

Applied Research and Evaluation

**DOES DISABILITY MATTER? DISABILITY IN
SEXUAL AND REPRODUCTIVE HEALTH
POLICIES AND RESEARCH IN GHANA**

WISDOM KWADWO MPRAH

Kwame Nkrumah University of Science and Technology, Kumasi, Ghana

PATRICIA ANAFI

The State University of New York at Potsdam

FRANK OWUSU SEKYERE

University of Winneba, Kumasi, Ghana

ABSTRACT

Gaps in national Ghanaian sexual and reproductive health (SRH) policies and research in terms of attention given to persons with disabilities are identified and ways to redirect policies to include them suggested. Policies and research in seven major documents from government sources and non-governmental organizations were reviewed for policy and practice statements relevant to disability to determine if and how they addressed SRH concerns of persons with disabilities. The findings indicated attention given to persons with disabilities has been cursory. There is need for more attention on disability issues in SRH research and policies to make the needs of persons with disabilities visible and to guide and provide disability-friendly services and information.

INTRODUCTION

Disability in Ghana

The general perception and treatment of persons with disabilities in Ghana is influenced by religious and cultural norms. Ghanaian folks perceive disability

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as the result of a curse, punishment for sins committed by persons with disabilities or their family members or the result of witchcraft, magic, or sorcery [1-3]. Traditionally, children born with disabilities may be kept out of public view; some were even killed at birth [1, 4]. A person could not be an ancestor if he or she had a disability. Even before marriage, the families of both the man and woman would seek to ensure that inherited disabilities did not exist in the respective family lines; existence of these traits would be a good reason for the annulment of a marriage [5].

According to Quayson [6] three factors influenced the general negative attributes about disability among Ghanaians. The first is the Ghanaian view of the relationship of physical wholeness and beauty with cultural status. This notion is the basis for disqualifying persons with disabilities from occupying certain key traditional leadership positions such as chief or queen mother. The second view associates bodily wholeness with economic independence; a prejudice that is given support by the large number of persons with disabilities who are dependent or engaged in begging. The third view draws a “connection between disability and an invisible metaphysical order of things” [6, p. 206]. This notion usually portrays persons with disabilities as objects that can bring fortune to one who gives alms to the disabled beggar. While disability is shunned and stigmatized [6], some persons with disabilities are able to perform reasonably well in the traditional production system and are integrated into Ghanaian society. For example, some persons with disabilities have been able to perform reasonably well in production of local music, weaving, and local art and craft.

Civil activism among persons with disabilities in Ghana on behalf of equal rights and opportunities has been generally low. Persons with disabilities in Ghana have not adopted some of the confrontational strategies used by their counterparts in developed countries to fight against discrimination. Ghana’s political system prior to constitutional rule appears to have hampered the development and growth of civil rights movements, particularly among minority groups [7]. According to Abdul-Gafaru [7], harassment and intimidation of civil organizations by dictatorial military regimes prior to constitutional rule severely curtailed their participation in political activities. However, the transition to civilian rule in 1992 seems to have given greater leverage to persons with disabilities. The transition transformed the political landscape, making it possible for civil society to assert itself more proactively [7]. In fact, the 1992 Constitution of Ghana explicitly gives legitimacy to rights-based activism and the protection of the fundamental human rights of the populace [8]. As a result, government at various levels has now become more tolerant of civil organizations, and this has greatly facilitated activism [7].

The transition to civilian rule in 1992 was followed by the formulation of the first disability policy and the enactment of the Persons With Disability Act (PWDA) in 2006. The PWDA has provisions for the protection of persons with disabilities against all forms of exploitation and discrimination. The Act

states that “A person shall not discriminate against, exploit or subject a person with disability to abusive or degrading treatment” [9, p. 4]. Additionally, the National Council on Disability, which is responsible for the formulation of strategies for the implementation of policies affecting persons with disabilities, was set up in 2009. Thus, disability organizations, previously ineffective, are becoming more active in their advocacy roles. The Ghana Federation of the Disabled (GFD), for instance, has been active in creating awareness about conditions of persons with disabilities in Ghana. It was involved in advocating for the passage of the PWDA [10].

