisation. That is the most important thing. It is difficult for them, they feel not wanted, feel something is missing from them. It is difficult to manage. You know if you give someone with an intellectual disability a hug they become so happy. Socialisation is important. –Professional*

While this professional is referring more to the willingness of others to socialise with children with autism, this arguably creates a damaging cyclical pattern whereby children with autism are unable to learn or practice appropriate socialisation skills given the resistance of others to interact with them. Clearly, the triad of impairments interact with each other as well as with societal and environmental barriers to form a complete and extremely complex pattern of behaviours that affect the child with autism's educational needs and prospects. Furthermore, it appears that this complete portrait of autism transcends cultural barriers and can be found amongst Ghanaian children.

### **3.4 Autism in Ghana**

The above exploration of autism in Ghana would seem to support research which argues for a relatively stable portrait of the triad of impairments across cultures (Cohen & Volkmar, 1997; Cuccaro et al., 1996; Daley, 2002; Volkmar et al., 2005) and diffuses suggestions that autism is found only in technologically advanced societies with a nuclear family structure (Sauna, 1984 in Dyches et al., 2004). However, upon closer reflection a potentially serious methodological flaw in this conclusion becomes apparent. Interview respondents above fall into two possible categories, those who are familiar with the label autism and those who are not.

In the first instance, many respondents, including the majority of community members and some professionals, were unfamiliar with the term 'autism'. As a result, they may not have been thinking about, or referring to, children I would define as having autism when giving accounts of autistic tendencies. As discussed above, many of the symptoms of autism are not unique to the disorder in isolation; it is the combination of challenges, which defines autism. Many of these behaviours also occur in typical development; it is the intensity and duration which make them indications of autism, not their mere existence. It is highly possible then that some responses above refer to a

child with a different impairment. Piecing these statements together to prove autism exists in Ghana is therefore potentially problematic.

The second group of respondents are those more familiar with the terminology and diagnostic criteria of autism, which includes the majority of parents and professionals quoted above. I am more confident that these respondents were referring to children with the combination of, and interaction between, the triad of impairments in their testimonies. In fact, many of the parents cited in this chapter have children who received an official diagnosis of autism and many of the teachers were those working in specialist programmes. Initially reassuring, this too is potentially problematic. If children have received an official diagnosis using criteria that outlines this triad of impairments, then finding these same behaviours would be expected!

Perhaps a better methodology would have been to independently observe a large group of children, identify those with possible undiagnosed autism and speak to their parents and teachers regarding these children. This too however, rests on identifying children based on my own previous conceptualisation of autism and its impairments. Here too, I am suggesting these impairments are ‘disabling’, an assumption which would first need to be validated in a Ghanaian context. Are these same traits- challenges with socialisation, communication and imagination- even seen as disordered behaviour in Ghana?

This tautological circle appears inevitable when it is acknowledged that both the label and concept of ‘autism’ in Ghana are entirely Western creations and imports. ‘Disabilities’ in Ghana are historically defined with the labels ‘mild, moderate and severe’. Even today, policies and provision often delineate ‘mental handicap’ only from vision or hearing impairments; very few distinctions are drawn within the large and heterogeneous class of ‘intellectual disabilities’.

*I do, I know it [autism] from working here but most Ghanaians won't know of it. We do not see a distinction between different mental problems, we only group them under one generic idea, they are all the same -Teacher*

*I heard the word 'autism' and I think I know a bit about autism people. Autism isn't big in this country; people don't understand autism very well. -Community Member*

If the purpose of my investigation in Ghana was to prove the existence of autism these challenges would indeed be a major methodological flaw. However, my research questions centred on exploring the beliefs *surrounding* autism. In order to explore the cultural understandings of, and reactions to, autism, I first need to define it. In doing so, I have necessarily placed my own perceptions about the impairments I would expect to find in children with autism onto Ghanaian society. While philosophically I may oppose this echo of imperialistic domination, in practice it seems impossible to avoid the inevitable transmission of ‘autism’ in a modern world of global information (Grinker, 2008a, 2008b). As shown above, parent advocacy groups for children with autism already exist in over 100 countries around the world, including Ghana. Furthermore, my personal experiences in Ghana over a period of three years leave me confident that autism, as I understand it, does indeed exist in this context, a supposition supported by increasing evidence of a biological aetiology to the disorder. Furthermore, acknowledging that the label and diagnosis criteria of autism are Western imports does not negate the importance of exploring the disability through a cross-cultural lens.

If the assertion that there is little or no variation in the presentation of symptoms is correct, one rationale for studying autism within a cultural context is that autism may be used as a tool to better understand culture. Similar symptomatology would allow for purer comparison of the contextual factors of the disorder by holding ‘differentness’ constant (Daley, 2002, pp. 537).

Taking autism as a constant then, it is now possible to explore its presentation in a Ghanaian context for the understanding of culture this illuminates.

Evidence from Ghana seems to support Daley’s (2002) supposition that the “most accurate view of autism is as a biological condition that is culturally shaped in symptoms and course” (pp. 543). If agreement on the disabling nature of the triad of impairments is reached, the ways in which they present and interact is still likely to be culturally constrained. For example, if authoritative hierarchical social structures in Ghana lead a doctor to expect a well-behaved child in his office to be mute or aloof, then these traits would not necessarily be identified as problematic on a clinical visit. Similarly, in China, gestures are discouraged and persistence is highly valued (First, 2008). These autistic tendencies then would be less problematic or ‘othering’ in such a culture. Lotter (1978) noted that some autistic tendencies were less common in African nations as compared to Britain. He particularly noted an absence of repetitive

stereotypic behaviours (such as hand flapping or head banging), a commonly occurring characteristic in other countries. So, while the diagnostic requirement of ‘markedly restricted repertoire of activities and interests’ may have been met, it was not commonly expressed through stereotyped body motions in Ghana. It is this *expression* of autism which is of central importance to the current study.

Even if differences in the expression of the triad of impairments across cultures are acknowledged, is this expression consistent *within* a given culture? In other words, are there groups of behaviours that are culturally bound or is the expression of these behaviours innately determined? If children in Ghana are less prone to display repetitive motor behaviours and simultaneously have less access to toys with which to focus their repetitive play, how will the restricted and repetitive interests of autism be expressed in Ghana and will this expression be consistent across children? Even if the impairments are expressed in similar ways, how will these behaviours be viewed through a cultural lens? For example, will a lack of eye contact be problematic in a culture where children do not typically look their elders in the eye? How will a disorder of social intuition and relatedness affect children in a relatively collective society?

### **3.5 Conclusion**

A picture is beginning to emerge that while the triad of impairments is evident in Ghanaian children with autism, the expression of each impairment, and its significance to daily life, are culturally bound. It is this expression, or experience of, autism that I turn to in chapter five. First however, chapter four will attempt to paint a picture of a relatively shared ‘Ghanaian worldview’, understood as the culturally mediated lens through which autism and impairment are viewed. This ‘worldview’ will then be used in subsequent chapters as a guide to understanding attitudes, beliefs and actions which impact upon the experience of autism in Ghana.



## Chapter 4

### Understanding Ghanaian Culture

#### Introduction

*Obadwemma hwɛ ade-dada so yɛ a, w'afuo yɛ foforo na cnto ade-dada ntwene yɛ foforo*

*A wise person looks at an old thing in order to make it a new one, and he does not throw away the old before making the new.*

(Appiah et al., 2007, pp. 20:184)

There can be no doubt of culture's existence and its importance in shaping and ordering our lives. One must look no further than the common experience of 'culture shock' when landing in a foreign country filled with unfamiliar sights, sounds, smells and behavioural norms. The further this 'culture' is from our own the more we initially struggle to make sense of, and operate within, it. After a period of time however, one adapts, settles in to a new way of thinking and doing things, only then to be 'shocked' once again upon return to their own culture. But what is this 'culture' that they are reacting to?

A culture is a group of people with a shared set of beliefs and practices, which are passed down from one generation to the next. These beliefs and practices are the cornerstone upon which individuals frame their understanding of the world around them and their role within this world (Groce, 1999b, pp. 288)

Culture, whether we understand it as a pattern of behaviour or as a system of meanings, is the product of a historically defined social group (Serpell, 1993, pp. 2)

Culture does not belong only to the past. It evolves in response to outside influences and to the fact that people innovate and create new cultural traits....Culture is the complex whole of knowledge, wisdom, values, attitudes, customs and multiple resources which a community have inherited, adopted or created in order to flourish in the context of its social and natural environment (Verhelst & Tyndale, 2002, pp. 10)

These three definitions seem together to create a complete and useful tool for understanding culture. The more dynamic nature of culture expressed by the latter two definitions are enhanced by Groce's (1999) respect for history and tradition as a continuing influence on beliefs and actions. Serpell (1993) recognises that culture is a *product* while Verhelst and Tyndale (2002) acknowledge that, in an ever globalising world, belief systems evolve as a result of external influences as much as historical

traditions. Importantly, all three definitions seem to acknowledge that culture, though dynamic, is also well anchored in tradition.

*We still stick to the traditional old way, one way. This is what my grandfather did, my great great grandfather did. So, this is what we must follow. Even after the school. - Parent*

It is important to recognise and respect that sometimes resistance to change is a conscious decision.

It is not all of our societal norms and values, customs, and beliefs that can be said to enhance development, but there are those that have helped to keep our people together for centuries and are such an important value system that, in spite of increasing modernisation and development, they need to be preserved for prosperity. (Interview with Susan Waffa-Ogoo, Secretary of State for Tourism and Culture of Gambia, in Verhelst & Tyndale, 2002 pp. 3)

While some values and traditions are cherished, others do seem to be malleable over time.

...changes have transformed Ghanaian society into what it is today. However, not everything has changed. Chieftaincy is still in practice; traditional kinships systems are still in practice; and our annual festivals continue to be held with even greater pomp and pageantry. Though these and many other features of our traditional culture are also changing, gradually, a study of Ghana without a knowledge of them and their past forms, organizations and functions will not give a true and complete picture of the country's current social reality (Nukunya, 2003, pp. 4)

Clearly, in Ghana, there are tensions between, and continual negations of, traditional values and ever expanding external influences. It is only through an exploration of, and appreciation for, cultural context and history, both traditional and evolving, that one can really begin to understand the perceptions of autism in Ghanaian society and the impact of this perception on inclusion in society. Critically, if individual attitudes and behaviours towards children with autism are influenced by a set of cultural norms, history and beliefs, then these must be understood and respected in any development programme which may serve, even accidentally, to act in opposition to them.

Verhelst and Tyndale (2002) suggest that any given culture has three 'dimensions': *the symbolic* (values, beliefs, myths, spirituality and religion), *the societal* (organisational structures of family and community) and *the technological* (skills, expertise and technology) (pp. 10). It will be useful to look at each of these dimensions in the Ghanaian context, though I will necessarily limit discussions of technological aspects to those relevant to education. Using these three dimensions of culture as a framework,

the remainder of this chapter will examine aspects of, and influences on, Ghanaian culture in as much as it can be defined. I will attempt to paint a picture of relatively shared ‘Ghanaian worldview’ (for lack of better terminology) which is understood as the cultural lens through which thoughts, beliefs, attitudes and subsequent actions are all filtered. Literature review<sup>13</sup>, interview responses and text analysis will all inform an understanding of Ghanaian culture as relevant to the current research, divided, somewhat arbitrarily, using the three dimensions of culture described above. The remainder of this thesis will then use this ‘worldview’ as a framework for understanding subsequent findings and I will attempt to demonstrate that this culturally influenced outlook on life affects how autism is understood and managed in Ghana, even if only subconsciously.

## **4.1 The Symbolic Dimension**

An abundance of what Verhelst and Tyndale term the ‘symbolic’ dimension of culture can be found in Ghana. Spirituality and religion seem to permeate almost all aspects of Ghanaian culture and daily life and as such necessarily influences the experience of autism in Ghanaian society. In addition, a long and rich history of symbolic art, storytelling, proverbs and oration both illuminates and further influences values which are cherished today. An understanding of the spiritual and artistic aspects of Ghanaian culture is explored below.

### **4.1.1 Proverbs**

The genius, wit and spirit of a Nation are discovered by their proverbs  
(Francis Bacon in Appiah et al., 2007, pp. xii).

Proverbs have long been used as interpretive devices in the understanding of African belief systems (Appiah et al., 2007; Devlieger, 1999) and no analysis of Ghanaian

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<sup>13</sup> Authors writing about Ghanaian culture from a variety of perspectives will aid this discussion. Kuanda & Chachah are Ghanaian authors who, upon living in Denmark for many years, felt the need to help foreigners “gain some understanding of the culturally prescribed rules of behaviour among Ghanaians” (preface). Their book is both written and published in Ghana. Salm & Falola are historians of West African culture, both working in History departments of American universities. Falola is Nigerian. Nukunya is a Ghanaian Professor of Sociology at the University of Ghana, Legon. Utley is a British teacher who originally volunteered in Ghana with VSO and has been carrying out educational research consultancy projects in the country since. He has a special interest in Ghanaian culture and language and has written this book with the purpose of assisting travellers or foreigners to understand Ghanaian culture, though it is not a traditional guide book.

culture would be complete without looking at the meaning and use of proverbs in Ghanaian society today. Ghanaian tribes have long used proverbs to both understand and express their reality (Akyeampong, E. & Obeng, 1995; Appiah et al., 2007). Today, proverbs remain respected tools of oration, wisdom and history. They can be used as a polite form of criticism in situations where direct disparagement could cause offence or to summarise what would otherwise be a long or tedious conversation (Appiah et al., 2007). While in-depth linguistic analysis of proverbs is beyond the scope of the current research, what is essential is an understanding of the use and power of proverbs in Ghanaian culture.

Proverbs contain the philosophy, humour, symbolism, and religion of the peoples who use them. They are imbued with a deep knowledge of the surrounding world, physical and spiritual, and of social realities. No one can appreciate the philosophy and beliefs of the Akan without studying their proverbs (Appiah et al., 2007).

As proverbs act as a frame of reference in the understanding of Ghanaian history, culture and belief systems they can be used to shed light on conceptualisations of childhood, personhood and disability in Ghanaian society throughout this thesis. Proverbs, gathered both during fieldwork and through text analysis, will be used as data throughout this thesis in an attempt to highlight significant aspects of Ghanaian culture. Additionally, chapter nine will highlight the potential of proverbs as a tool for combating discriminatory attitudes through advocacy efforts. Proverbs often accompany Adinkra symbols (see below) or are presented as the moral lesson which concludes a traditional folk-tale and as such are inseparable from these other aspects of symbolic culture.

### ***4.1.2 Folktales and Storytelling***

Ghana has a rich oral tradition of storytelling and folk-tales are believed to contain the history and collective wisdom of a people<sup>14</sup>. As they have no known author, it is often believed that the stories are as old as the various tribal nations which tell them (Cottrell, 2007). Some believe these stories and folk-tales were “composed by the sages to serve as a code of conduct for good and acceptable behaviour” (Cottrell, 2007, pp. xxii) and

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<sup>14</sup> For accounts of traditional Ghanaian folk-tales retold in English see (Addo, 1968; Appiah, 1966, 1967, 1979; Appiah & Dickson, 1969; Cottrell, 2007). All of these detail stories of the Ashanti with the exception of Cottrell (2007) who translates traditional Ewe folk-tales. There appear to be remarkable similarities across these stories. For interesting accounts of ‘African’ folk-lore beyond a strictly Ghanaian context see (Brew-Hammond, 2000; Mahama, 2000; Vernon-Jackson, 1999)

as such their significance in understanding Ghanaian culture and worldview cannot be understated. As with those who skilfully use proverbs, skilled orators and storytellers are highly respected in Ghanaian society, a position which is typically inflated by elder status. While space limitations do not allow for an intriguing diversion into an analysis of traditional folklore, it is worth a brief transgression to highlight the most salient aspects.

Anthropomorphism is a common theme in Ghanaian folklore; animals are imbued with human characteristics. Perhaps this is an attempt to make the events “believable yet inoffensive” as Cottrell (2007) suggests (pp. xxiii), or perhaps it is a result of spiritual beliefs in which all natural objects contain the spirit of a lesser god (see below).

Whatever the reason, these animals consistently appear to teach lessons through their attitudes and actions. Many creatures feature regularly in Ghanaian stories (such as a mean but clever cat, a stupid but loyal dog or the dim-witted but powerful Lion as King of the forest), but perhaps best known is the recurring character of the ignoble, mischievous but very clever spider (Appiah, 1967). Whether detailing the trickery of Ayiyi (to the Ewe) (Cottrell, 2007) or Kwaku Ananse (to the Ashanti) (Appiah, 1966) stories involving this spider typically end with a proverbial lesson not to follow in his footsteps. The content of these stories serves to impart the values, beliefs and history of Ghanaians to future generations. Much like the tales of Aesop or Grimm, Ghanaian folktales both teach desirable behaviour and chastise that which has been deemed immoral or unacceptable by a society (Appiah, 1967).

Valued aspects of Ghanaian culture, which will be reinforced below, are highlighted not only in the content of the tales but in the tradition and process of storytelling as well. For example, storytelling is an interactive collective process reinforcing the communal nature of society. Large groups of people may gather to hear the stories being told and are permitted to interrupt and contribute to the tale (Cottrell, 2007). Storytelling also teaches younger generations respect for the knowledge and wisdom of their elders. Not a tradition of days gone by, the act of storytelling itself is still very much a part of Ghanaian culture today (Cottrell, 2007). Whether told by elders under a tree, by mothers to their children as they cook, by schoolteachers to their class or translated and

written down for all to read, they can provide deep insight into the values, beliefs and culture of Ghanaians.

#### 4.1.3 Adinkra Symbols<sup>15</sup>



Adinkra is an ancient and traditional art form of the Akan people. There are discrepancies about its exact genesis but earliest accounts date its origin to the seventeenth century.

The Adinkra symbols reflect the complexity of traditional Akan social and spiritual existence. These historic Akan symbols depict the panorama of cultural life parables, aphorisms, proverbs, popular sayings, historical events, hairstyles, traits of animal behaviour, or inanimate or man-made objects. Adinkra symbols reflect cultural mores, communal values, philosophical concepts, or the codes of conduct, and the social standards of the Akan people. They are an expression of the Akan world view (Willis, 1998, pp. 28).

While today many retailers or wearers of Adinkra admire them for their aesthetic appeal and may not be able to 'read' their symbolic meaning (Willis, 1998), others are determined to keep this cultural treasure alive<sup>16</sup>.

Perhaps the most ubiquitous and revered Adinkra symbol is that of 'Gye Nyame'.



Gye Nyame, literally "Except God" or "Tis only God" is a symbol of the supremacy, omnipotence and omnipresence of God (Willis, 1998). Today, the Gye Nyame symbol adorns clothing, handbags, jewellery, handicrafts, paintings, signboards, taxi cabs and

<sup>15</sup> Traditional Adinkra images throughout this thesis have been obtained from <http://www.adinkra.org/>, pictures containing Adinkra symbols have been obtained through Google images.

<sup>16</sup> For example, I met an artisan who carved Adinkra symbols into his work. He knew both the meaning and significance of each symbol he used and would attempt to get to know his client to ensure the relevance of selected symbols when commissioned to create an original piece.

the sides of buildings throughout Ghana. Its popularity is a testament to the deeply religious nature of Ghanaians, a symbolic aspect of their culture to which we now turn.



#### 4.1.4 Spirituality & Religion

Ghanaians are generally religious and their shared religious beliefs constitute the fundamental basis of their sense of social identity, values, and destiny (Kuada & Chachah, 1999, pp. 36).

Ghanaian society is intensely religious. ...The Ghanaian cannot be separated from religion, and religion cannot be separated from the Ghanaian (Utley, 2009, pg. 46-7).

Religion is inseparable from virtually every aspect of Ghanaian life and important in the determination of worldview (Salm & Falola, 2002, pp. 32).

Throughout the ages, religion has been for Africans the normal way of looking at the world and experiencing life itself (TICCS, n.d., pp. 3).

Whereas individuals in some cultures may be influenced by ‘scientific’ or ‘factual’ thought, Ghanaians appear largely influenced and guided by their spiritual beliefs. Dei (2004), a Ghanaian himself, describes spirituality as the medium by which Ghanaians understand and make sense of their world. This spirituality is apparent in Ghanaian literature, folk tales, proverbs, art, media and was evident to some degree in each and every interview undertaken for the current study. Given this fundamental spirituality, it follows that religious belief systems undoubtedly influence the perceptions of, and treatments towards, individuals with autism in Ghanaian society.

As discussed in chapter 1, Christian, Muslim and indigenous beliefs are all widely held across Ghana. Space constraints do not allow for a detailed analysis on the ways in which belief systems impact differently upon Ghanaian worldview and subsequently on perceptions and management of autism. In addition, as will be shown, these belief systems are often so intertwined it would be virtually impossible to separate out influences even if space allowed.

*Your faith is your own; no one else can know it. You see some people going to Church in the morning and then coming out and going across the street to pour libations [to the traditional gods]. That is faith. I don't believe in the spiritual so I*

*believe in only one God. That is what my father taught me. These [lesser] gods are there, but I don't believe in them. –Professional*

Given this melding of belief systems, and inconsistency in purported beliefs even within a single sentence, it seems likely that different spiritual beliefs are invoked for different purposes at different times. Many Ghanaians interviewed did not make overt distinctions between Christian (or Islamic) beliefs systems and a belief in spirituality more consistent with traditional practices. Whatever religion people proclaimed to follow, many continue to maintain indigenous religious beliefs in supernatural forces and importantly, follow practices that accompany these beliefs (Salm & Falola, 2002, pp. 39). The following excerpt from an interview helps illuminate the influence of both belief systems on everyday Ghanaian life.

*I have a situation right now in my home, my younger sister there, she is in the navy....She went to bath and collapsed so she was rushed to the hospital, the sick bay of the [named] naval base...My brother went ... [to] go to see what was happening. He went and said she had collapsed and when she came around she was really not looking straight, she kept screaming 'where am I, I am not sick, why are you keeping me in the hospital'. So the doctor ...wanted to transfer her to...a psychiatric hospital. So we were all scared, how?! We don't think she is mad, why should they take her to psychiatry hospital. We refused and asked the doctor to transfer her to ... hospital in Accra. So she came and was there and the condition was really deteriorating and you could see complete mad symptoms in her and everybody was worried. And people kept telling us it is not normal, this is not medical condition, its superstition, somebody is witch-hunting her. Initially, I didn't know what to believe and then I was like, we shouldn't give her up, we should still think of the option that it is medical condition that is happening to her. Then after 3 weeks of being at [the] hospital the doctor who was examining her every day told me he is sorry but they conducted series of tests and they still can't find medically what is wrong with her. So at that point, I became like, what is it? So, I begin to yield into what people are saying, that the military, they are used to witch-hunting themselves, just trying to compete for positions. So... we were not sure that the outside, like going for prayers and blah blah would help, so we decided to leave her at the hospital where we could still occasionally call in pastors who came to pray with her. So we were having two beliefs, we didn't totally give in for the thought that it was purely spiritual but we also thought that its possible maybe there could be some medical condition and we still mind and see what happen. –Community Member*

Given the likely melding of different belief systems and the difficulty in separating religious influences, I will proceed using a general definition of religion offered by Nukunya (2003) for a Ghanaian context:

Religion may be described as all the beliefs and practices associated with the supernatural. Thus defined, the concept embraces many aspects of man's relations with the supernatural including magic, witchcraft, as well as practices associate with the dead, the ancestors (Nukunya, 2003, pp. 55)

While this definition focuses more on a shared spirituality it does not exclude the beliefs of organised religions. Using this definition the terms 'spirituality' and 'religion' will



be used interchangeably throughout this thesis, the name of a religion (e.g. Christianity) will be used when referring to a specific organised religious belief system. Respondents in the current study undoubtedly supported the conclusion that Ghanaians are deeply spiritual.

*But basically, as I have always said, we are very spiritual, you can't, you could **never** take that part out of our life. –Professional*

*We Christians we believe that everything that is physical come from the spiritual. Before a human being became a human being, it started from the spiritual. ....Spiritual is something that you cannot see physically with your eyes, you cannot feel with your senses, you cannot understand, [but] it is there, it is there. -Parent*

*If there is anything abnormal in our society, we attribute it to witchcraft. People here have many superstitions ... it may not be true but people will believe...if you believe then it is true -Professional*

## Inter-Connectiveness

Ghanaian personhood, at its heart, is influenced by a belief in the interconnection of all things. An invisible tie is thought to bind both seen (tangible) and unseen (spiritual) worlds (Kirby, 2006, n.d.; Salm & Falola, 2002), thereby binding humans both to each other and to spiritual forces. Similarly, life is comprised of two interconnected elements, spirit and matter (Kuada & Chachah, 1999). This 'life' extends beyond human life to a belief that all natural objects contained within the world (for example, rocks, trees, etc.) possess the dual elements of spirit and matter (ibid.).

*[Near] my family house in [the north], ...I can say the whole community, there is a very big Baba tree, and they worship that Baba tree. Right now if you go to the Baba tree, you will see feathers of fowls and some blood and some herbs, blood mixed with water and poured on the tree. They worship that tree and ... always they sacrifice some animals and perform some spiritual things there. So, they believe that that tree protects all the clans around. –Community Member*

The synergy of the two worlds is grounded in relationships which connect people to each other (Nukunya, 2003), to ancestors and a continuation of life after physical death (Kuada & Chachah, 1999; Salm & Falola, 2002), to nature (Akyeampong, E. & Obeng, 1995), and to the spiritual 'unseen' world (Kirby, 2006, n.d.). This belief in the interconnectedness of forces is insinuated throughout many interview responses but was also more overtly expressed at times:

*Actually, most people are very superstitious, they believe there are spirits, they believe there are the supernatural realm and the physical realm. –Community Member*

*Look, I am telling you, here, as for the spiritual aspect, it's everywhere – Parent*

*You see as much as you tackle the spiritual you must also tackle the physical ehhen<sup>17</sup>, and I know you cannot tackle physical things only, in this part of the world.... the spiritual thing, me I will not rubbish it, it's there, but you do not also dwell on it alone. It's fifty percent physically, fifty percent spiritual. So that is how we thinks. – Parent*

It is important to note that this 'interconnectedness' also includes relationships among the living. Kuada and Chachah (1999) describe this notion as 'three-fold harmony' in which people "live in harmony with nature, the spiritual world in general, and with each other" (pp. 38). The cause of perceived misfortune in any form (untimely death, disability, a poor harvest) is often attributed to an imbalance in one's relationship, either within the living family or in aspects of the spiritual side to life (Kuada & Chachah, 1999; Salm & Falola, 2002). As will be shown in chapter five, the belief in spiritual causal attributions of disability can have vast implications for the ways in which autism is understood, and the treatment options which are sought.

Another outcome of a spiritual outlook to life is the rejection of chance and happenstance, which do not feature heavily in belief systems that attribute all things to spiritual forces. This lends itself to the conclusion that the cause of one's misfortune, and by association a solution, can always be determined.

*In Ghana here everything happens because of something -Professional*

*So, I believe that ... nothing happens without a cause, nothing happens that has no cause. Okay, you may not be able to pinpoint the cause directly physically but as far as we are concerned in the spiritual realm, something must have happened. - Professional*

Critically, as will be shown in the next chapter, this contributes to the often protracted journey by some parents to determine both the cause and 'cure' for autism. It also contributes to the shaming and blaming of parents by others as it is thought that their transgressions must have brought about retribution in the form of a child with autism. The belief that spirits and ancestors watch over, punish and reward people translates into a belief that everyone is ultimately accountable for their actions (Avoke, M., 2002). Above all, this belief helps maintain social order and can compel individuals to follow a culturally dictated moral code. Interestingly, retribution for wrongdoing is a heavily featured theme in traditional Ghanaian folktales (Cottrell, 2007). An implicit fear of retribution for missteps, or the possibility of reward for living an honourable life, helps

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<sup>17</sup> Often used as an expression of emphasis.

ensure stability in society and social control. One story relayed during an interview will help illuminate the point:

*The person can behave like he won't mind you, he won't talk to you but if you enter the room he can do something cause you don't know the spirit that is in [him]. Eh my aunty told me a story about old man sitting and ... the lady wore short skirt to enter tro-tro<sup>18</sup> and the lady started to insult the man. She insult the man [but] the man didn't talk and the lady turned and do like this [waved finger]. When they reached the place where everyone must get down the lady cannot, she die in the car. – Community Member*

This story serves to highlight aspects of normative and respectable behaviour in the mind of this respondent (such as wearing a short skirt) as well as the belief in spiritual practices and in retribution for one's actions. In a collective society where harmony between community and family members is a deeply cherished cultural value, openly expressed hostility is taboo. Human nature of course ensures that conflicts, jealousy, and hatred do at times arise, which contributes to both the utility and maintenance of beliefs in magical forces in Ghanaian society. The power of witchcraft can be partially found in its ability to offer a socially acceptable means to commit otherwise taboo actions. For example, an accusation of witchcraft is one of only a few justifications (and perhaps the only un-provable one) for divorce in traditional Ghanaian society (Mair, 1969; Salm & Falola, 2002).

The 'cathartic' effect of the belief in witchcraft...allows people to express the hostilities that they ought not to feel, and are only justified in feeling if they can believe that they are suffering though someone else's unjustified hostility (Mair, 1969, pp. 210).

Despite the preponderance of spiritual beliefs apparent in interviews, descriptions of particular practices and methods appeared confused and inconsistent. While traditionally quite separate and distinct, traditional practices in Ghana (such as juju, witchcraft and herbal medicine) have overtime become highly interconnected, intricate, and at times confused.

Despite the apparent ubiquitous character of this phenomenon, its nature and modus operandi are quite confused in the minds of most people (Nukunya, 2003, pp. 59).

I proceed on the premise then that there is complex web of interactive spiritual beliefs through which Ghanaians attempt to interpret their experiences, and when necessary, seek solutions. For the purposes of this conclusion, the complexities of different religious beliefs are in many ways irrelevant. It is an ingrained belief in spiritual forces,

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<sup>18</sup> A traditional mode of public transportation similar to a small bus or van.

not in any specific religious ideology, which is of central importance in shaping Ghanaian worldview.

As the rest of this thesis will demonstrate, the continued and deeply held belief in magical forces profoundly shapes the lived experience of autism in Ghana. It is also clear that Ghanaian culture is multifaceted and distinctions between different aspects, such as spirituality and communal living, are in fact arbitrary. Given the interconnected nature of all things, each profoundly affects, and in turn is affected by, each other.

## 4.2 The Societal Dimension

*Baanu so dua a, enmia*  
*if two people carry wood it does not weigh them down (help lightens work)*  
 (Appiah et al., 2007, pp. 19:157)

Given the importance and relative permanence of spirituality in Ghanaian society it cannot be fully separated from a discussion of societal aspects of culture, especially as defined by Verhelst and Tyndale (2002) as inclusive of social relationships and family structures. Unlike many Western societies where individuality is praised and sought after, Ghanaian culture is defined, in large part, by communal relationships and responsibilities. Traditional kinship and tribal relations are still deeply respected. These organisational structures continue to impart valued rules and norms in society and serve to maintain social order in shared responsibility for, and accountability to, one another.

*Most of our communities, like in my village, we all belong to a clan. And the clan can be about 15 families forming a clan. And we have heads of the clan, you can have heads coming from about six of the families, and they are the elders of such clan. Mostly, they decide on issues that pertain to that clan. They may only take it to maybe the chief level when they feel certain issues [are] beyond them.....your clan is also affiliated with another clan, and we can have classes of clans that can form the whole community. –Community Member*

Normative rules of social behaviour, organised by these systems, can influence the perception of behaviour in children with autism in Ghana. For example, seniority and authority in a family is afforded by both gender and age with male elders commanding the most respect and obedience (Salm & Falola). Consequently, a child with autism

who does not understand an instruction due to a communication challenge may instead be viewed as wilfully disobedient and disrespectful of his elders. Furthermore, as will be shown in chapter seven, traditional hierarchical structures can also contribute to bureaucratic stalling and responsibility shifting within the educational system.

*Eba a, eka oni*  
*If it comes, it affects your relatives.*

(Appiah et al., 2007, pp 13:1)

The significance of kinship as a social structure in Ghanaian society is further evident in the notion of ‘familism’, where an individual’s behaviour reflects not only upon themselves but upon an entire community (Kuada & Chachah, 1999; Nukunya, 2003). Individual identity is inextricably linked with the family’s and the behaviour of a single individual reflects upon and is judged in relation to, the larger group. This strong belief in responsibility to the larger family or societal group serves to establish and maintain traditional order.

Obligations to the lineage keep members in good standing and permit them to draw on the membership benefits...Individual behaviours and actions reflect an individual’s moral character, as well as that of the entire family” (Salm & Falola, 2002, pp. 127).

This notion is evident in the Adinkra symbol and proverb representing a chain or link, a symbol of “unity, responsibility, interdependence, brotherhood and cooperation” (Willis, 1998, pp. 140).



*NKONSONKONSON*  
*We are linked in both life and death. Those who share common blood relations never break apart.*

(Willis, 1998, pp. 140)

As Salm and Falola highlight, this ‘familism’ can offer advantages to individual members of a collective group. In response to the Kofi story one respondent asked the following:

*Respondent: where does Kofi stay? Does he live in a compound or single house?*

*Interviewer: I am not sure, why do you ask?*

*Respondent: when children live in compound house there are more children all [the] time so he can play [with them], it makes the brain clever. It is better, better than if the family stays alone [in a single house]. –Community Member*

One example of the advantages communal living offers can be found in the kinship expectation that extended relations ‘parent’ all children as they grow and that children return to the home as adults to care for their own elderly parents. Whereas in some cultures the state provides for the elderly, in Ghana that duty traditionally falls to the grown children in a family.

*I think the role of the child right from the beginning is to grow up and to look after the adult. That is how I see it; that is what I think. The role of the child is to grow up, you know so you have this child and this child is your insurance policy. And em, you try and look after this child as best as you can so this child grows up to look after you...because there is no other way of sustaining yourself. I mean my children will. When you can't continue doing the things that you have been doing or if you having a business that the child will come and take over and support it.....We have a saying in Ashanti, literally it means ‘I have cared for you for all your teeth to grow so now you care for me for all my teeth to drop out’ ...So if you have a child who is not going to be successful or they are not going to be able to do that then that is a **really** big loss, that is a **massive** loss. –Professional*

While in research in Botswana suggested that devoted family care for the elderly in African countries is a ‘myth’ (Ingstad, 1999), and kinship rules in Ghana are certainly changing with global influences (Nukunya, 2003; Salm & Falola, 2002), familial responsibility to care for the elderly seems to remain “one of the cherished values of the Ghanaian society, a value which the citizens are determined to preserve” (Kuada & Chachah, 1999, pp 78).

Any investment in a child’s education then is offered under the assumption that it will enhance the child’s earning potential and with the expectation that the child will reinvest their future income back into the family. In this way contributing to a family member’s education is viewed as an “investment to yield dividends in folds” (Kuada & Chachah, 1999, pp. 74). Children with autism do not have the same earning potential, especially in societies where social stigma can prevent education and employment opportunities (see chapters five and six). It is clear that this expectation to ‘give back’ to one’s family, both financially and socially, is a barrier to the full membership of children with autism into a lineage group.

In addition, the relatively communal nature of society can result in systemic consequences of autism to the larger kinship group. Communal responsibility, paired with a belief in ultimate accountability for one's actions, results in a tendency to blame and ostracise parents, especially mothers, for the presence of autism in a family. These consequences will be explored in depth in chapter six. To summarise then, as Salm and Falola (2002) state best:

Ghanaian worldview, then, is associated with how people see themselves as individuals, as part of a community, and in their relationship to the spiritual and physical world around them (pp. 37).

### 4.3 The Technological Dimension

Verhelst and Tyndale (2002) also identify a 'technological' dimension to culture. This dimension is taken here to mean the skills, expertise, technology, management and political structures as relevant to the education system in Ghana. Issues of knowledge, pedagogic skills, teacher training and expertise, as pertains to autism, will be explored in detail throughout the rest of this thesis. What is important for the purposes of this discussion is the way in which the technological culture of Ghanaians is both expressed in, and influenced by, the relatively shared worldview which is beginning to emerge in this chapter.

This worldview is also influenced by traditional hierarchical positions of power, evidenced already in hierarchies of spiritual powers and kinship structures. An unfortunate result of this system is a relative lack of autonomy on behalf of teachers to make their own decisions on daily classroom operations, a potential barrier for IE.

Teachers in Ghana often must defer decision to their administrators:

*Teachers, most of these things, like kind of come from the top right. If the headmistress or the headmaster wants it [a child with a disability], they will be forced to take it. But if the headmaster doesn't understand or doesn't want it, you know, it becomes a policy in the school [to exclude children with disabilities] –Parent*

*I know when I worked at Dzorwulu [Special School for MH] that all the classification was done by the Head. The decision is made unilaterally by the Head, it is a single opinion. Once it is made, the decision is final. –Professional*

As will be demonstrated in chapter eight, teachers in Ghana can be resistant to the inclusion of students with SEN into their classrooms. It is suggested that this lack of

agency may be one contributing factor. Similarly, administrators often pass responsibility for controversial decisions further up the hierarchy:

*In fact, this headmaster told me that you have to speak to the owner [of the school] before [I would be allowed to enrol my child]. –Parent*

This hierarchical culture also seems to contribute to a culture of responsibility shifting within the education system which is compounded by a lack of collaboration and communication across departments responsible for educational provision. Departments within GES including Special Education, Basic Education and Curriculum Development are often unaware of each other's actions as well as those undertaken by related institutions such as the Ministry of Education, Department of Social Welfare, Assessment Centres and Teacher Training Colleges.

*We need to break down the walls. We just need to liaise with each other. [This] division, we can see ourselves as a coordinating body. We coordinate different areas. We should cut across quality, access, management, science and technology, etc. – Senior Professional*

The lack of communication across departments is immediately apparent to anyone attempting to access official information or records in Ghana. Ongoing efforts over a three year period to procure the National Disability Policy were met with repeated suggestions to contact various departments or individuals to obtain a copy. In the end, I was only able to secure a copy through an expatriate friend also researching disability in Ghana. Interview responses by senior officials at the national level illuminate this lack of communication and collaboration across departments:

*Interviewer: I wonder if you have any data or numbers on current enrolment rates that you might be willing to share with me?*

*Respondent: The Special Education Division will be able to give you all of that. They are the ones who are best informed on that. –Senior Professional*

*Interviewer: Yes, I have seen the [Persons with Disability] Bill but not the Act, would it be possible to get a copy of that from you?*

*Respondent: Social Welfare would be in a position to give you that, it is their department. –Senior Professional*

*There is a school in the Brong Ahafo region where three students have been placed. The Special Education Division would be in a position to inform you as to their progress. –Senior Professional*

It is argued that this bureaucracy within the education system can be traced, in part, to a culture that both respects traditional hierarchies of authority and believes in the ultimate accountability for one's actions. This has contributed to a culture of 'saving face' and shifting blame within the education system. It should be noted that many professionals



lamented the bureaucratic nature of the educational system and a lack of collaboration between departments.

