Parents and Special Educators' Perspectives on the Sexuality Educational Needs of Learners with Intellectual Developmental Disabilities in Ghanaian Special Schools

By

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Abstract

Despite the global efforts towards the inclusion of persons with disabilities in societies, Ghana's Educational Strategic Program is yet to include sexuality education for learners with intellectual developmental disabilities (IDDs) in special schools. Current social structures also exist to limit formally recognised sexual and reproductive access to persons with IDDs in Ghana. That notwithstanding, persons with IDDs have sexual needs like their non-disabled counterparts. In order to promote the sexualities of persons with IDDs in Ghana, this study sought to explore how parents and special educators construct and address the sexuality educational needs of learners with IDD in special schools. Realist Social constructionism and Sankofa (an anticolonial framework) served as the foundations for the study. It therefore acknowledged the role of impairment as a material reality as interacting with social realities. Taking into account the historical social, cultural, political and economic fabrics, which frame Ghanaian societies, and that parents and educators who are the primary agents of socialisation and advocates for these persons are a part of these communities, the study realised that learner's sexuality educational needs do not exist in a vacuum. They are constructed through experiences and interactions, with social and economic forces as well as parents' expectations for the future. The study took place in 5 out of 10 regions of the country and involved mostly interviews with parents and special educators. It is expected that the lessons gathered will be useful for the designing and implementation of sexuality education programmes for learners with IDD in Ghanaian special schools -programmes that resonate with the value systems of Ghanaian societies and serve as a step towards promotion of the sexualities of persons with IDDs in Ghana.
Dedication

I dedicate this work to Mamaga Miedoafe II (Queen mother of the Anlo Traditional Area) who passed away a few weeks to the completion of this project. This is for you. It’s just one step towards all the work ahead. The journey has only begun.

Thornton Dove,

Working with you, I realized that you and others like you have sexual needs. My inability to help you at the time set me on this journey.

Finally, to all persons with intellectual/developmental disabilities in Ghana who will soon benefit from a culturally relevant and appropriate sexuality education program, that will bring them closer to being publicly and legally recognized and respected as sexual beings.
Acknowledgement

Thanks to God for my Redeemer, Thanks for all Thou dost provide!
Thanks for times now but a memory, Thanks for Jesus by my side!
Thanks for pleasant, balmy springtime, Thanks for dark and stormy fall!
Thanks for tears by now forgotten, Thanks for peace within my soul!

To God Almighty for taking this journey with me – giving me a supervisor Marc Epprecht, for whom and to whom I am utterly grateful for this work done. It has been a great privilege to work with you. To every faculty member whose course has helped me take on this project, to Heather Aldersey and Richard Day especially, thank you for the potential you saw, contributions made and for being on my examination committee. I appreciate it all.

Thanks for prayers that Thou hast answered, Thanks for what Thou dost deny!
Thanks for storms that I have weathered, Thanks for all Thou dost supply!
Thanks for pain, and thanks for pleasure, Thanks for comfort in despair!
Thanks for grace that none can measure, Thanks for love beyond compare!

This has been more than just an intellectual journey. It has been loaded with physical, spiritual, psychological and emotional experiences, which have only made me stronger. Oh! The weight of my debt of gratitude to all of you who believed in me and stood by me all the way.

To my parents Seth and Lydia Gbewonyo, my siblings Elikplim and Eyram, I am so grateful for the support you have shown throughout this journey. I cannot begin to say how blessed I am to belong. Also to my church families in Kingston, how can I ever thank you enough? Indeed, God could not have planted me anywhere else. Iron does sharpen iron and I thank God for that process. In addition, my special thanks to Dr. F. Oehemeng, Sociology department, University of Ghana for your time and support during my data collection in Ghana.

The Autism Awareness Care and Training Centre (Mrs. Serwah Quaynor), Inclusion Ghana and Autism Society of Ghana, and Juniper Tree counselling center, your tremendous support throughout the research process cannot be over emphasised. To the participants - parents and educators - I am so grateful for all the input. As we say, “When you hear the cock crow tomorrow morning, know that it is sending a message of my appreciation to you”

Thanks for roses by the wayside, Thanks for thorns their stems contain!
Thanks for home and thanks for fireside, Thanks for hope, that sweet refrain!
Thanks for joy and thanks for sorrow, Thanks for heav’nly peace with Thee!
Thanks for hope in the tomorrow, Thanks through all eternity!

Mawuli Amedofu, God could not have brought you into my life at a better time than this. Thanks for every minute spent despite the uneven time zones. You have been there with me through it all.

Finally, to the many others whose names I have not been able to mention, this work is a done deal because of all of you. Though unseen, know that your names are etched on the very pages of thesis.
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<td>ESP</td>
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<td>HIV</td>
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<td>ICPD</td>
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<td>ID</td>
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<td>PDA</td>
<td>Persons with Disability Act</td>
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<td>Person(s) with Disability</td>
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<td>PWIDD</td>
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<td>United Kingdom</td>
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<td>UN</td>
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<td>United Nations Convention on the Rights of Persons with Disabilities</td>
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<td>UNESCO</td>
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<td>UNFPA</td>
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<td>UNHRO</td>
<td>United Nations Human Rights Office</td>
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<tr>
<td>USA</td>
<td>United States of America</td>
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CHAPTER 1 INTRODUCTION

1.1 Background of the Study

Ghana signed on to the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD) and passed the Persons with Disability Act (PDA) in 2006. Since then, many persons with disabilities, and disabled people's organizations in Ghana have become more involved in advocating for inclusion in education, employment, and equal remuneration, access to health, justice, and public spaces (Naami & Mikey-Iddrisu, 2013; Grischow, 2015). However, much has not been done towards the sexual and reproductive health concerns of these persons. Very little research has been conducted in this area (Kwadwo, Anafi, & Sekyere, 2014) - and especially for persons with intellectual and developmental disabilities (IDD) information in this area is almost non-existent. While many reasons may account for this gap in the practice of and research on the sexuality of persons with IDD, the situation is no surprise since persons with IDD are the most stigmatized and marginalized in Ghana (Inclusion Ghana, 2011). That notwithstanding, persons with IDD have similar sexual and reproductive health needs, are at higher risk for sexual abuse and are capable of committing sexual offences, (McCabe, Cummins, & Reid, 1994; Balogh, et al., 2001; Gill, 2015; Euser, et al., 2016) however their SRH needs are neglected.

Another reason for the gap in practice and research on the sexuality of persons with IDD is the seemingly taboo nature of the subject of sexuality itself not just in Ghana and Sub-Saharan Africa but also in parts of the Global North (Prah, 2011; Zimmerman, 2015). As a site of human reproduction on the one hand, and bodily pleasure and desire on the other, sexuality has always
been an important object of normalization and control for societies (Foucault, 1978) and prescribing norms of sexual behavior (Brickwell, 2009). These sexual regulations produce binaries of sex and sexuality such as normal, moral and permissible versus abnormal, sinful, and taboo (Seidman, 2003; Adams & Pigg, 2005; Foucault, 1978). However, this taboo subject became a subject of human rights in 1994 when, at the International Conference on Population and Development (ICPD), 179 countries came to a consensus and adopted a Programme of Action, to empower women especially—to make decisions about their reproductive and sexual health (UNFPA, 2013). The rights movements of the late twentieth century had also set the grounds for women, persons with physical disabilities and LGBTQI populations to advocate actively for their sexuality rights. The disability rights movement like all these over civil rights movements, sought to replace oppression and marginalization with empowerment and full inclusion into mainstream society (Winter, 2003). Even though attempts are being made to include persons with intellectual and developmental disabilities in this fight, it is important to understand that their access to these sexual rights will for many years continue to be done through two main agents of social control—above all parents and educators (Shtarkshall, Santelli & Hirsch, 2007; Sinclair, et al., 2017). This is because many persons with IDD continue to live at home (even after their school years) and are mostly under the care of parents; continue to be kept in institutions, and therefore have reduced privacy; are unlikely to have sustainable income; and unlikely to be given opportunities to explore and engage in sexual relationships (Best, 2005; Adams, 2015). Briefly put, they are still infantized and some childlike innocence is assumed of them - that their reduced intellectual capacity is reflective of their capacity to conceive in thought, develop and/or have sexual or intimate relationships (Gill, 2015). Yalon-Chamovitz (2000) and Greenspan (2002) both acknowledge that, the IQ tests used to measure academic
potential fail to measure other practical reasoning skills and abilities. Educators therefore end up underestimating the overall reasoning abilities or what Yalon-Chamovitz calls everyday wisdom of persons with intellectual/developmental disabilities. This thesis presents the perspectives on some aspects of these rights by exploring the sex education needs of these persons from the viewpoint of two main agents of social control - parents and educators. Hence, the matter at hand is as follows: Although persons with IDD have sexuality educational needs that need to be recognized, parents and educators serve as the main socializing agents and will only cater for the needs they perceive through their sociocultural lens and in ways Ghanaian societies deem as socioculturally appropriate.

1.2 Statement of the Problem

The Ghana Education Strategic Program (ESP) has HIV/AIDS prevention as one of its objectives in the educational program for mainstream schools and special schools for the persons with physical disabilities. Nonetheless, this focus is not included in the ESP’s section for special schools for learners with IDD (Ministry of Education, 2010). Although an inclusive education directive is underway for the inclusion of learners with non-severe mental and physical disabilities (Ministry of Education, 2010), special schools for learners with IDD continue to exist. Access to sexual and reproductive health information is a component of the sexual and reproductive health rights as defined by the WHO (WHO, 2006). A lack of provision for this population through sexuality education therefore, is an infringement on their sexual and reproductive health rights (WHO, 2006). Furthermore, The United Nations Population Fund (UNFPA) in 2014 introduced a "rights-based" approach to comprehensive sexuality education
(CSE), "whether in school or out of school" (UNFPA, 2015 pg. 11). Thus, CSE programs are to serve as an intervention for the promotion of equality, rights and promotion of the sexual, reproductive, and mental wellbeing of all young people including adolescents with intellectual and developmental disabilities.

Ghana has initiated the UNFPA's CSE (which acknowledges the role of culture in determining eligibility for and content of sexuality education) (UNFPA, 2015). Additionally, the impacts of local culture on the interpretation and application of sex education programs cannot be overlooked (Baxter, 1994). Indeed, the social, economic, political structures and the systems and arrangements, symbols and meaning they sustain, define the meanings associated with sexuality (Adams and Pigg, 1995). The situation, concerning intellectual disability is similar. There is therefore a need to explore the socio-cultural context of sexuality and intellectual disability in Ghana. That is, the perceptions, views, laws, mores, and values related to sexuality and disability. More specifically is the need to understand the position of parents and teachers, who act as the main agents of social control on one hand and advocates on the other in the sexual education and sexual socialization of learners with IDD in special schools (Craft & Brown, 1994; Rose & Jones, 1994). A social constructionist approach therefore provides an appropriate framework for this study.
1.3 **Research Question**

In order to address the problem stated above, the researcher asks the following question:

> How do parents and educators construct and address the sexuality needs of learners with IDD in special schools and what can we learn from this in the design and implementation of sexuality education programs for this population?

The researcher answered the question by exploring the realities of the behaviors of learners with IDD with respect to their sexuality, parents and educators' constructions of the sexuality and sexuality educational needs of learners and how those needs were addressed. Lessons were then drawn from these constructions and their related strategies, for future design and implementation of a culturally appropriate sexuality educational program that will enhance the sexual wellbeing and full participation of PWIDDS in local communities.

1.4 **Significance of the Study**

What does the social construction of sexuality and intellectual disability have to do with global development studies? Well, Groce (1999) emphasizes the study of disability within a society using multidisciplinary approaches since the issues affecting persons with disabilities and persons with intellectual developmental disabilities (PWIDDS) for that matter are determined by a myriad of social, political, and religious factors rooted in cultural norms and traditions of a society. In the quest for development, the rights of marginalized groups are gradually becoming a marker however; there exists a hegemonic discourse around such things as human rights, disability, and sexuality (Meekosha, 2008). Simply assuming, that signing unto charters translates to action towards the achievement of these international goals is to take for granted the
reality that the interpretation and application is subject to the social norms and traditions that exist within that society at the time.

With regards to the sexuality of persons with disabilities in Ghana and Sub Saharan Africa and more especially intellectual disabilities in the region, there remains very little research and so policies and strategies are set but on the foundations of studies conducted in the Global North. According to the World Health Organization (WHO) (2011) however, 80\% of the world's population of disabled persons are in the Global South. Meekosha (2008) recognizes the current position of the Global North in the development of Disability discourse where the voice of the Global South is rare and limited, especially in the context of sexuality. The cultural, economic, and social contexts are very different yet policies are adopted by parliaments with no consideration for the cultural relevance to their social institutions and then rather end up marginalizing persons with disabilities even further (Gomez, 2012). Again, the discourses around sexuality and disability in Africa have been rather negative marked with connotations of savagery and backwardness (Obono, 2010). However, there are value systems that can be harnessed to include persons with intellectual disabilities in this case, and promote their rights.

This study therefore will serve as reference material for advocates, policies makers, and legislators of persons with intellectual/developmental disabilities in Ghana as it presents the realities of sexuality education for learners with IDD in special schools a perspective of local empirical evidence. That way, policy that is more specific to their needs and institutional programs can be developed to promote the sexual and reproductive wellbeing of persons with intellectual and developmental disabilities in Ghana and the rest of the sub-region.
1.5 **Overview of the Methodology**

This study was qualitative and utilized semi-structured interviews to obtain data from parents and educators of learners with IDD in special schools in the country. In all 27 participants (parents and educators) were recruited for the study using non-probability (convenience and snowball) sampling methods. Interpretive phenomenological approach was used to draw various insights from the data with regards to the concerns of educators and parents’ concerns and approaches to the sexuality educational needs of learners with IDD in special schools. A detailed account of the methodology is given in Chapter 3.

1.6 **Scope/Delimitations and Limitations of the Study**

There were a few limitations to the study. Firstly, it looked specifically at learners in special schools for intellectual developmental disabilities; implying that persons with IDD in regular schools and those who do not go to school were not captured in the study. Secondly, persons with IDD are not a homogenous group and so many studies that focus on this group specifically targeted at subgroups such as persons with Down syndrome, autism, cerebral palsy or persons with cognitive impairment. In Ghana however, getting a conclusive diagnosis except in the case of Down syndrome and sometimes cerebral palsy is a challenge. The challenge stems from the lack of such knowledge among medical professionals and the scarcity of clinical psychologists in the country\(^1\). Given this background, this study does not emphasize what specific IDDs are captured in the study so long as the learner is in a school for learners with intellectual disabilities. Thirdly, the education in these special schools is (typically) non-

\(^{1}\) In October 2013 for instance, the Ghana News Agency (GNA), reported Dr A Kwasi Osei- the Chief Psychiatrist, saying that Ghana had only 4 clinical psychologists and only 12 practicing psychiatrists in the entire country.
progressive (Lamptey et al., 2015), and the age of the learner does not necessarily determine the class they are put in, thus, the age range of learners with IDD was not taken to cognizance except that they were aged 10 years and above. Fourth, with the adoption of the slogan “Nothing About Us Without Us” in disability discourse - which aims to promote the participation of persons with disabilities in the development of policies and programs for persons with disabilities - this study bears the limitation of not including the perspectives of PWIDDs themselves.

Additionally, this study pays little attention to non-conforming sexual norms such as same sex relationships because although in Ghana homosexuality does exist it is considered illegal (OHCHR, 2016) and although majority of the ethnic cultures are tolerant of its existence, they do not openly endorse it (Signorini, 1973; Geoffrion, 2013)². Thus, even though a few parents and teachers did talk about it, many parents especially out rightly dismissed it as an issue to be discussed since it is taboo. Furthermore, although the researcher is from Ghana and understood majority of the languages, some information may have been lost during translation especially where a translator was employed. Furthermore, the use of “Ghanaian English” might carry interpretations that persons outside the Ghanaian context will not readily understand hence some words and phrases were altered to convey the message the respondent sort to convey.

Finally, this study is not a full representation of the Ghanaian situation despite its attempt to cover five regions out of the eight regions that have special schools for learners with IDDs.

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² Signorini (1973) reports on same sex-marriage among the Nzema of Ghana but the dynamics of these relationships- whether or not they were indeed of a sexual nature was not clear. Furthermore, she reports that homosexuality is looked upon as a childish behavior that will phase out by the time the individual grows older. Geoffrion (2013) explores various spaces for trans persons in Ghana such as festivals that allow for cross-dressing. However, Tamule (2011) cautions that because Western language has dominated sexuality discourse, the meanings and constructions given to certain experiences are likely to reflect realities that are not outside of the local contexts in which the experiences are taking place. This challenge with language was very evident in Signorini’s work.
Time, as a limitation and funding accounted for these. That notwithstanding, given that no study of this kind has been conducted in the country, this work stands more as a foundation for others to build on in the future.

1.7 Organization of the Study

The research thesis is presented in six chapters with Chapter One being the introductory chapter which gives the background of the study, discusses the problem being addressed, the research questions, the significance of the study, an overview of methodology, the scope, and limitations of the study. Chapter Two presents a thorough review of literature, beginning with a theoretical framework and definitions of the various concepts. It also, undertakes an empirical review of the phenomena being researched. Chapter Three covers the Methodology discussing in detail the research design, methods, data collection procedure, and an overview of the research area being studied. The presentation, analysis, and discussion of findings are captured in Chapters Four and Five. Finally, Chapter Six concludes the thesis with recommendations and a discussion of the implications of the study to research and practice and suggests directions for future research.

1.8 Rationale

My decision to do this research stemmed greatly from my own experiences, primarily, having an aunt and two cousins with IDDs and from working with people who have intellectual and developmental disabilities through various institutions in the Greater Accra region of Ghana. While majority of the services available for the promotion of the rights of persons with IDD
mainly in the areas of education, issues regarding their sexuality remain unrecognized and are hardly even spoken about. Furthermore, education about the sexuality of these learners, by parents and teachers in most cases appear to be rare. Additionally, there are no public policy strategies to address specifically the sexual and reproductive health issues of persons with IDD. As an educator and community advocate, I had used social stories in the past to teach sexually appropriate behaviors, however, I found that my knowledge and skill to address these issues was limited. However, I did not know what constituted sexually appropriate behavior and to teach sexually appropriate behaviors and promote the sexuality of persons with IDD, in a way that is socially and culturally relevant to the Ghanaian society. I therefore decided to step out of the seemingly Western hegemonic influences of psychology and special education along with all their seemingly elaborate strategies, which address the problem in the individual, to understand better the reality of sexuality and intellectual disability in various societies across the country. This subject of sexuality education for persons with IDD spans beyond teaching and learning and is underlined with cultural norms, beliefs, perceptions and practices in spite of the policies that may exist. What is the reality on the ground and how can I develop that into a template for the promotion not only of sex education for this population but the promotion of their sexual and reproductive health and wellbeing in a way that is both culturally practical and globally acceptable? This study is a step towards this goal.
CHAPTER 2 THEORETICAL FOUNDATIONS AND LITERATURE REVIEW

This study draws on insights from various theoretical paradigms and perspectives in disability, education and development studies - mostly social constructionist and postcolonial (or more specifically anticolonial) perspectives. It will also review literature on the history and current situations of sexuality and sexuality education, intellectual disability and special education, and their Ghanaian situatedness to provide a context for the study.

2.1 THEORETICAL FOUNDATIONS

2.1.1 Social Constructionism
The fundamental thought of social constructionism (SC) is that social reality is socially constructed (Elder-vass, 2012; Berger & Luckmann, 1966). Therefore, the ways in which we perceive the social world is not the only reality that exists and thus we should approach social facts with a bit of skepticism (Burr, 2015). In addition, no single social constructionism exists (Stam, 2001; Burr, 2015) and various disciplines have adopted a social constructionist paradigm and adapted it for a myriad of purposes (Elder-vass, 2012a; Weinberg, 2014).

In relation to this study and its focus on sexuality and IDDs, is the social construction of the body. Social constructionist perspectives of the body, most especially those hinging on Butler and Foucault’s views have often been criticised as too radical (Salerno, 2004; Weinberg, 2014). This is because, although bodies do not exist apart from social forces, the body has its own

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3 For both Butler and Foucault, sexuality is socially produced and not biologically given and the body is a product of culture and a result of interplay of power. (Salerno, 2004; Weinberg, 2004; Salih, 2007)
forces\textsuperscript{4}, which we cannot ignore. It is first a biological agent (Siebers, 2001). Hence a moderate perspective that takes into account the reality of biological characteristics of the body and inform the physical expectations that individuals are to meet, or even determine the behaviour of an individual, is necessary (Weinberg 2014; Siebers, 2001). Elder-Vass (2012a) calls this perspective \textit{realist social constructionism}.

Elder-Vass (2012a) identifies two social forces as the main players in the process of social constructionism—norm circles and social structures/institutions. A norm circle comprises a group of people such as individuals in a family or religious group, committed to endorsing and enforcing specific norms or, some particular observable behavioural standards (Elder-Vass, 2012a; Elder-Vass, 2012b). The social structure (that is, the institutionalization of the norms), results from repetitive conformity to specific norms by others in the wider normative environment (Burger and Luckmann, 1966; Elder-vass, 2012a). Most projects in development have not been very successful because they employ the top-down approaches that do not involve the people at the very grassroots of the society (Brohman, 1996) at the expense of bottom-up approaches to development (Ray, 1998)\textsuperscript{5}. Given that disability (including IDD) and sexuality are both issues of concern in development discourse (Cornwall, 2014; Adams and Pigg, 1995; Grech, 2015) the ways in which special educators and parents construct learners sexuality needs will determine their ability to achieve full inclusion into society.

There is power at work in all social situations (Eldervass, 2012a) and as such, norm circles are not politically neutral, and are themselves influenced by other operations of power.

\textsuperscript{4} For example, Cantú et al (2014) have studied and observed changes in women’s behaviour towards men across the ovulatory cycle. Siebers (2001) also discusses the reality of the physical limitations encountered by persons with physical impairment.

\textsuperscript{5} In this study, the people at the grassroots besides the PWIDDs themselves are mainly the parents and educators. They are also the primary agents of socialization.
(Elder-vass, 2012) whether religion, state or international agencies. Foucault's perspectives on power, offers a productive way of exploring its operations in the industries of intellectual disability, sexuality and sexuality education. Generally, it enables for an exploration and understanding into the ways society uses education as a tool to either repress or produce subjects, and technologies of power (institutions such as welfare, special education, sexuality education) to normalise and maintain social equilibrium (Foucault, 1982; 1978) or in Elder-vass' (2012a) explanation disrupt it. Elements of biopower and biopolitics as well as subjectivity are realised in the way parents and educators exercise power over the lives of the learners, and how the state also regulate the sexualities of learners with IDDs. Beyond that, the state is also influenced by external powers from the West who determine what programs should exist and for whom. Thus, despite all the laws and policies that exist at the macro level or social structure (e.g. educational policy or sexual and reproductive health policies), this study acknowledges that the learners are subject to the control of these two actors at the micro level of the interactions (norm circle) that govern the sexuality of PWIDDS. Hence, their significant role in the promotion of sexuality education for this population cannot be ignored.

Gramsci's Hegemony, also a form of power, explains how dominantly Western discourses from the past and in the present, continue to run deep in policies and intellectual activities (such as the training of special educators, medical professionals among others in relation to the sexuality of PWIDDS (Ibrahim, 2017; Kreitzer et al., 2009) - and state institutional structures. These mostly colonial discourses of education, mental retardation/intellectual disability, and sexuality have shaped the constructions of PWIDDS and their sexuality especially on the state level. Our laws continue to perceive PWIDDS as incapable of being in legally recognised
relationship because of the dominant ideology of individual consent\(^6\). However, it appears that little is known by Ghanaians themselves about the traditional structures that supported the sexuality of PWIDDs, and which have altogether been abandoned\(^7\) especially at state institutional levels. These relationships determine the types of curriculum (content and objectives) that are adopted, employed, and at lower levels the mode of disseminating the curriculum- to manage the lives of PWIDDs, manage the school's instructional process, manage the nation's education process and manage the entire state.

There is interplay of power and hegemony in the construction of the social realities (Stoddart, 2007) of learners with IDDs with respect to their sexuality at the various levels of society. Although this study focuses on parents' and educators' perspectives, it takes into account that parents and educators are part of a wider community in which they as primary agents of socialization and change will either reinforce the existing constructions and norms around it or work to change it. In the spirit of developmental projects aimed at empowering PWIDDs, we cannot start out without knowing what exists and what contributes to the constructions that exist. To know what ought to be, we need to know what already exists so we can approach the promotion of the sexual wellbeing of PWIDDs from a culturally acceptable perspective - a perspective, which will encourage people in the community to pursue this cause because it resonates with their norms, values and beliefs. Given the seeming lack of academic discourse

\(^6\) Section 102 of Ghana's criminal Offences Act 1960 (Act 29) criminalizes sexual intercourse with "an idiot" whether or not they consent to it. (Even the word idiot is problematic in this day yet this law and others like it continue to exist). Section 47 of the mental health Act, which emphasises ability to consent and which further disqualifies PWIDDs from entering legally recognisable intimate relationships. Also, acts to ban the sexual activities of persons with mental disabilities on the clause of consent. Additionally, on page 27 of the document on the reproductive health situation in Ghana, the section on mental disability states that, contraceptives be provided to women with mental disability in consultation with all parties including person in loco parentis and trained service providers. The agency then of the person herself is not recognised.

\(^7\) This is not to say that there are no traditions that discriminate against and even endanger the lives of PWIDDs
relevant to the lives of PWIDDS in Ghana, this study is also taking this step to give a voice to parents and educators and subsequently PWIDDS so that culturally relevant programs can be set up to meet their sexuality educational needs.

2.1.2 Sankofa

*Sankofa*\(^8\) which in Akan, literally means, ‘go back to reclaim’ is an anti-colonial\(^9\) discursive framework (Dei 2008; 2004; Dei & Asgharzadeh, 2001) emerging from Akan philosophical thought and practice (Dei 2008; Quan-Baffour, 2012 in Clarke, 2015). The framework is founded on the notion that power does not only belong to the coloniser but the colonised can also exercise their power through local and social practices and indigenous knowledge (Dei & Asgharzadeh, 2001). The shift from post-colonialism to anti-colonialism for many African scholars has emerged in the wake of post-colonialism's failure to address the problems of colonialism and its continuous privileging of Western ways of knowledge over local ones\(^10\) (Spencer, 2006; Dei & Asgharzadeh, 2001). Sankofa challenges the overemphasis on the

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\(^8\) Sankofa is typically symbolized by a bird with its head turned backwards and an egg in its mouth. The backward gaze indicates that there is wisdom in learning from the past in order to understand the present and to shape the future. The egg in the mouth of the bird as represents the ‘gem’ or knowledge of the past upon which wisdom is based as well as the future. (Adjei, 2007; Quan-Baffour, 2012).

\(^9\) The anticolonial framework is a theorization of issues emerging from colonial relations. Colonial here refers to imposed and dominating and not just foreign or alien ideologies or structures (Dei, 2006). In the context of this study, I refer to pre-colonial then as ideologies, discourses that emerged from our indigenous beliefs and epistemologies and not necessarily in terms of time periods (Dei, 2002 and Dei, 2006).

\(^10\) Dei and Asgharzadeh, (2001) acknowledge that there are overlaps and that it emerged out of post colonialism and the decolonisation movement. Through an anti-colonialist lens, Dei (2008) presents the "post-colonial" as imposed on Ghanaian culture (Dei 2008). Anti-colonial thought therefore positions itself as an oppositional discourse to colonialism and its on-going effects (Nkomo, 2011). As an anti-colonial discursive thought and practice, the academic and political project - for knowledge that colonised groups can use to solve our own problems address our own challenges with practical and authentic ways - is what informs sankofa (Dei, 2006). Unlike post colonialism, anti-colonialism emphasises the strength of groups who are aware of their differences but unite around struggles against colonial social structures of oppression (Young, 2001; Dei and Asgharzadeh, 2001; Loomba, 2015). Sankofa is not a nationalist anticolonial model like Cesarie's Negritude. What sankofa does is requires that we look into the past and take elements of our indigenous cultures and see how we can apply them adapt and adopt them to solve today's issues.
failures of the Global South (largely due to colonialism and neo colonialism) at the expense of the successes at local community levels. It turns to historical traditions and takes the African cultural perspectives seriously in order to explore new ways of doing things (Dei, 2006). Sankofa is rooted deeply in indigenous ways of knowing, and the understanding of the spiritual sense of self and collective. This knowing situates the philosophy of holism as a key idiom of anti-colonial practice. (Dei 2006; Wane, 2006; Spencer, 2006) It involves a critical examination of culture and cultural values, histories, customs, traditions, identity and knowledge production which lead to a transformation in attitude and enhance dignity, and employing the insights gained to map out the future (Dei, 2006). As a practice, it brings Africans in touch with new awareness of their historical realities and identity (Quan-Baffour, 2012).

Sankofa and Ubuntu are similar in that they are both founded in indigenous thought and practise (Pervin, 2015). However, Booker (2014) makes a distinction between Ubuntu and Sankofa. Ubuntu is rooted in the interconnectedness of the people. The term is of South African origin and emphasises brotherhood, a shared sense and collective ownership of opportunities, responsibilities, and challenges, and the importance of people and relationships over things. Sankofa on the other hand, emphasizes drawing upon past lessons and modifying them to solve contemporary challenges. In effect, these are two different approaches although they are both used to drive various aspects of development and enhance the welfare of African and Black communities.

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11 Spirituality here refers to "an understanding of the personhood, a synergy of the mind, soul and body and an accompanying awareness for the wholeness of being, the interconnectedness of all things and a belief in a greater power beyond the capacities of the human senses to comprehend" (Dei, 2006 pg. 6).

12 Knowledge is produced through histories, experiences among others is highlighted in Dei (2006; 2008) and Dei and Asgharzadeh (2000).

13 Ubuntu in Zulu means 'I am because you are' and is of South African origin (Booker, 2014). Ubuntu is a concept that exists in the Bantuphone region of Africa but even in East and West Africa but under different names such as Teranga (from Senegal) and Ubukhosi (from Zimbabwe) (Murithi, 2006; 2007).
In relation to the sexualities of PWIDDs, very little is known about how we positively enhanced the lives of PWIDDs and promoted their sexualities in the past except for the discourses of maltreatment, sterilization, abuse and killings, which have dominated past and present Western discourse about our dealings with this group of persons. In the previous chapter, reference was made to Munyi (2012) who cites a study from Field (1937) of the Ga people who treat person with intellectual disabilities (feeble-mindedness) with kindness and are well treated since they are seen as reincarnated deities. Tooth's (1950) ethnographic accounts of responses to mental illness in the Northern and Southern parts of the country is cited in Ursula Read's study on mental health in the Brong Ahafo region of the Ghana. In Tooth's account, stigma to mental illness was lower in the North than in the South of the country. Although persons with mental illness in the North were chained, they were kept at home, well-fed and well-taken care of and were never left alone for a long period. They constantly according to Tooth's report enjoyed the company of family and friends. In the South on the other hand, persons with mental illness were shunned and separated from the communities.

