Université de Montréal

Legislation, health policy, and the utilisation of sexual and reproductive health services by people with disabilities: A mixed methods study in post-conflict Northern Uganda

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Legislation, health policy, and the utilisation of sexual and reproductive health services by people with disabilities: A mixed methods study in post-conflict Northern Uganda

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Résumé

Introduction : Les droits en matière de santé sexuelle et reproductive (SSR) sont essentiels pour parvenir à une couverture sanitaire universelle pour tous, y compris les personnes handicapées. L'Ouganda a émergé d'un conflit armé de 20 ans qui a engendré à la fois des handicaps et des dommages aux systèmes de santé, en particulier au nord du pays. Une personne sur cinq vit avec un handicap en Ouganda où plusieurs lois et politiques ont été adoptées promouvant les droits des personnes handicapées. Or, leur accès aux services de SSR demeure limité. Les rôles genrés restent omniprésents et les hommes et les jeunes handicapés sont moins ciblés par les programmes de SSR (article 1). Les politiques de santé et leur mise en œuvre nécessitent donc une analyse contextuelle plus approfondie pour protéger le droit à la santé des personnes handicapées. Cette thèse visait à examiner les relations perçues et empiriques entre la législation, les politiques de santé et l'utilisation des services de SSR par les personnes handicapées dans la région post-conflit au nord l'Ouganda.

Méthodes : Un devis séquentiel exploratoire de méthodes mixtes s'est appuyé sur le cadre d'analyse des politiques basée sur l'intersectionnalité (IBPA). 1) Nous avons mené une étude de cas multiples auprès de cinq groupes d'acteurs des politiques (personnes handicapées, prestataires de services, organisations de personnes handicapées, organisations nationales et internationales, et décideurs politiques nationaux), thématiquement analysé 45 entretiens approfondis et neuf groupes de discussion, et observé sept structures de santé en matière d'accessibilité. 2) Nous avons analysé des données secondaires provenant des enquêtes démographiques et sanitaires ougandaises de 2006, 2011 et 2016 à l'aide de régressions logistiques multivariées. Le but était d'analyser l'utilisation des services de SSR chez 15 739 personnes au cours de la décennie qui a suivi l'adoption de la Loi sur le handicap en Ouganda. 3) Une revue systématique a été réalisée pour examiner les relations entre la législation, les politiques de santé et l'utilisation des services de SSR parmi les populations vulnérables en Afrique subsaharienne (1994-2019).

Résultats : Cette thèse met en exergue quatre résultats principaux. 1) Le cadre de l'IBPA a mis en évidence des relations complexes entre la législation, les politiques de santé et l'utilisation des services de SSR chez les personnes handicapées au nord de l'Ouganda. Ces relations ont été marquées par des défis de mise en œuvre des politiques, la violation des droits des personnes handicapées, et des vulnérabilités croisées vécues par les personnes handicapées, exacerbées par les structures de pouvoir sociétales sous-jacentes. Les perceptions des différents groupes d'acteurs des politiques convergeaient en soulignant les iniquités persistantes en matière de SSR auxquelles sont confrontées les personnes handicapées (articles 2 et 3). L'utilisation des services de SSR s'est accrue au fil du temps. Cependant, elle ne s'est pas améliorée de la même manière pour tous. L'évolution de l'utilisation des services de SSR sur une décennie a révélé des tendances d'utilisation des services nuancées chez les personnes vivant avec différentes incapacités; notamment, les femmes plus nanties avec une incapacité auditive étaient moins susceptibles d'avoir utilisé les services de maternité comparativement aux femmes pauvres non handicapées (article 4). 2) Les cinq groupes d'acteurs des politiques ont identifié des défis en matière de mise en œuvre des politiques et ont émis plusieurs recommandations concrètes et complémentaires pour lever les barrières et rendre opérationnelles les mesures transformatrices, telles que la budgétisation et la collecte de données sur le handicap (articles 2 et 3). 3) Les résultats au niveau local (Ouganda) ont permis de contextualiser ceux au niveau régional (Afrique subsaharienne), et vice versa. Une revue systématique sur une période de 25 ans a montré que les personnes handicapées restent dans l'angle mort de la recherche sur l'analyse des politiques en matière d'utilisation des services SSR (article 5). 4) La pratique de la réflexivité tout au long de la recherche a mis en lumière les tensions dans l'application des normes éthiques dans le contexte de la recherche qualitative en santé mondiale avec des personnes handicapées menée dans le Sud (article 6).

Conclusion : Ces résultats permettent aux acteurs des politiques à différents niveaux d'agir – maintenant – pour aborder et corriger les iniquités sociales de santé vécues par les personnes handicapées. Le cadre de l'IBPA s'est avéré un outil analytique et théorique utile pour mieux comprendre les questions complexes liées aux politiques et aux vulnérabilités intersectionnelles auxquelles font face les personnes handicapées. Ce cadre pourrait enrichir d'autres cadres existants d'analyse des politiques. La thèse propose deux adaptations théoriques, soit le cadre du IBPA combiné au « Multiple Streams Framework» de Kingdon et au « Policy Triangle Model» de Walt et Gilson pour de futures recherches en santé mondiale sensibles au handicap et axées sur l'analyse des politiques basées sur l'équité.

Mots-clés : Santé mondiale, personnes handicapées, analyse des politiques basée sur l'intersectionnalité, équité en santé, politiques de santé, santé sexuelle et reproductive, utilisation de services, méthodes mixtes, post-conflit, Ouganda

Abstract

Introduction: Sexual and reproductive health (SRH) rights are essential to achieve universal health coverage (UHC) for all, including people with disabilities. Uganda emerged from a 20-year armed conflict which created both disability and damage to health systems, especially in the Northern region. One Ugandan in five lives with some disability. Uganda adopted a series of normative tools promoting the rights of people with disabilities. However, their access to SRH services remains limited. More broadly, ableist gendered roles remain pervasive and men and youth with disabilities are less targeted by SRH programmes (Article 1). Health policies and their implementation need deeper contextualised analysis to protect the right to health of people with disabilities. This thesis aimed to examine the perceived and empirical relationships among legislation, health policies, and SRH service utilisation among people with disabilities in post-conflict Northern Uganda.

Methods: A sequential exploratory mixed methods design was informed by the Intersectionality-based Policy Analysis (IPBA) framework. First, I conducted a multiple case study with five groups of policy actors (people with disabilities, service providers, disabled people's organisations, national and international organisations, and national policy-makers). I thematically analysed 45 in-depth interviews and nine focus groups and observed seven health facilities regarding accessibility. Second, I analysed secondary data with multivariable logistic regressions, from the 2006, 2011, and 2016 Uganda Demographic and Health Surveys regarding SRH service use among 15,739 individuals in the decade following the adoption of national legislation promoting the rights of people with disabilities. Third, I conducted a systematic review examining the relationships among legislation, health policies, and SRH service use among vulnerable populations in sub-Saharan Africa (1994-2019).

Results: This thesis highlights four main findings. First, the IBPA framework revealed complex relationships among legislation, health policy, and the use of SRH services by people with disabilities in Northern Uganda. These relationships were marked by policy implementation challenges, disability rights violation through multiple barriers to access, and intersecting vulnerabilities experienced by people with disabilities, exacerbated by underlying societal power structures. On one hand, the perceptions of different groups of policy actors converged by emphasising the ongoing SRH inequities faced by people with disabilities (Articles 2 and 3). On the other hand, although SRH service use improved over time, it did not improve equally for everyone. The 10-year SRH service use trend showed nuanced patterns across people with different impairments; notably, richer women with hearing impairments were less likely than poor non-disabled women to have used safe motherhood services (Article 4). Second, despite identifying legislation and policy implementation challenges, the five groups of policy actors suggested several concrete and complementary recommendations to address barriers and operationalise transformative measures, such as disability data collection and budgeting (Articles 2 and 3). Third, research findings at the local level (Uganda) contextualised the findings at the regional level (sub-Saharan Africa), and vice versa. A 25-year systematic review showed that people with disabilities continue to be a blind spot in research on SRH service use and policy analysis (Article 5). Finally, the practice of reflexivity throughout the research revealed tensions in the application of ethics norms in the context of global health qualitative research with people with disabilities conducted in the Global South (Article 6).

Conclusion: The IPBA framework proved to be a useful and transformation-oriented analytical tool to disentangle complex policy implementation issues and multiple intersecting vulnerabilities and barriers to SRH service access and utilisation by people with disabilities. This thesis proposes two adapted conceptual frameworks for future disability-sensitive research focusing on equity-focused policy analysis in global health, integrating IBPA with Kingdon's Policy Streams framework to enhance sensitivity to equity and Walt and Gilson's Policy Triangle model to enhance sensitivity to the multiple dimensions of (in)equity. The Sustainable Development Goals emphasise inclusiveness and accountability. UHC for *all* is only possible through transformative action and research to fill knowledge and programmatic gaps, focusing on equity and human and disability rights. This thesis provides evidence enabling policy actors at different levels to act – now – to address and redress the social health inequities experienced by people with disabilities.

Keywords: Global health, people with disabilities, intersectionality-based policy analysis, health equity, sexual and reproductive health, health policy, use of services, mixed methods, post-conflict, Uganda

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List of abbreviations

COREQ	Consolidated Criteria for Reporting Qualitative Research
CRPD	Convention on the Rights of Persons of Disabilities
DHS	Demographic and Health Survey
DPO	Disabled People's Organisations
ENTREQ	Enhancing Transparency in Reporting the Synthesis of Qualitative Research
GII	Gender Inequality Index
HDI	Human Development Index
IBPA	Intersectionality-Based Policy Analysis
ICPD	International Conference on Population and Development
LMIC	Low- and Middle-Income Country
MWD	Men with Disabilities
NGO	Non-Governmental Organisation
NUDIPU	National Union of Disabled People in Uganda
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PWD	People with Disabilities
SDG	Sustainable Development Goal
SRH	Sexual and Reproductive Health
SRHR	Sexual and Reproductive Health Rights
STI	Sexually Transmitted Infections
UHC	Universal Health Coverage

UN	United Nations
WHO	World Health Organization
WWD	Women with Disabilities
YWD	Youth with Disabilities

À mes parents.

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Statement of originality

The work presented in this thesis constitutes original scholarship and contributes to knowledge advancement in the fields of intersectionality-based policy analysis, disability, sexual and reproductive health, and health equity in the context of global public health in sub-Saharan Africa. For all manuscripts, I used the intersectional framework to guide analysis (Manuscripts 2, 3, and 5) or identify gaps (Manuscripts 1, 4, and 6).

In the first manuscript (published), I present a meta-synthesis on gender, disability, and reproductive health in sub-Saharan Africa. The objective of this review was to synthesise qualitative research on these topics and identify policy and programmatic gaps. In the following three manuscripts, I report the qualitative study findings. The second manuscript (published) documents and analyses the multiple barriers of access to and use of sexual and reproductive health services encountered by women and men with disabilities, the policy actors at the micro level, in the post-conflict northern region of Uganda. On one hand, it revealed the intersectional jeopardy people with disabilities experienced when seeking services, and the recommendations they proposed to concretely remove barriers and improve policy implementation measures, on the other hand. The third manuscript (published) documents and analyses the perceptions related to the above barriers and challenges among community health service providers and disabled people's organisations (policy actors at the meso level) and national and international organisations and national policy-makers (policy actors at the macro level). Both meso and macro level policy actors identified policy implementation challenges and recommended concrete transformative solutions to reduce health inequities faced by people with different disabilities. The fourth manuscript (under review) identifies disability and other key determinants of sexual and reproductive health service use in Uganda. This is the first intersectional analysis of repeated cross-sectional Demographic and Health Surveys which examined the associations between disability and the use of sexual and reproductive health services in Uganda between 2006 to 2016.

To contextualise the empirical findings related to Uganda, in the fifth manuscript (published), I describe and analyse the results of a systematic review on the relationships among pro-equity legislation and health policy and the utilisation of sexual and reproductive health services by vulnerable populations in sub-Saharan Africa, from 1994 to 2019. This systematic review analysed the effects of legislation and policy on the use of sexual and reproductive health services among vulnerable populations, across 14 countries in sub-Saharan Africa and spanning 25 years. The last manuscript (under review) exposes the complexity in the application of ethics norms in qualitative research and global health through a reflexive process. It provides suggestions for a more nuanced and respectful implementation of ethics in a disability and global health research context.

While I have received guidance from my supervisors and manuscript coauthors on substantive and methodological aspects of this thesis, I declare that the conception, execution, and writing of the work in this thesis are my own.

Chapter 1 – Introduction

To date, more than 180 Member States of the United Nations (UN), including Uganda, have ratified the Convention on the Rights of Persons with Disabilities (CRPD) (1). The CRPD further complements the Sustainable Development Goals (SDGs), adopted in September 2015 and pledging to "leave no one behind", irrespective of "age, sex, disability, race, ethnicity, origin, religion, economic or other status" (2). Despite legislative and normative tools which promote disability rights, people with disabilities have been historically excluded from basic health services, including sexual and reproductive health (SRH) (3). The fundamental rights of people with disabilities have been neglected (4-6) and their SRH rights silenced and denied (7). According to the 2020 World Health Statistics, SRH issues such as maternal health and HIV and AIDS still constitute a major global health challenge, affecting sub-Saharan African countries the most (8). Women and men with disabilities are often perceived as sexually inactive and have been largely excluded from SRH information and services (6, 9), hence jeopardising their basic right to health. Analysing legislation and health policy and their empirical associations with healthcare utilisation contributes to better understanding health equity, service utilisation (10), health rights (11), and how these are evolving over time to improve accountability and population health (10, 11), including people with disabilities' health.

The World Report on Disability estimates that 15.6% of the world's population – one person in seven – is living with some disability: 19% of women and 12% of men are reported to be disabled (4). In Uganda, one person in five (19%) lives with some disability (12). In the CRPD, people with disabilities are defined as "those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (13). This renewed social definition of disability, which emphasises societal solutions to remove barriers, contrasts with the traditional biomedical understanding of disability which focuses on people's physical, psychological and mental limitations and for which individuals are the source of their problems to be 'fixed' medically (14, 15). Eighty percent of people with disabilities live in low- and middle-income countries where the main causes of disability include maternal, newborn, and child health problems, illness complications, chronic diseases, violence, accidents, trauma, and ageing (4).

Considering the above context, this research examined the relationships among legislation, health policy, and the utilisation of SRH services by people with disabilities in the post-conflict northern region of Uganda. Intersectionality, which critically examines the interplay of intersecting social categories at multiple levels (micro, meso, and macro), power structures, context (time and space), reflexivity, diverse sources of knowledge and equity (16, 17) served as the theoretical and analytical framework to conduct a sequential mixed methods study. First, I conducted iterative analyses of the perceptions of people with disabilities, health service providers, disabled people's organisations, national and international organisations, and national policy-makers on the relationships among legislation, health policy, and the SRH service use by people with disabilities in three post-conflict northern districts of Uganda. Second, I examined the associations among disability, other social determinants, and the use of SRH services from three waves of Demographic and Health Surveys (DHS) of Uganda in 2006, 2011, and 2016. Third, I systematically reviewed the literature and analysed pro-equity legislation and health policy which promote the use of SRH services by vulnerable populations in sub-Saharan Africa, between 1994 and 2019.

My research was embedded in and complemented my Ph.D. Director's ongoing regional Mother Child Health Lacor-South Sudan (MoCHeLaSS) project which aims to improve the access to and utilisation of reproductive, maternal, and child health services in post-conflict settings of South Sudan and Northern Uganda. Though MoCHeLaSS focuses on the important issue of access to and utilisation of SRH services by vulnerable populations of women and children, it does not include equity analysis of legislation and health policy nor the utilisation of SRH services by vulnerable groups of people with disabilities. This doctoral initiative was connected to MoCHeLaSS local-based partners, namely the St-Mary's Hospital Lacor and its satellite health centres III in the Ugandan northern districts of Gulu, Amuru, and Omoro.

1.1 Problem statement

This research addresses a three-fold problem: 1) health service utilisation inequities between people with and without disabilities in a sub-Saharan African country, 2) the invisibility of people with disabilities in development practice and research despite the availability of pro-disability legislation and policy, and 3) the relationships among legislation, health policy and SRH service utilisation by people with disabilities in Uganda.