*The different divisions have roles and responsibilities yes, but those are the ones that they are the lead division for, they should facilitate those areas, to take the responsibility to coordinate all the divisions together for those areas which are for them to address... We need education but we need cooperation –Senior Professional*

The impact of the education system on opportunities for children with autism will be a particular focus of chapter seven. For now though, it is important to acknowledge aspects of accountability, responsibility shifting and hierarchical social structures in Ghanaian culture. Each of these aspects, alongside spirituality and communal living, will be shown to impact upon the perceptions of, and educational provision for, children with autism in Ghanaian society. It is suggested that these highly valued and intertwined cultural belief systems permeate all other aspects of life, influencing attitudes and behaviour and that a thorough understanding of these aspects is needed to fully understand disability in a Ghanaian context.

## **4.4 Conclusion**

In this chapter I have attempted, as much as possible from an outsider perspective, to understand Ghanaian culture. Verhelst and Tyndale's (2002) useful delineations of the 'symbolic', 'societal' and 'technological' dimensions to culture have been used in an attempt to identify those aspects of society where a relatively shared outlook or 'worldview' can be found. It should be acknowledged that there are of course many additional aspects to Ghanaian culture which I have not highlighted here, most notably tribal structure, languages and the political history of Ghana. These aspects, while central to a true understanding of Ghanaian culture, are not as salient to understandings of disability or the data which will be presented throughout this thesis and as such have been left out due to space constraints. This is regrettable but unavoidable.

Of course, as was acknowledged in the introduction to this chapter, culture is dynamic and individuals diverse. This chapter is not intended to group, classify or simplify unnecessarily. It is however, intended to highlight aspects of Ghanaian culture which I found, through my research and experiences living in Ghana, to impact upon the perception of children with autism. A number of shared values and beliefs can be safely

identified while nonetheless acknowledging that the interpretation of these values and the subsequent actions taken will of course be individually and situationally specific. I will attempt, throughout the remainder of this thesis, to demonstrate that the shared ‘worldview’ identified here can be deeply ingrained such that other ways of thought, like those imparted by international development agendas for example, are actively, or intuitively, resisted.

I have attempted the dissection of culture in this chapter as its understanding has fundamental and complex interrelated implications on the personhood and inclusion of an individual with autism into Ghanaian society. This chapter has demonstrated that Ghana has a rich culture, constantly evolving but influenced historically by myth, proverb, folklore, art and storytelling. The values highlighted by proverbs, folklore and Adinkra symbols are those traditionally respected in society and deemed worthy of passing on to the next generation. The communal and spiritual nature of Ghanaian society was highlighted as of particular significance and it is no surprise that both feature heavily in folklore and proverbs. The relatively communal nature of Ghanaian society and normative kinship structures were said to offer both detriment and benefit to the larger group. I have also attempted to demonstrate that many Ghanaians believe in inevitable consequences and accountability for their actions and that these consequences, whether good or bad, can befall the entire family. This, coupled with spiritual beliefs, resulted in a rejection of chance or happenstance, a belief which will prove critical in understanding the causal attributions of autism outlined in chapter five. Finally, a tendency toward responsibility shifting and hierarchical social structures was identified, which will be shown to have an effect on societal inclusion and educational provision for children with autism in Ghana.

Perhaps most importantly, I hope this chapter has illuminated the necessity of viewing disability through a cross-cultural lens. Disability is a complex process, within which “the role of culture and meaning is crucial, autonomous, and inescapable” (Shakespeare, 1997, pp 225). With a better understanding of Ghanaian culture, I now feel it is possible to turn my attention from the cultural influences on worldview to the *effects* of these beliefs on understanding and managing autism and related intellectual disabilities in Ghana. Using a framework based on Nora Groce’s earlier works, the next chapter

will explore the degree to which children with autism are meaningfully included in Ghanaian society by examining the perceived causes of autism, the degree to which certain traits are valued or devalued and the perceived future role and expectations of adults with autism (Groce, 1990, 1999a, 1999b, 1999c, 2000).

## Chapter 5

### Understanding Autism in Ghana

#### Introduction

‘Explanatory models’ can be thought of as the framework through which people understand health, impairment and disability (Groce, 1999c). Importantly, this framework is likely to be culturally bound such that the experience of being ‘disabled’ is linked to cultural belief systems surrounding disability (Daley, 2002; Grinker, 2008a; Groce, 1999c). Groce (1999a, 1999c) outlines three categories of beliefs which likely play a significant role in how an individual with an impairment will fare in any given community:

1. Causality- the cultural beliefs surrounding how and why impairment occurs
2. Valued or devalued traits- the physical or intellectual attributes which are significant or stigmatising in any given community
3. Anticipated role as an adult – the beliefs and expectations surrounding what an individual with an impairment is likely to do as an adult in the community.

Using Groce’s model as a framework, this chapter will attempt to understand the impact of worldview (as outlined in chapter four) on belief systems and explanatory models surrounding autism and (dis)ability in Ghana.

#### 5.1 Causality

The way in which an individual with an impairment is treated in any given society is, in part, based on cultural belief systems regarding how and why they became disabled (Groce, 1999a, 1999c). Just as is found in other cultures in the world, the perceived causes of autism in Ghana are complex and vary widely over time and circumstance. In attempting to understand the presence of autism, some people appear to turn to biomedical explanations while others look to spiritual forces. One teacher listed the following diverse causal beliefs she claimed were held by parents of children at the autism centre where she works:

*[I] hear the parents say different things. One mother says that her son had the measles and it was only after that time that he started behaving like this, abnormally. And one woman said her husband’s sister quarrelled with me and that is why she has*

*cursed me for my baby to be like that. [Another] woman said about the immunisations. So many different explanations. Another girl was 3 years and she had malaria. She went to the hospital [but] they treat her for Typhoid fever and after the cure she has never been same, she can't talk anymore and behaves abnormally. There are spiritual things too, cursed, my great grandfather did this thing and now our family is cursed so we have the autism....Some too they say it is witchcraft. - Teacher*

An exploration of causal explanations of autism in Ghana exposed two broad categories of attributions, biomedical and spiritual, both of which are highlighted in the quote above. Spiritual explanations can be further subdivided into two rough categories, those involving retribution from a higher power for an offence caused and those which are believed to result from the evil doing of a person acting through spiritual means such as curses, witchcraft or juju.

### **5.1.1 Biomedical**

To Western readers, biomedical 'scientific' explanations of impairment may hold a certain credibility and be more readily accepted than spiritual ones. In the case of autism however, the exact cause(s) remain a mystery even in cultures which hold a biomedical worldview and search for answers in the scientific. While an in depth discussion and analysis of the possible biomedical causes of autism is beyond the scope of this thesis, it is nonetheless clear that this lack of definitive information complicates international advocacy efforts and programme development.

There is little agreement, even in a single culture, about exactly what it [autism] is or how to treat it (Grinker, 2008a, pp. 3).

Only two respondents, both familiar with autism, mentioned this ambiguity when asked what they thought caused autism:

*Eh! We don't know yet. Cause I know even in the US, in the States, they also don't, if the researchers haven't come out there then [how can we know]. -Teacher*

*Well, I have been reading. You know, they don't know the actual cause but they think that its drugs and the environment induced. -Parent*

It is no wonder then that causal explanations offered by stakeholders reveal confusion. Multiple respondents referred to the belief that vaccines are a potential cause of autism, a theory which is now widely rejected by biomedical researchers<sup>19</sup> (Grinker, 2008a).

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<sup>19</sup> A potential causal link between autism and childhood vaccines remains a controversial and hotly debated topic. Both the use of Thimerosal (a Mercury containing preservative) in vaccines and the Measles Mumps Rubella combined vaccine (which never contained Thimerosal but was thought dangerous for the combination of three live viruses) have been suggested as potential causes of autism. Whereas scientific research has failed to reveal a definitive link between either cause, some families and advocacy groups continue to maintain the

*I know of one woman, she has a son with autism, she said when he was one year and about to take his first steps they went for their immunisations and it was after that that he lost his speech and would not walk. –Teacher*

The above example demonstrates the possible consequence of slow dissemination of accurate information to developing countries. It is certainly possible that this belief could lead parents to avoid giving their child necessary vaccines out of fear, as has occurred in other contexts (Dannetun et al., 2005). The possible ramifications of this however, could be much greater in a country where many diseases have not yet been eliminated from the general population. Psychoanalysts working in the USA in the 1960's and 70's were responsible for spreading the damaging 'refrigerator mom' theory, a belief that autism was caused by unloving or 'cold' mothers and their inability to relate to their children (Grinker, 2008a). This legacy has plagued parents for generations and while the myth has been largely eradicated in the US there is the danger that it may prove slower to disperse where access to information and awareness is limited.

*At first, we were thinking because ... he was very young... when he had an older brother, so we were thinking it was due to the care he wasn't having when he was a baby. Like he is a baby and they still gotten another baby so all attention is drawn to the smaller one so we thought it was something to do with love –Community Member*

These examples begin to reveal a tendency to blame the presence of autism on parents, particularly the mother. This is also evident in the belief that autism can be a result of poor prenatal care, seen as the sole responsibility of the mother.

*Maybe, maybe ehh ehh ehh, when the mother was pregnant you don't take drugs or you don't do what doctor told her to do. –Community Member*

*Sometimes they say if you are pregnant and you don't go to hospital [for] injection or medicine the children can behave like that. –Community Member*

*Not sleeping well. Like you know the body has a perfect form, so if you force the body to bend or to balance the body, you can affect that child...The mother, she should sleep straight [when pregnant], not like this [demonstrates curled in, foetal position], it affects the child inside there –Community Member*

The notion that quality medical care could have prevented impairment appeared widespread amongst respondents and largely seemed to blame the mother for her lack of prenatal care. The task now is to encourage education which not only teaches

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conviction that a link exists, claiming research is biased in that it is often conducted by companies involved in the manufacture and sale of the vaccines. While this was true in many initial studies, a preponderance of large, high-quality and independent studies to date appear to undeniably refute a causal link between autism and childhood vaccines. Despite this, mainstream media accounts and a few high profile parents still perpetuate this belief. See Grinker (2008a) for an overview and history of this debate.

appropriate prenatal care but diffuses any inaccurate information which unfairly condemns mothers for their actions.

Unfortunately, it is impossible to make accurate conclusions about some popularly offered biomedical explanations for the presence of autism in Ghana. For example, there seemed to be a common belief that autism was caused by severe illnesses, high fever or seizures (typically called ‘convulsion’) to the child at a young age:

*He used to get these measles, and measles you have to be on antibiotics. Yeah you have to save him. And the doctors advised me that is it was ... but that is the only way. When it comes he has very high temperatures, fever, **high** fever and the only thing is to give him eh suppress the fever and then put him antibiotics because of the infection. It's infection, there is very little they can do. ....So they used to give him antibiotics and I have read that those ones, they might [be responsible]. –Parent*

*Convulsion. The sickness started from convulsion. At four years of age. Until that time, he was fine. But he started having convulsions, we rushed him to the hospital but by the time we got there, he was out. He was in a coma for one month. And when he woke up everything was different. He could not speak at all, could not walk. - Parent*

*Sometimes when they are about six months of age, they can have a convulsion and if it is not treated well it will come into that autism –Community Member*

In practice, the accuracy of these statements for each individual child can be neither confirmed nor refuted. Severe illness, typically involving a high fever, may cause brain damage but the degree to which this damage, if it occurred, would manifest itself as similar symptoms and behaviours as those exhibited in children with autism remains unclear. Other biomedical explanations proposed as causes of autism refer to an illnesses or accident to the mother while pregnant,

*When we traced his history, his mother had fallen on her stomach during pregnancy - Professional*

*Some think it is due to some infections they had during pregnancy or the child falling down when he was a baby - Teacher*

or to failed abortion attempts, typically involving the ingestion of tonics.

*Sometimes the mother tries to abort the baby, we have all types of different medicines, afterwards they affect the baby. – Community Member*

*[It] has to do with terminating the pregnancy. If you try to terminate the pregnancy, have the medicine, that will have an effect. – Community Member*

Another belief I encountered many times in Ghana was that a lack of ‘maternal effort’ during childbirth could be responsible for the presence of a disability.

*And I remember when my wife gave birth...she was pushing it got to a time she didn't even want to push again and so ... You know those things so I was thinking ah, could it have been due to that small delay in pushing -Parent*

Without determining the accuracy of this statement, here too it appears that the default causal assumption is a result of maternal error. At other times, respondents (especially community members) were even more overt in their blame of mothers, citing social sources that are hard to validate or understand as a cause of autism, at least through my own disparate worldview.

*Maybe the woman does not have a husband. - Community Member*

*The mother was not faithful to the husband during pregnancy. Or she didn't do as she was supposed to, there are taboos. – Community Member*

While most of the above causal attributions could conceivably explain the presence of some impairments, it is unclear the degree to which severe illness, accident or emotional trauma to the mother while pregnant, or to a newly born infant, would each cause symptoms which mirror the behaviours of autism. As Grinker (2008a) reminds us, autism is diagnosed through the presence of behavioural symptoms; the DSM and ICD criteria do not evaluate causes. Under such a system “no matter how a patient got the symptoms, if he has them he can qualify for the diagnosis” of autism (Grinker 2008a, pp. 190). What is clear however, is that unlike the diagnostic criteria, stakeholders in Ghana appear more focused on identifying the cause of the impairment and thereby the source of blame.

The causes cited above can be classed as variations on biomedical or social attributions; I now turn towards an exploration of spiritual causal belief systems.

### **5.1.2 Spiritual**

As previously demonstrated, Ghanaians can be said to be deeply spiritual. These spiritual beliefs seem to provide a lens through which daily experiences are filtered. For example, seemingly inevitable accusations of magic, widely reported in the media, often occur during events of national significance such as elections or sporting events (Salm & Falola, 2002; Utley, 2009).

*In the Graphic [daily news] there was a man holding two [Guinea] fowls saying they represented the two goals the Black Stars were going to score that night. Maybe he was joking [they were playing Guinea] and it was coincidence [that they did score two goals] or maybe he was not joking and it was real- you can't tell. Maybe he was*



*a Christian, maybe he was a spiritualist, maybe he was somewhere in between. – Professional*

Given this propensity to look to spiritual forces to explain the unexpected (both prosperity and misfortune) (Kuada & Chachah, 1999; Nukunya, 2003; Salm & Falola, 2002), it is no surprise that the vast majority of attributions offered for the presence of disability in Ghana contained, to various degrees, a spiritual component.

*You see, so when you talk of autism, let me say, most of them are spiritual. – Professional*

*Yes, when I mean spiritual, is that in Africa here there is a culture doesn't go with Western part of the world culture and ...[the spiritual] seems to be something that we always have to drop out of a situation like autism and spirit children. – Community Member*

*They say its spirits, its spiritual thing. Like, enh, you child is going to sleep so you have to pray for him or her and if you don't do that, as for the witches, there they are doing their work. –Community Member*

*Some people even think its witchcraft or something. [Or] the child has been possessed, or [is] some kind of spirits. –Teacher*

As discussed above, the lines between spiritual mediums are increasingly blurred, the complexities of which are confusing even for most Ghanaians (Nukunya, 2003). While many respondents offered lengthy descriptions of the spiritual practices which could cause autism, the salient point for our discussion is not the exact procedures employed but the deeply held belief that spiritual forces do cause misfortune, including impairment. Discussions of spiritual practices in interviews were imprecise and at times highly confused, which necessitated a collapsing of different spiritual categories for the purposes of this discussion. Stakeholders were found to use terms interchangeably and the majority of respondents were likely not familiar enough with the intricate practices themselves to properly distinguish between them.

The following discussion therefore groups explanatory models into two loosely defined categories, those initiated by human actors and those thought to originate with higher powers. It should be noted that this distinction is relatively arbitrary and intended only to clarify the discussion. In practice, these mediums overlap. An exploration of spiritual causes initiated by human actors will include witchcraft, curses, traditional medicine and juju; all termed 'magic' for the purposes of this discussion. I will then turn to an examination of causal explanations which centre on retribution from a higher power, either God, the lesser gods or one's Ancestors. This chapter and the remainder of this thesis will also attempt to explore the consequences of these beliefs, the actions

they necessitate and the impact they may have on international development programmes.

## Human Actors

While the specifics are confused, the vast majority of respondents across the different stakeholder groups spoke of links between magic and ‘disability’. When impairment is believed to be caused by magic, it is typically thought to be retribution for a transgression committed against someone close to you who either directly enacts justice or hires a spiritual practitioner to do so for them.

*If an autism child comes from my neighbourhood or my village, he or she may consider to be a spirit child or a sickness. And they will always tell you, its buy-able disease....Something that you can transfer from somewhere to someone [through a spiritual practitioner] is buy-able. So, most people believe that children with autism in my part are spirit children or [it is] buy-able sickness that they have. –Community Member*

In the case of autism, it is generally believed that retribution has fallen upon the transgressor’s child or unborn infant. It is in this way that impairment present at infancy or apparent during very early childhood, before the child has had a chance to invite retribution through her own transgressions, is understood.

*They have been cursed, maybe as a result of their activities or the behaviours of their parents, they have been cursed. It is a punishment given to them, to their parents. Maybe their parents laughed at somebody, an elderly person, or somebody with a third eye, the parent offended that person so as a result he is punished and that affects children but don’t get parents directly. - Professional*

*The person wants to do bad things to him, he didn’t get me because I am strong, I am strong in prayer. And he can see that he can adhere that thing to my son. So [they try to] get my son and if I don’t do something [to avoid it] potentially... eheh that’s it - Parent*

*If I am witch and I don’t like you [but] there is no way to hunt you, I will pray till the day you get pregnant...the child that your gonna give birth, I’ll change him to whatever I want him to do, so I’ll have the remote there, to control that child. It could be they will wait for the time you will be happy. They know if you have a child, you are always happy. They will come and take that child spiritually. Possess that child with that sickness or that disease or whatever spirit it is. –Community Member*

*The main cause of it is that, people think, you know, you have kid like that then that means there is some kind of a witch. There is a witch in your house or your home who have been dealing with that at a time when you were conceiving the baby. – Community Member*

In Ghana, a culture grounded on harmony in relationships, openly expressed hostility is taboo and disrupts the natural harmony of communal living. Magic provides an outlet for this clash in allowing individuals to express a perceived injustice through direct use or accusation of magic. Magical practices in Ghana are often associated with anti-social

traits such as malevolence and jealousy (Kuada & Chachah, 1999; Nukunya, 2003; Salm & Falola, 2002; Utley, 2009) and many magical attributions were therefore thought to be attempted injustices by a jealous ‘rival’. Second wives or sisters and mothers in law are the most commonly accused ‘rivals’ in Ghana (in patriarchal clans) due to their competitive interest in the husband (Nukunya, 2003).

*Most of them say it is a curse, a family curse. Some problem with brother's wife [as an example]....And one woman said her husband's sister quarrelled with me and that is why she has cursed me for my baby to be like that. -Teacher*

*Like for example, someone went to...what she believed to be a prophet, to get some em, powers or whatever...her husband was cheating and all that ...she went and the prophet and [he] said oh you have a rival. -Professional*

*My grandmother or my aunty or cousin or somebody is affecting me in this way so em, yeah. Or maybe nobody that you know... There are a lot of reasons why this could be. -Professional*

As magic is always a voluntary act, one expected use is to “effect evil supernatural ends” (Nukunya, 2003, pp. 62). Utley (2009) talks of the ‘pull-him down’ mentality evoked by some Ghanaians when others around them are successful. This attitude was, perhaps surprisingly, extremely salient in interview responses:

*The whites have different mentality than the blacks. Here there are people who you think they are suffering, they don't have anything to eat, [so] you just buy maybe some cloth or something ... or give the person money. [But] they will think that ehhen, okay so he has money... he will go, he will rather go and do you juju! Or you know, physical attack or something! Here, those things, those foolish things are here....Here you need to always be strong and always pray for protection. Seriously. And there has been countless number of things done in some situation where the people have confessed...they were successful in attacking the person, or they were successful in collapsing the person business or something. That is Africa for you, so don't **don't** ignore that aspect. -Parent*

*Witch[craft] is a wicked idea that we have, ideology that makes someone lose and you gain. In Africa here we believe in that. -Community Member*

*Someone is after you, wants to bring you down...Trying to find ways to stop you from working and making money...If you have a child who has all these difficulties it is a way of draining you and making sure that you don't come...with your hammer and your cars and build big houses. -Professional*

Other cases of autism were explained as punishment for greed or failure to uphold the virtues Ghanaians value. ‘Juju money’ or ‘blood money’ is a spiritual practice intended to provide wealth, advancement and prosperity.

*...someone could choose to go to a witchdoctor to buy a money snake. The snake will ooze money to you forever but you must feed it... you feed it a human soul at least once every year. Fail [to] do this the snake will be forced to take a member of your family, someone close to you. Because the snake needs food, payment, the family is payment instead -Community Member*

*I will use you for my sacrifice, to the gods [who] I believe can provide me business to make money...Blood money has so many ways... But most of the people in this part, southern part [of Ghana], use their children. Or most of the children [with autism] are caused by that, cause they use them for rituals. They make money and you see their children [are] destroyed.... They use the children and they have autism after; that is where the spiritual is involved. The spirit that they goes to consult to get their money does not need to take the person's life but it's going to rip up your dignity, your respect, your senses. –Community Member*

Other times disability was described as a result of seeking fertility from spirits:

*After some years a mother and father cannot have a child so they go to the magician to ask for a child....After delivering they must take the baby back to the shrine to pour some small libations [to the invoked spirit], if they don't, this thing [impairment] will come. –Community Member*

These descriptions begin to merge retribution enacted by a human spiritual diviner with those enacted by higher powers. Often a spiritual diviner is able to bring about punishment or gifts only through contact with relevant higher powers. Importantly, angering the gods by failing to honour a promise, even made through a magician, is believed to invite retribution not from the magician, but from the god themselves.

The breaking of societal taboo or failure to follow through on an action promised to gods can bring their anger and lead to the introduction of evil spirits into the lives of the offenders and their families (Salm & Falola, 2002, pp. 41).

Divine retribution as a possible cause of autism will be discussed below. Further complicating the understating of spiritual attributions is the fact that while many respondents indicated that autism was *caused* by magic, others indicated that individuals with autism were themselves spirits or witches.

*They believe this child is a spirit child, this child is wicked and it's a witch. - Community Member*

Nukunya (2003) reminds us that no one is beyond suspicion of witchcraft though it is often associated with certain physical and behavioural characteristics. Amongst others these traits include 'loners', those with 'queer habits' or 'quarrelsome dispositions' and anyone 'considered anti-social' (pp. 60). Salm and Falola (2002) describe witches as "those who exhibit some variance of anti-social behaviour" such as "loners who do not partake in community duties" (pp. 43). When witchcraft is understood in this way its association with autism in the minds of Ghanaians becomes logical; these 'anti-social' traits are similar to those which could be used to describe a child with autism as explored in chapter three. However, although magical practices such as witchcraft and juju are feared in Ghana, they are not given the same deference as higher powers (Kuada & Chachah, 1999; Nukunya, 2003).

## Retribution from Higher Powers

*Nkrabea mu nni kwatibe*  
*You cannot avoid the destiny that God has assigned*

(Salm & Falola, 2002, pp 36)

While magical causes of autism can be initiated by a human practitioner calling on spiritual powers, these same spirits are also believed to be constantly watching over and judging the living realm themselves (Akyeampong & Obeng, 1995). When a sin is committed, it is believed that higher powers are entitled to punish the offender (Lewis, I.M., 1985; Nukunya, 2003). This punishment can take the form of disability or impairment (Avoke, M., 2002), as was noted by many respondents.

*They are thought to be not whole, not normal, sick. They are thought to be cursed by the gods, bewitched if you will. Senior Professional*

*That is what I am saying, [people believe in] superstition, that the parents have offended some gods. –Professional*

*Well the rural person will think it is gods, taboos, reincarnated spirits, punishment for wrong doings. –Professional*

*....maybe [they are] coming from the gods around them....They will say it's the bad sprits that are leading such disability into the clan or into the community –Community Member*

The belief in divine retribution, whether from the High God, lesser gods or ancestral spirits, serves as a social control mechanism and challenges individuals to uphold society's moral code, if not for reward in the afterlife, then for fear of punishment in this one.

The beliefs in the ability of the dead to punish wrong doing and reward good behaviour helps in no small way to regulate the social behaviour and serves as a challenge to people to do their best for their families, descent groups, and the community at large (Nukunya, pp. 59).

The lesser gods are typically associated with animals and nature's elements (Salm & Falola, 2002).

*It could be stone spirits. There are spirits that reside in the stone at the centre of the compound, the family alter if you will. But the spirits can move from the stone into the children like that. That is why we use the animal blood, to trap them inside. - Community Member*

Many stakeholders spoke of spirits contained within nature; spirits of water were particularly associated with autism. Mame-water (translated 'sea lady') and Nswoba (translated from Akan languages as 'water child' and typically associated with rivers) were mentioned more frequently in the current research than any other lesser god.

*They believe there are bad spirits in the air ...From the river, or you know, especially from the sea. I don't know if you have heard of mame-water spirits....People believe that there are dangerous spirits in the sea. So when they believe a child is evil and is of the sea spirit- for that one they don't take kind to it. - Community Member*

*A Nswoba is a water spirit disguised. It is hiding, inhabiting the body of [the] child. The child is not human; there is no element of a human spirit residing in the body, only the water spirit. -Community Member*

*Some people think too that they come from the water, from rivers. -Professional*

Anecdotally, 'Nswoba' and 'mame water' were terms that came up frequently in informal conversations with Ghanaians when discussing my work or the current research. Despite these stories, related when stakeholders were discussing autism, the label 'Nswoba', is identified by Agbenyega (2003) as specific to children with Down's Syndrome. Interestingly the term 'Nswoba' was also generated when critical friends, who were very familiar with autism, participated in the word picture activity described in chapter two. During the activity 'Nswoba' was grouped with 'possessed', which was both the most frequently produced label and later ranked as the most stigmatising.

At other times, retribution is seen to be brought about by the breaking of a cultural taboo:

*[It] is taboo to eat fish from the river, particular river. We can't eat the mudfish [because that] will anger the spirit. Some too think the fish are the spirit's children. If you anger the water spirit those things you ask, they can come in that way so we don't eat the fish. -Community Member*

Agbenyega (2003) cites this taboo of eating fish from the Nsuakoraa river in the Brong Afo region; eating the river spirit's children (fish) invokes retribution in the form of 'retardation'.

Interviews also suggest that the characteristics of autism (as a distinct disorder) may lend themselves to increased association with magic and divine retribution.

*But if you talk of the spiritual ones, ah, those children when they are like that you will think some will not even talk then one day someone will come and tell you your son talk today and the next day he cannot talk. You understand? It tells you that there is a spirit behind that, working on it. -Community Member*

Autism is a complex disorder marked by splinter skills, occasional regression and difficulty generalising a skill learned in one context to another. 'Childhood Disintegrative Disorder' (CDD), another pervasive development disorder similar in presentation to autism, is marked by typical development followed by rapid regression and could be responsible for the observation above. This sudden change, without

explanation, can further reinforce notions of witchcraft when alternative explanations are not available.

*Yeah, there should be, it could be like if you have a child today like 6, 5 months, let's say one year and your child is alright, playing all the time, all of a sudden something come and you see your child like this. Not playing, not smiling, all the time, nothing. Can't even talk. What does it makes you think? You will call it sickness. – Community Member*

When disabilities are visually obvious causal explanations may remain concrete (accident or illness) whereas mystical explanations appeared to be chosen when impairments do not result in obvious physical differences, as is the case for autism.

*When it comes to the mental, they, I think sometimes it is beyond their imagination....You agree with me that when a child is born deaf and dumb it's as just a normal child, there is no any physical deformity in the child. - Community Member*

It seems possible that the 'strange' unexplainable characteristics of autism, especially in the absence of physically obvious signs of impairment, will serve to reinforce spiritual causal explanations and most importantly, the blame and stigma which accompany them. On the other hand, one parent expressed relief that her child did not have a physical 'deformity'.

*I am grateful to God in the sense that it is better, this sickness [autism] the way I saw it [when I heard about it], I thought it [was] a deformation... the way it was explain to me. [But] this one is different from that one, physical disability...When I read it and saw the photographs of some [other children] I thank God that I have got this thing [autism] in such a state. –Parent*

Future research is needed to determine the degree to which the absence of physical impairment either contributes to, or can help mitigate, the stigma associated with autism and its 'unexplainable' or 'odd' behaviours.

## **Positive Spiritual Perceptions**

Causal explanations for disability vary by culture, degree of impairment and individual circumstance. In some cultures, disability is viewed positively (Grinker, 2008a; Groce, 1999c; Holzer et al., 1999; Ingstad, 1995; Ingstad & Whyte, 1995). In an unpublished dissertation Field (1937) notes that amongst the Ga tribe of Ghana the 'feeble-minded' were believed to be a reincarnated deities and treated with awe and compassion (in Nicholls, 1993). While the vast majority of causes relayed by stakeholders in Ghana could be classed as negative perceptions, positive attributions should be highlighted for their potential to act as catalysts in advocacy and awareness campaigns.

*My mother, the late Akosua, thought that it is a way God is using them to test our faith. -Professional*

*I feel God gave me Kojo because he thought I would be able to look after Kojo. - Parent [Ama in chapter six]*

*But [a] few people think that no, it is a way that has been arranged by God, it is just for us to stay with them, show mercy to them, show compassion, give them alms, so that God also bless us. But these people are not many. -Professional*

Future research in Ghana should examine whether the belief that your child is a ‘gift from God’ allows parents to avoid some of the stigma (and perhaps self-blame) associated with autism as Ingstad (1995) suggests is true of disability in Botswana.

### **5.1.3 Utility of Causal Explanations**

Explanatory models for autism in Ghana proved to be inconsistent, malleable and shaped by individual circumstances (Ingstad, 1995; Ingstad & Whyte, 1995; Masood et al., 2007). With the exception of witchcraft initiated by ‘evil’ or jealous rivals trying to ‘pull you down’, spiritual causes in Ghana almost exclusively blame the parents, particularly the mother. Importantly, gods and ancestors are never directly blamed, regardless of the explanation chosen the blame always rests on a human actions (Ingstad, 1995).

*Yeah that it is a problem with that family, there is a problem in that family...That you must have done something in your past, or it's just the family did something, somebody went to do something, it's always somebody –Parent*

*They said that they were shy that people would talk. That society would educate their family, that the whole thing would be blamed on the man's family or the woman's family. -Professional*

Biomedical explanations also served to blame families. Those detailed above by community members or professionals include taking drugs while pregnant, attempted abortion, poor pre-natal care, physiological trauma, a lack of ‘maternal effort’ during childbirth, not having a husband, marital indiscretion and failure to provide enough love for a child. In contrast, family members were likely to invoke biomedical explanations which distanced themselves from the cause including environmental factors, immunisations, disease (or high fever), infection, convulsions, prescribed medications and accidents. Spiritual causes cited by family members were also those distant from their own actions such as curses from rivals or relaying what ‘others’ believed to be the cause. One parent overtly rejected a genetic explanation

*...because I don't have those things in my family. -Parent*



This distancing could be viewed as a result of a cultural outlook which suggests misfortune is brought about by one's own misdeeds and therefore deserved. In response, family members appeared to choose explanations which removed this shame and blame from central family figures and placed it on outside forces. Individuals more removed from the child's situation, instead seemed to feel that impairment was 'earned' and cited causes associated with poor parenting or divine retribution for the misdeeds of the child or family. Groce (1999c) hypothesises that this blame may in part be a result of 'psychological distancing'. When the cause is believed to be a result of an avoidable transgression, it allows an individual to reassure themselves of their own control and trust that the same calamity will not befall them.

In addition, whereas the quest to identify and understand the source of impairment is an experience common to parents of children with autism across societies (Grinker, 2008a; Masood et al., 2007), in Ghana, it seems possible that a worldview which rejects chance seems to fuel an even greater quest for answers.

*So if something happens to me, then a lot of times people want to have answers. Because if it just turns out that...from our point of view that cause is via some spiritual research. And it could be **difficult** to identify. –Professional*

*Oh, they [parents] take it [the child] to the shrine, meet many many spiritualists. They see so many and at the end of it, they have still not found any cure. You see them hopping from church to church, from fetish priest to fetish priest. –Teacher*

These responses suggest that the belief in a cause which is always determinable may lead some parents of children with autism on a protracted search for this cause. The experiences of families and the impact of this belief will be explored further in the next chapter. For now, what is critical is that an outlook which rejects chance can result in a continual search for answers.

#### **5.1.4 Impact of Beliefs on Management of Autism**

According to Groce, the way children with impairments are treated in society is largely a result of cultural beliefs regarding how and why they became disabled (Groce, 1999a, 1999c). This cause and effect was clearly evident in interview responses:

*If they believe it is a curse, then you know how they treat the causes? Sometimes they looks [for] some kind of answers for a curse, they don't believe it is medical condition, so that they will not be motivate to find medical solutions to them. – Community Member*

*That is because they are mostly religious people and they just believe there are spirits. So no matter how the medical explanation you give to them, they might respond, 'all right, all right, all right [but just dismiss it]. -Professional*

While interrelated, it is important to distinguish between the belief that magic is responsible for the presence of autism and the belief that magic can cure autism. Both of these beliefs are commonly evoked in Ghana, usually, but not always mutually. Traditionally, magic as a treatment would have been sought only if magic was also the perceived cause of the misfortune. While still generally true, the lines between spiritual practices have become blurred over time, making them increasingly hard to deconstruct. In general, when the cause is thought to be curses brought on by magical forces, the solution will entail magical protection and counter curses.

*Then they captured the spirit and raised the child. Now that the witchcraft was stopped with a mixture Shea butter and some other stuffs from the herbalist so you will never really know... -Community Member*

When disharmony in spiritual relationships, with ancestors or lesser gods, is thought to be the cause, 'cures' will necessarily focus on discovering the source of strife and making amends to restore the rightful balance.

*And sometimes when somebody gives birth [to a child with an impairment], they go consult the oracle to tell them what kind of lesson that child came with. -Community Member*

Only when causes are thought to be biomedical, or alternatively when spiritual attributions are overtly rejected, will medical solutions be sought (in the first instance).

*[I knew a] woman had like severe pain every day, meanwhile the [pregnancy] term wasn't up. The people in the family believed the child is a spirit child trying to kill the mother before coming out. And you know by then I was also doing the research on spirit children and I didn't believe in that, I said "no look, this is not true, let's go to hospital. -Community Member*

*People do not do both, unless, those who do both, is those who are not really nailed down in Christianity. It means such person have doubts. But if you come across someone who really believe, I believe that there is one God, so it will be very difficult for me to accept anything but doctors treatment. I will only accept spiritual treatment when I know it is prayers coming from somebody who is a man of God. -Community Member*

Even when medical assistance is sought, it is usually accompanied by spiritual reinforcements.

*And there are certain illnesses that people will tell you very bluntly, what is the point of bringing to the doctors. Or, they might say, we go to the doctors but you should be applying your prayer, you should be going to see somebody else in addition to the doctor. You can't just do one; they have to do both.-Professional*

*You know at the hospital nobody will get spiritual treatment, its medical. But when they really see that the condition is very challenging, they do allow pastors to come to*

*the [hospital] church to have prayer sessions with the fellow. That is when the doctors think that what is happening really seems like getting out of or going beyond their medical experiences, sometimes they do allow pastors to come in.*

*A majority of the nurses that you see in the hospitals, the doctors here, they are Christian especially, or they are spiritual in some way, they would pray, yeah, with you. They would ask you to pray, in addition to the medication that they give to you.*  
-Professional

Similarly, the spirituality of Ghanaians guided them to a unanimous (among respondents) belief in prayer, in various forms, as at least one critical element in a potentially multifaceted approach to managing disability.

*I mean spiritual you cannot see any spirit and fight with the spirit, it's all by what praying, just say, prayer is just saying what you want to happen, that's all.... But in everything we do, there should be an element of prayer. - Parent*

*But even at that time right, they didn't know [what caused it], but I had the hope that, you know, he will be well, so I will pray, you know, and he will be well. So, we prayed and prayed and prayed and prayed and no response but probably it is the prayers that brought me here [Accra] where there is some help. -Parent*

*The prayer camps help. We also began giving him the drug the doctor said, that helped, along with the prayers. -Parent*

*I pray, I pray, I **pray** a lot and every time that I pray I tell God that it is Him that created him, you understand. I am his earthly father I know this...even if he is my son he is God's son and I know that every perfect kid every perfect thing comes from Him. I know and for Him everything is possible so He should change his situation around. And I will continue to pray until I see him change or I die. You see? -Parent*

One respondent even articulated a sentiment, of 'why not' with regards to prayer, a belief that it certainly couldn't hurt the situation.

*Because what do I lose when I say it, when I pray, what do I lose? Nothing goes out of me. You understand? Rather, you see, somebody was saying that two things, if you believe that there is a God and at the end of the day there is no God, you don't lose anything. But if you don't believe that there is a God and at the end of the day there is a God what do you do? [Laughs.] What do you lose as a matter of fact? -Parent*

The role of prayer and faith on a family's experience in Ghana will be discussed further in the next chapter. As I will show, spiritual beliefs can be a powerful tool towards acceptance and in many cases act as a coping mechanism. This same propensity towards understandings one's experiences through a religious worldview can however, also have extremely negative consequences.

## **Bloodshed**

*Some people use some crude means of tackling spiritual things. -Parent*

Unfortunately, the notion of 'disposing' of children with disabilities was mentioned by an alarming number of respondents.

*And some still believe these children are bad omen and some will still do anything to eliminate them because the belief they are not supposed to be. –Community Member*

*With the mental ones, most of them believe they are not normal human beings and can't be allowed to live. And even sometimes, it's like those who live, it's not all of them that was allowed to live by choice. -Professional*

As shown above, the perceived causes of autism dictate an action to be taken. When children with autism were thought to be bewitched by spirits of the lesser gods, the solution was thought to entail 'returning' the spirit to its natural home:

*A fetish priest takes child to the water and hides himself. When the spirit is alone, it will transform into true animal form, maybe mudfish I think. The priest can come out and shoot the animal, which returns to spirit into the water. –Community Member*

*Some people think too that they come from the water. From rivers...So they have to be returned to the river. They are taken to the riverside and killed. -Professional*

*They just say if you take them out to the bush and leave them that they will turn back to what they are, the type of animal they are. -Community Member*

*You can return the spirit home, to the water. –Teacher*

*The spirit cannot be removed from the body – there is no child left inside, just the spirit. The only thing to do is return the Nswoba back to the water spirit... some people would take the Nswoba to a fetish priest who will take it to the river's edge and retreat and hide and watch. When the Nswoba is alone, it feels safe and transforms into its animal form, its true self. The priest shoots the animal so that it falls back into the water [which] returns the spirit into the water. -Professional*

A variation of this latter tale was heard multiple times. However in some versions, when the spirit reverts to its animal form it becomes a mudfish or snake and slithers back into the water without being killed. Other ways of 'curing' children believed to be witches or possessed by spirits included leaving them in the forest, placing them on anthills or beating the spirit out of them.