In 2015, British journalist, Sophie Morgan, who is also a person with physical disability produced a BBC documentary in which she named Ghana as the worst place in the world for persons with disability. While there are injustices against persons with IDD and mental health challenges, these should not be perceived without thought to the socioeconomic factors that limit the ability of families to respond in better ways than the "traditional" method of chaining. However, in the spirit of Sankofa the attention to tradition and culture is not in favour of the "traditional act of chaining" but rather on the attitude of keeping persons with mental disability

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14 The person with mental illness was usually chained to a tree or huge log to keep them restrained and from escaping.
(and in relation to this study PWIDDS) as part of the community as was recorded in the North and the treatment of PWIDDS among the Ga people. Sankofa requests a re-evaluation of the practice of expulsion, seclusion, and confinement as reported in Tooth's account on the patterns of response in Southern Ghana, and which may have resulted from the establishment of psychiatric institutions around that time (Forster, 1962). A brief description of the colonial tradition of institutionalization is discussed in the section on the context of Ghana.

In exploring what their needs are, unlike Western disability discourse is promoting\textsuperscript{15}, this study seeks out this knowledge from parents and educators through their lived experiences with the learners. For Dei (2004), knowledge must be understood as coming from multiple formal and informal cultures, sources, and sites of learning. The social and political relevance of knowledge is determined by how much it synchronizes with the aspirations, lived experiences and daily practices of a people. While there is a tendency of "othering", there is also the tendency that approaching it the Western way given the sociocultural and economic context of our communities, will leave them less likely to be heard. Nonetheless, this position gives parents and educators the power to produce knowledge that will enhance the lives of the learners and

\textsuperscript{15} Many Western studies encourage having PWIDDS themselves as participants and try to promote them a having agency and the ability to speak for themselves. While this shows that their autonomy is of importance, there are other social dynamics within Ghanaian societies, which are likely to make such an approach a white elephant. In Ghana, there is a huge regard for age, and social status in communicating request. Traditionally, a younger person or person of lower social rank will have better audience before another of a higher social rank if he or she went with a spokes person. This is even continuously witnessed during traditional marriage ceremonies between families (where a linguist is hired), and among the Ewes the need to address an older person with your concerns through another who of closer rank (socially or relationally). I recall being made kyeame (linguist) last summer, when my distant cousins came to visit my aunt in our family home in the village. By relationship, I was closer to my aunt although I was about the same age as my cousins. My aunt therefore had to explain my position in terms of age and relationship to them and named me the kyeame for that conversation. From this example, it can be deduced that to have the needs of PWIDDS promoted at state levels, discourse that directly seeks the opinion of the learners with IDD themselves is almost unlikely to be heard not because they are not respected but because of the cultural fabric that defines how requests are brought before elders. The parents and educators are thus linguists for these learners.
determine how the strategies needed to help learners navigate through the complex community structures that exist\textsuperscript{16} (Dei 2004).

Using this framework, I approach sexuality education and intellectual disability education as institutional structures sanctioned by the state to serve the cultural, material and political interest of the state and its economic/social foundation. I do this, taking into consideration that the state is also a subject to the dictates of Western hegemonies of development, but also recognise that there are local modes of these institutions that are more reflective of the values and ideologies of the communities in which these structures are located. I am fully aware that these learners, educators and parents all come from communities and sociocultural backgrounds of varying worldviews and belief systems and are seeking to include these persons through avenues that resonate with ways of the local community. Finally, I approach my interpretation of the implications by situating it in the present context of promoting not just their sexuality but also their full participation in the local communities. While the current approach to promoting the rights of PWIDDs appears to be a top-bottom one (marked with policies and strategies that are not in effect), I propose a bottom-up approach that will enable community members support persons with intellectual/developmental disabilities. This will enable local community members and civil groups to push for recognition of their capacities to take on responsibilities as it relates to the sexuality. It is when there is success at the local communities that civil society can mobilize based on these positive outcomes to overthrow the current regimes of discourses, mechanisms and institutions that stifle rather than promote the capacities for PWIDDs to have fulfilling sexual lives. By fulfilling sexual lives, I mean, whether together with the community,

\textsuperscript{16} In effect, it conceptualizing marginalized groups “as subjects of their own experiences and histories and presents local communities as valuable sources of knowledge in theorizing and practicing reform and change” (Dei, 2004 pg.20).
they choose to be sexual or not, to engage in intimate relationships or not, to have children or not. It should be from a place where they will be able to get all the support they need and will be treated with respect, dignity and accepted despite their difference.
2.1.3 A Brief Homage to Feminism

This study, although not focused on a feminist approach to the topic at hand has benefitted from feminist ideologies and hence references are made to feminist scholars such as Tamale and Puar and who are non-Western feminists. Feminism has been criticized as being "unAfrican" (Tamale, 2013) however, it has a lot to offer this study as it confronts the politics of unusual sexualities in Ghana. Additionally, with the emphasis on the sexualities of PWIDDs, this study intersects very well with disability studies. The relationship between feminism and disability studies has been one founded on the shared experiences of embodiment and bodily difference, reproductive technology, issues of oppression and agency among others (Garland-Thompson, 2002). Like persons with IDD, women too are considered as incapable, dependent, weak, and vulnerable among many other social constructions and these constructions pervade every aspect of their social, political, and cultural identities and experiences as well as societies expectations for them (Garland-Thompson, 2002; Morris, 1993). Borrowing from feminist ideology in this study enables for a multifaceted understanding of the cultural history of the body as scholars as Puar and Tamale have done in a number of their works.
2.2 LITERATURE REVIEW

2.2.1 Education

As already established, education is a mechanism of productive constraints, an instrument of biopower, a space, period and process where discipline ensures conformity to the established social norms (Foucault, 1982). The term "education" comprises formal and informal social processes of engagement with multiple social actors across varying social contexts (Humphreys, et al., 2008) and goes beyond schooling (Peters, 2010). According to Dei (2012) education confers knowledge and banishes ignorance. Since knowledge is power (Foucault, 1978; 1982), education leads to the attainment of power (Dei, 2012). Therefore, it is power - the present hegemony, the dominant ideology - that determines the kind of knowledge that will be disseminated.

In Ghana and many other African nations and former Western colonies, the educational structure and curricula are rooted in colonial and Western discourse (Dei & Simmons, 2011; Dei, 2012). The systems were neither grounded in African thought processes nor did they reflect the values of pre-colonial African societies (Tedla, 1995). Ghana has gone through a series of educational reforms motivated by Western influence in the area of funding. In a later section of this study, the implications of the Structural Adjustment Program of the 1980s-90s is discussed and highlights a few of the challenges that the education sector of Ghana faced and continues to face as a result of this program. Agbemabiese (2010) also states that Ghana's current school system does not adequately address the cultural needs of the learners. Thus, students are unable

\[^{17}\text{Peters (1996) suggests that education is much deeper than learning facts or skills, as it has been reduced to by its common use. Instead, it involves a "linking of concepts by the learner to gain a wider understanding of the world" (Barlett and Burton, 2016 p. 13). Education, according to Peters, should be worthwhile, inseparable from value judgements; learning should be done in a morally acceptable manner; and should not be coercive (Barlett and Burton, 2016).}\]

\[^{18}\text{According to Dei, these educational systems were imposed on the peoples.}\]
to reconcile what they learn in school with what exists within the society (Dei, 2012). Subjects such as social studies and cultural studies, general science and agricultural science among others have been integrated over the years thus, leaving out many essential aspects of the two disciplines (Agbemabiese, 2010). Dei & Simmons (2011), Obeng (2002) among others discuss extensively the beneficial aspects of pre-colonial education in Ghanaian societies and challenges that have stemmed from the colonial educational legacies that continue to run in Ghana and other African societies. Among these are social inequalities, high unemployment rates, and social vices stemming from lack of moral and value training.

In effect, for education to be relevant there is a need for it to prepare the learners to face the realities of the society in which they live and from which they come. The education of learners with IDD ought to include the cultural norms, practises and understandings of sexuality and culturally acceptable avenues for sexual expression without much compromise to their welfare. Building the competencies of these persons in the social and cultural norms, nuances, and mores of society, will open up doors for proper integration and inclusion into mainstream society when they leave school. As the Akan proverb says, "abofra a onim ne nsa horo no, one mpanyinfo didi" (A child that knows how to wash his hands well, eats with the elders).

2.2.2 Sexuality

Sexuality is a social fact, interwoven into and sustained by the fabric of social, economic, political structures, values and interpretations (Adams & Pigg, 2005). Seidman (2010) and Weeks (2003) discuss the role of the social institutions in shaping the sexuality of people in society namely the family, education, religion, the state, economic and political environments and globalisation. Weeks (2003) further suggests that daily interactions within cultural and social
institutions such government, law, education, and religion bring us into contact with the sexual norms of our society. This leads us to develop some perspective, regarding particular sexual behaviors—(what is desirable and what is not, what is legal and what is criminal, what is encouraged and what is stigmatized)—and their boundaries within the milieu of these social and cultural interactions (Simon, 1996) in Weeks (2003). In effect, sexuality and the meanings associated with the behaviors and conducts associated with it are interpreted differently across different spaces and times. For instance, the age for consent to sexual relationships and marriage differs in different nation states. Within Ghana consent for sex within some traditional communities occurred as soon as a girl started menstruation but has been changed to age 16 at the level of the state (Archampong & Baidoo, 2011).

Despite the varying interpretations and responses to sexuality in various societies, international efforts have and are constantly being developed in order to have universal standards and designs that can be applied globally. These international standards of sexuality are founded mostly on hegemonic Western thought and as such, most social analyses of sexuality therefore, revolve around Western sexualities (Adams & Pigg, 2005) while African sexualities are commonly portrayed in scholarship as simple or discussed in the context of disease and gender-based violence (Obono, 2010). Furthermore, sexuality is a domain of power (Foucault, 1978) and so with Western colonialist language dominating the discourse on sexuality, studies on African sexualities themselves appear to perpetuate and sustain the binaries and constructions of African sexualities (Tamale, 2011).

19 These international sexuality codes and conducts are founded on Hegemonic Western thought. For instance, they are founded on the notion of individual rights which do not necessarily align with the sense of community and communal welfare that is valued over the individual in many local African communities and as evident in values such as Ubuntu (Chinouya & Keefe 2006; Du Toit, 2014; van Zyl, 2015).
Arnfred (2004) therefore calls for dissolution of the dichotomies that place Western sexualities at the centre and as the ideal, thereby criminalise, and stigmatise some acts in Africa (Tamale, 2011). Since the sexualities of the African peoples are not homogenous, there is a need to conceptualize it outside the normative and dominant epistemological frameworks offered by Western discourse (Tamale, 2011). For instance, the HIV epistemologies of the West along their interventions have been criticised for alienating the people from the efforts to curb the spread of the disease (Chilisa, 2006; Hlabangane, 2017). There are social, structural and cultural practices which have led to the spread of HIV/AIDS beyond the behaviours of people from Africa. However, Western HIV epistemologies focus on the individual - the colonial perception of the colonized who is simply driven by bodily desires and without restraint - without recognition of the ties to community and community values and practices that might spread the disease (Hlabangane, 2017). For instance, widow inheritance and virgin cleansing are not captured in proposed Western prevention interventions to HIV/AIDS. Furthermore, socio-economic inequalities and even the impact of structural reforms have all contributed in one way or the other to the spread of HIV/AIDS (Hlabangane, 2017). A more detailed effect of the Structural Adjustment Program in Ghana captures its implication on the spread of HIV/AIDS as well. The adoption of unconventional and culturally sensitive methods to capture the complexities of Africa sexualities is imperative to bringing attention to the invisible and silenced knowledge about the sexualities of Africa peoples and challenges the associated stereotypes that have typified this discourse (Tamale, 2011).

Sexuality in Ghana as an area of research has also been approached a lot more from the perspective of reproductive health and disease, and HIV/AIDS, gender inequality as well as in terms of sexual knowledge and sexuality education, sexual behaviours and practices as evident in
works of scholars such as Awusabo-Asare, Ankomah, Tenkorang among others. In recent times however, the issue of same-sex relationships is also becoming an area of growing interest in Ghanaian sexuality scholarship. Over the next few paragraphs, I will give a brief overview of sexuality in Ghana in relation to beliefs, expectations, practises and norms as they cut across HIV/AIDS and reproductive health issues, premarital and marital relationships, same sex relationships, transgenderism, the place of women as perceived in public discourses on sexuality. Bochow (2012) mentions sex talk follows intergenerational norms of respect, which are often subverted when convenient for the older person who sanctions such conversation. This is probably one of the reasons for the general impression that sex talk is taboo exists.

Currently, in Ghana, HIV does not appear to be a present reality for many people. In 2014, the national prevalence according to a USAID report was at 1.6%. The attitudes towards HIV/AIDS risk and infection has been shown in studies conducted by Opoku (2010) and Yeboah and Appai (2015) who realised that knowledge about HIV/AIDS - risk factors and prevention - did not necessarily translate into a change of behaviour with regards to condom-use. The sexually active women interviewed in these two studies appeared to be more concerned about getting pregnant than about contracting HIV/AIDS. Sabin et al., (2013) have recorded similar attitude towards HIV among MSMs (i.e. Men who sleep with men) in a study in the country. The statement, "HIV used to frighten people but it is no longer serious" as recorded in that study, may account for the relaxed attitude to HIV/AIDS despite the stigma that still exists around the disease (Tenkorang, 2013). Additionally, three quarters of those interviewed in the Sabin et al’s. study had tested positive for HIV.

Concerning issues of gender non-conformity, the issues of transgenderism and same sex relationships have met with respectively with tolerance and silence to some extent in the country.
It was not until in 2006 when the President of the Gay and Lesbians association of Ghana came public on Joy fm (one of the country's most prestigious radio stations) to remind Ghanaians of the rights of homosexuals (O'mara, 2007). Since then, a current of homophobic winds have swept across the general population and subsequent outcries against these persons have intensified with the recent campaigns and pressures from the West to legalize same sex relationships (O'mara, 2007; Geoffrion, 2013a).

Over the years, however, traditional communities and modern societies provided safe spaces for cross-dressing which Geoffrion (2013) refers to as festive transvestism. Notable among such spaces are secondary school events where students cross-dress and play roles of a different gender, as well as cross-dressing to perform cultural dances such as Bambaya of the Northern region or the southern region linguist (Kyeame or Okyeame) roles during traditional marriages. Furthermore, there are terms such as Kojo Besia (female Kojo) which were used loosely and really did not carry severe consequence (Geoffrion, 2012). With regards to same sex relationships however, apart from Signorini's (1973) study of the Nzemas (as earlier mentioned) many Ghanaian communities consider same sex relationships as taboo and a practice that does not preserve the lineage. Although its occurrence is common knowledge, the secrecy around it remains and it is not spoken about (Dankwah, 2009) until a person is caught red-handed. Besides, in Ghana, according to Dankwah (2009), fixed sexual identities do not exist since practice does not necessarily define a person. With the growing discussions on LGBT identities in Ghana, more studies will have to be conducted to know whether this worldview has changed as well as studies to know how the LGBT debate has impacted these safe-spaces.

In Ghana, there exists blurred lines between marital relationship and premarital sexual relationships as the roles and responsibilities in marital relationships are being played in the
premarital relationships (Bochow, 2012). Exchange and reciprocity is a prominent feature of all Ghanaian relationships. This element of exchange makes a definition of bribery challenging and the curbing of child sexual abuses a Herculean task (Torsello, 2011; Attah, 2016). Although by tradition and as per the dictates of religion in Ghana, sex within marriage is the preferred norm, current realities show otherwise (Geugten et al., 2013). However sexual relationships whether marital or premarital like all others are seen through the lenses of exchange (Ankomah, 1999; 1996; Boschow, 2012; Kyei 1992; Anarfi, 2003).

Prior to a marital relationship and throughout the marriage process and life, there are exchanges between the man and the woman (Kyei, 1992; Bochow, 2102). Traditionally, among the Akan the young man upon making his intentions known might work on his prospective father in law’s farm, might bring gifts such as meat, to the woman (Kyei, 1992). The woman in turn might bring food to the man or help his mother at home and this was carried on into the marriage, which took place not too long after the courtship period (Kyei, 1992). Today, with modernity and urbanization, the dynamics of exchange have changed. Money has become the currency and in exchange, sex is required or given; young people are spending more years in school, are reaching social adulthood much later and are marrying later but also find themselves needing to satisfy various needs, needs that years before would have been met in a marriage situation (Bochow, 2012; Ankomah, 1999; Ankomah 1992). In Ghana love is an action word measured by the indicators of care and provision between the partners (Bochow 2012; Ankomah 1999). The man must provide for his wife and children and the woman must be willing to in return give sex and reproduce (Ankomah, 1999). However, in a premarital relationship there appears to be the likelihood of mistrust and doubt about the woman's capacity to love and respect
the man even when the man has nothing to offer (Boshow, 2012; Ankomah, 1996; Ankomah, 1999). This influences commitment to the relationship.

Economic security thus plays a very important role in both marital and premarital relationships however, with marital relationships because they are formally recognised by the family, each party is encouraged to play their part well (Kyei, 1992). It is no wonder there is much emphasis on abstinence until marriage so that parties can be held responsible to play their roles as per the dictates of the religious institution. Abstinence is understood in the church as a way to test one’s will and to build trust within the relationship (Bochow, 2012). Today, although urbanization and modernity has somewhat stripped the powers of extended family members and elders of the community from the private life of the individual, the churches and mosques have become gate keepers and can serve as a great support (Hanson, 2005; McCauley, 2014) when it comes to the sexualities of its members. Further studies however, need to be conducted to know the extent to which these religious systems in Ghanaian have positively impacted the sexualities of members.

Reproduction is not entirely separate from Ghanaian sexuality as reproduction continues to be a desired outcome of every marriage. Both men and women attain full social adult status when they have children (Boshow, 2012) hence this desire. According to Ankomah (1996), some successful women in their 30s and 40s are pressured by family members to go have children with a married man if finding a husband becomes a challenge. This is also because, the more successful she is, the more men find her to be a threat to their social manhood (Ankomah 1999;1996).

As previously mentioned, intimate relationships of exchange are not the same as transactional relationships which are also popular in Ghana. The phenomenon of sugar mummies
and sugar daddies (Dinan, 1983; Kuate-Defo, 2004) is also prevalent especially among students. These sugar mummies and daddies are usually older and married but rely on younger partners for sexual support and they in turn have their material needs such as school fees, rents etc provided. Prostitution is illegal in Ghana although prostitution is a popular phenomenon (Anarfi, 1998; Asamoah-Adu et al., 2001). One other addition to the phenomenon of transactional sex is the MSM. Sabin et al’s., (2013) study confirmed the common view that MSM did it for the money. Unfortunately, such transactional sex were most unlikely to involve condom use or as in the case of prostitutes, a client who pays a higher price to have unprotected sex is likely to have his or her wishes satisfied in spite of the risks of contracting HIV/AIDS. (Sabin et al., 2013; Asampong 1992)

2.2.3 Sexuality Education

Sex education is ageless, (Magoon, 2009) and exists in one form or the other in every culture. Zimmerman (2016), Magoon (2009) and Kendall (2012) trace the histories of sex education in its earliest forms in the 20th century Europe was introduced to address the challenges that emerged at the time. Sex education in its earliest forms in the 20th century came to address the challenges that emerged with the breakdown of Judeo-Christian influence that prescribed the boundaries of morality; the emergence of sexual determinism and rise in sexual autonomy; the growing exploration of unions outside of marriage; the separation of sex and sexual pleasure from reproduction; and the increased visibility of homosexuals; as well as the emergence of disease (Zimmerman 2015, Duncan and Goddard 2005). Zimmerman (2015) discusses the effects of the world wars, international drive for family planning and emergence of HIV/AIDS as influencing the trends of sexuality education across Europe, America and even Africa in the 20th century and how Europe and America appear to dictate the scope, content and methods for delivering sexuality education in the rest of the world. After WW2 sex education became known as family life education in the USA. It was focused on teaching gender roles and proper upbringing of children. The trends did not only affect the scope and content but the labels of these programs as well. From family life education, moral education and family hygiene, to Sex education and now sexuality education, these programs have and will continue to be altered to suit the times (Zimmerman, 2015; Kendall, 2012).
sexuality education from the early 1900s to current debates on Comprehensive Sexuality Education as per the WHO, UNESCO and UNFPA’s policies and other human rights charters. UNESCO took up sexuality education at the international level to develop a global sexuality education program in 2007. Although the guidelines have been drafted, Yankah and Aggleton (2017) indicate that there still exists a challenge of ensuring the implementation of these guidelines within countries in the Global South. This is because, the success of sexuality education programmes lies in them being formally recognized and purposefully targeted to address the sexuality needs of members of the society (Duncan & Goddard, 2005).

Two major forms of sex education currently exist although they are in no way mutually exclusive (Lesko, 2010). Goddard and Duncan (2005), Kendall (2012) and Zimmerman (2015) like other scholars in sexuality education distinguishes between the Abstinence Only (until Marriage) Sexuality education and Comprehensive sexuality education (CSE). CSE was introduced as; "a right-based and gender-focused approach to sexuality education, whether in school or out of school" (UNFPA, 2015 pg. 11). With rights at the centre of the current development agenda, CSE is promoted as a more "progressive" form of sexuality education

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23 “Formally” here refer to recognition within the local jurisdiction of the state. According to Duncan and Goddard (2005) they must instill the norms and values of the society into its members in ways that resonate with the expectations that the society has for them. It should not just be about sexuality education but sexuality socialization.

24 Tiffany Jones (2011) also argues against the dichotomous approaches. She discusses 28 different frameworks but concluded that they are not mutually exclusive. She also argues that there is no flawless universal sex education that will suit every student or every context.

25 Although these authors focus on Family Life Education, which from their definition is imbued with Christian values of abstinence, they still dictate a few pages to talking about comprehensive sexuality education and abstinence only programs.

26 More efforts are being made to encourage nations especially member states of the United Nations to implement comprehensive sexuality education programs in their countries. In October 2014, the UNFPA held a comprehensive sexuality education (CSE) evaluation expert meeting to assess and build consensus on a framework for the identification and measurement of indicators of an "empowerment approach" to CSE.

27 The SDGs aim to increase access to CSE especially in schools and improve SRH knowledge so that young people make healthy, informed choices about their sexuality and reproductive lives.
(Rasmussen, 2010). Nonetheless, Abstinence\textsuperscript{29} programs have been the most preferred form for many religious societies because CSE has secular, value-free, liberal intonations, which conflict with the values of communities where religion and religious values is the glue that holds the community together (Kendall, 2012).

Rasmussen (2010) in her work on Secularism, Religion and Progressive Sexuality Education highlight the underlying principles of CSE. According to her, CSE is marked by the basic assumptions that many young people are sexually active and may be at risk of STIs and unwanted pregnancies; not everyone is heterosexual; sexuality education should be supported by expert knowledge; and that young people are autonomous subjects with the right to be informed in order to make educated decisions about sex (Rasmussen, 2010). For Rasmussen (2010), CSE takes a secular stance - one that emphasizes scientific fact over (religious) values - defined as progressive but that has the potential of othering religions groups such as Muslims (Asad, 2003). Similarly, this suggested "progressive" form of sex education acts as Rasmussen (2011) calls it, appears to act as a form of imperial disruption of the African culture where religion runs through every fibre of society\textsuperscript{30}.

According to (Boonstra, 2015) implementation of sexuality education programs takes place at multiple levels. At the micro level, educators and parents are the main human actors in the delivery of sexuality education. Literature indicates that parents are the most ideal educators

\textsuperscript{28}The progressiveness lies in the fact that it is liberal in its approach to diversity, recognition, and inclusion and relies on scientific rationality and empowers the individual to make informed decisions related to their own sexuality (Kendall, 2012).

\textsuperscript{29}Some Abstinence programs also teach about contraception but emphasize the benefits of abstinence until marriage (Kendall, 2012; Duncan & Goddard, 2005). CSE programs are expected to serve as an intervention for the promotion of equality, rights and promotion of the sexual, reproductive, and mental wellbeing of all young people including adolescents with intellectual and developmental disabilities.

\textsuperscript{30}According to the United Nations Human rights Office of the high commissioner, the Sustainable development goals (SDGs) unlike the Millennium development goals (MDGs) covers issues related to all human rights.

\textsuperscript{30}Our (African) cultural values and thought are woven in the fabric of beliefs about God and the supernatuaral.
of their children/adolescents Krauss and Miller (2012) with mothers being the main actors in that process.  

However, factors such as the age of the child (dren) (Kakavoulis, 2001) and the fear of promoting sexual activity also affect the content and mode of delivery. Literature also indicates that discussions about sex are usually technical, centered on HIV and STI prevention and focused on the consequences (La Sala, 2015; Kapungu, et al 2010). This helps to convey their messages of disapproval of children engaging in sexual relationships (Elliot, 2010). Fear tactics were employed mostly for girls (Pluhar & Kuriloff, 2004). Despite the long and continuous struggle between parents and educational institutions about the content of sexuality education delivered to their children some studies in the Global North have shown that parents are more supportive of sexuality educational programs that are abstinence-based and not abstinence-only (Howard-Barr et al., 2011; Eisenberg et al., 2008; Kirby 2007).

Studies from parts of Africa have indicated similar patterns (e.g. Musa et al 2008 (Nigeria) and Kumikyere et al, 2007 (Ghana)). Determinants of sexual communication and education between parents and children on the contrary have been communicated as mostly influenced by parent's level of education, occupation, traditional norms and religion (Kamangu et al., 2017). Furthermore, as indicated in studies from the West, sex education occurs more frequently for girls than for boys - reason being the concern about risks of pregnancies for girls (Kamangu et al 2017). Customarily in some communities, grandparents and not parents are the main actors in the process. Mothers are more likely to be involved in the sex education of their children than fathers (Morgan, Thorne & Zurbriggan, 2010; Harris et al 2013). Sex communication occurs mostly between mothers and daughters, (Kapungu et al, 2010; Wisnieski, Sieving and Garwick, 2015). Although boys receive more sex information from their fathers (Tobey, et. al 2011) and girls from their mothers (Kampungu et al, 2010).

Many parents think that their children are innocent until they are approaching teenager years (Pluhar et al 2006). When they begin to deliver sexuality education, issues about sexual pleasure are avoided and instead abstinence is promoted and emphasised (Aronowitz et. al, 2010) because parents are concerned about sending the wrong message and endorsing sexual activity (Kakavouliis, 2001; Wilson, Dalberth, and Gard, 2010).

Mothers more than fathers are engaged in sex education/communication and sex communication is low.
ones in some customs who do the education. Having parents do it, is a role with which they are unfamiliar (Kamangu et al. 2017).

Generally, educators have also reported that confidence levels in delivering particular topics, and personal limitations (which is quite vague) influenced teaching sex education although they too are primary sexuality educators. In studies in Sub Saharan Africa, there have been reports of positive confidence levels among teachers. For example, a study by Helleve et al. (2009) found that teachers/educators in urban and rural South Africa and Tanzania reported being fairly confident in teaching HIV/AIDS and sexuality. However, religion of educators has been found to also determine how educators delivered sex education in African communities (Iyer and Aggleton, 2014). Iyer and Aggleton (2014) report that, sex education in African schools is mostly centered around HIV prevention through abstinence first and then contraception education (which is only mentioned and not discussed into much detail). This is because most African societies encourage sex only in marriage and thus to teach explicitly about protection will be to encourage such activity; instead, emphasis is placed on God and a moral/religious code (Iyer and Aggleton, 2014). Additionally, sexuality education is covered across various aspects of the school curricula such as integrated science or biology, religious and moral education, citizenship education or social studies among others (Iyer and Aggleton 2014). Other schools run sexuality education programs separately however there are constraints such as altering existing curricula to accommodate the separate programs (Vanwesenbeek et al., 2015). Other modes of delivering sex education reported in other studies includde one-on-one counselling and the use of the fear model. (Awusabo-Asare et al., 2017). The language used and

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34 In a study in Australia by Duffy, Fotinatos, Smith and Burke (2013) puberty health educators reported low confidence discussing menstruation, wet dreams and sexual intercourse. Another study in the USA however reported that educators were very confident about delivering sexuality education levels (Fisher & Cummings, 2016).
focus of these studies, presentation and representation of findings in the Global North and Global South in the light of Western power and hegemony will be worth undertaking.

2.2.4 Intellectual Disability and Sexuality (Education)

Intellectual disability has undergone over a hundred years of categorisation, recategorisation, naming, and renaming (Rapley, 2004). From idiots to morons, imbeciles and feebleminded, mentally handicapped and now, persons with intellectual disabilities (PWIDS), labels and the social constructions that have been associated with these persons have and keep evolving with time and across various spaces (Rapley, 2004; Noll and Trent, 2004; Wright, 2011). A number of authors e.g. Kempton and Khan 1991; Trent 1994; Mutua et al., 2011) have recounted the histories of PWIDDS in the West. The history of IDD education can be traced back to the 1700s in Europe where the likes of Jean- Marc Itard and Johann Pestalozzi, developed programs that helped to train persons who were classified as mentally retarded (Kempton and Khan, 1991). However, in 1886, the Idiots Act was passed in the UK leading to the building of special schools and asylums although they were no different from institutions for those with mental illness (Mutua, et al., 2011; Trent, 1994).

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35 Rapley (2004) acknowledges the power of discourse in the construction of intellectual disabilities. The categorisation and recategorisations have been since the mid 1800s and been facilitated mostly by the science of psychology.
36 Focuses specifically on Down syndrome and how science over the years, has helped to shape attitudes towards and interventions for these people.
37 How persons with intellectual disabilities in Europe and America moved from being taken care of by the church to moving into mental institutions where they were separated from society to the current perspectives on special education and inclusion.
38 Developed the first systematic and documented skills based program as an intervention model for the feeble-minded (Maulik & Harbour, 2010).
39 For Trent, the economic vulnerability of PWIDDS was the main reason for the discrimination and institutionalization.
Concurrently, there is a long history to the sexuality of PWIDDs woven in eras of eugenics, virgin cleansing\(^{40}\), repression and punishment (Groce, 2004; Kempton and Khan, 1991; Griffiths et al., 2004). The scientific discourse at the time presented their sexuality as fearful, dangerous, out of control and if they were allowed to reproduce, could damage society by spreading undesirable genetic characteristics\(^{41}\) (Rhodes, 2010; Kempton and Khan, 1991). However, with groups of parents organising for better services for their children in the 60s, the spread of the philosophy of normalisation\(^{42}\), coupled with the civil rights movement, and acceptance of sex education in schools, their sexuality begun to be viewed differently (Kempton and Khan, 1991; Noll and Trent, 2004). Since then, research into the sexuality needs of learners continues to grow touching on various aspects of sexuality as well as studies on curricula and program development and implementation that will meet the ever-evolving needs of these persons. (e.g. Giles, 1987; Blanchet and Wolfe, 2002; Bambury, et al., 1999; Caster 1988; Schaafisma et al., 2013; 2015). Today, many more opportunities are opening up mostly in the Global North for the recognition of the sexuality of PWIDDs in ways that are more positive (Gill, 2012; Morales, Lopez and Mullet, 2011; Rogers, 2009; Dukes & McGuire, 2009, Morin et al., 2013\(^{43}\)).