Although it has been reported that persons with disabilities engage in lobbying for changes in policies, their focus has been on the most basic issues such as education and employment [2]. Sexual and reproductive health (SRH) seemed not a priority despite the fact that it is a general major public health problem for the country. The lack of concern for SRH issues may be due to the fact that persons with disabilities are more concerned about other basic needs that directly affect their well-being, such as employment and education. They may see exclusion from these opportunities as more fundamental issues that must be addressed first. In fact, it has been observed that SRH has not been a priority for disability organizations, generally [11].

Sexual and Reproductive Issues

The past three decades have seen increased interest in SRH issues because risks associated with SRH are among the major causes of morbidity and mortality, especially in developing countries such as Ghana [12]. Governments and other stakeholders are increasing their efforts to address the consequences of poor SRH on individuals, families, and society at large. A major landmark in this direction was at the United Nations sponsored International Conference on Population and Development (ICPD) in Cairo in 1994, where a common course of action was taken to find lasting solutions to the problem [13, 14].

At the ICPD conference, delegates from the 179 countries attending adopted a Program of Action on Population and Development [13]. The Program of Action, which was developed through negotiation and consensus building among the delegates, endorses a wide range of SRH principles [14]. Specifically, the document recognizes the connection between human rights and underlying social, political, cultural, and legal determinants of SRH [14, 15]. In addition, it stresses the importance of meeting the needs of individual women and men rather than achieving a decline in population growth rate [13]. The ICPD also recognizes the importance of access to SRH information and services as vital resources for preventing sexually transmitted infections (STIs) among men, women, and young adults. As part of the strategy to increase access, family planning was to be made universal and governments were called upon to provide the needed resources [13, 16].

With respect to the SRH needs of persons with disabilities, the ICPD Program of Action calls for measures to create awareness about disability issues and urges governments to improve access to education, training, and rehabilitation services for persons with disabilities. Additionally, it calls on governments to eradicate all forms of discrimination encountered by persons with disabilities so that they could exercise their sexual and reproductive rights [13].

The article 25 of the Convention on the Right of Persons with Disabilities (CRPD), which focuses on healthcare, addresses issues relating to accessibility, quality of care, non-discrimination in healthcare provision, and affordable health-care services for persons with disabilities. For example, it directs governments to ensure that persons with disabilities receive the highest possible standards of health (including sexual and reproductive health), at a cost that is affordable, and with the same range, quality, and standard on an equal basis as others [17]. The CRPD also recognizes the right of persons with disabilities to free and informed consent and personal autonomy and dignity, and advocated for the promulgation of ethical standards to prevent discrimination and abuses in public and private healthcare systems [17].

However, very little of the Program of Action's agenda seems to have been realized since the ICPD. For example, while access to quality SRH information and services is fundamental to enhancing quality of life, many people are unable to make informed decisions because they lack access to detailed, accurate, and meaningful information on their sexuality and reproduction [14]. Moreover, though there are inexpensive and effective interventions for preventing unintended pregnancies, providing safe abortions, facilitating safe pregnancy and child birth, and preventing and treating sexually transmitted infections, services are still largely unavailable to many in the Global South [12].

More importantly, the concerns of persons with disabilities have not been addressed adequately since the ICPD because of cultural, attitudinal, and institutional barriers [18]. Persons with disabilities share many of the same SRH concerns as persons without disabilities, but they often face serious barriers to information and services due to ignorance, negative attitudes, and lack of services tailored to accommodate their unique needs [18-20]. They are rarely included in SRH prevention and outreach programs, and SRH information is often not provided in accessible formats or tailored to cater for their needs [18, 19]. For instance, the lack of information in accessible forms such as Braille, large print, simple language, pictures, and sign languages, deprive access to those with visual, hearing, and intellectual disabilities [18]. Low literacy levels among persons with disabilities compound the issue, especially in developing countries, where many are without access to SRH education in schools or lack adequate health literacy school programs [18, 20].

In Ghana, the formulation of the first Population Policy in 1969, which aimed at addressing high fertility and excessive population growth through the provision of family planning information and services, was one of the first major steps taken

to address SRH problems in the country [21]. In 1994, the policy was revised to take into account emerging issues such as the environment, and issues concerning the aged, children, youth, persons with disabilities and HIV/AIDS [22]. Apart from the Population Policy, specific policies have been formulated to deal with specific issues and to target groups that have unique needs, but their needs may not have been captured in policies for the general population. The HIV/AIDS and STI Policy and the Adolescent Reproductive Health Policy are notable examples. In addition, research and studies have been conducted to identify groups at high risk. However, while these policies and studies were meant to expand family planning and SRH services especially for groups at high risk, persons with disabilities have been excluded from many of these interventions. The intent of this review is therefore to examine whether and how SRH policies and research have included issues on disability. The aim is to push for policy change to make the SRH concerns of persons with disabilities visible for action.