*Sometimes they are thrown on anthills for the ants to dispose of them. Or they are just taken and left in the bush. Or given alcohol to drink which will kill them. –Community Member*

*There are times too they just throw him away into the bush. Even at times on an anthill, so the ants just do their marking. At times even into the river. At times into the wild forest, maybe to be eaten up by some wilderness. Then, most we agree that they were whipped, they were flogged, just to get the devil out of them. –Professional*

*A lot of children get whipped, whipping out the devil in them, beating it out of them. I am sure [those who do not] get killed, get maimed, you know, get worse. -Professional*

Each of these responses indicates a belief that 'some people' still carry out these practices often with disclaimers that they happen only in rural areas or in the past. In no case did a respondent admit to actually being responsible for, or even considering, these purported practices. In fact, despite the alarming rate at which death was mentioned as

a solution, many stakeholders, particularly professionals, were quick to claim that 'disposal' and infanticide are outdated practices.

*We came to learn in one district, that as soon as they are born and a problem is detected they are sent off.... they were sent to a certain village ...there was a spiritualist there they were taken in front of and once those that were disabled went to that village they did not come back. But you have to take this all in context. This was in the past, before the Catholic Church. Now people understand that it is natural, that they are normal children. -Professional*

*It is felt by many that they are not needed. Often they are disposed of from birth, killed....It's not as it used to be, things are changing. Maybe in some communities you will still find this but not everywhere. Sometimes they are hidden away or disposed of but in small pockets. -Professional*

*The old ways are drying out. They are not longer as shy to come out. People no longer always believe they are cursed. They are beginning to learn it is the result of a medical condition. Also through our education reforms. -Senior Professional*

*I will say that today it has changed. The perception [has changed], like especially the killings have stopped. -Professional*

Despite a desire to attribute the stories above to exaggerated and memorable accounts of extinct practices, a few instances, claimed to be directly known to the respondent, were relayed in interviews.

*If I may cite an example, I know a lady...and her first child was this kind of mental retarded, like slow growing.... I never had the opportunity to go see the baby but the baby was in Korlebu [Hospital] for very long and when they discharged her from the hospital and took her home, after some time, the family members they all had meeting agree that the baby was a dwarf so they have to kill the baby. Which they did. So as I talk to you, the baby is no more -Community Member*

One professional in particular related a long and detailed account of a cleansing ritual:

*The professor [psychologist] here in my office told me a story which you may want to hear about. Em, I think it was a story that happened in the Central Region. And em, I think ...people had claimed that they could cure children with Cerebral Palsy and autism and children with various disorders. So, the [professor] went to go and have a look...And he said how it has happened, the whole thing takes place at the seaside...so he said they went and they were just watching the guys drumming and dancing, local people, some fetish other people, and all kinds of things. And the children had been lined up in front of these particular trees by the water... cause these are...water children. So, they were going to present them to the water, to transform them....At some point he said, everybody had to leave, because this was a private thing ...so the parents and everybody had to leave. And he said...they cut a tree...and they tied all the children up somewhere around in the water. Basically, what they did is they shot all the children, they killed them. **Openly**. They killed them and um, children were **washed** into the sea. And so, [the professor] went and hid somewhere and watched all that was going on. So when they took the tree, however they dropped the tree, got the tree back in place, that place was very quiet and very still and they [families] were thinking that the water had come to take the children away....Basically, I am trying to tell you, and this is not like 50 years ago, I don't even think it was like 10 years ago, it was just a little while ago but not that long ago.*

Again, it should of course be stressed that in no instance did family members ever indicate a desire to be rid of their children or even indicate that others had suggested

this as a solution, as they did with other spiritual cures. Family views and experiences are the focus of the next chapter.

These practices seem to be declining, especially in urban areas. It is likely that these few isolated incidents were relayed as they are both memorable and shocking, even to those who are telling them. This by itself indicates a lack of normalcy in these stories. While an understanding of the history of autism in Ghana is critical, readers with an inclination to judge these practices as inhumane or primitive are reminded of the countless accounts of similar treatment in European history. The ‘refrigerator mom’ theory of autism and the infanticide of an entire disabled population by Hitler are tragic reminders of the recent past. They are not however, taken as indications for how individuals with disabilities are treated in European societies today. The history of Ghana should be viewed in the same way, understood for its shaping of worldview and understandings of disability today, but malleable and in a state of constant evolution.

It is clear that casual attributions for autism in Ghana are complex. Whether biomedical or spiritual the only consistency seems to be that causal explanations almost entirely serve to blame and shame the individual or their family, particularly the mother. It is also clear that a preponderance of spiritual explanations for disability do exist amongst Ghanaian respondents and that these beliefs fit comfortably with the worldview outlined in the last chapter. Continuing to follow the framework outlined by Groce, I now turn to an exploration of valued or stigmatising traits in Ghanaian society and the degree to which these traits influence the experience of a child with autism.

## **5.2 Valued or Devalued Societal Traits**

In any society, implicit norms or ‘rules’ govern what is commonly deemed acceptable or objectionable behaviour (Groce 1999a, c). If customary norms are specific to a society then it follows that behaviours and actions which are viewed as abnormal (or ‘disordered’) are similarly culturally bound. In a culture based on collectiveness and harmony, it is logical that Ghanaians are known for ‘unquestioning acquiescence’ to the status quo (Kuada & Chachah, 1999). In this way, traits that make an individual

salient, or behaviour which is visibly different from the normative expectation, may be viewed as ‘disordered’.

### **5.2.1 Socialisation**

As I have shown, one of the primary difficulties for children with autism lies in social skills. This challenge, while ostracising in any society, may be particularly debilitating in Ghana where collectiveness, interdependence and reciprocal obligations to one’s community and family are the dominate worldview. Understandably then, any tendency towards isolation and reclusiveness on behalf of children with autism in Ghana is likely bewildering and stigmatising.

One culturally specific social skill required in Ghana is participation in significant rites of passages, marked by elaborate ceremonies which celebrate the birth, puberty, marriage and death of an individual. In addition to the cultural values they highlight, festivals and rites of passage ceremonies are treasured social arenas. Unfortunately, these events are virtually impossible for a child with autism to navigate. Not only do they often require an understanding and obedience to ritualistic protocol; they are typically loud, busy, unstructured and potentially over-stimulating environments. These facets of social environments are those most likely to lead to hyperactivity and challenging behaviour for a child with autism, especially one with sensory processing difficulties or without the ability to understand or communicate their discomfort and needs. An inability to participate in these festivities could contribute to the possible alienation of children with autism and their families from their community.

In addition, a lack of imaginative play skills is seen as a debilitating challenge to typical childhood socialisation in Western cultures. It is unclear however, how this translates to Ghana where toys and imaginative play props are far less common and especially unlikely to be used in educational settings. Play is naturally restricted by a lack of resources and tends to be (from observation) highly centred on organised sports or playground type games. It is possible that this lessening of imaginative play in group situations could ease social interactions for students with autism. However, imaginative play is still very much a pattern of typical development and despite a lack of toys, children in Ghana were observed making use of the materials available to them in

imaginative ways. One girl was seen on the street tying a plastic bag to the end of a stick and running with it behind her like a kite. Another time, two small boys were observed removing a cardboard box from a rubbish heap and using it to enact a typical tro-tro (similar to a small bus) experience. It is clear that without these skills, children with autism are likely excluded from many typical socialisation opportunities, a situation which is compounded by social stigma and discrimination in Ghana.

## Social-Communication

It was clear from multiple respondents that the ability to communicate is a highly valued skill, perhaps historically as a result of oral traditions. The absence of speech was often considered debilitating for children with autism.

*They bring them here for behaviour training or for the child to talk. Most brings the children because they want them to talk so they think when the child comes here the children will start talking within one week [laughs]. –Teacher*

*Most of the people who come to us are already concerned, child is difficult or not talking, concerned about the speech. That is the most important thing. Most of them have been to some sort of preschool and they have been withdrawn. But mainly it is about the speech when they come [here]. –Professional*

*[There is] fear...in the sense that is he going to speak? Is he going to be normal child? Even the father told me to ask the doctor 'is he going to make it talking in the near future?'. –Parent*

These quotes highlight speech as an important and valued trait. Greeting is a valued social and communicative custom in Ghana (Kuada & Chachah, 1999; Salm & Falola, 2002) and is a mark of respect shown to others (Utley, 2009). The protocol varies with the person you are greeting, their status (a combination of gender and age) and your relationship to them. While ritual is relaxing or changing over time, the need to show respect by greeting someone is still a valued custom in Ghana, as the respondent below makes clear.

*This one girl, whenever the girl passed would greet, say “good afternoon” or if it was in the morning say “good morning”. And the sister would interpret it to us. I said “look, hey, madam, stop it. I can hear the girl.... What is your problem? Let her speak for herself.” She said “she doesn’t do anything”. I said “look, because you are doing this to her she cannot learn anything, let her do things for herself if she is willing to do it”. She said “no, she is not normal”. I said “oh! She is rather normal because she always greets us, you don’t greet sometimes, even though you are normal”. –Community Member*

Ironically, in this case, it is the individual with a disability who is thought to have the better manners by demonstrating greeting skills. Parents of children with autism also reinforced this notion of greetings as important in relaying their experiences. Two



parents in the next chapter independently indicated that the failure to come out and greet the car when they arrived home was an indication something was wrong with their child. Another parent indicated their child's autism was improving as he was now able to greet people:

*...cause when you say "how are you?" his response [now is] "I'm fine". –Parent*

The struggle to appropriately greet someone may be the result of a child with autism's aloof personality, their difficulty in registering faces, poor communication skills or a failure to assimilate the social protocol of greeting through observation alone. It should be noted however, that the ritualised nature of greeting in Ghana may serve to provide the needed structure for a student with autism to learn and maintain this skill.

Nonetheless, until such time when greeting skills are expressly taught through targeted curriculum this advantage is likely to go unnoticed and the failure to greet will remain a salient indication of difference for many children with autism in Ghana.

## **Respect**

Greeting is just one of many valued demonstrations of respect in Ghanaian culture. Above all else, children in Ghana are expected to be courteous, respectful and obedient, especially of their elders (Dei, 2004; Kuada & Chachah, 1999; Salm & Falola, 2002; Utley, 2009).

*Ok, the child has some responsibilities, like being obedient. –Community Member*

It is believed that elders have achieved old age by living in harmony with their families and the spiritual realm and that they should therefore be afforded the respect and admiration of younger generations (Utley, 2009).

Children are at the bottom of the social ladder. They are valued, to be sure, but they are also taught to respect age and status and perform their duties without objecting. Children are expected to learn the mores of the community so that they do not disgrace themselves and their family, their elders, and their ancestors (Salm & Falola, 2002, pp. 138-9).

Despite many challenges associated with expected behaviour, some aspects of these traditional customs appear potentially advantageous to children with autism. An inability to make eye contact is arguably less detrimental when it is thought that "children who look elders in the eye are challenging their status and authority" (Salm & Falola, 2002, pp. 149). Children are however, still expected to show respect by

standing still without fidgeting and looking down towards the ground, skills a child with autism may struggle to perfect.

The ‘unusual’ behaviour of some children with autism is likely to be considered a sign of disrespect in Ghana and may contribute to the belief that they are simply stubborn and misbehave.

Children who fail to observe these social values are considered untrained and uncultured (Salm & Falola, 2002, pp. 149).

As children are a reflection of their parents, ‘disrespectful’ children can bring shame to families, increasing the shame and stigma already attached to autism. Of particular salience in Ghana, where the status quo is typically respected, is the hyperactive or challenging behaviour on the part of some children with autism.

## Challenging Behaviour

While not part of the diagnostic criteria, challenging behaviour is typically associated with autism (Dawson & Osterling, 1997; Grinker, 2008a; Volkmar et al., 2005) and can often be understood as a result of underdeveloped communication systems, socialisation challenges or a sensory processing difficulty (Dawson & Osterling, 1997; Diament, 2009).

*When he grows angry, [when] he wants something I don't know what he wants, he starts hitting me. –Parent*

In Ghana, hyperactivity and challenging behaviours were often identified as one of the most frustrating and ‘othering’ aspects of autism.

*[Child's name] was very hyperactive. They gave him to me on only my 3rd day here and by the end of the day, I almost left this place for good, stopped work. He was running everywhere and wouldn't stay in one place at all. By the end of the day I was so tired...It was the behaviour that I found very abnormal. They are always jumping and can't stay in one place. –Teacher*

*Peter likes spinning and jumping and when he is doing that, [the other students] are just standing there looking at him. Some will say 'Peter stop!', and other will just be looking. They will come and tell you 'auntie, auntie, look at him'. After telling Peter to stop and Peter is not stopping some will go to him hold him [motions grabbing shoulders with two hands] and say 'Peter stop!', and someone else comes [to me] and says 'auntie I am telling Peter to stop and he is not stopping!' –Teacher*

*Because their behaviours are quite different from the behaviours of other children. We take the fact that they are not talking, it's not just that they'll be making noise, jumping, going up and down. –Senior Professional*

*His [father's] prayer is that God should just let him to settle, to be a normal child, even if the speech does not come, he will accept this....settle down, if the behaviour comes down ... if only he can settle. - Parent*

It is likely that the saliency and unacceptability of these behaviours in Ghanaian society is a result of the traditional role of a child in the community as subordinate and obedient to his or her elders. Parents also commented on the impact of challenging behaviour on their experience of autism, which will be discussed in the next chapter.

### **5.2.2 Becoming an Ancestor**

While death is clearly a prerequisite to becoming an ancestor it is by no means sufficient to be bestowed with ancestral status; there are number of criteria which must be fulfilled. As becoming an ancestor is considered to be the 'goal of life' (Kirby, n.d.), the criteria by which membership to this exclusive group is granted can be used to illuminate some of the values held in esteem in society. To become an ancestor one must live to an old age, lead an honourable life, have aided in the affairs of his/her lineage or community, have had children and die a 'clean' or natural death (Kuada & Chachah, 1999; Nukunya, 2003; Salm & Falola, 2002; TICCS, n.d.). Critically, each of these criteria is expected of an adult in Ghanaian society and each is extremely difficult for an individual with autism to achieve given the belief systems and societal structures outlined in chapter four.

#### **Unclean death**

Amongst others, commonly listed unnatural deaths include suicide, leprosy, lunacy and accident, any of which can occur as a result of angering the lesser gods or ancestors (Kuada & Chachah, 1999). While never specifically mentioned by name in the literature, it is likely that a person with autism would, by definition of their disability, be deemed to have died an unclean death in Ghanaian society.

#### **Marriage/Children**

*Nothing is as painful as when one dies without leaving a child behind*

(Utley, 2009, pp. 44)

In Ghanaian society, “marrying and bearing children are more than expectations; rather they are requirements or obligations to society” (Utley, 2009, pp. 43). Interviews revealed an assumption that individuals with autism would not marry or have children, either because they were not able to, or because of societal stigma which prevents their full inclusion in this ritual.

*They are forbidden to marry. [Laughs loudly] Yeah because [pause], well let me put it this way, if I am autism patient, would you like to marry me? So when they consider someone as useless, this is the way they do [not allow them to marry]... They will wash you out of the family. They know you can eat, you can drink, but talking of marriage, no. –Community Member*

*They do not consider you as a human being [so] you can't produce any family. – Community Member*

*The physically disabled are able to marry and raise a family. With autism, nobody will approach them; even their families may shun them. How can they marry? – Professional*

Interestingly, the professional above places the blame on the way autism is perceived, not on any intrinsic characteristics. Wherever the blame is placed, it seems there is agreement in the perception that individuals with autism are unlikely to marry in Ghanaian society, as things stand today. This not only excludes individuals with autism from full membership in society while alive, it prevents them from achieving the honour of ancestral status in death.

## **Elderly Age**

There were also indications in interviews that neglect, a lack of knowledge and limited resources, alongside an inability to provide for themselves, would prevent many individuals with autism from living to an old age.

*These days they [parents] may not kill them outright but they also may not intervene on their behalf. Let's call it a 'neutral attention'. Maybe they will not send them to the hospital as fast as they would send another child, or they think the problem is just part of the disability not a separate illness that they would need to go to the hospital for. Or maybe they would not give them as much food [so they] starve them. – Professional*

*Hardly any will go into adulthood. Even if when the mother is around the child's life is guaranteed, when the mother dies no one addresses his or her needs so the child may not survive....[The extended family] have to survive, they cannot take the time to look after him, they have to go to work....The attention and support given to the one with a disability is suddenly withdrawn. Maybe there will be an accident when the rest of the family is at work and no one is watching him. Or maybe they will just not have enough food for him; there is a general reduction in care after the mother dies. That is what I have observed anyway. Most of them will not survive into adulthood. – Professional*

*I know one man, he is about 50 years and every day I enter the bus with him. I have not seen that before [someone with autism reaching that age] –Teacher*

Groce (1990) notes that the withholding of resources, especially when scarce, becomes logical if cultural beliefs dictate that someone will not survive. This belief then becomes a self-fulfilling prophecy. In a culture where elders are highly respected, the inability of children with autism to live to an elderly age, whether real or perceived, excludes them from full membership in society.

### **Contribute to the Affairs of Society**

A child in Ghana is expected to be disciplined, hardworking and significantly contribute to the daily running of the family. It is essential to understand the role of a child in Ghanaian society before it is possible to understand the degree to which the inability to contribute to a household is viewed as ‘disordered’.

*Let’s say at certain age a child, the [parents] start to enrol a child into some house chore...some houses even before eight [years old], they will already start teaching the child to wash dishes. If I can set myself as an example, very tender age, like say primary three, I eat my lunch, I change, the next thing, my mother gathers some stuff ready for me to go sell them. So, you come from school, you go to do some selling, just to earn more income for the house. Then you come back, you wash dish, then my big sisters are responsible for house chores such as cooking. Then weekends, they do washing. When I was around primary six ... my mother will first start by letting you wash your own clothes. And then, as time goes on my sisters leave...and the family is getting smaller again so maybe you have to wash your own clothes to a certain point then you feel that you are big enough then you start washing your mummies clothes as well, and so on, that is how it goes. –Community Member*

Unfortunately then, the inability to contribute to these tasks, whether real or perceived, contributes to the notion that children with autism are ‘useless’.

*...so this is what they think, this guy has no use, he is useless...You cannot even contribute, you have no contribution to the family. –Community Member*

*He’s completely useless, he didn’t go to school, I think all he does for himself is bath, dress up, and he walks about in the community. He never schooled. –Community Member*

*Interviewer: Does he contribute to the household chores and responsibilities the same as his sister?*

*Respondent: Oh, no, not really. He doesn’t. He doesn’t. [Pause, quieter]  
Sometimes when he eats, we want him to wash the plates... [trails off]. –  
Parent*

In response to the Kofi story, one community member gave the following explanation for his behaviour:

*It is stubbornness. The behaviour comes from the parents, they don’t train their children well, they spoil them, they go without hard work so they become stubborn to do things.*

Groce (1990) notes that “childcare, housekeeping, the growing and processing of foods and other household responsibilities done by disabled children and adults frequently make important contributions to the overall functioning of the family unit” (pp. 5). While certainly in the minority, a few stakeholders did mention similar beliefs in Ghana.

*Because those children will live to be security in the house. Even if they have nothing to do, at least the only thing they can do for you, he will be a security in the house. He is in the house and somebody comes in, he can ask you “what do you want?” For you. That is the least thing they can do, if they cannot even do anything, they can do that. - Community Member*

*Respondent: In some families where those children exist, they are seen as a relief. They will work for a long time, maybe take care of the animals, for many years without complaining. Other children will grow and want to do other things, so these children are needed.*

*Interviewer: That is a lovely thought, are there other examples you can think of where the families see the child in a positive light?*

*Respondent: Well, the preference is for the family not liking the existence of such a child. But if they are trained to be useful. There was a child with MR [mental retardation] in my village and she worked very hard. She did not complain, the family fed her well because she was a very hard worker and she came to be seen as a blessing. [Long pause] but they still wish she was normal. - Professional*

*Some people also think that it is good to have them....There is a removed few [who believe] that if you are with them, if you stay with them, if you help them, you will also receive some blessings. That it is a good sign to stay with them. That aspect is not so much widespread... that one is not so much. -Professional*

Clearly, both dedication and the ability to work hard are valued traits in Ghanaian society. The perception that children with autism are stubborn, useless or unable to be independent is a barrier to their full membership in society. Given these feelings, it is unlikely that individuals with autism would be given the opportunity to ‘contribute to the affairs of society’ as is needed to earn the respect necessary for ancestral status.

### **Ancestral status**

The reverence afforded to ancestors is clear; to be afforded this status is in many ways akin to full inclusion into Ghanaian society. The attributes which qualify one for membership in this group are those deemed important to the social order. Outlooks which see individuals with autism as unworthy of marriage, incapable of contributing to society and afflicted with an ‘unclean’ disease prevent them from consideration for ancestral status, or even the opportunity to strive towards that goal. At times, social neglect prohibits living to an old age, another important criteria for ancestral status. As long as these perceptions and behaviours persist, individuals with autism will never be

afforded full membership in a society which holds becoming an ancestor as the ultimate achievement in life.

Valued and devalued traits in Ghana society clearly cannot be separated from views on prospects for a successful life. Valued traits such as hard work, independence and the ability to contribute to the shared responsibilities of a family or community all impact upon perceived role of an adult and future life prospects.

## **5.3 Anticipated Role in Adulthood**

Independence and self-reliance is an important skill in Ghana. Stakeholders appeared unanimous in their belief that the ultimate role of a productive member of society is contribution to one's family or community.

As outlined in chapter four, contribution to the family extends beyond financial responsibilities. Caring for the elders of a family is a duty that traditionally falls to the younger generation (Kuada & Chachah, 1999; Nukunya, 2003; Utley, 2009). The inability to give back to the family, to care for those who cared for you, seems to be a significant barrier to the acceptance of children with autism.

### **5.3.1 Job prospects**

As I have demonstrated throughout and above, a general perception that individuals with autism are 'useless' and therefore not able to learn, work or contribute to society was abundant in interviews. It was generally assumed that as adults, individuals with autism will not be able to contribute to the household, as is expected of all family members. When asked specifically about job prospects the majority of respondents indicated that individuals with milder 'mental' disabilities would be able to learn a traditional trade craft or participate in manual labour.

*Respondent: It is hard, many of them have a short memory and can't learn well but even some are educatable, the academic may not be there but life skills can be taught, this they can do. Tie Dye, Batik, making door mats, drawing...*

*Interviewer: When they graduate from school, will they make use of these skills in the community?*

*Respondent: Some will. Those who are mild. I know a girl who graduated and became a seamstress; they give her some things to do sometimes.*

*Interviewer: you mentioned those with mild disabilities, what will happen to those with more moderate to severe disabilities after education?*

*Respondent: Well what can they do? Just play some games or something. [Long pause] - Professional*

*There are a few of them that I know that do minor jobs just to take care of themselves....Physical jobs. Like back at my place, they normally prepare pito<sup>20</sup>. Some of them are able to do physical job like splitting the firewood into pieces. – Community Member*

*...those with mild disabilities can do certain jobs, such as driving, construction – they would help carry water or materials, they can work in market places as porters, or they can take care of animals- like a shepherd, they can do farming, or fishing if they live near water. –Professional*

Unfortunately, the belief that they may learn a ‘useful’ skill was often qualified with the sentiment that they would not be able to independently make use of this skill, either due to their own inability,

*Interviewer: So, what about as they grow. When they are adults, what will they do?*

*Respondent: They can do handicrafts and things.*

*Interviewer: Do you know anyone who sells?*

*Respondent: No, no they can't sell.*

*Interviewer: How come?*

*Respondent: Well, how do I say, maybe they don't have the brain to sell. Those schools don't teach them things like money or maths. Only something they can sit down and do, like handicrafts. Something to just keep them busy doing something. –Community Member*

*They will [learn] sewing or hairdressing but normally [employers] don't take them seriously, because they can spoil things. Because their mind is not correct people are not taking them...unless like, big big companies and they will just to work there to clean there but you won't see them at a typical place... they don't take them because they cannot get straight mind to do the thing. –Community Member*

or the inability of the community to accept them.

*People don't give them jobs. No, people don't give them jobs. Even they prefer to get someone to fetch them water, instead of they themselves doing it...Yes, they think they cannot do anything.-Community Member*

*They might think well because he is not normal, whatever he has done, it is not going to last so they don't buy from you, they go to the other person to buy from....The fellow who is going to buy, the buyer is even ashamed, looking out that somebody is looking at him or her [afraid they will see that he is], going to buy something from, or [is] standing in front of a disabled person try to bargain with him. –Parent*

*If a student is dull but physically strong he can go to the farm and produce a living but if the mind is weak, the community does not accept him. -Professional*

It seems then that the perceived inability to fulfil the primary expected role of an adult in Ghanaian society, the contribution to one's family and community, is a barrier to the inclusion of many individuals with autism, at least as things stand today.

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<sup>20</sup> <sup>20</sup> A traditional alcoholic drink made from fermented millet.



## 5.4 Evolving Worldview

While beliefs about disability are often exceptionally-long standing and intricately woven into many other aspects of the traditional culture, it is important to be aware that belief systems can change over time (Groce, 1999b, pp. 289).

Culture is dynamic, beliefs and values are both subject to, and shaped by, outside influences. The understanding of disability and use of explanatory models in Ghana is constantly evolving, perhaps even more so in an age of urbanisation, globalisation and Westernisation. Numerous stakeholder responses reinforced this notion in Ghana, often citing education as the catalyst for this change.

*What I know, mostly, in Ghana, even in this century, when there is more education, people get to know these things are normal situation that can occur during birth or sometimes in the course of your growing up you could be disabled. But some still attribute it to superstition. - Community Member*

*That in particular was a long time ago. Now it is becoming more accepted that the physiology of the child is the problem and that no one is to blame. We cannot blame anyone. Our understanding is clearer. -Senior Professional*

*When I came [here], I got to know that they can't turn into an animal because they are not an animal; all these things are just a big lie. I came to know it was like a disease, something came from the brain, that is why I used to educate plenty people to tell them all is a lie. -Teacher*

Globalisation, in the form of global media, travel, international business and the internet bring outside cultural influences into everyday Ghanaian life with ever increasing frequency and help to shape a constantly evolving culture and worldview (Salm & Falola, 2002). However, when foreign aspects are integrated they are, more often than not, first adapted to fit into traditional values. Missionaries of Christianity sought to convert Ghanaians and urged them to dismiss their own indigenous practices. Instead, Christian (and Islamic) beliefs were integrated into traditional belief systems, allowing for consistency in worldview. Salm and Falola (2002) cite the example of the belief in a traditional hierarchy of powers in which, upon influence by missionaries, the Christian God was easily included as the 'Supreme Being', as the top of this hierarchy. In this way, traditional belief systems were maintained while incorporating external influences.

*There are some people...they only go to church [but] they don't really believe that the only way for salvation is [the one Christian] God. So sometimes they can try both ends. [When a family member was sick] I spoke with somebody who was telling me "why don't you go to look at treatment, you should go and consult the fetish, look God understands those things, God even said that he helps those that help themselves" ...by making the move to go consulting oracles... you are trying to help yourself and in that case God will also come in to help you. -Community Member*

When asked directly about the potential discrepancy between one Christian God and a belief in multiple lesser gods, one participant replied simply:

*...because God creates the gods. – Community Member*

In Ghana, modern medicine is recognised for its effectiveness against certain diseases, but it is often considered useless against illnesses caused by spiritual forces (Salm & Falola). One parent spoke of how God uses modern medicine as a medium through which He works:

*I try to pray over the medication before he takes. And I have a prayer too for that. God should use the medication to heal cause [him]. He gave the knowledge to doctors and scientists to prescribe medicines for sick....So I do believe that God can clear whatever is in the system, I strongly believe that God can heal [him] by taking medication. - Parent*

While conducting research on Autism in South Africa, Grinker (2008a, 2008b) met a family who experienced this melding of tradition and ‘development’ firsthand. Initially, the parents of a child named Big Boy were resistant to the idea of taking him to a traditional Zulu healer but eventually conceded to the wishes of their own parents. To their surprise the traditional healer concluded “I know what is wrong with Big Boy, he has autism” (Grinker, 2008b, pp. 5). Having read about autism and its symptoms on the internet, the traditional witchdoctor determined that this was what was afflicting Big Boy. Importantly however, the *reason* Big Boy had autism was explained to the parents as a transgression against their ancestors, which was worsened by a failure to right this transgression through demanded sacrifices; in their increased anger “they gave Big Boy a white man’s disease: autism” (Grinker, 2008a, pp. 241). The worsening of Big Boy’s symptoms over time was therefore explainable by a failure to restore harmony with the ancestral spirits, invoking additional anger which resulted in a worsening of the possession.

This story is consistent with the assertion Lewis (1985) makes, that witchcraft is often invoked in explanations for ‘why’ a disability occurs while explanations of the ‘how’ remain concrete. For example, when explaining the ‘how’ a parent might state their child’s autism originated from a high fever. However, when explaining the ‘why’, this fever may very well have been caused by magic or divine retribution.

*There are certain things you can tackle the physical but the root cause will still be there you know. We can cut the tumour but it will come, it will still come because the cause is down there. But in our side of the world, as for the spiritual aspect, we do*

*not downplay, we do not forget about it, it is there but those who are ignorant you know concentrate on one side and leave the other side. –Parent*

This merging of biological and spiritual explanations is an example of how Ghanaians adapt, rather than replace, their traditional worldview. The melding of traditional beliefs with newer influences is further evidenced by the adoption of the traditional Gye Nyame Adinkra symbol by the Christian church, and its followers, as representative of the High God. Clearly, “The underlying contributors to attitude formation are complex and interrelated” (Gaad, 2004, pp. 321).

## **5.5 Conclusion**

This chapter has attempted to use the three categories identified by Groce (1999c) namely, causality, valued or de-valued traits and the expected role of an adult in society, as a framework for understanding the perception and management of autism in Ghana. Clearly, despite following Groce’s useful framework, it is very difficult to discreetly distinguish between causal beliefs, valued traits and the role of an adult in Ghanaian society. If nothing else, this chapter has demonstrated the complexity and interdependence of each of these cultural influences on the experience of autism in Ghana.

Causal beliefs generally fit into two categories, those biomedical or spiritual in nature. Stakeholders were found to differ, not by which of these they purported, but by the blame and degree of distance different causal explanations afforded. Family members were found to largely provide explanations which served to distance them from this blame. In contrast, professionals and community members tended to cite causal explanations which served to place blame on the parents, particularly mothers. Poor pre-natal care, marital indiscretion and punishment from higher powers are but a few of the many examples provided above.

A discussion of valued and devalued traits in Ghanaian society reinforced notions of Ghanaian worldview outlined in chapter four. The ability to communicate and socialise with one’s family and community, while maintaining ritual and expected norms of behaviour, were highly valued traits. Children with autism in Ghana are hindered in these efforts both through their own impairment as well as through societal attitudes and

expectations, or Disability. This examination of valued traits and expected roles in Ghanaian society also illuminated the importance of independence and the ability to contribute to one's family. The ability to live an independent life yet still maintain family connections and fulfil responsibilities to one's kinship was found to be essential for full membership in society.

A propensity to search for answers in the spiritual, a belief in ultimate accountability for one's actions, maintenance of the 'status quo' and the significance of communal social structures uncovered in this chapter are all consistent with the cultural lens, or worldview, identified in chapter four. These cultural belief systems were both extended to, and influenced by, understandings and management of autism in Ghana. This chapter largely explored the impact of spiritual beliefs consistent with cultural understandings of disability but the interconnectiveness of these beliefs with communal social structures cannot be downplayed. In a collective society with strong kinship ties, individual identity is inextricably linked with one's kinship group; the behaviour of a single individual reflects upon and is judged in relation to one's family. In Ghana then, the 'experience' of autism is not solely an individual one and the next chapter will necessarily explore the family's experience of autism in Ghana.

## Chapter 6

# Experiencing Autism in Ghana: The Family Perspective

The last chapter aimed to explore the perception of autism in Ghana through an examination of the perceived causes, valued and devalued traits in society and the future role of an individual in their community. The preponderance of beliefs were negative and served to marginalise children with autism. The Ghanaian worldview outlined in chapter four was shown to shape not only the perception of autism, but the experience of those affected by it. The deeply religious nature of most Ghanaians contributed to beliefs in spiritual causes and solutions to autism. Perhaps more importantly however, this spirituality, combined with the communal nature of Ghanaian society and the belief in accountability for one's actions, lead to increased stigma for family members of a child with autism. In Ghana, as has been found in other contexts, the presence of a person with a disability in a family affects the way the entire family is viewed in society (Grinker, 2008a, 2008b; Ingstad, 1995). As disability was defined as an *experience* in chapter one, I attempt an exploration of the lived experience of autism for the families of children with autism in Ghana.

## 6.1 The Families

The journey families take in the face of autism is a difficult and lengthy one, which I feel cannot be done justice in short quotes. In order to honour the time given, and the trust shown in their honest open accounts, I have chosen to follow the journey of a few select families throughout this chapter. An in depth look at a few carefully selected families allows for a greater understanding of their experiences than a more cursory examination of all the families I spoke with. These families were selected as generally representative of shared experiences and their stories will of course be supplemented by excerpts from other family experiences as necessary.

Samuel is the father of a young boy named Prince who was six years old at the time of interview. Prince is largely non-verbal but learned new skills quickly. He is quite hyperactive but generally well tempered. Samuel and his wife are both highly educated

by Ghanaian standards, own two houses and send their three children to private school. Samuel is a pharmacist and travels outside of Ghana for work quite frequently.

Abraham is the father of Kwaku. Kwaku was his first of two children and his only son. Kwaku was eight years old at the time of interview and has regressive autism. After typical development until around 3 years of age, he then quickly regressed and lost his speech. Abraham, a public servant and biologist, went to university in Holland and returned to Ghana to start a family.

Ama is the mother of a 10 year old son named Kojo who was diagnosed with autism in the UK. Kojo had no speech and fairly severe behavioural challenges when I met him. Ama had recently returned to Ghana with her two sons, the other typically developing, after a divorce. Her journey is one of a search for acceptance in, and understanding of, a culture and family she had left years earlier. When I met her, she was still settling into Ghana and searching for educational services for Kojo.

Patience is the Grandmother of Joseph, four years old. His parents live in the UK and have sent him back to Ghana to live with his grandmother. Responses indicate that they felt spiritual guidance, and possibly a solution, to Joseph's challenges could be found in Ghana, an opinion his grandmother seemed to share. Joseph has never been officially diagnosed though his grandmother does refer to him as having autism, a conclusion that my own observations support.

## **6.2 The Initial Journey**

Learning your child has autism, or any disability for that matter, can be a painful and life changing experience, in any culture. Parents the world over want the best for their children; they undoubtedly have hopes and dreams for their child's future success and happiness. Every single parent of a child with autism that I have encountered over the past 12 years, whether in the USA, England or Ghana, has a similar tale to tell. It is one of initial grief, shock and eventual begrudging acceptance that their lives, and the lives of their children, did not turn out the way they might have imagined. In many cases, this later turned into a deep and perhaps special love for their child and acceptance of

different but cherished experiences. Dozens of memoirs published by parents of children with autism, and a few by high functioning individuals with autism themselves, echo this same tale<sup>21</sup>. This journey is of course a deeply personal one, different for each individual and each family.

Chapter four suggested that a belief in God (or gods) as the determiner of all things leads many to reject notions of chance and happenstance in Ghana. This was found to contribute to an often protracted journey on the part of family members in search of a cause of their child's autism. This same worldview also seems to suggest that parents may have a greater propensity to look for both the causes of, and solutions for, impairment in spiritual and communal aspects of their culture.

*But those days. Ah! What could have been the cause of this?? Is it through child birth or maybe it's when he got sick?....So it couldn't have been the measles, so what could it have been? ....Meanwhile he also never fell. So, I don't know! ...Eh, I was trying to look for what would have caused it. To answer the question, what could have caused this thing?? But later on, because I am not finding any tangible answer I've just closed my mind. And I don't want to...hear those things. Because it takes me back, I don't want it. You understand? -Samuel*

*We have been to many churches, on crusades, all to no avail. No one has seen anything extra ordinary to say what exactly caused him to be that way- what the spiritual cause is so they can't help -Parent*

Parents, in any culture, seem to go through a period of mourning, adaptation and eventual acceptance when their child is diagnosed with autism (see for example Gaad, 2004; or Grinker, 2008a). This initial period of shock and grief was also experienced by parents I met in Ghana.

*I was, ahhh!! I was depressed, I was depressed, it pained me. I was disturbed....I couldn't do anything, I was depressed, all my hopes were... [trailed off] - Abraham*

*... Initially, you were a bit ashamed to tell somebody. "Chale"<sup>22</sup>, [lowers voice] my child is autistic, or he is not, you know, normal"... and initially, because I did not know about autism and I did not know you know that there was this terrible something*

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<sup>21</sup> For a some of my personal favourite memoirs of parents (chosen for their diversity) see: 1) Just This Side of Normal: Glimpses into Life With Autism by Elizabeth King Gerlach, 2) A Real Boy: A True Story of Autism, Early Intervention, and Recovery by Christina Adams, 3) Unstrange Minds: Remapping the World of Autism by Roy Richard Grinker, 4) Let Me Hear Your Voice: A Family's Triumph over Autism by Catherine Maurice.

For autobiographies written by individuals with autism see: 1) Nobody Nowhere: the Extraordinary Autobiography of an Autistic and 2) Somebody Somewhere: Breaking Free from the World of Autism both by Donna Williams or 3) Thinking in Pictures: My Life with Autism and 4) The Way I See It: A Personal Look at Autism and Asperger's both by Temple Grandin.

<sup>22</sup> Often used phrase which is roughly analogous to 'friend' and is used similarly to the way 'mate' would be used in the UK.