\(^{40}\) Virgin Cleansing was a practise of sleeping with virgins to get cured of some disease or to avert spiritual bad luck. Persons with IDD have been seen as asexual and as such virgins. For this reason, in 16th century Europe, persons who had gonorrhea and syphilis would sleep with PWIDDDs to cure their diseases. In some part of Africa, some of these practises still exist especially in relation to curing HIV/AIDS. Groce (2004) in Rohleder (2010) have mentioned this practise.

\(^{41}\) At the time, there was "scientific evidence" about mental retardation being the cause of all social ills and society needed to be protected from these persons (Mutua, Siders & Bakken, 2011).

\(^{42}\) This resulted in more research, training of staff in specialized institutions, the set-up of special education classes in public schools and better opportunities for socialization such as dances were organized for these persons although these were done under strict surveillance. (Kempton and Khan, 1991) This philosophy of Normalization spread from Europe to America and aimed to give PWIDDDs a normal life as possible- normal education, normal job opportunities and increased community participation.

\(^{43}\) The study revealed that there were more positive attitudes towards the sexuality of PWIDDDs among younger and more educated members of the public (in Quebec)
In sub-Saharan Africa, there is little research into the histories\(^{44}\) of PWIDDs. However particular forms such as those comorbid with epilepsy, lack or difficulties in speech, behavioural challenges and severe physical disability were marked as a curse or punishment from ancestors or spiritual, objects of good luck, ancestral reincarnation or spirit possession (Munyi, 2012). According to Munyi (2012), the Ga of Ghana treated persons with IDD with respect and kindness because they are believed to be deities. In communities where they are perceived as bringing misfortune and as a curse, they are locked away and sometimes killed (Munyi, 2012). The establishment of psychiatry also led to the little knowledge about PWIDDs and hence they even suffer discrimination when trying to access general health care service\(^{45}\). With respect to state involvement, special schools for PWIDDs in Ghana receive very little funding in the face of the limited government resources\(^{46}\). Today, in many parts of Africa knowledge about IDD and interventions to facilitate their full inclusion is low (Mckenzie et al, 2013).

Literature indicates that PWIDDs in Africa are at risk for abuse however their sexuality remains neglected and still met with the historical notions of asexuality\(^{47}\) and inability to develop intimate relationships on the one hand and hypersexuality on the other hand (Mckenzie, McConkey & Adnams, 2013; Aderemi, 2014). They are therefore discouraged and shielded against or prohibited from encounters likely to end in sexual interaction (Mckenzie et al, 2013).

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\(^{44}\) Lotter (1978) gives possible reasons such as IDD not fitting the Specified behavioural criteria (in the case of autism), differences in diagnostic labels. Other reasons for the low incidence at the time also included low interest in this areas in the midst of more pressing development issues such as poverty, and disease, malnutrition and the physical disabilities.

\(^{45}\) Inclusion Ghana’s Access to health report (2013) indicates that medical professionals such as nurses discriminate against PWIDDs because they are unaware of their needs and how to meet them. They refer them to the psychiatric hospital even when they come down with general ailments like malaria. Additionally the label of mental handicap which appears to make IDD synonymous with mental disability has also accounted for this.

\(^{46}\) The researcher, witnessed a public accounts committee presentation in June 2016 where the Minister of Gender and Social Protection reported a lack of state budgetary allocation for special schools for learners with IDD.

\(^{47}\) It is this notion that makes them victims of virgin cleansing (Mackenzie et al, 2013)
PWIDDs in schools are no different. They lack adequate knowledge about sexuality, are thus very prone to sexual abuse, and are at risk of HIV infections (Aderemi 2014; Phasha & Nyokangi, 2012; Phasha & Nyokangi, 2012a; Dawood et al., 2006). Despite the high exposure to sexual information especially through the media (Dawood et al., 2006), factors such as inability to communicate abuse; peer pressure, arranged relationships and transactional sex, expose them to sexual relationships, sexual violence and increase their risk for HIV infection (Nyokangi & Phasha, 2016; Aderemi, 2014). Hanass-Hancock (2009) mentions that PWIDDs may themselves also engage in sexual activity to prove that they are capable of having sex and reproducing or to gain love\(^48\).

Generally, educators' role in sex education is crucial but continues to be hampered by teacher unpreparedness/ lack of skills, negative perceptions and attitudes, inappropriate curriculum. For example, in Aderemi (2014) and Rohleder et al. (2012) and Hanass-Hancock (2008) the authors indicate that curricula made primarily for use in mainstream schools are not tailored to meet the specific needs of persons with disabilities. There is also the inherent tensions that exist between the discourses of human rights and discourses that restrict sexual behaviours (Rohleder and Swartz, 2009) as well as the structure of the special class (with multiple age groups in one class) (De Reus et al., 2015). De Reus et al. (2015) also found that parents as well as educators' own colleagues and community members, and the cultural upbringing influenced the kind of sexuality education educators gives to the learners. In effect, topics addressed were mostly limited to bodily development, personal hygiene and abstinence while topics on sexual behaviours such as masturbation were not addressed (De Reus et al., 2015).

\(^{48}\) The need to prove may be from the cultural link between sexual activity, reproduction and maturity/adulthood.
2.2.5 Ghana: Socio-Demographics and History in the Context of IDD and Sex Education

Formerly known as the British Gold Coast, the Republic of Ghana, located along the Gulf of Guinea and Atlantic Ocean was the first country in Sub-Saharan Africa to obtain independence in 1957. It has a population of about 25 million and has ten Administrative regions (Ghana Statistical Service (GSS), 2012). Ghana is very multiethnic and multi-tribal, however, the Akan, Mole Dagbani, Ewe, and Ga Adangbe are the predominant ethnic groups in the country (GSS, 2012). In 2013, WIN- Gallup International released a global poll, which named Ghana the most religious country in the world. According to the 2010 census, 71% profess to be Christians, 17.6% Muslims, 5.2% practice animism and 5.3% no religion (GSS, 2012). The Northern Region is predominantly Muslim (60%) while all the other nine (9) regions are predominantly Christian. Anarfi and Owusu (2010) have indicated that religion and culture exerts the most influence on sexual socialization in Ghana with the three dominant religions dictating the sexual norms that exist within the society. This is not surprising because like many African countries, Ghanaian customs and traditions are enshrined in beliefs in the supernatural and the state runs a pluralistic governance system where there is no separation between the religion and the secular.

\[49\] Subgroups of the Akan which include the Asante, Fante Akyem, Akwamu, Nzema, Akuapen among others (Gocking, 1994). Some scholars conclude that the Ewe and Ga are part of the Kwa group while others dispute it and attribute the resemblance is some linguistic phrases and nuances to cultural borrowing through intertribal trade and settlement. The Moshi- Dagomba belong to the Gur language group of West African Savanna region. The Kwa and Gur are the major language groups of that region. (Gocking, 1994)

\[50\] Akan the Moshi- Dagomba belong to the Gur language group of West African Savannah region. The Kwa and Gur are the major language groups of the region.

\[51\] Beliefs in a supernatural being, ancestors and other gods. The belief that there is a spiritual force that drives the physical. It is that sense of the spiritual that unites individuals as a community. The spirit of various communities and groups are expressed in the totems and symbols such as the Golden stool of the Ashanti (Adams 2010; Danquah, 2014) and totem bonds which regulate sexual practises (Freud, 2004; Alun, 2005)
The role of the state, religion, and customs or culture in the context of IDD and sex education have not been explored together by many scholars. Nonetheless, various literature touch on aspects that will give a comprehensive overview of the current situation (e.g. Anarfi & Owusu (2011); Owusu & Anarfi (2010) do include the context of IDD). According to the 2010 census, 15.2% of the population of persons with disability are reported to have IDD. The Inclusion Ghana website lists 13 segregated special schools for persons with IDD (which are mostly residential), 24 integrated schools for PWIDDS and two established private schools.

Ghana is known to be a patriarchal society (Nukunya, 2003). Children are socialized early in life along distinct sex roles (Ankomah, 2004; Nukunya 2003). Women were generally responsible for the chores, cooking and general upkeep of the home while men were expected to make an income for the upkeep of the home (Ankomah, 2004). Besides biological development (especially menstruation for females) maturity is traditionally defined along the lines of one's ability to fulfill these roles (Ankomah, 2004). Presently newer and more complex ways of defining identity such as completion of schooling, employment, ability to rent or perhaps purchase a living quarters of your own (especially for men) and marriage (Ansell, 2016; Burrell, 2012; Asampong et al 2013) have emerged. Thus, for many persons with disabilities and for

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52 Although this can be contested given that many of these children are hidden away because of the associated stigma.
53 Although these are called inclusive schools, my experience with implementing an inclusive model at the Autism centre in Accra which actually entails the child being a part of the mainstream school with support systems made available to facilitate full functioning within that environment informs my choice of definition. These schools on the other hand appear to only be inclusive according to the government based on the fact that the buildings are located within the compound of the mainstream school. Unfortunately, there is a complete difference in curriculum structure. Moreover, these schools run till midday while the mainstream runs until 2 -3 p.m.
54 Given that the largest ethnic group (Akan) is matrilineal whether this was the case prior to colonialism is worth investigating. Could it be a description the colonialists created themselves? Additionally, Gocking (1990) in a presentation and analysis of historical documents refers to the anthropological work of Polly Hill who mentions how Christian marriage established and legitimized patriarchal authority in Ghana.
55 These are however changing with many more women working outside the home and men supporting with the chores.
PWIDDs in special schools in particular, achieving maturity/adulthood is almost impracticable as there is no clear age for graduating (Lamptey et al., 2015; Gregorius, 2014). It takes a whole village to raise a child. This Ghanaian maxim (though not limited to Ghana) goes to show that the socialization that takes place in the life of an individual goes beyond the nuclear and even extended families.

Ghana's current educational system appears to struggle due to the adoption and copying of postcolonial educational systems and policies (Obeng, 2002; Dei, 2004). Adjei (2007) indicates that Ghana’s schooling and education system is still dominated by Euro-American norms, worldview, and epistemology and does not take into account the sociocultural difference that exists among learners (Dei, 2004). Beside this, there is inadequate public funding for mainstream public schools (Dei, 2004). One can therefore wonder what the situation is for learners with IDD in special schools. Thankfully, religious organisations (mostly, churches), non-governmental and private agencies/persons continue to support the educational system of the country by setting up schools, and intervention programs for persons with intellectual/developmental disabilities in the country56.

Prior to the introduction of formal education in the mid-1800s however, PWIDDs did not exist as a distinct category. Additionally, the mental asylums that catered for PWIDDs were also built almost a century after western education was initiated57. Literature from African scholars such as Mfum-Mensah (2017), indicate that African education prior to the arrival of the Europeans, was inclusive of persons with disabilities, including those with IDD. Nigerian

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56 A number of special education sites for PWIDD integrated schools are located on mission school compounds
57 Quarshie (2011) in his research on the lunatic asylums of the Gold coast from 1887-1906 narrates from Forster's (1962) account. He mentions discrepancies in how lunacy was determined and how the lunatics served as labourers and were tasked to manual labour. Although the institution catered for persons who suffered from mania, melancholia, dementia and idiocy, he mentions that there were records that suggested that the confinement of females especially was premeditated given the differentiated labor tasks at the asylum.
scholars, Adeyemi and Adeyinka (2012) have however cautioned that not all African beliefs were accommodating of persons with disabilities. For communities that accommodated disabilities, disabled persons were included; and because their contribution to the community was appreciated, no matter how small, they were given opportunities to be productive in their communities (Mfum-Mensah, 2017). This history is confirmed by present studies in other African countries that have shown that children with IDD in rural areas are more socially capable than their counterparts in urban settings (Pillay, 2003). Furthermore, Ghanaian proverbs such as, "Nyame bo onifereni no, obor ne boafo" (When God created the blind man he created his helper) give some indication that not all African societies treated persons with disability negatively. Previous examples from the Ga people and the people of Northern Ghana have been mentioned in the previous sections.

Sex education also existed prior to colonisation. Through rites of passage and in everyday interactions, girls in particular were taught the intricacies of sexual pleasure, safe periods, and self-care and sex taboos\(^58\) (Ankomah, 2004; Nukunya, 2003). Today religion, custom and the state combine to regulate the sexuality of Ghanaians. According to previous custom, a girl was sent into marriage not too long after she starts menstruating\(^59\). These have changed since puberty rites are almost non-existent and the waiting period between menarche and marriage has increased because of schooling and other socioeconomic factors (Ankomah, 2004).

\(^{58}\) In the Northern half of the country groups such as the Konkomba practice childhood betrothal and so menstruation only meant that the girl was mature and ready to move to her marital home. There were also taboos related to sexuality such as those related to the ceremonial uncleanness of a woman when she was menstruating. Many of such taboos have become irrelevant with Christianity, education and other aspects of modernity, which might include the availability of sanitary towels.

\(^{59}\) Historical literature indicates that girls were reaching puberty at a later age, average 15 years old
The researcher did not find any records about whether or not any persons with intellectual and developmental disability went through these rites but we can assume that this is so because it was not a distinct category among the Ghanaian societies, and for the colonialists, not a category of interest, given that they too were in the eugenics era\textsuperscript{60}. On the other hand, we can also assume that in societies where they were not accepted, they were killed\textsuperscript{61}. Marriage in many communities occurred shortly after puberty rites. Although there are women with intellectual disabilities who have children of their own in some rural communities, very little is known about whether or not aspects of traditional marriage such as the given of the "head drink" or "paying of bride wealth" was performed. These are areas that are worth investigating.

Ghana's laws and customs are vested in religious beliefs. The influence of religion runs deep when it comes to sexuality and IDD. As mentioned earlier perceptions of these children span from curses or punishments form the gods, to blessings from God. Customarily, spirituality is at the centre of every rite of passage and ubiquitous in everyday life and cannot be over emphasized and the taboos are enshrined in the religious beliefs of the people. There is a social order in which the individual operates. The individual is at the heart of a number of relationships namely family, lineage, clan, ethnic group and state and a shared value of neighborliness (Ayete-Nyampong, 2008; Nukunya, 2003). The role of elders and community leaders such as chiefs and queen-mothers are further reinforced by these relationships. For instance, in the event of a death, the chiefs and elders are informed, hence it is common to witness on posters that announce the death of a community member, a list of traditional authorities (Chiefs and elders), before the family, as the ones announcing the death of the person. The roles of external family members

\textsuperscript{60} As previously stated, the eugenics period lasted till the mid 1900s and colonial rule in Ghana did not end till 1957.

\textsuperscript{61} "yeko gya no kwan" (to see him/her off) is a phrase used by the Akan in Ghana to denote giving back a spirit child to the forest or river god. This was carried out on children who were born with visible deformities.

Chiefs are regarded as the custodians of culture and the land and in modern times continue to wield public authority in Ghana, likely as a result of the governmental structures in place. There is a Ministry for Chieftaincy and Religious affairs (previously Ministry for Chieftaincy and Traditional Affairs), 10 regional house of chiefs (and queen-mothers) representing every regions and one national house of chiefs (and queen-mothers). This network is likely the catalyst driving development and accountability at traditional community levels (Yarrow, 2008; Kleist 2011) in spite of their individual flaws as evident in land disputes and scandals related to mining (Quarshie, 2015). Similarly, queen-mothers have also retained their role when it comes to addressing issues of women and especially female children. They lead and perform various rituals as they pertain to puberty rites (as is evident during the Dipo and bragoro rites of the Krobo and Akan), marriage and funerals, as well as dispute resolution and caring for vulnerable persons (Lund & Agyei-Mensah, 2008; Steegstra, 2009; Brempong, 2009; Brydon, 1996). Being the custodians of the land and its resources as well as the spiritual head of the people, Ghana through the ministry of Chieftaincy and Religious Affairs (have worked and continue to collaborate on the abolition of certain customary practices that have become outdated and that are harmful such as the Trokosi system, female genital mutilation. The position and role of Queen mothers in the support of vulnerable children have not been documented much but Lund and Agyei-Mensah (2008) found that along with the extended family system, they provide security and support especially with children orphaned by HIV/AIDS. No studies have been conducted to know specifically the roles traditional rulers have played in the lives of PWIDDs,
however to be able to harness their potential in driving the inclusion of PWIDDs at all levels, such research is worth undertaking.

At national level, the state uses the school system and laws\textsuperscript{62} to regulate sexuality (Foucault, 1978) however, there is a legal pluralism that exists that at times leads to conflict\textsuperscript{63} (Aderinto, 2015). The need for school-based sex education came with the school system (which increased the duration of waiting between menarche and marriage and created an adolescence stage) (Ankomah, 2004). This gap created by the school system, meant that many males and females are unlikely to receive the formal traditional sex education that existed prior to colonisation\textsuperscript{64}. Beyond that are various legislature and policies that support Adolescent sexual and reproductive health as previously mentioned. Yet for learners with IDD, their need for sexuality education remains unmet even in spite of this development.

Finally, Christianity and Islam play very important roles in regulating the sexuality of members of any Ghanaian society although most studies appear biased towards Christianity or occurred in non-Islamic communities (e.g. Anafi and Owusu, 2011; Mcfaland, Uecker & Regnerus 2011). For example, Osafo, Asampong and Langmagne (2014) reported that elevated religiosity\textsuperscript{65}, reduced incidence of premarital sex among Catholics and conservative Protestants. However, the same was not true among the liberal to moderate Protestants (Chamlin, Beegghley and Fenwick, 2004). Early Christianity reordered sexual norms through the conflation of ordinance marriage with Christian marriage, the discouraging of some puberty rites, and

\textsuperscript{62} Such as Section 102 of the Criminal Offences code (Act29) which criminalizes sexual intercourse with a person with intellectual/developmental disability as mentioned earlier.

\textsuperscript{63} For instance, there is an ongoing "national" "war" against child marriage (i.e. however the state allows sexual consent to be obtainable at 16 but marriage only after 18.)

\textsuperscript{64} Therefore, in most homes and in the communities, most sexuality information besides abstinence (with emphasis on females) is left until just before marriage (Anafi and Owusu, 2010).

\textsuperscript{65} Which they defined as church attendance and strength of religious identification.
establishment of the formal educational system (Obeng, 1996; Ross, 1957). For many years, the orthodox churches, Catholics, Presbyterians (Basel mission), Evangelical Presbyterian (Bremen Mission) Anglican and Methodists were the main churches in the country and they used the Bible and education to propagate their mission (Ross, 1957).

Christianity has taken deep roots in Ghana with the influx of various church denominations. Gyadu (2005) in Lauterbach (2006) identifies 3 waves of Pentecostal Christianity- the sunsum sore (spiritual churches) established and led by local prophets 66; the classical Pentecostal churches introduced by foreign missionaries. e.g. Apostolic church, church of Pentecost; Neo Pentecostal/ Charismatic 67 (comprising new indigenous/independent churches, trans-denominational fellowships, and charismatic groups). While some studies have shown Orthodox Christians to be more conservative than Pentecostals on the issues of sexuality, other studies have shown that Pentecostals are less likely to have liberal views towards sex than traditional orthodox Christians who are thought to be more conservative (e.g. in Kay and Hunt, 2014; Lauterbach, 2006; 2010; 2016). For example, churches like the Deeper life Ministries and recent incidents of public shaming (and caning and two teenagers who had an affair, which resulted in pregnancy in a spiritual church in Ghana), show that there exist various Pentecostal movements. Thus, depending on the mission, vision and values of the church, as well as the emphasis of their ministry, different levels of attentions might be paid to different areas of Christian living and community life, including sexuality (Barna, 2000; Unruh and Sider, 2005).

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66 Emphasis was on healing and the manifestation of the Holy Spirit (Sunsum Kronkron).
67 What distinguishes them from the classical Pentecostal churches is that the pastors are well educated. Many classical Pentecostal churches have more strict rules regarding worship and have dress codes. (Lauterbach, 2006)
Literature suggests that there is an emergence of new spaces for sexual information and activity for young people in Ghana such as pornography, mainstream media and social media. The implication of these spaces is that the youth are getting sexual information but without direction and increasing risk to sexual violence and abuse (Anderson, 2016). Other studies have indicated that few churches (especially of the Charismatic wave) are also emerging as avenues for sexuality education in the wake of the "moral crises". However, the tendency that this still excludes a great majority of young people including those with IDD exists. Sexuality education is therefore necessary at both school, home and community levels.

This section has demonstrated that although sexuality education or sexual socialization existed in various forms prior to colonialism, the changes informed by colonialism, have confined intentional sexuality education to the classroom in schools, or in Charismatic churches or for in the homes mostly when a child is old enough to marry (i.e. has a source of income). These make unlikely opportunities for PWIDDS to receive any form of direct sexuality education. Additionally, although new avenues for sex information have emerged, there is limited guidance for the general population and thus for PWIDDS as well (i.e. considerations for

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68 There is a growing number of Sex talk shows on mainstream as well as online radio a sex talk shows. Notable among such were Sex in the City (which has everything sex-related as the name suggests) and Sister-Sister (which focuses on sexuality and relationship issues of women). These were structured to suit the urban and elite cultures. Shows aired in the local language and for local consumption included Woba Ada Anaa (is your child asleep?) and Akumaa Mama Zimbie radio and TV shows - which also stream on the internet and are very explicit in language. Today, almost every media station, except national television runs at least one of such program. I believe this dispels the idea that Ghanaian culture frowns about open sex talk. The proliferation of soap operas, and rise of the Ghallywood (Ghana) and Nollywood (Nigeria) film industries have also opened up new spaces for sexual information for the youth.

69 The emergence of social media has also increased access to porn and exposed to young people in Ghana to ideas about sex and sexuality that they were naïve about. Anderson 2016 (found in a study that about 90% of female Junior high school students cape coast who used "whatsapp" mostly exchanged pornographic material with their peers. A new culture of taking nude "selfies" to send to lovers also put females especially in compromising positions of public ridicule shame and embarrassment. There is a need for more research into this area to understand this new development and how it can be addressed especially, to promote the dignity of young women in Ghana.
societal values of morality and its associated risks). Furthermore, in the context of persons with IDD there is very little research to enable policy makers to know what their needs are and how to address them. Despite the growing advocacy in Ghana for the full inclusion of PWIDDS in Ghana (including the right to family life), PWIDDS cannot make the right choices around sexuality if they are not engaged in some intentional process of sexuality education. Although many studies in the West have directly consulted PWIDDS about their sexuality needs (e.g. Bernert & Olgetree, 2013; Turner & Crane 2016; Garbutt et al., 2010 among others) within Ghana, given the communal nature of the society, there is the need to address this issue in a culturally acceptable way.

2.2.6 Structural Adjustment Programmes to Sustainable Development Goals and Effects on Social Development in Ghana

Given that this study is in the context of Global Development, there is a need to capture the development context as it relates to the economic and political environment and its effects on (special) education, disability, health, HIV/AIDS, social welfare and other areas of public life. Addison (2015) identifies three stages of development programming in the last 30 years of African development SAP, MDGs and the current Post-2015 SDGs. This section will present a brief account of these three regimes and discuss their effects on Education, Health (especially HIV), and social welfare in Ghana.

Many African countries like Ghana soon after independence were doing very well economically and many were exporting, primary produce and were self-sufficient and public services such as education and healthcare were free (Addison, 2015; Nguyen, 2010). However, things turned around in from the 1970s, leaving many African countries worse-off than they
started when they attained independence. Notable among these are the oil price hikes in the 70’s along with falling world prices of primary produce such as cocoa and mineral like gold Bauxite and manganese in the case of Ghana, the Western facilitated coups and corrupt dictatorships as well as inter-ethnic and civil wars (Frimpong-Ansah, 1991; Addison, 2015; Laird, 2008).

SAP was a neo-liberal policy (Brooks 2016) that consisted of a set of conditions proposed by the World Bank and IMF to many African countries at the time before lending to them. Ghana was a socialist state prior to the implementation of SAP (Frimpong-Ansah, 1991). Major reform actions led to introduction of service user fees in public sectors of health and education, removal of agricultural subsidies, privatization of certain public sector organizations, allowing international competition within the local economy and an influx of international NGOs in the areas of social development (Laird, 2008; Addison, 2015; Dlamini, 2008; Ofori-Addo, 1995). The imposition of school fees had many effects on the society including reduced access to higher education for many women and hence lower opportunities for employment, thus driving many of such women into what Epprecht (2013) calls “survival sex”. Additionally, with the disincentives for agriculture came an increase in rural-urban migration in search of jobs which split families and encouraged extra marital sexual encounters (Klein, Easton and Parker, 2002).

According to Awusabo - Asare et al. (1993), the first case of AIDS in Ghana was recorded in March 1986. The patient was a Ghanaian who was resident in Germany, and 80% of the new cases after that were among Ghanaians who were return migrants from abroad thus leading to the perception that AIDS was a foreign disease (Awusabo-Asare et al., 1993). Sex work also became popular as well as sexual favours for jobs and contracts during the period and thus increased risks for contracting HIV/AIDS (Awusabo-Asare et al., 1993; Ankomah, 1999).

71 These coups were in a bid to topple communism (Laird 2008)
HIV/AIDS during SAP received a lot of attention at the expense of other diseases such as malaria (Nguyen, 2010). Furthermore, there was a considerable decline in the access and utilization of health services and in effect poor quality of health. With the cash and carry system - which demanded upfront payment for health services - as well as the decline in household incomes, postponement of medical treatment, self-medication, and the use of alternative medicines by spiritual and traditional healers became the norm (Nguyen, 2010) not only in the Ivory Coast but in Ghana as well. This further impacted health negatively especially during the HIV/AIDS epidemic where testing and early treatment was necessary for survival (Nguyen; Parker 2002). NGOs did step in mostly in the rural district areas and set up mutual health insurance schemes, to enable persons have access to affordable healthcare. However, many of these were not sustained after the projects ended or funding ceased (Ofori-Addo, 1995; Kuyini et al., 2011).

The Ministry of Employment and Social Welfare since the 1960s was mandated to see to the welfare and rehabilitation of person with disabilities in the country (Laird, 2008; Ofori-Addo, 1995). Unfortunately, due to government cuts on social development, the Ministry suffered huge underfunding hence the introduction of community-based rehabilitation in 1992 by the UNDP to take on some of the social development projects especially in relation to persons with disabilities (Laird, 2008; Ofori Addo, 1995). Service to PWIDDs were provided by the Ministry in collaboration with the Ministry of education and Ghana education Service prior to SAP. Community-Based rehabilitation was therefore introduced in 1992 to support the ministry by taking on some of the social development projects at district levels and these included special education and vocational rehabilitation programs (Ofori – Addo, 1995). Currently, the
Department of social welfare (as presently known) still lacks funds to support persons with disabilities and other vulnerable populations in the society (Laird, 2008).

Education also suffered during SAP as mentioned earlier, leading to systematic gender discrimination. Although there is scarce information on the impact on special education likely because much of it has been captured under social welfare, the systematic gender discrimination that resulted from SAP is an indicator of what special education has suffered and still suffers as a result of this program. Indeed, persons with disabilities -as mentioned in the homage paid to feminism and its contribution to my work – and women face similar social structural and institutional challenges.

To rectify the challenges brought about by the SAP and in reaction to its criticisms, the World Bank and IMF introduced the HIPC initiative which was meant to cancel the debts owed and give countries a fresh start. What followed was the millennium development Goals (MDGs) which was introduced in 2000. The MDGs however were criticized by an Egyptian economist Saimr Amin as a Western Imperialist imposition on the Global South (Mutasa, 2015). Among other criticisms were the exclusion of persons with disabilities and inadaptability to national needs (Fehling, Nelson & Venkatapuram, 2013; Wolbring et al., 2013). According to Masset and White (2004), the MDGs left out the chronically poor; a population of which PWIDDs form a considerable proportion. Despite the fact that Ghana has achieved some progress in terms of education with the MDGs, the progress has been rather slow (Birdsall, Levine & Ibrahim, 2005) and the welfare of PWIDDs appear not to have featured at all in the country's development plans.

Currently the post 2015 sustainable development agenda is on-going in Ghana like in other nations of the world. Taking into consideration the convention on the rights of Person with disabilities (CRPD) persons with disabilities explicitly mentioned and their needs included in
goals towards; No poverty (Goal 1), Zero Hunger (Goal 2), Good health and Wellbeing (Goal 3), Quality education (Goal 4), Gender equality (Goal 5), Clean water and sanitation (Goal 6), Affordable clean energy (Goal 7), Decent Work (Goal 9), Reduced inequalities (Goal 10), Sustainable cities and communities (Goal 11), Climate Action (Goal 13), Peace, Justice and strong institutions, (Goal 16) and in Partnership for the goals (Goal 17). With respect to this study however, the sexual and reproductive health of PWIDDs and sexual and reproductive health education for this population and its relationship to global development applies to goals 1, 3, 4, 5, 9, 10 and 16 of the Sustainable development agenda.

Working towards these goals might give hope to PWIDDs in Ghana and increase participation and inclusion into mainstream society. However, in so doing, it is necessary to look at the sociocultural landscape of our local communities and work with local authorities and other stakeholders such as traditional and religious leaders, and harness the networks of the extended family to push forward the agenda for the benefit of PWIDDs.

2.2.7 Overview on Empirical studies on sexuality (needs) and (intellectual) disabilities in Ghana

The sexualities of persons with disabilities are gaining visibility in Ghana however much study remains to be conducted in this area. Studies on the sexuality of the deaf\textsuperscript{72} and visually\textsuperscript{73} impaired appear to be the most dominant with IDD receiving being part of broader studies (e.g. in Mprah 2011; Mprah, 2013; Mprah, Anarfi & Sekyere, 2014; Abdul Karimu, 2017; Agbenyega, 2016). Some of the studies also focus more on abuse than other aspects of sexuality.

\textsuperscript{72} Mprah (2013) has conducted Sexual and Reproductive Health (SRH) assessment with deaf people in Ghana and perception about barriers to SRH information and service among deaf, knowledge of contraception methods among deaf

\textsuperscript{73} For instance, Abdulkarimu (2017) who explored SRH issues among visually impaired women.
such as Opoku et al's., (2016) examination of barriers to reporting sexual violence perpetuated against women with physical, hearing and visual impairment in the Ashanti region of Ghana. Similar to that is Agbenyega & Deku's (2016) cross sectional study, which examines locus of control and perceived vulnerability of children with visual, hearing and intellectual impairment to sexual and physical assault. In relation to HIV/AIDS, knowledge and attitudes to HIV/AIDS among persons with hearing impairments have been explored by Mprah (2013b), while Tun et al (2016) have explored HIV services for PWDs in Ghana, Uganda and Zambia however their study did not include persons with intellectual disabilities. Such studies however focus more on the discourse of vulnerability of persons with disability to abuse and make protection from abuse a primary need, thus neglecting needs that establish their capabilities to have sexually fulfilled lives. Besides that, there is an obvious gap in information regarding the sexuality of PWIDDs in the country. Filling this gap in academic literature is very necessary for policy and practise in the area of sexuality education for PWIDDs and subsequently, visibility and inclusion as it relates to access to opportunities for developing healthy sexual lives.