First, the uptake of SRH services has improved globally including in the sub-Saharan African region, however, maternal mortality rates (18) and HIV prevalence (19) remain the highest in sub-Saharan Africa. When improvement in SRH service utilisation was reported, intra-country inequities in SRH service utilisation, mainly based on the rural/urban (20-22) and poor/rich (20, 21, 23) divides persisted. As indicated in Table 1, selected SRH indicators in Northern Uganda are relatively worse than average rates in Uganda and other parts of the world.

Tableau 1. – Selected SRH indicators (2010-2019)

Indicator	**Northern Uganda**	**Uganda**	**Sub-Saharan Africa**	**Worldwide**
Use of any methods of contraception among women aged 15-49 years old (%)	23.9 (24)	30.0 (24)	23.0 (25)	63.5 (25)
Skilled birth attendant (%)	50.2 (26)	58.0 (26)	49-63 (27)	71-81 (27)
HIV prevalence in adults aged 15-49 (%)	7.2 (Mid-North region) (28)	6.2 (28)	3.9 (29)	0.8 (29)

Major barriers to access and utilisation of SRH services by women have been reported to be associated with their sociodemographic statuses such as age and education (21, 30), place of residence and wealth status (21, 22), the distance between homes and health facilities, negative attitudes of health staff and sub-standard quality of SRH care (31). These are exacerbated in post-conflict contexts (32, 33), constituting a powerful negative determinant to health (34). Not only do non-disabled women face barriers in access, but vulnerable groups of people with disabilities (35) experience additional obstacles in utilising SRH services due to various attitudinal (e.g. of health professionals), environmental (e.g. physical and communication), and structural barriers (e.g. policy and legislation related) (3, 4, 9, 36).

Second, the invisibility of more than 15% of the world's population in development and research discourses (37-40) is one of the most pressing problems contemporary research is facing concerning access to health services, health equity (41-43), and global health governance (44), especially at the level of disability research (45, 46) and disability health research (47). Contributing to this invisibility is the "historic neglect" (48) experienced by generations of people with disabilities. This is fueled by the hegemony of ableism which promotes the " normalness" and "completeness" of the able-bodied (37, 49) as well as the pervasive belief that people with disabilities are sexually inactive, thus not in need of sexual rights nor reproductive healthcare (6, 9). The ultimate goals of any pro-disability legislation and policy should reassert the existence and the rights of people with disabilities, and be translated into better outcomes, health included (42, 50), for populations with disabilities (47, 51, 52).

Third, Uganda is cited as an exemplary disability rights promoter among sub-Saharan African countries for adopting several pro-disability national laws and policies (52-54). However, little is known about the linkages among the legal space provided by legislation and health policy promoting disability rights and the utilisation of SRH services by vulnerable groups of people with disabilities, when compared to their non-disabled peers in Uganda. Hence, the overall doctoral research objective was to examine the relationships among legislation, health policy, and the utilisation of SRH services by people with disabilities in the post-conflict northern region of Uganda, between 2006 and 2019.

1.1 Research objectives

This doctoral research sought:

1. To examine how five key groups of policy actors – people with disabilities, health service providers, disabled people's organisations, national and international organisations, and national policy-makers – perceived the relationships among legislation, health policy, and the utilisation of SRH services by people with disabilities in the post-conflict northern region of Uganda.
2. To examine how disability was associated with selected SRH service utilisation in Uganda between 2006 (year of Uganda's adoption of the Disability Act) and 2016.
3. To systematically review the existing body of evidence on pro-equity legislation, health policy, and the utilisation of SRH services by vulnerable populations in sub-Saharan Africa from 1994 to 2019.

1.3 Background to the dissertation

1.3.1 Uganda

Located in eastern sub-Saharan Africa, Uganda is bordered in the north by South Sudan, in the east by Kenya, in the south by Tanzania, and in the west by the Democratic Republic of Congo. Uganda gained independence from the United Kingdom in 1962. Its post-independence history was punctuated by the following periods (55). From 1971-1979, the dictatorial regime of Idi Amin murdered more than 300,000 political opponents and civilians. The following five years under Milton Obote were characterised by guerrilla war and human rights violations, where at least 100,000 people were killed (55). Since 1986 to date, President Yoweri Museveni has ruled in Uganda and has brought relative stability and economic growth to the country, though human rights violations persist (55).

In 2006, the Government of Uganda negotiated with the Lord's Resistance Army (LRA) to end 21 years of armed conflict which mostly affected the northern region of Uganda, comprising the Acholiland and Lago and Teso regions (56). From 2004 to 2006, at the height of displacement and deaths in the northern region, approximately two million internally displaced people lived in protected camps (56). Although the conflict has ended, in many Ugandans' minds, Northern Uganda still has unanswered questions concerning a true peace deal (57). Past drivers which fueled the conflict, such as land grabbing, corruption, and competition over natural resources, still prevail (57). Emerging from conflict, the northern region bore the brunt of the consequences, notably disturbed and weakened socioeconomic and healthcare systems. Sexual and gender-based violence and unwanted pregnancies were frequent and negatively affected women's and girls' health (33, 58). Poor access to maternal health (33, 58) and reproductive health services, such as family planning and HIV services, was pervasive (59). According to a systematic review examining the effects of armed conflict on children's health and development, these conflicts generated direct effects such as injuries, illnesses, the experience of violence including sexual, disability, and torture, and indirect effects such as social marginalisation, birth defects, and limited access to healthcare and education (60).

Also in 2006, Uganda adopted its national Disability Act. The National Union of Disabled Persons of Uganda (NUDIPU), established in 1987 and one of Uganda's main disabled people's organisations (DPO), spearheaded the disability movement and has been instrumental in advocating for equal opportunities and the involvement of people with disabilities in policy and programme development in Uganda (61). In 2008, the country ratified the CRPD. The official endorsement of these legal instruments is embedded in a legal space which promotes disability rights, starting from the enactment of the Ugandan Constitution in 1995 and its amendment in 2005, by making explicit the rights of marginalised groups including people with disabilities. Since 1995, Uganda has adopted several other pieces of legislation, such as the Equal Opportunity Act (2006) and policies such as the National Policy on Reproductive, Maternal, Newborn, and Child Health (2016) (62). However, despite these legal and normative instruments, the presence of a National Council on Disability and a representation of elected officials with disabilities at different levels of the Government (53, 63), their translation into concrete action promoting and protecting the rights of people with disabilities remains a challenge (52-54). According to NUDIPU, the Disability Act was weak and poorly applied (52). The national DPO deplored that the 2006 Act did not align with the CRPD's language and scope of action (64). To address this, policy-makers, legislators, and DPOs debated for more than a decade and finally replaced the initial version of the Disability Act with a more comprehensive Act, adopted at the end of 2019 (65).

At the population level in 2018, about one-fourth of its population (23.8%) of 42.7 million people lived in urban areas. Among 189 counties worldwide, Uganda ranks 159th, with a Human Development Index (HDI) of 0.528; this positions Uganda among the lowest HDIs in the world and below the sub-Saharan African mean HDI of 0.541 (66). When Uganda's HDI is adjusted for 'loss' in human development due to inequality, this level decreases to 0.387 (66). On the Gender Inequality Index (GII), which considers gender empowerment, reproductive health, and economic activity, it ranks 127th (0.531) out of 162 countries (66).

Uganda devotes 7.2% of the national gross domestic product (GDP) to health expenditures, while the total expenditure on health per capita is equivalent to $133 (67). The healthcare system in Uganda, led by the Ministry of Health, is structured into seven functional levels based on the types of services they provide and the catchment area they serve (68). At the district and sub-district levels, there are community-based preventive and promotive health services provided by health centres of level II-IV; in addition to these, more specialised care is provided by general and referral hospitals at the regional level, and comprehensive specialist services are provided by the national referral hospitals in the capital (68). In Uganda, health facilities are 45.16% owned by the public sector, 40.31% by the private sector, and 14.53% by private-not-for-profit organisations, often faith-based (68). As for gender and disability issues, the responsible government body is the Ministry of Gender Labour and Social Development. It promotes social protection, gender equality, human rights, and empowerment for different groups such as women, children and youth, internally displaced people, and people with disabilities (69).

1.3.2 Positionality of author

The decision to pursue doctoral studies has been inspired by my work with and for women and men with disabilities in Asia and sub-Saharan Africa, and my refusal to accept that social injustice and rights violations continue to exclude, abuse, and harm people based on their social identities. From 2008 to 2015, I worked on the SRH rights of people with disabilities, including HIV and AIDS, and protection against sexual and gender-based violence. From one mission to another with Humanity and Inclusion (HI), formally called Handicap International, I advocated for the inclusion of disability in national and international health and SRH related policies and programmes. I was confronted with the recurrent mixed messages on disability inclusion among development partners, such as international and national non-governmental organisations (NGOs), bilateral and multilateral donors as well as national health authorities. Although they readily acknowledged the importance of disability, they were less eager to actively and effectively include people with disabilities into their policy, programmes, and budget plans. To address this growing discomfort, I needed to take a break and – consciously – reflect and pause. In September 2015, I stepped down from my position as Head of the Prevention and Health Unit, based at the headquarters of HI in Lyon, France. This professional experience and personal stance constitute the background to the undertaking of this doctoral project. With other Ph.D. candidates, I led an editorial, published in 2017 in the *Canadian Journal of Public Health*, reasserting our commitment to another type of 'global health' that is more intersectional and humble, a global health that is inclusive of vulnerable and marginalised populations such as people with disabilities (70). While I took this doctoral project head on, I was also aware of my uncomfortable transitioning positionality as a field practitioner to a student-researcher who had to find a renewed sense of belonging amid global health scholarship and praxis. To cope with this dissonance, in 2018, I joined a group of junior global health researchers and practitioners working on reflexivity in global health. As a result, each of us contributed to a section of a collective piece. I shared my reflections regarding my intersectional multiple identities engulfed in my global health journey (71). The conclusion in addressing this 'situation' is discussed at the end of this thesis.

1.4 Dissertation structure

The format of this thesis is manuscript-based and includes six manuscripts. The background, problem statement, and three research objectives are presented in Chapter 1. Chapter 2 presents the intersectional framework as well as the state of the knowledge regarding legislation and policy related to the rights of people with disabilities, and utilisation of sexual and reproductive health services by people with disabilities. It includes Manuscript 1, a meta-synthesis on gender, disability, and reproductive health in sub-Saharan Africa published in 2017, and an update to 2021 of the literature covered in the meta-synthesis. Chapter 3 details the overall thesis methodology. The Results chapters (4, 5, and 6) adopt a local context to broader context approach in presenting research findings, starting with research findings from Uganda before presenting evidence at the sub-Saharan African regional level. Chapter 4 reports on the findings of a primary qualitative study which examined the perceptions of five groups of policy actors on the relationships among legislation, health policy, and the use and experience of SRH services by people with disabilities in post-conflict Northern Uganda. Manuscript 2 explored the perspectives of policy actors of people with disabilities at the micro level and Manuscript 3 explored the perspectives of policy actors at the meso and macro levels. Chapter 5 reports the results of a secondary quantitative data analysis which examined the associations between disability and other key factors and the SRH service utilisation trends in Uganda, between 2006 and 2016 (Manuscript 4). Chapter 6 presents the results of a systematic review which examined the relationships among pro-equity legislation and health policy, and the utilisation of SRH services by vulnerable populations in sub-Saharan Africa between 1994 and 2019 (Manuscript 5). The systematic review is placed after the empirical qualitative and quantitative manuscripts to contextualise locally obtained data in a broader body of knowledge and ensure that a ‘conversation’ between empirical evidence related to Uganda (national level) and findings at the sub-Saharan level (regional level) remains locally grounded and ‘bottom-up’. Chapter 7 is the overall discussion and includes the synthesis of findings, knowledge translation activities, the dissertation’s substantive and theoretical contributions, strengths and challenges, limitations, and recommendations, and my reflexive notes. Reflecting on the challenges highlighted in conducting qualitative research with people with disabilities in a global health context, Manuscript 6 discusses the complexity of navigating the application of Canadian and Uganda ethics norms when conducting global health qualitative research which involves people with disabilities. Chapter 8 presents the conclusion of the thesis. References and appendices are listed at the end of this document.

Chapter 2 – Conceptual framework and state of knowledge

2.1 Intersectionality framework

Before critical study scholars started to be interested in intersectionality to highlight inequality and the interactions of multiple oppressions experienced by marginalised groups (38, 72-75), Black African American anti-slavery feminists such as Sojourner Truth in the 19th century (76, 77), and feminists and lesbians of the Combahee River Collective were embracing core concepts of this framework and approach in their struggle in the 1970s (78). Intersectionality has its roots in coalition-building and social justice-seeking movements. It “originally focused on transformative counter-hegemonic knowledge production and radical politics of social justice” (79). The term ‘intersectionality’ was first coined in 1989 by Kimberlé Williams Crenshaw, a Black African American lawyer, scholar, and activist to address the multiple discriminations faced by her lay female counterparts who fell outside of the protection of both anti-racism and anti-sexism legislation (73, 80). Over the years, intersectionality has been qualified as a paradigm (81), meta-principle (82) as well as a theory and praxis (75). Though there are several ways of defining intersectionality (83), all are guided by the core concepts of social inequality, power structures, social context, complexity, relationality between all concepts, reflexivity, and social justice, the ultimate goal of intersectionality (16, 84). The following definition of intersectionality proposed by Collins and Bilge captures its main essence (16):

> *Intersectionality is a way of understanding and analyzing the complexity in the world, in people, and in human experiences. The events and conditions of social and political life and the self can seldom be understood as shaped by one factor. They are generally shaped by many factors in diverse and mutually influencing ways. When it comes to social inequality, people’s lives and the organization of power in a given society are better understood as being shaped not only by a single axis of social division, be it race or gender or class, but by many axes that work together and influence each other. Intersectionality as an analytic tool gives people better access to the complexity of the world and of themselves*. (p.2)

Intersectionality rejects classical binary understandings of the world (e.g. woman/man, young/old, disabled/able-bodied, etc.) but accepts the complexity and 'messiness' that characterises people with multiple interlocking identities or social categories, situated in systems of power structures (such as sexism, racism, classism, patriarchy, heterosexism, ableism, colonialism, and others), and within a specific context (83, 85). As a theoretical and analytical tool, intersectionality enables researchers to make visible multiple concomitant social inequalities experienced by marginalised groups (17, 84), including people with disabilities (38, 86-88). It has also attracted the attention of the public (17, 89-92) and global health practitioners and specialists (70, 93), and in the context of low- and middle-income countries (94) to promote population health and equity. In one of the editorials of the *BMJ Global Health* journal published in 2019, alongside colleagues of the *Agence Universitaire de la Francophonie*, I argued that intersectionality constitutes one of the innovations for the future of global health as "we can no longer keep unchecked the invisibility – both at theoretical and praxis level – of marginalised populations, such as vulnerable groups of women and girls, people with disabilities, indigenous peoples, sexual minorities, migrants, refugees, etc." (95).

The research reported in this thesis is operationalised through the intersectionality-based policy analysis (IBPA) framework, which has a specific focus on public health (17, 96). The IBPA framework has been applied in various settings, such as those related to maternity care policy, Indigenous health, or HIV prevention funding for gay men (96). It promotes attention to key principles including intersecting categories, power, diverse sources of knowledge, time and space (the context), multiple levels of analysis, reflexivity, and social justice and equity. These principles are methodologically translated into two sets of overarching guiding questions, descriptive and transformative, as promoted by the Canadian Intersectionality scholar Olena Hankivsky and shown in Table 2 (84, 96). The descriptive questions identify the main problems and how they are represented, while the objectives of the transformative questions are to shed light on the potential solutions to redress inequities and highlight the positionality of actors involved in the reflection and analysis at stake.

Tableau 2. – Intersectionality-based policy analysis' overarching guiding questions

Descriptive questions

1. What knowledge, values, and experiences do you bring to this area of policy analysis?
2. What is the policy 'problem' under consideration?
3. How have representations of the 'problem' come about?
4. How are groups differently affected by this representation of the 'problem'?
5. What is the current policy response to the 'problem'?