*[going on, so] you tend to compare your child to every other child. Right? And so you find, children, normal children, talking, playing, asking questions, you know and you find your child [is not] ...and it's like you are ashamed. –Samuel*

*Initially they [parents] didn't know [what was wrong] and the wife senses that the speech is delayed, so it is only speech which has delayed but whatever is causing she didn't know. But whatever they [doctors] suggested she didn't want to accept it cause they are seeing this disease in a different form [medical] so she refused to accept it. So, me too I didn't know that [anything was wrong with their son] until I brought him [back to Ghana]. I found this article, I read it and it seemed that the situation good fit....Strong faith tells me this [autism] will not remain. Accept it as a challenge. - Patience*

Children are cherished spiritually in Ghanaian society as the rebirth of a new life and the continuation of the family's lineage and heritage (Kuada & Chachah, 1999; Salm & Falola, 2002). Large families can indicate prosperity and fertility and were traditionally a mark of status and standing in one's community (Salm & Falola, 2002). It is possible that the expectation of childbirth as a duty to society and the increased status children bring to parents make the acceptance of disability even harder to come to terms with for Ghanaian families. This was evidenced by findings that the presence or absence of other children in the family appears to influence the perception of the child with autism. Where fertility is celebrated and large families expected, another child may fulfil the 'necessary' contribution to the extended family. Some responses did indicate that additional children may alleviate some of the pain or sense of loss parents may feel:

*But fortunately, he is not my only child. I have two other children. They are very brilliant so [it is okay] – Samuel*

Other responses indicated that a lack of other children, particularly the absence of a 'healthy' male child can further exaggerate a sense of loss:

*I was depressed, all my hopes were...because my second born is a lady, small girl, she is about five. Yes, because there are only two... -Abraham*

And later in the interview:

*But I hope to give him the best cause, well I have only two children. Eheeh.*

And when Abraham was asked what he thought differentiated highly motivated parents from other less active parents he responded:

*Maybe they have so many [other] children.*

While the specifics likely differ by situation and context, the overall experience of dealing with the initial shock of autism was remarkably similar for parents of children in Ghana as compared to those detailed in literature from other parts of the world. Most parents spoke openly about their initial disappointment, about later coming to terms



with the situation, about managing their current daily struggles and about their dreams for their child's future. Despite a relative universality in initial feelings, there did appear to be marked difference in the path to a diagnosis of autism in Ghana.

### 6.2.1 Diagnosis

As parents first realise their child has delays and begin to search for answers, the degree of assistance, information and support which is available to them can make a critical psychological difference (Gaad, 2004; Grinker, 2008a). For many families in Ghana this initial period is made even more difficult by a lack of understanding of autism in the Ghanaian medical or educational systems. Despite his medical background, Samuel was not familiar with autism and did not recognise initial symptoms as problematic. His struggle for answers and help took the better part of three years:

*As a matter of fact, when Prince was about 8 months, I decided to travel outside, ...Germany for one year and come back... I went and he was perfectly normal when I was leaving, you know, I didn't notice anything, He was okay, he responded to sounds when he is in the room and he sees or he hears ehhe my car coming or something...Then I went. And my wife too, couldn't notice such thing early. Um, whenever I call her [and ask] "is he talking?", she say "yes, he say some words". But we all didn't realise, and people you know, people were saying, oh he is a small kid and so later on, when as he grows he will speak, he will talk. When I returned he was...about 1 year 6 months, there about. So, you see the first day I landed and I got home I was expecting to see my boy coming to meet me I brought some toys and things but when I, it was like he didn't care about me, you know. Prince he didn't care about me much and all the toys I brought, if you want to give him the toys it's like he is afraid, he doesn't want to touch it. Ahh! Ohh, I was a bit worried and in fact, I didn't know what was happening. But my attention was only on the speech... At that time too, I did not notice any ehhe, bad behaviours or any abnormal behaviours. Well, probably I wasn't observing very well, probably. And he is my first child and I you know I didn't have any experience apart from him so I didn't know. The only thing I noticed was the speech so I decided to take him to school [crèche]. Because he was 1 year something something and I thought maybe it is because he has not started school...so that he mingle with [other children].... After you know, he got sick [temperature] and he was also still not speaking I became much more aware and so I was looking out for you know, these things. ...So, I took him to a specialist in Kumasi, ENT specialist... the doctor told me ehhe he is suffering from...what... hearing impairment or something something ...They did some sound tests you know...But even at that time right, they didn't know, but I had the hope that, you know, he will be well, so I will pray, you know, and he will be well....[When I took him for hearing test], the first day he responded on the right one....so they told me to come back for a check up the following week. I went and he was not responding from here [indicates right ear]; it was rather the left one. So they were confused and they said okay if that is the case, I should leave him for a while. If he grows ah, there are some kids... if he grows up maybe he will change. Then I took him to a specialist, He too did the test and he said ...he doesn't hear very well it's only the residual sound that he hears. So, maybe hearing aid and that day I cried out because **ah! Why?!** Because I wasn't expecting anything abnormal. I was just taking him because people said I should take him to you know. Cause I thought when he grows he will start speaking, some people speak*

*late. So, it was within that time that I was transferred [for work] to Accra. And I took him to a normal school. You know it was then that the headmistress, the school had a doctor so the headmistress introduced me to the school doctor and the doctor also directed me to 37 [military hospital]...and then the 37 doctor also directed me to Dr. [name], ... a neurologist... So, it was there that I got to know that it's, you know that there is something called autism and this is it. You understand. Even though I am a pharmacist .... So then I became aware, ok. He has autism. So, what do I do? - Samuel*

The early experiences of Samuel speak to many points. His initial anguish is apparent in his shock at an original diagnosis of hearing impairment and later diagnosis of autism. There was no referral system from the school or assistance in finding support, it was Samuel's persistence alone which led to Prince's medical assessments. The experience also highlights a lack of awareness of autism on the part of the medical community. Not only had he never heard of autism despite his medical background and contacts, Samuel was also bounced around between professionals repeatedly without any answers.

While typical of most parents in Ghana, Samuel's experience differs markedly from that of Abraham and Kwaku, which was in many ways, much more straight forward.

*We had Kwaku in 2000. And because we are working parents we put him in a day nursery very early, maybe 3 months. So he started talking, reciting rhymes, very very early. First year, second year, but we didn't realise when the thing [speech] was going. So once the headmistress called me and said that Kwaku was eh, he was about two and a half, three years, that Kwaku was eh normal speech was delayed. It was then that we realised the thing had deteriorated. Because at first when I am coming to the house and he hears the sound of the car, he rushed right- welcome daddy, those things. But was normal, [he would say] "I am jumping" these things, was playing. So we didn't realise when the thing was going. So when the woman told me, we realised that there was a problem, so we sent him to the hospital- first to the paediatrician ... So then he referred us... to test the hearing. So they tested the parents, they tested myself and my wife, they listened to our history, to the family history, and they realised that there was nothing wrong with his hearing and his speech... Then they realised that when they mentioned a word that he repeats the same thing. So they gave him, I have forgotten the medicine, to actually activate the part of the brain, I don't know that part. Then they asked us to observe him for about 6 months. But we realised that the thing [speech] was coming down. All the things he used to say were going. So it came to a point where he was only mentioning my name... So, eh, our doctor, medical doctor, he is paediatrician, he referred us to eh, a psychiatric hospital, we have a specialist there, the one doctor and he observed him and said that it is possible he is autistic. Because he look at the various conditions, like repetition words and he had this peculiar behaviour ...Yes, those things. But they say normally, but we also read several literature from the net and so forth, eh every autistic child is different, it depends to the degree. So, we should just observe it because, cause Kwaku's case ... as he grows we expect will that he will pick up things gradually. - Abraham*

It seems then that the quest for answers and a diagnosis can differ substantially across families. Whereas Samuel searched for years to discover the source of Prince's

difficulties, Abraham was directed to a doctor who was able to recognise and diagnose autism straight away. Admittedly, Abraham's situation is rather unique compared to other parents I encountered in Ghana during my years living there, the majority of whom struggled to find answers and acquire a diagnosis. While Abraham may have had an easier route to diagnosis, there are also similarities in both parents' experiences. Interestingly, as is often the case in the USA, both children were first directed to audiologists for hearing tests. Other stakeholder responses indicate this experience was not unique to Samuel and Abraham:

*At first they thought it was hearing problems but they realised that they have been taking him to speech therapy but afterwards they realised it wasn't any ear problem so. And then he was diagnosed with having autism. –Professional*

This course is logical as the failure to develop speech (or to respond to others) is often the earliest salient warning sign for first time parents. A lack of awareness of autism as a condition, coupled with a cultural propensity to provide any answer rather than risk letting someone down, left both parents struggling with a 'wait and see' approach.

Both Samuel and Abraham also pointed to a lack of greeting behaviour and speech as early warning signs, underscoring again the importance of these skills in Ghanaian society. Finally, both experiences help to highlight the emotional relief an official diagnosis can provide for families. It seems that the answer to what is wrong allowed Samuel to finally accept the challenge of autism and begin to move forward with action plans for Prince's future, while information Abraham found on the internet provided relief in the form of hope that Kwaku may 'pick things up gradually' as he grows.

In addition to the physical experiences of both families, there are similarities in their emotional journeys as well. Both stories highlight initial feelings of disbelief and loss, followed by eventual acceptance. There are also elements of self-blame apparent in both stories, an attribution which has been found to cut across cultures (Masood et al., 2007). Both parents remarked that they did not notice warning signs. In addition, Samuel later lamented ignoring a friend who first recognised the problem years before Samuel came to trust in the diagnosis:

*But all this while, not even, none of the doctors, or myself, or anybody suggested it was autism. It was another colleague pharmacist who has a child an autistic child who said it may be autism...when I was going [to the doctor] I saw my friend and I told him 'Chale, my boy is not speaking one and a half years' and he says 'Chale, it*

*may be autism'. I say 'my friend, what autism?' [but] I took him to the doctor, the doctor told me ehh he is suffering from...hearing impairment or something [and so I dismissed it]. -Samuel*

Samuel blamed himself for the fact that he did not heed his friends warning earlier but spoke of confusion in the early days, a lack of knowledge and incorrect information from professionals. The degree to which parents engage in self-blame clearly varies across individuals but is also likely influenced by cultural worldview (Masood et al., 2007). In Ghana, where children are revered and believed to contain the spirits of their parents (Kuada & Chachah, 1999), one might expect invoking of self-blame to be even more severe. Interestingly, it may be that the intensity of external blame in Ghana mitigates some of this self-blame as parents actively rebuke against societal stereotypes and discrimination. Future research is needed to explore these possibilities.

It also appears that the explanatory models of family members are malleable over time. Lewis (1985) describes 'multiplicity' in causal explanations invoked by the Zande who recognise and respect overlapping but reinforcing explanations. Ingstad (1995) found that explanatory models in response to severe handicap were revised by parents from the result of breaking a traditional taboo to one in which the disability 'just happened'. In Ghana, nothing 'just happens' but parents nonetheless seemed to adjust their belief systems over time. Responses also supported the merging of concrete and spiritual beliefs, as discussed in the last chapter.

*But in our side of the world, as for the spiritual aspect, we do not downplay, we do not forget about it, it is there but those who are ignorant you know concentrate on one side and leave the other side. The guy [Prince] is not talking, [tackle the] spiritual fine, we pray to God but we make the effort, the bible does not talk about anywhere that there is a spiritual thing [but] there is an effort. Jesus Christ healing spiritually he made an effort. That is the physical effort. You just tell Him then you just do this thing... I pray a lot and ... I know and for Him everything is possible so he should change his [Prince's] situation around....But it does not mean that oh I have prayed this morning so I don't need to tackle things and I don't need to let Prince go to school .... But those people who think that, okay if there is [only] spiritual aspect then they should keep their children in the house and let them become doctors. You don't learn but you become a doctor? No! You go and you pray that God should help your child to become a doctor but you do not leave the child in the house you still let the child go to school. -Samuel*

On the other hand, there were indications that the presence of autism may reinforce or 'prove' the existence of spiritual forces.

*And all the time, when these things started, I see it is real. First I don't believe in spiritual things but God opened my eyes to see those things, if this is real thing. It is real. -Parent*

A strong sense of spirituality and faith common to many Ghanaians (see chapter four) was found to contribute both positively and negatively to the experience of families. Certainly, prayer, to varying degrees, seemed to be an important coping mechanism for many parents. This notion is supported throughout interview quotes in this chapter and was mentioned overtly at times as well:

*It all depend on you and how you know God. He allow certain things to happen to bring us more closer to him.... So we have to take all this, the supreme power, he owns us, if he doesn't exist human beings would not be, our children would not be born. That is how I have been coping with this situation and I hope that my son has accepted this. Cause when I look at him [Joseph], I thank God, say thank you, because I have seen worse cases. So thank God for this. -Patience*

As the last chapter demonstrated, explanatory models often change, or are justified, by the social distance one has to the person with a disability. At the same time, spiritual and biomedical causes alike were often blamed on misdeeds of the parents. Ingstad's (1995) research in Botswana suggests that parents may choose explanatory models which allow them social distance from the cause, and therefore the blame, of the disability. Unfortunately, in Ghana, a mentality which rejects chance and happenstance may also make it difficult for families to achieve this social distancing and could have been a contributing factor to their potentially protracted quest to discover the source of disability. An exploration of actual family perceptions and the disparities between these accounts follows.

### **6.3 Searching for Acceptance in the Community**

A spiritual and interconnected outlook to life discovered in chapter four lends itself to the belief that spiritual powers watch over, guide, reward and occasionally punish individuals living in the mortal realm. Combined with a collective social identity, rewards for an individuals' exemplary behaviour can be bestowed on an entire family or community and that same community can be held responsible for the transgressions of an individual.

The beliefs that people are ultimately accountable for their (or their family's) actions and that transgressions will inevitably invoke retribution seems to be at least in part responsible for the tendency to blame parents in the causal explanations for autism

outlined in the last chapter. Whether these causal attributions were biomedical or spiritual, parents were typically held responsible for something they did or failed to do.

*Respondent: It is the work of his family, they know Kofi has a future and someone wants to spoil him. It is either from his mother's side of the family or the father's side, it is impossible to tell*

*Interviewer: So it is only from the family?*

*Respondent: Yes, yes, only the family*

*Interviewer: So no one from outside the family could be the cause?*

*Respondent: No never.*

*-Community Member in response to the Kofi story*

A large gender difference was apparent as well; in the majority of cases, this blame seemed to rest almost solely on the mother.

*Interviewer: You mentioned blaming the mother, are there ever stories told that blame the father?*

*Respondent: No never. As for fathers, fathers are always right –Professional*

The reason for this gender difference is not clear from the current research though it can reasonably be suggested it is rooted in traditional gender roles and patriarchal family structures of many tribes.

Groce (1990) notes that in cultures where disability is seen as punishment for wrongdoings, the presence of a child with a disability can be something the family is ostracised for or potentially ashamed of. Whereas community member and professional respondents seemed to support this view, parents themselves spoke of economic challenges, a lack of available information or service options and feeling ostracised from their families and communities. There was a large and obvious discrepancy between responses generated by those within, and those external to, the family.

### **6.3.1 'Hidden Disabled'?**

Respondents external to the family often supported the notion of the 'hidden disabled' (Ingstad, 1995, 1999) claiming that family members were likely to hide children with disabilities away.

*If in your family, maybe will cause people to point, and at the family or something. People won't even want you to know they have such people in their home; they will do everything possible to hide them. – Community Member*

*One possibility is that they are in hiding or that the families are hiding them – Professional*

*Sometime later, the door opened and out came this child naked and he started climbing all over things as if a monkey. These are two very educated people, a man and woman, how can they do this? When I say they have schools, if anything special schools where she can go, why don't you at least put her in one? They said. ...it would shame them. -Professional*

*Some of them won't... [laughing] eh, how should I put it, they think it's a bad omen on their family, they shouldn't have such people in their family. -Community Member*

*No one wants a disabled person in their home -Professional*

*They are also rejected from their home, pushed out. The family can be ashamed of them. -Professional*

This view was extremely widespread amongst community member and professional stakeholders but families expressed the exact opposite!

*I should keep him in the room, [no] that is not what God wants to see, that is not what the Bible says. I have just taken it because you cannot hide it. Normally it comes up when they ask you how many children you have...or [if] I tell somebody I live in [suburb town] but my children go to school in Accra, or one of them go to [a different] school...They say, "ah, why?" You see, it comes in, so you have to explain. I will not lie to you....If you decided to hide them...It's their own headache, cause for how long can you hide them? Sometimes as a matter of fact, there are places that ... none of the children will go...because I won't take the two [siblings] and leave [Prince], that thing no, the three of them must go. If you say that he will worry you so you want to leave him, [just] take the other two, no. Even from the house too, sometimes maybe my wife is going to pick something from the office, she just take the two and I don't take kindly to it. -Samuel*

*Well, we go out, when we meet I just tell you well he is autistic so you have to accommodate him because that is my son. -Abraham*

*I've been talking about Kojo from day one. But emm, I had people from Ghana community tell me don't say anything to anybody because they would laugh and not help. And that didn't stop me because I think the more people I could tell that could help or help themselves is better than to keep quiet about it. What do you gain by keeping quiet about it? A problem, you know. So no, but that is the answer to you, don't talk about it, people will laugh...You see, I think it is you and...if people saw me being bad to Kojo, I think they would be bad to Kojo. If people see me loving Kojo and say he's my son and you have to accept all of us or not. You know? So I think it's you. I think it is up to the parents, it the parents acceptance. To [say to] people yes, there is something wrong and lets work towards it. You know. -Ama*

*You know I always try and talk about [my] experience. At first it was hard, at church, and the supermarket difficult. People looking at me, wonder[ing] why she cannot discipline her child. Cause he looks normal. So I just say "ok here you go, take him, you discipline him". [laughs]...For me I will talk about my son everywhere I go, at church...that is how I started raising awareness, I came I told people I have this child look at him [he is] normal. Whatever, he may hit you, he has autism, autism is this, I explained to people, I told people if you know a child like this please call me, it doesn't matter what time, please call me. -Parent*

While some parents initially held reservations about the visibility of their children and the stigma they might bring, the parents I spoke to for this study universally became advocates for their children and autism, eventually using visibility as a tool in this battle. The ability to advocate for their children, to work towards changing

discriminatory societal attitudes and increasing services, seemed to be a coping mechanism for many families. Parents seemed to feel a responsibility to put in their own effort, whether through advocacy, example or experience. It should of course be acknowledged that the parents I was able to speak to are understandably the ones who are willing to admit the presence of, and talk about, their children. If indeed families are hiding their children away, as other respondents suggested, then those parents are not likely to come forward for an interview or to access services. The situation is likely to be compounded by the relative wealth and education level of parents I was able to speak with; not only were they willing to advocate for their children, they were in a position to do so. Ingstad (1995, 1999) highlights the ‘myth of the hidden disabled’ whereby many parents who are perceived to hide their children away out of apathy or malice actually do so, when they do so at all, out of a lack of viable alternatives. For example, Ingstad (1995) cites the case of a young boy in Botswana where neighbours indicated the child was ‘hidden’ in a hut separate to the main house. Upon meeting the parents however, Ingstad instead found that the boy was confined out of fear of, and warnings from, officials threatening to remove the child if their son escaped and harmed anyone. There were also indications in interview responses and anecdotal conversations that this ‘hiding’ in Ghana is most prevalent in rural and Northern areas where my own data collection did not extend. Nonetheless, without ruling out the possibility that some children are hidden away, the widespread assumption that this is the dominant course of action has at least been called into question by the parents I interviewed.

### **6.3.2 Shaming & Blaming?**

Similarly to the ‘myth of the hidden disabled’, there appeared to be a belief amongst respondents external to the family that parents felt burdened by, or were unwilling to care for, their children with autism.

*Many parents feel their children are a burden to them. It always amazed me that on the day of closing [of a residential special school] some children would not be picked up, they could be there some 1-2 weeks after closing. But on the day of opening, the parents are there with their child waiting at the gates at 6am when the gates open. Parents are inhibited from their normal duties when they have to care for such a child. –Professional*

*They don't send them there to go and learn, it's just to keep them away from home. - Community Member*



These responses seem to blame parents and assume apathy. Avoke (2001) instead allows for the possibility, in Ghana, that this may be due to a lack of alternative options.

The residential model [of special education] is seen as the 'model relieving pressure and stress on some parents'....It is usually not a question of whether the children are themselves benefited as one of lack of options and choice (Avoke, 2001, pp. 32).

Nonetheless, there were widespread indications amongst professional and community member respondents that parents of children with disabilities feel ashamed of, and burdened by, their children.

*The parents are the first to be blamed so then it leads to the parents not accepting the child. -Professional*

*We need to change the perception of parents, they do not see the positive in their child. -Professional*

*Another problem is that parents wouldn't want to come up with any issue about their child if the child is not "normal" [made air quotes]. We need sensitisation and education- Professional*

*They do not get out of school, the severe are permanently there. They become a burden on parents if they are released. -Professional*

*They reduce their own independence, for the mother, the whole family. Having a child with a disability can bar you from taking part in the community, from taking part in business. Can you imagine having a child who drools and looks funny hanging around your stall while you are trying to sell fruit? No one would buy. And you can't leave and go to the farm because you have to watch them, and no one can carry them to the farm and then come back with a big load as well. - Teacher*

*...Parents realise, no their kids cannot do well in anything at all, like, he becomes somebody useless, who cannot even realise of himself....So, parent get fed up. - Community Member*

Instead, I was often overwhelmed by the commitment, dedication and generosity that parents demonstrated. In a country with limited information and services, parents of children with autism in Ghana were innovative and resourceful, often seeking out assistance wherever it could be obtained. Some parents took time off from work, passed on advancement opportunities or simply extended their commute to send their child to a school further from their home but willing to accept their child. Despite living approximately three hours outside of Accra, I met Ama when she brought Kojo to Accra in search of services for him. Patience welcomed Joseph into her home despite financial difficulties and, following her own faith, took him to countless pastors and spiritual healers. She spent a preponderance of her time and money on what she believed would be of the most assistance to him.

*I have taken it in good faith, by God grace, you know, strong faith in the Lord, whatever comes your way you accept it....I'm a Catholic and this one we have healing*

*period during the mass service...the priest will pray or after the mass we will have a special pray over [him], lay hands on them and if it is a demonic sort of, you evoke Jesus own ways of healing people. So he lay hands on them and then prayer whatever be the force of illness, so God you are the most healer, you can take [your] own medicine [but] if God does not heal [Joseph] cannot heal, so this is our faith. So we have set last Friday of every month aside, whereby the priests, there are plenty priests over there they all do it lay hands, a lot of people come.*

Abraham spoke of taking Kwaku to Winneba for speech services twice a week at a time when road conditions would have seen him driving a minimum of two hours each way. Later he passed on work opportunities to be home with his son and ensure his education.

*We were going twice a week to out of town, [for speech services], we started twice but it was difficult for me so we brought down to once. There was one professor at...Winneba University...I was going twice a week but it was very far and later, it was very difficult for me.... [Also] I close at 5:00 every day but because of Kwaku, I don't go out to lunch. We normally have one and a half hours lunch [but I don't go] so that I can leave early and pick him up. Because my wife [is] going to school....When you are a working parent like myself, it is difficult, it is difficult, I have to combine my work with Kwaku. Yeah it is difficult and...I normally travel. And those are the days Kwaku doesn't have to come to school. He stays in the house because my wife she can't bring Kwaku to school and I'm not around...So in this case I want to be sure that if there are any travels that is more than 2 days, I don't go up for those travels, even for official work. I have to delegate it to my assistant, if I have to travel outside of the country. For about two years now I have not travelled out of the country. -Abraham*

In addition to providing as many opportunities for their children as possible today, both parents spoke of actively planning to ensure opportunities for their children in the future.

*Something normal [for him] to do. Even if I will create a factory and him be packing, I don't know but that is something I'm thinking and planning of....I mean, if I can you know create something for him to do independently, that is my biggest prayer, that he must be independent. But the how? It's the problem. -Samuel*

*But I have to confide in you, ehh, I am trying to make sure that I have a place and I have my own place and I am trying to... and my wife has been teaching for the past 20 years....That is, we get special children and then we start the training, I employ people... Because we don't have such facilities here in Ghana ... Yes. I have a place myself but I might, I am building another house, I might move to the place and I will use this place for that peoples then get a .... Something like that but it is not mature yet because she has to go [for training]...So it's far away, it's not yet- Abraham*

To find additional evidence of the dedication of parents in Ghana one must look no further than Auntie<sup>23</sup> Serwah, the founder of the Autism Awareness Care and Training Centre (AACT) in Accra. The parent of a now adult son with autism, Auntie Serwah returned to Ghana after many years of living in the USA. Finding no information or

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<sup>23</sup> The term 'Auntie' is a mark of respect –in this case 'Auntie' Serwah was the name by which she is known throughout the community.

services for her son, she founded AACT, initially a parent support centre. Open to the pleas of parents she began allowing some of their children to come to her house during the day where she hired a trained teacher to watch over and assist them. When the number of children attending outgrew her living room, Auntie Serwah raised funds to buy a home, now converted into the small centre in Kokomlemle. Still dissatisfied that she is not reaching enough parents Auntie Serwah has imminent plans to open another site in Tema and longer term plans to offer outreach parent training seminars to the far corners of Ghana.

These parents are a far cry from those described by external stakeholders. Rather than ashamed or ambivalent parents, I discovered active, engaged and proud parents, willing to do whatever is necessary to provide for their children, both today and in the future. It of course has to be noted that the parents I was able to speak to were largely known to me through specialist private services and as such are likely to be disproportionately representative of parents with a higher income bracket and education level. The desire to separate out the experiences of autism from other disabilities led me, necessarily, to speak with parents who were at least aware of this label and likely excluded many other families. This difficulty in attempting to research a disorder which is not yet widely recognised or understood was a reoccurring methodological challenge and will be discussed in more detail in chapter nine.

### **6.3.3 Isolation & Stigma**

Instead of feeling ashamed of, or burdened by, their children with autism, parents, at least those I was able to speak to, instead expressed feeling isolated from, and ostracised by, their communities.

*I have never heard anybody talking about me, but probably behind me they will say hey Chale, maybe the child, you know is behaving abnormally or something. Behind me they will talk -Samuel*

*Ama: What people will say. Yeah. What people will say. That is more of a killer than the disease itself, what people will say...*

*Interviewer: Yesterday I heard you say 'African mentality', could you explain what you meant by that?*

*Ama: It's this belief thing that they won't let go. That is not helping us but they don't see, they don't see....And if that is what you want to believe fine, but it's when it is not helping the child, you know, it's not helping them, but they still don't see... It's the understanding. Umm, and the refusal to believe or accept that there is a problem....You know, everything that is not the norm, everything that is not the*

*same, some people believe it's a curse...Umm, you know, it's the shameful thing, keep it under wraps. Problems are generally not discussed in public, you know? Who is going to sympathise with you? So, parents are on their own, you know, we are on our own.-Ama*

One parent also spoke about a lack of assistance and even potential abuse of her son from her rural community:

*One problem I have with him is that he will never stay at home. He wanders off and when he is alone in town I worry about people molesting him. It has happened before, people beat him. One time someone accused him of sending a small boy away but then the boy turned up fine. Everyone had been upset with him and it was hard on us. We make complaints to the police about people molesting him but they are not usually willing to take up the case, they do not take it very seriously. -Parent*

In line with this isolation, parents spoke of the difficulties attending church, celebrations or community events that having a child with autism presented. Often it appeared to be the hyperactivity or challenging behaviour of a child which was the most salient in public places.

*Yeah sometimes, you go to church and you cannot sit down because he will not sit down. You know, you go to a function and you cannot even wear your best clothes because you must always be carrying him if you put him down he will be running up and down making noise. So you always have to stay outside. -Samuel*

*Most of the parents I see find social behaviour as most difficult, they begin to feel ostracised, can't go to church to functions. Child behaviour [is] difficult to manage and people who are there do not know or understand child, they think it is bad parenting or something is wrong with your child [so] why not stay home and mind them. I find that a lot of parents find this very difficult. -Professional*

Hyperactivity and repetitive behaviours were also found to contribute to exclusion from mainstream schooling, as demonstrated below. In a culture where attending church and community events are not only a primary social outlet but can also represent honoured traditions and obligations, the failure to participate can be particularly isolating and stigmatising. Samuel spoke of how he was recognised as a result of Prince's salient behaviour.

*But as a matter of fact, I met somebody, well she claimed to know me from the church that I was attending in Kumasi. I met the person in Accra. And what she used to identify me was my child, she said, "ah, are you not the one, you know, the other time I met you this church and your child was worrying you, you were sitting in front of me, your child was soooo [difficult]"....But [I] close my ears and my mind to maybe what people be saying. Because people, most people probably ehh, haven't had that experience or haven't seen such children, hyper, you know, very hyperactive children. And so, you go to a function and things and they will be, just be looking at you.... But me I close my mind to all those things- Samuel*

In a communal society such as Ghana, the consequences of autism are not simply felt by the individual themselves; parents also spoke of systemic consequences. Despite the

possible stigma associated with having a ‘difficult’ child, parents seemed to comment instead on their worries about the impact of autism on other children within the family. In particular, the belief that autism is representative of spiritual curses which reflect on the larger family seemed to endanger the ability of siblings to marry.

*And it could affect the whole family, maybe nobody might marry into the family because they say there is a curse there, there is something not right in that family. You can't marry that into that family. In fact, at one time I feared for my other son that who will want to marry into the family. I feared, but I put that aside as to whatever will happen will happen. Um, I can't control everything, so, yeah. I just try to be very positive about it, very positive. Cause otherwise I will have nothing. –Ama*

*Once people know you have such sickness in your family there is the chances of future reproduction so when people are choosing their spouse they investigate all this, to make sure that your family traits do not have such things, because they believe it is genetic. –Community Member*

*Or when someone would go to marry people would ask about the people in that house and someone might say no, don't go to that house because they have people [with disabilities] in there and then they think if you marry you will have problems in your family too. They think maybe there is a family curse. –Senior Professional*

The experience of families in Ghana then clearly highlights feelings of isolation and stigma. Unfortunately, the data reported here can only begin to speak to the experiences of relatively wealthy and educated parents who are not likely to be representative of the many families who may be struggling under different circumstances.

We should not forget, however, that these spokespeople are usually an elite as far as education and ambitions are concerned, and do not necessarily represent the needs of poor people with disabilities living in rural areas of developing countries. The voices of the latter group must also be heard (Ingstad, 1999, pp. 758)

In Ghana, where family relations are central to personhood, the way in which autism results in supportive or distorted relationships with family members is likely to be a critical component in the experience of autism. Although anecdotal conversations and experiences in Ghana seem to suggest that autism may contribute to family strife and hardship, future research is needed to verify this assumption.

## 6.4 Family Relations

The relatively shared worldview of Ghanaians would seem to suggest that autism may result in impaired family relationships. While other indications throughout this thesis indicate this may be true, families themselves talked little about their family relationships during interviews. Perhaps it was socially inappropriate to do so or perhaps this was not their primary concern. Ama however, spoke openly about the

differences in worldview she encountered, particularly amongst her family, upon her recent return to Ghana with her two children. She spoke of both the challenges and advantages she perceived in being back in Ghana. When asked how her family had received her she responded:

*I mean a lot of people are telling me when he grows up it [autism] will go. How can it go? And what if it doesn't go? And they believe, for me to believe that, as a mother [then] I am not helping his growth or his betterment...They don't want to sit down and work, they just leave it to the Almighty, you know, who sometimes I feel is tired! [Both laugh]. He needs a break. You know? I mean if my fellow Ghanaians hear me saying this, this is blasphemous. So um, deny it, pray and it will go [sarcastic] and then I don't where you imagine because you've prayed its gone? ... [The family thinks] that [my] prayer is not good enough, you have to go to other people who have prayed and miracles have happened even though we have not witnessed it. Personally, I like my own interpretation of the bible, umm, but I cannot convince you know, even my sister in law that I live with, you know, because the husband is trying to be em, its really my cousins wife, yeah, and my cousin, and my cousin is my brother and my sister in law....they want me to pray to eradicate the problem...Take Kojo's condition away from him and replace it with what? And oh my God you can't say that! You are causing these problems to be worse. You know? It is what you believe; that's why he hasn't improved [laughs]. -Ama*

Patience, as the grandmother of Joseph, spoke of the different reactions of both sides of the family to Joseph's autism.

*[His mother thinks] it's awful sickness so [she] doesn't want to talk about it, it's awful, as if it can never be healed, and this boy is going to be like that forever so that is why [she] doesn't want the relatives to know that the son is suffering from such sickness...As for my side, the fathers side, they have accepted the disability, they know it is something around disability. And I show them some photographs and all that and they say we are lucky [because he looks normal] and he is friendly, he moves with everybody. -Patience*

Samuel also mentioned the importance of a strong partnership with his wife as well as initial reservation on the part of his external family followed by eventual acceptance:

*Umm, as for my wife, we were in the soup together, so we were looking for solutions. It wasn't any such thing, any serious thing. But my relatives and my, you know they were all consoling me even when the child was not talking and I was taking him to the hospital they were all wondering what was it. Is it spiritual or it is whatever. Sometimes I think, ahh, they want to find solutions, but not now. Now they have forgotten about it. But those days. Ah! -Samuel*

Given the communal nature of family in Ghana, siblings of children with autism often became advocates for and caregivers to, their brother or sister with autism. Siblings can be amazing advocates. They also act as play partners, and at times, teachers, which can be especially valuable when children with autism are socially disadvantaged by a lack of educational placements or acceptance by peers in the community.

*Samuel: They [his siblings] have all realised that he has, you know, difficulty, in speaking. Ehh, so sometimes when he mentions a word then they'll tell me*

*"Prince is saying \_\_, you know." And sometimes they go to him "Prince, say 'ah'" you see then he'll say 'ah' and say 'too' and then he also say 'too'.*

*Interviewer: many teachers!*

*Samuel: Yes. Because they hear us saying that, they also want to. Sometimes, mommy will come and they say "when we say 'Prince say mommy' he say 'mom-aay'". You see.*

*They play....Sometimes when the other children are doing their assignments, he will just come and take the paper then take the pencil then start writing or start scribbling.*  
*—Abraham*

Perhaps surprisingly, multiple respondents indicated that families living abroad may return to Ghana themselves or send their child to live with relatives back home, where they feel their child's needs can better be met. Supporting the notion of Ghanaian worldview outlined in chapter four, the reasons cited for this migration included both spiritual and community support.

*Because they come for prayers. See a lot of time they come for prayers and because they are talking to their families ...and they say, bring the child down, there is this pastor here, there is this prophet here, he is very good, he does very well, you know you going to take the child to that place. And I **know** a lot of that is happening because that is the belief.... I mean you can't find that [abroad] -Professional*

Patience spoke throughout her interview of the additional spiritual guidance and healing which was possible for Joseph in Ghana but ascribed his parent's choice to send him back as largely a financial one.

*Because financially things were not easy for them...it was not easy for them to send him to school and then caring for the [other] little one and all that so they decided I should come and [bring] him to Ghana and there they can have a little time to work and finance. So I have just retired [in order to look after him]. -Patience*

It is clear that family and communal bonds which provide this support can be advantageous. Similarly, in describing why she migrated back to Ghana, Ama mentioned the support she felt she would receive through community living.

*I'm divorced with two children and emm I just felt that it's going to get worse especially when he goes through puberty, I'm on my own ....[Here you have] access to people around you. I mean since we came people have worked for us in the house. We have inherited one or two boys and he is looking after the house now whilst we are here and there is another person too, who has become our 'uncle'. Even the hotel we stayed in [while looking for a house], two people have called in already. -Ama*

Others spoke of the support afford by family assistance and the duty of extended relations:

*But now because I have, I have another person at home. My wife's sister, she's a small girl. Finish[ed] JSS [junior secondary school], now attending vocational school so on Sundays he is also close to church so he takes care of him ... During the weekends too she teaches him, you know to struggle with all those things. -Abraham*

It seems then that a culture of family support and communal responsibility is one coping mechanism for managing autism in Ghana. Despite indications in the last chapter that autism would create strife within extended families the only evidence of this in parent responses was in disagreement over spiritual healing methods or concern over the inability of siblings to marry. Parents did not speak of shame or fear; instead, they became outspoken advocates for their children. Parents did of course also speak of challenges associated with autism; autism can make it harder for parents to socialise and attend functions. There were also indications that parents struggled to balance time and work commitments but this was mitigated to some degree by family support. In addition, each family member mentioned the increased financial burden that a child with autism can place on already stretched resources.

## 6.5 Financial Hardship

*Also, a doctor prescribed a drug and it seemed as if it was really helping a lot but it is so expensive and we cannot afford it so he has not been getting it. -Parent*

*Also, you have to go to people, lots of people, and these things are not free. -Ama*

*Challenges, well let me see....The main is finances, the financial, because here [AACT] I pay about 80 [new]<sup>24</sup> Ghana Cedis a month, and then I have employed this lady [supporter] for Kwaku I pay and that is about 180 [new] Ghana Cedis a month. So if you spread this over 3 months it is a substantial. -Abraham*

Of course, the degree to which financial hardship impacts families will depend both on their socioeconomic status (SES) as well as on their level of commitment to, and willingness to pay for, extra services. Clearly, the parents I spoke with are in the somewhat unique position of being able to afford private services. Nevertheless, interviews still highlighted economic tensions in parental choices. Some families expressed benefits of having the child around the house for security reasons, to assist with chores or to bring in additional income provided by begging and charity. Other families however, prioritised long term benefits in the choice to send their child to school, citing future hopes of economic and personal independence for their children. While parents were honest about the financial hardships they encountered, they did not express feelings of being ‘burdened’. Instead, they expressed worries regarding

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<sup>24</sup> In 2007 the Ghana cedi was re-valued. 10,000 was set to 10 new Cedis such that 80,000 ‘Cedis’ became 80 ‘Ghana Cedis’. As of December 2009, 1 Ghana Cedis is worth approximately 1.40 US Dollars.



financial challenges alongside a commitment to their children and to increasing their efforts to provide as much as possible.

*So I am trying to at least save as much money, invest, I have got to invest for his future, once you have the capital... [trailed off] –Abraham*

*If the things [services] are there you will become aware and you would like to find ways of funding because these things are always not free. It becomes extra cost, because you pay school fees, you pay the attendant ... And then extra, the extras become, you know, well quite, quite difficult. -Samuel*

Abraham described saving to invest in Kwaku's future while Samuel claims he would find a way to fund extra services if they were available to him. Despite these efforts, professionals within the educational system often attributed the opposite views to parents:

*It boils down to finance. Even if you train them to sew when they graduate who will buy them a sewing machine? The family will not see this as a priority. –Professional*

*People feel that they do not want to waste resources on a child with a disability....Why waste resources, that is the attitude, there are others in the family that work hard. -Professional*

*Some of them think the children will never be beneficial to society. And they don't even see why they should spend money on children like that. -Professional*

However, one teacher recognised the effort caring parents put in:

*They ask specialists questions or what to do and they kind of buy learning materials for the child to playing with or learning with. They are ready to spend on their children cause they know their children can do something. Yes. They do try. -Teacher*

Here again, responses by parents were markedly different from those of professional and community member stakeholders who felt that parents would not be willing to dedicate money or resources to their children with autism. Of course, the parents in this study were in a position to do so but these results nonetheless reinforce Ingstad's (1995, 1999) notion of 'the myths of disability' in society. Perhaps when parents are seen not to provide necessary resources it is due to a lack of options rather than a lack of care. When families are in a position of relative wealth, this research suggests that they do contribute as much as possible to the health, education and well-being of their children.