2.2.8 Assessing Sexuality Educational Needs of PWIDDs

Bruess & Greenberg (2004) suggest that to determine the sexuality educational needs of a population of learners, educators can use school record to conduct some diagnostic evaluation e.g. number of previous pregnancies, consult data on incidence of venereal diseases, rape or sexual abuse or sexual behavior statistics or reports. In addition, they recognize the role of the knowledge level of learners; their ethnic backgrounds (race, gender and ethnicity) in helping the educator determine the content and style of delivery that is most appropriate. Greenberg and
Bruess’ (2004) approach combines both quantitative and qualitative means of evaluating the needs of learners.

As an instrument of biopolitics, quantitative data has been instrumental in regulating various populations (Haking, 1982; Manzeschke, Assadi, Viehover, 2016). Methods used in assessing a range of the sexuality needs of PWIDDs, have emerged from the discourses of psychology and thus quantitative in approach. Notable among these are these studies have been mostly quantitative McCabe's (1994) sexual knowledge experience feeling needs scale (Sex-Ken), the socio-sexual sexual knowledge and attitudes tests (SSKAT) by Wish, McCombs & Edmonson (1980) and the general sexuality knowledge questionnaire (QSKQ) initially developed by Bender, Aitman & Huag (1983) and redeveloped by Talbot and Langdon (2006) among others. Although standardized quantitative tests are able to assess the sexual knowledge, attitudes, skills and needs of persons with IDD like is evident with quantitative data, they are not sensitive to the socio-cultural backgrounds of the learners for which reason qualitative methods are employed to give more meaning to the data (Mertens, 2015).

For parents and educators in special schools in Ghana, these quantitative measures are unlikely to be the way by which they assess the needs of these learners. Darling and Cassidy (2014) distinguish between felt needs and ascribed needs in the delivery of family life/sexuality education. Although felt needs are important and reflect the perspective of the learner, the authors acknowledge the importance of ascribed needs, as eligibility to access family life education for the learner is dependent on the needs ascribed by the educators and parents. Darling and Cassidy (2014) also recognized that a third need - future needs- are also relevant in preparing the learner for situations that they are likely to face in the future. Having established
the socio-cultural context, this study seeks to explore the ascribed needs of PWIDDs as from the perspectives of parents and educators of learners with IDD in special schools in Ghana.

2.2.9 Operational definitions
For the purpose of this study the following concepts have been explained:

- **Intellectual developmental disabilities (IDD):** are lifelong disorders that are usually present at birth or noticeable before the age of 5 years and that negatively affect the course of the individual's intellectual, physical, social and emotional development. Emphasis was more on the presence of intellectual disability, which is determined at the National education assessment centre and for which reason learners are referred to the special school. Thus, in this study learners who have intellectual disabilities or have who have other disorders such as autism spectrum disorders and cerebral palsy comorbid with intellectual disability comprised the focus of discussion. From my experience in special education in Ghana, persons with severe IDD who need 24 hour care are usually not admitted in the special schools because there is limited capacity to train them.

- **Special Educators:** comprise of persons who may or may not be trained in social education but who work as special education teachers in the classroom. They are involved in teaching and lesson planning. They are therefore different from caregivers and housemothers in the case of residential schools who give support in the classroom or over see the learners welfare in the dormitories.
2.2.10 Conclusion

This chapter reviewed historical and empirical studies in the fields of intellectual disability, sexuality and sexuality education from the West, the African continent and Ghana. It drew attention to the local and international relations that socially, culturally, politically affect access to sexuality education and recognition the sexuality of learners with IDD in special schools. The chapter also pointed out the need for sexuality education programmes for this group of individuals in ways that resonate with the indigenous thoughts and daily practices of the people. However, the development of such programs is only possible if the needs of these learners are known. The role of parents and educators in determining these needs is emphasised as they are the main actors. This chapter also took into consideration the development context of Ghana from structural adjustment to the current post 2015 sustainable development goals. Finally, the chapter presented the theoretical foundation of this study. The next chapter describes the methodological approach to the study.
CHAPTER 3 METHODOLOGY & ANALYSIS

3.1 Research design & Rationale

The researcher adopted a qualitative research design, namely Interpretative Phenomenological Approach (IPA) (Pietkiewicz & Smith, 2014; Smith, et al, 2009; Smith & 2004). Phenomenology as a methodological approach focus on people’s perspectives (that is their perceptions and actions) and experiences (Langdrige, 2008; Von Eckartsberg, 1998) and seeks to describe rather than explain a phenomenon. It is also called descriptive phenomenology in that it presents the situation or phenomenon as it appears, it focuses on the essences of the phenomenon without trying to read any meaning into it (Liamputtong, 2009). Interpretive phenomenology otherwise known as hermeneutic phenomenology (Connelly, 2010) is a combination of two processes - phenomenology, which simply describes lived experiences and hermeneutics, which comprises an interpretation of those lived experience by focusing on the text and/or language used by the other to share their experience (Sloan & Bowe 2013). The methodological framework of IPA is interested in capturing the realities of the lived experiences of individuals in relation to some phenomena through their narrative and emphasizes interpreting instead of only describing the phenomenon (Husserl, 1970; Moustakas, 1994; Sloan &Bowe, 2013).

Using IPA allowed the researcher the flexibility of exploring the phenomena under study - specifically the lived experiences of parents and educators in identifying and addressing sexuality educational needs of learners with IDD in special schools - rather than explaining or generating a theory. (Mackey, 2005; Lincoln & Guba, 1985) It also enabled the researcher to

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74 By needs, the researcher relied on Bruess and Greenberg’s (2004) recommended approach to identifying sexuality educational needs of learners as already discussed in the previous chapter.

75 Grounded theory would have been ideal if the purpose of the research was to help generate a new theory
understand this phenomenon from the perspective of the participants - that is, through participants’ detailed reports of their experiences. (Collingridge & Gantt, 2008; Creswell et al., 2007; Smith, 1996).

IPA has been largely used in health and psychological research and been applied in Education, Anthropology, and other social research context. (Smith & Osborn, 2007; e.g. in Warren & Quine, 2013) Moreover, it is also particularly useful when examining topics that are complex, sensitive and emotionally laden. (Smith & Osborn, 2007; Eatough & Smith, 2006) and has also been used in studies similar studies to this which focus on the sexualities of persons with IDD. (e.g. in Aderemi, 2014; Pownall et al., 2011) Above all, IPA places priority on participants' experiences while acknowledging the role of historical and cultural contexts (including language and social norms) and their influences on any given experience (Denzin & Lincoln, 2008). Thus, by expressing their concerns and providing detailed accounts of incidents surrounding the sexuality of the learners with IDD and how they address these concerns, the educators and parents enable the researcher to understand their perspectives better and accurately interpret and report their personal thoughts and experiences regarding the sexuality educational needs of learners with IDD.

3.2 Duration & Research setting/ Study sites

The study took place from 20th of June to the 18th August 2016 in five (5) out of the ten (10) regions of Ghana - namely, the Greater Accra, Central, Ashanti, Volta and Northern regions. Data was collected in special schools (for mostly teachers/educators) and homes or places of work (for most parents). The researcher spent 4-7 days collecting data at a special school and in a
community of each of the five regions. Eight schools were contacted based on their geographical location (i.e. within the capital city of the regions)\textsuperscript{76} out of which five responded. The regions/demographics are identifying information that can expose the identity of the respondents particularly the educators and school heads therefore the regions of data collection have not been attached to the responses to protect the identities of the educators primarily because there are very few special schools in the capital towns of country.

3.3 Population and Sampling

Purposive and convenient sampling methods were used to recruit participants for the study. Letters of introduction (See Appendix B & C) were first sent to various member organizations of Inclusion Ghana requesting their support and permission for the researcher to interview parents and educators on the topic under study. Given that the topic is a sensitive one, prior attempts to reach the schools directly failed although the researcher is well known for her work in advocating for the rights of PWIDDs in the country. Approaching the schools through member organizations therefore enabled the schools especially and the parents to be confident of the intentions of the study, receptive and open to participating in the study.

The researcher also used a convenient sampling method based on the school's availability at the time the researcher was in the country and the school's willingness to participate to select participating schools, but used snowballing to recruit educators (and parents). This was because the school year was ending and most schools were to go on vacation by end of July. Once

\textsuperscript{76} Currently, according to the list of schools on the Inclusion Ghana website, there are special schools for learners with intellectual and developmental disabilities in eight out of the ten regions in the country. The decision to include only schools in the capital was to enable me to have easy access to the school and reduce the stress associated with commuting an accommodation, to have access to social amenities like electricity to power my equipment.
permission was granted by the school heads (who also agreed to participate), they referred the researcher to other educators in the school who were either responsible for the SRH education program (if they had one) or other educators who worked closely with learners aged 10 years and above. Despite the high probability of bias, snowball-sampling method allows researchers to conveniently include participants in a study based on their availability, suitability and willingness to participate\textsuperscript{77} (Creswell, 2009)

### 3.4 Data Collection Instruments

The study utilized mostly semi-structured interviews, informal conversations, and observations to collect data. Interviews, enable participants to discuss their interpretations of the world, express how they perceive particular situations (Cohen, et al., 2007), and enable researchers to explore the experiences of participants, and understand/interpret key aspects of their lives, and reveal them in a way that reflects the situations in which people find themselves (Kvale, 1996). Smith and Osborn (2007) recommend that in an IPA study semi structured interviews be used in the collection of data. Semi-structured interview schedules were therefore developed to guide the discussion with participants and allow the researcher to probe into more interesting and novel areas that arose out of the discussion. Interviews lasted between an hour to two and half hours. Since the researcher’s role in a semi-structured interview is to guide the conversation rather than determine the outcome of the encounter, the researcher did not restrict the respondents by asking specific questions but rather asked broad questions and redirected the conversation only when it was necessary.

\textsuperscript{77} This also made IPA the best method for data collection.
The interview guide was in three parts. The first part of the interview guide sought to capture the socio demographic information of the respondent. For educators, this included their reason for entering special education for IDD and the kind of professional training they had to go through\textsuperscript{78}. The second part sought to know form a range of experiences of the respondents, including their concerns, perceptions, thoughts, and responses to the sexuality of children\textsuperscript{79}/learners with IDD were, and how they delivered sex education. The domains of McCabe's (1994) Sexual Knowledge, Experience and Needs Scale for Intellectual Disability (Sex-Ken-ID) although not exclusively, served to guide the discussion and probe further into various aspects of the sexuality of the learners as perceived by their parents and educators. The domains on the Sex-Ken ID are Friendship; Dating and Intimacy; Marriage; Body Part Identification; Sex and Sex Education; Menstruation; Sexual Interaction; Contraception; Pregnancy, Abortion and Childbirth; Sexually Transmitted Infections; Masturbation and Homosexuality. Attention was paid to the connections between the actions and perceptions of parents and educators, and factors such as religion, ethnicity, and also school policy (in the case of educators). For parents, the second part sought to explore from their range of experiences from diagnosis up until the child's current stage of development and the dynamics of raising a child who is now (becoming) an adult in the light of issues around sexuality. Their thoughts, concerns, wishes, expectations, and hopes were all sought as well as their response plans for their children as regards to their sex life. Funnelling, a technique used to elicit respondents’ general views and responses to more specific concerns were asked was employed in the third part (that is

\textsuperscript{78} This was necessary to understand the various influences on the constructions they had about the learners with IDD

\textsuperscript{79} The term "children" or "child" is used in terms of the relationship (parent-child) and does not allude to a stage of human development (childhood).
towards the end\textsuperscript{80}) of the interview. (Smith and Osborn, 2007) Parents were asked what they felt the school, community, and government respectively could do to promote the sexual wellbeing of their children. Educators on the other hand were also asked what they thought that parents, the community, and the government could do to promote the sexual wellbeing of the learners. The specifics of these questions cut across response of community members to the learners, government policies, and laws.

3.5 Procedure

All interviews were conducted face to face with participants. However, the respondents were given the letters of information and interview guide in advance, to inform them of the nature of questions that will be asked during the interview. The interviews were scheduled to take place at a time and place that the participants considered appropriate and comfortable. Participants' permissions were obtained to have the interview video\textsuperscript{81} or audio recorded prior to commencing the interview. The letter of information and the consent form were also read and explained to participants by the researcher and her translator, and any issue that the participants had regarding the content of the form were clarified before the participant signed the consent form for the interview to begin. Interviews conducted primarily in English and where necessary two local Ghanaian languages - Dagbani\textsuperscript{82} and Twi\textsuperscript{83} and Translations into English were done during the interview process to ensure that there was no misinterpretation of information. All the

\begin{itemize}
  \item Conducting it at the beginning would have produced responses that are biased towards the researcher's prior and concerns (Smith & Osborn, 2007).
  \item There was the option of video because from my media campaign experiences, I find that more parents are more enthusiastic about and will show up for TV interviews than radio interviews during such campaigns. Having the video also enabled the researcher to capture gestures and facial expressions without necessarily having to write these down during the interview.
  \item Widely spoken in the Northern part of the country.
  \item Spoken widely in the south of the country.
\end{itemize}
interviews were either audio or video recorded depending on the preference of the participant. This enabled the researcher to also capture the tone of voice, moods, emotions and verbal and non-verbal expressions in audio and film.

3.6 Ethical considerations

The researcher before the commencement of the study presented a proposal of the research to the Queen’s University General Research Ethics Board for review and clearance before commencement. She received ethical approval on the 16th of June 2016 and the study commenced on the 20th of June. This document was made available to the Autism Society of Ghana and Inclusion Ghana who also gave me letters of introduction to the member organizations and schools. All participants took part in this research on voluntary basis and they reserved their right to withdraw their consent to participate in this research at any stage except after the researcher had returned to Canada without any sanctions against them. The researcher had arranged with Juniper Tree Counselling centre to assist with professional psychological and counselling services to counsel any distressed participant to ease should such a situation arise. Fortunately, the researcher had not need for this service. Participants also had the opportunity to decline to answer any questions they did not feel comfortable answering without losing any benefits to participating.

3.7 Data analysis

Data analysis was conducted manually. Analysis was conducted in three stages. First, by reading through the transcripts to look out for patterns of meaning and matters of potential interest within the data. The researcher then highlighted relevant material and attached brief comments which enabled her to define and redefine meaningful descriptive coding schemes and
groups as she progressed. The researcher then used manila cards to sort out the various codes into potential themes. The themes were not dependent on quantifiable measures, but in terms of whether they captured information relevant to the overall research question. Finally, the researcher developed and redefined the themes to establish logical connections between them and then come by the interpretations. After that, she clustered the descriptive codes, derived interpretations from the clusters in relation to the research question, before applying the interpretative code to a full data set.

3.8 **Epoché (Subjectivity and reflexivity)**

Epoché\textsuperscript{84} as it is known in phenomenological research is a process by which the researcher continually sets aside their own assumptions prior to data collection and analysis of the data received. I conducted this process by electronically and manually journaling prior to and during the data collection and through analysis process - placing my thoughts, perceptions and personal feelings towards the information I had received into perspective. Miles & Huberman (1994) acknowledge that researchers, being products of some other culture themselves, possess their own understandings, convictions and conceptual orientations and will be affected by what they hear and observe in the field in ways often overlooked.

This study is within a situation with which I have close and personal relationships. I have an aunt and two older cousins with intellectual disabilities and have been an educator and community advocate for persons with IDD for over five years. It is expected that my ‘voice’ plays a significant role in the interpretation of the data. I therefore had to consider throughout the data collection and analysis process how my own my beliefs, values, cultural and social

\textsuperscript{84} Some scholars such as Beech (1999) and Ray (1990) in Gearing (2004) were cited as using the term epoché and bracketing synonymously. In Ahern (1999), Myerhoff and Ruby (1992) refer to it as reflexivity.
background, gender and knowledge will affect my views of the informants and the information they provided me. Hence, it was necessary to acknowledge from the onset my role in this research and my perceived bias as an insider in the phenomenon, which I undertake to study. Even though I have tried to keep an open mind to listen to the story of the informants I will not like to pretend that my own voice is not presented being an insider. Being an insider or outsider during a research process could be defined in terms of the role the researcher plays in a particular situation (Dwyer & Buckle, 2009). An insider can be someone of the same language, the same ethnic group, or the same profession (Dwyer & Buckle, 2009). I consider myself as an insider during the data collection process based on my profession and an outsider in terms of the geographical locations of the interview settings and sociocultural contexts (majority of the interview took place in regions in which I did not know much about the culture) and so kept an open-mind of just listening and learning. However, I believe my background helped me to win the respect and trust of my informants. I became approachable and the informants felt free to answer my questions and converse with me - all these I believe, have strengthened the validity and reliability of this study.
CHAPTER 4 EDUCATORS’ PERSPECTIVE ON SEXUALITY EDUCATIONAL NEEDS

4.1 Background
Thirteen (13) educators from the following schools were interviewed to explore the needs of learners with IDD that teachers had identified, how they responded to those needs and the support they required to promote the SRH of their learners with IDD. The regions of the schools have not been included because they serve as identifying information, which might jeopardize the privacy of my respondent.

A. Anglican Mission Day School under GES with SPED unit (3 Educators)
B. Government-owned Specialized Residential school for PWIDDs (3 Educators)
C. Government-owned specialised Day school for PWIDDs (3 educators)
D. Methodist Mission Day School under GES with SPED Unit (2 Educators)
E. Privately owned Specialized day school for PWIDDs (2 Educators)

4.2 Role and Significance of Special Educators
The researcher often began the interviews by asking teachers about their journeys so far, why they chose to be special educators for PWIDDs, and how their professional preparation equipped them to meet the demands of their profession. This helps to understand the influences to their construction of IDD and sexuality over time.

All trained special educators received their professional preparation for special educators at the University of Education, Winneba (UEW). Two educators however were MSC degree holders in Disability and Rehabilitation studies at the Kwame Nkrumah University of Science and Technology (KNUST), another two were pursuing a diploma in basic education, while another one had pursued an MPhil in Health education. According to the teachers, the practical
sessions of observing and working with the learners in other special education settings prepared them for the challenges of the career path they had chosen. They also had been educated about the rights of these learners including their sexuality rights.

"In the Masters' program we learned that all persons have the right to reproduce, have their privacy so they should not be interrupted by anybody" – Female, Wala, Catholic, School B

"We also had sex education on the campus (in the special education program)... there is a topic on that... so that's when I said aahhhh85 ... its true, they are also human beings and go through the same developmental stages, so the feelings will automatically come... so its normal. - Female, Sisala, Muslim, School C

However, the main focus of their preparation as special educators was the promotion of the independence of learners with IDD. Thus, as teachers, they were mainly trained to help the learners acquire daily living and vocational skills.

As to what the motivations were for the respondents to choose to this professional path, passion to support the vulnerable appeared to be the main driver for entering into Special Education specifically for learners with IDD. The educators were passionate about helping these persons become responsible and independent citizens in the communities and not the remuneration that comes with it86. All except four of those who were interviewed started out at teachers in the regular/mainstream school. One educator (SCH E) however became a special educator because her son had IDD while some others just took to special education out of curiosity. Another educator (SCH D) who entered this career path nine years earlier started out as a volunteer for four years while her application to become a special education class attendant was pending at Regional Education Office. Prior to that, she had never come into contact with PWIDDs and so said she was afraid when she first saw them, but later developed attachment

85 An expression of agreement to an idea or argument
86 At least two of the teachers mentioned that they receive the same salary as mainstream teachers and did not even receives external benefits such as those that came from extra class fees as was typical of mainstream school teaching.
towards them. One educator (SCH C) explained how he thought SPED for IDD was going to be easy but has found the opposite to be true. In the end however, he said he has not regretted his decision and has come to enjoy working with the learners. One educator (SCH B) talked about his job as being a ministry, something for which God will hold him accountable. Salifu (2015) gathered similar responses in an explorative study of drivers of teacher professionalism in Ghana- selfless and internal factors such as service to God and society and help students, passion for teaching. However, unlike the mainstream school teachers in Salifu’s (2015) study, the motive of flexibility of time in the teaching job did not reflect in any of the responses in this study despite the fact that in all the four public schools, school ended at about noon.

The educators also appeared to be very involved in the learners’ lives often more than the parents were. From observations and from both parents and educators reports, the parents appeared to also acknowledge the significance of the educators in the lives of the learners and this was recounted in the interviews with the parents. Some educators and school heads in all the schools except school E reported that parents had come to share their concerns and need for assistance in the area of marriage and finding partners for their sons or daughters especially after they realised the child had mastered some trade. Special educators are like an extension of the family and are consulted on issues. There is no clear divide between home issues and school issues when it comes to the lives of these learners. They took up cases of sexual assault, which happened in the community and outside of the school, assisted with job placements and are continuously involved in the lives of these learners monitoring to make sure they are doing well.

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87 Given that, two of the respondents were training to be basic education teachers, and 7 others were previously basic education teachers before transitioning into special education, Salifu’s (2015) study supports these results.

88 In Salifu's (2015) study, the teachers mentioned that the teaching job was flexible and teachers had more time on their hands due to early closing times, holiday and school vacations.
The school head of School C mentioned how they continued to be in touch with the employers of
the learners even after the learners had graduated from the school.

The following statements made by educators from each school led to this conclusion;

"we have one girl who was abused severally. She is pregnant. Parents didn’t care about
her we would bath her in school and dress her up. The family used to take her school
uniform from her so we keep the uniform in school. We heard that people sleep with her.
So we asked her and she seemed to enjoy it. she says she likes that man but then she won’t
tell us who the man is. So, we went to look for her mum and she said she has tried all she
can but the girl will not sit. So, she doesn’t know what to do. She has left her to us. (School C)

One parent came to tell me that her daughter doesn’t stay at home. And so I interviewed
her and she said she goes to cook for a man and sometimes spend the week there. so I
asked her if she has been sleeping with him and she said yes and that it is sweet. So, I
asked if she knows she can get pregnant and so I asked did he use condom she said yes so
we advised her. She hasn’t stopped but she doesn’t go as frequently. (School D)

A parent told me about one of our adult learners has been fingering other children at
home. He is about 21-22 but we haven’t experienced this. So, we spoke to the boy and are
keeping an eye on him. I call him and advise him. He likes coming to school so I told him
if you do it you won’t come to school again. (School A)

I go to the parents. They also need support. A special need s child may not have any
support at home because the parents have other children in school. Also, some families
break up because of these children and so the child is being catered for (mostly) by a
single mum, a sister or grandmother so you (the teacher) must train him to a point where
the community can accept him. (School B)

In school B one learner who graduated was now employed in the very school that had educated
him and the educators were even consulted on issues regarding his marriage and involved in the
ceremony.

**Interviewer:** So, tell me about Mr. Issac

**Respondent (Male, Bono, Pentecostal, SCH B):** The process started when he left
school. We needed someone to continue the teaching of envelop making... So we
contacted his father he said good idea, ... so we recruited him... and put him on payroll.

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89 Pseudonym. As a researcher, I was also impressed by the fact that this educator and other staff in the school,
prefix his name with Mr. This showed that they acknowledged him as one of them and no longer as one of their
students. He was now a colleague. I also had no choice then but to refer to him that way.
One day ...the father he wants him to marry. That’s why I am saying that it is the home that the parents come from and the influence of the school.... so, the process begun - looking for a lady for him. We were even thinking that they will look for a disabled girl because of the man's disability but surprisingly they didn’t go for a disabled girl. We told the family they have done very well. So, we all went for the initial ceremony preparing the (bride wealth). ...(as) people who have trained this boy we were happy to make a story out of what he was able to do - training a disabled person and helping him to get married...

Therefore, to have parents come to talk about marriage for their children with the educators and for educators to be involved in the children’s lives even when they are away from school and integrated in the communities, goes to show the extent of influence that teachers have not only in the lives of the learners but even in the learners' families. This could also be the reason why the educators did not mention "flexibility of time" as a reason for entering into special education for learners with IDDs because their job in the life of the child continues even after the learners finish school.

Community members also appeared from the educators reports as well as from my observation of parents teachers relations that took place during my stay at the schools, to acknowledge the role of special educators/special education teachers in the life of the learners with IDD. The educators were very involved even in advocating for the wellbeing of these learners in the community. In the schools located in Akan speaking communities the term “momma” (your children) and was typical in the narrated reports by the community members of behaviours of learners to their special educators. The researcher also witnessed a parent’s conversation with special educator in which the parent referred to the learners with IDD including her own child as the children of the educators (in Ewe, miaviwo - meaning “your children”). Community members and the parents themselves from the reports appeared to see the special educators as foster parents of the learners with IDD. Educators generally have been the ideal candidates for fosterage in Ghana. Coe (2015) highlights the continuous role of teachers in
educational fosterage in Ghana. Although different in that these PWIDDS do not live with the educators, it can be that parents and community members realise that the educators are more capable of not just educating but raising their children for them. There is a need for further studies to be conducted to understand why community members especially refer to the children as children of the educators and not the parents.

For example, in School D, one of the teachers explained how some community members who had observed two learners engage in same sex relations in an uncompleted building, came to lodge a complaint to the special education teachers and not the parents. The school head also confirmed this story.

Two of the boys in the class when they close from school, on the way home, they go and "do their own thing". So, it was people in their neighbourhood who came to report to us. So we invited the parents as well and we are working on it seriously. - Head, (SCH D)

Being a close-knit community, one would have thought that the community members would have told the parents but instead, the educators were the first to be informed. These educators in turn informed the parents and are working hand in hand with them to prevent the boys from engaging in these activities. Some educators, however, also shared the negative reactions they have had in the community in which they work "people think they are contagious and that if you work with them, you will be like them."

In schools B and C the educators (specifically school heads) also talked about their experiences in seeking legal justice for their learners with IDD even when parents were not interested in taking the cases up when there was sexual abuse.

.... it has happened twice and the first time the man run off and the second one I made an arrest. Parents didn’t want to take on the case but I pushed for it and they had him put in the cell for two months and bonded⁹⁰. - SCHOOL B

⁹⁰ Signing a bond to be of good behaviour.
... if others abuse them (PWIDS) from outside we take up the case because some of them (community members) capitalize on their (learners’) situation and try to abuse them physically, sexually, verbally and even psychologically. So, when we know of that, we take you on and send you to DOVVSU91. I think I’ve done that before ... send you to DOVVSU so that they discipline you. eh... if we start from the level of the family and we are not getting anywhere then we go ahead and send you to DOVVSU so they can take care of you. - SCHOOL C

It can be seen here that even when the family is not prepared to take up the case, some of the educators take it up, confirming their significant role in the lives of the learners.

4.3 Perspectives on the Sex Drive (Atinka) and PWIDDs

Educators were asked what they thought about the sex drive in general and in relation to persons with IDD. Every educator agreed that the sex drive was natural and every human being irrespective of ability or disability had it. All except two educators also mentioned pleasure as the main purpose for the sex drive and the researcher had to ask the place of reproduction to which many said it was not the main issue. Some of the educators who were married talked about how pleasure in each other, more than reproduction was the main purpose even for marrying. One cited his Christian values as source of such perception.

…When it came to me and my wife, during our counselling the counselors asked us what we will do if we didn’t have children and we both said it won’t be a big deal and they were very happy because they said the main purpose in marriage according to the bible was for companionship not children. So, it’s good we have that understanding Right now we don’t have children but we are enjoying each other in the marriage. (Male, Ewe, Catholic, School A)

With respect to the sex drive of persons with IDD, although there was the general perception of learners with IDD as having high sex drive i.e. being hypersexual it was also mentioned that if they did not have IDD it would have not been anything extra ordinary. As the educator in school A said,

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91 Domestic Violence Victims Support Unit
“Had it not been that they were having a slight problem, like we’d have seen what they are doing to be normal. Look at their peers... the only thing is we have to teach them that you don’t just do it anywhere, we can just teach them” (Male, Ewe, Catholic, School A)

The common phrase to that captured the perception of hypersexuality was “they like sex papa”. This perception of the majority of teachers was also reported in Phasha, & Myaka (2014) and Aderemi (2014). Only one educator from the Ashanti region supported the perception with the attribution of hypersexuality in persons with IDD to a damaged limbic system. However, with regards to educators' perceptions of the sex drives of person with IDD prior to entering special education, the educators reported that they thought that because the learners’ brains were "damaged" or "not working", that part (that controls the sexual drive/behaviour) of the learner was also damaged. Two educators though, said they did not have any prior perception of the sex drive of PWIDDS because it simply never occurred to them and so were shocked when they first encountered their learners exhibiting sexual behaviors.

This issue of rights was mentioned by all educators either explicitly or implicitly in response to the question regarding the extent to which it appropriate or inappropriate for persons with IDD to express their sex drive. One educator in school A responded saying, persons with IDD "... also have their rights so they should be allowed to exercise it." Other educators responded similarly, by using phrases such as, "they too are human beings and have feelings". The inappropriateness of the expression was in how and where it was done. But essentially, no educator had anything against the learners’ expression of the sex drive so long as there was no sexual activity in the school, learners were not engaged in any culturally inappropriate sexual
relations and they observed the privacy that goes with it. This supports Aunos & Feldman (2002) study that revealed educators had more positive attitudes towards the sexuality of learners with IDD.

4.4 Sexual and Reproductive Health Concerns
Educators were asked what concerns they had about the sexuality of their learners. The responses were categorised according to coming of age; SRH expectations; exposure to sexual activities; exhibition, social/sexual behaviors, learners' questions or indication of a need or intentions for intimate relationship; abuse & vulnerability to abuse/be abused.

4.4.1 Coming of Age
For many girls, according to the educators, coming of age (the onset of menstruation) was a main concern because if "care was not taken" the girl could become pregnant. Besides pregnancy, menstrual hygiene was also a main concern when the learner is of age because of the complexities of menstrual care and hygiene. Coming of age for a woman was also marked with the ability to cater for a home. Thus, even when parents wanted their learners with IDD to marry, these were also evaluated by the school and advice was given.

> When a lady is of age, sometimes (the family) go in for men for (the lady) to be able to give them children. Depending on the age of the (lady) if the (she), knows how to keep herself then good...some parents will go in for that especially when they don’t have many children in the family. - Male, Bono, Pentecostal, School B

> ... the woman who called me now, she said if she should get a man to marry her daughter, she will prefer that. She said her daughter is a human being and has the feelings but getting the man is very difficult because the girl cannot cater for herself. So how will she cope if she has a baby? But if they can get domestic support why not? If

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92 Educators mostly mentioned same sex relations and rape as inappropriate sexual expressions.
people with CP (cerebral palsy) can be married, why not (those with IDD)? I think they only need support. They are human beings. This parent has expressed her feelings. She would ask, "so will my child remain single forever? She has been asking me, "Where will I get a man for her?" That’s her main concern. - Female, Fanti/Ewe, Charismatic, School D

In relation to ability to care for a home as "coming of age", in an informal conversation, one of the educators in school B narrated an incident where a 22-year old learner told him that she had a boyfriend and was going to marry soon. This learner has cerebral palsy comorbid with intellectual disability and according to his narration refuses to get involved in any activity although she has some mobility capacity. His response to her was, "You are you grown? Can you take care of your home? How can you take care of the house if you have not learnt to do it yet?" According to him, she just laughed at him. He later took time to advise her later on trying to take up responsibilities within her capacity at school so that when she marries so that she can make a good wife.