Transformative questions

6. What inequities actually exist in relation to the 'problem'?
7. Where and how can interventions be made to improve the problem?
8. What are feasible short, medium, and long-term solutions?
9. How will the proposed policy responses reduce inequities?
10. How will implementation and uptake be assured?
11. How will you know inequities have been reduced?
12. How has the process of engaging in an intersectionality-based policy analysis transformed:
    - Your thinking about relations and structures of power and inequity?
    - The ways in which you and others engage in the work of policy development, implementation, and evaluation?
    - Broader conceptualisations, relations, and effects of power asymmetry in the everyday world?

Source: Hankivsky O, Grace D, Hunting G, Giesbrecht M, Fridkin A, Rudrum S, et al. An intersectionality-based policy analysis framework: critical reflections on a methodology for advancing equity. International Journal for Equity in Health. 2014;13(1):119; p4.

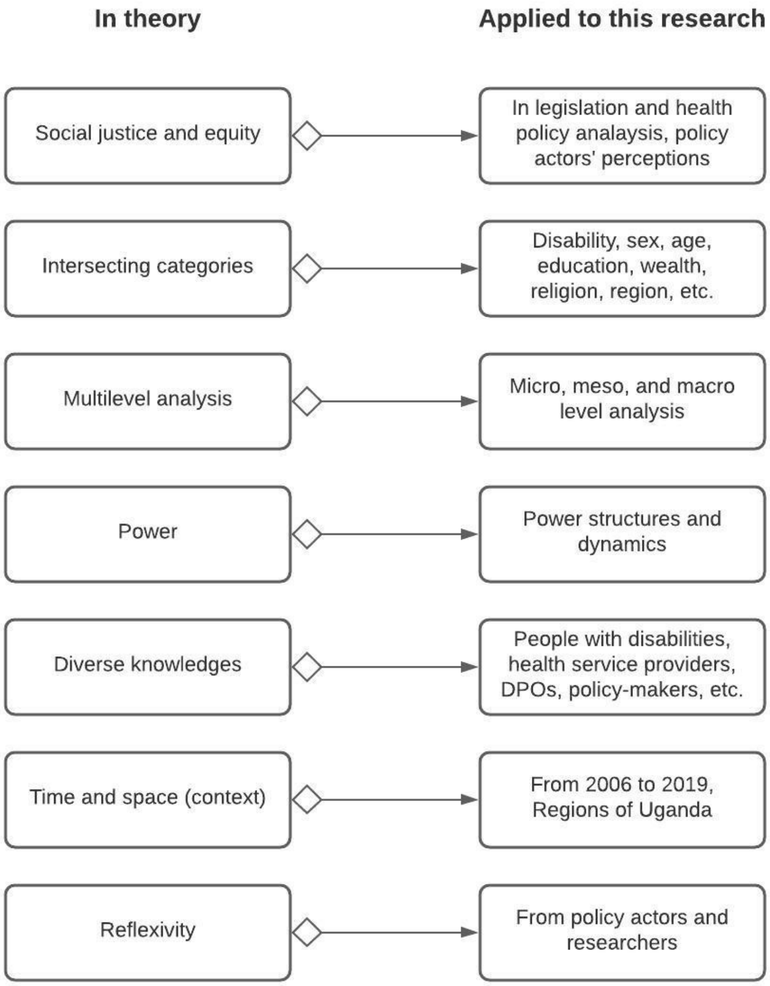
The intersectional framework extends the understanding of public and health policy analysis through a critical lens (97). Literature reports some key public policy and health policy analysis frameworks and approaches, such as the Multiple Streams Framework (98, 99), Policy Triangle Model (96, 100), Sex and Gender-Based Analysis, and Health Impact Assessment tools (96). The Multiple Streams Framework, developed by Kingdon in the 1980s, posits that policy agenda-setting evolves through the combination of three 'streams', namely the problem, policy, and politics, with policy emerging when a window of opportunity is captured by policy advocates (98). According to Kingdon, when all streams meet, "a problem is recogni[s]ed, a solution is available, the political conditions are right, and the three streams get joined together. So advocates develop their ideas over a long period of time" (98). Although this framework is widely used in public policy analysis, it does not examine equity issues (99) nor explicitly analyse power dynamics. On the other hand, the Policy Triangle Model, elaborated by Walt and Gilson, addresses the positions of actors in power structures along with the analysis of policy content, process, and context, whereby the actors both influence and are influenced by the main elements of the model

(100). The Sex and Gender-based Analysis, promoted by the Government of Canada, is an analytical tool to assess the differentiated experiences of women and men among the Government's legislation, policy, and initiatives (101). However, neither the Policy Triangle Model nor this type of analysis considers the diversity of interlocking inequities experienced by different population groups and sub-groups of women and men (96). While the Health Impact Assessments, promoted by the WHO (102), and their subsequent iterations assess the impacts of policy and programmes on health and equity through the perspectives of social determinants of health, this type of analysis fails to address the relations between all these elements (96).

Given the above theoretical strengths and limitations, the intersectional framework and praxis have been adopted as it addresses the relationships between individuals' multiple social categories, power dynamics, the context, issues of equity, in addition to considering the positionality of policy actors and analysing these relationships more comprehensively at different levels (97). For this thesis, the key IBPA principles have been used and adapted to the main issues that were examined and analysed in this research, as illustrated in Figure 1. On the left, we can find the key IBPA principles (96) which are applied to all elements that are important to this research (on the right). The IBPA framework provides a flexible and innovative approach to analysing policy, especially its blind spots, highlighting equity issues, while consciously taking into account the multiple identities of groups, including vulnerable populations of people with disabilities (17, 91). Hence, the IBPA framework was selected to analyse the different contours related to legislation and policy and the use of sexual and reproductive health services by people with disabilities, including the perceptions of five groups of policy actors situated at the micro, meso, and macro levels, rather than frameworks and models more conventionally used to analyse health policy, such as the Linear Model of Grindle and Thomas (103), the Multiple Streams Framework of Kingdon (98), the Policy Triangle Model of Walt and Gilson (100), or the Sex- and Gender-based Analysis framework of the Canadian government (101).

In the subsequent chapters (Results chapters), the different key principles of the IBPA will be highlighted, explained, and analysed.

Figure 1. – Conceptual application of the IBPA principles to this research



2.2 Legislation and policy promoting the rights of people with disabilities

The Convention on the Rights of Persons with Disabilities (CRPD) is considered by many authors and civil society organisations as one of the most important international human rights treaties adopted in the 21st century. It is the first legally binding instrument that officially recognises people with disabilities as human rights holders and not as objects of pity and charity (51, 104, 105). With its adoption, it has brought people with disabilities "out of the darkness" and invisibility to the limelight of legislation and policy formulation (104). The CRPD is thus highlighting a paradigm shift from the medical model of disability, which focuses on people's impairments at an individual level and medical cure or response, to the social model which locates disability in the social environment and as a result of barriers to the participation of people with disabilities: the society is creating disability and has the responsibility to remove barriers (104). Theoretically, the CRPD should compensate for the “historical disadvantages” experienced by people with disabilities (104) and provide guidance for the UN Member States to remove environmental, attitudinal, and structural barriers (106). By ratifying the CRPD, these states acknowledge the 50 articles of the Convention (e.g. article 25 on health and article 31 on statistics) and commit to formulate new laws or amend existing legal tools to reinforce the rights of people with disabilities (51). Thus far, 182 countries have ratified the UNCRPD, including Uganda in 2008 (107).

Studying public policies allows us to better understand the interplay between “agenda-setting, formulation, decision-making, and implementation to evaluation” as well as policy outcomes (108), in addition to the complex relationships among policy content and process, context, and actors (100, 109). Broadly speaking, public policies are understood as actions intentionally taken by a government toward specific goals and addressing specific problems concerning the public (108). Policies encompass three dimensions: 1) the scope, which refers to the range of choices a government takes; 2) the means by which a government implements policy choices; and 3) the distribution aspect, which refers to who benefits from policy (110). According to the WHO, health policy specifically refers to “decisions, plans, and actions that are undertaken to achieve specific health care goals within a society” (111). Health policy analysis is important for equity and distribution of resources such as health in society (10) as well as contributing to addressing wider social justice issues (112). The study of health policy, embedded in a larger body of scholarship on health policy and systems research, considers the roles of policy actors in policy processes over time, the influence of power relations, and global political economy issues (10). Within national settings, policy actors include three main groups: 1) those who “have specific responsibility for developing formal policies in the public or private sectors”; 2) those who influence how policies are implemented, such as healthcare workers and users; and 3) those who “seek to influence the formal policy processes” such as interest groups and civil society organisations at both national and international levels (10).

Literature further reports that examining issues of human rights and public policies in health and SRH plays a crucial role in identifying rights violations, discriminatory measures, and services that are not made available and accessible by the government (113-115). However, important disparities have been reported between the ratification of international legislation and the capacity of governments to concretely identify and measure discrimination at the health system level (115). Specifically, public authorities often do not have the capacity to collect data and conduct equity-based policy analysis through the CRPD and disability angles (45). Moreover, not only is there a need to collect disability disaggregated data (116, 117) at the national level (63) but also at the regional and district levels to adequately inform policy-makers, decision-makers, and service managers alike (118).

2.3 Utilisation of sexual and reproductive health services by people with disabilities

Since the 1994 International Conference on Population and Development (ICPD), the international community officially recognised SRH as a fundamental right which comprises family planning, antenatal, during pregnancy, and postnatal care, prevention and treatment of sterility, safe abortion, management of reproductive tract diseases, prevention and treatment of sexually transmitted infections (STIs), including HIV and AIDS, sexual education and health, and prevention and protection against sexual violence (119). With the UNCRPD global adoption in 2006, SRH has evolved to also take into consideration gender-sensitive markers (13). A study whose objective was to identify correlates of maternal mortality in 82 developing countries found that maternal mortality ratio was inversely correlated with antenatal coverage, skilled birth attendance, access to an improved water source and sanitation and adult literacy rate, and the Gross National Income per capita (120). Access to contraception and safe abortion services was reported to prevent maternal deaths (121), while antenatal care was reported to predict health facility-based delivery and postnatal care (122). Concerning HIV and AIDS, the uptake of HIV testing and counselling was identified to be an important factor contributing to early access to antiretroviral treatment and care (123).

Over the past decades, SRH has improved globally. The world's maternal mortality ratio has decreased from 342 deaths per 100,000 live births in 2000 to 211 in 2017 (18). In 2020, 76% of women of reproductive age (15-49 years old) had their family planning needs met, while 95% of maternal deaths continue to mainly occur in low- and middle-income countries, including in the sub-Saharan countries (8). Over 80% of deliveries were attended by skilled birth workers in the Americas, Europe, and Western Pacific regions, while it was only 59% in the African continent (8). The global HIV incidence has also decreased. However, HIV still affects sub-Saharan Africa the most heavily, where 59% of new HIV infections were registered in women (8). Despite these notable positive changes, the sub-Saharan African region still reports the worst SRH indicators, with the highest average of maternal mortality ratio and HIV prevalence (8), exacerbated in contexts of war and social conflict, afflicting many countries and impacting on the sociodemographic and health development of the region (20). The main determinants and barriers to the access and utilisation of SRH services are associated with women's age (21), education level (21, 30) and marital status (21), as well as the location of residence (20-22) and level of household wealth (20, 21, 23, 124). A consistent disparity along with the rural/urban (20-22) and poor/rich (20, 21, 23) divides has been reported across countries and SRH services. To examine health inequities, most studies have used data from Demographic and Health Surveys (DHS) (20, 23, 122, 125-127).

For each woman who could not get services on time and died during the perinatal period in developing countries, 20-30 other women would undergo disabling complications related to hemorrhage, infection, hypertension, prolonged labour, and obstetrical fistulas (128, 129). Studies examining the access of people with disabilities to various SRH services in sub-Saharan Africa have also found numerous barriers experienced by people with disabilities related to physical and communication accessibility, negative attitudes of health professionals, distance from home to a health facility, and financial costs (130-133). According to the 2018 joint launch of the Guttmacher-Lancet Commission on SRH rights, people with disabilities constitute underserved populations who do not receive adequate information and targeted resources to respond to their different SRH needs and are still subjected to harmful stereotypes and discriminations (134). Very few studies have examined disparities between people with disabilities and non-disabled people in the context of health (135, 136). In one quasi-experimental study conducted in a sub-Saharan African country, no difference in SRH access was reported between women with disabilities and their non-disabled counterparts (137). A systematic review and meta-synthesis on HIV prevalence among adults with disabilities showed that women with disabilities were at heightened risk to HIV compared to people without disabilities and men with disabilities (138). A more recent study conducted in Uganda found that the prevalence of the various forms of intimate partner violence (emotional, physical, and sexual) was higher among women with disabilities compared to non-disabled women (139), suggesting a differentiated experience in SRH related outcomes between populations with and without disabilities.

2.3.1 Preface to meta-synthesis (Manuscript 1)

As described earlier, given the potential intersections among disability, gender, and sexual and reproductive health in sub-Saharan Africa, I was interested to further explore the qualitative literature in regard to these intersections and identify gaps. A meta-synthesis (140, 141) which synthesises qualitative studies was hence conducted for the period between 2001 and 2016. The original manuscript (142) was written and published in French in 2017 to address the hegemonic position of English in scientific publications (143). The initial rationale was to facilitate access to the synthesis of knowledge among French-speaking colleagues interested to learn more about the synthesis of findings. Besides the core manuscript being written in French, the journal requested that the title, abstract, and keywords be written in both French and English for their international readership. For the reporting in this thesis, the title, abstract, and keywords are shared in their original English version. The other core sections of the article, including the figures and tables, are reported in their original French version.

2.3.2 Manuscript 1: Une méta-synthèse sur le genre, le handicap et la santé reproductive en Afrique subsaharienne [A meta-synthesis on gender, disability, and reproductive health in sub-Saharan Africa]

Publication status: This manuscript is open access and published in *Santé Publique* in 2017 (142). Official permission to reproduce it was granted by the journal. The manuscript can be cited as:

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Abstract

Reproductive health remains a major global health issue. People with disabilities face additional discrimination and barriers to access which need to be better understood. To contribute to future interventions, we examined the intersections between gender and disability related to reproductive health in sub-Saharan Africa in qualitative literature.

Methodology: We conducted a meta-synthesis, using a taxonomic analysis. An inductive and iterative approach has been adopted to allow exploration of new and emergent semantic variations in themes. The coding of themes has been supported by NVivo 11 Plus.

Results: Ten qualitative studies from six sub-Saharan African countries have been analysed. Two main thematic areas emerged from the analysis: 1) gendered roles of people with disabilities are programmed by sociocultural normativity, including perceptions about sexuality. They are exacerbated by the hegemony of ableism and influenced by the type of reproductive health issue people with disabilities experience; and 2) experiences of disability in interaction with a reproductive health issue are exacerbated by the type of disability, influenced by the type of barriers in access, and perceived differently depending upon actors involved.

Discussion: The intersections between gender and disability embodied by people with disabilities are multiple and complex. Not only are gendered roles influencing people with disabilities' lives imposed on them, but their experiences of disability are intricately linked to gender. An intersectional analysis is offered as a useful support to developing future perspectives.

Keywords

Meta-synthesis, intersections, gender, disability, reproductive health, sub-Saharan Africa

Introduction

D’après le premier rapport mondial sur le handicap, on estime que 15% de la population mondiale est en situation de handicap, soit un milliard d’individus; parmi les femmes, ce taux est estimé à une femme sur cinq (19.5%) (2). Selon l’Organisation des Nations Unies, le terme personnes handicapées[1] désigne « des personnes qui présentent des incapacités physiques, mentales, intellectuelles ou sensorielles durables dont l’interaction avec diverses barrières peut faire obstacle à leur pleine et effective participation à la société sur la base de l’égalité avec les autres » (3). Ces situations de handicap découlent le plus souvent de complications relatives aux maladies, de conditions de santé chroniques, de problèmes liés à la malnutrition et à la santé des mères et des enfants, d’accidents et de traumas, et du vieillissement. Bien que constituant une population non négligeable, les personnes handicapées sont encore souvent exclues des services sanitaires de base, incluant la santé reproductive, et leurs droits fondamentaux sont régulièrement bafoués (2, 4), tels que de vivre une vie sexuelle, d’établir une famille ou de nourrir des relations intimes, car elles sont souvent perçues comme des êtres dépourvus de sexualité (5).