METHODS

Sampling of Documents

Seven SRH documents were reviewed to determine whether and how SRH needs of persons with disabilities have been addressed. These included national policy documents and research reports. The documents reviewed were the 2008 Ghana Demographic and Health Survey (GDHS) [23], the Ghana Population Policy [24], the Reproductive Health Service Policy and Standards [22, 25], the Adolescents Reproductive Health Policy [26], the National HIV/AIDS and STI Policy [27], the Criminal Code on Abortion [28], and the National Survey of Adolescents (NSA) [29]. The NSA is research conducted under the Alan Guttmacher Institute's (AGI) project. The AGI is a non-governmental organization (NGO) that promotes quality SRH worldwide. The seven documents were obtained without cost from the Ghana Population Council Library and Internet using the following keyword search: disability, disabled, HIV and AIDS, sexual health, reproductive health, policies, and Ghana. The basis for selecting the documents were their relevance to the subject, population coverage, and their sources.

We focused on government documents based on the belief that government policies and programs, including those on health, must not be discriminatory; as such, it is expected that SRH policies and research sponsored by government should include the concerns of persons with disabilities. The NSA report from AGI was included in the review to examine the extent to which non-governmental organizations (NGOs) advancing SRH rights have included disabilities issues in their activities. The AGI was chosen because of its focus on promoting sexual and reproductive health and rights through research, policy analysis, and education, and the fact that one of its main values is to give priority to those whose

needs, concerns, and rights to information and services on SRH may be hampered due to discrimination [30]. Persons with disabilities encounter problems accessing SRH information and services [19, 20] and, as a result, they fall under AGI’s “needy” group requiring attention. AGI has also sponsored a nationwide research on SRH in Ghana since 2004 and their reports are accessible online for review. There are other NGOs, such the Planned Parenthood Association of Ghana and the African Youth Alliance, that engage in advocating for access to SRH information and services, but their involvement in research is minimal.

Since the aim of the review is to ascertain the presence of disability in the documents and also examine how disability has been treated, we utilized relational analysis, a component of content analysis which seeks to identify and explore the relationships and meaning among concepts in a text [31]. We reviewed each document separately for policy or practice statements relevant to disability to determine whether and how each addressed the SRH concerns of persons with disabilities. We first read through each document thoroughly to identify concepts that are used to describe disability; the presence of these concepts in a document suggests that attention has been given to disability while absence means no attention has been given to disability. Relevant sections of each document—sections that have something on disability—were marked out. The next stage involved examining the meaning and relationships of these concepts with other concepts; that is, how disability has been treated in the documents. The final stage involved classifying the relevant ideas into themes. Three themes were identified: no attention given to disability, attention given is cursory, and attention given is negative. Based on these themes, we presented the findings.

FINDINGS

Findings of the review indicated that while policies have been formulated to address SRH problems and research conducted to identify groups at high risk in Ghana, some of the policies and research have not given any attention to concerns of persons with disabilities. The review also found that in a few cases where attention is given, it is either often cursory or focused on the negative.

No Attention Given to Disability

Three out of the seven documents reviewed—the GDHS, NSA, and National HIV/AIDS and STI Policy—did not target persons with disabilities. There were efforts in these documents to examine factors that could predispose people to risky SRH behavior as well as strategies to target groups at high risk. For example, the GDHS, which provides a broad understanding of the demographic characteristics and health status of the general population in Ghana [23], examined the relationships between SRH and a set of variables. These variables included age, marital status, education, place of residence, ethnicity, and sex [23]. The aim

was to understand how these variables influence SRH behavior and so doing, identify groups at risk for appropriate policy and programmatic interventions. The NSA provided comprehensive information on adolescents' risk-taking and health-seeking behavior in regards to sexually transmitted diseases (STDs) and unintended pregnancies. The range of issues that were examined included social, behavioral, and economic factors that could potentially increase adolescents' risk to vulnerability for SRH problems, knowledge about means of prevention, trusted sources of information and healthcare, and barriers to the implementation of knowledge acquired. In the case of the National HIV/AIDS and STI Policy, targeting young people and empowering them were key strategies. Other intervention strategies outlined in the policy include initiating educational and poverty alleviating programs to reduce vulnerability [27]. Finally, the policy supported efforts to reduce the vulnerability of women to sexual exploitation and exposure by empowering them through economic opportunities [27].