The only direct mention of the phrase "coming of age" for a male was recorded when an educator in School A narrated an incident of a boy with excessive body odor not wanting a caregiver to bathe him in the school because he had started developing pubic hairs. It can be inferred then that a sense of awareness about bodily privacy is one indication of coming of age. However, as literature has indicated, manhood or male adulthood in Ghana is defined along social lines of completing school and being independent and capable of caring for a family (Ansell, 2016a; Asampong et al., 2013). Some non-direct references to coming of age were also recorded. For example, many educators said they would ask learners who were found to be involved in sexual or intimate relationships if they were ready. This readiness included

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93 This statement may have come owing from the fact that persons with cerebral palsy are referred to as "Nsuo ba" (child of the river god) or 'snakes'. Media reports by Ghana News Agency (2015) stated that mothers of persons with cerebral palsy complained of such derogatory names being used for their children.

94 In all the schools studied, the attendants and caregivers were female.
graduating from school, having a vocation and having some level of economic independence; hence, the phrases "someone is already taking care of you...", "you are still in school...", "do you have money?" and other similar phrases were present in all responses in the interviews.

4.4.2 Future Expectations
The main sexual and reproductive health expectations discussed pertained to developing and entering into formalised intimate relationships and the ability to maintain a family. Generally, all the educators had the expectation that most of their learners will be able to marry in future but admitted that they will need some domestic support. There were also reports in three (B, C, E) out of the five schools of learners being married - two male learners and a female. Again, of the two cases, one of the male learners and the female learner were both from the Northern part of the country and were from Muslim homes while the other male was from the Southern part and from a Christian home. In all three instances, the (former) learners had some vocational skill that they engaged in (e.g. Envelope-making and basket weaving) and were earning an income. The school was still very involved in the lives of these individuals who are not fully independent from the influence of their educators.

When a mildly\textsuperscript{95} ID girl or boy is empowered economically, maybe managing a small shop or business, when they can afford basic economic necessities, they can marry. Pay rent, buy food, etc. (Male, Catholic, Konkomba, School C)

\textsuperscript{95} The researcher found that educators who talked about mild IDD (called it learning disability). The main difference they stated was that those with mild IDD had the potential to be integrated into the mainstream schools and live close to "normal lives". However, those who were in the special schools full time were referred to as having IDD. It was observed that, here is currently no support for severe IDD in many of the schools except in school E, which was a private school. In all the other schools, my conversation with the head was that the assessment centre did the job of referring the learners to the school to determine whether or not they were "educable". No child at any of the schools were observed to need 24-hour care except in school E where such child came to school with a caregiver.
This statement attests to the fact that sexual intercourse and as such marriage, is for adults. Provided however, that a person with IDD can attain society’s newer and more complex ways of defining adulthood, including employment and ability to rent or perhaps purchase a living quarters of your own as mentioned earlier in Ansell (2016), Burrell (2012), and Asampong et al (2013) then, nothing stops them from marrying. However, it also poses challenges for learners who are not considered - according to this educator's report- as having mild IDD because, their likelihood of attaining this level is very slim. This does not mean that they will not be exposed to sexual encounters. However, the researcher did not ask what the educators think will happen to those who cannot be married and how their sexuality should be handled given that there was almost no chance of having a publicly recognised relationship, as they cannot meet the current socio-economic standards of adulthood. The situation for this category of learners based on this description by the educators could be carried out as a separate study in future.

The marriages that had taken place were also reported to have taken place under either customary or Islamic law. One reason for this could be the confluence of Ordinance marriage with Christian marriage (Gocking, 1990). Whereas Ordinance marriage involves two consenting adults (that is, the couple) in the presence of two or more witnesses, customary marriage requires the involvement of the families of the couple (Higgins & Fenrich, 2011). Such legal conditions make it challenging for PWIDDs to be married under the ordinance or in a Christian way. However, the customary marriage has the benefits of family overseeing the relationship and being able to watch over the relationship and render the necessary support to ensure that the couple have a fulfilling life.
While some educators expected persons with IDD to marry another person with IDD either because they felt that they were not desirable to persons without IDD some others appeared to expect persons with IDD to marry persons without an IDD. This was to prevent or minimize the risk of having children with IDD especially if the condition is genetic.

Researcher: You were talking about pairing them; do you mean persons with IDD themselves?

Educator: you have HIV/AIDS, you can't sleep with persons without HIV. You yourself will not feel comfortable. So, those with LD\(^\text{96}\) or mild IDs they can go to the normal ones but those with IDD they can go to another different IDD we can manage the two of them... (he gives an example of learners within the class who can be paired) ... well that’s my opinion. If the deaf can pair themselves then this one there is no problem.\(^\text{97}\) (Male, Ewe, Catholic, School A)

Another Educator said,

"In the case of children with ID, I wish parents have understood the categories of children they have so that they would put some measures to make them not to be... (paused). Even if they have sex, they should not be reproducing among themselves but maybe an individual who is normal can marry someone who has ID so that he can give that person support, ... (paused) with the intention of making babies so they can take care of the baby and even if there is hereditary (factor) it won’t be too much. But when they marry themselves, they will produce their own kind. I'm not sure they will have children better than they are and so I prefer that there is a cross-breeding\(^\text{98}\) of normal people with mildly ID persons so there can be a balance." (Male, Konkomba, Catholic, School C)

The earlier response came from an educator from a school that had never witnessed a socially recognizable relationship between a PWIDD and a non-disabled person while the latter response came from an educator from a school where they had witnessed marriage between PWIDDs and persons without IDD. The kind of exposure that educators had within the communities they

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96 Learning disabilities (LD) is categorised among the educators as less severe than intellectual disability (ID) itself.

97 As a researcher, I wondered if the educator himself thought that persons with IDD would be unattractive to another without an IDD. I also wondered if his impression would have changed had he met Mr. Isaac from school B. Through my informal interaction with the educators, they mentioned that Mr. Isaac could not carry a conversation beyond two or three sentences because he also has communication impairment. He answered mostly yes or no questions but had a wife and daughter. One of the educators said, "Now he is having phone. He can call the wife and ask," how are you?". I also observed him as he tried to communicate something to a colleague, but the colleague was having a hard time understanding him and so told him he will follow him to see what exactly he was trying to tell him.

98 The use of this term is common and can mean marrying across races, ethnic groups or in this case abilities. Its use in the Ghanaian social context is not meant to be derogatory.
served in also appeared to influence their perspectives about PWIDDs ability to enter into such relationships.

In all, three marriages were recorded during the study and the educators from the schools where these learners came were very proud of this and saw it as an achievement.

4.4.3 Vulnerability
There was a consensus around the vulnerability of learners with IDD. All teachers reported a high risk of girls especially becoming victims of sex abuse because of the inappropriate social behaviours (such as overfriendliness), lack of sense of privacy\(^99\), dependence on others, and begging. Begging led to some form of transactional sex and it was reported as occurring both among the learners themselves and among the learners and older men or women in the community (Aderemi, 2014; Phasha, 2009). For the value of as little as one Cedi (GH₵1) (equivalent to about 3.8 cents) female learners especially were reported to sleep with men in the communities and even their peers. One case was reported of a male learner who also regularly slept with an older woman in the community for one Cedi. Having been warned severally by the educators, he eventually stopped attending school.

Many learners according to the educators still had challenges with self-grooming and needed to be supervised during any self-grooming activity of have the grooming done for them (e.g. bathing and shaving of intimate areas). This lack of bodily agency and privacy, coupled with the inability to sense social danger, make informed decisions and challenges in speech and communication, according to the educators, make the learners vulnerable to sex abuse.

... (the learners) buy gifts and give to those they want to sleep with, when you do the interrogation, you will find that the boys especially will give money to the

\(^99\) Mostly exhibited in undressing or urinating in the open, talking about issues culturally considered private in the open (e.g. announcing menstruation and talking about sexual encounters of themselves or others openly)
girls... this is just like the normal person. These people take the money and they know the basic thing about giving a gift to open the door to have sex with the girl. ... There is one boy (name) here who does that... What he does is more of what a normal person would do so we monitor him... (Male, Konkomba, Catholic, School C)

It is obvious from the above response that even the learners are aware of the need to engage in some form of exchange when in a sexual relationship as earlier indicated in the literature. As the educator mentioned, this was depicting of what a non-IDD person would do meaning it was socially appropriate all right, but the educator appeared to be in shock that they knew how to navigate through the cultural system. This means that learners can be culturally aware and must therefore be taught to apply their awareness within socially appropriate contexts and so that they can make a distinction between the already blur lines between transactional sex and intimate commitments, which in our Ghanaian cultures involves exchange (Ankomah 1999; 1996; Boschow 2012; Kyei 1992; Anarfi, 2003).

Two schools had reported that there had been incidences of pregnancy but those pregnancies had occurred during the vacation when the learners where at home. In all except one case, the girls were allowed by their families to give birth. In Ghana, abortions are culturally considered as murder and for females, the status of motherhood out of wedlock might carry stigma only for a little while. Kilson (1972) reports on how child bearing for Ga women give a woman some prestige and authority. As indicated in the literature, puberty rites and not marriage was the prerequisite for having children in traditional Akan societies (Fortes, 1978).

4.4.4 Exposure to sexual activities
Almost all the educators mentioned that learners are exposed to pornographic materials and/or sexualized by their non-disabled peers and other non-disabled community members including family members. In one instance, an educator mentioned how he tried to talk to a mother about
her son's sexual behaviours and she mentioned that she was not surprised because her husband (the boy's father) was a womanizer. Reports of parents sleeping in the same bedroom as their children with IDD due to economic constraints\textsuperscript{100} or simply to enable the parents to keep an eye on the disabled child was mentioned but at least one educator in four of the schools among a few teachers who expressed concerns about where learners must have learned about sex intercourse. According to the educators, they caution parents not to sleep in the same room with their child(ren) with IDD. Parents, according to all the educators I spoke to assume that the learners are still children and not aware of what the parents do, or are simply asleep. A parent mentioned that her adult son sleeps on the same bed with her for which reason she does not want him to be given sex education. The learners in turn come to school and try to practise what they saw, or talk about it to peers or other educators. It was also reported that learners were also exposed through television, internet and other media. One educator shared an experience around pornography:

\textit{We had a boy here who couldn’t do anything but operate the computer nicely and in the course of that goes to some nude pictures … and watch pornography… he cannot do anything but knows how to hold and squeeze a lady. …- (Head, Muslim, Sisala, School C)}

Another educator from School E, also mentioned how discovering pornographic material among her learners in class became a concern that pushed for the institution of a sexual and reproductive health education program. According to this educator, one of her learners was being sold

\textsuperscript{100} In Ghana, sharing of room by the father, mother, and children is not an uncommon phenomenon. According to Addo (2013) either the parents sleep on the bed, and the children on a mat spread on the floor or if the household has access to an enclosed veranda in front of their room, that section is converted into a sleeping area for the children.
pornographic CDs by vendors in a community. She mentioned that upon interrogating the learner she found that, the learner's friends introduced him to it and would have him use his money to purchase it so they can all watch it.

"There was this one boy who was having problems because as we teach here he goes home and there's no parental support so the peer pressure at home is great. He has a single dad, so the influence on him negative influence so he was not able to let go of pornographic materials so I brought in the principal and we have this collaboration with someone outside (abroad) one psychologist. He mentioned that his friends in the community have been encouraging him to buy so they watch so he will use all his money for that."

Aderemi (2014) reports similar incidences in Nigeria of community members introducing learners with IDD to pornography and having them pay to access it. This is can be described as a form of sexual and economic exploitation given that the learner will easily become addicted and is likely to spend a lot of money to access the material (Pang & Masiran, 2017).

4.4.5 Exhibition of sexual behaviours
Concerns related to the sexuality of these learners included the presence and exhibition of certain sexual behaviors. Notable among the behaviors mentioned by educators were male learners touching breasts and buttocks of other female learners and even the female educators, masturbation among both males and females, holding and touching private parts in public, intimate heterosexual and same-sex relations.

There was a time when these grown-up girls ... sometimes will put their hands in their vagina. - Male, Bono, Pentecostal, school B

They masturbate a lot... someone said he was going to urinate and I asked someone to follow him because he will go masturbate and come back dirty. Normally, it is the boys.
He will come back with cobwebs\textsuperscript{101} in his hair etc. The boys also like to touch the girls ... we have told the girls to tell the boys to stop and shout - Female, Ewe, Pentecostal, School A

From the report of the male educator from School B, such incidents no longer occur. Masturbation appeared to be the reason for the perception on hypersexuality. However, it is evident that there is no privacy for them to masturbate outside public view (Abdul Karimu, 2017). The presence of disability in a person's life and its associated limitations (whether bodily, social or intellectual) leave little room for privacy. Besides, that, most households leave little room for privacy because of the living arrangements, there is a need for research into the role of living arrangements in Ghana and how that affects sexual expression or contributes to "public" masturbation among PWIDDS.

Predictably, many of the concerns raised also appeared to be female biased because of the consequence of unwanted pregnancy. On many occasions, the interviewer had to ask the question, "what about the boys?"

\textit{Respondent:} as an adolescent, you have a sex drive but you have to get a way of controlling it if you don't you would go out to do certain things that will affect your life like, going out with men, for men they are there. Even if you are young, some man will come and confuse your mind but you have to control your lust .... if you are moving with boys you must know how to move with them.

\textit{Interviewer:} but how about the boys I see that all the emphasis is on girls

\textit{Respondent:} .... the main reason we focus on girls is that if the boy or man confuses you, if you get pregnant, the boy will go on with his education you are stuck, and if you decide to abort sometimes the end result is death. To the boys we say if you get a girl pregnant what will you do? So I tell the boys to control it. Engage yourself by playing football or

\textsuperscript{101}Spiderwebs/ cobwebs were in the toilets of these schools. in an informal discussion with this educator, he narrated how they had caught the boy a few times masturbating in the toilet after they had wondered on many occasions how it is that he returns from the toilet with cobwebs in his hair. Additionally, these toilets are located away from the classrooms and were not too clean.
erasure that thing from your mind. Go to the library read and by enjoying the story you forget about that desire. Engage in activities to erase that from your mind and it's good to be attending church to build that moral aspect and the Word of God says not to do this before marriage and as you hear the word of God it helps you to tune your mind.

(Female, Akan-Ewe, Christian, SCH D)

The issue of same-sex relations as a concern, from my observation and the interviews, was a concern mentioned only in schools where educators had either witnessed it or heard reports from community members or other learners. All the educators in the four schools where it was mentioned during sex education talked about it without any sense of disgust despite the recent and ongoing public backlash at the LGBT community in the country. The educators' attributed their reaction to, and impression of homosexual acts among the learners to the learners' unawareness of sexual mores, inability to appropriately express their sexuality, and even more commonly a behaviour learned through such interaction with a non-disabled person. The head of the school where they did not teach it mentioned that she was sure that many of her learners already knew that it was taboo and were aware of the social implications, but also stated her awareness of the need to teach about it so that other members of the community do not lure the learners into it.

4.4.6 Learners' verbal and non-verbal expression of desire for intimacy
All the educators had reports of the learners expressing their desire for sexual intimacy and marriage in various ways, although they agreed that not all of them expressed this desire. Notable among them included the learners' directly telling teachers how they felt about another person usually of the opposite sex, either on the campus or in the community or directly telling the person they desire or to whom they are attracted. Although most accounts were of male learners, expressing their desire towards female teachers and their female peers, there were some
reports of female learners trying to lure their male peers to the bathroom, or trying to get a male teacher’s attention.

When the girls see a male teacher, they behave shy, flirty, last year they went for sports in Accra and the report came to us that while one of the male teachers was bathing one girl went to fetch water and tried to bring it to him in the bathroom. The person is already bathing ooo... so we reported to the head and she advised that during communication time we talk about it. (Female, Asante, Presbyterian, School D)

Some educators also shared accounts from their teaching practise experience.

… they (the learners) have those feelings in them. I saw that at the DS School. When I went there was a boy who said I was his wife. If I want to fetch water, he would offer to do that for me. Another colleague also experienced that with another boy to the extent that when another man spoke to her he (the learner) became very jealous. - Female, Ewe, Pentecostal (School A)

In School A, an educator shared how his learners will sometimes try to hold his wedding band and say they also want to wear it one day. An educator also reported that some male learners in Schools C told some of the females that they will wed them. In school B. the teachers talked about the brother-sister phenomenon, where girls and boys will say they are siblings as a way of hiding their relationship. Despite these expressions, many of the teachers said that they doubt if these learners, especially the females could remain committed to one sexual partner. Informal conversations revealed that educators felt that the females could be lured easily with money, candy, yoghurt among other. Educators gave examples of such incidents, pointing out a few females who have either been lured by their own mates or other males in the community. Every school had an example from "she said the man gives her yoghurt" to "she said the man gives her GHC 1."

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102 This refers to the practical sessions of teacher training. It usually takes place in a school other than where the educator is stationed after completing the program.

103 Growing up, this was very common among us where we told everyone in school that a particular person of the opposite sex was a cousin so that our amorous relationships were not exposed.
4.5 **Responses and Reactions**
The researcher asked the educators what their reactions and responses, and that of their colleagues had been to the behaviours and concerns of the learners. Educators reported responses ranging from education to punishments, as the main responses and a few unconventional responses that ranged from laughing (mockery) to crying (and shock) and other controversial actions.

4.5.1 **Education**
Education was in two forms. Educating the learners themselves and educating their parents

4.5.1.1 Education of learners
According to all the educators, education for the learners was mostly reactive - in response to the behaviours that learners exhibited. They reported calling the learner(s) involved privately, educating, counselling him or her individually or in the presence of peers who were present when the incident occurred, and consistently checking on the learner to monitor progress in the behaviour. Additionally, all the educators appeared to point the learners towards a time in the future when they will be able to marry, have sex and have children - when they finish school.

One educator's account;

*I catch some of them masturbating in the toilet (narrated a few incidents) and I educate them. Do you want to marry? don’t worry when you finish school you can marry.* - Male, Ewe, Catholic, Sch A.

This implies that the learner should wait to have sex rather than masturbate. It also supports previous literature that finishing school is a prerequisite to getting married and those two have become ways by which maturity is defined. Hence, the learner is encouraged to wait and not masturbate, wait for marriage to have sex.
Only two schools (D and E) had sex education as a part of the weekly schedule. One of the schools did not have sex education as a continuous program in the school curriculum but carried out individual education as often as the learners needed it. In the other schools, according to the reports of the educators, sex education was delivered at least once a month or twice a term but mostly in the form of group-based instruction with the focus mostly on personal hygiene and changes in the body. Other topics of focus mentioned by the educators were consequences of sexual activity with the opposite sex such as sexually transmitted diseases and HIV/ AIDS and unwanted pregnancy.

Educators reported that they tried to be as practical as possible although they were skeptical about the approach and this was observed by the educator in schools A, C, D and E. In School B, the educators were hesitant and claimed that the learners knew that plainly mentioning certain terms was not the norm and would scream and run out of the class during the lesson. The lessons obviously excited the learners and had them bluntly repeating term such as penis, vagina, or sex, in English and then the local languages, which at times made the educators themselves uncomfortable since they feared the reactions of parents to such education. A result of this “raw” education as one educator in school B mentioned is that, “(the learners) will go around saying ‘etwe, etwe, etwe’\(^{104}\) for no reason and parent will come and start asking us questions.”

In communities where speaking with proverbs and idiomatic expressions is privileged over plain language, especially when discussing sensitive issues like sexuality and trying to emphasise a point there is a need to evaluate how the school system can also impact that knowledge to the learners. Boaduo (2012) and Kwamena-Poh (1975) have noted the importance of speaking in

\(^{104}\) Means “Vagina” in (Asante Twi) and is considered vulgar. Most educators mentioned though that it didn’t sound as vulgar when said in English.
idiomatic expressions and proverbs and the value placed on cultured speech in Ghanaian societies. From educators’ reports and the researchers’ observations, the learners themselves appeared to be conscious of this norm while for the educators coming from this background and having to teach the learners in plain language appeared to lead to some conflict of a sort.

A topic on the prevention of sexual abuse mostly focused on the girls. Only one school included a topic on same-sex activity in their education. Other avenues that educators mentioned, for sex education during the term were morning devotion periods or assembly, and Sunday service at the residential school. However, the content was limited to the religious and moral aspects of sexuality.

Besides changes in behaviours, the education given has also empowered some of the learners to prevent sexual abuse. An educator gives an account of one student who reported an incident that occurred during the last school break:

**Respondent:** There was a girl who one day said she was in the hall\(^{105}\), the place was hot... she had removed her brassiere leaving only her panties and was in the living room. She said a man came into the room, and so she shouted, "What do you want? Don’t you see I have (taken off) all my clothing go out" she shouted and this man was still coming on her and so she shouted because we have been teaching them that at their age, some men will be interested in them so they should be careful. We have also taught them that when a man is drawing near, coming to touch your breast and doing those things he has an intention to do... (gestures\(^{106}\)) exactly! So, when this... (gestures) she shouted until people came.

4.5.1.2 Parent education
According to the educators, parents were invited, counselled and educated in confidence by the School Head and class teacher when their child(ren) were involved in sexual misconduct. Besides that, however, parent education was also given to alert the parents when the learners

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\(^{105}\) Living room

\(^{106}\) Pounce
came of age and advise them on measures to prevent pregnancy, or improve personal hygiene. For female learners who were observed to be sexually vulnerable or sexually active, educators advised contraception (mostly the implant). This was the case in three out of the five schools. The parent education was only reported to occur only when a particular child was involved in certain behaviours and so the parents were called in confidence and advised. In School D however, the school authorities had tried bringing parents together to educate them on family planning methods for their female children but the parents declined the invitation with the excuse that their children "were not like that." Only one responded to the invitation and her daughter has been on the Norplant (implant) contraceptive for the last four years. Teachers in other schools also reported that they had at least one female on the Norplant contraception.

4.5.2 Negative Sanctions
In many other instances, the mere threat of suspension and dismissal yielded remarkable results. According to all the educators, most of the learners' only opportunity to go out and be social rests in the process of schooling. The learners like to be in school. They are not as regarded in the community as they are in school and are often teased and excluded. In the school, they are appreciated; some have positions like class prefects, bell boys. They are called by nicknames and pet names that raise their self-esteem. Therefore, when there is sexual misconduct, educators reportedly threaten them with suspension and dismissal. "...Madam be yi wo adi" was a very common saying in two of the schools even among peers who felt sexually offended by another learner. According to educators, where these threats did not yield results, punishments ranging

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107 Not sexually active or are innocent
108 The female learner was not told the real reason why they were getting the implant or what exactly it was. This was to prevent promoting promiscuity. According to the educators, because they talked about sex and pregnancy, to tell a female learner that the implant was to protect against pregnancy invariably served as a licence for promiscuity.
109 "Madam will dismiss you from school" (in Asante Twi). Similar phrases were used in schools located in non-Akan speaking communities.
from picking the compound, shaming at assembly, suspension or outright dismissal were met out to learners who exhibited sexual behaviors or had sexual encounters in the school. From their reports, the shaming at assembly took two forms:

- Corporal punishment (or caning) by the school head in the presence of whole school. In this case, the head is required according to the Ghana education service) to tell the whole school why the learner is being caned and cane the learner in the full glare of his or her peers or school mates to deter the other learners from exhibiting such behaviour. Abdul-Karimu, (2017) has reported this practise in a study on the sexualities of learners in special schools for the visually impaired. However, this form of sanction is not limited to special schools. It is a general sanction applied in all public schools for various offences (Aklamanu, 2016; Agbenyega, 2006).

- A lesser form of shaming which involves calling the perpetrator(s) before the assembly of learners, telling them what the learner has done and asking them to all hoot at the perpetrator(s) (say, "shame"). It also provides the educators the opportunity of encouraging the other learners to police one another, and report any such incidences to make sure that perpetrator(s) do not repeat their mistakes.

However, the lesser form of shaming was the more dominant form of sanction. According to the educators, caning, suspension, and outright dismissal were under rare and extreme situations and after all the education, counselling and warnings had failed.

Furthermore, reports from the educators indicated that males were more likely to be withdrawn or dismissed from the school than females since all the stories recounted only talked about the male being suspended or dismissed.
Before, we had many cases but minimized now. We have put certain measures in place. ... We... relocated the girls’ dormitory... There was a nineteen-year-old boy who waited for the housemother to sleep and pounced on another particular boy. So, we have sleeping times. He was doing it repeatedly and so we called parents and they confirmed that other men did it to him at home so we had to dismiss him because he has been socialised that way and was socialising others. Another boy also started pouncing on the girls and we realised and (were giving) him time-out. ... That was when he moved to a boy. That incident was witnessed by the housemother who wept the whole day. (Head, Asante, Charismatic, School B)

4.5.3 Unconventional response strategies
From the previous narration, some of the unconventional responses of educators in response to behaviors in the residential school have been; taking turns to sleep at night (relocating the girls to another dormitory block and the initial reaction of crying by the housemother who was shocked at the "taboo" incident as the educator later described it. In one of the day-schools, one of the educators reported that she permitted learners, mostly boys who wanted to masturbate to go to the bathroom while in another an educator reported that she allowed male learners to lie on their belly for some time because that was usually their request when they had erections. Others reported shouting at them to stop or simply shouting out their names so that they knew that they were being watched and stop what they were doing.110

Another educator reported that on discovering the circulation of pornographic videos in her class and on the cell phones of her learners (mostly, adults) she had all the students delete the videos from their phones. Following that, she showed them a pornographic video and explained that all they saw was not real, and was simply acted.

**Respondent:** I let them delete the porn from their phones and laptops and we dealt with it. ... we had to come and start all over again with the laptop of one of the students, we googled the site and made them aware that the porn is not real. The principal also came

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110 According to the educators, the masturbation in class normally happened when the learners became absent-minded and so the learners were closely watched and interrupted when they were found masturbation in the class.
in and said so... I told them that big penis they are seeing is not real, I did not play around it. I was plain....

Other unconventional response reported in two schools was calling other educators to come and laugh at the learners especially if they were caught pants down or trying to touch others inappropriately.

Some female educators also explained that they tried to keep their distance from male learners who were either turned on by their presence or tried to touch them inappropriately. Sometimes the help of a male educator was solicited to counsel the male learner. It was observed that most schools had very few male teachers. They explained that all these had improved the behaviours of the learner and reduced the incidence of inappropriate sexual behaviours in the school. The gender dynamics in the enrollments of learners versus the enrollment of special educators is noteworthy. While many more male learners were enrolled in the schools, there were fewer male educators. For instance, in two out of the five schools there was only male educator out of six educators and out of seven educators respectively.

4.6 Scope, Methods of Sex Education
All the educators interviewed said they were comfortable talking about sexuality and sexual intercourse with the learners. Teaching was done in both English and the local language in all four public schools (Bamgbose, 2004). In the private school, however, instruction was only in English. To understand the scope and methods used in delivering sex education, the interviewer asked what aspects of sex education the educators actually taught and felt should be taught. All teachers agreed that everything regarding sexuality should be taught although they did not teach certain aspects. For example, in school C the educators mentioned that they did not teach about same sex relations because it had not come up as a behavioural concern. Abortions was also not
taught at all in any of the schools because all the educators mentioned that it will encourage the learners to try it in case there was pregnancy. For all the educators who identified as either Christian or Muslim, abortion was murder. The school head of school B narrated an incident where a family of one learner tried to abort the learner’s pregnancy, which was over four months old. The family members namely the learner’s aunt, according to the school head did not want “her failure to raise the child well” to be exposed since the learner’s mother was abroad and had handed the learner’s care over to this aunt. To prevent the abortion, the school head together with the district director of schools agreed to keep the girl who was a non-residential student in the residential system until she had delivered. The aunt was however able to come to the school and give the said learner a concoction that caused her to miscarry in the middle of the night. This led to the withdrawal of the learner from the school. The act as the school head described it was “an abomination” and could encourage others. Traditionally and among the Christians and Muslims religious communities, there is a strong disapproval towards abortions as it contradicts the belief in the value of prosperity and continuity of lineage and value for human life (Mate, 2002; Bleek, 1990). Topics most mentioned as being taught were; the body (and changes in the body), personal hygiene, "anti-begging", moral education (with abstinence focus) contraception (especially for those who have already started) and self-protection from abuse. Nonetheless, in the two schools that had weekly sex education lessons, the educators reported telling learners about the dangers of same sex relations and masturbation such as risks of infections, psychological risks, addiction and lack of self-control, injury to the anus, vagina or penis and stroke from excessive masturbation and effects on general social life. Educators also teach coping strategies to avoid or reduce masturbation. Some of the coping strategies are captured in the following responses.
Respondent: I let them know that masturbation wasn’t the right thing to do as at that point in time. And it wasn’t fair on their part, in terms of their health, future relationship with opposite sex and even their social relationships with siblings and yeah! peers in that when they do such things it affects them emotionally, psychologically, it affects them and it becomes part of them and each and every time they would want to have the urge and drive to masturbate. ... for them to prevent masturbation they must stop watching pornographic stuff, nude pictures ... anytime they have the urge, they should pick a healthy book to read the Quran if you are a Muslim, and if Christian, Bible, so I introduced them to the library and take some books to them to go and read. Respondent: that very moment if you have that feeling to masturbate, (you should) should take in a lot of water and exercise, take a cold bath and go sleep. Take a book, as (you are) reading you will sleep off.

With regards to the methods, sex education was mostly verbal and contained a lot of rote, according to the educators. Role-play and using the students themselves as models was also recorded among almost every educator in the schools, which carried out sex education as part of the school program. The educators also shared their own life experiences, or other example from the learners’ own experiences to help educate learners even when sex education took place privately.

Using they themselves as examples, (I) tell them about dating, tell them the age I started and how I knew it was time to marry.... in our traditional setting, we use occupation...

once you have started working and earning a living you can marry - Female,

Charismatic, Ewe, School A

While it may appear culturally appropriate for the educator to use herself as a role model, there is a need to acknowledge the difference between her situation as a non-disabled person and her learners’ situations as persons with intellectual disability. Addlakha (2007) and Chappell (2013) emphasize the need for positive role models for PWDs in the area of access to sexual expression and recognition of their sexualities. However, having educators as the role models might only make their aspirations bleak in that, they felt the need to meet “normal” standards (which include...
finishing school and getting a job) which to many of them, might appear unreachable. One educator mentioned how one learner who stopped coming to school told him how school had nothing to offer him and so had entered the bread making and was trying to woo a certain lady at his workplace. Some of the learners might feel trapped in the school system but may not be able to get out because of the parents or family expectations. In effect, who needs school if you can get a job and gain independence without it? An evaluation of the school system and the extent to which it meets the needs of adult learners to develop independence and function in society is worth undertaking.