## 6.6 Accessing Services

Grinker (2008a, 2008b) tells the stories of parents from India, South Africa and Korea who all struggle in the face of limited information and virtually no awareness of autism in their respective countries. Ironically, parents in the USA today often lament a

plethora of confusing and conflicting information regarding the causes and management of autism. Accurate information then is critical in any context. In Ghana, a lack of readily available information appears confounded by the *misinformation* that is often provided. Professionals often seemed resistant to admitting ‘I don’t know’. Unfortunately, this approach costs many families in Ghana valuable time and leaves them ‘waiting’ for answers, at times under false pretences of improvement, for extended periods of time. In addition to the delay in diagnosis, parents also spoke of long waiting times with regards to assessment for educational purposes.

*I went to a special needs place in Koforidua and emm they said I had to go...for an assessment before emm they will admit him. And I went...they did the assessment and then they also took me to a psychiatrist who also did the assessment, this was about 4 weeks ago, and the report is still not ready. –Ama*

### **6.6.1 Educational Services**

The experience of autism for many parents in Ghana was riddled with expressions of frustration at the lack of available educational options for their child and the lack of acceptance they found when attempting to access services which do exist.

*Abraham: So we went through speech therapy sessions and [she] said that well, the way she sees things, eh well, basically confirmed that, so we should just try and put him in a special school. Because he was then getting to six [years old] and you know after six the way [he was] not talking [meant we couldn’t go] to any normal school so we had to take him out ...So basically, that has been the case. But of late, he actually he is improving.*

*Interviewer: So you said after six they wouldn’t accept him in a...*

*Abraham: [interrupting] In a normal school... well when he was attending the normal school we didn’t have any assistance, you know now I have employed this girl [attendant] ...I discussed this with [the headmistress where] he used to be at the nursery school, but the lady there said well we don’t have that facility.*

*My biggest challenge presently is how to integrate him into, you know a normal school. His acceptability. As a matter of fact I have not tried anyway because I was told that he needs some time to calm down to be able to sit down and to, you know, has to do certain things before I can even look out [for schools]. But it’s quite difficult, you know for normal schools to accept children with autism. –Samuel*

Parents even spoke of their willingness to provide support for their children in mainstream schools if necessary.

*I thought I’ll bring Kojo to Ghana, get somebody to help me, even if I got like em a teaching assistant sit with him in normal school, and just, so that he can be with other kids.... and then just attend to his needs you know? But I haven’t been able to achieve that [laughs] since I came....–Ama*

*And I was trying, because I wanted him to integrate into the normal system...I want... to send Kwaku to the normal school twice a week but this time I have the lady [attendant] who [can] go with him to the normal school -Abraham*

As Ghana begins to implement inclusive education, it is important to look at the first hand experiences of families attempting to access this provision. Some family responses suggest that their children were placed in classrooms not yet equipped to meet their child's needs.

*There was a very sad experience... you know they admitted him, he was there but one day I think the following week, the second week, I was there and I went to drop him and the teacher said the headmistress wanted to see me. So, I went to see the headmistress. The first thing that the headmistress also asked me was "ah! Your child is behaving abnormally, why?" Just like this. [quieter and sombre] "Your child is behaving abnormally, why?" I say "what is the matter?" "Oh, you see when if he wants to drink water [he goes to take] the water that they use to clean their hands..." You see because he cannot express himself and there is no water available you know... he wants to go and drink that water but when you give him the clean water he doesn't want to take and when he is going to drink the water too he goes down with his mouth. I mean he hasn't... Look it was a painful thing, I mean for me to hear that my child, you know, out of the lot, my child is behaving abnormally. Ohhhh- I couldn't take it. The whole day, I was **down** the whole day, the whoole day. Until later on I decided, ok. -Samuel*

*You<sup>25</sup> might send your child to a school and the way they treat your child you might have to remove him immediately from the school, the way they will look at him, so it depends. -Patience*

These experiences highlight both the saliency and stigma associated with 'odd' or non-conformist behaviour in Ghana as well as a lack of compassion or understanding regarding difference or disability. Other families attempted to access inclusive education in line with national policies only to be denied access or granted initial access and then asked to leave.

*He goes to school now, a unit school for the mentally handicapped here in [a semi-rural] town. He started at a normal school but the Head drove him away. They pity him. It was embarrassing for the parents. This was when he was 13 years. He was in Primary one at 12 years, that is when they sent him away. —Parent [children are officially 6-7 years at time of enrolment in primary one].*

*Yeah, I went to a private school behind where we live and I said my son is autistic and they asked me does he bully other children. And I think what they meant is, is he aggressive? And he can be sometimes, so that stopped me.... And if the teacher didn't understand his needs I didn't want him to be lost or a spectacle you know, I really wanted him to belong to, yeah.... [but later] I went back to the school to ask them whether they will take Kojo for just two hours so that he is amongst other children because he is getting bored at home- they didn't want to know.... So I thought I would be able to educate them somehow but slowly I'm seeing that it is not going to be easy. -Ama*

The families I spoke to are arguably the lucky ones. Despite often lengthy searches, they did eventually come across information and knowledgeable individuals. Few and far between, these professionals made a remarkable difference to the experience of

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<sup>25</sup> Incidentally, this is just one of many examples throughout this thesis of the tendency to use 'you' instead of 'I' as discussed in the pronoun reversal section in chapter three.

autism in Ghana, as they do the world over (Grinker, 2008a). Parents often spoke of the support and understanding they were offered at AACT:

*So I came here [AACT]. And emm, and I felt it was the right place, you know so far, I felt they really understand, and yesterday's lecture I came to was fantastic. You know just to prompt me, help me you know, know what to do because I do run out of ideas, you know of what to do. Yeah. [pause, getting visibly upset] I mean I am so glad somebody here understands. We need to surround ourselves with more people who understand and that is the only way and hopefully the wider community will accept it.*  
-Ama

However, it was also apparent that the desire for inclusive educational services may be in conflict with another commonly expressed goal of parents, that of ultimate independence for their children. While vocational and life skills training are not necessarily incompatible with inclusive education as understood internationally, the next chapter will demonstrate that these goals may in fact be contradictory as things stand in Ghana today.

*Handicrafts and skills he can use. Not pure academic skills. He needs to take care of himself. – Parent*

*Kwaku, I am trying to you know, I'm trying to get the area but you know he should be good in one area. So, I told them [teachers] that they actually have to explore the area that he schooled in then we will see what we can do. So basically, I don't know... Because, look Kwaku can do something. Because if its exam, he might not be able to attain the academic level but he can get something like a technical training. Handiworks. We set him up because you know this boy he can be good at something. And whilst he is specialised in that area, I think he can make it. And he is still young. Enheeh. -Abraham*

*And then, the last and the biggest challenge is you know, how I can make him as independent as possible. You know, the future. That's what I always think about.... I think to be independent. That's all. I know he is not going to be, I mean, should I say as normal as I am to be doing algebra and things. It's possible he may, he may develop that talent. And I know everything, anything and everything is possible. Since we don't know about tomorrow, nobody knows about tomorrow. Things can change.... anything can happen. So I am minding hopes on you know, what God can do in the future. -Samuel*

### **6.6.2 Additional Services**

Parents also spoke consistently of practitioners, both medical and spiritual, whom they felt were either unable to provide them with any assistance, or who had actively led them astray. Already a failure on the part of medically trained professionals (or the medical system) to identify autism has been identified. A lack of understanding from the medical community seems exaggerated by some of the spiritual beliefs uncovered in the last chapter. There were indications that medical professionals may play a role in

preserving the notion that children with impairments are ‘useless’ and perpetuating a belief in spiritual causal attributions.

*And I think, I have em, one of my clients whose son is like...twelve years old now, told me that when she had a son and it was discovered that the son was deaf, the nurse...said ohh, like no problem, oh I am sure you can have another child. And she said, so what is wrong with my child then and she said, you know like he is deaf. So [he is] nobody as far as she is concerned -Professional*

*[The development of programmes] needs to go simultaneously or alongside the training or awareness, awareness not just amongst parents in the community. Doctors, doctors...and teachers and doctors and doctors... and **doctors** because they are still assuring parents that their children are [spiritual] ... they don't know the signs. -Professional*

*The hospital said they cannot cure him and that it is hopeless, they said it was spiritual too and that is why they could not help more. -Parent*

Parents who choose to access the medical community may therefore still be confronted with spiritual explanations for their child's difficulties. Parents spoke of their frustrations with this practice and of becoming increasingly suspicious of spiritual explanations or solutions over time.

*They encourage somebody has done something wrong and therefore let's take them to this fetish priest, you know (laughs) and therefore those things worry me as well. You know, worry me a lot. And the Christianity bit worries me a lot. -Ama*

There were also underlying indications of an abuse of power by some spiritual leaders taking advantage of the ‘naivety’ of those seeking guidance.

*So when those news go out people [are] forced to believe it's true...So, most people believe in certain things that they haven't seen but they are forced to believe because they trust or they believe the people that are giving them the information. - Community Member*

*But most of the time the parents are in fear, are in fear. And you're being lied to by the so called people who know, or messages from God, enheh. That's how I feel... No evidence but people are able to convince people so much that they believe what they have been told.... Most of the time the priest will tell them, don't even mention the word, because if they accept the diagnosis it means it's not going to go but God works in a mysterious way. Do not accept, do not accept! [Laughs] you know? - Ama*

*I think that the problem is that, people who go outside, now especially, I mean I can speak for Christian, oh not just Christian, but even people the traditional fetishes and all these other people, there are a lot of them that are in it for money...Money has become everything for us Ghanaians now and so there are a lot of young people who are studying to be prophet or priest or whatever, cause of money. And so, a lot of people get duped. -Professional*

It seems clear that whether actively sought out or not, traditions of spirituality in Ghana impact upon the experience of autism for children with autism and their families.

Whereas Patience and Samuel spoke of their faith and the healing potential of prayer, Ama and others spoke of the denial or lack of acceptance which were directly linked

with many of these same beliefs. Perhaps the only thing that is clear is that while common influences and themes emerged, the journey of each family of a child with autism in Ghana will differ dramatically.

## **6.7 Conclusion**

What I encountered in Ghana, both while living there and during the current research, was loving, dedicated parents. They were without a doubt a far cry from families who bemoan and are ashamed of their children as described by other stakeholders. Despite an almost universality in initial shock and a period of mourning in response to shattered expectations, the severity and length of this period, as well actions and the coping mechanisms employed afterwards, appear to differ markedly. Perhaps surprisingly however, the results of the current research seem to suggest greater differences across individuals or stakeholder group than across cultures. Whereas community member and professional stakeholders often disparaged parents for their lack of support, love or commitment to their children, results indicate nothing could be further from the truth, at least as applies to family members in the current study. Whereas those outside the family spoke of parents feeling shame, being burdened and shunning their children, parents instead spoke of economic challenges, a lack of available information or service options and feeling ostracised from their families and communities. They spoke of their fears for their child's future, the systemic consequences of societal attitudes on siblings and about expectations and action plans. While some parents did mention spiritual cures and the healing power of prayer, they also spoke of medical, speech and educational services. Parents did not describe shame brought upon them by their children, only of the shame others expected them to carry. Parents didn't speak of the ignorance of their children but that of society. Parents appeared to dream of acceptance and understanding for their children, not of hiding them away.

It is important to yet again acknowledge the limited generalisability of the data generated by families in this research; their financial and social circumstances necessarily affect their experiences. Future research is needed to explore the degree to which parents with less education and resources corroborate the views of parents in the

current study, or perhaps instead, the degree to which they reinforce claims made by community member and professional stakeholders.

This chapter also served to underscore the significance of cultural influences on experience or the 'worldview' outlined in chapter four. The significance of spirituality and kinship support were reinforced in the coping mechanisms of families confronting autism. Communal family and societal structures and spiritual beliefs played a part in each family's experience, both in positive and negative ways. Spiritual beliefs offered comfort and hope for some families while others seemed frustrated by the perceived lack of accountability or responsibility reliance on these beliefs could generate. In addition, while families spoke, at times implicitly, of the comfort and hope spiritual beliefs afforded them, they also frequently bemoaned the fear, misunderstanding, blame and shame these same beliefs generated in the community. Similarly, kinship structure and family responsibilities, while by and large a support system, also have the potential to increase family strife or alienate an individual from their extended family as appeared to be a fear experienced by Joseph's mother. The next chapter will extend this discussion to an exploration of educational access, policy, provision and pedagogy for students with autism in Ghana at a national level.

## **Chapter 7**

### **Educational Access, Policy and Provision for Students with Intellectual Disabilities in Ghana**

#### **Introduction**

In an increasingly globalised world, developing nations are almost invariably influenced by international movements. Much like other international development work, approaches to disability and SEN have seen the rise and fall of numerous international trends. The 1970's were marked by movements towards 'deinstitutionalisation' and 'normalisation' while the 1980's saw the rise of the WHO's CBR model and the beginnings of 'integration' of individuals with disabilities into mainstream society. In the 1990's re-conceptualisation of disability as a human rights issue was marked by the expansion of DPOs, emancipatory research and increasing movement towards a social definition of disability (Miles, M., 1999). Today, rights based provision and the social model has resulted in increasing dedication to inclusive education (IE) for groups of marginalised students, including those with disabilities.

International movements have influenced policy and provision in Ghana over time. A history of institutions and segregated special schools for individuals with disabilities, rooted in charity and medical conceptualisations of impairment, were initially the result of missionary services and later expanded by colonial powers (Anthony and Kwadade 2006; Miles, M, 1999). Today, Ghana has ratified all international treaties on the rights of people with disabilities and has made domestic constitutional provisions for their education (GES, 2005). The Education Strategic Plan (ESP) specifically mandates IE at a policy level as the most appropriate provision of education for students with special needs (Obi et. al, 2007).

Two years after the assent of 'The Persons with Disability Act' (2006), a parliamentary committee assessed public awareness and understanding of the Act and concluded that "awareness is low and the implementation slow or nil" (Asiamah, 22 June 2006). While this is lamentable, the government's subsequent decision to distribute 2000 free copies



of the Act in public institutions (ibid.) is commendable and reinforces their dedication to ensuring legislated rights are upheld. On the 7<sup>th</sup> April 2009, newly acceded President Atta Mills formed a National Council on Persons with Disabilities (NCPD) as mandated by the Persons with Disabilities Act, 2006 (Asiamah, 22 June 2006). The NCPD is charged with “proposing and evolving policies and strategies to enable persons with disability to enter and participate in the mainstream of the national development process” (Parliament of the Republic of Ghana, 2006, article 42.1). Clearly, the government of Ghana has taken positive steps forward in securing the rights of people with disabilities.

However, it is my contention that despite declaring allegiance to international ideals, local policies, as well as the provision which is generated by them, are at times confused and in opposition to the international conceptualisations on which they are based. This chapter will attempt to show that this confusion arises, in large part, due to an inherent conflict between international and local conceptualisations of disability. Chapter four attempted to paint a picture of a relative shared cultural ‘worldview’. It was suggested that this worldview influences how disability is understood and managed in Ghana such that other ways of thought are actively, or intuitively, resisted. It is to the impact of this underlying understanding of disability and its inherent tension with commitments to international conventions rooted in a social model to which I now turn. Using the social and individual models as a framework, this chapter will explore the impact of the intuitive understanding of disability in Ghana on both policy and provision alongside progress towards meeting the aims of ratified large scale international movements such as EFA and IE.

## **7.1 Policy**

### ***7.1.1 International Influence***

There can be no doubt of international influences on Ghana’s policies. The language of the Children’s Act and the Persons with Disabilities Act echoes that of international discourse on human rights and equalisation of opportunities. In addition, the Constitution of Ghana, the SEN Policy Framework, the National Disability Policy, the

Persons with Disabilities Act and the ESP each *overtly* express a commitment to relevant international conventions. For example, Ghana's SEN Policy Framework lists the 1990 World Conference on EFA, the 'Standard Rules on the Equalization of Opportunities for People with Disabilities', the Salamanca Statement and Framework for Action, the Dakar World Education Forum and the 2001 EFA Flagship on Education and Disability in a section entitled 'Influences on Government's Policy on Special Needs Education'.

These international treaties and others informed the Ghana government's direction on special educational provision (GES, 2005, pp. 4).

It is clear then that the government of Ghana has committed itself, at both the international and national policy levels, to the human rights, equalisation of opportunities and provision of educational services (amongst others) for individuals with disabilities. It is also clear that international declarations have been the 'driving force' in the formulation of these national policies (GES, 2005).

### **7.1.2 Contradictions and Confusion in Local Policy**

As this chapter will attempt to demonstrate, conceptualisation of disability in Ghana is largely more consistent with an individual model of disability than with a social model. As such, national policy, influenced by international discourse which conflicts with this local conceptualisation, is at times inconsistent and confused. For example, the stated rationale for Ghana's National Disability Policy (MoESW, 2000) is as follows:

Persons with disabilities met with many obstacles preventing them from fully participating in everyday life activities. Some of these problems were environmentally sensitive & required new conceptualisation of disability & handicap. The Disability policy *therefore*, recognises & addresses the needs of PwDs [persons with disabilities] to receive appropriate training, adequate technical aids and necessary support to increase *their capabilities* (pp.1, emphasis added).

Here, international influences of a social model can clearly be seen in the first two sentences while the third returns to an individual model whereby the onus of change and adaptation falls to the people with disabilities. Similarly, the aim of this policy is:

...to create an enabling environment for persons with disabilities... and to enhance *their capacity* to perform better to improve their socio-economic status (MoESW, 2000, pp. 6, emphasis added)

Confusion and potential conflict between the individual and social models of disability is evident in each of these quotes.

Also, the notion that IE is not appropriate for *all* individuals with disabilities is at odds with international understandings of inclusion but clearly evident in Ghanaian national policy. The Persons with Disabilities Act states that the government shall “establish special schools for persons with disability who by reason of their disability cannot be enrolled in formal schools” (Article 18.2). Article 20 details that no child can be refused admission to a school on account of their disability *excepting* students “who clearly requires [sic] to be in a special school”. There is no description of what these requirements might entail, it is assumed to be self-evident. Indeed, policies specific to IE aim to include only those with ‘mild to moderate’ or ‘non-severe’ disabilities. The seemingly arbitrary deadline of 100% enrolment into mainstream schools by 2015 (Republic of Ghana, 2003b) is likely another indication of international influence as it is consistent with both the MGD and EFA goal timelines. It appears then that segregated education for children with more severe disabilities is consistent with current policy, despite a resounding political cry for movements towards IE.

### **7.1.3 Access**

Accessing SEN provision in Ghana typically requires an official assessment of need, as it does in many countries. The GES ‘Manual on Basic Screening Techniques’ proclaims a dual role of assessment for the purposes of both IE and admission into special schools (GES, 2006a). This again supports the notion of multi-track SEN provision within the educational system of Ghana. Interestingly, a detailed reading of this screening manual suggests superior knowledge and comfort in providing for children with sensory impairments than those with intellectual challenges (GES, 2006a). The procedures for screening hearing and vision are formulaic and clearly defined. Procedures detailed for the screening of ID largely involve observation coupled with a few simple tasks (such as building a tower). While it is more difficult to screen for the vast range of disorders which could be encapsulated under GES’s label of ‘mental handicap’, it is argued that the understanding of this category reflected within the manual is itself contradictory. ID is here narrowly defined as having sub-average intelligence. However, disabilities such as ADHD, emotional behavioural disorders and ‘epileptic and autistic behaviours’ are listed in a section entitled ‘characteristics of children with ID’, without any explanation of these terms (pp. 8). Notably, the policy

definition of ID would not extend to all children with autism, many of whom are of average or above average intellectual functioning<sup>26</sup>. Whether Ghana chooses to embrace an individual or social model of SEN classification, inconsistencies in terminology and concepts, both within and across documents, can only lead to confusion.

In line with IE policies the number of ‘inclusive schools’ in Ghana has risen dramatically in recent years, from 35 in 2004 to 129 in 2008 (MoESS, 2008). However, the purported adoption of IE in Ghana as a fundamental human right and strategy towards fulfilling international EFA commitments appears to tacitly exclude children with autism and intellectual disabilities. There appears to be an implicit assumption that children with intellectual disabilities cannot, by definition, fit into this ‘non-severe’ category and therefore into education in inclusive schools. Government reports indicate that IE is largely tailored to students with vision or hearing impairments (GES, 2005; MoESS, 2005; MoESS, 2008) and that access to IE for “the severely intellectually disabled is non-existent” (GES, 2005, pp. 14). Furthermore, in discussing IE, reports indicate “the only enrolment of MH students reported appears to be in *special classes* at the vocational/technical level” (MoESS 2008, emphasis added). In discussing strategies to meet IE policy outputs, GES (2005) pledges to “construct 10 three-classroom *units* for children with ID by 2008” and “expand infrastructural facilities in *special schools* to admit at least 50% of learners with profound and multiple disabilities” (pp. 14, emphasis added). Confusion, or perhaps even disagreement, regarding what constitutes inclusive education is clearly evident in these reports. Here enrolment in segregated classes offered onsite within mainstream schools is considered ‘inclusive’ despite being inconsistent with definitions outlined by international agendas on which Ghana’s policies are based.

It is argued that this arises not from a difference in commitment to rights based provision but in divergent conceptualisations of ‘inclusion’, likely a result of the tension between international conceptualisations of disability rooted in a social model with

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<sup>26</sup> ‘intelligence’ and the ways in which it is measured are both hotly contested issues beyond the scope of this thesis. What is relevant however, is the diagnostic criteria of autism does not necessitate cognitive or ‘intellectual’ impairment.

conceptualisations of disability in Ghana understood through an, often implicit, individual model. For example, the prelude of the SEN Policy Framework describes inclusion as a ‘new strategy’ aimed at combating previous discrimination which took the form of “special boarding schools located in the outskirts of towns, separated from mainstream *society*” (GES, 2005, pp. 2, emphasis added). Here it appears it is a move towards inclusion of people with disabilities into the community, not necessarily the classroom, which is of central importance to policy makers. While this may not actualise inclusive education as intended in international declarations, it is nonetheless a leap forward in the visibility and inclusion of people with disabilities in Ghanaian society and progress on an ever evolving path towards inclusive education and communities. This sentiment also reinforces Lewin’s (2007) caution against assuming homogeneous starting points in large scale international agendas.

Commitment to IE at the policy level in Ghana is both assured and commendable but these demonstrated tensions in national educational policies result in even further confusion at the provision level. An examination of the extent to which IE policies are currently being actualised in practice follows.

## **7.2 Assessment & Educational Placement**

As shown in chapter one, government SEN services take three main forms, segregated special schools, segregated units attached to mainstream schools and IE. Special services, including special schools, are traditionally based on three broad categories of disability: vision impairment (VI), hearing impairment (HI) and mental disability (MD)/intellectual disability (ID)<sup>27</sup>. The use of only three broad categories of special needs to date, results in a broad understanding of ‘mental handicap’ as a catch-all category for any student not better defined as having a HI or VI. This conceptualisation of ID in practice is inconsistent with policies which officially define ID, and as such leads to confused service provision. Official government documents use the internationally accepted criteria<sup>28</sup> in defining ID as an individual with sub-average intelligence and

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<sup>27</sup> Recently staff at SpEd have begun using the term ‘intellectually disabled’ or ‘intellectually handicapped’ in place of ‘mental handicap’ but, to my knowledge, this change in terminology has not been officially recognised and its use remains sporadic and inconsistent.

<sup>28</sup> As in the ICD-10 or DSM-IV-TR

deficits in adaptive behaviour (GES, 2006a). Critically, this definition is intended to demarcate a *specific* impairment, not to classify a larger group of diverse disabilities. In Ghana, policy is consistent with the first usage whereas the second is used in practice, largely as a consequence of having only three categories into which all students with SEN must be placed.

Addressing the “inadequate classification/categorization scheme that define [sic] disability” is one objective listed in the SEN Policy Framework (GES, 2005, pp. 5). Similarly, one of its 10 policy objectives is to “determine the prevalence rates of different disabilities and SEN in Ghana” (objective #2, pp. 12). An argument surrounding the utility and validity of categorisation for educational purposes is beyond the scope of this discussion. What is relevant however, is that a projected move towards categorisation of specific disabilities again suggests a conceptualisation of disability through an individual model (Eide & Loeb, 2005). Ironically, the perceived need for additional disability categorisation is largely in response to national IE efforts, themselves a response to international calls for inclusion entrenched in human rights and a social model of disability. In designing IE, a tension exists in the desire to create high quality mainstream educational programmes which naturally adapt to the needs of each student and the need to first identify these needs in order to adapt (Eide & Loeb, 2005; Florian & McLaughlin, 2008; Norwich, 2008a).

Despite this policy objective however, a large scale screening project was recently undertaken using the same three traditional categories of impairment (GES, 2006b). In May 2006, ten district teams were tasked with the screening of all pupils in 3-4 schools across their district (GES, 2006b). Here too it appears that IE is conceptualised, at least at the provision level, as meeting the needs of students with mild disabilities. It is unlikely that those with disabilities that are more moderate to severe would currently be attending mainstream schools in which screening procedures were conducted. The conclusion that current efforts of IE are not intended to replace segregated schools in Ghana, but rather to operate alongside them, seems justified.

While the policy definition of ID would not extend to all children with autism, they are nonetheless included in services and ‘special schools for the mentally disabled’.

*Respondent 1: It can be a problem that they have mild problems and then enter those [special school] programs where they may even be pulled back rather than helped.*

*Respondent 2: Sometimes because children are placed in those schools the teachers will treat them like that, they will think because they are in a school for the intellectually disabled that they are that way.*

*Respondent 1: You know autism is not even included as its own category when we do our national census, they are still included with the intellectually challenged. It was even only some 3-4 years ago that I even got to hear about autism. It was when an NGO came to do some training. They had one seminar and it was very good but then that was all. - A conversation with two professionals*

*That is why they [students with autism] need a special program, they are just included in the programme for the mentally handicapped even though they may not even have a mental problem. –Senior Professional*

Further indications that ‘appropriate’ placement is complicated by a lack of distinct categorisation or services was apparent:

*When they put children in classrooms, they just put the very hyperactive one’s with autistic ones- Teacher*

*In most special schools, the defining characteristics of a disability seem randomly determined. They are not specific. A mild intellectual disability for a child who is also spastic will cause him to be placed in a severe classroom. –Professional*

*They just put **all** [students] together. But we should now be looking at distinction, who are they, where are they? And then we need to do education as to who they [children with autism] are, raise the awareness. –Senior Professional*

Interview responses indicate an ingrained and likely previously unquestioned belief that children with disabilities *require* specialised provision. Similarly, the notion that children with autism are ‘different’ serves as a consistent attitudinal barrier to their full membership in society and lends itself to the view that children with disabilities ‘belong’ in their own institutions.

*Most of them don’t go to these normal school, you know the government ones. They have their own schools ...By all means they will go to their own schools. Their behaving is different than the other children, they have their own place... Because they are sick...The way they are. –Community Member*

These quotes reinforce the conclusion that disability in Ghana is largely constructed through an individual model, even if not explicitly termed as such. They indicate a desire, at a senior level, for *distinctive* and segregated services despite recent commitments to IE. It is argued that the tension between a view of disability as intrinsic to an individual and policies which conflict with local belief systems hinder the successful implementation of burgeoning IE efforts in Ghana.

### 7.2.1 Referral

The referral system for students already in school can be confusing and inefficient. Officially,

*The class teacher should really notice a problem and inform the peri-officer for that district. Then the peri officer will do some background work and pass it on to the Department of Social Welfare. They will take up the case and recommend a doctor if necessary or make any school recommendations. They will maybe suggest a new school if appropriate. –Senior Professional*

In reality however, teachers are often unaware of what would constitute the need for a referral and may be resistant to the extra work and responsibility a referral requires. Some professionals, as well as family members, may also resist referrals due to a subsequent lack in available services once a referral is made.

*Then when we are able to be able to know them and identify them then what do we do? –Professional*

A medical doctor lamented the fact that no services were available if he were to offer a diagnosis of autism:

*[you have to provide] a guarded prognosis in the sense that you know there are no services that are going to take place...then what is going to happen? This child is not going to come out and work independently. I see them for diagnosis, I don't see them again, they disappear. I never get to do follow up....it's natural, you tell me something that is not nice, you are not giving me a medicine or a service that is going to help my child....I think we have reached a stage where we should be trying to provide a [diagnostic] service and education at the same time, if we have these two working hand in hand with time you will convince [parents] that it is actually better to come and see you....they go home, they go to see others [who say] this disease is a spiritual one, and they don't come [back] because I have not offered you any information to take home, only this is the name of this disease; we call this 'autism' - Professional*

Indeed, raising awareness of autism without appropriate service provision in place walks an extremely thin ethical line.

*You see, in raising the awareness the ability for you to let the person know that this thing cannot be solved but at the end of the day, this is the kid that you get. That is the most important thing. But not saying, okay there is something called autism, autism is this this this and this this this. That will not help. People want solutions. In as much as you are telling them there is a problem, you know, there should be a process and there should be a product....Or for you to give hope, that there is hope. - Professional*

In addition, the referral process outlined above is only potentially responsive to children already accessing school. When questioned on the procedures for children who were not yet of school age a senior official remarked:



*Well then, the problem lies within the health sector's responsibility not yet with education. They will monitor the child and make sure that they are reporting his weight at least one time every month so they can follow up on the growth of the child and notice if there is a problem. The parents can contact what we call public health officers who can then refer them to the hospital. The hospital should get Social Welfare involved; they are responsible for anyone age one year to six years. –Senior Professional*

This quote not only reveals a narrow understanding of impairment (viewed through a medical model and measured through monthly weighing), more importantly it also hints at the complexity of the system that parents are charged with navigating if they wish to actualise the rights afforded to their child at the policy level.

### 7.3 Teacher Training

As was the case for institutional arrangements, interviews reflected the belief that teacher training on SEN should necessarily be specialist.

*...maybe they have to induce, they have to get special teachers, special training. No, I don't think they have special teachers for that people. The special teachers are sent to the deaf, the blind, the deaf and dumb, but you don't have teachers for autism...I don't think they have that expert in Ghana now.... Once they have confidence in themselves then they have the confidence to teach the children. But you see, if I don't know anything about autism how can I teach the children because I don't know anything about it? -Parent*

This quote continues to reinforce implicit understandings of disability as rooted in an individual model. It also reinforces a tradition of, and respect for, expert knowledge, which is perceived to be necessary for the instruction of children with disabilities.

*The problem is they are given no training to prepare them. In the teacher training colleges, training only addresses the average. We do not look at the gifted or at the disabled. -Professional*

*We focus on the average student, teachers are not aware of how to educate SEN, the gifted and the handicapped. –Senior Professional*

Recent reforms in teacher education have therefore attempted to address a perceived gap in *specialist* disability knowledge despite their stated aim of facilitating IE initiatives. Whereas SEN was previously an (unpopular) optional adjunct to teacher training, a mandatory 'Special Needs Education Studies' course was recently added to the three-year Basic Education Diploma requirement (MoESS, 2008). This is certainly a positive step forward and ensures that many newly trained teachers will have a basic knowledge of 'disabilities', though I would argue these efforts at TT revision would be better focused on imparting inclusive pedagogy. However, it should be noted that this

requirement only applies to the 3-year degree programme and teachers in training colleges, while encouraged to study SEN, are still able to opt out of this training.

*We are asking teachers in training colleges to [voluntarily] take Special Education as their 2nd subject, that way if they reach a district and there are no experts or Peri officers there they can at least keep the programme going in the mean time. –Senior Professional*

Given the possible stigma and fear associated with disabilities in Ghana and the perception that students with SEN require significantly extra work (Agbenyega, 2007; Gyimah et al., 2008; Kuyini & Desai, 2007), it seems unlikely that this voluntary approach will entice many teachers to take SEN courses. Currently underway, an additional government training initiative aims to reach teachers already in-service to prepare them for the inclusion of students with SEN into their classrooms (Anthony & Kwadade, 2006). Curiously, these training measures appear inconsistent with the implementation of the IE policies they were designed to support. Both the special education teacher training course and the in-service training teach classifications such as hearing impairment, Down's Syndrome and more recently autism (Anthony & Kwadade, 2006; Avoke, M, 2001; Loeb et al., 2008). The information disseminated is often highly technical and medical in nature and therefore remains grounded in an individual model of disability. The tension between an educational system which traditionally respects hierarchical power relationships and values 'expert' knowledge and progressive IE efforts is evident in these reforms.

In addition, the Department of Special Education at the University of Education, Winneba, continues to train special education teachers on three distinct programmes, Education of the HI, Education of the VI and Education of the MH (Gadagbui, n.d.). While teachers are encouraged to take second subjects on alternative courses, their training is largely disability specific and unlikely to be sufficient in preparing teachers for the inclusion of diverse students into mainstream classrooms. Furthermore, the special needs curriculum content of teacher training colleges (TTCs) focuses mainly on the identification of impairments, their causes and training of referral procedures (Casely-Hayford, 2002). In examining initial teacher education curriculum from Ghana as part of a larger project, Croft (2006) found that 'difference' was understood through a normative lens of child development where problems were located within an individual. This conceptualisation of difference is suggestive of an 'integrated'

approach to special education (Croft, 2006; Stubbs, 2002) which does little beyond the cursory physical placement of children within classrooms to address the real learning needs of the child, discriminatory attitudes or larger human rights issues and as such is consistent with an individual model of disability.

As discussed in chapter one, traditional disability classifications (such as autism) may not be the most valid or useful categorisations when planning pragmatic pedagogic strategies in the classroom (Lewis, A. & Norwich, 2005). I would argue this is almost certain to be the case when the information presented represents highly technical and prestigious knowledge. It is hard to see how Ghanaian teachers can acquire the values and principles of inclusion, as recent policy mandates, when teacher training initiatives still highlight difference and reinforce distinction in a manner consistent with an individual model.

Unfortunately, an example of uncritical exportation of knowledge and assumption of shared cultural relevance can be found in my own work. In 2005, I was contracted as a consultant with a USAID funded project to collaborate with the Special Education Division of GES on the development of the in-service inclusive education training programme described above. Having been trained in the US, and in collaboration with donors from the US, I instinctively described 'learning disability' as it is used in that context, namely as a class of disabilities (such as dyslexia or dyscalculia) associated with difficulties in understanding or using language, which affects the ability to learn in the domains of reading, writing, spelling or math (Speece, 2008). Upon studying in England however, I learned that this term is used quite differently throughout much of the English speaking world, including Ghana, as a term typically associated with a diverse group of disabilities involving cognitive impairments, at times including autism and Down's Syndrome. Unaware of this difference, I unintentionally passed on culturally insensitive knowledge that likely conflicts with existing teacher training initiatives.

To date then, IE policies in Ghana may have raised awareness of the inadequacies of teaching for SEN but teacher training reforms have, as of yet, failed to support the underlying philosophy, principles and pedagogy of IE on which they are based, at least

as conceptualised internationally. I therefore suggested that teacher training efforts should be reconceptualised to minimise transmission of disability specific and highly technical information and instead focus on teaching inclusive pedagogy, building positive attitudes and demystifying IE and impairment specific groupings.

## 7.4 Pedagogy

For the purposes of this discussion I have adopted Norwich & Lewis's (2001) broad definition of pedagogy "to mean the cluster of decisions and actions which aim to promote school learning" (pp. 314). This encompasses teaching activities, learning materials, instructional strategies, curriculum and environmental modifications as well as the use of motivational or disciplinary strategies.

Students with autism benefit from teaching strategies which are repetitive, tailored to their 'restricted' interests, highly concrete and presented in multiple formats including visual supports and tangible materials (Baron-Cohen, 1995; Baron-Cohen et al., 1994; Cohen & Volkmar, 1997; Edelson, 2008; Grinker, 2008a, 2008b; Happé, 1994; Iovannone et al., 2003; Jordan, 1997; Jordan & Jones, 1999; Larsson, n.d.; Lovaas, 1987; Steiner-Bell & Kirby, 1998; Volkmar et al., 2005). Consistency in the teaching methods employed and predictability of expectations can also serve to maximise attention and learning for students with autism (Dawson & Osterling, 1997; Jordan, 1997).

In line with these learning needs, and those outlined in chapter one, children with autism often benefit from prolonged repetition and practice of a desired skill (Lovaas, 1987; Machalicek et al., 2008). Many teachers, including myself, have found tremendous patience to be an essential pedagogic skill in teaching students with autism in any context. Respondents in Ghana noted this same challenge:

*If you teach them something today, the next day they forget it. Yeah, but if you have the heart to keep teaching them you know, the same thing every day every day every day, they become used to it... Then one day one day you can tell... this kid is picking [things] up. - Community Member*

*Interviewer: You mentioned challenges, what do you find challenging about working with these students?*

*Respondent: trying to add something [when] they didn't getting it when you want them to or sooner than later, its ahhhhhhh! -Teacher*

When asked what she found most rewarding about teaching student with autism, one teacher replied:

*When you are teaching them and you realise that they are responding. Just like, [it took] me almost a year to teach John to say "bye bye" and [now] he is saying it- just last Friday. I was soooo happy. When you realise they are trying to do something you are asking them to do, all the trouble and things, the stress you have, you forget about them. -Teacher*

In the last chapter, many families expressed a desire for their children with autism to ultimately be independent. Teachers and community members echoed this same sentiment in the view that the goal of education for students with SEN was independence and the acquisition of vocational or self-help skills.

*They must be useful to themselves. Self-help skills and socialisation [are important].  
- Teacher*

*Interviewer: So how do you feel about the move towards inclusion in public schools for children with autism?*

*Respondent: I don't think it will help them....[trailed off]*

*Interviewer: Hmm, so what do you think we should do?*

*Respondent: We can make one big school one big workshop. And we need to create jobs for them too. -Teacher*

*So, for them, ... [education] means they can go to school then they can earn a job and they can probably feed themselves, have some shelter above their heads. -Community Member*

*It is the difference between needing a full time care worker or not. -Teacher*

The acquisition of self-help and vocational skills is not necessarily inconsistent with international understanding of IE based on a social model of disability. The teaching of these skills is however incompatible with *current* mainstream classroom environments, curriculum and knowledge of inclusive pedagogy in Ghana. Samuel, a parent introduced in the last chapter, spoke at length about wanting to see his child included in mainstream classrooms yet he later shared the sentiment expressed by other stakeholders that these same classrooms were not appropriate for his son with autism:

*You see, it's like coming to draw a programme for these children [with autism] and doing a programme for you know normal children in class too. You will draw two different programmes. You cannot take the programme that my [typical] child who is now learning how to write words or sentences [at] 4 years [old] to come and do here [AACT], no... You see there are two different worlds they have been given you cannot interchange. - Samuel*

Similarly, another parent indicated:

*So [a specialist] was telling me I need to take him to where more children are, maybe if he attended school, like where they will be playing and picking up. [But] I said he is not the type, he doesn't concentrate, he doesn't sit. If they are playing, anyway he won't play. -Parent*

A lack of understanding as to how an inclusive environment could be adapted to meet the learning needs of all students can lend itself to the conclusion that mainstream classrooms are not appropriate for all students.