Près de vingt-cinq ans après la Conférence mondiale sur la population et le développement de 1994, la santé reproductive constitue encore un enjeu de santé mondiale important pour des millions de femmes à travers le globe (6). Celle-ci recouvre la santé et l’éducation sexuelle, la planification familiale, la santé maternelle, les infections sexuellement transmises, le VIH/sida, les violences sexuelles, les cancers associés aux organes reproducteurs ainsi que les soins relatifs à l’avortement (7). Malgré des progrès notables en matière d’utilisation des méthodes contraceptives modernes, le taux de fertilité reste toutefois élevé, notamment dans les pays africains; qui plus est, les relations sexuelles non protégées représenteraient l’une des causes principales d’invalidité ou de décès au sein des communautés pauvres, principalement à cause d’avortements clandestins et de complications liées à la grossesse (6).

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[1] Le terme « personnes handicapées » est un terme internationalement utilisé selon la Convention onusienne relative aux droits des personnes handicapées (CDPH), adoptée en 2008 et ratifiée par plus de 150 pays à ce jour. La CDPH promeut le modèle social du handicap selon lequel le handicap est créé à travers l’interaction entre une personne vivant avec une incapacité et un environnement parsemé de barrières. Dans ce manuscrit, le terme des « personnes handicapées » sera utilisé de façon interchangeable avec le terme des « personnes en situation de handicap ». Celui-ci s’inscrit dans le modèle social du handicap.

Dans les pays à ressources limitées, de nombreux obstacles entravent l'accès aux services de santé reproductive pour les femmes. On compte parmi ceux-ci des barrières relatives à la distance entre les foyers et les structures sanitaires, aux coûts du transport et des services de santé connexes, au bas niveau de qualité des services, aux attitudes négatives du personnel soignant ainsi qu'à des pratiques de prise de décisions familiales et/ou masculines délétères (8, 9). Les dynamiques de vulnérabilité et de discrimination sont complexes, interagissent entre elles, et doivent être envisagées en fonction du contexte dans lequel les populations évoluent (10). On rapporte par ailleurs que les personnes pauvres et vulnérables, faisant face à un fardeau de maladies plus élevé, ont un accès moindre aux services de santé reproductive lorsque comparées aux individus plus favorisés (11). De plus, les conséquences liées à une gestion inadéquate de la santé maternelle et infantile peuvent être lourdes à gérer et entrainer des « souffrances cachées » associées au décès et à un handicap chez les femmes touchées en âge de procréer.

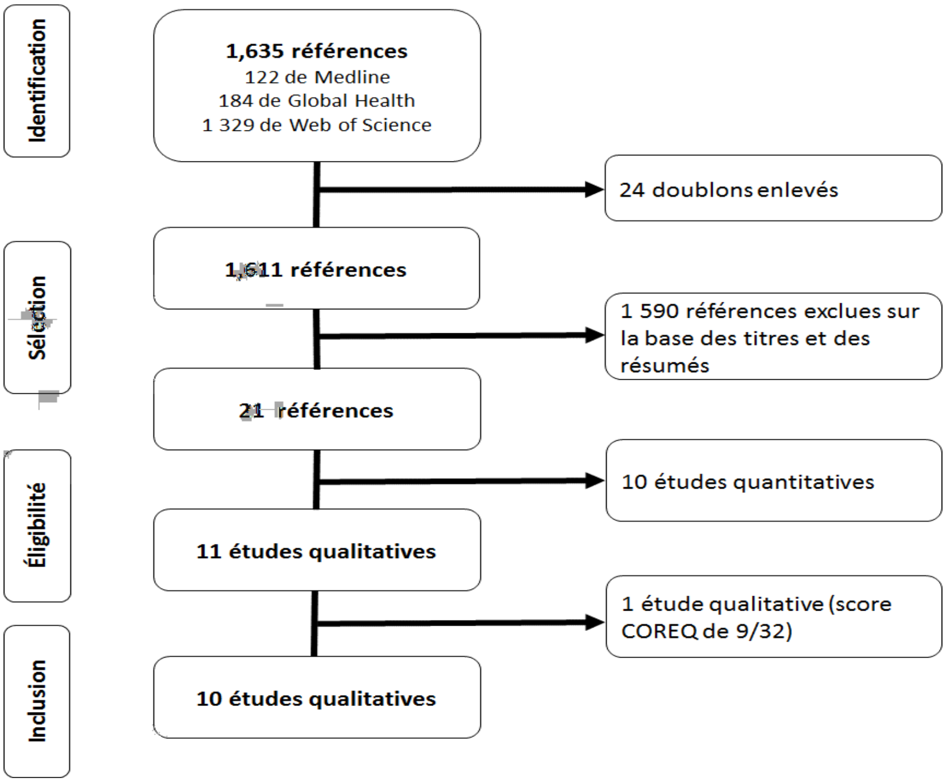
L'approche en termes d'intersectionnalité nous apparaît indispensable, afin de mieux appréhender les questions d'accès et d'équité en santé (10), notamment en santé reproductive. L'intersectionnalité s'appuie sur une analyse de la confluence d'identités multiples et indivisibles (10) telles le genre, défini comme un construit social et associé aux normes culturelles pour les femmes/filles et les hommes/garçons (12) et le handicap, découlant de l'interaction entre les barrières que peuvent vivre les personnes ayant des incapacités et leur environnement (3). Selon les théories critiques relatives au genre et au handicap, l'intersection des différentes réalités et luttes des femmes handicapées sont encore peu discutées (13). On se contente généralement de souligner que les femmes handicapées vivent une double discrimination au vu de leur handicap et le fait d'être femme (14). La réalité s'avère cependant plus complexe. Ainsi, des résultats d'une étude transversale au Sierra Leone ont démontré que les femmes handicapées avaient autant accès aux services de santé maternelle que leurs consœurs non handicapées, contredisant ainsi l'hypothèse qu'elles soient exclues des services de santé reproductive (15). C'est cette complexité des rapports sociaux imbriqués que notre article propose d'explorer.

Cet article s'appuie sur une revue exploratoire (*scoping review*) (16) préalable réalisée pour faire le point sur les connaissances dans la littérature quant au genre et au handicap en matière de santé reproductive en Afrique subsaharienne (17). Au total, 10 études quantitatives et 11 études qualitatives ont été retenues. Le présent article propose une synthèse de ces études qualitatives pour mieux comprendre le phénomène en question, et de développer de nouvelles connaissances à partir de résultats qualitatifs existants (18). La question de recherche qui guide cette méta-synthèse est la suivante : En quoi les recherches qualitatives nous informent-elles sur les intersections entre le genre et le handicap en matière de santé reproductive en Afrique subsaharienne?

Méthodologie

Les études qualitatives qui font l'objet de cette méta-synthèse ont été obtenues à partir des résultats de ladite revue exploratoire, dont la question originale de recherche était : « De la littérature existante, quelles connaissances a-t-on sur le genre et le handicap en matière de santé reproductive en Afrique subsaharienne? ». *Stratégie de recherche :* Une recherche bibliographique avait été réalisée selon les quatre notions-clés de la question de la revue exploratoire, soit : 1) le genre, 2) le handicap, 3) la santé reproductive et 4) l'Afrique subsaharienne. Trois bases bibliographiques, dont *Medline*, *Global Health* et *Web of Science*, avaient permis d'identifier 1 635 références. *Sélection :* Sur 1 611 études (excluant 24 doublons), 21 études avaient été initialement retenues, selon les critères d'inclusion suivants : 1) être issues d'une recherche originale (qualitative, quantitative ou mixte); 2) être une recherche qui incluait les quatre notions-clés des stratégies de recherche, avec la « santé reproductive » comprenant la santé et l'éducation sexuelle, la planification familiale et la contraception, la santé maternelle, le VIH/sida, les infections sexuellement transmises, les violences sexuelles ou l'avortement (7); et 3) être une recherche menée entre 2001 et mai 2016. *Éligibilité :* Sur 21 études, 11 études qualitatives ont été éligibles pour la présente méta-synthèse. *Inclusion :* À partir de celles-ci, 10 études qualitatives sont incluses. La figure 2 illustre le processus, adapté de PRISMA (19) pour la synthèse d'études qualitatives.

Figure 2. – Processus de sélection des études qualitatives adapté à partir de PRISMA



<u>Évaluation des études qualitatives :</u> L'évaluation de la qualité des recherches qualitatives a été réalisée selon la liste de contrôle COREQ[2] (*Consolidated criteria for reporting qualitative research*) de 32 items, avec trois domaines principaux, soit : l'équipe de recherche et la réflexivité, la conception de l'étude et l'analyse et les résultats (20). À ce titre, une étude a été exclue à la suite de l'évaluation selon COREQ, ayant rempli moins du tiers des éléments requis. La qualité de la méta-synthèse, quant à elle, a été évaluée selon la grille ENTREQ[3] (*Enhancing transparency in reporting the synthesis of qualitative research*) (21), de 21 items, divisée en cinq domaines, dont : l'introduction, les méthodes et la méthodologie, la recherche de la littérature et sa sélection, l'évaluation et la synthèse des résultats.

<u>Méthode et analyse :</u> Pour répondre à la présente question de recherche, une méta-synthèse, soit une synthèse de la recherche qualitative sur un phénomène donné (22), est menée. Celle-ci permet d'intégrer les résultats de recherche qualitative de différentes natures. La plupart de ces 10 études qualitatives sont de caractère qualitatif descriptif. Tous les verbatims et les interprétations ont été

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[2] Appendix 1 Lise the contrôle COREQ.

[3] Appendix 2 Liste de contrôle ENTREQ.

extraits électroniquement des articles inclus, et saisis dans le logiciel NVivo11 Plus (par QSR International). L'approche de l'analyse taxonomique a été adoptée, car elle permet de « démontrer l'ampleur conceptuelle des résultats et de permettre d'établir les bases d'un développement de descriptions conceptuelles, de modèles, de théories, ou d'hypothèses en cours » (22) (p.199-200). Elle permet aussi d'identifier ce qui manque quant aux résultats empiriques issus des études qualitatives existantes. L'analyse a été réalisée de façon inductive et itérative en lisant plusieurs fois, ligne par ligne, tous les résultats des études existantes. Une arborescence de nœuds a été générée à partir des résultats et des thématiques existants. Une attention particulière fut portée aux relations émergentes entre les différents nœuds principaux et secondaires, et les interconnexions potentielles les liant entre eux. Une nouvelle variation dans les relations sémantiques a été élaborée de façon progressive, reflétant les nouvelles interprétations des contextes dans lesquels les résultats ont émané (22), et en enrichissant les thématiques-clés existantes.

Résultats

Le tableau 3 résume les caractéristiques principales des 10 études retenues, provenant de l'Ouganda (23), du Cameroun (24), de l'Afrique du Sud (25-27), du Zimbabwe (28), du Ghana (29) et de la Zambie (30-32). La majorité des études concernent des femmes vivant avec un handicap physique, et dans certaines études, les personnes avec des incapacités sensorielles et intellectuelles, ainsi que des personnes handicapées vivant avec le VIH ont aussi été ciblées. Les thématiques existantes issues des études originales (tableau 4, colonne gauche) traitent des barrières d'accès aux services de santé reproductive (23-25, 30), d'une marginalisation et d'une discrimination sociale continue ainsi que d'une stigmatisation liée au handicap (23, 26, 28). Les sentiments des personnes handicapées (24, 26), les réactions de leur entourage et leurs expériences dans les structures sanitaires sont aussi évoqués lorsque leur santé reproductive était remise en question (24, 27, 30, 31). De plus, les personnes handicapées faisant face à des problèmes de santé reproductive devaient renégocier leurs rôles de genre (31, 32), subissaient des abus (26, 29) et devaient s'adapter aux changements ayant des conséquences sur leur sexualité et leur intimité (25, 31). En analysant les articles et les verbatims originaux, deux thématiques principales ont émergé de l'analyse taxonomique (tableau 4, colonne droite) : 1) les rôles genrés[4] des personnes handicapées sont programmés par la normativité socioculturelle, exacerbés par l'hégémonie du capacitisme et modulés par le type de problème de santé reproductive auquel elles font face, et 2) les expériences du handicap et ce, en interaction avec un enjeu de santé reproductive sont exacerbées par le type de handicap, modulées par le type de barrières et perçues différemment par les acteurs concernés.

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[4] Les rôles genrés (*gendered roles*) se réfèrent aux rôles socialement construits et attribués aux femmes/filles et aux hommes/garçons. Selon nous, ces rôles dénotent un processus socialement construit et s'appuie sur la littérature féministe et les études critiques.

Tableau 3. – Information concernant les recherches qualitatives sélectionnées

Auteurs	**Méthodologie**[5]	**Cas sélectionnés**	**Analyse des données**	**Thématiques principales**
Ahumuza et al. 2014 (130)	(Description qualitative)	40 PH physiques (20F) et 10 représentants de PH, d'agences et des personnels de santé	Analyse thématique	▪ Inaccessibilité physique ▪ Longue attente au sein des structures sanitaires ▪ Marginalisation et discrimination sociale des PH physiques
Bremer et al. 2010 (131)	Phénoménologie	8 FH motrices et discussions avec le personnel de santé	Analyse thématique manuelle	▪ Compréhension limitée de la santé reproductive chez les femmes interviewées ▪ Peur autour de la grossesse ▪ Réactions positives et négatives de la famille et de la communauté à l'endroit de leur santé reproductive
Hanass-Hancock et al. 2015 (144)	Description qualitative	19 personnes (10F) vivant avec le VIH et des incapacités, issues d'un hôpital public	Analyse qualitative collaborative (Jackson, 2008) déductive-inductive	▪ Restrictions dans les activités et la participation associées aux normes genrées
Kassah et al. 2014 (145)	(Description qualitative)	5 FH physiques travaillant dans un centre de réadaptation	Analyse thématique	▪ Expériences d'abus social, verbal, physique et sexuel ▪ Stratégies d'adaptation
Mavuso & Maharaj 2015 (132)	(Description qualitative)	16 PH (10F)	Analyse thématique	▪ Attitudes envers la sexualité et la santé sexuelle; différences entre les H et les F ▪ Connaissances, sensibilisation et sources des informations ▪ Expériences négatives au sein des structures sanitaires ▪ Barrières d'accès aux services de santé sexuelle et reproductive

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[5] Même si la méthodologie n'a pas été spécifiée, elle a été néanmoins identifiée dans la mesure du possible et ce, à partir des éléments donnés dans l'article; dans ce cas-ci, elle sera mise entre parenthèses.