4.7 Determinants
The researcher also sought to find out what factors influenced the scope and methods of sex education delivery and the reactions to learners' sexualities. Educators' responses were categorised into religious and customary values, the behaviours of the learners, parents, the lack of teaching resources, curriculum and educational policies and multilateral agencies.

4.7.1 Religion:
The influence of religion and customs appeared to be dominant in the lives and values of the educators themselves. Each of them identified as either Christian or Muslim. The traditions and customs of their origin as well as the communities in which they worked also influenced their actions and inactions. From the methods to the scope and approach to addressing the concerns previously highlighted in this study, the power of religion and customs cannot be over emphasised. Additionally, according to the educators, almost all the learners came from either Christian or Muslim backgrounds. Besides that, many hold the belief that in every aspect of their life, including their work, they are accountable to God. Moreover, all the schools including the government schools from my observation started the day with a morning assembly time that
included a time of prayers and singing of praises to God. Some of the schools were also mission schools and so could not go contrary to the mission of the religious authority of the schools (Olivier & Wodon, 2014). Religious and customary values against homosexuality were the reason why some respondents did not touch on the subject. In three schools however, the educators talked to the learners about same-sex relationships, explaining to them that it was taboo in Ghanaian culture and was also against the Bible. This supports Iyer and Aggleton’s (2014) study that showed that religion determines how educators delivered sex education in African communities.

4.7.2 Learners' Behaviours
The behavior of learners, as captured in the section in the SRH concerns influenced the methods of delivering sex education. One educator mentioned how the learners already knew the actual names of the reproductive organs and so they had to start mentioning it plainly, although the school was in a conservatively Islamic community.

...initially we were not allowed to mention the words plainly but realised the children were more advanced than us, because of access to technology... (Female, Sisala, Muslim, SCH C)

The role of behaviours also influenced the topics that were treated. If there were reports of some sexual behaviours among learners the next few lessons will likely focus on that aspect. The occurrence of same sex relations among the learners was stated as the reason for including that aspect of sex education in all the three schools.
4.7.3 Parents
As per instructions in the curriculum, for schools where the curriculum was in use, they mentioned how it was indicated in various sections relating to sex and contraception that teachers discuss with parents before teaching. This simply deterred some teachers from even venturing to teach about that because they want to avoid confrontation with the parents. All the educators mentioned that parents mostly were involved in the sexualities of their children only when the learner was involved in sexual misconduct in the school or at home. Either the educators called the parents to the misbehaviour or the parents came to report their inability to handle the child’s sexual misbehaviour at home and in the community. In one of the coastal region schools one educator recounted how some parents of adolescent and adult females refused to show up for family planning training because they claimed their females did not go out and were "not like that" (i.e. not sexually active). None of the school had the opportunity of talking about the sexuality of the learners to the parents as a group. In every school except school E, the educators reported that in the event of pregnancy or any of the learners, educators' attempt to find out under what circumstance the pregnancy occurred, was usually not welcomed by the family.

_Sometimes we want to report if (pregnancy) was a result of abuse but the family feels it will become an issue of washing one’s dirty linen in public._ (Male, Konkomba, Catholic, School B).

4.7.4 Non-teaching or other special education staff
"You are spoiling the children ooo". This and similar remarks were reported as dominant in three of the schools where sex education was being taught. During the interview, educators talked about the influences of and responses to sex education programs from other teaching and non-teaching staff who did not think it was appropriate to teach these learners about their
sexuality. According to those against the program, these educators were tainting the innocence of
the learners. Additionally, while some teaching and non-teaching staff found the plain
mentioning of the private parts without the preceding clause of "excuse me to say" was crude on
behalf of the educator. This also influenced how the teachers delivered the lessons so as not to
offend the sensibilities of these other teachers. In schools D and E however, the teachers reported
that their other colleagues were very cooperative during these lessons.

4.6.5 Economic resources acquiring TLM
According to all the educators in all four public schools, the lack of teaching-learning materials
(TLMs) made it typically challenging for them to deliver sex education in the way that they
wanted. Chirawu et al (2014) has reported similar in South Africa. It was observed that the
lessons were mostly oral and full of rote except in schools D and E where they had some TLMs.
In many informal discussions, educators will mention how having videos, picture and models
would have reduced the complexities of describing actions, processes or situations related to sex
and sexuality. In school D the educator demonstrated to the researcher how she teaches about
menstruation using washable pads and how that has made a difference.

"When you want to use the real pads they are expensive. you open one and teach
them and they all use it. Even how many times can you use it to teach them? Some will
also not understand that you don’t share the pad. But with the washable pad every female
child has one set with the pant so we can teach them using their own pad. So we go over
with them.” - Female, Presbyterian, Asante, School D

These washable pads, donated by some foreigners were similar to the local amonsen\textsuperscript{111} used at
home. According to the educators, having TLMS that can help with replication of the lesson at
home or in a real-life situation was very necessary in order to make impact.

\textsuperscript{111}Local red fabric used as sanitary towel during a woman's menses. The washable pads were similar but of a better
material. Besides being a useful teaching material, it was also practically useful for every female.
Some educators further complained that they had either to make these resources from scratch or spend their personal monies purchasing materials that they felt will enhance the learners understanding of the lesson. Every public-school educator interviewed called for government to provide teaching-learning materials and allocate enough resources to the special schools for the IDD. The educators from the one private school did not raise a lack of TLMs as influencing the way they delivered SRHE. On the contrary, they made references to the use of these materials in their lessons.

*I have a picture of a human being of the board and I ask them to tell me what parts of the body are private. Some come up to point and some are shy. And I tell them you can touch that place when you are bathing but not unnecessarily when you are there.* (Female, Ga, Charismatic, Sch E)

The two unit schools educators also mentioned about the lack of space. As many as a hundred children in one of the school were housed in a three-classroom block, which ideally should take about thirty learners with IDD. The other one school had no electricity and the toilets were far from the classroom block. Additionally, unit schools only run until noon and do not leave enough time to engage students effectively. According to all the educators in these a schools, a German professor who started the integrative schools program explained to them that the learners could not be taught for more than four hours although in their opinion they felt that they could spend more time and do more with the learners. Since then, the GES has also run these schools until noon. The cost of menstrual pads on the market, according to some educators also made it challenging for female learners to come to school when they have their periods. Thus, interrupting their program as they have to repeat lessons not only for the sake of the impaired ability to grasp what is taught quickly but because of absence due to periods.
4.7.6 Education policy and curriculum

The interviewer asked to what extent the curriculum addressed the SRH needs of the learners and prepared them for transition into their communities. All the teachers in the public schools said it did not adequately address the SRHE needs of their learners. According to the teachers in schools A, B, D, E, the curriculum that the public schools were using had been developed by a German educator over a decade ago. This school curriculum, which includes a section on sexual and reproductive health education, was adopted on a pilot basis and has not seen any alterations since it was introduced about 15 years ago.

Two of the schools (Schools A and B) were using the GES curriculum, School C had no specific program and delivered SRHE as and when the need arose (usually from inappropriate sexual behaviours). School D had adopted the Stay Alive program as their SRH education program. A glance through and quick observation of the curriculum of School D (Stay Alive) and its use also revealed that it privileged “able-bodiedness”. There were no characters like the learners and the person in the curriculum become white-collar professionals when they graduated from college, got married and had a family. The challenge here was that that did not reflect the least possible future reality of the learners with IDD in that particular setting. Chappell (2013) has reported similar challenges of compulsory “able-bodiedness” present in the sex education curriculum of persons with disabilities in South Africa.

In school E, there was a very consistent program, specific to persons with IDD. The educator in this school used different resource books specifically for learners with IDD (online and from foreign volunteers) to develop a chronological program, which she followed. According to her, she was able to adapt to also suit the need of the learners and was also culturally sensitive in that it emphasised marriage as the ideal situation for sexual intercourse,
emphasised the privacy of sexual expression to the extent that the learners had been socialized about the appropriate spaces for sex talk.\textsuperscript{112} It also took into consideration attitudes towards sex outside marriage, masturbation, homosexuality, indecent dressing.\textsuperscript{113} The approach in school E was also likely possible because they are not accountable to any governmental or religious educational authority.

In School B, educators said they did not have access to that curriculum and in Schools D and E even though they had it, they did not use it and used other curricula. All the educators who used the curriculum said it did not sufficiently meet the sexual and reproductive health needs of the learners and needed to be modified. The inadequacy of the curricula used in various African settings are also reported in studies by Aderemi (2014), Chirawu (2014) among others.

4.7.7 Influence of multilateral agencies

In school D and E respectively, the teachers talked about how volunteers and other agencies such as Reach the Children\textsuperscript{114} and the Peace Corps respectively had influenced the sex education they delivered. The educators in School D mentioned that they used the Stay Alive

\textsuperscript{112} They were socialised and taught not to extend the sexual conversations beyond the times that were allocated and outside of that private space. Also, specific instructors were assigned to listen to these learners would they have need to discuss their thoughts, concerns, and feelings with anyone. A breech of this "privacy code" meant suspension from the group sessions. The educator was observed during a few lessons with the learners. At the beginning, she would let them all repeat the code, summed up as all talk in that space was private, genital/ reproductive areas of the body are private and if anybody asks you what was discussed or wants to see or touch those private parts, the response should be "no! It is private".

\textsuperscript{113} Wearing clothing that exposed parts of the breasts, stomach and thighs (which are considered private), sagging one’s pants/ trousers.

\textsuperscript{114} The Stay Alive HIV/AIDS Prevention Education Program is administered and implemented by Reach the Children, Inc., an international, humanitarian organization. The Stay Alive Program is being implemented in many other African countries. According to their web information and the curriculum that was being used in school D, stay alive is a not defined as religious or secular but emphasizes abstinence until marriage, and promotes love, respect and value for family life. Therefore, it aims to reach children before they become sexually active. It teaches the consequences of choices and empowers learners/ children to make responsible decision in spite of the negativity around them (e.g. Drug and substance abuse, truancy, which might expose them to sexual promiscuity) so that they can live a life free from HIV/AIDS. This program was taking place only in that school district, and was not a national program.
program, which they adapted to the intellectual and cognitive level of the learner. In school E, the educators also mentioned how a Peace Corps volunteer's HIV/AIDS project, initiated discussions on the topic of safe sex and condom use.

The challenges resulting from a lack of curriculum was also recorded by Aderemi (2014) and Wilson et al 2011. While according to Aderemi (2014) this led to non-structured discussions, similar to what was occurring in school B, which took place only on suspicion of sexual misconduct. Even in the presence of a curriculum we realise how staff rely on their own beliefs as to what is appropriate or inappropriate (e.g. In the case of deterring learners from masturbating) (Wilson et al., 2011). The educator from school E who had adapted and adopted materials from online and used stroke as a reason why one should not masturbate, mentioned that although masturbation was encouraged, she personally felt that it did not suit our cultural context. In an informal conversation later that day, the educator mentioned that she used stroke as a reason why one should not masturbate was only a fear tactic. In her own words she said, "that was the only tactic" she could think of. Culturally, many Ghanaian communities do not endorse masturbation (Ankomah, 2004) but to cite stroke as a reason not to, is questionable. Aderemi (2014) has also reported that fear tactics are common among the teachers in the study conducted in Nigeria.

4.7 Conclusion
This chapter has presented and discussed the findings resulting from the interviews with thirteen special educators in the country. Firstly, the findings indicated that educators appeared to be accommodating of the sexuality behaviours of PWIDDs and were positive about the benefits of delivering sexuality education. With the absence of social workers, and other professionals,
special educators in Ghana play an added-on role of involvement in the personal lives of the learners when they are outside the school premises and even after they cease to be students. This was also because it appeared that the community also trusted them with the wellbeing and welfare of the learners.

From the perspectives of the educators, the sexuality educational needs of learners with IDD ranged from care for the body, developing bodily awareness and agency, knowledge about social relationships such as the boundaries of family relationships and friendships, and Marriage (exclusivity in sexual relationships) and develop capacities for preventing, and reporting abuse, knowledge about sexual taboos/vides such as pornography, public masturbation and homosexual relations and their implications within our social, cultural and legal setting. While educators identified the need for contraception knowledge, many feared it would encourage sexual activity.

Currently, mostly reactive sexuality education and personal advice, moral education which emphasises God as the reference point, and the use of negative sanctions are used to teach what constitutes appropriate sexual behaviour and what does not. Role-play and stories from educators’ personal experiences were also among the responses for strategies for delivery of sexuality education. The education was limited to the functions of the body, abuse prevention, and the mention of condoms although these are not made available to the learners. Interestingly HIV/AIDS was not of prime concern to the educators as the pregnancy of the female learners. This could be because Ghana has a generally lower HIV prevalence rate\textsuperscript{115} - i.e. 1.6% in 2015 according to the Ghana UNAIDS office - compared to other African nations. Moreover, although, educators were positive that some of the learners be in publicly recognised relationships either among themselves or with non-disabled persons but indicated that this was

\textsuperscript{115} This prevalence rate is for adults aged 15 to 49 years.
dependent more on the family expectations for the learner. Finally, religious and customary values of the educators themselves and of the community in which they work, the behaviours of the learners, expectation of parents, availability or lack of teaching resources, the availability of and instructions within the available curricula, and influence of multilateral agencies influenced the modes, scope and content of the kind of sexuality education delivered.

This section has demonstrated that the sexuality education needs of learners with IDD are broader than a list of specific behavioural concerns. They are intertwined in the socio-economic and cultural expectations for members of the society, presence of state and international regulation and influence and require partnership with parents and community members. However, the curriculum does not appear to take due consideration of the Ghanaian customs and avenues in Ghanaian customs that can facilitate the full participation of learners in mainstream society apart from the economic aspect of having employable skills. "Activities for daily living" in Ghana includes cultural knowledge, which evidently is not a part of teachers' education curriculum and hence is missing in learners' curriculum as well. A deeper understanding of the cultural dynamics of our societies needs to be achieved if we are to find avenues through which learners with IDD can participate in mainstream society more effectively and educators must be part of that process. Development is not a lineal process and does not only subscribe to Western standards of doing things; Cultural knowledge is also important and has potential for development especially for the promotion of the welfare of PWIDDs in Ghana.
CHAPTER 5 PARENTS’ PERSPECTIVES ON SEXUALITY EDUCATIONAL NEEDS

5.1 Background

Fifteen parents, comprising two fathers and thirteen mothers were interviewed. One of the mothers was also a special educator. All those interviewed had learners with IDD attending various special schools in the five regions across the country. The youngest child among these parents was 11 and the oldest 31. As indicated earlier, there is no defined school leaving age for these learners in the public schools (Lamptey et al., 2015). Three parents had their children in residential school while the other parents all had their children in day schools of which three, were in private/ non-governmental special education centres. The sexes of the children were ten males and six females. Seven of the learners were on the Autism spectrum, three Down Syndrome, one was head injury during early childhood and the other five have other IDDs that the parents did not know the etiology. One parent had two sons with autism. The typical description the parents gave in the instance of the five with unknown IDD was that their children had the brain of a child or that the child's brain was slow. Very often, the parents referred to the child as being sick or unwell (yarefo). Other expression were n’adwene sua or okita akorla adwene, (having the mind of a child) This is because there appeared to be no local term for intellectual disability other than the one used for mental disability. According to one parent, she mentioned that she thought her son was “mad”\(^\text{116}\) (bodam- in Twi) but her doctor told her that the boy was simply slow and could not learn like the other children and so referred her to the National assessment centre in Accra for appropriate placement. This construction of slow learning, or having a “slight problem” as one of the parents put it, also impacted how parents

\(^{116}\) This assumption came from a community member telling her that there was a school for such children at the Accra psychiatric Hospital. The association of a psychiatric hospital with intellectual disability appears to contribute to the negative construction of madness that some community members might have about persons with intellectual disabilities.
thought about their children. All except one of the parents of the learners with unknown IDD condition were confident that their children could marry someday and were planning towards it.

The interview gave parents the opportunity of recounting their journey of parenting their child with IDD, success and challenges, present concerns and also to discuss their hopes and expectations for their future. The interviewer then asked a series of questions to identify what parents perceived the needs of their learners to be in terms of their sexuality and reproductive health, the determinant of those needs are perceived by the parent and how those needs were being address or could be addressed.

5.2 It's Not Easy

For many parents, the journey of raising a child with IDD has been arduous. Although they sadly recounted the early days, the times prior to and after getting a diagnosis, and the confusion and frustrations that followed, none of them spoke about ever thinking the child was a curse or punishment. One parent however mentioned that when her son failed to walk by age two and appeared not to be growing, her husband, the boy’s father tried to take him to a shrine to be killed because they were spending too much money on trying to get him cured and doctors could not tell them what exactly was wrong with the child. The woman was thrown out along with her seven children, when she decided not to go along with his plan. While there have been narrations about the killings of persons with pronounced defects as earlier indicated in literature, the role of doctors’ ability/inability to communicate what is "wrong" with the child to parents and its implications in the light of such actions should be investigated (Reynolds 2010).

All the parents were however pleased with the progress that the children had made over the years spent in school and praised the educators for the good work. They felt that their hope had been restored to a point. This is because getting a diagnosis of intellectual disability felt like
“a death sentence” according to two parents who lamented how doctors only told each of them that the child was “not normal” in one case and “that the child had been struck with illness while in the womb” in the case of the other. These diagnoses which were given in the local language may have been given based on doctors’ inability to find suitable language to adequately explain the phenomenon of disability to the parents. It could also account for the reason why parents described their children as yarefo (sick person). According to another parents’ report, she did not understand the implications of the child’s diagnosis until her son was asked to withdraw from mainstream school after primary six (grade 6) and at the age of thirteen (13). Unlike Down syndrome which comes with obvious features, all the other parents mentioned that they noticed that their children were not normal when they were delayed in acquiring speech. Ability to communicate verbally in Ghana is of great importance given that it is the various ethnic cultures propagate traditions orally (Masko & Bosiwah, 2016) and it is hence a great disadvantage for persons with IDD. One of the parents with Down syndrome kept asking the researcher through the interview, “Can’t we do anything so that my son can speak well?” Even when she expressed her gratitude for the progress her now 25-year-old son has made she still said, “the speech that is my problem”. The inability to express oneself (clearly) appears to have made parents the spokesperson for their children even after they become adults. While this spokesperson role is not new (as indicated in the literature review), modern technologies of communication also exacerbate the need to verbally express oneself. For persons with IDD for whom spelling might also be a challenge, texting is not an option unlike the case for their hearing or speech impaired

117 The expressions used by the two parents respectively was “doctor no se Onye normal” and “doctor no se, yare kaa no wo me ye’m”.

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counterparts. However, given that there is a culture of using symbols like the Adinkra\textsuperscript{118} to communicate, culturally appropriate symbolism can be explored, adopted and adapted to enhance communication for PWIDDS.

5.3 SRH Needs/Concerns
The interviewer asked the participants what they considered as the SRH needs and concerns of their children with IDD in special schools. Those with adolescent children said they did not really see sexual and reproductive health issues as a pressing concern but mentioned that once the core issues of self-care and learning a trade or skill was achieved, it would be worth thinking about. Parents whose children were adults by the laws of the land (i.e. aged 16 and above) expressed more concerns around that because they were faced with realities such as the undefined school leaving age and likely celibacy of their child and the uncertainty of continuous care for their children in the event of the death of the parents. The following are the sexuality education concerns as expressed by the participants;

5.3.1 Personal Hygiene
All parents put a premium on personal hygiene although it was emphasised more for the females than the males. It comprised;

5.3.1.1 Menstrual care and hygiene
All the parents of female learners who were already menstruating reported that their learners had no problem with menstrual hygiene. They knew how to wear and change their pads but their mothers or if they were in the residential school, the housemothers kept the pads. According to some of them, it also served as a way of monitoring for pregnancy. For instance, one parent

\textsuperscript{118} As mentioned in the literature review they are symbols, which convey aphorisms, proverbs, they enhance a system of communication that culturally symbolizes wisdom.
narrated an incidence where a month went by without his daughter requesting for the sanitary pads from her mother. This raised suspicion of pregnancy.

5.3.1.2 Shaving intimate areas and facial hairs
Shaving of intimate areas is a very popular Ghanaian tradition. Underarm and pubic areas are to be kept shaven or trimmed and not overly bushy as this promotes body odor. While this teaching is common in the curriculum, parents (mostly mothers) also try to help their learners achieve this. At least half of the parents mentioned carry out this activity for their children or having a family member or caregiver assist with shaving. Male children also have the additional task of keeping their faces shaven because they are in school. The parents whose learners have been able to carry out this task independently narrated how it took the joint efforts of the school and home. Others also expressed their frustrations in trying to achieve the goal of a clean pubic area and armpits. One parent of an eleven-year old female narrated her frustration over her inability to shave her daughter's pubic region. "She won't allow me to shave her, that’s my problem" she exclaimed.

Among other issues related to personal hygiene, were teeth brushing and drooling. These were major concerns for parents of learners who had difficulties in these areas.

5.3.2 Behaviours
All the parents except those with children with autism explained that their children's overfriendliness was a concern for them because it made them vulnerable to abuse. All parents except two admitted that their sons were involved in masturbation, did not really see it as a major concern because he always did it in private. Many of the parents did not even want to think about it. The parent of the eleven-year old female however admitted that when she undresses her
daughter to give her a bath and leaves her for a minute or two to get something, she would find her daughter playing with her genitals.

5.3.3 Risk of Abuse
While all the parents of female learners with IDD thought their children were at high risk of being sexually abused, only two parents of male thought their sons had such risk. However, the risk for the males was more in terms of them being abusers. One parent recounted the experience of his daughter who was sexually abused twice in two weeks. The abuse occurred when she was attending the mainstream school. She was abused first by her peer and then by a community member. Both incidents occurred in bushes on her way to the house from school. Although the cases were reported to the police, justice was not served through the law enforcement and judicial systems. Subsequently, the whole community heard about the incident and this led to them having to move to another community because they suffered stigmatization. The family reputation was destroyed as the parent who was a church elder suffered mockery even in the church.

This appears to explain why in the event of sexual abuse, families decide not to take up the case. Pursuing such cases are often socially, economically and more importantly psychologically burdensome for the family. The stigma of being known as a bad parent is doubled\(^{119}\) and this has the potential of ruining even the lives of the siblings of the person abused.

\(^{119}\) I say this because when parents have a disabled child; it is believed by some that they may have committed some evil for which they are paying the price. Although many parents did not hold this view and felt that God was the one who gave them their children, this belief appears to still be present and active in the minds of community members.
5.3.4 Risk of pregnancy
All the parents interviewed who had female learners with IDD expressed fears about their learners having unwanted pregnancies, not when they were in school but mostly when they were on vacation. One parent mentioned how he suspected that his daughter was pregnant at a certain stage because she did not go to her mother for sanitary towels for a month. According to him, they queried her and after a few weeks, they found a huge clot of blood in the toilet (and suspected a likely induced miscarriage given that they had queried her). All parents of females who had started menstruating reported that the females came to them for sanitary towels when they had their periods.
Many parents did not mention risk of sexually transmitted infections as a concern but reported using it as a fear tactic when the children got involved in any sexual misbehaviour.

5.3.5 I want to marry
Two mothers admitted that their children (one male age 18 and female aged 25) keep expressing their desire to be married. Both of these parents believed that when they get married, they will not need anyone to teach them about sex. The mother with a son put it this way;

"as for my son if he marries he is ready to sleep with the woman. ... once he himself has expressed it and I can see that in the morning (she makes a gesture to suggest an erection) then he can marry. So, we are just pray that Allah will make it happen."

This reinforces why parents see no need for sex education. Sex education appears to emphasise that the education is centered around sexual intimacy, which as indicated earlier is a component of the training given during puberty rites. There is a need for investigating how the cultural/pre-colonial interpretation of sexuality or sex education affects the way parents especially respond to it.
5.4 Reactions

5.4.1 Policing
All the parents mentioned that they do not allowed their child to be alone. Policing was to prevent them from being abused or becoming abusers. Mothers serve as the main police agents but at times would request the support of siblings or other community members.

As one mother put it; “I will maintain¹²⁰ (my daughter), I won’t allow her to be alone so no one can take advantage of her” (Dinah, Ewe, mother of 12 year old daughter)

Male children are also policed to prevent them from abusing. Despite that, two mothers narrated incidences where their sons acted inappropriately towards females in the community. These reports were made to the mothers by the females themselves. Some mothers also reported waiting outside the bathroom and timing their sons when they bathed to prevent masturbating in the bathroom.

5.4.2 No sex education
Sex education will rather make the learners explore with sex and contract diseases. “Just tell them what to do”. “Tell them what is necessary”. This was the response of two parents.

According to them, they did not even want the schools to teach sex education as the minds of these children were not focused on that (that is to say, they are innocent). Their minds were focused on school and so teachers should promote that and rather focus on personal hygiene and care, and chastise the children if they do something bad (“Oye biribi na se enye a, tia no, na ongyai” – Twi). However, after explaining to them that there was also a risk of other learners in the schools sexualizing their children, they begun to have second thoughts and mentioned that the sex education should be one that discourages them from experimenting with sex.

¹²⁰ This term and others such as “cover” were used to mean policing the child and keeping the child in close proximity so that he or she is not taken advantage of or does not get into trouble.
5.4.3 Education
The education parents said they delivered to their children was mostly in the form of advice and counsel, modelling and in two cases teaching “appropriate” sexual responses.

5.4.3.1 As counsel/Advice (mostly using a fear approach)
Some parents mentioned that they did talk about sex but with a fear model. According to them, by telling them all the negative effects of sex outside marriage, you prevent the person from engaging in it until the appropriate time. Only parents of female children mentioned using the advice approach. The main reason was that they did not want their child to be taken advantage of and impregnated by an "irresponsible man".

All except the parents of the 11 year old and 12 year old made statements such as, "when I see her playing with a boy, I tell her if you play with boys you will become pregnant" and "when a man calls you don’t go, tell him me, your mother I said you should come and report him". In an informal conversation with another parent of a 16-year old female, she mentioned that her warnings have helped her daughter keep distance from men. According to her, "she (her child) does not even shake any man's hand. She does not hug any man except her father when he was alive."

Advice and counsel also appeared to be limited to conduct and from the conversations, reactive and in response to behaviour that the mothers especially felt could increase the children's risk of being abused.

5.4.3.2 Practise & Modelling
Auntie Dinah whose daughter is 12 and has not yet started menstruating mentioned her strategy for teaching menstrual care and hygiene.

\[121\] I use the term “appropriate” very cautiously. “Appropriate” in the sense that it does not allow for public criticism and ridicule.
"if I’m menstruating I let her be with me as I put on the pad and she will be saying, "Mama see blood". So she too will know how to do it."

Another parent of a 16-year old female with autism who had used that strategy in the past prior to her daughter reaching menarche attested to the efficacy of that strategy.

Modelling was not limited to the females. The only father with a son with IDD in the study, mentioned how he modelled shaving of facial and underarm hairs, and also practised with his son. Apart from him, there were two other mothers, who reported that although their husbands lived in the same household they were not available to practise with their male children. They both mentioned that it needed a lot of patience and time that the fathers could not afford. Thus, they solicited help from male neighbours in the area or in the case of the other the child's older sibling when he came home for vacation. Although Morgan, Thorne and Zurbriggen (2010) have mentioned that sex communication is likely to take place more between mothers and their children than fathers and their children, opportunities for modelling may serve as a platform to enhance such communication.

5.4.3.3 Teaching appropriate sexual response
One parent who is also a special education teacher narrated her response to her son's masturbation.

...for my son, I must say there was one time we were going to school, we dressed up, ready to go to school and I went to buy something. When I came, ... I lived with my auntie who sells outside the house....so she said he has put a mat on the floor and undressed himself.... she told me (respondent emphasises) ...so as I got there I realised he was doing something to his body (she tried to describe using her hand). I almost shouted but something told me to calm down. So, he said what has he done (most likely at the facial expression of his mother) but I said he hasn't done anything so I just told him to get ready so we go... I later bought
Apart from her, no other parent mentioned responding to masturbation this way. Her profession as a special educator could have informed this as well as her religious position as a Charismatic Christian.

Another parent made reference to teaching appropriate sexual response when she mentioned that her daughter who is 16 and has autism did not allow boys in her dance class to hug her. She mentioned that the dance instructor made that observation with fascination. To which she made them understand that she had taught her not to hug boys or men but allowed handshakes.

5.4.4 Contraception

Only one parent reported that his wife had the talk of contraception with his daughter but this was only after a suspected case of an abortion. All the other parents said they had not talked to their children about it. For many, the answer was simply "for what?" According to the parents, the children should rather be encouraged to focus on their books, finish school and then after that they can talk about marriage or relationship. Talking about contraception in the context of a relationship leading to marriage is most ideal.

One parent however mentioned that she intends to put her daughter now 12 on contraception because she is still not fully toilet trained yet and so it will be more challenging to deal with menstruation and toilet training at the same time. She however mentioned that she is worried

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122 This was also a contrary to my own experience, many years ago of the reactions of a mother of a son with autism. As a staunch Catholic and given her background of being raised by catholic sisters, she would spank her then 16 year old for masturbating or pour water on him to stop. But no sex education given.
about the side effects and so her other alternative is to keep the girl in diapers when she starts menstruating.

5.5 Parents’ Scope
The researchers posed two main questions to understand the scope of sex education that parents delivered to their children. Since realising that your child was attaining puberty or becoming an adult, what form of sex education have you given or been giving to your child?

The parents interviewed reported that they limited the scope of sex education to personal hygiene and self-care. For the females, the clause "watch how you play with boys" was added when the females started menstruating. Furthermore, until there was an incident that involved the child engaging in sexual misconduct, topics around sexuality was not discussed.

The researcher also asked parents if they took the opportunity to talk about sexual acts such as kissing and fondling or contraception adverts on the television to educate their children. Some said their children did not watch television while those whose children did watch television responded in the negative and even wondered if the child even understood what was going on the television.

Modelling has been a good method besides the verbal instructions as indicated in the examples of the mothers who made sure that their daughters were with them as they wore and changed their pads during their periods. Two mothers also mentioned how older male siblings or a trusted male neighbour helped to teach shaving of facial underarm and pubic hairs through modelling.

From the reports, it appeared that the males received very little or no sex education at all because there was no threat of pregnancy. Additionally, mothers than fathers were more involved in the training of their sons, even when the fathers were in the household, and so the mothers appeared
not to know exactly what else their sons needed to know except for personal hygiene and when necessary caution against inappropriate behaviours exhibited.

Additionally, mothers appeared to be the main support of their children with IDD although there were more parents with sons than with daughters. This mostly included widows and single mothers. Where both parents were present, the mothers still took major responsibility in the raising of the child. The two fathers who participated in the study however were very involved in the raising of their children with IDD even though their wives were present.