In addition, a top down dictation of the national curriculum, coupled with national assessment of students, can result in little to no agency for teachers to use creative pedagogy or individualise curriculum (Croft, 2006; Dei, 2005; Kadingdi, 2004). A pedagogic history in Ghana of rote didactic teaching, choral responding and at times, memorisation of facts in isolation from meaning or context (Akyeampong, K. et al., 2006), seems to have contributed to inflexibility in conceptualising imaginative pedagogy for children with SEN. This historical influence is a challenge to meaningful educational opportunities for children with autism in both inclusive and segregated classrooms in Ghana. The needs of most students with autism can be met in inclusive classrooms but the underlying information processing challenges of autism, coupled with the heterogeneous presentation of the triad of impairments, may offer additional and rigorous pedagogic challenges for a mainstream teacher.

In addition, the challenging behaviour of some students with autism was identified in chapter five as particularly stigmatising and its management is likely to be another pedagogic challenge to teachers in inclusive classrooms. Take for example a student with autism's apparent unwillingness to follow a teacher's instruction. Given the shared information processing challenges associated with autism it is likely this student would struggle to follow instructions, yet the reasons underlying this struggle could vary immensely between individuals and across time. This student may have a receptive language processing delay such that they do not understand the instruction 'sit down'. Alternatively, the challenge with communication might be a more fundamental failure to grasp the very purpose of language; they may not understand that you are giving them an instruction at all. On the other hand, the student may fully understand both the communicative intent and the instruction itself and their failure to comply may be a behavioural issue or represent a sensory aversion to the chair they are being asked to sit in. In each of these instances the teacher's response would differ, she must understand the cause of the non-compliance to effectively determine an appropriate intervention approach. Similarly, a student who does not remain seated is not

necessarily hyperactive or ‘stubborn’ but may, for example, have a sensory aversion to the noise the feet of the chair make when scraped across a hard floor. Designing an appropriate intervention for this student will require his teacher to understand the sensory processing challenges inherent to many children with autism (shared feature) alongside his particular sensory aversion to some sounds (individual characteristic) and to identify any environmental barriers such as a lack of alternative seating choices or perhaps an insufficient communication system through which this student could express or explain his discomfort. The combination of these features result in the experience of disability. Clearly, teachers of inclusive classrooms can be trained to recognise and respond to the underlying utility of challenging behaviours; this knowledge is essential if a teacher is expected to both prevent and manage any behaviours which would serve to exclude a student with autism from meaningful learning opportunities.

There were however glimpses of hope for the future directions of inclusive pedagogy in Ghana. For example, one professional detailed possible benefits of group and peer-mediated learning strategies for children with SEN:

*You know we are moving towards inclusion so teachers need to use other students to help them. You can ask the gifted to help which encourages them and set students learning together and helping those who need support.—Professional*

A worldview which lends itself to understanding disability through an individual model seems to lend itself to the conclusion that students must ‘fit’ within, or adapt themselves to, current mainstream contexts. Croft (2006), has suggested that the conceptualisation of difference amongst pupils can be shaped by the broader cultural attitudes to individualism/ collectivism within that society. Whereas teachers in highly individualistic societies respond to individual differences in students, teachers within collective societies may teach to the larger, assumed to be homogeneous, group. These differences in conceptualisation of disability, alongside traditions of didactic pedagogy, translate to the implementation of ‘inclusion’ in Ghana better suited to an international definition of integration.

## **7.5 Curriculum**

Recognising that meeting commitments to IE centres on more than just institutional arrangements, the Ghanaian government has made strides in curriculum modification.

As of June 2008 the curriculum for children with ID had been reviewed and modified but not yet distributed to special schools (MoESS, 2008). While updating the curriculum is laudable, revision began in 1998 and the curriculum was printed and launched in 2001 (GES, 2001). It is hard to understand a failure to distribute this curriculum to schools, even after completion, for nine years. Recent attempts to determine if it has now been distributed have been unsuccessful. One professional explained that the curriculum would not be appropriate for students with autism as they may not demonstrate cognitive delays (Edelson, 2008; Grinker, 2008a; Jordan & Jones, 1999). However, in examining the curriculum itself, it is in many ways consistent with the wishes of parents for educational provision of their children with autism. Chapter six demonstrated that some parents expressed a desire for their child to learn self-help and vocational skills with the ultimate aim of independence and self-sufficiency. The curriculum for children with intellectual disability focuses on practical skills (such as the use of money and reading of street signs), allows for explicit instruction of self-help skills (such as dressing, washing and toileting) and devotes over 30 pages to vocational skills (such as basket, soap or dress making) (GES, 2001).

It is important to remember that this curriculum is intended for use in special schools for intellectual disability. It seems then that priorities of families for the education of their children with autism are conflicting in the current Ghanaian education system. As shown in the last chapter, many families did indeed desire, and attempt to access, IE placements for their children. Often they were met with resistance from head teachers and those that did succeed in accessing classrooms typically found them unsupportive to the needs of their child. It seems that under the current educational system in Ghana these two priorities of parents are incompatible. These priorities need not be seen as in opposition to one another but a greater understanding of creative pedagogy and curriculum modifications, as well as the teacher training and autonomy to make such changes, will be required before IE classrooms in Ghana can meet these vocational aims. Incidentally, these changes would likely benefit all children with an impairment or SEN.

Understanding and getting it right for children with ASD can be a way of getting it right for everyone (Jordan, 2008, pp. 14).



In addition, the very notion of a specialised curriculum for children with intellectual disability in Ghana is in opposition to ratified international declarations. For example, the Salamanca Statement proclaims:

Children with special needs should receive additional instructional support in the context of the regular curriculum, not a different curriculum (UNESCO, 1994, pp. 22).

Rather than devising a separate curriculum some countries have developed a system of ‘individualised education plans’ (IEP) which details, for each individual child with special needs, the supports, additional services and curriculum modifications which are necessary to ensure the student’s meaningful inclusion. Perhaps one of the greatest examples of uncritical exportation of external systems into Ghana through well meaning development programmes is that of the IEP. The IEP is mentioned as a strategic output in Ghana’s SEN Policy Framework and guidelines for the development of IEPs and a corresponding IEP document template were issued by the Special Education Division of GES (GES, n.d.). In this document, an IEP is described as a “documented educational plan or curriculum that allows for the provision of special services, appropriate placement and suitable curriculum according to the needs of each individual student” (pp. 1). The language of this statement, and the rest of the document, is clearly influenced by external sources with little understanding of the realities of Ghanaian culture or educational environments. It is noteworthy that the first line of the IEP guidelines reads:

The whole idea of Individualized Education Plan (IEP) emanated from the United States of America (USA) through passage of Public Law 94-142 by Congress in 1974 (pp. 1).

Attending to the individual needs of a single student through modifications to the curriculum, adapting pedagogy with a move away from traditional didactic teaching and documenting these procedures would all require changes to the teaching and learning culture of schools in Ghana. These changes are noteworthy goals but would seemingly be prerequisites to the successful implementation of the proposed IEP. While the use of an IEP could conceivably facilitate some of these changes, it is suggested that attempts to implement such an IEP procedure given current realities would be largely ignored in practice thereby wasting time and money and negating any possible changes as a result of its use.

The IEP guidelines also set out a schedule for termly meetings with the students' team including the regional special education officer, classroom teacher, Head of school, related services and the parents or guardians. Meetings of this type are exceptionally uncommon within the educational system in Ghana today and as such would be unlikely to occur without at least one highly motivated member of the team, likely a parent, advocating for such a meeting. The guidelines also appear to ignore current realities of Special Education Officers<sup>29</sup> (SEO). Many districts remain without an SEO and where one is appointed they are responsible for a vast amount of students across great distances. It is difficult to imagine a single individual managing the workload of all screening, referrals, IEP meetings and individual student visits across an entire district even when reliable transport can be assured. Finally, the IEP document itself is eight pages long and requires regular and lengthy teacher documentation, not to mention photocopying capabilities. The majority of teachers in Ghana are likely to be unfamiliar with, and resistant to, lengthy documentation and data collection procedures. The proposed IEP document is inconsistent with an oral culture in which little is formally written down. In addition, this procedure ignores the lack of autonomy of the teacher in the Ghanaian education system to modify curriculum. It is suggested that all of these realities are sidelined as a result of importation of an IEP system from international sources without the necessary critical adaptation to local culture and circumstance.

## 7.6 Translating Policy into Provision

To me, the IEP procedures described above are a clear testament of external influences on educational provision and to the lack of adaptation, even in the language of the document, for the Ghanaian context. As with international declarations on human rights and IE, shared values, skills, knowledge and understanding seem to be assumed. At least one parent in the current study was concerned about international influences on national policy and a potential lack of cultural relevancy:

*Like you persuade them to take your policy, but the policy should be you know fitted in our values and our cultures and things so that they can take. Otherwise, you better stay in your country. -Parent*

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<sup>29</sup> Formally peripatetic or 'peri' officer

While others simply expressed scepticism that policy would ever translate into meaningful practice:

*But the implementation, I hope that they will... here, normally policies are policies. And for implementing them, [it] becomes a problem. - Parent*

*The steps to achieving that thing [inclusion] by 2015. I haven't seen them start. Because if they want to, then they must start training, you know, they must start training people, they must start making provision for all. You know piloting and these things. -Parent*

While the government has, in my view, begun taking steps towards inclusion as this parent suggests, the visibility of these efforts seems to still be illusive. This chapter has suggested that inconsistency between national policy, based on international influences which adhere to a social model of disability, and provision rooted in a (perhaps latent) individual model, can result in the actualisation of inclusive education in a manner more consistent with international notions of 'integration'.

Despite ratification of conventions which require a social conceptualisation of disability, policy, service provision and teacher training in Ghana appear to remain grounded in understandings of disability consistent with an individual model. This has contributed to limited uptake of policy at the provision level. IE policies have been shown to be largely rhetoric, mirroring international trends but failing to result in meaningful changes to practice. In reviewing the history of special education in Ghana, Avoke (2000) concludes that:

Attempts to incorporate other (British) influences have not significantly changed the nature of education and service delivery from a practical viewpoint. What perhaps changes from time to time is the rhetoric of special education...recently, the international position adopted on inclusive education (pg 39).

Well-meaning large international movements can be held accountable for some of the pressures and competing priorities in Ghana at a national level. Politically reverberant pressure to meet EFA deadlines in Ghana has contributed to increasingly overcrowded classes, insufficiently trained teachers and declining quality. This, alongside pressures for quality SEN provision and IE, represent potentially conflicting priorities for already stretched education budgets.

*Interviewer: So, do you think it's possible, the goal of total inclusion by the year 2015?*

*Respondent: [laughs]. I don't think so no. Even as we are looking at the numbers, as some go up others go down. One thing improves but it negatively impacts upon another. - Senior Professional*

In other words, it appears, in Ghana at least, that efforts to meet EFA deadlines may actually be working against *inclusive* education for children with SEN.

Understanding the worldview outlined in chapter four is critical to understanding barriers to implementation of well intentioned policies; differing conceptualisations of disability suggest adoption of different educational programmes and policies (Borsay, 1997; Lindsay, 2003) and affect attitudes towards IE (Gaad, 2004; Peters et al., 2005). A view of disability consistent with the social model implies the equalisation of educational arrangements and lends itself to inclusive education. When examined closely, understandings of disability in Ghana, and the subsequent policy and provision which is adopted for children with SEN, are highly consistent with an individual model of disability. The cause of disability, whether biomedical or spiritual, is almost always fundamentally located within the individual, not with disabling social structures (see chapter five). ‘Cures’ aim to ‘fix’ the individual (or disharmonious relationships) in question and restore ‘normal’ functioning. This chapter has reinforced the conclusion that disability in Ghana is largely constructed through an individual model and has demonstrated its influence on educational policy and provision for students with autism, even if only at a mostly intuitive level.

Recent international discourse on education for children with disabilities has become passionately pro-inclusion, as if tagline proclamations of the Salamanca Statement, namely the effectiveness of IE and its power to combat discriminatory attitudes, are unassailable truths. The Salamanca Statement asserts that:

Regular schools with this inclusive orientation are the most effective means of combating discriminatory attitudes, creating welcoming communities, building an inclusive society, and achieving Education for All; moreover, they provide an effective education to the majority of children. (UNESCO, 1994, pp. ix).

However, there is a paucity of research confirming this politically powerful sentiment. This widely quoted passage from the Salamanca statement is often used as *evidence* of IE’s effectiveness and success in mitigating prejudices (see for example UNESCO, 2003). It is this ‘strong’ message which is propagated in international declarations and then adopted by local governments of developing countries and which has been shown, at least in Ghana, to lead to confused local policy and provision. It is this extreme view to which aid and funding often appear to be tied and it is this extreme view which is

often at odds with the generally shared worldview identified in chapter four and conceptualisations of disability in Ghana. Intuitive understanding of disability through an individual model is inherently in conflict with international understandings rooted in a social model.

The implementation of universalist international development agendas has the potential at least to ignore local culture and authority (Mohan and Holland 2001). In designing educational programmes for students with disabilities it is critical to understand the cultural lens through which disability is viewed and to avoid the all too frequent development of international programmes which may serve, even accidentally, to act in opposition to these belief systems.

To be absolutely clear, this is not an argument against the utility of the social model of disability or IE and is not in any way a challenge to the universal human rights afforded to individuals with disabilities. There is undoubtedly a role for even the extreme view of the social model in international discourse. Its emancipatory approach which aims to transform entire repressive societies and educational systems through a foundation on values such as tolerance, respect, dignity and celebration of diversity has been instrumental in uniting societies towards increased acceptance of diversity and the slow erosion of Disability as a form of social oppression. The social model has been a powerful rallying cry to action for disabled peoples movements, academic disability studies and international human rights policy advocates for people with disabilities. This is not an argument against such uses of the social model, its continued use is paramount in the quest for social justice and the ultimate eradication of oppression and Disablism (Thomas, C., 1999). The current research does however suggest that ‘development’ needs to ensure not just the *adoption* of laudable international declarations but their *adaptation* in subsequent implementation consistent with locally evolving conceptualisations of disability and the belief systems on which those conceptualisations are based. As I will argue in the concluding chapter, consistency with local belief systems (i.e. an understanding of disability through an individual model) is not necessarily in opposition to burgeoning or progressive reform (such as towards IE).

## 7.7 Conclusion

This chapter has attempted to examine the state of educational policy and provision in Ghana for children with SEN with a special focus on students with intellectual disability, the category into which children with autism are typically required to fit. An examination of international influences on local policy was followed by an examination of the degree to which these policies have, or have not, been translated into practice.

The degree to which recent policies, designed to secure the rights of people with disabilities and ensure equitable and inclusive education, have been implemented to date, varies. Placement challenges for students with autism are confounded by the use of differential identification and labelling of SEN for different purposes. Policies often use the categories ‘mild’, ‘moderate’ and ‘severe’ without explicitly defining them. The stated goal of integrating all students with ‘non-severe disabilities’ is one such example. However, GES delineates services for students using their HI, VI and MH labels. Designing policy based on one set of terminology, and provision based on another equally subjective set, clearly creates numerous challenges in the assessment and placement of children with SEN into meaningful education. Moreover, teacher training initiatives, sometimes designed in response to IE policies, often teach disability specific labels which are then not recognised within the educational system.

The complex nature of the educational system in Ghana compounds the difficulties of accessing appropriate provision. There are multiple agencies in charge of various aspects of special education provision throughout Ghana (see chapter one) and it can often be confusing, especially to parents, to know who is responsible for what. Policy changes can be slow to trickle down to provision in practice, as evidenced clearly by the delays in distributing the revised curriculum for students with MH. Responsibility for such delays is often shifted across various agencies responsible for aspects of SEN provision. This responsibility shifting likely serves as a further barrier to the inclusion of students with autism in Ghana and contributes to a lack of communication and collaboration across agencies responsible for varying aspects of SEN provision. The bureaucratic barriers to provision are further evidenced in protracted and inconsistent assessment, referral and placement procedures.

As some cultures have moved towards an implicit agreement to redefine disability through a social model lens, both services and aid offered to developing countries have followed suit without critical examination of this model for cultural relevance in those countries. In Ghana, a tension between commitments to these international declarations grounded on a social model of disability and underlying local conceptualisation consistent with an individual model has resulted in confused SEN definition, policy, teacher training and IE provision. International movements, though well intentioned, need to better recognise and incorporate disparate worldviews and allow for variation in strategies which aim to actualise human rights agendas.

Clearly, at a policy level, IE has been embraced in Ghana. However, despite commitments to the principles of desegregation and equalisation of educational opportunities, 'inclusive' education, as defined in chapter one and as understood in international declarations, is still illusory. This chapter revealed policies to be largely rhetoric to date, and when implemented, to be more consistent with integration than with inclusion. The next chapter will attempt to examine the reasons behind this failure, at least to date, to turn progressive policy into commendable inclusive provision as applies specifically to children with autism in Ghana.

## **Chapter 8**

# **Inclusive Education for Students with Autism in Ghana**

### **Introduction**

The last chapter traced the current educational policy and provision for students with intellectual disabilities in Ghana which demonstrated that progressive IE policies are not currently translated into meaningful and inclusive practice. This chapter will attempt to trace the reasons behind this disconnect and examine the challenges of educating students with autism in inclusive environments in Ghana.

### **8.1 Autism and Inclusive Education**

Autism remains a complex, unique and perplexing disorder so it is no surprise that impassioned controversy exists regarding appropriate education and intervention strategies for children with ASD and that copious amounts of research has, as of yet, failed to identify an educational strategy appropriate for all children on the spectrum or one superior to its alternatives (Dawson & Osterling, 1997; Iovannone et al., 2003; Jordan & Jones, 1999). Chapter one detailed the features of autism and underlying information processing challenges, both of which seemed to suggest a disability specific pattern of educational needs for students with autism. Importantly, all children on the autism spectrum demonstrate some degree of impairment in social and emotional understanding, communication and flexibility in thinking. The transactional nature of autism is such that these features are likely to interact with, and compound upon, one another. For example, impaired language skills may exacerbate difficulties with social relatedness in a classroom setting, making a conversation with a peer that much more challenging (Jordan, 2005). A diagnosis of autism is based on the concurrence of these broad features while the specific manifestations of, and interactions between, each of these impairments can vary dramatically across individuals with autism as well as within an individual across time. In addition, intelligence varies independently from severity of autism, there is no clear linear correlation and many children with autism have no intellectual delay (Jordan, 2005, 2008).



Despite the highly individualistic portrait of skills across children with autism, research does support the need to teach ‘core skills’, skills that are lacking in individuals with autism due to the nature of the disorder and which are prerequisites to the acquisition of other knowledge (Dawson & Osterling, 1997; Grinker, 2008a; Iovannone et al., 2003; Jordan & Jones, 1999). For example, if a child cannot understand the language of a lesson they will certainly fail to grasp the concept presented using that language. The ability to imitate is another core skill, required as a prerequisite to learning through observation. Dawson and Osterling (1997) identify five essential skill domains, which they feel should be explicitly addressed through curricular content in education programmes for students with autism. These core skills are: the ability to attend to elements of the environment, the ability to imitate others, the ability to comprehend and use language, the ability to play appropriately with toys and the ability to socially interact with others. These skill sets would seem to easily translate as appropriate in a Ghanaian context, with the potential exception of ‘appropriate play with toys’ which may need modification to ensure cultural relevance.

Critically for IE initiatives, these core skills are often prerequisites, or at least significant challenges, to a student’s ability to learn in mainstream environments which require these skills. In addition, as demonstrated in chapter one, a teacher’s understanding of the shared features of autism and the underlying information processing challenges, or ‘autism-ness’, may also prove essential to the meaningful inclusion of students with autism into mainstream classrooms. As Jordan (2008) suggests, IE teachers need not be experts in autism but they need to be familiar with principles of teaching and learning which go beyond the delivery of prescribed packages. Curriculum content which expressly teaches the core skills identified above is necessary if students with autism are to be included (as opposed to integrated) and teachers of children with autism must have the skills, agency and motivation to adapt the mainstream curriculum accordingly. If a child initially failed to learn core skills through non-formal educational opportunities and exploration of their natural environment, then repeating observational and intangible opportunities for learning in formalised ‘inclusive’ education may be a lesson in futility.

In light of these challenges, the successful education of students with autism in inclusive settings can be difficult, perhaps even more so than with other impairments. Having shown that autism offers unique *disorder specific* challenges to successful IE, I now turn to an exploration of *context specific* challenges to inclusion, which in many cases extend to all children with SEN across Ghana.

## 8.2 Ghana and Inclusive Education

*[The inclusion policy] is a positive sign but there are many challenges. Challenges that need to be met early on otherwise the target will pass like other clichés that have come and gone. –Teacher*

### 8.2.1 Resource Barriers

In Ghanaian schooling today, (unequal) power relations exist, as seen in the differential allocation of, and access to resources among social groups and economic sectors, as well as regions of the country (Dei, 2005, pg. 270).

A lack of sufficient resources is widely accepted as a serious challenge to the successful implementation of IE (Avoke, M, 2001; Inclusion International, 2009a; Miles, S., 2000a, 2000b; MoESS, 2008; Pinnock & Lewis, 2008; Rieser, 2008; Stubbs, 2002; Urwick & Elliot, 2008). This barrier transcends cultural, economic and geographic boundaries to such an extent that even those in the most resourced communities often cite it as an excuse for not undertaking IE (Miles, S., 2000b). For the purposes of this discussion, it is useful to follow Miles' sub-categories of resource barriers:

1. Economic or financial resources
2. Human resources (the number of qualified teachers, specialists, doctors, etc.)
3. Knowledge resources (access to knowledge and information about disability, autism and/or inclusive education)

### Economic Resources

Economic barriers plague the UPE and EFA initiatives, with many countries in danger of missing the 2015 deadline due to a lack of financial resources (Lewin, 2007; UNESCO, 2008). Given an overall lack in sufficient financing, the way available funds are allocated for different educational initiatives points to the priorities of a

government. As the conversation below illustrates, the allocation of funds for special education services in Ghana is based on the number of students with disabilities who have been previously identified.

*You see the things that are very expensive tend to get ignored; we push them to the side. Special Education is very expensive...People believe that because they need so much money to make any real difference that only a little will not make any impact so it is only wasted on those departments. The other thing is that the 'sharing of the national cake' is based on numbers. If you count up all the students the abled make up the great majority, so that is where the greatest proportion of the money goes. And it is not only us but I also blame the NGO's and Development agencies, they too give where they can say they make the greatest impact. If you give 10,000 [Ghana Cedis] to the able-bodied maybe you can impact upon 1,000 students but if you give the same amount to special education maybe you can only impact upon 20 students. People want to make the biggest impact.-Senior Professional*

Allocating funds based on enrolment figures, which currently total only 5,654 pupils across all special education services (MoESS, 2008), has resulted in insufficient special education provision to date. Without adequate placement opportunities, a majority of students with disabilities do not have access to schools and are therefore not tallied into budgetary calculations for the provision of future SEN services. Dividing resources based on identified students seems counterproductive to the stated aims of IE, as does spending extremely scarce resources on the building and operation of additional segregated services. It is hard to see how these procedures support the stated inclusive education priorities of the Ghana government.

In 2004, the budget allocated to SEN was just 0.5% of the total government education budget (MoESS, 2005) and dropped even further to just 0.3% by 2008 (MoESS, 2008). The relative decrease in budget, viewed alongside the reported increase in services (see chapter one), has an even greater impact per student.

[In 2007-2008, the Special Education Division of GES] could not achieve 35% of its proposed activities as many planned activities were not given budget lines. With the budget of the Ministry already being stretched, priority is not given to special education (MoESS, 2008, pp. 57-58).

This is particularly worrying given research which indicates that if funds are not explicitly allocated in support of inclusion policies then its implementation is unlikely to occur (UNESCO, 2003).

*Inclusive education, teacher training it all costs....-Senior Professional*

The disparity and devaluation of education for children with disabilities can be seen clearly in the funding and priorities afforded to the Special Education Division (SpEd)

of GES. The majority of GES divisions are located together on a large and easily accessible site in central Accra alongside the Ministry of Education<sup>30</sup>. SpEd however, as the newest division, is located in a distant, poor and rundown suburb. When you finally arrive, there is no sign to indicate you have reached the SpEd offices, which are then only accessible by a precarious stairway at the back of the building. These third floor offices are clearly not likely to be accessible to, or inclusive of, either staff or visitors with physical impairments. In addition, the SpEd offices are still waiting for the internet capabilities which have been promised to them and which are afforded to the other divisions on the main site. The Director of SpEd spends much of her time in traffic crossing town to attend meetings at the central GES cite while other officers frequently leave the office to access the internet or spend much of their day waiting to use the few shared computers.

...the attitudinal barrier to inclusion is so great that the level of resourcing is irrelevant. It is people's attitudes to those resources and the way they utilise them, that is crucial to the promotion of inclusive education (Miles, S., 2000b, pp. 1)

The eventual social and economic costs of not *effectively* educating students with SEN must also be acknowledged, for both the family and the larger community (UNESCO, 2003). Akyeampong (2008) reminds us of lessons learnt from previous education initiatives in Ghana:

Education developments in the 1980's and 90's have shown that good access to poor quality basic education will not yield the private and social returns of investments to promote economic growth (pg 6).

Education is not just an issue of supply, but also one of demand; families need to see the return of sending their child, any child, to school (Akyeampong, K., 2008; Akyeampong, K. et al., 2007; Jonsson & Wiman, 2001; Lewin, 2007). These concerns were largely mirrored by families in the current research and interviews highlight economic tensions in their schooling choices (see chapter six). If IE fails to provide an *effective* education for students with SEN, claims of its economic efficiency can hardly be justified (Lindsay, 2003). This assertion however resonates with both IE and segregated classrooms, if special schools in Ghana are themselves not effectively educating students with disabilities, cost calculations which criticise the ineffectiveness and repetition rates of IE, are immaterial. Regardless of whether services are segregated or inclusive, it is clear that financial resources must be committed to ensure

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<sup>30</sup> The Inspectorate Division of GES also has its own site

their success; the current provision of resources earmarked for children with SEN in Ghana is insufficient to meet the policy goal of either EFA or IE for all by 2015.

### **Human Resources:**

The dedication to EFA goals in Ghana has led to a recent and rapid expansion in enrolment in basic education (Avoke, M, 2001; MoESS, 2005; MoESS, 2008). Basic education is plagued by acute teacher shortages, especially in rural areas, and poor teacher motivation and attendance (Akyeampong, K. et al., 2007). Overcrowded classrooms coupled with a shortage of qualified teachers makes the implementation of IE for students with disabilities that much more challenging. Insufficiently trained teachers was a common concern amongst respondents.

*There are not enough teachers to even manage the classes now. There are not enough teachers to go around. –Professional*

*Unless they train, YES! It [inclusion] will be very difficult. –Teacher*

One teacher even expressed concerns that the physical environment of classrooms was currently too crowded to accommodate the extra bodies required to provide such assistance.

*It will be very difficult. Because our classrooms are not even big enough for only the children to be in there. And now with the children with autism they must go with somebody, an assistant, so it's a great it's a very great idea but [pause] personally it will be difficult. –Teacher*

Implicit in this quote is the assumption that including a child with autism in mainstream environments would require the child to have an assistant, a belief shared by other respondents and also demonstrated by parents in chapter six.

*We need to maybe have some people in the classroom to help them. Not teachers with full training but some small specialised training. This is a big challenge. –Senior Professional*

*[For inclusion] they must train more people on autism so they will be put in our classrooms with a classroom teacher... so that while the classroom teacher is taking care of those ones [the class] the one with autism training will also be working [with the student with autism] –Teacher*

As an experienced teacher of students with autism in inclusive classrooms, I am acutely aware of times when a second set of hands is critical, especially when dealing with an eruption of unexpected challenging or aggressive behaviour in which the student is at risk of injuring themselves or others. It is worth remembering that many children with autism included in mainstream classrooms in the USA and UK attend with the

assistance of an aid (often provided by the state), who is charged with ensuring teaching strategies and classroom modifications are adapted to the learning needs of that student. Even in classrooms without one-on-one assistance for each child with autism, the teacher to student ratio is likely to be higher (Dawson & Osterling, 1997) and the enrolment of a child with autism into a mainstream classroom usually prompts an examination into whether additional teaching assistance is necessary.

The degree of daily assistance available to teachers of inclusion classrooms in Ghana however is, in most cases, negligible. Officially, at the primary level, each district should have at least one SEO. These officers are responsible for managing the needs of all students with SEN in their district. This can encapsulate a large number of students, often over great distances with varying degrees of reliable transport. In reality though, it is likely that many districts, especially those that are newly formed, do not have access to even one SEO (Avoke, M, 2001).

*Well, some districts are still waiting for their Peri officers. And we are expanding the districts too, so we will need to call up more officers. –Senior Professional*

Another senior professional within the same department however provided conflicting, and much more optimistic information.

*Every district has one [SEO], if fact in some there are even two. We even have some resources teachers attached to the classrooms where we are pilot testing the inclusion. –Senior Professional*

This lack of consistency reinforces difficulties in record keeping and obtaining accurate information, as discussed in chapter four. In addition, a quality educational service for children with SEN usually requires the collaboration of a multi-disciplinary team. In Ghana, the IEP guidelines described in the last chapter call for this team. However, a short line has been seemingly retrospectively added to the end of this section which states “unfortunately, in Ghana, few of these services are available” (GES, n.d., pp. 2).

The challenge of overcrowded and under-resourced classrooms is certainly not unique to either Ghana or inclusive settings but, in any context, an already overstretched and possibly untrained teacher may be less likely to embrace students with autism in ways that will allow for their meaningful inclusion. Even if a teacher in Ghana is open to educating students with SEN into their classroom, few have been given the necessary

information or training to meaningfully do so. It is clear then that ‘human resources’ are inseparable from ‘knowledge resources’.

## Knowledge Resources

Research data and supporting literature throughout this thesis has repeatedly illuminated a widespread lack of knowledge and information regarding disability in general and autism in particular.

*Interviewer: Previously in the US and here in Ghana too I was working with children who have a disability called autism. Do you know it?*

*Respondent: No. The spelling please.*

*Interviewer: A-U-T-I-S-M.*

*Respondent: [no response, blank look]*

*Interviewer: [long pause]. [Described autism, gave examples of difficulty with socialisation, communication, imagination, no real physical signs, repetitive interests and behaviours].*

*Respondent: It has never even occurred to me to look at that. I didn't know there are people of that calibre. See we don't have people who can diagnose these things, we don't have experts.*

This interview, with an extremely senior education officer did, disappointingly, reinforce the assertion that many ‘experts’ lack sufficient knowledge of autism to provide appropriate services. In addition, the last chapter demonstrated that, to date, teacher training in Ghana has largely failed to impart the knowledge, skills or attitudes that teachers' likely need in order to successfully include children with autism into mainstream classrooms. All stakeholder groups independently cited a lack of specialist knowledge and teacher training as a serious barrier to the success of IE efforts.

*The problem is we have no experts to spread knowledge. –Senior Professional*

*Many schools are also run by untrained teachers; they don't know how to manage inclusion. –Professional*

*The special educators, the officers, the districts, we don't even know much about autism –Senior Professional*

Research also supports the notion that even when teachers are offered training on SEN it does not always adequately prepare them for *inclusive* education (Avoke, M, 2001; Mawutor & Hayford, 2000), a view which was shared by respondents in the current study.

*Well the training they receive is not sufficient at all. If you go to the field you see this. The challenges there are many and there is no expertise –Senior Professional*

*Interviewer: How are teachers already in the field prepared for this new inclusion?*

*Respondent: That is the major problem [laughs]. There is no training in the field. – Senior Professional*

The beliefs and attitudes of teachers towards disability and inclusion are fundamental to the success of IE policies in Ghana (Agbenyega, 2007; Gyimah et al., 2009; Ocloo & Subbey, 2008). Teacher training is a critical component in this success as “attitudes can and do influence teachers’ behaviours in the classroom” (Ocloo & Subbey, 2008, pp. 640). Kuyini and Desai (2007) found both positive attitudes regarding inclusion, and greater knowledge of IE, to be predictive of effective teaching practices for students with SEN in mainstream classrooms in Ghana.

Discouragingly, local research on the attitudes of teachers and administrators has consistently identified resistance to the inclusion of children with disabilities into mainstream classrooms (Agbenyega, 2007; Atkinson et al., 1997; Avoke, M, 2001; Avoke, Mawutor & Avoke, 2004; Kuyini & Desai, 2007; Obeng, 2007; Obi et al., 2007; Ocloo & Subbey, 2008; Osei, 2006). Gyimah et. al. (2008) suggest that the inclusion of children with disabilities into mainstream classrooms in Ghana caused teachers to experience psychological stress and job dissatisfaction. A notable exception, Gyimah et al. (2009) found that teachers with previous experience of a specific impairment were generally positive about inclusion for students with that same impairment. Unfortunately, these results were found to differ by both type and severity of impairment and did not extend, amongst others, to students with ‘severe intellectual disabilities’ (autism was not specifically considered). These finding that teachers in Ghana may be resistant to IE are corroborated, in part, by some interview responses.

*Interviewer: How do the teachers in the field feel about the inclusion policy?*

*Respondent: They are not happy, it takes more effort. Unless maybe they have a disability themselves, they are not dedicated. There are two problems to address, one is the lack of teachers’ passion and dedication and the other is the attitudes of the colleagues, that is the other students. –Senior Professional*

*The student I was just telling you about, they [teachers] wanted to sack her from the school rather than counselling her to see what was wrong. Or taking the time to talk to the parents....People do not take the time to figure it out, they give up on the students. -Professional*

Notably, no teachers in the current research echoed this view. However, results of the local research cited above attributes the negative attitudes surrounding IE by some teachers to a lack of ongoing support and the perceived inadequacies of training in preparing teachers for inclusive education. A sample of 60 teachers in Winneba responded to questionnaires; 77% had taken a pre-service course on SEN but 57% felt



they had little knowledge about disability, 63% felt their training did not adequately prepare them for IE and 80% felt they did not have the necessary skills to modify instructional materials (Obi et al., 2007). Obeng (2007) found that an ‘overwhelming number’ of teachers in their sample would be unwilling to teach children with disabilities in mainstream classrooms even with proper training and support. Perhaps even more worrying however is the finding that a great number of teachers (especially males) would consider leaving the teaching profession altogether if IE were implemented on a large scale (Obi et al., 2007). Agbenyega (2007) concludes that the IE policy in Ghana has not resulted in equitable or appropriate educational opportunities for children with disabilities, in large part due to insufficient teacher training and negative attitudes surrounding inclusion of children with SEN on the part of classroom teachers. Despite methodological challenges to much of this research, its preponderance suggests a common view. The resistance by teachers towards actively including students with disabilities is a serious barrier to the actualisation of IE policies in Ghana, as families in the current research frequently encountered first hand (see chapter six).

### **8.2.2 System and Bureaucratic Barriers**

An examination of the technological dimension of Ghanaian culture in Chapter four suggested that hierarchical social structures, a respect for expert knowledge, a propensity towards denying accountability and poor record keeping lent itself to bureaucratic barriers to the effective implementation of education policies and little cooperation or information sharing across relevant departments. These are serious challenges to translating progressive policies into quality practice. One professional concerned with SEN noted a need for collaboration to actualise IE policies:

*We need a larger definition of special education, if we are including all children in inclusion then what is Special Education Division's role? Should not be so 'special'. By emphasising they are special we are widening the gap, need to de-emphasise that.... The new model of education is for all inclusive. Nobody should be too special. All are individuals; all have special abilities in some way. All of GES needs to be addressing special education. The main objective is that no child should be denied a basic free quality education. –Senior Professional*

Research supports the notion implicit in this quote, that separate responsibility for students with SEN within Ministries or segregated education departments (such as

SpEd) can constitute a barrier to accessing mainstream education for students with impairments (Inclusion International, 2009a; Rieser, 2008). Respondents also pointed to a tradition of competition within the Ghanaian education system which also constitutes a challenge to burgeoning IE efforts.

*There is also a problem in how we view education in general. Education in Ghana is seen as a competition not cooperation. In school, you either do well or they will forget about you. Teachers only have time for the good students, if you cannot cope you will be labelled and the rest of the class goes [ahead]. For example, in class students sit in pairs but if you watch you will see them hiding their paper with their arm. The feeling is that you do your work independently and beat others. ....Inclusion calls for cooperation. Inclusion is about child learning and child to child cooperation. For inclusion to succeed there needs to be a whole paradigm shift from competition to cooperation. And then the same needs to happen in the community. There is a need for systematic education and awareness. –Professional*

Consumers of education in Ghana are traditionally influenced by school rankings, which increase pressure on administrators and teachers to produce top student test scores (Akyeampong, K., 2008). Currently, only 49% of qualified applicants are accepted to all public universities while 60-90% of students accepted to the University of Ghana were found to come from the top 50 (or less than 10%) of Senior Secondary Schools in the country (Oduro & Senadza, 2004, Addae- Mensah, 2000, both cited in Akyeampong, 2008). This competition may serve as a further barrier to the inclusion of students with disabilities as standardised testing can work against IE policies as they typically lead to school and student ranking, as is the case in Ghana, which then fosters further competition. In addition, national assessment and school ranking can lead to a narrowing of the curriculum in an effort to ‘teach to the test’ (UNESCO, 2003). This in turn has the potential to reinforce segregation and the exclusion of children with disabilities. As long as the success of one student is dependent on the failure of another, systems which foster exclusion will continue to exist.

Advocates of IE argue that a history of special schools, special educators and special methodologies, despite best intentions, has created many of the existing barriers to the development of inclusive societies by promoting the idea that individuals with disabilities are inherently unequal; that they require segregation and ‘special’ treatment. Dei (2005) argues that postcolonial education in Ghana has largely denied heterogeneity amongst students with the result that “education has undoubtedly helped create and maintain the glaring disparities and inequities...which persist and grow” (pg 269). Ghana’s relatively long history of service provision for students with SEN may

ultimately prove detrimental to the implementation of inclusion as some believe it may be easier to implement IE when no previous services exist than it is to try and reform a system based on a significant tradition of segregation (Pinnock & Lewis, 2008).

Ironically, the formation of the SpEd division in Ghana was initially a move towards ensuring the right to equitable education for people with disabilities and an effort to simplify operations as students with SEN were previously managed by multiple ministries and departments (Avoke, M, 2001). Despite international support to do so at the time (ibid.), today international movements advocate for 'disability mainstreaming' and the closure of separate special education departments all together (Inclusion International, 2009a; Rieser, 2008).