Meer & Combrinck 2015 (146)	(Description qualitative)	58 prestataires de services directs et indirects travaillant avec des FH intellectuelles	Analyse thématique	▪ Stigmatisation liée au handicap ▪ Mythes et superstitions culturelles ▪ Stigma et sexualité ▪ Stigma des femmes handicapées intellectuelles qui ne devraient pas être crues ▪ Auto-stigmatisation et auto-image négative
Peta et al. 2015 (147)	Biographie narrative interprétative	Une FH	Analyse narrative de l'histoire d'une femme	▪ Mépris et rejet ▪ Stigma genré relatif à la sexualité et entrainant des conséquences sur la santé ▪ Différences en termes de genre dans les expériences relatives au handicap ▪ Discours culturellement genrés
Smith et al. 2004 (133)	(Description qualitative)	24 FH et 25 prestataires de services de santé maternelle et reproductive	Analyse thématique	▪ Accès physique aux services de maternité et les problèmes de référencement ▪ Croyances et attitudes générant des barrières dans les structures sanitaires ▪ Barrières associées à la pauvreté
Yoshida et al. 2014 (88)	(Description qualitative)	21 PH vivant avec le VIH (12F)	Analyse multi-phase et collaborative	▪ Négocier les significations liées au VIH et au handicap ▪ Espaces d'oppression et de négociation ▪ Le rôle du genre dans la négociation des rôles et des relations
Wickenden et al. 2013 (148)	Qualitative interprétative	12 FH vivant avec le VIH	Analyse thématique collaborative et à deux niveaux	▪ Changements et impacts sur l'intimité ▪ Rupture et renégociation des rôles genrés et de l'identité

Légende : PH : personnes handicapées   FH : femmes handicapées   F : femmes   H : hommes

Tableau 4. – Thématiques des recherches qualitatives existantes et thématiques émergentes de la méta-synthèse

Thématiques des études qualitatives existantes	**Thématiques émergentes de la méta-synthèse**
▪ Barrières d'accès et inaccessibilité des services ▪ Marginalisation et discrimination sociale, et stigmatisation liée au handicap ▪ Sentiments des personnes handicapées ▪ Réactions des familles et de la communauté ▪ Expériences dans les structures sanitaires ▪ Restrictions sociales associées au genre ▪ Renégociations des rôles ▪ Expériences d'abus et d'adaptation ▪ Sexualité et connaissances et attitudes ▪ Changements et impacts sur l'intimité	▪ **Rôles genrés des personnes handicapées** o Programmés par la normativité socioculturelle ▪ Sexualité et attentes sociales ▪ Infantilisation et sur protection o Exacerbés par l'hégémonie du capacitisme ▪ Contrôle de la reproduction – avortement ▪ Stigmatisation et discrimination o Modulés par le type de problème de santé reproductive ▪ VIH/sida ▪ Santé sexuelle/sexualité et éducation ▪ **Expériences du handicap et ce, en interaction avec un enjeu de santé reproductive** o Exacerbées par le type de handicap o Modulées par le type de barrières ▪ Physique et de communication ▪ Financières ▪ Attitudes et formations du personnel de santé o Perçues différemment ▪ De leur part ▪ De la famille ▪ De la communauté

Les rôles genrés des personnes handicapées

Programmés par la normativité socioculturelle

Traversant la plupart des résultats existants, la majorité des personnes handicapées ont exprimé le poids des rôles genrés que leur communauté leur impose, lesquels sont souvent étroitement liés aux perceptions que leur entourage et que la communauté confèrent à leur sexualité. Ces rôles sont souvent programmés par la normativité socioculturelle qui dicte ce que les femmes et les hommes doivent accomplir dans la société, que ce soit dans les sphères publiques et jusque dans les recoins les plus intimes de leur vie. Lorsque les personnes évoluent avec un handicap, celles-ci sont supposées de ne pas être sexuellement actives (23-25), car n'étant pas considérées comme des individus « parfaits » ni normaux (26).

> *Je me sens mal. Ne suis-je pas supposée d'avoir un enfant? Ne suis-je pas une femme?* [6] (Une femme handicapée du Cameroun) (24).

Cette normativité socioculturelle et les perceptions à l'endroit des personnes handicapées, notamment des femmes, entrainent, de ce fait, des attentes biaisées en matière de mariage (28, 29) ou de parenté (23). En effet, la société s'attend à ce que les femmes et les hommes puissent accomplir les rôles qu'on leur confère dans la mesure où ils répondent à des normes sociales majoritairement établies (13). Pour bien des femmes handicapées, le mariage ou le fait d'entretenir des relations intimes semblent être des aspirations difficilement atteignables, dès lors qu'elles vivent avec un handicap et sont dépendantes de leur famille, de leur entourage et de la communauté pour subvenir à leurs besoins (24).

> *J'ai dit à Farai que j'étais enceinte. Il a refusé de me marier. Il m'a dit « Je ne peux pas te marier, tu es handicapée, tu es un lourd fardeau à porter »*. (D'une femme handicapée du Zimbabwe) (28).

Celles qui sont autorisées à se marier par leur famille, le sont pour être prises en charge (24). Les personnes handicapées, en plus d'être écartées la plupart du temps de la possibilité de tisser des

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[6] Traduction libre de tous les verbatims.

relations conjugales comme toute autre personne, sont aussi infantilisées au point d'être surprotégées afin de ne pas entrer en contact avec quiconque (26), de peur qu'elles ne se fassent abuser, ou ne tombent enceintes, s'agissant des jeunes femmes (23).

> *Les filles handicapées sont tellement protégées par leur famille qui suppose qu'elles n'auront aucune relation sexuelle. Elles sont souvent mises à l'écart des discussions sur le sexe ou la reproduction, que ce soit à la maison ou dans la communauté. Ainsi, les personnes handicapées ne reçoivent que des informations [sur la santé sexuelle] qu'une fois que c'est trop tard, et qu'elles arrivent au centre de santé.* (D'un(e) informateur/trice-clé(e) de l'Ouganda) (23).

Exacerbés par l'hégémonie du capacitisme

Non seulement les personnes handicapées sont assujetties à des normes genrées socialement différentes de celles qui ne le sont pas, mais elles subissent aussi l'hégémonie du capacitisme (33) qui prône une discrimination systématique envers les individus qui sont jugés «incapables ». Ce type de préjugé est, d'ailleurs, promu par le modèle médical du handicap qui situe les incapacités au niveau individuel, responsabilisant et culpabilisant ainsi la personne de ses dysfonctions et de ses « erreurs » physiques (34). À cet effet, les sociétés dans lesquelles évoluent les personnes handicapées, du corpus des études incluses, usent de plusieurs stratégies pour contrôler la reproduction des personnes handicapées pour qu'elles ne procréent aucun autre être qui soit « invalide ». Dans ces cas, la stérilisation et l'avortement des femmes handicapées enceintes ont été, ouvertement, proposées à celles-ci, par la famille ou par les professionnels de santé (24, 25).

> *Quand tu vas à la clinique, et tu leur dis que tu es là pour la planification familiale, ils sursautent et disent « Quoi? Elle veut une planification familiale! Est-ce qu'elle a un homme? ». Vous voyez, c'est ça le problème. Ils sont choqués. Ils vous demandent « Pourquoi ne vous faites-vous pas stériliser? ». Nous ne sommes pas encouragées à utiliser d'autres méthodes.* (D'une femme handicapée de l'Afrique du sud) (25).

Ces situations ne sont pas uniques, car elles sont aussi accompagnées de discriminations constantes que vivent au quotidien les femmes et les hommes handicapés. Régulièrement, ces derniers subissent la honte (24), le rejet (25) ou l'abandon (31), du simple fait de vivre avec un handicap. Certaines femmes handicapées relatent leurs parcours de vie semés de stigmatisation, souvent perpétrée par leurs propres proches et parents.

> *La discrimination contre les personnes handicapées commence dès l'enfance… Les filles handicapées sont souvent rejetées par leurs pères et sont laissées aux soins de leurs mères et de leurs grands-mères.* (D'une femme handicapée du Ghana) (29).

Les hommes handicapés, quant à eux, ne sont malheureusement pas épargnés des commentaires discriminants, par exemple, de la part du personnel de santé.

> *Une fois, j'ai essayé de recevoir des informations sur la santé sexuelle et reproductive, mais l'infirmière m'a dit que c'était inutile à cause de ma condition [en étant un homme handicapé], selon elle, les chances que je rende une femme enceinte sont très limitées.* (D'un homme handicapé de l'Ouganda) (23).

Modulés par le type de problème de santé reproductive

Les rôles des femmes et des hommes handicapés s'inscrivent dans une trame complexe, entre l'articulation des différentes expériences du handicap et les problèmes de santé reproductive avec lesquels ils vivent. À cet égard, les femmes handicapées paient le lourd fardeau d'être handicapées et malades, alors que leurs homologues masculins semblent, socialement, mieux s'en tirer (26, 27, 29). Par exemple, lorsque les femmes séropositives en situation de handicap tombent malades, il est fréquent que leurs conjoints les abandonnent et les laissent seules en charge des enfants et des dépenses familiales. À l'inverse, les hommes handicapés vivant avec le VIH sont soignés par leurs femmes et soutenus par la famille (27).

> *Quant à la famille, j'avais un mari. Alors mon mari, il voyait bien que je tombais malade, il a donc décidé de me quitter et d'aller dans sa famille… Je me suis faite testée [du VIH], je lui ai dit « Écoute, ils m'ont trouvé avec la maladie », et il a dit « Je ne peux pas m'occuper d'une femme*

> *qui est malade, alors c'est mieux que je parte et que je cherche d'autres femmes qui sont pas malades. Reste avec tes maladies ».* (D'une femme handicapée de l'Afrique du sud) (27).
>
> *Contrairement à Thandi et Judy [deux femmes handicapées vivant avec le VIH], Dixon [un homme handicapé vivant avec le VIH], décrivait comment il pouvait compter sur les soins de sa femme. Dixon disait que la déclaration de son statut était « facile », sa famille l'acceptant et le soutenant de plusieurs manières, y compris en lui rappelant à chaque jour de prendre ses médicaments. Il pense que dévoiler sa séropositivité fut plus simple car il était déjà handicapé.* (Des résultats d'une étude menée en Afrique du Sud) (32).

Ainsi, les femmes handicapées subissent un traitement différencié face à un problème de santé reproductive. Mais elles font aussi face à divers types de violences, notamment des abus sexuels, physiques et verbaux de la part des membres de leur famille rapprochée (24, 26, 28, 29).

> *Une fois j'ai dit à ma mère que j'étais violée, et ma mère ne m'a pas crue. Elle m'a dit « Qui te violerait? ». Je suis restée avec cette blessure, avec cette douleur. Vous savez avec cette blessure saignante, et personne ne vous croit.* (D'une femme handicapée de l'Afrique du Sud) (25).

À la lumière des différentes facettes des principaux rôles genrés, force est de constater que les attentes sociales peuvent être préjudiciables envers les personnes handicapées, particulièrement lorsque ces dernières sont des femmes et ont peu, voire aucune information concernant leur santé reproductive et sexuelle. Pour plusieurs, la seule croyance qu'elles soient asexuelles est assez puissante pour que les personnes handicapées soient complètement exclues de sessions d'éducation sur la santé sexuelle, ou d'information de base sur la santé reproductive (24).

Les expériences du handicap en interaction avec un enjeu de santé reproductive

Exacerbées par le type de handicap

Parmi les femmes handicapées, certaines sont davantage marginalisées de par leur type de handicap. Par exemple, les femmes avec un handicap intellectuel sont souvent perçues comme « incapables »,

« soumises », « silencieuses » et « invisibles », les rendant de « parfaites victimes » aux yeux des abuseurs en quête de « proies faciles » (26). Qui plus est, leur crédibilité est mise à mal lorsqu'elles dénoncent des cas d'abus, sous prétexte qu'elles manifestent des comportements « sexuellement inappropriés » et des propos « inconstants », qui contribuent à les discréditer (26). Celles-ci sont souvent perçues, à leur insu, comme des êtres hypersexués, de par leurs comportements désinhibés et par le manque d'éducation sexuelle prodiguée à leur égard.

> *Elles sont là, et vous disent que quelque chose s'est passé – il se peut que rien ne s'est passé ce jour-là, il se peut que ça soit pas cet abuseur, mais quelque chose s'est passé. Quelque chose de profondément violent et de personnel.* (D'une participante de l'Afrique du Sud) (26).

Modulées par le type de barrières

Outre la violence et les abus vécus et subis, les personnes handicapées sont aux prises avec diverses barrières d'ordre physique, communicationnel, financier et avec des attitudes négatives de la part du personnel de santé (23-25). Ces obstacles auxquels elles font face modulent leur expérience du handicap, que ce soit négativement, ce qui est le plus fréquent, ou positivement, dans certaines situations, par exemple par l'entremise du soutien « émotionnel, psychologique, physique et financier » de la part de leur entourage (24). Au niveau physique, les témoignages sont nombreux. Les personnes handicapées ont un accès difficile (23-25), voire limité aux services de santé reproductive de base, remettant ainsi en question leur dignité humaine.

> *Ils [les centres de santé] sont très mauvais. Les civières sont très hautes. Ça prend du temps pour monter sur la civière et en plus l'infirmière vous gronde. Elle vous gronde et vous dit « Dépêchez-vous! » […] Rien n'a été conçu pour une personne handicapée.* (D'une femme handicapée de l'Afrique du Sud) (25).

Concernant les barrières communicationnelles, les messages de prévention en matière de santé reproductive ne sont pas toujours adéquatement diffusés (25). Au plan des barrières financières, malgré le fait que les services de santé de base dans plusieurs pays devraient être gratuits, les personnes voulant en recevoir doivent souvent financer leurs soins (23), payer les frais de transport pour s’y rendre (23), accoucher à la maison si elles ne peuvent payer (30), ou avoir recours à des services de santé privés pour éviter les mauvais traitements du personnel de santé en structure publique (25). Dans ce contexte, les mauvaises attitudes des professionnels de santé et leur manque de formation pour prodiguer des soins adéquats et de qualité à l’endroit des personnes handicapées ont été déplorés dans les études (23, 25). Les personnes handicapées pensent même que si le personnel de santé était mieux préparé au niveau professionnel, ceci faciliterait leurs contacts et les soins qu’elles reçoivent (23, 24). Les situations restent relativement hétérogènes.

> *Dans mon cas, quand je suis allée à la clinique anténatale et que j’étais enceinte, le personnel de santé ont dit « Même vous, dans cet état, vous couchez avec des hommes, et en plus vous acceptez d’être enceinte? ».* (D’une femme handicapée de l’Ouganda) (23).

> *Pour me rendre à l’aise, quand je suis allée à la clinique [anténatale], elles [les infirmières] m’ont servie d’abord, avant les autres personnes pour que je puisse rentrer à la maison et me reposer.* (D’une femme handicapée du Cameroun) (24).

Perçues différemment par les acteurs

Pour pallier ces difficultés, les réactions des personnes handicapées, des familles et de la communauté diffèrent. Face à la marginalisation sociale causée par le handicap, les personnes handicapées ont recours à des stratégies d’acceptation pour composer avec leur situation (32). Pour les femmes handicapées qui ont subi des abus, une gamme de stratagèmes ont été adoptés tels l’évitement, la reconstruction de la confiance en soi, la confrontation, les échanges de sympathie parmi celles qui ont survécu à la violence, et la demande d’aide (26). Quant à la famille et à la communauté, les réactions sont contrastées, à la fois empathiques et aidantes (27, 31), mais aussi empreintes de mépris et de rejet (29, 31).

> *La plupart des femmes [handicapées] vivent l’ostracisme de quelques membres de la famille ou au sein de leur communauté. Mais, il existe des exemples de soutien des membres de la communauté et de la famille : « Quand je dis que je suis malade, ils [la famille] accourent pour prendre soin de moi. Oui. Quand que je dis « Ah, je ne me sens pas bien », « Quel est le problème? », rapidement, ils prennent soin de moi ».* (D’une participante de la Zambie) (31).

> *J'ai dit à ma mère que j'étais enceinte seulement à six mois. J'avais peur qu'ils me battent et me jettent dehors.* (D'une femme handicapée du Cameroun) (24).

Discussion

Cette méta-synthèse nous a permis de faire émerger les relations entre les différentes thématiques existantes ainsi que deux nouvelles thématiques à l'intersection entre le genre et le handicap en matière de santé reproductive en Afrique subsaharienne. Si les rôles des personnes handicapées sont programmés par des normes sociales genrées, les situations de handicap sont vécus différemment par les femmes et les hommes et ce, dans le contexte parfois compliqué de la santé reproductive dans divers pays de l'Afrique subsaharienne. Le phénomène n'est ainsi ni mono-axe ni homogène, mais entrelacé de plusieurs phénomènes sous-jacents s'ajustant les uns aux autres, comme l'illustrent les sous-thématiques émergeant de la nouvelle interprétation des résultats provenant des études initiales.

Tout d'abord, les données des études originales ainsi que les nouvelles thématiques contredisent les croyances selon lesquelles les personnes handicapées ne sont pas sexuellement actives et ne sont pas concernées par la santé reproductive (25, 31). Au contraire, bien qu'elles soient confrontées à de multiples obstacles physiques et sociétaux, elles vivent bel et bien une sexualité (28, 31), et doivent aussi composer avec des problèmes de santé reproductive, requérant une attention particulière du personnel de santé (25) ainsi que de recevoir une éducation sur la santé sexuelle et reproductive (23-25), au même titre que toute autre personne. À cet égard, le manque de formation des professionnels de santé sur la santé sexuelle et reproductive des personnes handicapées exacerbent la marginalisation de ces dernières, en ne les incluant pas dans la prestation des services ordinaires (23, 25, 26).