5.6 Determinants of Sex Education and Response to Sexual Concerns

The researcher asked parents what determined why and when they delivered and any form of sex education as well as their responses to sexual and reproductive health issues as it pertains to their children with IDD. The determinants captured are as follows;

5.6.1 Behaviour

Some parents ended up delivering some sex education only when there was an issue. Among such issues were inappropriate touching, masturbation, reports from neighbours or school authorities of any inappropriate sexual behaviours. This reactive form of sex education was noticed in a few interviews where parents admitted delivering some form of sex education. In an interview with Auntie Agartha she recounts how reports of “lesbian” activities involving her daughter was brought to her attention by school authorities and how she and her husband handled it.

"well there was an issue here in school a few years ago. and I was told she and another girl were fingering each other in the bathroom. so we spoke to her and advised her when she came for vacation. .... we told her that if she sleeps with a woman she will become sick and if she sleeps with a man she will get pregnant” – Agartha, Asante, Catholic, Female child, 30 years
5.6.2 Role of religion/culture
All the parents interviewed were religious and professed to be either Christian or Muslim. Religion, however for all but one Christian parent, did not seem like a drawback to delivering sex education, as for almost parents, the reason for not wanting their children to have sex education was simply to prevent "awakening the sex sense." When asked what role their religion played in this decision, many responded that it did not have anything to do with it. In the instance of the Muslim parents however, only one mentioned that religion had nothing to do with it while the others mentioned that it did. The influence of Islam was also very evident as a majority of my interviews with the Muslim parents took place in the Holy month of Ramadan. It resulted in some Sunni Muslim parents refusing to mention words such as “sex”, “penis” and “vagina”. I therefore had to go back to them after the fast to finish the interviews.

According to these Muslim parents, Islam does not permit corrupting the innocence of children and they believed that their children were innocent, still very child-like and so sex education was not necessary until they are ready to use the information within the proper context of marriage. Additionally, all except one Muslim parent was confident that their children could marry and mentioned that Islam encourages people to marry them as a way of supporting them and ensuring their welfare.

The parent who taught appropriate sexual behaviour mentioned that she did not see any conflict between teaching her son to go to the bathroom whenever he felt like masturbating because so long as he had the feeling it would be difficult for him to control it an in order to prevent public disgrace and ridicule from.

**Researcher:** How would you say that religion inhibits or promotes your ability to deliver sex education the way you want to do it. do you ever feel like there is a conflict?
Respondent: I don’t think religious values have something to do with that. Yes because everyone knows the child is a special child, the brain is not functioning like how it should and you should help that child so by helping the child, that doesn’t mean that you are teaching the child anything bad you need to explain it, come down to his level, so that he doesn’t go and do these things openly because as you know in this our society a lot of people don’t understand them, and so you can imagine if this child is by the roadside and he bends down an his... trying to ... I don’t know how to say it... but because he is having the feeling... you know... and people will start saying den na oye no tise jw). (why is he behaving like a snake?) an even start throwing stones at him meanwhile he is having the feeling too. ... I mean sometimes he can run, do something else but if he is still feeling and wants to pull on his genital on the roadside what can you do ... so you teach him to also go to the bathroom when he has the feeling” (Mother of a 19 year old son)
She also expressed concern about her son not being circumcised and the cultural implications especially when he wants to be married. According to her, her son has also asked her when he will be cut (circumcised). Circumcision is very important in many Ghanaian culture and boys who are not circumcised are ridiculed. The term “Kɔte bɔtɔ” literally meaning “penis sack” in Akan is used to ridicule males who have not been circumcised. Apparently she had been told by doctors when he was young to not circumcise him at the time for medical reasons but the delay after he became a teenager was due to her concerns about his disability and the fact that he is unlikely to use his penis for the purposes of reproduction.

The role of religion was also evident in the general perceptions that drove the attitude of parents towards their children. As one parents put it, "no child is useless... every child is useful no matter what. God knows why he gives us these children and so in everything we should give thanks to God.”

Many other parents did attribute their child's condition to the will of God or Allah. They did express their worries of what the future will be but again consoled themselves in the fact that God will help where they cannot.
Even when I asked a parent, what they think the government can do to promote the sexual wellbeing of learners with IDD in the country her response was, "...the world has become a dangerous place. What can the government do? We need prayers. Prayer, prayer!"

### 5.6.3 Role of community

Parents admitted that the community played a role in the sexuality issues relating their children. Some of the parents who have taken decisions to police their children mentioned having done it on the advice of community members and that these community members sometimes help to police the children. During my interview with Auntie Maggie in the market place at her stall, her daughter sat close to her. When she got up to refer a customer to another vendor in the market which took about seven minutes, she asked the vendor beside her to watch over her daughter who is twenty-five years old to which the vendor kindly agreed and asked the lady with IDD to some sit by her. Other parents shared how stories of what some parents with IDD have done in the past have also influenced how they deal with the sexuality of their children. One parent mentioned that if her child was a female she may have considered dealing with her child's sexuality in a particular way. According to the mother of 28 year old Nana, her son is the last of 7 children and is male. However, if he was an only child and female when may have considered this option.

*There is one lady in our area, some years ago she had a daughter with CP. The girl could not do anything so they always carry her to the veranda or sitting room. If you see her nice girl but... (respondent coils herself in a bid to show the researcher what she means without verbally describing) you see what I mean? (researcher nods). So, she is like that but the lady will intentionally leave her at home and go out. Everyone knows its intentional. She got pregnant three times. Now the children are almost grown. If you see the children... beautiful children. So now, the lady has grandchildren, if she dies those*
grandchildren will take care of their mother. But my child is a boy. So, what can I can I do. I have to take him everywhere.123

Two parents reported that some community members also caused them heartache by not rendering support. A father shared his experience after different men abused his daughter now 27 years old on three separate occasions. He had pursued the first two cases and it became public knowledge in the community. According to him, the police refused to take up the case because they said that there was no evidence. Going public with it appeared to bring them more hurt as he believes that that led to the third incident of abuse.

"I felt very bad. I am a church elder eehhh .... hmmm... I don’t know. You see, you will be going (in the community) then people will point fingers at you and say "this is the father oooo" and when you hear it you can't stop and go and ask the person why he is saying that... Because of that we even had to move. It was becoming too much.”

A parent who lives in a community she considers unsafe also mentioned how that informed how she ensured that her daughter does not become victim to abuse.

“as for (abuse) I’ve thought it for a long time so I don’t leave her alone. She is always with me. I take her everywhere I go and in my community there are lots of bad men around... in the community they used to spoil children124 ... they take advantage of these kind of people”- Juliana, Charismatic, Seamstress, female Child, 11

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123 As a researcher, I must say, while it is easy to approach this practise from the perspective of a human rights abuse, the lack of social welfare services appear to leave some parents, especially those who cannot find any other support for their growing children, in positions that warrant such actions. In a conversation with the late Queen mother of the Anlo Traditional area of the Volta, prior to the study, she mentioned that similar practise has been ongoing among the Anlo for a long time. The purpose was to ensure that there is support for the PWIDD when his or her own parents or siblings die. Additionally, the belief that a person who does not care for his/her own parents will incur the wrath of God or the gods ensures that children always try to care for their parents. Moreover, a Ghanaian proverb says, "The parent cares for the child till it grows its teeth and the child looks after the parent when he or she loses their teeth". Thus, the forms and complexities of such a practice though necessary for a comprehensive understanding of what the hegemonic human rights discourse might term "sexual abuse" in this context; a practise that appears to be encouraged by the local community are an area of study for another day.

124 Sexualize children and abuse them.
5.6.4 **Role of educational system**

Being in school makes the learners continually infantile, children even when they are grown.

Some parents with children as old as 25 maintained that the learners were still children

The parents with children in the residential schools admitted that they did not deliver sexuality education because they knew that the school will do it since they are in a better position to train the child. Even those whose children did not attend residential schools and were in support of teaching sex education mentioned that they were confident that if the educator delivered it, it will be in a way that the learners will understand and produce positive results.

"...one of the teachers who used to be here, he said that these children like sex. He said I should be careful about my daughter. He said some girls (with IDD) have tried to sleep with him before." - (Dinah, Ewe, Trader, Charismatic, Female, 12)

All three of the parents interviewed, whose children had residential status in the residential schools appeared less enthusiastic about letting their children marry or having families of their own one day even though they admitted that they were developing the capabilities to do so. These learners were all adults but the parents kept saying they were still not mature enough. Further studies must be conducted to determine the difference between future expectations of parents whose children are in residential special schools and those whose children are not to better understand the role such educational arrangement has on integration and inclusion in society.

5.6.5 **Living arrangement**

At least two mothers who live alone with their sons and in one case a house help, mentioned that they share a room and bed with their sons.
Interviewer: have you spoken to your son about issues relating to sex and marriage since he started mentioning that this lady is his wife?

Respondent: No I haven't! (exclaimed) I sleep on the same bed with him... so why will I tell him about sex! ....Why sex education? is he in a relationship? if you teach him and he doesn’t have a girl what will he do with the knowledge. - Mother of 28 year old son with down syndrome

This is situation makes sex education a challenge, as they fear that their sons will attempt having sexual relations with them. This living arrangement was also justified as a way of policing the child and making sure that he does not get into any mischief. A mother of a 22 year old mentioned that her son sleeps in the same room with her because, "*He roams too much. He likes funerals and parties. When there is a wake keeping in the area, he will leave the house and so I wake up in the middle of the night and he is not there and I have to go out and look for the nearest wake-keeping."

In another parent's account, the absence of a female sibling for his son makes it challenging to teach his son about the difference between boys and girls. He explained how challenging it is to use his wife as an example because she is a grown woman and his son has not been able to grasp the similarities between his mother and any other female. Therefore, he still treats other females especially girls his age, as he would treat his brothers. For example, he would punch them in the chest as they played (thereby hitting their breast). His son has autism.

5.6.6 Expectations for Future Intimate Relations
The interviewer asked parents what their expectations were regarding the future of their children as it pertains to sexual relationships. All except one of the ten parents of learners aged 18 years and above could not foresee their children marrying any time in the near future although two were not too enthusiastic about it as mentioned earlier.
5.6.6.1 Menstruation and the morning erection:
None of the parents had carried out any medical examination to know whether the child had any reproductive health issues such as infertility. According to them, once the child has an erection in the morning (for males) and once there is menstruation in the case of females, they are fertile and can have children.

In an interview with Auntie Cece, whose daughter is 31 years and in a residential special school, the interviewer asked what were her concerns regarding her daughter's ability and capacity to have and cater for her own children in future. Her response;

    Well if she marries she can. Because she already knows how to put a child behind her back. She will need to bath the child, feed the child and when the child start walking you send the child to school. I will help to bathe the child. She already baby-sits for her younger sister. She can even bathe the child; that child is not too young. But if she just goes and gets pregnant (outside wedlock), well she will have to face God. That is against his word.

**Interviewer**: Now that she is in school... at 31 aren't you afraid of menopause hitting soon.
**Auntie Cece**: OOO the menopause won't come now. She laughs. Besides when a man calls her, she won't go.
**Interviewer**: Have you had any reproductive health screening done ....
**Auntie Cece**: No we were only asked to check speech. As for a woman once you menstruate, you can have children so I haven't thought of such screening.

5.6.6.2 Ability to choose a partner:
All parents who felt that their children could be married someday acknowledged that choosing a partner is beyond the capacity of their children. They also mentioned their role in choosing the spouse. This was to ensure that the spouse would not abuse their son or daughter. Interestingly, none of the parents in this category spoke about their son or daughter also marrying someone with IDD. Although one of parents, said she would not mind if her son married another person

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125 It is typical for mothers to come help to bathe the baby when they are very young.
with IDD so long as they could support each other to some extent and both families were willing to support the marriage in every way, especially economically.

On the other hand, there were parents who did not mind helping their children to find spouses. In the case of parents of Islamic religion or from the Northern part of the country, this was no exception to the general rule of arranged marriages (Al-Aoufi, Al-Zyoud & Shahminan, 2012).

5.6.6.3 Communication
One of the parents, a father of a thirteen-year-old male on the autism spectrum however said he couldn’t imagine his son in an intimate relationship because he could not communicate, was very anti social and would have meltdowns when he had uninvited people in his personal space.

Communication was the most mentioned as a major concern for parents of male children and many asked how their son will propose to a woman he likes, if he cannot communicate. The mother of a 28-year old also expressed how her son was almost independent but was not confident about him being able to marry because he has communication challenges.

Communication in Ghana is complex in terms of the rules that pertain to intergenerational communication, interpersonal communication, communicating within particular social settings and the use of appropriate verbal (which includes the use of anecdotes, parables and proverbs\textsuperscript{126}) and nonverbal language in communicating and the use of approaches such as foregrounding for which reason proverbs are of great significance (Yankah, 1989). According to Yankah (1989), in Akan speaking communities, if one spoke without proverbs, they were thought to be simple-minded, and their "speech was not completely sweet" (asem no nwie de yo) (pg. 328).

\textsuperscript{126}Ebe, Abe, Kasakoa (Akan) or Lododowo (Ewe). Proverbs are a part of everyday speech in Ghana and are used at a very high intensity. In fact, one's ability to use proverbs and understand proverbs is what proves a person's level of knowledge and intelligence. As one proverb says, "we speak to the wise child using proverbs and not plain language". With the removal of cultural studies from the school curriculum in Ghana, very few avenues have been left for the students to learn how to use proverbs.
The use of proverbs is multimedia and pervades every aspect of our lives. The designs on cloths besides the colour determine who should be wearing it and for what occasion, Adinkra symbols, sayings on trotros (local buses), appellations sung during occasions and in addressing others, among many other forms. The use of a linguist during intergenerational communication for instance has been mentioned in the literature and by Yankah (1989). Boschow (2012) mentioned that sex talk between adults and children was only possible when the older person sanctioned it however, culturally, a younger person can sanction sex talk but through proverbs or a linguist (since the linguist's role is to modify the language to properly address the authority hearing the message (Yankah 1989)). According to Yankah (1989) such skills as foregrounding speech in proverbs set the tone for certain discussions. There is thus great need to teach the use of proverbs to these learners at home and in schools. Parents must partner with the schools to carry out this task, especially since the learners do not have the privilege of such partaking in such communication and socialisation in the community due to the many hours spent in school and few hours spent interacting in the community due to constant policing by their parents.

5.6.6.4 Economic independence
Economic independence was of great importance for parents of males and females. All the parents mentioned that it was important for their child to have some vocation or employable skill, a n earn an income before they can qualify for marriage. Although, parents with males reported that the case would have been different if their children were females.

**Interviewer:** Do you think your child is capable to being married and having and caring for her own children or his family (if male)?

**Respondent with 30-year old daughter:** Well she can give birth... but she is in school. She is learning a vocation.... she must have some job of her own before I can allow her.... the school "has not matured her" yet. Right now, she needs a vocation first.

**Respondent with 28 year old son:** You are not working, you want to marry? even if he is working how much is he getting? can you take care of somebody?
Respondent with two sons with autism (23 and 28 years): they can marry. But how will they take care of their families. You have to find work. Look at them what work can they do? If we sort that one out then we can think of marriage. You can't take care of yourself, how can you take care of another person. Look at them, by now they should be working and married, they are handsome but you need to be having some income. What will happen when me and their father are no more? You have to at least be working. You ant just get up and marry.

It can be inferred from this statement that economic independence is also a mark of maturity and makes one eligible to marry.

5.6.6.5 Sense of responsibility and ability to maintain a home:
Many parents of parents of females interviewed mentioned that the ability to take care of a home and raise children was a key determinant in showing eligibility and ability to be involved in intimate relations. For the males, most parents mentioned that once they portrayed a sense of responsibility such as knowing where things should be positioned in any home, have a sense of environmental safety, can transport himself to and from one location to the other, then they could marry.

5.6.6.6 Future care and welfare
Many parents could not imagine their children living alone and mentioned that in the absence of social welfare systems they would have preferred that their children could have children of their own who will care for them.

Now that her father (is dead), I can't imagine (my daughter) living alone. …I wish she can have children, neurotypical children that can take care of her. But look at my age and my daughters age. I had her late. Will it happen before I die? if I'm not there who will take care of her? I have three brothers and they all have their own challenges. My elder sister is also a grandmother. When I had to do my PhD, it was only my husband, all my siblings said they could not (help). We got a house-help to support… (but she was abusive[127])- Mother of 16 year old female

[127] Narrates accounts of abuse her daughter suffered at the hands of the house-help and the trauma it caused her child.
If they could have children then at least the children will take care of them when they grow old. The two of them will be too much for their sister. If she marries and has her own children she cannot be taking care of them too. So we will see. If they can have children it will help. Otherwise, where can they go when we are no more? The extended family can help but if you have your own children, they will never leave you. I don’t like to think about it. - (Mother of two sons with autism (23 and 28 years) Dagomba, Muslim)

On the contrary, two parents mentioned that they would not want their child to marry and have children because of their experience of the economic and social burden that characterizes catering for children such as theirs.

"I’m a single mum, I have suffered a lot taking care of my son. if he has another child I won’t be able to handle it. Again, what if he has a child like himself? What will I do? I can’t go through the suffering again. I cry a lot." (Parent, Ga, Charismatic, Male child 19)

5.6.7 Who will marry my child?
About seven parents asked similar questions around who will marry their child with IDD. Interestingly, although only one of them was Muslim she was not from the Northern part of the country. She was however still optimistic and was also willing to settle for a partner who also has an IDD.

"...he keeps showing me women that he likes but who will marry him? Because his mind is not developed- its child-like. His intellect is low. No one may want to marry him.... but if he finds someone in the school I will be happy and wont object "koraa" (at all). if someone is interested in him outside the school too no problem but the question is who? - Mother of 22-year old son with IDD, Muslim, Asante.
According to Auntie Margret although her husband is of similar ethnic background in Nigeria as the North of Ghana, and in that custom, they believe that marrying these persons brings good luck, she still questioned if it was possible to find a husband for her daughter. She however felt the situation would have been different if they lived in the Northern part of the country or were in Nigeria.

5.6.8 Role of perceived cognitive level
“Will they understand?” was a very popular phrase among all the parents both those who mentioned that they give some sex education and those who do not. All parents wondered if their learners could understand sexuality and issues around it without practical experience. All parents mentioned that they had been told that their children learn more by through practise. How then will they understand issues about sex, contraception and intimate relationships without practise? This need for practise also appeared to be the reason why parents did not deliver sex education and those who did limited it mostly to the scope of their behaviours. All parents however came to the conclusion that the school might have ways of delivering it that will not need or lead to sexual practises on the part of the learners.

5.7 Conclusion
Many of the parents did not know that sex education was part of the school curriculum and were quite hesitant about its usefulness to the learners. This might have been because it is not clear what sex education entailed. However, upon explaining why it was necessary and the content, they had no objection to it. Many wondered how the learners were going to make sense of the information but mentioned that they trusted the teachers to be able to do it in such a way that it will not encourage the learners to practise it. As stated earlier only one parent said that it was a bad idea and should not be done. Despite this view, parents expressed concerns around
their children’s inability to appreciate social boundaries, challenges with personal hygiene, self-stimulation and masturbation, vulnerability to abuse and the adult children’s expressed desire to be married. Parents also admitted their lack of capacity to deliver sexuality education to their children but did not have any challenges modelling activities that would enhance their competencies in the area of menstrual hygiene. Although previous literature indicated that parents are the primary sources of sexuality education for their children, in the case of learners with IDD in Ghana, the opposite is true. Apart from topic around the changes in the body and in the case of females, warning against males, very little is done to teach these learners about their sexuality.

Given that the children were in school, many parents tried not to think about marriage and childbirth although they were concerned about future welfare of their children. As found, the assurance that one’s own child will not abandon the parent appears to be the main reason for which a parent will want their child with IDD to have (a) child(ren). Finally, with regards to family life, religion appears to play a very important role, with Islam being more accepting of the marriages of PWIDDs while on the other hand, the confluence of Christian marriage with ordinance marriage could be one reason why Christian parents, may have little hope in their children marrying. Additionally, the study corroborated earlier ethnographic accounts that have attested to positive attitudes towards PWIDDs in the North of the country and respect for them despite their deviation from the norm of intelligence and cognitive functioning. It is important that an evaluation of the values of Islam, Northern Ghanaian customs and values and overall pre-colonial customs, which are foundational to Ghanaian customary marriage, be conducted and useful elements of these aspects of culture adopted and adapted for the promotion of sexual and reproductive welfare of PWIDDs.
CHAPTER 6 CONCLUSIONS AND RECOMMENDATIONS

6.1 Introduction

This chapter gives a background the entire study and summarises the main findings of the study with reference to the research questions. The implication of the study to the promotion of the sexual wellbeing of PWIDDS in Ghana is also given. Finally, recommendations for future research, policy and practise in IDD education, IDD sexual wellbeing promotion and sexuality education are given.

6.2 Background and summary of research findings

6.2.1 Background

At the beginning of the study, it was established that despite the international call for equal opportunities for all persons, implementation of inclusive education policy in Ghana, and the signing unto the CSE program, learners with IDD in special schools have been exempted from sexuality (HIV/AIDS) education as per the government's current education strategic plan. PWIDDS in general also have no specific strategies aimed at the promotion of their sexuality. Additionally, the programs signed on to for the most part do not resonate with the values and daily lives of Ghanaian people, they are instruments of colonialism, and for which reason many of them fail to bring about the change it was thought to bring. The important role of parent and educators as primary agents of socialization and sexuality education, in the promotion of sexuality education and sexual wellbeing of PWIDDS was established.

In the absence of specific governmental strategies towards the sexual rights of PWIDDS as it were, parents and educators remain the main channels for changing the status of PWIDDS at the local levels of their communities. However, being products of local communities themselves,
they are more likely to promote the sexual wellbeing not as per the dictates of rights discourse or international policies but as per their own construction of PWIDDs and their sexuality. Besides current social structures like special education and the legal structure that currently govern sexuality appear to have made PWIDDs more invisible by placing them within educational provisions that are likely to infantize them for life and discourage their active participation in sexual and married life.

The study therefore sought to answer the question;

*How do parents and educators construct and address the sexuality needs of learners with IDD in special schools and what can we learn from this in the design and implementation of sexuality education programs for this population?*

To arrive at the answer, the study tried to explore the realities of the behaviors of learners with IDD with respect to their sexuality, parents and educators' constructions of the sexuality and sexuality educational needs of learners and how they addressed those needs. Lessons were drawn from these constructions and their related strategies for future design and implementation of a culturally appropriate sexuality educational program that will enhance the sexual wellbeing and full participation of PWIDDs in local communities.
6.2.2 Findings

The findings have revealed that learners with intellectual and developmental disabilities (IDD) are just like their counterparts without disabilities and their behaviors especially sexual behaviors, cover a range of behaviors just like the normal population. The perceived abnormality of their sexuality results from labeling and the structures of special education, medicine and law that perpetuate this label and minimize their opportunities for normal participation in society. Once a learner graduates from the institution and engages in some profitable economic activity the label appears to become insignificant. The study also gave evidence to the fact that the behaviors of learners with IDD are learned. Thus, with the right exposure learners can improve their behaviors and express their sexuality in socially appropriate ways. Moreover, no two persons with IDD are the same and although they may all have some impairment in intellectual and cognitive functioning, and in some cases communication, with the right support some can achieve some reasonable level of independence and take on responsibilities associated with sex and family life.

The construction of PWIDDs starts form birth in the case of those with visible features such as Down syndrome or as late as adolescence when they fail to meet the normal range of mainstream school intelligence. The medical institution also helps to frame the construction of illness and so many parents refer to the children with IDD as being somewhat sick. However, belief in a God who has reasons for allowing both good and misfortunes also framed the construction of these persons as children of God and for who caring for will bring a reward. Additionally, in a culture that privileges speech, the child's inability to talk properly leaves a parent feeling that the child will be dependent on them for life. Being unable to properly
articulate themselves, these learners might choose to remain quiet to avoid ridicule especially from their peers and other community member, but at the same time create the impression in the minds of the parents that the child is ignorant or does not pay attention to what goes on around him or her.

Again, the special education system especially in relation to the residential system - although celebrated for the improvements made in the life of the children - the absence of a school leaving age, appeared to reinforce the parents’ constructions of childhood even when their children become full grown adults. Awareness of adulthood or maturity of the learners, for many parents, comes with the biological changes that occur in adolescence. However, this awareness appears to be silenced by the contemporary determinants of adulthood or maturity which will ideally be in this order; possession of a school leaving certificate or evidence of employable skills, employment and a demonstration of financial responsibility towards another, marriage and childbirth. Parents’ construction of their children therefore is that until they meet these requirements in some way, their children will never be old enough to leave home. Even more, childhood is also synonymous with vulnerability, inability to take on major responsibilities, lacking understanding, self-control and judgement, dependent among others. However, this construction did not make them useless. Every parent recognised that their child had something to offer no matter how little and appreciated that they could count on them to take on even the smallest responsibilities within the household but questioned whether that was enough to allow them enter into sexual relationships.

As the findings established, educators come into the profession with a passion to help these persons be better than society has constructed them. This passion is tied to the belief
that this area of education is a ministry to which one is called. As such, educators wear multiple hats - advocates in the communities, foster parents, teachers of the learners, and advisors to the families of these learners. From the study, they appeared to have more positive constructions of these learners' sexualities than many of the parents. They see them as having a greater sense of awareness of what goes on around them, able to take on tasks and responsibilities, educable, and in essence, not different from their non-disabled counterparts. As the report indicated, they appreciated that they too are humans and have sexual urges. Educators are also aware of their vulnerabilities, which stem not only from the seeming complexities of their disability but also because the society has not taken time to know about them. Thus, they embrace opportunities to educate the public and show how far a person with IDD can go if given the opportunity. This is probably one of the reasons for community members and occasionally, birth parents of the learners to refer to the educators as the learners' parents.

While the educator's professional training adds to the constructions that have been formed, the experiences of the educators during the one-year teaching practise and in the subsequent years of taking on the profession appears to have also exposed them to a plethora of presentations of IDD and IDD behaviours. These experiences have also sharpened their skills in addressing various needs that have contributed to the quantifiable progress in the lives of the learners. To the educators therefore, these children can and do grow to become adults - but it takes conscious and continuous effort. In summary, the basic construction of educators about the learners with IDD is that they too are human, maybe different but not less.

The findings further established on the whole that educators and parents have divergent approaches to the sexualities of learners with IDD. Although all the parents acknowledged that
the learners are growing, parents felt that because the learners are in school, they should be more focused on acquiring a school leaving certificates before even thinking about marriage, let alone sex. Their thinking process appeared to take into cognizance the biological age of the children; it is no wonder the only trigger to anything about their sexuality is the changes in the body during adolescence. Once the child becomes an adult, the thought of a “child trapped in an adult body” appears to normalize in their minds until the child exhibits some behavior to let them know that they too are sexual or communicates his or her need for sexual intimacy. The behaviors then call for a reactive form of education mostly fear-based to deter them from such behavior or a form of counselling that to cast the learners’ hopes to a time after they have their school leaving certificate and a job – a time, which may come too late. Until then, parents only focus on personal care of the body, leaving out the emotional and social needs for intimacy, bodily agency and respect.

A strict surveillance otherwise described as “policing” appears to form the major response towards the sexuality of these persons so that they do not fall victim to abusers and in the case of females become pregnant. Parents are not ready to bear the added responsibility that comes with unplanned pregnancies more especially for these learners who themselves are contributing very little or nothing economically to the household. Additionally, given that they perceive them as lacking understanding they are afraid to talk about issues related to sexuality lest it awakens the curiosities of the learners and drives them to practice it out of the approved contexts.

In the case of educators, their experiences especially with respect to the sexualities of the learners makes them open-minded to various options of addressing their sex educational needs. They also understand that the learners are simply engaging in activities that their non-disabled peers engage in. However, they are careful to do it in ways that will not implicate them as
promoting sexual promiscuity. Being aware that the learners understand what goes on around
them, educators try to present the issues in ways that will not be misinterpreted. They tend to
more frequently give advice, but with regards to major sexual misbehaviours they rely on
reactive forms of sex education because they can then give a context to the behaviors and explain
why it is not appropriate. Sanctions are also employed where necessary because the learners are
fully aware of their actions to deter them from practices that are unacceptable within the school
context. Should some inappropriate behavior take place outside the school, simple advice or
counseling is sought for the behavior and the attention of the parents brought to it.

Additionally, having been able to teach them all manner of skills and appropriate
behaviors across the learners’ lives, the educators appeared convinced that they could and were
trying their best to deliver sex education in some way- whatever way they could, so that the
learners were somewhat able to take the right decisions. The findings further indicated that
educators did employ the fear model to some extent but also mentioned the joy and benefit of
sexual intimacy in the context of marriage, using themselves as examples. Although they also
emphasized the current social indicators of adulthood, they appeared to do so with hope that their
learners would develop skills and be integrated in mainstream society - which is the aim of the
educators. Once the learners are integrated, they will have to face the possibilities of attracting or
being attracted to someone (of the opposite sex) and of course entering into some sexual union.
They also understand that the vulnerabilities of the learners make them targets in the
communities especially given the lack of family, legal and community support in prosecuting
perpetrators.

The educators were fully aware that some learners are already involved in sexual unions
but emphasized the value of the “right context” while addressing details like condom use. Birth
control is advised but with a clause, that the learner does not know. This is because the consequence of pregnancy has been the main reason for dissuading learners from engaging in sexual activities and thus awareness of the non-existence of that threat can lead the learner to willfully experiment.

Language and the cultural appropriation of certain terms within sexuality discourse also provided challenges. This is because, while it may be appropriate to mention some of these terms in English without being vulgar, mentioning it in the local language creates its own complications. Educators know that learners are aware of the cultural norms and taboo and mores around sexuality and sex talk and so they try not to teach sex education in isolation of the cultural norms around it. With respect to culture, the researcher inferred from educators’ and parents’ perspective that giving gifts or being generous to these persons contributed to socializing them to become vulnerable. By encouraging such behavior, the learners are encouraged into begging which makes them prey to unruly members of the community and thus increases their risk of abuse. Again, it might be one of the reasons why economic independence is tied to their entering into sexual unions of any sort because it will serve to prevent them from being cheaply lured into having sex.

Furthermore, there appears to be a gap in effective social welfare for PWIDDs in Ghana. This lack coupled with the construction of continuous dependence appears be the main reason why parents would want their children to start families or at least have one child. Having children in Ghana are an insurance towards old age and for PWIDDs the earlier they can have children so that the children can be old enough to take care of the PWIDD before the demise of the parent the better for all.
Finally, concerning the lessons learned for the designing and implementation of sexuality education programs for PWIDDS, the study revealed that PWIDDs have similar sexuality educational needs and that for learners with IDD special schools do not exist in a vacuum. The findings demonstrated that, from the perspective of parents and educators, the sexuality educational needs of learners with IDD broadly revolved around the needs to;

- develop competencies in self-care and developing bodily awareness and agency and competencies that facilitate appropriate sexual expression; language, social skills, knowledge of social norms and social boundaries
- develop their awareness and sense of danger and be able to avoid situations that make them vulnerable to abuse and avoid or fight against them
- develop their economic capacities to be able to navigate through the social frameworks that currently define adulthood increase their desirability within the community.
- develop a sense of responsibility to enable take on the roles and responsibilities of caring for a home and a family
- to have their corporal reality acknowledged but that should not serve as a hindrance to having a fulfilled life. They all have different levels of functioning and no single hat fits all.