None of these documents included disability, although disability is potentially an important variable for health issues [32]. The NSA report identified groups at high risk of sexually transmitted diseases (STDs), who were often excluded from adolescents' SRH studies in Ghana to be street children, young girls living in traditional shrines known as the Trokosi system, and HIV/AIDS orphans [29]. Persons with disabilities were not included although they are equally at high risk and missing in many studies on STDs. Similarly, the National HIV/AIDS and STI Policy did not target persons with disabilities, although the policy recognized the importance of targeting "special groups" in reproductive health policies [28].

Attention Given is Cursory

Two documents, the Ghana Population Policy and the Adolescents Reproductive Health Policy, fall under the category of documents that did not give much attention to disability. The Ghana Population Policy made provisions for appropriate actions to ensure the full integration of the aged, children, youth, and persons with disabilities into society [24]. Although no specific mention was made of SRH issues, the broader policy of integration of persons with disabilities should, in theory, increase their access to SRH information and services. However, policy implementation on issues concerning persons with disabilities was cursory compared with other groups, such as adolescents and women without disabilities. For example, there were strategies in the policy to review or abolish traditional norms and religious practices that perpetuated discrimination against women. Employment and income generation programs also were set up to enhance their economic independence. Furthermore, public awareness about the consequences of high fertility and risks associated with pregnancy were initiated. In the case of adolescents, programs were developed to promote employment for parents and guardians to ensure better child care and maintenance. In addition, counseling

services, Information, Education, and Communication (IEC), and family planning services were to be provided for adolescents to reduce SRH related problems.

However, even though there were provisions in the policy to eliminate discrimination against persons with disabilities, there was nothing specific regarding access to SRH information and services. Also, whereas women and adolescents were treated separately in the policy, persons with disabilities and the aged were treated as one group and the same strategies prescribed for both, although they do not have the same set of concerns and needs.

There were efforts to formulate policies for specific groups whose peculiar needs would make it impossible for them to benefit from policies for the general population. A typical example is the Adolescent Reproductive Health Policy (ARHP). The ARHP specifically identified commercial sex workers, street children, teenage parents, adolescent couples, young people living with HIV and AIDS, marginalized groups, females in shrines, and people labeled as “mentally disturbed” and “physically challenged,” as “special groups” who need attention [26]. These groups have been categorized as “special” because their concerns are vastly different from other groups, and adolescents in these groups are likely to be excluded from programs for adolescents in the general population [26]. For example, the policy states that:

Their needs, demands and the strategies for meeting their needs could be different for each of the groups. Moreover, some of the groups in this category tend to be left out in the design and implementation of programmes and activities on adolescent reproductive health. Therefore, it is necessary to identify them so as to ensure that their needs are considered and taken care of in sexual and reproductive health programming [26, p. 13].

The policy clearly acknowledges the need to develop special programs to meet the specific needs of these subgroups. However, there is very little in the policy to serve as guidelines for defining the targeted individuals; for example, who are the “mentally disturbed” or the “physically challenged” population. It is also not clear if people who are deaf and hard of hearing and visually impaired form part of the “physically challenged” population. And even if the “physically challenged” are included, there is nothing in the policy that addressed how the service system should respond to their unique needs, such as communication barriers for the deaf and physical barriers for the blind and wheelchair users.

Attention Given is Negative

The Criminal Code and the Reproductive Health Policy and Standards were the two documents in this category. The review revealed that these documents have provisions that have significance for persons with disabilities in several respects, but the way they represented disability was negative.

There were specific portions of these documents that are of interest for persons with disabilities, and they included sections that focused on the reproductive

functions of persons with disabilities and the termination of fetuses that are considered “abnormal.” For example, provisions of the law on abortion that have some significance for persons with disabilities are portions that detailed the circumstances under which abortion is permitted. Although abortion is illegal and a criminal offence in Ghana, the criminal code provides exemptions for women with developmental disabilities, referred to as “female idiots” and those situations “where there is substantial risk that if child were born it may suffer from or later develop a serious physical abnormality or disease” [29, p. 81]. The law also requires that before any abortion, the consent of the pregnant woman should be sought. However, if the woman lacks the capacity to give consent to abortion, such as in the case of women with developmental disabilities, consent should be given on her behalf by her next of kin [29, p. 81]. Similarly, the Reproductive Health Policy and Standards focused mainly on birth control for “mentally disabled” women. The policy states that decisions regarding family planning for the “mentally disabled” should be made by the next of kin.