Comme les études critiques sur le handicap le soulignent, la place hégémonique que prend le capacitisme, selon le modèle médical (33, 34), est encore très ancrée dans diverses sociétés africaines et au sein du corps médical où la normativité sociale des individus « valides » prime avant tout (28). Les rôles sociaux culturellement établis indiquent la marche à suivre ou à proscrire pour les femmes et les hommes (27). Lorsque ces derniers ne cadrent pas avec ces normes, ils sont exclus ou mis sous tutelle par différentes stratégies, surtout quand leurs fonctions reproductrices sont en jeu (4). Les femmes handicapées vivent davantage de marginalisation quand elles font face à un problème de santé reproductive; et même lorsqu'elles sont en bonne santé, elles sont écartées du mariage, de la parenté ou de l'idée d'avoir des relations affectives (4). Souvent, elles ne sont pas impliquées dans l'éducation relative à la santé sexuelle (25), et l'apprennent à leur dépend, une fois rendues au centre de santé (23). Une recension des écrits sur le VIH et le handicap, menée en Afrique australe, rapporte un manque d'éducation sexuelle, un niveau de vulnérabilité élevé à l'abus sexuel du fait d'être dépendant des autres pour des soins quotidiens, et un accès difficile aux soins de santé causé par des barrières physiques et d'attitudes à l'endroit des personnes handicapées (35).

Dans cet article, une analyse intersectionnelle est adoptée pour mieux appréhender les interactions entre le genre et le handicap, selon laquelle les systèmes de domination et d'oppressions sont examinés (10). Force est de constater, à partir des résultats existants, que les personnes handicapées vivent de l'abus et de la violence à répétition de la part de leur entourage et de la société (26, 29). À cet effet, des études montrent, ailleurs dans le monde, que les femmes handicapées subissent davantage d'abus que leurs consœurs non handicapées (36). Une revue systématique et une méta-analyse d'études observationnelles ont montré que les personnes handicapées subissent plus de violence que les personnes non handicapées; et celles vivant avec un handicap intellectuel ou mental seraient davantage victimes d'abus divers (37). Quant aux hommes selon les résultats existants, loin d'être épargnés, ceux-ci semblent, par contre, subir, dans une moindre mesure, les dictats sociaux associés au genre et au handicap (32).

Limites méthodologiques

À partir de la recherche qualitative, l'objectif principal de cette méta-synthèse était d'intégrer les connaissances existantes quant aux intersections entre le genre et le handicap en matière de santé reproductive en Afrique subsaharienne. L'une des principales limites réside dans la restriction des bases de données bibliographiques initialement utilisées, ainsi que l'utilisation unique de la langue anglaise dans les stratégies de recherche. En effet, cette approche a pu restreindre la découverte de l'ampleur de la richesse des expériences vécues par les personnes handicapées provenant d'autres régions d'Afrique subsaharienne, par exemple des pays francophones et lusophones où l'histoire et le contexte socio-culturel diffèrent. Selon l'analyse intersectionnelle, une meilleure compréhension de cette diversité est essentielle, pour saisir les inégalités sociales et les relations de pouvoirs et ce, dans un contexte social donné (10). La qualité de la méta-synthèse et des études qualitatives a cependant été validée, respectivement, par les listes de contrôle ENTREQ et COREQ.

Conclusion : Réduire les angles morts dans la recherche et la pratique, entendre les silences, et combler les lacunes

À la lumière des thématiques émergentes quant aux rôles genrés des personnes handicapées et leurs expériences du handicap en interaction avec un enjeu de santé reproductive, la question des droits sexuels et reproductifs des personnes handicapées fait figure de grande absente. La plupart des pays en Afrique subsaharienne ont ratifié la Convention relative aux droits des personnes handicapées, entrée en vigueur en 2008 (38). Ceci souligne, d'une part, l'absence de sensibilisation des personnes handicapées quant à l'exercice de leurs propres droits, et d'autre part, le manque de reddition de comptes des autorités publiques et des prestataires de services à l'égard de leurs concitoyens handicapés (23, 39). Par ailleurs, le manque d'information chez les personnes handicapées et de mise en œuvre des politiques chez les décideurs et les praticiens pourrait accentuer les problèmes de santé sexuelle et reproductive chez ces dernières, de sorte qu'elles se retrouvent dans des spirales de marginalisation, de production du handicap, voire d'exclusion sociale (40). À cet effet, les études existantes fournissent peu de données quant aux impacts en santé reproductive que subissent les personnes handicapées du fait d'être structurellement abusées, et à leur participation sociale au sein de la communauté.

Concernant les personnes handicapées impliquées, peu de données proviennent des hommes et des jeunes hommes quant à leurs perceptions de leurs rôles dans la société et de leurs expériences du handicap. Si les témoignages des femmes handicapées provenant des différents pays anglophones d'Afrique subsaharienne sont riches, les récits des hommes sont rares (23). Loin d'être homogènes, les contextes des personnes vivant avec différents types de handicap sont nombreux. Plus de confrontation des visions genrées des femmes et des hommes handicapés, vieux et jeunes, permettrait aussi une meilleure interprétation de la complexité que les sous-groupes de population handicapée peuvent vivre (10). À cet effet, l'utilisation de la perspective théorique et de la praxis intersectionnelle (10) ajouterait à la compréhension des différents contours des oppressions multiples que vivent les personnes handicapées, et des aspirations vers lesquelles elles souhaitent tendre. Cette méta-synthèse nous offre néanmoins des nouvelles informations importantes concernant les intersections plurielles et complexes du genre et du handicap, animant les personnes handicapées en matière de santé reproductive en Afrique subsaharienne. Ce phénomène fut longtemps négligé en santé publique mondiale (39). Les résultats de cette étude ont le potentiel non seulement de contribuer à réduire les angles morts quant à la prestation de services en santé reproductive et d'accès pour une population vulnérable, mais de contribuer aussi à des interventions en santé publique qui tiennent compte des réalités et des perceptions des populations handicapées vivant dans les pays subsahariens d'Afrique.

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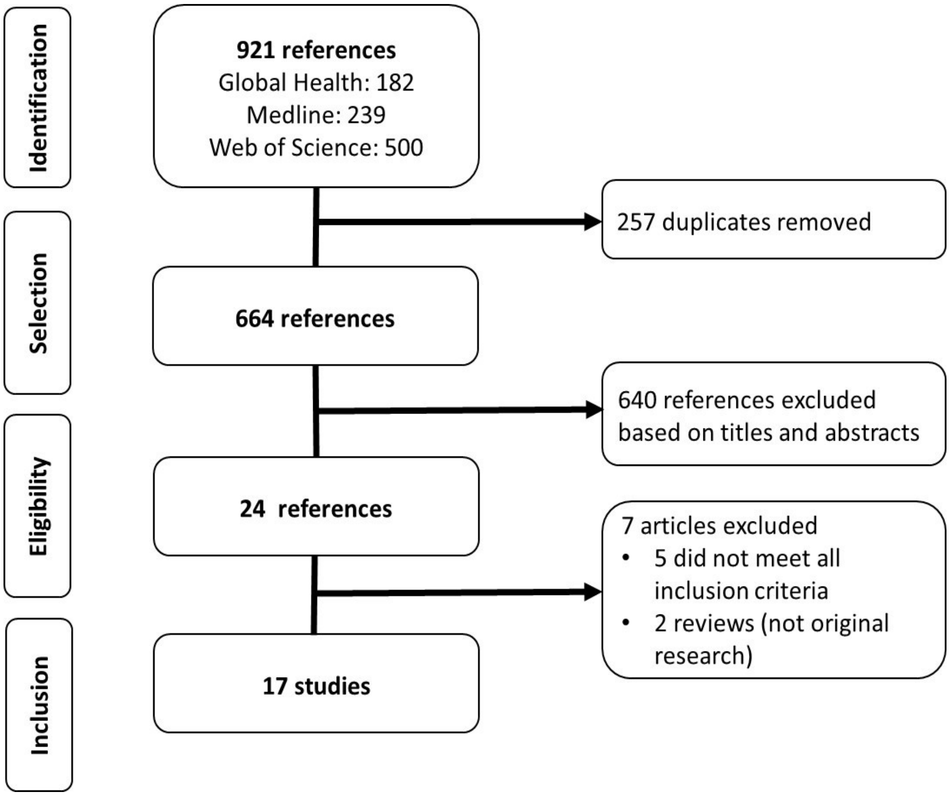
2.3.2.1. Meta-synthesis update (2016-May 2021)

An update of the meta-synthesis published in December 2017 (142) was conducted for the period between 2016 and May 2021, using the same three bibliographic databases: Global Health, Medline, and Web of Science. The 2017 meta-synthesis covered the period between 2001 and May 2016 and included 10 original qualitative studies which simultaneously addressed four main concepts of interest: 1) gender, 2) disability, 3) reproductive health, and 4) countries in sub-Saharan Africa. Studies included in the published meta-synthesis were conducted in six countries: Cameroon, Ghana, South Africa, Uganda, Zambia, and Zimbabwe. Two main thematic areas emerged from the taxonomic analysis (140). First, gendered roles of people with disabilities were strongly shaped by sociocultural normativity, including perceptions about sexuality. They were exacerbated by the hegemony of ableism and influenced by the type of reproductive health issue people with disabilities experience. Second, the experiences of disability in interaction with a reproductive health issue were exacerbated by the type of impairment, influenced by the type of barriers in access, and perceived differently depending upon the actors involved (people with disabilities, their family, and the community) (142). Two major gaps were identified in the included studies. The first gap pertained to the limited information available concerning men and young people with disabilities in the context of sexual and reproductive health. The lack of discussion on the SRH rights of people with disabilities was the second gap highlighted to be further addressed in subsequent research (142).

The update conducted in May 2021 yielded an additional set of 17 original qualitative studies from 664 references selected for title and abstract review out of 921 citations resulting from the keyword search (Figure 3). One of the 17 identified primary studies is a manuscript, included in this dissertation, on the intersections of gender, disability, and sexual and reproductive health (SRH) (149). Out of the two reviews identified but excluded from this update of primary literature, one was our published meta-synthesis presented in the previous section (142). The second review highlighted stigma, discrimination and the multiple vulnerabilities such as sexual and gender-based violence women with communication disabilities experienced in humanitarian contexts (150). Both reviews corroborate the conclusion that the intersection of gender and disability created additional challenges and SRH rights violation faced by women with disabilities (6, 151). Table 5 summarises the main characteristics of the studies included in the update. They were conducted in nine sub-Saharan countries: Ghana, Nigeria, Rwanda, Senegal, South Africa, Tanzania, Uganda, Zambia, Zimbabwe. Two main findings are briefly discussed here. First, the major themes which emerged from the initial taxonomic analysis still apply to the new set of studies included, with more examples of how traditionally conceived gendered roles are exacerbated by pervasive ableist attitudes (149, 152-160) and how the experiences of disability continue to be influenced by the type of disabilities and barriers in various sub-Saharan African countries (149, 152, 154, 156, 161-163).

Figure 3. – Flow chart of the meta-synthesis update (2016-May 2021)



Second, the gaps and blind spots which were identified from the initial meta-synthesis have begun to be addressed by some of the included studies. The perspectives of men with disabilities on their SRH were sought and reported in six out of 17 (35%) studies (149, 152, 155, 157, 164-166). Similarly to their female counterparts, men with disabilities are also subjected to ableist gendered norms such as performative masculinity related to sexuality: “[When] I started the Lavitra [a medication for erectile dysfunction]… it worked for me… Then I felt like, okay, I’m back to normal now cause it’s working now for me.” (A man with disabilities, South Africa) (155). Two out of 17 (12%) studies specifically examined the SRH realities of youth with disabilities (162, 165). In sub-Saharan Africa, both adolescents without disabilities, especially young women and girls (167) and those with disabilities are expected to abstain from sex. However, we found that both young women and men with disabilities not only have the desire for intimate relationships but are also discriminated against due to their age, adding another layer of complexity to the intersection of gender and disability they already experience (165). Finally, only two (12%) other studies out of the 17 adopted a rights-based framework and addressed the SRH rights of women (156) and people (149) with disabilities by explicitly referring to the UN Convention of the Rights of Persons with Disabilities and the rights of people with disabilities to SRH and to have children. Two seminal reports published in 2018 and not included in this formal meta-synthesis update underline the importance of explicit attention to rights. According to the 2018 United Nations’ Flagship on Disability and Development Report, the exercise of SRH rights by people with disabilities continues to be limited and their access to SRH services such as skilled birth attendants and family planning are lower than that of non-disabled women (168). The joint Guttmacher-Lancet Commission on SRH rights recommends that additional support should be provided to groups that are marginalised, disadvantaged, and subject to discrimination, such as people with disabilities, to improve health equity and access to services (134).

In conclusion, an updated review of literature published between 2016 and 2021 found a large number of publications with relevant keywords but a small number of original studies addressing the intersection of gender, disability, and sexual and reproductive health in sub-Saharan Africa. Among included studies, there was some progress in the inclusion of men and youth with disabilities although there was minimal progress on highlighting the SRH rights of people with disabilities. The key challenges, obstacles, and biases that were identified in the meta-synthesis covering qualitative research published between 2001 and 2016 remain relevant.

Tableau 5. – Characteristics of studies in meta-synthesis update (2016-May 2021)

Authors & country	**Methodology**	**Population**	**Type of analysis**	**Main themes**
Apolot et al. (2019) (161) Uganda	Qualitative descriptive	4 women with walking disabilities	Thematic analysis	▪ Family support and acceptance ▪ Communities’ acceptance ▪ Difficulty finding transport ▪ Physical accessibility barriers
Burke et al. (2017) (152) Senegal	Qualitative peer-to-peer	27 WWD and 23 MWD in interviews 61 WWD and 67 MWD in focus groups	Thematic analysis	▪ SRH needs and vulnerabilities of YWD ▪ Norms around sexuality and the use of contraception ▪ Sexual violence ▪ Barriers to access SRH information and services for YWD
Ganle et al. (2016) (154) Ghana	Qualitative descriptive	72 WWD	Attride-Stirling thematic network analysis framework	▪ The desire for children and experiences with pregnancy and childbirth ▪ Challenges to maternal healthcare access ▪ Unfriendly healthcare infrastructure ▪ Healthcare providers’ insensibility and lack of knowledge
Ganle et al. (2020) (153) Ghana	Qualitative descriptive	77 WWD	Thematic content analysis	▪ Desire for children ▪ Motivations for childbearing ▪ The joy of motherhood ▪ Challenging stigma and negative stereotypes ▪ Children as social security
Hunt et al. (2018) (155) South Africa	Sequential mixed qualitative methodology	13 PWD (8 women and 5 men)	Thematic analysis	▪ Difficulties having satisfying sex ▪ The need to satisfy a lover ▪ Finding sexual mutuality ▪ Sexual self-esteem
Mac-Seing et al. (2020) (149) Uganda	Multiple case studies	17 WWD and 15 MWD in interviews	Thematic analysis informed by the intersectionality-	▪ Multiple intersections (disability, gender, violence, and HIV/STIs) when using SRH services

		6 WWD and 6 MWD in focus groups	based policy analysis framework	▪ Experiences of discrimination and accessibility barriers ▪ Expectations to exercise rights despite policy implementation challenges ▪ Multiple concrete solutions and recommendations proposed
Mesiaislehto et al. (2021) (162) Tanzania	Empathy-based stories	136 female YWD	Thematic analysis following the Levesque Model of Healthcare Access	▪ Supportive networks and access ▪ Social acceptability of service users ▪ Interpersonal characteristics of service providers ▪ Violence within and outside of health facilities
Owojuyigbe et al. (2017) Nigeria	Descriptive cross-sectional	12 women disabled from FGM and 10 male partners	Thematic analysis	▪ Coping among FGM (as sexual disability) victims ▪ Coping among spouses of FGM victims
Peta (2017) (169) Zimbabwe	Biographic narrative interpretative methods	16 WWD	Narrative analysis	▪ Sexual coercion and rape ▪ Physical abuse ▪ Risk of acquiring HIV
Peta (2017) (156) Zimbabwe	Biographic narrative interpretative methods	16 WWD	Narrative analysis	▪ Accessibility barriers such as communication for deaf women ▪ Sexual abuse ▪ Not viewed as “normal” ▪ Childbearing aspirations
Rugoho (2020) (165) Zimbabwe	Qualitative descriptive	20 YWD (9 women and 11 men)	Thematic analysis	▪ Experiences during childhood in the family, at school, and using SRH services ▪ Becoming sexuality active ▪ Getting married ▪ Becoming a parent
Stern et al. (2019) (157)	Qualitative descriptive	31 PWD (16 women and 15 men)	Thematic inductive analysis	▪ Gendered disability stigma and discrimination ▪ Exclusion and isolation