Again, the study established that, these needs cannot be met without the norm circles being actively involved in the process. Parents, educators and community members, must be actively and continuously part of that process before change can be achieved at the social structure level. Indeed, granting persons with (intellectual developmental) disabilities "access to education, employment and public space the more they will have the social, cultural and economic capital"
to fully participate in all aspects of society including that which pertains to their sexual wellbeing (Shakespeare, 2013 pg 212-213).

6.3 Implications

The implications of this study realised that the discourse of vulnerability is a very dominant feature in the construction of the sexuality of these learners. That notwithstanding, educators appear to have the key role of providing sexuality education and must work together in the development of sexuality educational programs, so that PWIDDS do not live two contradicting realities. Currently while on the one hand, they are seen as adults and have their sexuality acknowledged, as it was the case with most of the teachers, on the other their slightest expression of sexuality is forbidden (at home) although there were few exceptions. That way the same approaches can be used at home and in school thus providing the learner with the necessary reinforcements that can empower them with the knowledge and skills that promote their sexual wellbeing. This study has also shown that sexuality in some parts of Africa need to be considered beyond the discourse of HIV/AIDS. Indeed, HIV/AIDS is important and its eradication central to the discourses of global health and development however, simply limiting sexuality and sexuality education to HIV/AIDS alone does not address sexual wellbeing. However, in the case of Ghana, efforts must be made to keep a balance between the two especially for learners with IDD for who the disease might also not be a reality.

The study has revealed that although at national level, very little appears to be done by the state in addressing sexual and reproductive health education for persons with IDD, at local levels, various initiatives are taking place such as the Stay Alive program. It also emphasizes the approach of a community-based program or community specific programs which can be carry
the right facts and messages but needs to be approached from culturally appropriate or specific perspectives, taking into consideration the norms and customs of the communities and the realities of these learners. However, the need for government intervention in the area of funding for such projects is of great importance as all the government school complained about funding and its implications on delivering sexuality education in ways that are accessible for PWIDDS.

Furthermore, this study has implications for our law enforcement system as a country. More attention needs to be paid to the abuse of PWIDDS. The study showed that besides parents’ unwillingness to prosecute perpetrators in the event of abuse because of the stigma attached to such issues, parents are also discouraged because of the long and unsuccessful outcomes of seeking justice for their children. The study also showed that in some cases where educators took up the case, action was taken. This means that parents and educators must work together in the event of such occurrences.

Finally, the lack of collaboration of the schools and community members with social workers and the department of social welfare is realized in this study. There was neither mention of the department nor any social work professional. Educators appeared to be carrying out the duties of social workers. This re-emphasized the challenges and lack of capacity of the department of social welfare to cater for persons with IDDs- an obvious indication that Ghana’s social welfare institution has not recovered from the brunt of the structural adjustment program hence a need to strengthen traditional communal systems that serve as a safety net and can work together with the special schools to promote the wellbeing of learners with IDD in their communities.
6.4 Recommendations

6.4.1 Recommendations for Further Research

In the spirit of Sankofa, there is a need for research into the marriage and family lives of PWIDDs to ascertain their competencies when it comes to their participation in family life, the manner of extended family support and local community supports that have facilitated that participation. This can help to modify policy framework that place western standardised capacity to consent at the centre of marital life. Given that marriage under Ghanaian customary law involve not just the two consenting partners but entire families, there is some level of accountability that can be garnered from the families and community to ensure that persons with IDD are respected and their sexual wellbeing promoted. Additionally, spaces such as polygamous marriage that exist under customary practises just be explored to see how such provisions serve to positively meet the family life needs of persons with IDD and provide domestic support to the PWIDD outside of the extended family network.

HIV/ AIDS research with respect to PWIDDs is of great importance to parents’ and educators’ assessment of their risk. This area did not feature very much in this study and parents and educators appeared more concerned about the consequences of unwanted pregnancy than the consequence of disease. Finally, given that this study took place in regions that have special education services for learners with IDD in Ghana, it will be of great benefit to know about the social and sexual lives of PWIDDs in the Upper East and Upper Western regions of the country. What are the constructions of these persons, their sexuality, and what opportunities do they have for full participation within their local communities.
6.4.2 Policy-Based Recommendations
Various policies that inform social, educational and political lives of PWIDDs are very necessary for the promotion of their sexual wellbeing.

- Special educational policies should include the following;
  - A defined year of completion of the school program or years beyond which the learner will no longer be considered a student and must be integrated into mainstream society.
  - Regular evaluation of special education and sexuality education programs should be carried out to provide policy makers with the needed information to modify the curriculum at least every 3-5 years.

- Incentives for local businesses that employ persons with IDD who have completed programs.

- Abolition of laws that forbid sexual activities of PWIDDs and institution of laws to provide opportunities for full participation in conjugal relationships.

- Policies within the Christian council that encourage and recognise marriage of PWIDDs and design support systems that can ensure that the learners are not abused in those relationships.

6.4.3 Practise-Based Recommendations
Sex education should go by a different name – one that will incorporate a holistic approach to sexuality as highlighted in the summary of findings. The design and implementation of such a program should involve parents, community leaders, especially chiefs and queen mothers and the regional directorates of education. Culturally, delivering sex education (as was
done during puberty rites) preceded marriage as mentioned earlier and so for PWIDDs who have no definite time of completing school, and having some means to sustainable income, what will they use sex education for. Based on this, educators, parents, policy makers and regional directorate of the various institutions (health, education, welfare among others) with the help of the cultural leaders can reach some agreement on what constitutes sexuality education. The creation of a traditional leader for vulnerable populations, specifically Persons with Disabilities, will further enhance a culturally sensitive and also progressive approach to the wellbeing of PWIDDS. This will also revive the importance of our traditional political system to the development of the country.

At community levels, durbar grounds during traditional festivals are a good place to highlight the wellbeing of PWIDDs in general. Community members who have contributed to their wellbeing in the community should be honoured during the annual festivals. This will encourage community members to recognise their importance. Similarly, traditional courts should include the case of PWIDDs so that they can take the cases on legally. The learner is not only a child of his parents. He is a child of the community. Hence, all authorities must be involved. In effect, there should be a conscious effort to involve them in everyday life and use such opportunities to make them visible and make the efforts of community members to include and respect them count. As we say, “It takes a village to raise a child” and persons with IDD are also children of the land. We must all be involved.
REFERENCES


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APPENDICES

A. ETHICAL CLEARANCE

June 14, 2016

Miss Yemutor Gbewonyo
Master’s Student
Department of Global Development studies
Queen’s University
Mackintosh-Corry Hall B401
Kingston, ON, K7L 3N6

GREB Ref #: GDEVS-041-16; Romeo # 6018400
Title: "GDEVS-041-16 Sexuality Education for Adolescents with Intellectual and Developmental Disabilities in Residential Special Schools in Ghana"

Dear Miss Gbewonyo:

The General Research Ethics Board (GREB), by means of a delegated board review, has cleared your proposal entitled "GDEVS-041-16 Sexuality Education for Adolescents with Intellectual and Developmental Disabilities in Residential Special Schools in Ghana" for ethical compliance with the Tri-Council Guidelines (TCPS 2 (2014)) and Queen’s ethics policies. In accordance with the Tri-Council Guidelines (Article 6.14) and Standard Operating Procedures (405.001), your project has been cleared for one year. You are reminded of your obligation to submit an annual renewal form prior to the annual renewal due date (access this form at http://www.queensu.ca/traq/signon.html; click on "Events”; under "Create New Event” click on "General Research Ethics Board Annual Renewal/Closure Form for Cleared Studies”). Please note that when your research project is completed, you need to submit an Annual Renewal/Closure Form in Romeo/traq indicating that the project is ‘completed’ so that the file can be closed. This should be submitted at the time of completion; there is no need to wait until the annual renewal due date.

You are reminded of your obligation to advise the GREB of any adverse event(s) that occur during this one year period (access this form at http://www.queensu.ca/traq/signon.html; click on "Events”; under "Create New Event” click on "General Research Ethics Board Adverse Event Form”). An adverse event includes, but is not limited to, a complaint, a change or unexpected event that alters the level of risk for the researcher or participants or situation that requires a substantial change in approach to a participant(s). You are also advised that all adverse events must be reported to the GREB within 48 hours.

You are also reminded that all changes that might affect human participants must be cleared by the GREB. For example, you must report changes to the level of risk, applicant characteristics, and implementation of new procedures. To submit an amendment form, access the application by at http://www.queensu.ca/traq/signon.html; click on "Events”; under "Create New Event” click on "General Research Ethics Board Request for the Amendment of Approved Studies". Once submitted, these changes will automatically be sent to the Ethics Coordinator, Ms. Gail Irving, at the Office of Research Services for further review and clearance by the GREB or GREB Chair.

On behalf of the General Research Ethics Board, I wish you continued success in your research.

Sincerely,

John Freeman, Ph.D.
Chair
General Research Ethics Board

c: Dr. Marc Epprecht, Supervisor
Dr. Richard Day, Chair, Unit REB
B. PARENTS

RECRUITMENT NOTICE TO INCLUSION GHANA FOR PARENT PARTICIPANTS

PARTICIPANTS NEEDED FOR ACADEMIC RESEARCH

Study: Sexuality Education for Adolescents with IDD in special schools in Ghana
Researcher: Yesutor Gbewonyo, Queen's University, Kingston, Ontario

Desired Participants: Parents of Adolescents with IDD (aged 10-24 years) in special schools

The above-mentioned study is being conducted from June 20 to August 18, 2016. It is a purely academic study. The interviews will take one (1) hour of your time and will seek to understand parents' journey perceptions, and concerns, challenges about the sexuality of their adolescents with IDD and the expectations of what kind of sexuality education should be delivered to their adolescent at school. It will also seek to understand how parents address various sexual behaviors of their adolescents, and how these promote or inhibit the adolescents’ participation in society and what help parents need to ensure that their adolescents' sexuality does not lead to exclusion. Adolescents should be in residential special schools in the country.

Some questions are of sensitive nature however, you are not under any obligation to answer those questions. Counseling services will also be available to help participants who suffer any emotional and psychological risks from the interview. Prospective participants may withdraw from the study at any time without any consequence. Interviews will be tape-recorded. Information collected will not be associated with you as a participant unless you emphatically request so. However, any participant who wishes to have their interview video-recorded and wants information from the interview to be directly associated with him/her will have to sign the bottom section of the consent form and have their consent to be filmed video-recorded.

Text "Parent Participant" to the researcher on 0242666943 or Inclusion Ghana on 0208151523 by June 20, 2016 to be part of the study. Ten (10) Participants will be randomly selected from the texts received.

Letters of Information and Consent forms will be made available to interested participants upon scheduling the interview.

Preferably, all respondents must be able to speak English.

For further enquiries, call the researcher or inclusion Ghana.

Thank You.
Letter of Information
This study has been granted clearance according to the recommended principles of Canadian ethics guidelines, and Queen’s policies. Any questions about study participation may be directed to the Researcher Yesutor Gbewonyo at 15yag@queensu.ca or 613 4848707/ +233 242666943 (Gh) or her supervisor Marc Epprecht at epprecht@queensu.ca. Department of Global Development Studies Queen’s University, Kingston Ontario, Canada, or, Queen’s University, Kingston Ontario, Canada; any ethical concerns about the study may be directed to the Chair of the General Research Ethics Board at chair.GREB@queensu.ca or 613-533-6081.

What is this research about? The purpose of this study is to investigate what factors determine whether and when a person can be involved in intimate relationships, what intimate conducts are socially/legally/traditionally/religiously acceptable, what kinds of sexual and reproductive health commodities the individual can consume and how these disqualify persons with IDD in Ghana. It will also seek to find out what policies, programs and strategies exist within various social institutions to promote the sexual health of persons with intellectual and developmental disabilities in Ghana. The interview with you will seek to understand your journey as a parent, raising an adolescent with IDD, your perceptions, and concerns about the sexuality of your adolescent with IDD, how sexual behaviors are addressed at home, and your expectations of the sexuality education delivered to your adolescent in school. The study will require about one (1) hour of your time to participate in an interview. Though there are no physical, social and economic risks associated with the interview. Some of the questions however are sensitive and may evoke feelings of frustrations and psychological and emotional pain in you as a parent. Should this happen, the interview will be immediately stopped and you will be made to communicate immediately with a staff of Juniper Counseling centre and subsequent counseling follow-ups made to ensure that you recover completely from that state.

Is my participation voluntary? Yes. Although it would be greatly appreciated if you would answer all questions as frankly as possible, you should not feel obliged to answer any question that you find objectionable or that makes you feel uncomfortable. You may also withdraw at any time with no effect on your benefits from participating in this study. Guaranteed benefits include the right to request results from the study as well as the provision of refreshments (soda/fruit drinks and pastries) to compensate for your time.

What will happen to my responses? We will keep your responses confidential. Only the researcher, research assistant/transcriber, her supervisor and members of her thesis committee will have access to this information. The Research assistant/transcriber will be made to sign an agreement to the effect that they shall not reveal in any way to any person other than the researcher any data gathered for the study by means of their services. The interviews will be tape-recorded and all tapes and transcripts will be safely kept in a locked filing cabinet in the researcher’s apartment during her stay in Ghana and in her office at Queen’s University when she returns to Canada after fieldwork. When the researcher is working with the data, it will be stored on a password-protected computer. Electronic data in the form of audio files, transcripts
and analysis will be kept in secure networks which will be encrypted. The information will be used in a thesis, and may also be published in professional journals or presented at scientific conferences, but any such presentations will be of general findings and will never breach individual confidentiality. Should you be interested, you are entitled to a copy of the findings. Your actual names in addition to any other information that have potential to make any of the participants identifiable will not be included in the dissertation, academic publications or conference presentations, instead, they will be replaced with pseudonyms. However, your actual name will be recorded in the interviews strictly for the purposes of identifying the source of data/information received but they will subsequently be destroyed and replaced by codes/pseudonyms during transcription to protect your true identity.

**Will I be compensated for my participation?** Yes, you will receive refreshments after the interview. This is regardless of whether you complete the interview or not.

Again, thank you. Your interest in participating in this research is greatly appreciated.
Parents' Consent Form

1. I have read the Letter of Information and have had all questions answered to my satisfaction.

2. I understand that I will be participating in the study called “Sexuality in Ghana and implications for sexuality education for Learners with Intellectual/Developmental Disabilities in Residential Special Schools”. I understand that this means that I will be asked to participate in an interview, which will be tape-recorded and last for about one (1) hour.

3. I understand that my participation in this study is voluntary and I may withdraw at any time. I understand that every effort will be made to maintain the confidentiality of the data now and in the future. Only the researcher and research assistant or transcribers, his supervisor and members of her thesis committee will have access to this information. The research assistant/transcriber shall not to reveal to any person other than the researcher any data gathered for the study by means of their services. The information I give in my interview will be used in a thesis, and may also be published in professional journals or presented at academic conferences. Any such presentations however, will mostly be of general findings and will no way breach individual confidentiality unless I emphatically state that I want to be associated with the information gathered from my interview.

4. I am aware that if I have any questions or concerns about the study, I may contact the researcher Yesutor Gbewonyo at 15yag@queensu.ca or 613 4848707/ +233 242666943 (GH.) or her supervisor Marc Epprecht at epprecht@queensu.ca. Department of Global Development Studies Queen’s University, Kingston Ontario, Canada. Any concerns about the rights I have during my participation in the study may be directed to the Chair of the General Research Ethics Board at chair.GREB@queensu.ca or 001-613- 533-6081. Any other concerns about study participation may be directed to Inclusion Ghana, Accra Rehabilitation Centre, Barnes Road, Adabraka, Accra - Ghana at info@inclusion-ghana.org or 0208151523
DECLARATION OF CONSENT
(TICK ALL THAT APPLY AND SIGN)

☐ I give permission to this research interviewer to **tape-record** my interview and record my consent to participate in the study in audio format in the following words: “I have read the above statements and as a result freely consent to participate in this study and also agree to have my interview tape-recorded”.

Please sign here: ______________________________________________

Additional consent for Filming (video and signed)

☐ **Consent by participant:**
"I (name) having read all the above statements, and fully aware of the risks, freely give the researcher my full permission to **film** this interview for the purposes stated. I agree that it may be shown in academic or public domains to advance the sexual and reproductive health of persons with IDD in Ghana and that all information received will be directly associated with me as the source"

Please sign here: ______________________________________________
Name: 
Date:

Consent to be directly identified as a contributor to the study (i.e. you will be directly identified when references are made to your words and /or statements)

☐ **Consent by participant:**
"I (name) having read all the above statements, freely give the researcher my full permission to **directly identify** me as the source of contribution I will make during the interview for the purposes stated. I agree that it may be shown in academic or public domains to advance the sexual and reproductive health of persons with IDD in Ghana

Please sign here: ______________________________________________
Name: 
Designation: 
Date:
Parents’ Interview Guide

Name ......................................................... Date .................................................

**Pre interview questionnaire**

**Biographical data of Parents**
- Gender; Marital Status; Relationship to the Child, Education Level, Occupation; Level of Education; Religious Affiliation/beliefs, Ethnicity/tribe, Family size/ number of people in household.

**Biographical data of child**
- Gender: Age: Formal Diagnosis of IDD Status: Ethnic/tribe:
- Sibling position

**Main interview questionnaire**

- How has the journey of raising a child with IDD been? *What are some of the good things that have happened? What were some of the challenges in the beginning? How has your life been affected (positively and negatively)? What are the challenges now? What are some of the improvements you are happy about? In your opinion, what are the things that account for this progress?*
- When did you notice that your child was beginning to attain puberty? *What were some of the signs, how did you feel about it? What did you do or what have you been doing about it? (for girls) sterilization?*
- What have been your concerns since your child begun to attain puberty? *Issues about your child’s sexuality (menstruation, personal hygiene, etc)? Abuse? Masturbation? Developing intimate relationships? Marriage? Bearing children?*
- What sexual behaviors does your child exhibit if any? *Do you think that your child is at any risk of sexual abuse? Why is that? Have there been instances where you feel he/she been sexually abused? How does/did it make you feel as a parent? What do you do in such circumstances?*
- Have you accessed any form of Sexual and Reproductive Health support or commodities for your child from any facility? E.g. birth control, condoms, arranged and/or facilitated sex?
- What expectations do you have of your child concerning his/her sexuality? Have they changed? Why?
- What aspects of sexual education have you given to your child?
- What are some of the ways you go about it?
- What influences the kind of sexuality education/support you give or are considering to give to your child?
- With what aspects of your child’s sexuality do you require support?
- How do you want teachers in your child school to teach him/her about sexuality
- What topics would you not want them to teach your child? Why?
- How do you and your relatives regard your child in terms of his/her ability to develop any intimate relationships and have a family?
- What would you want the government to do to help your child be able to participate in society in terms of his or her sexuality?
• What would you want your community to do to help your child be able to participate in society in terms of his or her sexuality?

CLOSING REMARK
These are all the questions I have for you. Are there any other comments you would like to add? Do you have any questions for me to answer? Thank you again for your time.
C. SPECIAL EDUCATORS/TEACHERS

RECRUITMENT NOTICE TO INCLUSION GHANA FOR PARENT PARTICIPANTS
PARTICIPANTS NEEDED FOR ACADEMIC RESEARCH

Study: Sexuality Education for Adolescents with IDD in special schools in Ghana
Researcher: Yesutor Gbewonyo, Queen's University, Kingston, Ontario
Desired Participants: Special Educators of Adolescents with IDD (aged 10-24 years) in residential special schools

The above-mentioned study is being conducted from June 20 to August 18, 2016. It is a purely academic study. The interviews, which will take one (1) hour of your time, will seek to understand special educators' perceptions and concerns about the sexuality of their adolescent learners with IDD and delivering sexuality education to these learners in school. It will also try to understand what sociocultural challenges they face in understanding and addressing sexuality behaviors exhibited by these adolescent learners in school.

Some questions are of sensitive nature however, you are not under any obligation to answer those questions. Counseling services will also be available to help participants who suffer any emotional and psychological risks from the interview. Prospective participants may withdraw from the study at anytime without any consequence. Interviews will be tape-recorded. Information collected will not be associated with you as a participant unless you emphatically request so. However, any participant who wishes to have their interview video-recorded and wants information from the interview to be directly associated with him/her will have to sign the bottom section of the consent form and have their consent to be filmed video-recorded.

Text "SPED Participant" to the researcher on 0242666943 or Inclusion Ghana on 0208151523 by June 20, 2016 to be part of the study. Fifteen (15) Participants will be contacted from the texts received.

Letters of Information and Consent forms will be made available to interested participants upon scheduling the interview.

For further enquires, call the researcher or inclusion Ghana.

Thank You.
Letter to SPED, GES
30th May, 2016

Dear Madam,

Request to conduct Study: Sexuality Education for Adolescents with Intellectual and Developmental Disabilities in Ghana

My name is Yesutor Gbewonyo and I write to seek permission to undertake the above-mentioned research under the supervision of Professor Marc Epprecht, in the Global Development Studies Department at Queen's University in Kingston, Ontario, Canada.

The study will require the participation of 10 Special Education Teachers and 5 School Heads from 5 residential special schools from the Greater Accra, Ashanti, Northern, Volta and Central Regions of Ghana in interviews. Interviews will last for one hour and will seek to understand special educators’ perceptions and concerns about the sexuality of their adolescent learners with IDD and delivering sexuality education to these learners in school. It will also try to understand what sociocultural challenges they face in understanding and addressing sexuality behaviors exhibited by these adolescent learners in school.

I also seek permission to carry out an observation of sexuality education lessons in the five schools I will be visiting. The observations, which I hope to film, will seek to find what is being taught, how it is being taught and do the students appear to understand the lessons. It will seek to answer the questions; Are the learners engaged in the lesson? What appears to influence or inform how the teacher delivers the lesson? Does the teacher appear comfortable and confident when teaching the lesson? How engaged are the students during the lesson.

The study will take place from June 20 to August 18, 2016.

The researcher would be most grateful if you could assist him to identify potential participants for this study through your institution. Kindly find attached further details about the study. Please find attached a letter of introduction and a recruitment notice from Inclusion Ghana, letters of information among other documents for your perusal; however, I am yet to receive ethical approval from my university.

I hope to permission will be granted so that I can begin as soon as ethical approval is received.

Thank You
Sincerely
Yesutor Gbewonyo.
Letter of Information

This study has been granted clearance according to the recommended principles of Canadian ethics guidelines, and Queen’s policies. Any questions about study participation may be directed to the Researcher Yesutor Gbewonyo at 15yag@queensu.ca or 613 4848707/ +233 242666943 (GH) or her supervisor Marc Epprecht at epprecht@queensu.ca. Department of Global Development Studies Queen’s University, Kingston Ontario, Canada; or, Queen’s University, Kingston Ontario, Canada; any ethical concerns about the study may be directed to the Chair of the General Research Ethics Board at chair.GREB@queensu.ca or 613-533-6081.

What is this research about? The purpose of this study is to investigate what factors determine whether and when a person can be involved in intimate relationships, what intimate conducts are socially/legally/traditionally/religiously acceptable, what kinds of sexual and reproductive health commodities the individual can consume and how these disqualify persons with IDD in Ghana. It will also seek to find out what policies, programs and strategies exist within various social institutions to promote the sexual health of persons with intellectual and developmental disabilities in Ghana. The interview with you will seek to understand special educators' perceptions and concerns about the sexuality of their adolescent learners with IDD and delivering sexuality education to these learners in school. It will also try to understand what sociocultural challenges they face in understanding and addressing sexuality behaviors exhibited by these adolescent learners in school. The study will require about one (1) hour of your time to participate in an interview. Though there are no physical, social and economic risks associated with the interview. Some of the questions however are sensitive and may evoke feelings of frustrations and psychological and emotional pain in you as a parent. Should this happen, the interview will be immediately stopped and you will be made to communicate immediately with a staff of Juniper Counseling centre and subsequent counseling follow-ups made to ensure that you recover completely from that state.

Is my participation voluntary? Yes. Although it would be greatly appreciated if you would answer all questions as frankly as possible, you should not feel obliged to answer any question that you find objectionable or that makes you feel uncomfortable. You may also withdraw at any time with no effect on your benefits from participating in this study. Guaranteed benefits include the right to request results from the study as well as the provision of refreshments (soda/fruit drinks and pastries) to compensate for your time.

What will happen to my responses? We will keep your responses confidential. Only the researcher, research assistant/transcriber, her supervisor and members of her thesis committee will have access to this information. The Research assistant/transcriber will be made to sign an agreement to the effect that they shall not reveal in any way to any person other than the researcher any data gathered for the study by means of their services. The interviews will be tape-recorded and all tapes and transcripts will be safely kept in a locked filing cabinet in the researcher’s apartment during her stay in Ghana and in her office at Queen’s University when she returns to Canada after fieldwork. When the researcher is working with the data, it will be
stored on a password-protected computer. Electronic data in the form of audio files, transcripts and analysis will be kept in secure networks which will be encrypted. The information will be used in a thesis, and may also be published in professional journals or presented at scientific conferences, but any such presentations will be of general findings and will never breach individual confidentiality. Should you be interested, you are entitled to a copy of the findings. Your actual names in addition to any other information that have potential to make any of the participants identifiable will not be included in the dissertation, academic publications or conference presentations, instead, they will be replaced with pseudonyms. However, your actual name will be recorded in the interviews strictly for the purposes of identifying the source of data/information received but they will subsequently be destroyed and replaced by codes/pseudonyms during transcription to protect your true identity.

**Will I be compensated for my participation?** Yes, you will receive refreshments after the interview. This is regardless of whether you complete the interview or not.

Again, thank you. Your interest in participating in this research is greatly appreciated.
Sped Educators' Consent Form

1. I have read the Letter of Information and have had all questions answered to my satisfaction.

2. I understand that I will be participating in the study called “Sexuality in Ghana and implications for sexuality education for Learners with Intellectual/Developmental Disabilities in Special Schools”. I understand that this means that I will be asked to participate in an interview, which will be tape-recorded and last for about one (1) hour.

3. I understand that my participation in this study is voluntary and I may withdraw at any time. I understand that every effort will be made to maintain the confidentiality of the data now and in the future. Only the researcher and research assistant or transcribers, his supervisor and members of her thesis committee will have access to this information. The research assistant/transcriber shall not to reveal to any person other than the researcher any data gathered for the study by means of their services. The information I give in my interview will be used in a thesis, and may also be published in professional journals or presented at academic conferences. Any such presentations however, will mostly be of general findings and will no way breach individual confidentiality unless I emphatically state that I want to be associated with the information gathered from my interview.

4. I am aware that if I have any questions or concerns about the study, I may contact the researcher Yesutor Gbewonyo at 15yag@queensu.ca or 613 4848707/ +233 24266943 (GH.) or her supervisor Marc Epprecht at epprecht@queensu.ca. Department of Global Development Studies Queen’s University, Kingston Ontario, Canada. Any concerns about the rights I have during my participation in the study may be directed to the Chair of the General Research Ethics Board at chair.GREB@queensu.ca or 001-613-533-6081. Any other concerns about study participation may be directed to Inclusion Ghana, Accra Rehabilitation Centre, Barnes Road, Adabraka, Accra - Ghana at info@inclusion-ghana.org or 0208151523
DECLARATION OF CONSENT
(TICK ALL THAT APPLY AND SIGN)

☐ I give permission to this research interviewer to **tape-record** my interview and record my consent to participate in the study in audio format in the following words: “I have read the above statements and as a result freely consent to participate in this study and also agree to have my interview tape-recorded”.

*Please sign here:_____________________________________________

Additional consent for Filming (video and signed)

☐ **Consent by participant:**

"I (name) having read all the above statements, and fully aware of the risks, freely give the researcher my full permission to **film** this interview for the purposes stated. I agree that it may be shown in academic or public domains to advance the sexual and reproductive health of persons with IDD in Ghana and that all information received will be directly associated with me as the source"

*Please sign here:_____________________________________________

Name:
Date:

Consent to be directly identified as a contributor to the study (i.e. you will be directly identified when references are made to your words and/or statements)

☐ **Consent by participant:**

"I (name) having read all the above statements, freely give the researcher my full permission to **directly identify** me as the source of contribution I will make during the interview for the purposes stated. I agree that it may be shown in academic or public domains to advance the sexual and reproductive health of persons with IDD in Ghana."

*Please sign here:_____________________________________________

Name:
Designation:
Date:
Special Educators Interview Guide

Pre interview questionnaire
Biographical data of Educator.
- Gender; No of years in profession; Reason for being sped teacher for persons with IDD; highest Level of Education; Religious Affiliation/beliefs; Ethnic/tribe; Marital status; no of children in class

Main interview questionnaire
- How has the journey of teaching children with IDD been?
- Can you explain to me the type of professional preparation you have received with respect to IDD?
- What in your opinion is the main purpose of the sex drive

- Do you believe that persons with IDD have a sex drive? how proper of improper do you think the expression of this sex drive in their case is?
- What were your perceptions or assumptions about the sexuality of persons with IDD before you started teaching? How have they changed over time?
- What have been your concerns about your adolescent learners who have attained or are attaining puberty? (Issues about their sexuality (menstruation, personal hygiene, etc)? Abuse? Developing intimate relationships? Marriage? Bearing children? Do you think they are capable of developing amorous relationships?)
- What sexual behaviors do these learners exhibit if any? What are your reactions and reactions of other teachers

- Do you think these learners are at any risk of sexual abuse? Why is that? Have there been reports of such incidences by the learners themselves? or have other teachers reported or made mention of any such issues? how about parents reports on such issues? Can you narrate one or two of such incidents and what actions were taken? What do/did you do in those circumstances?
- What kind of sex education
- In what ways do you think persons with IDD can benefit from sex education?
- Have you/ the school accessed any form of Sexual and Reproductive Health support or commodities for your learners from any facility? E.g. birth control, condoms, arranged and/or facilitated sex, sex education by a professional, reproductive health screening? how/why?
- What aspects of sexual education do (or have) you give(n) to your learners? What are some of the ways you go about it? What topics would you not want them to teach? Why?
- How have issues of conduct (sex activities), relationships and
- What influences the kind of sexuality education/ support you give to your learners? (personal upbringing, religion, traditional customs)
- With what aspects of your learners’ sexuality do you require support?
- How do you think parents can support you to teach learners about their sexuality
• What would you want your community to do to help your child be able to participate in society in terms of his or her sexuality?
• What would you want the government to do to help your child be able to participate in society in terms of his or her sexuality?

CLOSING REMARKS
These are all the questions I have for you.
Are there any other comments you would like to add?
Do you have any questions for me to answer?
Thank you again for your time.