DISCUSSIONS

Omissions and Negative Treatment of Disability

Undoubtedly, the review shows that persons with disabilities have received little attention in SRH policies and research in Ghana. While findings indicated that major studies on SRH issues such as the GDHS and NSA do not have data on persons with disabilities, it cannot be concluded that persons with disabilities were not included in these studies. Perhaps some persons with disabilities were included, but the lack of data on disability makes it difficult to tell whether some of the participants were themselves persons with disabilities. Thus, it is impossible to determine how many persons with disabilities were included and their SRH status.

The findings that provisions in some of the policies focused on the negative are problematic in several respects. First, permitting the reproductive rights of women with disabilities to be controlled by others is discriminatory and infringe on the reproductive rights of persons with disabilities, especially women with (developmental) disabilities. These provisions assume that such individuals do not have the capacity to make informed decisions and as a result someone else should make the decision for them, which is a clear violation of their right to self-determination. Second, granted that there are some women with mental disabilities who cannot make such decisions, differentiating between those who can make such decisions and those who cannot will be hard. In fact, the decision will be left at the discretion of professionals, many of whom lack positive attitude toward disability. Third, there are many ambiguities that would permit varying interpretation of the provisions, thus creating problems in their application. For instance, the abortion law is not clear on what constitutes “serious physical abnormality” or how to define a “female idiot.” Such ambiguities provide a great

deal of discretion to medical personnel to determine the legality of abortion. And since disability is negatively perceived in Ghana [3, 6], medical personnel are likely to counsel parents and next of kin based on their own prejudices and stereotypes about disability.

In the same vein, the Reproductive Health Policy and Standards did not provide a clear definition of “mentally disabled,” allowing too much elasticity in the application provisions in the policy. Such flexibility has the tendency to infringe on the rights of women with various cognitive disabilities who may have the capacity of independently making SRH decisions. In fact, depriving any person, irrespective of cognitive acuity, of access to SRH information and services is a violation of his or her right to health. In addition, the policy treated the concerns of those labeled “mentally disabled” not differently from the concerns of women generally; assuming the two groups would have the same SRH concerns and needs. Studies suggest that women with cognitive disabilities need more assistance to access SRH information and pregnancy services than other women [33]. Moreover, by focusing on women with mental illness, the policy has ignored people with other forms of disabilities, and seemed to be primarily more concerned with the reproductive functions of persons with disabilities, rather than their overall SRH concerns.

Possible Reasons for Omission

There are no clear reasons for the little attention given to disability in SRH studies and policies. However, a review of the literature suggests several possible reasons for the neglect. First, although negative practices such as the use of defamatory language, discrimination, and maltreatment that made it difficult for persons with disabilities to survive are now considered criminal acts under the Constitution of Ghana and Person with Disability Act [8, 9], negative perceptions about persons with disabilities still persist [3, 6]. And since public policies are reflections of societal assumptions [34], the minimal attention given to persons with disabilities in policies in Ghana may be due to these negative perceptions. As noted above, in the few cases where attention is given, it was quiet ambiguous and negative and it mainly targeted women with disabilities. Therefore, SRH policy making seems to be motivated more by the quest to control the reproductive functions of person with disabilities, particularly women, rather than a concern for their SRH wellbeing.

Second, persons with disabilities may not be perceived as contributing to the population growth problem in Ghana. One of the main aims of SRH policies is to address Ghana’s ever increasing population and its socioeconomic consequences through the prevention of unintended pregnancies [26]. The population policy states that “If this trend [population growth rate] continues, a point will be reached where future generations will be born into a world in which their very numbers my condemn them to life-long poverty and misery” [sic] [24, p. 1].