Ghana, Rwanda, South Africa (and Tajikistan)				▪ Intersections of disability, gender, and violence ▪ Barriers to inclusion in intimate partner violence ▪ Benefits of participation in intimate partner violence programming
Thurston et al. (2020) (166) South Africa	Qualitative descriptive	10 PWD (8 women and 2 men)	Thematic content analysis	▪ Psychological consequences after injury-causing paraplegia ▪ Perceived lack of support systems ▪ Disabled by society ▪ Moving towards meaningful relationships
Tun et al. (2016) (163) Ghana, Uganda, and Zambia	Qualitative descriptive	76 PWD (41 women and 35 men)	Framework analysis	▪ Barriers to HIV testing and services ▪ Facility-level barriers ▪ Economic barriers ▪ Stigma related to HIV and disabilities ▪ Access to services by sex (perceived harder for WWD)
Van der Heijden et al. (2018) (159) South Africa	Qualitative descriptive	30 women with physical impairments	Descriptive narrative analysis	▪ Limited opportunities to meet potential sexual partners ▪ Restricted sexual contact 'dating in the dark' ▪ Not being a 'proper wife' ▪ Unattainable motherhood ▪ Positive examples
Van der Heijden et al. (2019) (158) South Africa	Qualitative descriptive	30 women with physical impairments	Thematic inductive analysis	▪ Neglect and deprivation from schooltime to adulthood ▪ Psychological violence in a lifetime and disability-related stigma ▪ Financial abuse (dependence upon others) ▪ Physical violence ▪ Sexual violence
Van der Heijden et al. (2019) (160)	Qualitative descriptive	30 women with physical	Thematic analysis	▪ Disability-related factors (functional barriers)

South Africa		impairments and 19 GBV service providers		▪ Disability-related stigma ▪ Dependency ▪ Personal factors

Legend

GBV	Gender-Based violence
FGM	Female Genital Mutilation
MWD	Men With Disabilities (of different impairments)
SRH	Sexual and Reproductive Health
YWD	Youth With Disabilities (of different impairments)
WWD	Women With Disabilities (of different impairments)

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2.4 Limits in the current knowledge

The literature has demonstrated that SRH still constitutes a global health issue (170, 171). To date, studies have mostly focused on health and SRH use disparities among non-disabled populations (20-23), but less on learning from vulnerable populations such as people with disabilities (135, 137) who are mostly living in developing countries (4). The findings of our meta-synthesis of qualitative studies, including those of the update, further showed that when questions of SRH service access and use among people with disabilities in sub-Saharan Africa were examined, men and youth with disabilities were less consulted when compared to women with disabilities and evidence on the perceptions of people with disabilities of the impacts of health policy on their exercise of the right to health remains limited (142). The literature further indicates the importance of studying legislation and policy in the context of health equity analysis (34, 172-176) and health rights (11). The lack of information on the relationships among legislation, health policy, and the utilisation of SRH services by people with disabilities in sub-Saharan Africa is a major gap in the literature, in particular in post-conflict contexts, where access and utilisation of services are jeopardised and the capacity of the healthcare system to provide services is compromised (33, 177). Studying these relationships in Uganda – including its post-conflict northern region – represents an opportunity to enhance the understanding of disability legislation and policy implementation, and to improve SRH service delivery to and utilisation by one of its most invisible marginalised and vulnerable populations. Uganda is the only country in the sub-Saharan African region to have three waves of Demographic and Health Surveys with the inclusion of information on disability. Yet, these data have not been capitalised to examine health service utilisation inequities between women and men with and without disabilities over time. This doctoral thesis hence examined the relationships among legislation, health policy, and the utilisation of SRH service by people with disabilities in post-conflict northern region of Uganda.

Chapter 3 – Methods

This chapter provides an overview of the methods used to address the study's research objectives. The empirical manuscripts provide further methodological details.

Overall objective:

- To examine the relationships among legislation, health policy, and the utilisation of SRH services by people with disabilities in the post-conflict Northern region of Uganda, between 2006 and 2019.

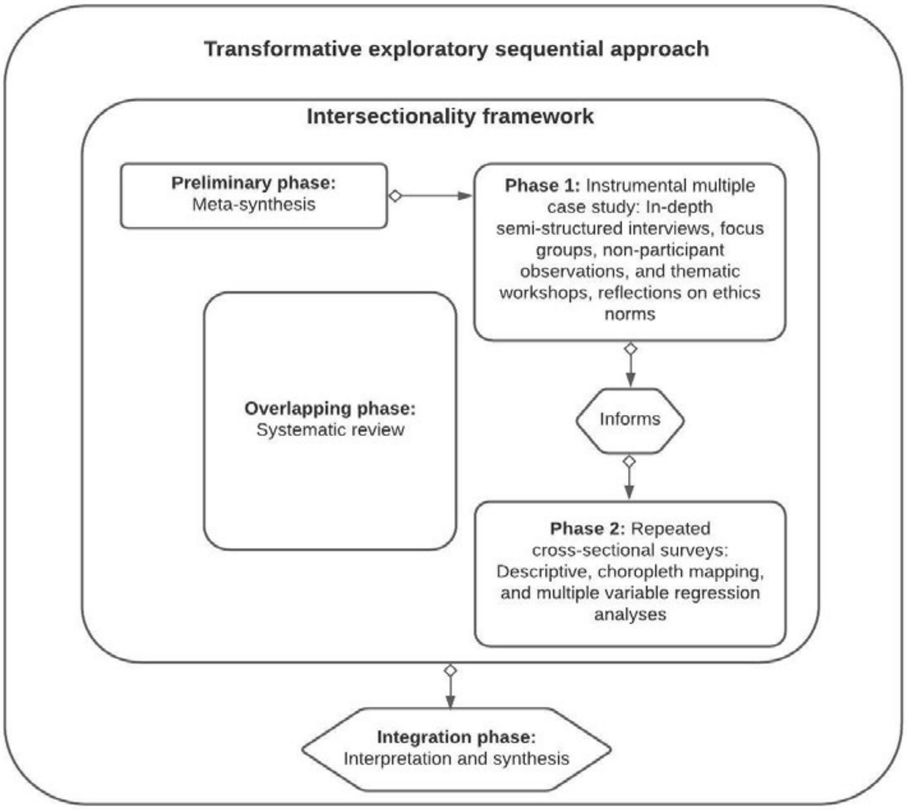
Specific objectives:

1. To examine how five key groups of policy actors – people with disabilities, health service providers, disabled people's organisations, national and international organisations, and national policy-makers — perceived the relationships among legislation, health policy, and the utilisation of SRH services by people with disabilities in the post-conflict Northern region of Uganda.
2. To examine how disability was associated with selected SRH service utilisation in Uganda between 2006 (year of Uganda's adoption of the Disability Act) and 2016.
3. To systematically review the existing body of evidence on pro-equity legislation, health policy, and the utilisation of SRH services by vulnerable populations in sub-Saharan Africa from 1994 to 2019.

3.1 Overall research design

To achieve these objectives, I adopted a transformative exploratory sequential mixed methods research design (178) (Figure 3), where the transformative nature of the design refers to the use of the intersectionality framework for critical analysis of evidence. In an exploratory sequential approach, a qualitative study (Phase 1, Objective 1), explores key research information and informs a subsequent quantitative study (Phase 2, Objective 2) (178). For pragmatic reasons, the implementation, analysis, and synthesis of the systematic review (Objective 3) overlapped the period of implementation of both the qualitative and quantitative phases (178).

Figure 4. – Visual model of the mixed methods research design



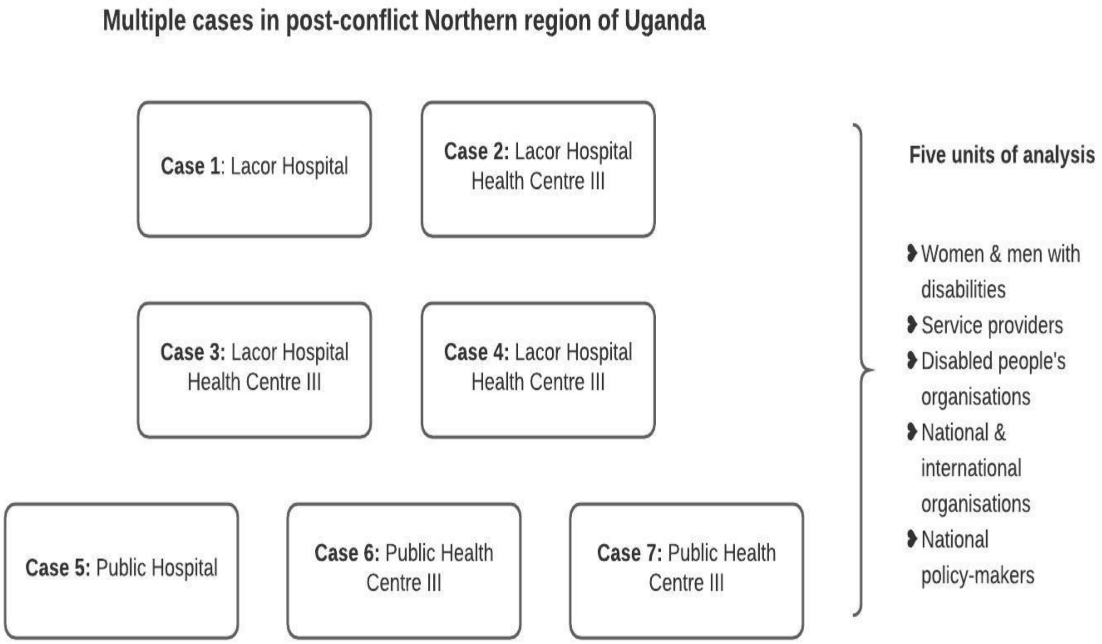
A mixed methods design is defined as “an intellectual and practical synthesis based on qualitative and quantitative research” (179) (p.129). It rejects the traditional scientific dualism of positivism and constructivism and maximises the intrinsic strengths of quantitative and qualitative research (179). This type of research further allows answering complex questions that could not be addressed by only one type of research paradigm (180, 181) and is also conducted for triangulation purposes of both qualitative and quantitative findings (182). With this design, the study qualitative findings provided depth and insight into the selection of quantitative variables, while the quantitative results enlightened qualitative perceptions from the study's five groups of policy actors (178).

3.2 Objective 1: Perceptions of five groups of policy actors, relationships among legislation, health policy, and the use of sexual and reproductive health services among people with disabilities in post-conflict Northern Uganda

3.2.1 Multiple case study design

For the qualitative study, a multiple instrumental case study approach was used (183) (Figure 4). A case study allows researchers to learn in-depth about a case that could be defined as a particular person, a specific location, or an event; it can be *intrinsic* (i.e. one wants to learn about and understand a particular case) or *instrumental* (i.e. “a particular case is examined mainly to provide insight into an issue or to redraw a generalization”), and it is linked to a specific context where experiential knowledges and experiences of actors are revealed through the testimonies of context-based actors (183). A multiple instrumental case study was used, where the case was the post-conflict northern region of Uganda. The multiple cases include: 1) the private-not-for-profit St-Mary’s Hospital Lacor, which provides a wide range of preventive, curative, and specialised health services and in-service training (68) and its three satellite health centres III, which provide preventive, promotive, outpatient, maternity, inpatient, and basic laboratory services (68), and 2) the three closest public health facilities of the same level of service provision, located in the districts of Gulu, Amuru, and Omoro in the northern region. This approach was used to understand how the five study groups of policy actors perceived the relationships among legislation, health policy, and utilisation of SRH services by people with disabilities (i.e. the instrumental nature of this case) in the post-conflict northern region of Uganda. Policy actors include three broad groups of people who: 1) are responsible for developing formal policies in the public or private sectors, 2) influence how policies are put into practice, 3) seek to influence the policy process (10). In this research, policy actors are women and men with disabilities (third group), health service providers (second group), disabled people's organisations (second and third groups), national and international organisations (first and second groups), and national decision-makers (first group).

Figure 5. – Components of the multiple instrumental case study



3.2.2 Study population

A theoretical and purposive sampling approach was adopted (184, 185), and recruitment of study participants continued until saturation (186). Concretely, given the importance of seeking the perceptions of policy actors located at different levels (micro, meso, and macro), a diverse group of participants was selected to reflect the theoretical underpinning of the IBPA framework, which promotes *diverse knowledges* as one of the key principles (17). Study participants were further purposefully selected based on disability type, gender, district, willingness to share their perspectives, and diversity of views (185). At the micro level, adult women and men with different impairments (physical, vision, hearing, mental/intellectual) were recruited for in-depth semi-structured interviews and focus groups. When people with hearing impairments were interviewed, local Ugandan sign language interpreters were hired. People with disabilities had to be interested in divulging their views on their own, without the recourse to a third party such as a family member, friend, or healthcare provider. At the meso level, health staff from seven health facilities, who were providing any SRH services, and representatives of disabled people's organisations of people with different impairments were recruited to participate in focus groups at the district level. At the macro level, national policy-makers, and representatives of international organisations and national NGOs, who were involved in disability-related policy and decision making and/or who were involved in the SRH service delivery process were recruited to be individually interviewed, given their schedule. In total, 159 people participated in the qualitative study conducted in Uganda (Table 5).

Tableau 6. – Qualitative study sample characteristics

Levels	**Total**	**Women (%)**	**Men (%)**	**People with disabilities (%)**
Micro (3 districts)	**44**	**23 (52.3)**	**21 (47.7)**	**44 (100)**
People with disabilities	44	23 (52.3)	21 (47.7)	44 (100)
Meso (3 districts)	**102**	**55 (53.9)**	**47 (46.1)**	**7 (7)**
Health service providers	60	34 (56.7)	26 (43.3)	1 (2)
Representatives of DPOs	8	2 (25)	6 (75)	6 (75)

Participants of a 2-day disability-friendly health service provision workshop	34	19 (55.9)	15 (44.1)	0 (0)
Macro (Kampala)	**13**	**6 (46.2)**	**7 (53.8)**	**5 (38.5)**
National policy-makers and representatives of national and international organisations	13	6 (46.2)	7 (53.8)	5 (38.5)
Total	**159**	**84 (52.8)**	**75 (47.2)**	**56 (35.2)**

3.2.3 Data collection

A prolonged field data collection in Uganda was conducted from November 2017 to April 2018 and consisted of three phases. Phase 1 was dedicated to identifying key knowledge brokers, learning more about the local context, and exploring research etiquette. Phase 1 also included recruiting and training the local research team composed of two research assistants, Ugandan sign language interpreters, and two *boda-boda* (moto-taxi) drivers. Two young social science undergraduates who had experience in collecting qualitative data and working with people with disabilities in Northern Uganda were recruited as research assistants. Local Ugandan sign language interpreters fluent in English were identified for interviews with people with hearing impairments. Two trusted boda-boda drivers recommended by the Research Department of the St-Mary's Hospital Lacor (my base in Uganda) were also interviewed and hired for daily trips to villages in the three districts of Gulu, Amuru, and Omoro.

Phase 2 focused on community mobilisation, which involved courtesy visits to local health and administrative authorities, development and testing of data collection instruments, recruitment of study participants, data collection, and transcription of interviews. Interview and focus group guidelines were informed by the IBPA framework and adapted for this research. The guidelines included the two sets of IBPA questions (17): 1) descriptive questions related to the problem of SRH utilisation by people with disabilities and information on policy implementation processes, and 2) transformative questions related to solutions aimed at reducing inequities and promoting social justice. Data collection tools (Appendix 1) – in-depth semi-structured interview, focus group, and non-participant observation guidelines – were first discussed among research team members and then field-tested with a group of people with different impairments to explore their understanding of questions and to identify how to improve the guidelines. We also developed a glossary of key research and SRH vocabulary in Luo and English (Appendix 2) for consistency and follow-up during each interview and focus group conducted.