### **8.2.3 Additional Attitudinal Barriers to IE**

Recognised as one of the hardest barriers to overcome, attitudinal exclusion often contributes to inequitable access to education and resources (Ingstad & Whyte, 1995; Miles, S., 2000b; Pinnock & Lewis, 2008; Stone, 1999b). The Ministry of Education highlights the attitudinal barriers students with disabilities face in Ghana when it recognises:

An important issue is society's generally negative attitude towards persons with disabilities. The education of children with disabilities is undervalued by families, there is a lack of awareness about the potential of children with disabilities, children with disabilities in mainstream schools receive less attention from teachers and there is an over-emphasis on academic achievement and examination as opposed to all round development of children. Furthermore, there is often unacceptance of intellectually disabled children on transitional attachment programmes by service providers (MoESS, 2008, pp. 60-61).

Some of these assertions seem to be supported by the current research, while others, such as the undervaluing of education by families, are called into question. An additional attitudinal barrier to the inclusion of children with autism into mainstream educational environments in Ghana is the widespread belief that disabilities are contagious. This belief was repeatedly encountered during my three years in Ghana and was voiced as a concern during both word picture activities, first with critical friends and later with family members. Many respondents also spoke to this concern during interviews:

*...[is disability contagious?] this one parents ask me all the time. Other parents are worried about their children being in classrooms which include children with*

*disabilities and ask if their child can catch the “illness” [making air quotes with finger] -Professional*

*Parents need to be well educated. The primary concern of parents is that the disability is contagious. There are even examples of parents withdrawing their children from school when a student with a disability enrolls, they do not want their child to catch it. Parents need to be taught it is not contagious and not to withdrawal their children. -Teacher*

*The main concern is to keep the spirit away from other people so it doesn't transfer. - Teacher*

The misconception that disability is contagious is an ongoing barrier to the realisation of IE efforts and must be addressed through specific awareness raising campaigns. This belief leads to reservation on the part of many parents of children without disabilities towards the inclusion of disabled students into their child's mainstream classroom. This resistance is likely exaggerated by the competitive nature of the education system described above coupled with the commonplace view that a student with SEN will require the teachers' full attention to the detriment of instructional time for their own child.

*Even if you find a teacher that is pro-inclusion but they are managing six classrooms to themselves then I don't think they are justified to devote time to only one student. - Professional*

*I don't think it [IE] will help them. They have some 20 children, 30 children, the teacher cannot concentrate on only the one and even if they take time and concentrate on the one it will be neglecting the other students, the class will delay. – Teacher*

While acknowledging that the realities of classrooms may be different from those detailed here, the views expressed above nonetheless reflect common understandings of pedagogy in Ghana and highlight the need for additional teacher training on the philosophy of inclusion if policy declarations are to be met.

During interviews, I often got the chance to ask participants their views on the best way to raise awareness and combat attitudinal barriers to inclusion, both in education and society. Many pointed to familiar strategies such as media campaigns. Others pointed to the need for, or power of, increased visibility and awareness of disability in the community.

*I went to a wedding in Takoradi and the bride's sister was disabled...She was out in the community which increases awareness and can be an eye opener. –Senior Professional*

*There was another boy too who ... I also took him to the [shared compound] house for them to get to know him. They came to see it was not like what they are thinking at all. –Teacher*

*But everything has to change on a community level. I went to the bank the other day and there was a long queue. A man entered but did not join the queue and pushed ahead but I noticed...there was something wrong with his eyes. There was a man in front of me who grew angry and wanted to shout with him and I had to tell him no, that man has trouble with his eyes so you have to consider him. He hadn't noticed, he wasn't watching for that.... The public does not care, this is very discouraging. That is why I keep saying special education goes beyond the classroom, it extends into homes, industry and work places. -Professional*

Some participants also spoke of the significance traditional leaders could have in supporting advocacy efforts.

*[In advocating for people with disabilities] we should make use of community leaders. Church leaders, well let me say faith based leaders, whether they are church or mosque. But there are also people in each community who are general opinion leaders. They are valued members of their community, whatever they say people will listen and trust...they have charisma, authority, knowledge, they are natural leaders. The community has so much trust in that person, whatever they say will go. In a typical rural setting, if they don't hear it from the master they will not believe it. It can be on the radio or signboards but ... they have to hear it from this leader to believe. -Professional*

The significance of religion and community in Ghanaian culture (as described in chapter four) are both apparent in these suggestions, and their relevance to advancing the disability cause in Ghana seems apposite.

### **8.3 Challenges to IE: Autism *in* Ghana**

This chapter has demonstrated that the successful implementation of IE for children with autism is particularly challenging as the autism specific challenges to inclusion are combined with, and compounded by, the context specific barriers to IE in Ghana. The combination of these two challenges then makes the current and meaningful *inclusion* of students with autism in Ghana highly illusory.

An example of the challenges of IE for students with autism in Ghana will help illuminate the situation. Environmental challenges, coupled with a challenge in processing language, mystified a young boy with autism named Matthew who was observed<sup>31</sup> in an inclusive preschool classroom at a private urban school in Ghana. On one occasion, the teacher attempted to engage students in handwriting practice on slate. After intensive and protracted effort on the part of the teacher (at the expense of

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<sup>31</sup> While observation was not an official method used during this research, interviews and previous contacts frequently took me into primary schools where I was able to observe inclusion in action. This situation was particularly illuminating and as such is used to supplement primary data collection strategies.

attending to other children who were asking for help) Matthew was finally engaged in this writing activity. However, since his engagement took so long to achieve, he had only a few brief minutes until the activity ended without warning. The other students began lining up at the door to go outside, incidentally, without specifically being instructed to do so. Matthew remained focused on scribbling on his slate and did not appear to take notice of the other students moving around. When his teacher called his name from the door and told him to ‘come’, he appeared to ignore her. Matthew likely did not respond to his name in this situation due to sensory processing challenges and may have been unfamiliar with the instruction ‘come’.

When Matthew did not respond, a peer yanked the slate out from under him while he was writing, which resulted in a tantrum. Matthew threw the chalk he was using at the student who, as a result of trying to protect himself from the chalk, dropped the slate, which broke in two. Matthew was then hit by the teacher for throwing and dragged outside while still screaming. The teacher was visibly upset during this interaction, the other students in the classroom observed the whole process and his parents were later charged for the broken slate. This interaction highlights the potential benefit of specialist knowledge about autism and its shared characteristics. Interpreted by the teacher as disobedience followed by aggression, it is likely that Matthew failed to follow her instruction either because he lacked the receptive language skills to understand the instruction or because he experienced sensory processing difficulties and was in a sense ‘deaf’ to the noise around him while intently concentrating on another task. A better understanding of the shared features of autism could have assisted the teacher to initially engage Matthew in the activity quicker, could have prompted her to give Matthew a warning before the transition, may have allowed her to better predict the result of the peer’s actions, ideally prompting her to intervene before the behaviour occurred and could have assisted her in understanding and handling the tantrum once it did occur.

Challenging behaviour, often a result of information processing or communication challenges, can accompany autism. To effectively prevent and manage challenging behaviour in the classroom, thereby increasing opportunities for engagement and learning, a teacher must possess both the motivation and the skills to critically examine

a behaviour for its intent, and to recognise that it is the function of that behaviour, not the behaviour itself, which needs to be understood and mediated (Jordan, 2008).

Executive functioning challenges, such as those experienced by Matthew, can result in exactly the behaviours which, in Ghana as probably elsewhere, were attributed to stubbornness, wilful disobedience or ‘stupidity’ (see chapter five). If a teacher understood this executive functioning challenge in children with autism he may better understand a child with autism’s actions and be better prepared to prevent and manage challenging behaviour. The use of punishment (such as hitting) is generally not effective in altering challenging behaviour in children with autism (Jordan, 1997).

Punishment, most often in the form of verbal admonishment, or less often in the form of physical aggression, was observed to be commonplace in classrooms in Ghana whereas positive reinforcement and praise at times appeared to be viewed as superfluous. In Matthew’s case, executive functioning and communication challenges fundamental to autism, paired with an unpredictable and inconsistent classroom environment, little teacher understanding of the shared features of autism and the use of punishment to manage challenging behaviour combined to compound the difficulties of IE for students with autism with those of IE in the Ghanaian context.

Another challenge faced by Matthew in this classroom was the fact that materials such as books and toys were placed high on a shelf so as to purposely be out of reach of the students. When asked about this the teacher felt that students were likely to tear the books or break the toys if not properly supervised. This attitude is likely a result of generally under-resourced classrooms and scarcity of learning materials. Unfortunately, this left Matthew at a distinct disadvantage as he was not able to communicate his desire for materials up on the shelf. Worse still, many of these books and toys had been specifically procured for Matthew by his parents to engage his interests while at school and they were therefore materials he often wanted access to. He was frequently observed grabbing books away from other students who had successfully asked for them to be brought down off the shelf. The teacher again interpreted this as ‘naughty’ behaviour and did not appear to understand the possible link between his impairment (limited communication) and his behaviour. A focused communication (pointing) intervention which enabled him to request these materials was implemented by the teachers upon training (by myself). Matthew quickly acquired this skill which

successfully prevented the challenging behaviours previously demonstrated. Learning to request materials also made Matthew a desirable play partner to other peers in the classroom as the limited books and toys needed to be shared. This intervention also had a noticeable positive effect on both teacher and peer attitudes towards Matthew. Teachers in the school remarked that he was ‘not stupid’ and able to learn a new skill very quickly; he therefore became ‘educatable’ in their eyes. They also began to understand that his tantrums had a communicative function which, though not initially understood, was nonetheless an attempt at communicating a need, not merely stubborn or naughty behaviour. Significantly, this understanding translated to another student who was later enrolled in the same class. I observed the teacher telling students that the new student’s ‘aggressive’ behaviour (throwing pencils against the wall) was a result of not being able to communicate. While this may not have actually been true in this instance, what is important is that this teacher understood the need to identify the underlying causes of behaviour, a skill which she can utilise in the instruction of any student. Additional instruction on how to identify potentially diverse underlying causes of behaviour, and how to prevent and manage them, required further training and practice.

Prior to training, teachers in Matthew’s school were frustrated with his behaviour and lack of progress. They viewed him as an ‘un-teachable’ burden and felt that his family should send him to a special school. Given a lack of cultural awareness of autism, a history of didactic instruction, insufficient teacher training and a professional culture which discourages agency, their attitudes and actions were certainly understandable. This story has demonstrated however, that meaningful inclusive education is possible, despite the compounding challenges of IE for a student with autism in Ghana, when the proper supports, materials and training are provided. It also demonstrates that when inclusion is implemented in such a way that it results in a positive experience for the students, teachers and families involved, it can and has lead to a demystification of autism and a greater understanding of inclusive pedagogy which in turn, in time, could lead to a greater overall respect for diversity. It is precisely for this reason that many feel IE has the power to combat discriminatory attitudes and why students of all abilities can and should be *included* in mainstream classrooms. When however, integration

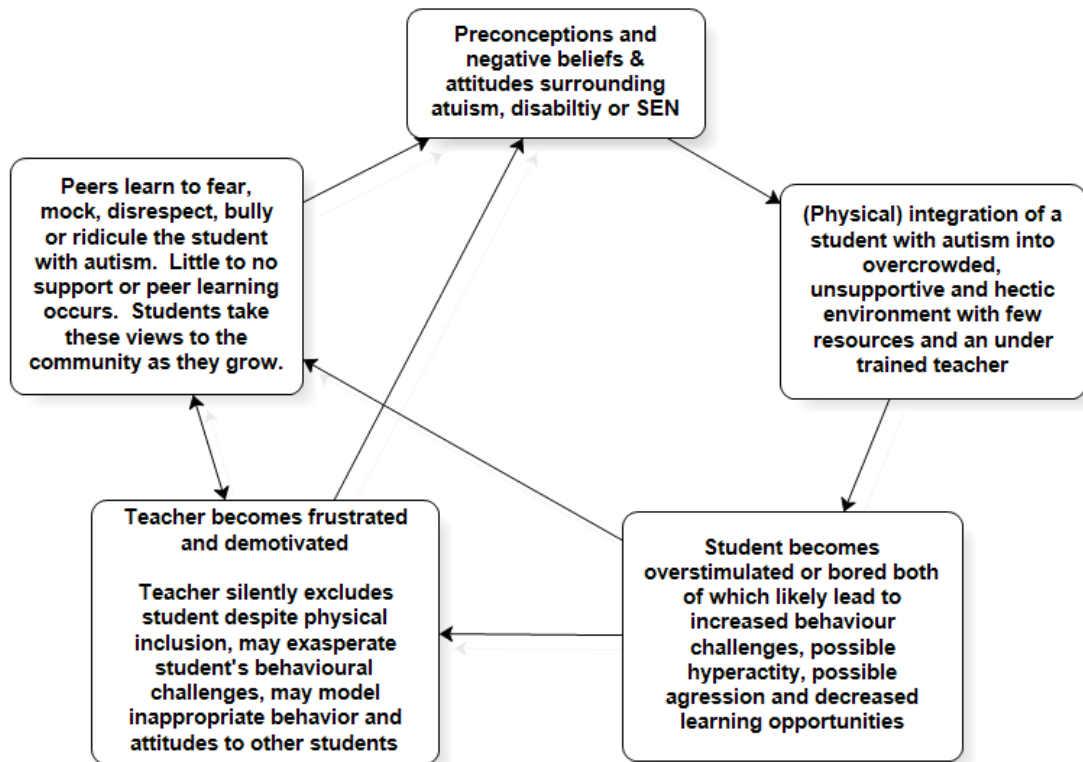


occurs in place of inclusion, the experience for a child with autism and their family, in Ghana today, is likely to be ineffective at best and detrimental at worst.

As Figure 1 demonstrates, it is easy to imagine how placing a student with autism in an unsupportive classroom could compound their already impaired abilities thereby inhibiting functioning and learning that might be possible in a more supportive environment. One of the underlying features of autism is a strict adherence to sameness; this necessitates a need for predictability and routine. Students with autism often benefit from a highly structured teaching environment which is free from extraneous sensory input, predictable and routine (Dawson & Osterling, 1997; Grinker, 2008a; Iovannone et al., 2003).

...it is now known that many children with developmental disabilities are quite capable of gaining skills in more complex environments that typically involve small or even large groups of children. However, this may not be the case for a child with autism. We speculate that children with autism have such severe information processing impairments that they have difficulty attending to and encoding critical information such as gestures, language and facial expressions when such information is presented in a highly complex environment (Dawson & Osterling, 1997, pp. 317).

Take for example a student with autism who uses repetitive body movements such as running or spinning as a coping strategy in hectic environments. Exasperation with these behaviours may cause a teacher to become inundated as the challenges of having this student in her class reaffirm initial reservations at his inclusion. The 'odd' behaviours of the student could frustrate the teacher and alienate the student from his peers, possibly reinforcing pre-existing beliefs or fears surrounding autism. Without the proper training and support, and for a lack of viable alternatives, the teacher may begin to ignore the student, thereby silently excluding him from any true learning. The teacher may also inadvertently model inappropriate behaviour towards the student or overtly fail to teach lessons of tolerance and diversity to the rest of the class. Peers may eventually take these beliefs, perhaps unknowingly, with them into the larger community thereby reinforcing discriminating views in society rather than combating them. As time goes on this cycle may repeat itself, compounding the student's isolation from learning, from his peers and from inclusion in the school community, all despite his physical 'inclusion' in the classroom. Figure 1 illustrates this cycle of exclusion.



**Figure 1: Cycle of Exclusion**

Proponents of inclusion could correctly assert that this example can only truly claim to constitute integration. However, as I have tried to demonstrate, inclusion for students with autism can be exceedingly difficult and may require knowledge, skills and attitudes without which the situation described above could easily emerge.

It is possible to accommodate this dependency on consistency and routine through strategies which mitigate unexpected changes. Supportive strategies can aid a child with autism in any educational setting and can certainly be used effectively, albeit with modifications, in inclusive environments. However, a student with autism who is merely integrated, without these supports, is unlikely to be afforded meaningful opportunities for learning in a mainstream classroom environment.

Unfortunately, the actual experiences of parents seeking inclusive education seem to reinforce the view that truly inclusive services in Ghana remain elusive.

*...the previous school, they were not very attentive, cause I normally went there to watch, I can leave my work early, go and stand behind the wall, and I would look at the compound and you could see that the teacher...I realised he wasn't very particular. I realised that when Kwaku went out, she doesn't follow. So Kwaku was*

*almost always outside the class whilst the other kids were inside. Which means Kwaku couldn't pick up anything. –Abraham [see chapter 6]*

One story of a teacher who had a child diagnosed with autism introduced into her classroom is particularly illuminating:

*I was a teacher in the nursery school, where he was brought. He wouldn't do anything, he wouldn't talk, he wouldn't eat, he wouldn't walk properly and always screaming. And he was also in my class. So I ignored all the other children and I paid much attention for him. Like teaching him how to eat. Playing with him so that he would stop screaming and all that. And I realised that he was responding to all the things I was teaching and when I [realised that] I stopped going there, I stopped [teaching at] the school [to work with him at home]. –Teacher*

Here, government IE initiatives led to the student being 'included' but ultimately resulted in both the classroom teacher and the student leaving a mainstream environment to focus on 'specialised' instruction at home. Even when students remain in classrooms, a student's mere physical presence certainly does not signify inclusion and, as this thesis has attempted to show, *integration* is increasingly the result of burgeoning inclusive education policies in Ghana (Dei, 2004; Gyimah et al., 2008). Given the educational needs detailed in chapter 1, the successful *inclusion* of students with autism into mainstream classrooms likely requires a greater understanding of autism as a specific disorder than is currently evident in Ghana today. I also believe the success of IE rests largely on the skills, attitudes and dedication of classroom teachers.

*Teachers need passion, they need that passion for all people. If a teacher is not good, they can cause further harm. –Senior Professional*

Successful IE for students with any impairment may require the majority of the teaching workforce in Ghana to reach a standard of teaching where diversity is understood, celebrated and accommodated. While certainly possible, this thesis suggests that many teachers in Ghana may not yet possess the level of theoretical knowledge, diversity of pedagogic skills or agency needed to meaningfully educate students with autism in inclusive environments. Ironically, an understanding of the shared features of autism seems essential to the success of IE for these students. While adherence to a social model may dictate IE (see chapter one), successful inclusion still requires disorder specific knowledge more consistent with an individual model of disability. Accurate prevalence statistics, thought to be needed to ensure adequate provision in Ghana (see above), necessitates categorisation of disabilities, which, at the very least, requires acknowledgement of inherent impairments (Eide & Loeb, 2005), something an extreme

version of the social model would admonish. Clearly, ‘inclusion’, both its necessity and efficacy, are controversial and contested concepts in any culture or context.

## **8.4 Conclusion**

This chapter has attempted to demonstrate that the resource, knowledge and attitudinal barriers to successful IE in Ghana at times combine with the autism specific learning challenges in inclusive environments such that students with autism are typically excluded from learning in mainstream environments in Ghana. Finally, I now turn to a discussion of the findings this thesis has generated and offer some suggestions in moving forward towards a more inclusive society.

## Chapter 9

### Putting the Pieces Together: A Discussion and Way Forward

#### **Contribution to Knowledge**

This thesis has attempted to highlight beliefs surrounding autism in Ghana and explore the impact of these beliefs with regards to educational access, policy, provision and inclusion in society, both for the individual with autism and for their family.

There is a paucity of research examining autism outside of Western cultures in general, and even fewer studies which examine autism through a cultural lens (Daley, 2002; Daley & Sigman, 2002; Dyches et al., 2004; Fryers, 1986; Ingstad & Whyte, 1995).

Despite this, there is emerging evidence that autism is indeed a universal phenomenon, with the shared core characteristics of social and communication impairments alongside a restricted range of interests and repetitive behaviour patterns (Dyches et al., 2004).

Chapter three explored this triad of impairments for cultural consistency and relevance in Ghana. Socialisation and communication challenges, a restricted range of interests, insistence on sameness and repetitive motor patterns were all demonstrated in Ghanaian children with autism. I concluded, like researchers before me, that ‘autism’ does indeed exist across cultures, though its presentation is culturally bound.

However, methodological challenges made it difficult to conclusively prove the existence of autism in Ghana, understood and diagnosed in Western cultures as the *combination* of these traits, as this would have required the piecing together of participant responses on each of these impairments in isolation. Instead, it was possible to study the traits of autism in a cultural context and to explore the presentation of autism in Ghana. While each of the triad of impairments was discovered, the expression of these impairments, and of autism as a whole, was found to be influenced by Ghanaian culture and context. For example, the expectation of relative conformity in behaviour and respect afforded to one’s elders by all children in Ghanaian society impacts upon the child with autism in both positive and challenging ways. Failing to establish eye-contact, often perceived as problematic for children with autism in

Western countries, is not typically viewed as such in Ghana given the expectation that respectful children do not look their elders directly in the eye. However, failing to follow directions as a result of a receptive communication impairment is often interpreted as wilful disobedience and stubbornness. Similarly, the fairly typical presentation of autism which results in children preferring to play alone or not engage with others may be interpreted as a well-behaved, quiet and respectful child in Ghana while the presentation of hyperactive behaviours was found to particularly 'othering' in a society which expects conformist and deferential behaviour of all children. Children in Ghanaian society are also expected to contribute to their household, often at a very early age, and a perceived inability to do so further distances them from their families and community. Serpell (1993) highlights this expectation of 'servability' as one of the most significant indicators of intelligence amongst some Akan tribes. Other, more practical differences across societies also affected the presentation of autism in Ghana. For example, in Western cultures a restricted range of interests and a tendency to focus on concrete topics often leads to very limited, unimaginative and repetitive play with toys (such as spinning the wheels on a car repeatedly). In Ghana however, play with toys is not commonplace, especially in educational settings, and children with autism therefore have less access to toys on which to focus their repetitive play.

Interpretation and understandings of this presentation of autism were influenced by often intuitive aspects of Ghanaian culture or 'worldview' (outlined in chapter four), which were subsequently found to impact upon educational policy and provision. Critically, normative rules of social behaviour, influenced by shared beliefs and values, influenced those traits which were valued and respected in Ghanaian society and thereby, those which were considered 'disordered'. In particular, respondents were found to be deeply spiritual and to believe in a hierarchy of powers and the interconnectivity of all things. Interconnections in all aspects of life translated to communal values and kinship obligations whereby individuality is often sidelined for the good of the larger group. These beliefs were found to permeate other aspects of life, including the socially constructed experience of disability, sometimes in quite subtle ways. For example, traditional kinship relationships are still deeply respected in Ghanaian society today, despite the dynamic nature of culture. These kinship structures dictate both responsibility and accountability to one's family and as such were found to

impact upon the construction of autism. As noted above, a child who did not comply with a verbal instruction due to communication challenges was likely to be perceived as wilfully disobedient and disrespectful of his elders. This perception of being disrespectful then seemed to reflect negatively upon the child's parents, particularly the mother. The cultural expectation to 'give back' to one's family, both financially and socially, was highlighted as a barrier to the full membership of children with autism into both their family and larger community. An exploration of causal attributions, valued and de-valued personhood traits and the expected role of an adult in society each highlighted significant influences on the perception and management of autism in Ghana.

Significantly, shared responsibility and accountability for one's actions often led to the blaming of families for the presence of autism, often attributed to a transgression on the part of the child's parents, particularly the mother. Despite the tendency to blame families however, the results of the current research seem to suggest differences in the perception of autism across stakeholder groups. Parents were not found to reject, bemoan or feel ashamed of their children, as responses by other stakeholders would suggest. Community member and professional stakeholders often disparaged parents but parents themselves often spoke of feeling rejected from, and blamed by, their families and communities. Given the relatively communal nature of Ghanaian society, this feeling of isolation may have an even greater impact on their day to day experience of disability than in more individualistic societies, as seems to be suggested by the experiences of family members detailed in chapter six.

In addition, all stakeholders appeared to construct the experience of autism through, at least in part, a deeply felt spirituality. Whereas community members and professionals seemed to largely turn to spiritual forces to explain the presence of autism, parents often spoke instead of the management of autism and the healing power of prayer. While community members and professionals attributed causes of autism to the behaviour of parents, family members tended to locate this blame outside of the immediate family; it was in the degree of psychological distance to these causes where stakeholders were found to significantly differ in their beliefs. One of the most significant findings of this research is highlighted in these divergent accounts and future research should explore

the experiences of families across a wider participant group and in more detail. Future research is also needed on the psychological coping mechanisms for families in Ghana and the degree to which spiritual and communal beliefs contribute to, or result in the rejection of, self-blame.

Perhaps the most significant contribution of this research is in its detailed description of the social construction of disability in Ghanaian society and many of the influences on these constructions. Understandings of disability and autism discovered in Ghana resonated with lesser explored descriptions of impairment as understood through cultural or religious frameworks. Many researchers have found that responses to illness, impairment or disability are deeply embedded in the traditions, religion and culture of indigenous ethnic groups (Grinker, 2008a; Hutchinson, 2006; Miles, M., 1995; Peters et al., 2005; Streefland, 1985). Hutchinson (2006) explores the impact of Western religions on understandings of, and reactions to, disability, while Miles (1995) does the same for Eastern religions. In many cases, understanding of disability as punishment from ancestors or gods permeates; Coleridge (1993) terms this the 'traditional model' of disability. At the same time, many authors are quick to point out that religious constructions of disability need not result solely in negative or discriminatory views of individuals with disabilities, in some cultures or under some circumstances, impairment can be seen as a blessing or gift from God (Devlieger, 2005; Fadiman, 1997; Hutchinson, 2006; Ingstad & Whyte, 1995; Miles, M., 1992, 1995), a result also discovered in Ghana (see chapter five).

I have argued throughout this thesis that conceptualisations of disability in Ghana are largely, and often intuitively, understood through an individual model of disability. The 'causes' of autism identified in chapter five, the educational policies highlighted in chapter seven and understandings of inclusion more consistent with international notions of integration, are just a few of the many examples. Interviews seemed to demonstrate that disability and autism were both largely understood in Ghana as a 'personal tragedy', consistent with the individual model (Hutchinson, 2006). However, to truly understand the conceptualisation of autism discovered in this thesis, the individual model must be further interpreted through a lens of social-relational causation and management. This social-relational lens must account for not only



interactions between impairment and disability (Thomas, C., 2004a, 2004c) but also for the spiritual and communal nature of Ghanaian society. Despite consistency with the ‘individual’ model where autism is seen as a ‘tragedy’ and must be ‘fixed’, the relative communal nature of Ghanaian culture, with shared responsibility and accountability to both one’s gods and kinship, seem to result in a constructed experience of disability which is rarely limited to the ‘individual’ with autism. The consequences of autism are certainly felt beyond the individual in other cultures as well, for example, in the demonstrated higher divorce rate amongst parents of children with autism in the USA (Bolman, 2006; Mauldon, 1992). However, this may be even more salient in Ghana due to the direct culpability, blaming and shaming felt by family members as a result of communal obligations and responsibility still very much an active part of Ghanaian culture today (see chapter 6). Significantly then, ‘disability’ in Ghana was found to be largely understood as intrinsic to the individual despite causation and management which were often socially mediated.

If disability is truly seen as a social construct, then a deep appreciation for, and understanding of, each culture’s construction of disability is essential in advancing international initiatives such as EFA and IE. I argued, in chapters seven and eight, that tensions between local understandings of disability focused on the individual and international conceptualisations through the social model, resulted in confused policies which conflict with local belief systems and are therefore slow to translate into successful practice, including the implementation of IE efforts.

The challenge of planning inclusive education within local contexts is to channel disability-affirming local norms, while maintaining universal norms of universal educational rights agreed upon by signatories of Education for All (Peters, 2005, pp. 141).

In Ghana, as in other places, context specific resource and attitudinal barriers to meaningful IE for students with SEN were found to combine with, and compound, the disorder specific challenges of educating students with autism in inclusive environments. I argued that to date, teachers in Ghana have insufficient knowledge or skills needed to modify curriculum or instructional strategies to the needs of all learners and have even less agency to do so. Chapter eight concluded, somewhat reluctantly, that the social stigma of impairment operating in tandem with current logistical,

resource and systematic barriers in Ghana, makes *meaningful* inclusive opportunities for learning in mainstream educational environments illusive for most students with autism. International development efforts should not stop with advocating for the adoption of rights based initiatives but should support and ensure their adaptation in subsequent implementation consistent with local understandings of disability and the belief systems from which these are based. This research has attempted to highlight some of these tensions and offer a window to understanding how autism is perceived and managed in Ghana, in the hope that Ghanaians and other international actors can use this information to better negotiate sustainable approaches to the inclusion of children with autism and to recognise their right to full and active membership in society.

## **9.1 Reflections on Methodology**

How to best understand, discuss and write about ‘autism’ has been a recurring methodological challenge of this research. I set out to discover the beliefs surrounding, and treatment of, children with autism specifically. However, my research was conducted in a location where autism is largely unrecognised. How then do I proceed to ensure the information respondents are relaying to me is specific to autism, when autism itself is not well known and even less well understood? Initial cognisance of this challenge led me to attempt the word picture activity with critical friends, the goal of which was to produce culturally sensitive words I could use to discuss my concept of autism but which would be understood by all participants (see chapter two and appendix one). Such words did not appear to exist and words that were generated by this activity (such as ‘useless’ or ‘possessed’) while a useful source of data, were deemed inappropriate for the usage I had intended. The Kofi story (see appendix five), used largely with community members who had no previous experience of autism, was another attempt to mitigate this challenge. However, despite implicit understandings of disability through an individual model, discrete categorisation of different impairments is uncommon in Ghana. Even after reading the Kofi story, it is likely that some respondents may have had a wider view of an intellectual impairment during our conversations. In line with this, national policy and programmes are not specific to autism, they address only intellectual disability. At times, it has therefore been

necessary to broaden my discussion beyond autism specifically, as seen most clearly in chapter seven where I discuss current educational policy and provision in Ghana.

There is also something of a tension throughout this thesis in trying to generalise about a disorder best understood as a spectrum. I have tried to highlight the possible diversity in presentation of, and interaction between, autism's triad of impairments.

Nevertheless, at times it has been necessary to generalise about the likely skills, abilities and educational needs of 'children with autism'. To be clear, autism and the impairments which accompany it exist on a spectrum of functioning; on a pragmatic level, no two children with autism are the same and should of course be recognised as diverse individuals with diverse learning needs.

Due to these challenges, both my prior specialisation in autism and my previous experience living in, and knowledge of, Ghanaian culture became an essential lens through which my data was continually filtered. For example, many respondents indicated in their interviews that children with autism would likely become street beggars. However, in the years I spent living and working in Ghana I only observed beggars with sensory disabilities (such as vision impairment) or physical disabilities such as (limb deficiencies). These responses, among others, indicate that participants did not always share my understanding of autism or veered from discussions of autism in their responses. I have done my best throughout this thesis to tease out the results which are the most likely to pertain specifically to autism or which are generally applicable to the experience of disability, in any form, in Ghanaian society. This has been a continual and delicate process, one which I could never claim to be entirely free from subjectivity. I do however believe, that my previous knowledge and expertise, both with autism and in Ghana, have ultimately been to the advantage of this research.

Finally, I am conscious of the somewhat limited population to which this thesis can ultimately claim to speak. The majority of accounts of disability in developing countries speak to a national level although there is perhaps a greater range of attitudes towards disability within countries than there is between them (Groce, 1990). This may be especially true in West Africa where country borders were arbitrarily drawn by colonial powers and do not reflect delineation by tribe or religion. While urbanisation

and globalisation contribute to an increasingly heterogeneous population in urban areas, especially Accra, this thesis is nonetheless somewhat limited in scope. Logistical constraints made data collection in truly rural areas or Northern regions unfeasible. This thesis is therefore particularly relevant to government urban schools located in the southern regions of Ghana. In addition, and partially because of this, the families I spoke with may not be truly representative of the many families scattered across Ghana who experience autism on a daily basis with little information or assistance. Finally, I am extremely conscious of the lack of voice afforded to either children or individuals with autism in this thesis. As mentioned in chapter two, persons with intellectual impairments may be hardest to engage in self advocacy due to the nature of their disability. With autism, social and communication impairments likely compound this challenge. In Ghana, the fear and stigma associated with disability almost certainly combines with these impairments to make self-advocacy, for either individuals with autism or their families, even more of a struggle and commitment. Nevertheless, there is a long history of DPO's in Ghana for sensory impairments and emergent groups advocating for the rights and needs of persons with intellectual impairments. Despite making initial contacts, attending a parent meeting and attempting to ask interview questions of a few higher functioning children with autism, it is regrettable that these efforts were not a fruitful source of data and that these groups are not better represented in this research. Additional and alternative methods are likely necessary to meaningfully engage children and adults with autism but I hope that future efforts may allow them, and DPOs advocating on their behalf, a louder voice.

## **9.2 Towards Inclusion**

As I have discovered while writing this thesis, it is easy to get caught up in theoretical and philosophical debates surrounding the fundamental rights of EFA and IE. It is much harder to remain focused on the realities of context and to balance philosophic ideals with pragmatic solutions. The dilemmas surrounding educational placements for children with autism are complex and likely best negotiated as specific to cultural context and individual circumstance, at any given point in time.

International discourse and declarations often cite ‘universal’ or ‘fundamental’ human rights but typically fail, at least overtly, to acknowledge that the realities of assuring these rights in many contexts may require difficult and controversial choices, at both the individual and national level.

Local priorities and conditions may, and sometimes do, contradict basic human rights and universal access to education (Peters et. al, 2005, pp. 141).

Limited resources can force situationally specific prioritisation at both a national and individual level. Many families must balance the right to education for their child with the right to health care, food or shelter of the entire family. These must also be balanced with other rights such as the right to choice of educational provision, the right to live with one’s family and the right to inclusion and membership in a larger community. International discourse appears to assume many of these rights will automatically accompany efforts at IE but the current research suggests that, in Ghana at least, these rights may actually compete or conflict with one another.

The evidence presented in this thesis suggests that the average government primary school in urban Ghana is not yet equipped to *meaningfully* include students with autism. It therefore becomes a moral debate as to whether, until such a time when both are possible, the greater ethical transgression lies in failing to integrate children with autism in mainstream environments or in failing to offer them meaningful learning opportunities. It is unlikely consensus on this morality will ever be reached. At what point do we include children to change the system or change the system to better include children? The CRPD states that access to education for children with disabilities should be “on an equal basis with others in the communities in which they live” (UN, 2006, Article 24, section 2b). How does one measure this equality? Physical access to mainstream classrooms in Ghana may offer equitable opportunities to be *taught* but seem unlikely to currently offer equitable opportunities for students with autism to *learn*. To Lawrence’s (2004) assertion that “school is not synonymous with education” (pp. 16), I would add ‘teaching is not synonymous with learning’.

The basic dilemma is whether to recognise and respond or not to recognise and respond to differences, as either way there are some negative implications or risks associated with stigma, devaluation, rejection or denial of relevant and quality opportunities (Norwich, 2008a, pp. 1).

Similarly, Lindsay (2003) highlights an inherent tension in the Salamanca Statement as a “proposed system for all children and a view that it may not be effective for all” (pp. 4).

In talking to a mother of a child with ID in the United Emirates, Gaad (2004) discovered the mother believed her son to be ‘included’ despite attending a special classroom on site within a mainstream school. When the researcher ‘explained’ [imposed] that this did not constitute inclusion, the mother indicated her son attended the same school and rode the same bus as his family and neighbours. The mother therefore felt her son was included and was happy with his provision. Chapter one defined disability as an ‘experience’ and I remain confident that it is this experience which is critical in defining and realising ‘inclusion’ on an individual level. Perhaps the elimination, not of segregated educational placements altogether, but of the default assumption of their necessity, should be the goal of inclusive societies. For this to happen, policy makers, families and educators alike must come to believe that the need for segregated placements must be truly ‘special’, not just easier.

Historically, children with impairments in Ghana were placed in segregated special schools due to a lack of knowledge, choice or at times, concern. Swinging to the opposite extreme whereby all children are placed in mainstream classrooms regardless of need or the appropriateness of this placement, is potentially just as problematic. Placing a child with autism in an unsupportive ‘inclusive’ classroom in Ghana, or in any country for that matter, could further disadvantage them educationally and possibly reinforce discriminatory societal attitudes and beliefs. In Ghana, where communal and family relationships are fundamentally intertwined in daily life, ‘inclusion’ in one’s community may be a powerful catalyst to change discriminatory attitudes.

In addition to individual and cultural dilemmas of inclusion, the disorder specific features of autism are a further challenge to a rights based or social model rationale for inclusive education.

### **9.2.1 Autism and IE: An Ethical Paradox?**

It is interesting to note that while IE is typically advocated on the principles of rights based provision and a social model of disability, these tenets can be called into question as relates to autism. Given difficulties in social relatedness and communication, requiring students with autism to interact in mainstream classrooms could be viewed as forced adaptation to the mainstream paradigm, which is consistent with an individual model of disability. If the highest aim of the social model places the onus of change on societal systems and attitudes, not on the child themselves, then one must allow for the possibility that alternative placement options may better uphold these principles for students on the autism spectrum. Paradoxically, upholding the right to equitable learning opportunities for some students with autism may require the provision of alternative or specialist services. Integration into a mainstream environment typically requires the student to adapt to the expectations of a normative social and educational environment. For example, meaningful learning opportunities for some students with autism may require the removal of extraneous sensory inputs such as are inevitable in a busy classroom. Again, this is where individual circumstance is critical; students with autism may have varying degrees of sensory sensitivity; whereas one child with autism may benefit from earplugs, another may require, as a last resort, a quieter space to learn for part, or all, of the day.

Inclusion came to be seen as a right and a matter of social justice and the only question then became how children, like those with ASD, were to access their entitlement, as if the conceptualisation of those values was not in itself often discriminatory, being based on a model of typical development (Jordan, 2008, pp. 12).

This thesis has demonstrated that autism presents unique and specific challenges to both the rights based argument supporting IE as well as to its implementation in practice. To what degree should social and play skills be expressly taught and to what degree do you respect diversity in the preference to play alone? To what degree can and should a culture's normative and expected social behaviour (such as greetings) be taught effectively? Is it realistic to expect a student who, by the nature of their disorder has impairments in social relatedness, theory of mind, executive functioning and communication, to navigate a classroom which requires considerable social and verbal negotiation? Can students who learn concretely, through visual and tactile stimulation,

be expected to learn in an environment often dominated by abstract ideas and auditory language?

Inclusion requires adaptation of the educational environment, curriculum and pedagogic strategies to fit the learning needs of a particular student. However, while successful inclusion in mainstream environments requires adherence to a social definition of disability, does a definition of disability based on a social model similarly *require* mainstream placements? Can other strategies still uphold the right to education, provide learning opportunities for students with autism and act as a catalyst to change discriminatory attitudes? I would argue that one should at least allow for the possibility that they can; future research is needed to explore these issues in much greater depth. What I find potentially hubristic and unhelpful is the current iconic status of ‘inclusion’, especially as sometimes propagated to, and interpreted by, national governments, as the only appropriate and morally justifiable strategy for educating children with impairments.