Additionally, Ghana's population is considered young, with the greatest potential to add to the existing population pressures. This has drawn policy makers' attention to the need to focus on the youth in SRH policies and programs [24]. Persons with disabilities may be seen as a group that is sexually inactive [11, 19] and, thus, not a risk to the high population growth rate. There is also the perception in Ghana that sex is a physical activity performed by people who are physically strong and its frequency diminishes with age [35]. Perhaps the minimal attention given to persons with disabilities is due to the belief that they are not strong enough to engage in sex due to the general perception that associates disability with "sickness" [2]. Recall that in the Ghana Population Policy, persons with disabilities and the aged were treated as a group and the same strategies prescribed for them [24].

Fourth, the economic productivity of persons with disabilities is often perceived as insignificant [18]. A major rationale for giving priority to sexually transmitted diseases such as HIV/AIDS is its potentially grave consequence to reduce the economic productivity in the population [27, 31]. Thus, the widely held view that persons with disabilities are sexually inactive and not at risk, and economically unproductive [17] may reduce the urgency for including them in HIV/AIDS related policies that are fostered for economic reasons.

Finally, since SRH programs in Ghana rely heavily on donor funding, governments do not have complete control over the scope, content, and direction of SRH policies and programs [36]. Donors may have their own agenda, which are often tied to the policies of the aid they provided for various programs [37]. For example, in a study on official development assistance to persons with disabilities in Ghana from 1994-1995, only two out of the 16 major donors involved in the study "subscribed to disability policies or mandates (United Nations High Commission for Refugees and the United States Peace Corps), and none took affirmative steps to include disabled people in their mainstream projects and programmes" [38 p. 479]. Neither of the two donors that targeted disability-related policies addressed SRH issues [38].

Therefore, it can be argued that the quest to eliminate disability from the population appears to be the main reason for excluding persons with disabilities from SRH research and policies. For example, while the law does not provide reasons for the termination of pregnancies for women with developmental disabilities, there are two plausible reasons that can be adduced. It might be that women with developmental disabilities are not considered capable of taking care of children. Allowing them to procreate will therefore likely increase the number of street and wayward children in the country. This argument is, however, flawed because the law does not permit women without disabilities who feel they are incapable of taking care of their children to terminate their pregnancies. Another possible reason is the fear that such women would give birth to their likes and thus increase the number of persons with developmental disabilities in Ghana. This reason seems to be consistent with the second reason under which

abortion is permitted mentioned previously [39], hence supporting the view that the fear of disability is likely to be the main reason for the little attention given to persons with disabilities in SRH research and policies. This is the possible reason why in traditional Ghanaian society, before marriage the families of both the man and women would ensure that no traits of disability—insanity, leprosy, tuberculosis, deafness, blindness, and mobility impairment—are found in the families of their prospective would-be in-laws. A proof of any of the above traits could cause the annulment of the marriage as mentioned earlier.

POLICY IMPLICATIONS

The study provides some initial perspective on the need to target specific subgroups, which many policies and programs tend to ignore. Some groups, defined by socio-demographic characteristics such as age, gender, or educational attainment are more vulnerable to SRH problems than the general population [21, 29]. A number of studies have examined such at risk groups in Ghana: adolescents [29, 40, 41], street children [42], and women [21]. However, as indicated in the review, the association between disability and risk for SRH problems has received little attention in Ghana. As a result, little is known about how disability affects one's SRH behavior and the resultant risks. The present review sought to broaden the conception of vulnerability to include a specific group (the disability community) within the larger Ghanaian community. Furthermore, the review has the potential to make SRH needs of persons with disabilities visible and create awareness about other issues concerning this sub-group and, thus, possibly ignite interests in disability in national policy making and research.

CONCLUSION

The review was conducted to assess the extent to which national policies and research on SRH have included the concerns of persons with disabilities. The intent was to identify gaps that could act as bases for future actions. The findings showed that there is lack of sufficient consideration for persons with disabilities in SRH policies in Ghana. Negative perceptions about disability and lack of societal understanding of the concerns of persons with disabilities seem to be the overriding factors that have contributed to the neglect of people with disabilities in SRH policies in Ghana. The insufficient attention given to disability is likely to increase the invisibility of this population to policy makers, program designers, and service providers. As a result, there is the need for a clear understanding of the concerns of persons with disabilities and more concerted efforts by the government and other stakeholders to guide the development of more inclusive policies and programs that will address the SRH needs of persons with disabilities.

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Direct reprint requests to:

Patricia Anafi, Ph.D.
 Assistant Professor
 Dept. of Community Health
 SUNY-Potsdam
 Potsdam, NY 13676
 e-mail: anafip@potdam.edu