‘Inclusion’ has become something of an international buzz –word...it is now *de rigueur* for mission statements...and policy documents of all kinds. It has become a cliché-obligatory in the discourse of all right-thinking people (Thomas, G. & O'Hanlon, 2001, pp. vii).

As a former teacher in multiple countries, I have witnessed first-hand the successful education of many students with autism in high quality inclusive mainstream classrooms. This typically requires large multidisciplinary teams, highly trained teachers, additional support systems and supplementary out of hours individualised tutoring. Often additional resources are earmarked to ensure appropriate curriculum and material modifications are made. I agree with Jordan (2008) that “teaching students with ASD is hard” (pp. 13). It is both easier to include students with less complex needs into mainstream classrooms and to teach students with autism in less complex educational environments. It is almost certainly easier to provide meaningful inclusive opportunities when resources and training are available. However, just because something is hard is not a reason or excuse for not doing it. Meaningful IE is not only possible but apposite for the majority of students with autism and this discussion should not be viewed as a condemnation of this in any way. What I struggle to accept then is not the position that IE can meet the needs of most students with autism, but the



assertion that it is the only morally justifiable way of doing so, regardless of circumstance.

### **9.2.2 A Way Forward**

*We must all stand together. The school and education cannot do much alone. The problem is Ghana is not fighting. In the UK, there are many organisations and people are fighting [for] themselves... But here no one is fighting and no one is fighting for them. [The department of] education cannot do it on our own, it is a society problem. –Senior Professional*

This thesis has called into question the truthfulness of this sentiment. Many dedicated individuals I would call ‘fighters’ have been identified throughout; nevertheless, it represents a belief I encountered numerous times, itself evidence that efforts have not yet resulted in sufficient visibility of people with disabilities or those advocating on their behalf in Ghanaian society.

Inclusion is a process, one towards which measurable progress in Ghana can be identified. In the three short years since this research began, Ghana has ratified the Persons with Disabilities Act, formed a National Council for Persons with Disabilities begun piloting IE, expanded and improved SEN teacher training, begun observing a yearly National Day of the Disabled, signed the UN CRPD and has actively promoted awareness of its disability legislation. To date however, this commendable progress at a national level does not appear to have significantly impacted upon practice for people with disabilities on the ground. A finding which seems to clearly emerge from this research is the existence of tensions between local and international conceptualisations of ‘disability’ and ‘inclusion’. This seems to suggest that translating international declarations into local policy, and subsequently into local practice, needs to be better negotiated alongside culturally relevant systems and beliefs.

This thesis has highlighted an imbued sense of spirituality amongst many Ghanaians as well as the power of faith and prayer as a coping mechanism for families. In light of this, one service provider felt strongly that her efforts at supporting parents and educating students with autism could be aided by the merging of educational services with the spiritual and prayer aspects families often seek out:

*It can be very difficult if you have somebody [a student who]... goes missing for weeks or months to go for prayer [camp], or to go and stay...at the shrine, and then*

*surface maybe even 6 months later and then comes to you for some support and then disappears after another while. I think it is difficult because you never know how effective your own therapy is and well it can't be, because you are not able to offer consistent support. So, and, no matter, I say **no matter** what you say or do, people will still go and seek out spiritual support because it is very very strong belief that you know, we are not our own masters on this earth.... Okay, so my point is have maybe a praying group attached to the service, made up of people that have been tested, that you know are honest.... Cause then you can say, well I have a group of people who are praying warriors and who are very good and will match the same as you get if you take your child away....[then] there is no need for them to take their child away and break that therapy support and then come back. And then I am also sure, I am also certain that um, they are not coming back worse off.... I don't think it spoils anything, all these things about empirical evidence, it is not going to take that away. You know, it is an opportunity for people to do something else... I think that it is an important component in this part of the world. -Professional*

Some international agencies may be, understandably, politically reluctant to design or support programmes with a religious component. Nevertheless, it is precisely this cultural relevancy this research suggests might help to ensure the success of education and advocacy initiatives for children with autism in Ghana.

Today there is an increasing (though probably insufficient) awareness that quite different paths can be taken to improve human welfare, and that no programme can bring positive and lasting results unless it is well anchored in the cultural norms and values of the society in question (Verhelst & Tyndale, 2002, pp. 2).

Samuel, a parent introduced in chapter six, spoke of a lack of political will surrounding autism and the belief that greater knowledge and experience of autism promotes acceptance and understanding:

*And I hope and pray that... one day a politicians relative, or son or daughter, becomes autistic. And then they will start thinking... Because the thing is, if you don't have the feel of it, you'll not know. You understand? Because me, until this thing, I never thought, [about] what autism [is]? -Samuel*

This thesis would certainly seem to support Samuel's suggestion that closeness to, and familiarity with, autism can help demystify the disorder and combat negative preconceptions. It also seems possible, given the findings of this research, that biomedical explanations (such as the label 'autism') could be a tool in countering pejorative explanatory models and the consequences of those models for children with disabilities and their families. This alternative explanation sits well with the individual model of disability which is likely to be intuitively accepted, yet may still serve to remove stigma or blame from the immediate family, particularly mothers.

As I have attempted to show, Ghanaian values, often rooted in spiritual beliefs and communal responsibilities, are imbued with virtues such as compassion, generosity,

honesty and respect for all life. It is these constantly evolving values, and the behaviours they may incite, which represent already present strengths in Ghanaian society and upon which local and international development efforts could conceivably build.

*You see traditionally there are positives in the way people think so why should we not be able to act on that. Traditional beliefs tell us that if someone is poor sighted and the eyes are weak this will make the other senses stronger....We believe then that when something is taken, something else is added to compensate. We believe that God provides for us. This is a positive belief. We should be encouraged by that. – Senior Professional*

Of course, the notion that one sense will necessarily compensate for another is not always true and again reinforces notions of limited understanding and knowledge of impairment. Nonetheless, the sentiment here is powerful; the deeply rooted notion that positives can be born out of hardship suggests a potent advocacy tool.

Importantly, the strategy of countering one belief with another is culturally relevant, as evidenced in the traditional use of folktales and proverbs to debate an issue. For example, I once witnessed Auntie Serwah counter the view that a child with autism was ‘possessed’ and should therefore be ‘sent off’ with another embedded belief similar to:

God is the giver of life and the controller of destiny. No one [else] has the right to take away life (TICCS, n.d., pp. 5).

There may be an untapped resource then in the symbolic dimension of Ghanaian culture described in chapter four. The respected use of proverbs for debate could potentially be used to advocate for disability rights and inclusive education in Ghanaian society.

Ghanaians use proverbs widely to impart wisdom (Utley, 2009, pp. 40)

Proverbs are often contradictory to each other, as can be seen, for example, in the proverbs chosen to reflect the social and individual models of disability in chapter one. There exists a potential to counter one with the other to generate discussion and debate about disability in Ghanaian society and thereby potentially raise the awareness and visibility of people with disabilities. It is suggested that proverbs, and the Adinkra symbols or folktales which accompany them, could be powerful tools for DPOs and international development efforts. An example may help illustrate the point.



*FUNTUMFUNEFU-DENKYEMFUNEFU*

According to Akan legend Funtummireku and Denkyemmireku are Siamese twin crocodiles who share a common stomach yet still quarrel over food. The myth and Adinkra symbol are often used to convey the message ‘unity in diversity’; although members of a family or group may differ, they can and should cooperate to achieve mutual goals and strength (Willis, 1998, pp. 110-11). It is suggested that this symbol and story may be a useful tool in generating both discussion and awareness of disability and inclusion in Ghanaian society. Their use in future research could also be explored. For example, perhaps this symbol could be used in interviews to further draw out the experiences of families of children with impairments and possible supports or tensions in kinship structures. Another example, of which there could be many more if space permitted, is the symbol Nkyinkyin or ‘twistings’.



*NKYINKYIN*

This popular symbol refers to a person’s ability to adapt and persevere through the many twists and turns life can bring. It is a symbol of “toughness, adaptability, selfless devotion to service and an ability to withstand hardships and difficulties” (Willis, 1998, pp. 148). As such, its potential to empower self-advocates, families and DPOs within Ghana is self explanatory. Traditional folktales, often linked to proverbs or Adinkra symbols, describe both the values one is meant to aspire to and those which are admonished in society and therefore may offer an additional contextually relevant

avenue for discussion and advocacy. Significantly, the deeply respected and traditional use of tales in oration and proverbs in debate may be met with greater reception, trust and acceptance than less culturally relevant advocacy methods.

Local and international stakeholders then are challenged with the simultaneous negotiation and navigation of valued traditional beliefs, a dynamic and continually contested culture and international human rights movements such as EFA and IE. It is my contention that this negotiation is best directed by Ghanaians with the support and encouragement of international stakeholders.

### **9.3 Conclusion**

The beliefs surrounding disability and autism uncovered in this thesis were, perhaps unsurprisingly, diverse, complex and malleable to circumstance. An examination of personhood and causal explanations revealed that it was the ‘odd’ or non-conformist behaviours associated with autism which were perhaps the most stigmatising in Ghanaian society. Children in Ghana were expected to be well-behaved, obedient and respectful. Teachers were therefore found to struggle with the challenging, hyperactive or repetitive behaviours associated with autism and parents found these behaviours to be the most visible and stigmatising feature of their child’s disability. Community members also commented on salient behaviour, which was typically interpreted as a spiritual attribution or simply ‘stubborn’ or wilfully disobedient behaviour. Significantly, these behaviours were also found to be a barrier for parents of children with autism who attempted to access inclusive educational environments in line with national policies.

In addition, kinship structures in Ghana dictated a responsibility to, and for, members of one’s family. Obligation to one’s kin seemed to contribute to the perception that children with autism were ‘useless’, as it was felt they would not be independent or able to contribute to their family. Shared accountability seemed to lead to a relatively default assumption that parents, particularly mothers, are to blame for the presence of disability in the household. Interestingly, the degree to which respondents external to the family attributed disability to spiritual, social or biomedical causes did not mitigate

this blame, which remained a relative contestant. In contrast, family members seemed to choose causal attributions which distanced themselves from culpability. Positive consequences of communal kinship structures were also found, such as in the support they afforded to family members, sometimes to such an extent that parents moved or sent their child back to Ghana to take advantage of this support.

Another significant finding of this research was the degree to which stakeholder accounts differed across groups. Community members and professionals suggested that parents of children with autism would likely feel burdened by, or choose to hide, their children. Instead, parents in this study appeared to offer unconditional love to their children with autism and provided support and resources to the greatest of their ability.

This research also discovered disparities between international and local conceptualisation of disability such that international declarations largely rooted in a social understanding of disability conflicted with intuitive conceptualisation of disability through an individual model. This tension was found to result in confused national policy and implementation of 'inclusion' more consistent with international understandings of integration. However, while understandings of autism in Ghana were deeply rooted in an individual model, they were nevertheless shaped by a larger worldview of spirituality and collective values. Significantly, an individual model did not appear to equate to biomedical understandings of disability as it seems to do in many Western cultures. Instead, despite being fundamentally located in the individual, the conceptualisation of disability discovered in Ghana was one of social-relational causation and management.

The current research also highlights the importance of distinguishing between the social *definition* (social model) of disability and the social *construction* of disability, the process by which individual and cultural norms, values and history influence beliefs and actions. This social construction, in Ghana, was found to be influenced by intuitive and ingrained culturally mediated beliefs such as a deep sense of spirituality and responsibility to one's kin. I have argued that culture, although dynamic and hard to define, does influence, even if only subconsciously, the way individuals view and respond to (dis)ability and autism.

In light of this, I suggest that no meaningful development assistance can be offered without a deep understanding of, and respect for, the culture in which one hopes to make a difference. It is not enough to simply impart knowledge gleaned in a disparate culture and hope for relevance (Ainscow, 1998). This thesis has therefore attempted to answer the numerous cries for culturally specific understandings of disability through an exploration of autism in Ghana. I have sought to further understandings of ‘disability’ as an experience and to broaden this view to one which also allows for the significance of family and community experiences.

As Ghanaians must ultimately have the last word with regards to their own development, I conclude by giving voice to one last participant:

*The best thing, if they want to help us here, then they must study us, our values and our cultures and things, they must get somebody who be able interpret [these things] and let the people understand [me] as I am. –Parent*

I hope in some small way that this thesis has done just that, that it offers a bridge to understanding divergent belief systems and suggests a pragmatic path forward in the advocacy for, and education of, children with autism in Ghana.

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## Appendix 1: Word Picture Activity

### Instructions

**Step 1: Brainstorm** (approx 10 min): What words, phrases, sayings, terms, proverbs, etc. are used in Ghana to describe children with autism? Please list all terms that people *may* use, even if you disagree with the terminology.

Please write **one** term, phrase or proverb per card. Write as many as you can - there is no limit! Don't worry if you come up with the same idea as someone else, duplicates are okay.

**Step 2: Sorting/Grouping** (approx 10 min): Let's group answers that are the same or very similar. This gives me a great idea of how widely used terms are and which ones are most prevalent in society.

**Step 3: Ranking** (approx 20 min): Now we will arrange the terms generated in order from the ones with the least stigma for children with autism to the ones you feel attach the most stigma. Which terms are most damaging for children?

**Step 4: Selection** (approx 10 min): Many of the people I hope to speak with will not be familiar with the term 'autism' or have an understanding of the disability. Please help me select terms that are appropriate to use under these circumstances to ensure we are discussing the same children.

### Results

Six critical friends generated, grouped and ranked the following terms during an initial focus groups consultation. The grouping 'title' was selected by participants; words under each title are transcribed exactly as they were generated. My additions or comments are in parentheses:

1. Possessed (10 occurrences):
  - Possessed
  - Possessed
  - snake child
  - snake child
  - possessed by spirits
  - possessed by the devil
  - Nsuoba (means water/river child)
  - Nsuo ba (river child)
  - Bosom Ba ("the child of the shrine")
  - Cursed (Me: 'are cursed and possessed the same thing?' Critical friend: 'when you are cursed you are possessed by bad spirits')
2. Mad (4 occurrences)
  - Deranged
  - Not Normal
  - Abnormal

- Mad
- 3. Useless (3 occurrences)
  - Useless
  - “Jimi Jimi” or “kwasea kwasea” (means ‘stupid stupid’)
  - Gyimigyimi (stupid)
- 4. Sick (3 occurrences)
  - Sick
  - yarefo) translates as ‘sick’; ‘)’ represents character they drew at the end of the word like a sideways U).
  - )yarefo (translates as ‘sick’; this time sideways U was drawn at beginning of word)
- 5. Can’t Learn (3 occurrences)
  - Can’t learn
  - Mentally Retarded
  - Retarded

**Note:** A lot of discussion went into trying to rank ‘mad’ and ‘useless’. Ultimately, critical friends placed 2<sup>nd</sup> – 5<sup>th</sup> rankings on row parallel to each other.

- 6. Dangerous (2 occurrences)
  - Dangerous
  - Violent
- 7. Disabled (1 occurrence)
- 8. Contagious (1 occurrence)
- 9. Difficult (2 occurrences)
  - Difficult
  - Difficult to manage
- 10. Hyperactive (3 occurrences)
  - Hyper Active
  - basa basa (‘some slight different but similar’ to hyperactive)
  - Hyperactive, 'heja heja,'; can’t sit still

**Note:** 9<sup>th</sup> and 10<sup>th</sup> rankings placed parallel to each other.

- 11. Lazy (2 occurrences)
  - Lazy
  - Lazy
- 12. Withdrawn (3 occurrences)
  - Withdrawn
  - Anti So (anti-social)
  - Anti So
- 13. Can’t Play (1 occurrence)

**Note:** Placed 12<sup>th</sup> and 13<sup>th</sup> rankings placed parallel to each other.



## **Appendix 2: Pilot Tested Methods**

As described in chapter two, the following methods were pilot tested but not ultimately used during primary data collection.

### ***Tree Drawings***

Two respondents were asked to participate in a tree-drawing activity at the conclusion of their pilot interview. They were each given a pre-drawn picture of a tree with visible roots and branches. It was explained that the roots of the tree represented the cause or origins of disability and they were asked to identify the ‘roots’ of ‘disability’ just as a tree starts from its roots. Once they had done this, I explained that the branches of a tree represent the effects of the causes identified, i.e. what grows from the roots? Both participants were noticeably uncomfortable with the exercise. Each asked for repeated clarification and did not seem to understand the abstract nature of the activity. One of the participants declined to participate in the activity by making a quick excuse to leave after a second clarification. The other participant completed the activity but ended up simply repeating what was said in the prior interview.

### ***Body Mapping***

Body Mapping was initially used as an attempt to identify ‘unhealthy’ areas of the body and possibly reveal assumptions underlying the perceived nature and cause of autism. This method was pilot tested with four participants. In the first two cases, I simply presented the participant with an outline of an adult and child body, giving them the choice of which one to use. Following body mapping procedures from previous research, participants were given different colour pens and asked, one at a time, to mark the source/cause of the problem with one colour, the parts of the body affected by the disability with another and any area that can be ‘fixed’ with a third colour. Both participants simply placed a tick mark near the brain for the first and second questions and did not believe anything could be fixed for the third. I did not feel this was getting at the information I wanted and attempted a variation (based on suggestions made by critical friends) in the third and fourth instances.

After giving the participants a blank body outline I then asked them to draw, one at a time, the heart, brain, stomach, blood and soul. It is important to note that eyes, ears, nose, mouth, fingers and toes were already evident on the body. The same procedure described above was then used. This adaptation did increase awareness of, and participation in, the activity. However, it was decided that this revised procedure had taken on an inherent methodological flaw. Asking participants to draw a soul seemed very leading while leaving it out seemed to ignore the spiritual aspect of personhood in Ghanaian society. This method was not ultimately included in primary data collection.

### ***Picture/Video Interpretation***

Pictures and videos were taken of children with autism, with permission, at the Autism Awareness Care and Training Centre (AACT) in Accra. Ten photographs and ten short (less than one minute each) video clips were selected. The photographs were chosen such that five children were represented in two pictures each. To me, one of these photographs demonstrated a visible trait of autism; the other was selected as the child looked 'normal'. Of course, autism is not a physical impairment and it is really only through movements and behaviour that one begins to notice indications of autism. For this reason, video clips were also used to demonstrate traits such as spinning in circles, making loud noises or academic work at a level unusual for the student's age. Video clips were shown only after respondents had examined and commented on still photographs. This method was pilot tested with two respondents, both belonging to the community member stakeholder group. Both had surprisingly mild reactions to the photographs and video clips saying some things were strange but most were within limits of normal childhood behaviour. This absence of reaction was interesting in itself and I initially decided to continue using this method during data collection. However, interviews often became quite lengthy and in respecting time constraints of my participants, the use of picture and video analysis was not ultimately possible. In a few select instances (five in total), I was able to meet with participants a second time and in those cases I did attempt picture and video analysis. Given its limited usage, this untapped and potentially powerful methodology was not central to this research project.

### **Appendix 3: Informed Consent Form**

Hello. My name is Jane Anthony. I have formerly worked and volunteer with children with Intellectual Disabilities in Ghana from 2004-2006 and in that time I came to believe that a greater understanding of their situation was necessary. To that end, I am currently conducting research on children with disabilities in Ghana. I am particularly interested in exploring attitudes and awareness regarding disabilities as well as access to primary school education for such students.

In order to do this I would greatly appreciate your taking the time to speak with me. I greatly value your knowledge and opinions. I am interested in your experiences; there are no right or wrong responses. If you choose to speak with me, the interview will take approximately 1 hour. You are encouraged to stop the interview at any time if you are uncomfortable or simply wish to be finished. You may also decline to answer any question and we will simply move on to the next question.

In addition to asking questions, I may ask you to examine some short videos or complete some written exercises during the interview. You may decline to participate in any or all of these tasks.

Information shared with me will not be passed along to anyone else. Your answers will remain confidential at all times. When reported, your answers will be combined with other answers and no names will be used. It will be impossible to tell what your specific comments were when I write and share my final report.

If you have any questions please ask me to explain further. If you would like to participate or have additional questions, you can contact me at 0244.118.079.

Thank you very much for your consideration,  
Jane H. Anthony

I wish to participate in this research. I understand the purpose of the research and the interview process. I understand I may withdrawal at any time. I have been given the chance to ask any questions I may have and understand I can continue to do so during and after the interview.

Name: \_\_\_\_\_

Date: \_\_\_\_\_

Signature: \_\_\_\_\_

## Appendix 4: Sample Interview

**Respondent:** Mother [‘Ama’ in Chapter 3]

**Date:** 26 Feb 2008, 10:00 am

Recorded: Yes

Consent: Oral

**Background Information:** [excerpt from Chapter 6]. Ama is the mother of a 10 year old son named Kojo who was diagnosed with autism in the UK. Kojo had no speech and severe behavioural challenges when I met him. Ama had recently returned to Ghana with her two sons, the other typically developing, after a divorce. Her journey is one of a search for acceptance in, and understanding of, a culture and family she had left years earlier. When I met her, she was still settling into Ghana and searching for educational services for Kojo.

**JANE:** Explained research. Asked for oral consent- granted. Asked for permission to record- granted. Opened interview by asking her to tell her story.

**AMA:** I mean, why did I come [back] to Ghana, I’ve always wanted to come back to my roots. In London, I felt with Kojo, they didn’t really know what to do with him *again*. You know so, I thought I’ll bring Kojo to Ghana, get somebody to help me, even if I got like em a teaching assistant sit with him in normal school, and just, so that he can be with other kids. But really, em I was going to direct his emm learning cause he wasn’t getting anywhere with him in London you know they didn’t know what to do with him again because they said he was regressing and I didn’t have any clues. I didn’t know how I was going to, emm, I didn’t know how I was going to combine work and ...<sup>32</sup> yeah, and then when I came to Ghana emm I went to a special needs place in [my home town] and emm they said I had to go to the OIC for an assessment before emm they will admit him. And I went to the OIC, they did the assessment and then they also took me to a psychiatrist who also did the assessment, this was about 4 weeks ago, and the report is still not ready. I went back to the school to ask them whether they will take Kojo for just two hours so that he is amongst other children because he is getting bored at home, they didn’t want to know. So, I started looking elsewhere.

**JANE:** This was a government school?

**AMA:** Yeah, this was a government special school, yeah. So I went to New Horizons [private special school] and I went to Dzworlu [government special school] and then they directed us to this place [AACT]. And emm, and I felt it was the right place, you know so far, I felt they really understand, and yesterday’s lecture I came to was fantastic. You know just to prompt me, help me you know, know what to do emm because I do run out of ideas [*laughs*] you know of what to do. Yeah. [*Pause*] But yes definitely, I mean, a lot of works needs doing so that people of Ghana can accept that there are some children who are not the same and they need extra help and care and attention in the community. And then I hope I could help make that happen one day. I hope.

**JANE:** Yeah? When you say there is a lot to be done, what do you think...

**AMA:** It’s the understanding. Umm, and the refusal to believe or accept that there is a problem. I mean a lot of people are telling me when he grows up it will go. How can it go? And what if it doesn’t go? And they believe, for me to believe that, as a mother [then] I am not helping his growth or his betterment. You know? Its... they don’t want to sit down and work, they just leave it to the Almighty, you know, who sometimes I feel is tired! [*Both laugh*] He needs a break. You know? I mean if my fellow Ghanaians hear me saying this, this is blasphemous. So, parents are on their own, you know, we are on our own. I mean I am so glad somebody

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<sup>32</sup> The interview is presented in its full and uncut form. In this appendix dots (...) are used to signify speech trailing off or pauses.

here understands [*referring to Auntie Serwah at AACT. Long pause, was visibly getting a bit upset*]. We need to surround ourselves with more people who understand and that is the only way and hopefully the wider community will accept it.

**JANE:** You said people have been saying, "oh it will go, it will go"... What about neighbours or people that you used to know that didn't know your son before?

**AMA:** Oh, people who didn't know, I've been talking about Kojo from day one. But emm, I had people from Ghana community tell me don't say anything to anybody because they would laugh and not help. And that didn't stop me because I think the more people I could tell, that could help or help themselves, is better than to keep quiet about it. What do you gain by keeping quiet about it? A problem, you know. So no, but that is the answer to you, don't talk about it, people will laugh.

**JANE:** Why do you think that is? Why do you not talk about it in society, is it sort of a taboo?

**AMA:** You know, everything that is not the norm, everything that is not the same, some people believe it's a curse, it's a curse, you know. Umm, you know, it's the shameful thing, keep it under wraps. Problems are generally not discussed in public, you know? Sometimes I'm sure that is why a lot of diseases that should not spread, spread. Because who is going to sympathise with you? You know? Who is going to sympathise with you? Brother, you'd be ostracised. So um, deny it, pray and it will go [*sarcastic*] and then I don't where you imagine because you've prayed its gone, so you can, yeah... Pray and it will go, so who will diagnose that it's gone? Whatever the disease is, so now you can go on and spread it because it's gone.

**JANE:** But if you say pray and it will go, let's say you pray for some time, long time, and it hasn't gone, what is the next response?

**AMA:** That the prayer is not good enough, you have to go to other people who have prayed and miracles have happened even though we have not witnessed it. You have to go to people, and these things are not free. You know? Unhuh. Errr, what you do you call it? Personally, I like my own interpretation of the bible, umm, but I cannot convince you know, even my sister in law that I live with, you know, because the husband is trying to be em, its really my cousins wife, yeah, and my cousin, and my cousin is my brother and my sister in law. I say [to them] that you know, I feel God game me Kojo because he thought I would be able to look after Kojo, umm, He should help me to manage him. And they want me to pray to eradicate the problem and I said God is tired, he's got so much responsibilities. For example, somebody might look normal but you don't know what lies beneath. They have got all sorts of conditions, take Kojo's condition away from him and replace it with what? And oh my God you can't say that! You are causing these problems to be worse. You know? It is what you believe [and] that's why he hasn't improved [*laughs a lot*]. So, I don't know how we are going to get other Ghanaians, unless the parents have seen it, and want to come forward. Most of the time the priest will tell them, don't even mention the word, because if they accept the diagnosis it means it's not going to go, but God works in a mysterious way. Do not accept, do not accept! And you see. [*Long pause*] Sometimes I wonder why I came! [*Loud laugh*] I know when I went to London in the beginning it was hard and I know that it's going to be hard but I've met you, you know so it's a positive beginning.

**JANE:** I do wonder though, if there are those challenges, but you also felt there were challenges in England, so what are the differences?

**AMA:** I think the acceptance that there is something wrong in London, you know. And let's work towards acceptance; that it's a problem that we need to tackle. That it's going to take a long time but let's carry on. Here the denial and not wanting to help, you know. In London, as I said, the last time we went to psychiatrist [he] said what do you want me to do? The school said there's a problem and I just felt isn't it part of the symptoms of autism that no two persons are the same and he is just different. He is just different but they were saying there is something extra wrong apart from the autism. But then nobody could give us answers you see. I'm

divorced with two children and emm I just felt that it's going to get worse, especially when he goes through puberty. I'm on my own and therefore if I could have it, when he said we should go back to [?] and the teachers said they don't know what to do with him again, but he would have carried on going to school you know and they kept raising that there is something extra wrong, and the psychiatrist saying what do you want me to do, I just thought you know let me come to Ghana and then have somebody sit with him in a mainstream school and then just attend to his needs you know. But I haven't been able to achieve that *[laughs]* since I came. Just mingle and not expect, just want him to be happy, not expect the things we are expecting of him, that is not conducive you know? Just let him be but help him. What I was worried about too I think was his self personal care, you know? I think I used to do a lot for him because I'm in a hurry to go to work and after work I'm tired so I will do a lot for him. I didn't allow him to do the things. So I even thought I'll get help to do his personal care.

**JANE:** And you felt you could get that here but not in England?

**AMA:** That's how I felt you know.

**JANE:** You also mentioned having people around?

**AMA:** Yes, yes.

**JANE:** You feel you have access to more...

**AMA:** People around you. I mean since we came people have worked for us in the house, we have inherited one or two boys and he is looking after the house now whilst we are here and there is another person too, Kojo, who has become our Uncle, even the hotel we stayed in, two people have called already.

**JANE:** And how do those people react to Kojo?

**AMA:** You see, I think it is you and what, if people saw me being bad to Kojo I think they would be bad to Kojo. If people see me loving Kojo and say he's my son and you have to accept all of us or not. You know? So I think it's you. Yeah.

**JANE:** So what do you think then is the best way to change people's perceptions?

**AMA:** I think it is up to the parents, it the parents acceptance. To people yes, there is something wrong and lets work towards it. You know. But most of the time the parents are in fear, are in fear. And you're being lied to by the so called people who know, or messages from God, enheh. That's how I feel.

**JANE:** You know the fear? What are they afraid of?

**AMA:** What people will say. Yeah. What people will say. That is more of a killer than the disease itself, what people will say. And it could affect the whole family, maybe nobody might marry into the family because they say there is a curse there, there is something not right in that family. You can't marry that into that family. In fact, at one time I feared for my son, this one *[points to younger son without autism]*. I feared for my other son that who will want to marry into the family. I feared, but I put that aside as to whatever will happen will happen. Um, I can't control everything, so, yeah. I just try to be very positive about it, very positive. Cause otherwise I will have nothing.....See because you don't understand, *[then you think]* there is a problem in that family, so it could be hereditary. You see? That is the problem, even though we don't know, there are some people who profess to know. *[Laughs]* You know? That you must have done something in your past, or it's just the family did something, somebody went to do something, it's always somebody. No evidence but people are able to convince people so much that they believe what they have been told. It's the belief more than anything *[they]* will read.

**JANE:** You mean the belief in the curse?

**AMA:** Yes, yes. And the priests, what do you call it, they exaggerate it or make it worse that you have your prayers, you know, are not strengthen enough, you know.

**JANE:** What kind of priests do you mean? Are you talking about a specific type or a specific religion?

**AMA:** I meant all Christianity.

**JANE:** So you are not even talking of traditional medicine, you are talking of Christianity.

**AMA:** Oh! Since I have been, somebody has suggested that em some black magic, they mentioned 'ibbibbi-dro'. [*spelling phonetically*] 'Ibbibi' is black or African Magic. They know somewhere that we can go and it will go. [*Younger son Jon enters the room*]

**JON:** African Magic that's a TV program.

**JANE:** It's a TV program?

**AMA:** Yeah, yes.

**JANE:** What do they show on it? I just might be interested in watching it.

**AMA:** I think it is one of the channels on the satellite. Look, even I brought my children here to learn culture as well because I really felt as a black single parent the conditions abroad did not help me cause I also lived on a council estate and I really feared that em we would not have positive role models and they would fall into wrong hands and children that I saw coming from this country seems to, seems hungry and prepared for the challenges of the working life, you know? Em, if you see somebody as a teacher or in a good position they normally have had some background, a lot of them from a native country and I really felt it would help my children. However, what do you call it, emm, the belief... I've lost track of my thought. [*Pause*] Sorry, there was something I wanted to say... Yeah, the television programs. They encourage somebody has done something wrong and therefore let's take them to this fetish priest, you know [*laughs*] and therefore those things worry me as well. You know, worry me a lot. And the Christianity bit worries me a lot. But still it is early days and I still feel we are to give it a try.

**JANE:** You mentioned both the priests and the television shows as things that sort of perpetuate that negative opinion, is there anything else that perpetuates those negative views of children who are different?

**AMA:** I don't know. Also, maybe, there isn't money in this society. Therefore em, children are not listened to, they are not listened to. We seem to also, yeah, we don't listen to children, we don't think children have new and wonderful ideas that are worth listening to, even because they have been to school. We still stick to the traditional old way, one way. This is what my grandfather did, my great great grandfather did. So, this is what we must follow. Even after the school. There is a lot of fear. I remember, unfortunately, somebody who had actually trained to be doctor, the woman he wanted to marry died, only 24. Um, he had actually bought the wedding dress and given [it] to the... which was at the brides house or whatever, and because the girl died he had to have the dress back otherwise the family would do something to it and he would never be able to marry again. He went to the funeral, he wouldn't eat a thing because the curses that have happened for the child to die might happen to you. And this is a medical doctor. You know? So this belief thing....

**JANE:** Yesterday I heard you say 'African mentality', could you explain what you meant by that?

**AMA:** It's this belief thing that they won't let go. That is not helping us but they don't see, they don't see. I suppose I would be in the same boat if I hadn't travelled at a very young age. You know? Yeah, but I also understand where here is coming from. And if that is what you want to believe fine but it's when it is not helping the child, you know, it's not helping them, but they still don't see.

**JANE:** I know you said you went to the special school in [town] and they wouldn't accept him until you had the assessment, but I think you also mentioned that you would prefer to have him in a mainstream school with an assistant. Have you had any interactions with those schools?

**AMA:** Yeah, I went to a private school behind where we live and I said my son is autistic and they asked me does he bully other children. And I think what they meant is, is he aggressive? And he can be sometimes so that stopped me. So then if I could find somebody who understands his needs. If I can find somebody who understands his needs and can be with him at the school then I'll take him but would you accept this? But at the moment, at that time, I hadn't found any for him. You know? And if the teacher didn't understand his needs I didn't want him to be lost or a spectacle you know, I really wanted him to belong to, yeah. So I thought I would be able to educate them somehow but slowly I'm seeing that it is not going to be easy.

**JANE:** So that school will accept him if you bring somebody with him?

**AMA:** In fact, this headmaster told me that you have to speak to the owner [*of the school*]. Before. We didn't go the next day, but I haven't stopped asking, yeah, I'll keep asking.

**JANE:** Jon [younger brother], can I ask you some questions? [I looked at mom for permission at same time, Ama nodded]

**JON:** nodded.

**JANE:** What about, I mean you just got to Ghana, how do you find it?

**JON:** Hot

**JANE:** Do you like it here?

**JON:** Just a bit

**JANE:** Hmm, why just a bit? What's different?

**JON:** [talking very quietly, can't really hear at all. From mother's comments can tell he is talking about not liking his school.]

**JANE:** You don't like it? Why?

**JON:** Because they use canes.

**JANE:** Oh, they use canes!

**JON:** Yes

**JANE:** When would they use them?

**JON:** When they are bad.

**JANE:** What kind of things make them bad?

**JON:** [can't hear response, something about standing up]

**JANE:** If they stand up the teacher will use a cane?

**JON:** If they stand up in the place, sharpen pencils.

**AMA:** See now that worries me. Because standing up and sharpening pencils, now what do you think, is that bad? [*Directed at Jon*]

**JON:** No

**AMA:** So, I don't want him to confuse what is bad.

**JANE:** Yeah, sure. [*to Jon*] When you say they use a cane, do they give a child warning? Do they ask the child to sit down first, what happens?

**JON:** Right away

**AMA:** I'm moving him to another place right away. When we came, we were told the house we were coming to live in was ready, it wasn't. We had to stay a month in a hotel and they were getting bored and I didn't know the area very well so that was the first school that I was told had a good name.



**JANE:** So is this a government school?

**AMA:** No no, it's a private school. £110 a term, you know? And I'm not happy with it. I think he should go to a school with a smaller class.

**JON:** She wants me to finish the term because she has paid for the school lunch, and I don't even like the school lunch.

**AMA:** Yeah, I told him he should finish the term but he is not happy, and everyday there are things actually that I am not happy about. So, I'm really not sure what is best to do. Not let him go at all? Or let him finish the term?

**JANE:** Yeah...Which would you prefer Jon?

**JON:** [can't hear response]

**JANE:** What about, have you seen Kojo playing with other children in Ghana?

**JON:** shakes head no

[Removed long back and forth conversation with Jon which strayed from topic]

Interruption for birthday cake brought into room from staff.

**JANE:** Well, I don't want to keep you too long, but is there anything else? I mean I have told you a bit about my research, so is there anything else you think I should know or anything you want to ask me?

*Children began coming in room, interview came to a natural conclusion after 36 min and I did not try to reengage as I was aware they needed to get back on the road for their journey home.*

## **Appendix 5: Kofi Story**

Kofi is six years of age. He is a very handsome boy and has a nice smile. He should be going to school every day but his last school sent him away. They said he was difficult to handle, was hyperactive and he could not learn well. Other local schools have not been able to accept him. The Head of one school suggested he rather go to a special school.

Kofi's family is very worried about him. Kofi does not look or respond when they call his name. At first Kofi's family was worried he was not hearing well so they took him to an audiologist. They didn't find anything wrong with his ears. When Kofi does talk to others his words are hard to understand, his voice sounds strange.

Kofi spends a lot of time playing alone. People talk of him and call him withdrawn. His favourite thing is a football. He plays with it plenty and sometimes becomes very upset if other someone tries to take it from him.

Kofi's parents say that he is hard to handle. Kofi has started getting very upset often, especially when his day changes and something different happens, something he does not expect. When he becomes upset he screams loudly and stomps his feet.

Kofi also acts out in public which makes his mother feel ashamed. He is always running around and climbing on things, he will not sit quietly. Sometimes Kofi will shake his hands or spin himself around and around. He also makes loud noises for no reason at all.

More and more his parents feel helpless and frustrated. They feel isolated from the community. His mother is embarrassed to take him shopping or to church. Both of Kofi's parents love their son very much and want to do all they can for him. They try hard. His parents have asked plenty of people for help and advice but it seems everyone has something different to say.

## Appendix 6: Advocacy Proverbs

These proverbs were generated by groups of teachers during an inclusive education in-service training. While not a primary source of data, they did inspire my thinking surrounding proverbs as a potential advocacy tool. All proverbs and meanings are direct transcriptions.

PROVERB	MEANING PROVIDED
Disability is not inability ( <i>slogan of GES SpEd</i> )	When one child is disabled in one area it does not mean one cannot perform in the other areas AND The disabled person can also perform some activities as the normal child
To have a disabled child is better than to be barren (Vivor nyo wu ko)	None provided
A dumb has tangible/good suggestions to make but could not be heard	A dumb has a capacity to give good advice and ideas but cannot express it
It is not yet night for the taper to be blamed	We need not put tags on the disabled while they are young
We start from the imperfection to the perfection (Aoglo dai wonona, hafi tsona dzodzoe to)	None provided
A tailless animal has God as the creator.	God cares for the weak in society
The human offspring cannot be likened to the offspring of the goat	Whatever limitations a human being is considered to have, his/herself reasoning ability cannot be seen as being as low as the instincts of a goat.
Gradually a stone is cooked to make it soft.	Patience makes the cook stay by the fire and cook. Therefore, little by little the disabled can be handled/helped.
Everybody has a part to play in the community	None provided
Agbe doe metia aybets o	None Provided
Even if life is difficult it is worth living	A person with disability can be an asset
A cripple can at least beat an immovable drum	If a person cannot walk he can at least shout