For the semi-structured interviews, I conducted all interviews and focus groups in English, and they were translated concurrently by research assistants into Luo/Acholi for people with disabilities either at their home or in the yard of the health facility they used, based on their preference. Participants in Kampala were interviewed in their offices. Focus groups with people with disabilities were held in Luo on the premises of one of the DPOs which was accessible to most people with disabilities. Focus groups with healthcare providers and representatives of DPOs were held in either English or Luo and at their work offices. Each interview and focus group lasted approximately one hour and was audio recorded with the permission of study participants. Both research assistants supported the translation of all interviews and focus groups that I conducted and led. For participants with hearing impairments, locally qualified Ugandan sign language interpreters, fluent in English and Luo, were occasionally hired. For non-participant observations, health facility managers were notified before this exercise. Our team spent at least half a day for initial visits in addition to follow-up visits. During our observations, we focused on various aspects of accessibility for each health facility.

For consistency and quality assurance, research assistants immediately transcribed the translated English parts of the recordings which I verified the following day. Daily debriefing sessions were conducted among the research team to improve the data collection process while sharing our meal at the end of the day. We discussed our observations and how to improve the data collection process as we went along with our study participant plan. During the fieldwork, a methodological and reflexive logbook (187) documented daily fieldnotes, methodological decisions as well as challenges and reflections on various emerging issues. The qualitative research process was appraised using the Consolidated Criteria for Reporting Qualitative Research (COREQ), a widely used tool to assess rigour in qualitative research (188).

The purpose of Phase 3 was to elaborate an evidence brief and disseminate the preliminary findings to study participants and stakeholders, as well as provide feedback to local health and administrative authorities. Prior to leaving Uganda, several knowledge transfer activities were organised to promote the understanding and eventual uptake of study findings for programmatic decisions and policy-making processes. These activities targeted diverse audiences of people with disabilities and their DPO representatives, healthcare providers from the districts of Gulu, Amuru, and Omoro, local and administrative authorities, as well as nationally based stakeholders.

3.2.4 Analysis

Triangulation of qualitative data occurred through the different data collection techniques and levels of analysis composed of the five groups of policy actors to capture “multiple perceptions” from study policy actors (183). In addition, before leaving Uganda, a thematic workshop was organised to further triangulate preliminary findings. I thematically analysed data in the approach recommended by Braun (189), informed by the intersectional framework (17). First, to become familiar with the qualitative dataset, I listened to all recordings, while noting preliminary impressions and thoughts related to data. Based on notes taken, I listened to selected recordings at least twice. All printed transcriptions were then read and re-read several times, noting additional impressions and initial ideas for codes. Second, using an inductive approach, an initial round of coding to identify and organise data relevant to this research was conducted. Third, interview transcripts were imported into QDAMiner (Provalis) and then coded. After all transcripts were coded, an iterative inductive-deductive approach was adopted, informed by intersectionality, to search for themes. As per the IBPA approach (17), when identifying themes, particular attention was paid to how study participants answered the two sets of questions (descriptive and transformative) asked during the in-depth interviews and focus groups. At this stage, connections between codes and broad themes were made. Fourth, I reviewed the data to check for the representativeness of themes. Fifth, the themes were reviewed and refined through discussion among research team members. Finally, the results were written up, guided by the IBPA's key principles (84): 1) intersecting social identities, 2) multilevel analysis (at micro, meso and macro levels), 3) power structures, 4) time and space (context), 5) diverse knowledges, 6) reflexivity, and 7) social justice and equity. Non-participant observations of health facilities related to accessibility were analysed in relation to emerging themes and compared with the narratives and experiences of study participants when accessing and using SRH services.

3.3 Objective 2: Disability, determinants of health, and associations with selected sexual and reproductive health service use in Uganda (2006-2016)

3.3.1 Repeated cross-sectional study design

A repeated cross-sectional survey, the Demographic and Health Survey, was analysed for the years 2006 (190), 2011 (24) and 2016 (12). The year of 2006 was used as the baseline year as this was when disability questions were first included for Uganda. It is also the year when the initial Disability Act was adopted and when the armed conflict ended.

3.3.2 Data sources

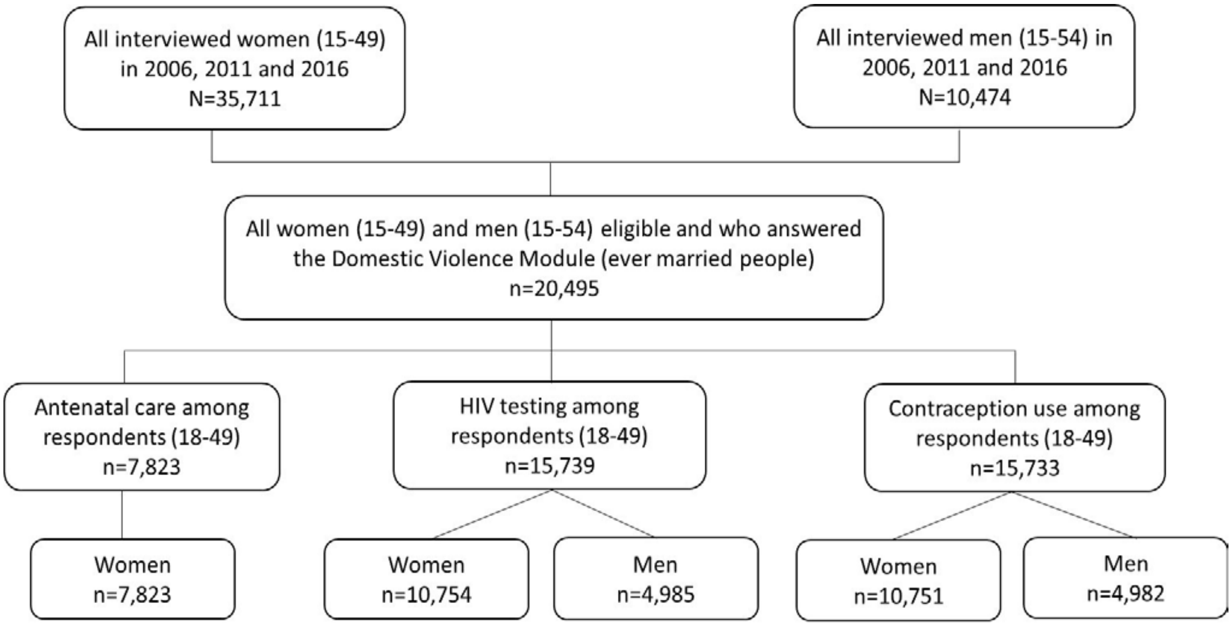
All secondary data were retrieved from the DHS repository available at www.dhsprogram.com. A formal request to use Uganda's DHS data was made by email and permission was granted by the DHS programme at the end of 2016. Each DHS used a stratified two-stage sample design and data were obtained from a nationally representative sample of the population of Uganda (12, 24, 190). In 2006, the survey was conducted from May to October 2006 and identified a representative probability sample of 9,864 households, where households were selected based on a complete listing of households from 321 clusters (190). In 2011, a representative sample of 10,086 households was selected from 404 clusters, from June to December 2011 (24). Following the same methodology and a governmental redefining of the number of regions from nine regions in 2006 and 10 regions in 2011 to 15 regions in 2016, a representative sample of 20,880 households was randomly selected from 694 enumeration areas, from April to December 2016 (12).

Of all available questionnaires, three different DHS questionnaires were used for this study: the Household Questionnaire, the Women's Questionnaire, and the Men's Questionnaire (12, 24, 190). Both Women's and Men's Questionnaires contain information on respondents' sociodemographic characteristics and health outcomes such as family planning, reproductive health, and HIV-related questions. The Household Questionnaire contains disability-related information for all respondents, in addition to the household's general information. More specifically, questions related to disability were asked in the Household Questionnaire in 2006 and 2011, while a specific disability module was added to the Household Questionnaire in 2016 (12). In the three DHS used, disability questions were posed for all people aged 5 years and above and were based on the Short Set of the questions developed by the Washington Group on Disability Statistics (12). Concerning the experience of violence, the eligibility of household members changed from one DHS year to another. In 2006, every eligible ever married woman (aged 15-49) was selected in every three households to respond to the Domestic Violence Module, while one ever married male (aged 15-54) respondent was selected in the remaining two households (190). In 2011, one woman per household was selected among the two-third of the households, while one man per household was selected in the one-third of the households (24). In the 2016 DHS, all households were invited to participate in the Module: one woman per household was randomly selected in two-thirds of the households, and in the remaining one-third of the households, a man per household responded to the questions (12). For eligible people to respond to the Domestic Violence Module, privacy needed to be guaranteed, otherwise, they were not interviewed (12, 24, 190). In 2006, 2011 and 2016, respectively, 2,087, 2,056 and 9,232 ever-married women (aged 15-49), and 1,852, 1,730 and 3,538 ever-married men (aged 15-54) responded to questions on violence (12, 24, 190).

3.3.3 Study population

The qualitative findings of Phase I highlighted the multiple layers of intersections people with disabilities faced in accessing and using maternal health care, contraception, and HIV testing, in addition to the experiences of violence they reported (149). Informed by the Phase 1 qualitative findings (149), the Phase 2 quantitative study focused on adult women and men aged 18 to 49 years old (reproductive age) who answered the questions related to selected SRH service utilisation – antenatal care, modern contraceptives, and HIV testing – and who also answered the Domestic Violence Module in 2006, 2011 and 2016. The flow diagram provides details on the study population included per studied SRH outcome (Figure 5).

Figure 6. – Study population



3.3.4 Outcomes and main exposure variables

In this study, there are three outcomes of interest: 1) antenatal care (last birth), 2) HIV testing during the last year, and 3) use of contraception type (current). The antenatal care visits were collected as an integer value and recategorized in a binary variable: 0 referred to “0-3 antenatal care visits”; 1 referred to “4 or more antenatal care visits”. The grouping was based on the World Health Organization recommendation of at least four antenatal care visits for a positive pregnancy experience (191). HIV testing was defined in its original two categories: 0 meant “No HIV testing”; 1 referred to “HIV testing done”. The use of contraception type was recategorized from four levels to as following: 0 was defined as “No use of contraception methods” or “Use of folkloric or traditional contraception” such as withdrawal and the use of moon beads; 1 was defined as “Use of modern contraception methods”, which include such as pills, injectables, male/female condoms, male/female sterilisation, intrauterine devices, implants and emergency contraception (12). Specifically, we checked whether different recoding of outcome variables, such as for the antenatal care variable using two categories: 0: 0-3 antenatal care visits; 1: 4 and > antenatal care visits, versus 0: 0 visit, 1: 1 antenatal visit, 2: 2 antenatal visits, 3: 3 antenatal visits, and 4: 4 and > antenatal care visits. Sensitivity analyses did not yield different effects.

The main exposure variable of interest was disability status. In the DHS, disability is captured as a ‘difficulty’ measure rather than a medical diagnosis. The DHS uses the Washington Group Short Set of Disability (WG) Questions, which is the preferred disability-related data collection method as it relies upon self-reporting during surveys rather than clinical assessments which need to be conducted by medical professionals (192). The WG examines six different functional dimensions: 1) seeing, 2) hearing, 3) walking or climbing stairs, 4) remembering or concentrating, 5) self-care, and 6) communication (193-197). In all three waves of DHS, respondents were asked if they had “no difficulty”, “some difficulty”, “a lot of difficulty”, “cannot do it all” or “don’t know” for each functional dimension. For the analysis, disability status was recoded into a binary variable: 0 “no disability”; 1 “some Disability” or “a lot of disability” or “cannot do it all”.

The WG recommends using the cut-off of at least “A lot of difficulty” in one of the functional dimensions for being disabled (198). According to disability statistic specialists, “there is more than one way to capture disability through the application of this set of core questions; resulting in not one but several possible prevalence estimates” (197). Hence, “multiple disability scenarios can be described depending on the domain(s) of interest and the choice of severity cut-off” (197). In the DHS reports of 2006 and 2011, Uganda reported that 19.8% (190) and 19.2% (24) of its population above 5 years old had “some” disability in at least one of the functional dimensions. In 2016, Uganda slightly changed the way it reported disability prevalence, with 19.8% had “some difficulty”, 5.8% had “a lot of difficulty” and 0.6% who could not do anything, in at least one of the functional domains (12). To ensure that we had enough power and we could examine whether outcomes would vary based on a disability cut-off using “some difficulty” and above in at least one of the six functional dimensions versus a cut-off using “a lot of difficulty” and above in at least one of the six functional dimensions, we checked if a different recoding of an overall disability variable would yield different results. Sensitivity analyses were conducted and the two different approaches to classifying disability did not yield any significant effect in any of the three outcomes. Given that disability was one of the main exposure variables in this study and to get more information how the disability type variable behaved while interacting with other variables of interest, we decided to use the different six functional dimensions and the cut-off using “some difficulty” and above in at least one functional dimensions.

The selection of exposure variables and covariates was based on literature (Chapter 2) and the qualitative study findings. We highlighted the importance of examining antenatal care, family planning as understood by the contraceptive method use, and HIV testing with the factor of disability (149) besides covariates. Other exposure variables of interest included were sex, age, marital status, region, education, wealth index, religion, year, and experience of violence. The following table summarises the variables of interest and how they were categorised.

Tableau 7. – Main variables of interest

Outcome variables	
Antenatal care visits	0: 0-3 antenatal care visits 1: 4> antenatal care visits
Modern contraception type use	0: No use/traditional and folkloric contraceptives 1: Modern contraceptives
HIV testing	0: No 1: Yes
Exposure variables	
Disability type ▪ Difficulty in seeing even with glasses ▪ Difficulty in hearing even with hearing aid ▪ Difficulty in walking/climbing steps ▪ Difficulty in remembering/concentrating ▪ Difficulty in self-care ▪ Difficulty in communication	0: No 1: Yes
Year	0: 2006 1: 2011 2: 2016
Sex	0: Man 1: Woman
Age	0: 18-19 years old 1: 20-24 years old 2: 25-29 years old 3: 30-34 years old 4: 35-39 years old 5 : 40 years old and >
Marital status	0: Married/in union 1: Separated/divorced/widow
Place of residence	0: Rural 1: Urban
Region	0: Kampala 1: North 2: Central 1 3: Central 2 4: East Central 5: Eastern 6: West Nile 7: Western 8: Southwest
Highest education level attainment	0: No education 1: Primary 2: Secondary and higher
Wealth index	0: Poorest 1: Poorer 2: Middle 3: Richer 4: Richest
Religion	0: Anglican 1: Catholic 2: Muslim 3: Seven Day Adventist/Pentecostal/Born Again/Evangelical 4: Other
Experience of violence type ▪ Emotional ▪ Physical ▪ Sexual	0: No 1: Yes

3.3.5 Analysis

Uganda DHS datasets of 2006, 2011, and 2016 were merged in one data set before the analysis was conducted. All data management, descriptive analyses, and multiple variable logistic regressions were conducted in R software (199) and QGIS software was used to produce bivariate choropleth maps (200). Descriptive analyses examined the outcomes at each time point as well as the exposures of interest and the other covariates. Before releasing DHS datasets to researchers and the public, the Uganda Bureau of Statistics has processed and cleaned the data for any aberrant values (12, 24, 190). In the case of our three binary dependent variables of interest, less than 1% of responses were missing (respondents did not answer or did not know the answer) and excluded from analyses. Bivariate choropleth maps were created to examine how disability and each outcome variable changed by region from 2006 to 2016. A multiple variable logistic regression was created for each outcome. Variables in the models were examined for multicollinearity through the Variance Inflation Factor (VIF) (201). Variables with a VIF above 10, indicating multicollinearity, were excluded from analyses (201). Each exposure variable in a regression model was treated as a set of dummy variables with the category "0" defined as the reference category. For each covariate, the reference level was purposefully selected to facilitate the interpretation of results (202). Given the intersectional approach adopted for this mixed methods study, key interaction (intersection) terms were explored (202), emphasising the 'multiplicative' nature of people's identity, notably the not mutually exclusive identity of a person with disabilities who, for example, could also be a woman, poor or educated (203). Different interaction terms were explored and included disability with sex, education, wealth index, and experience of violence. Model selection was based on the Akaike Information Criterion (204) and variables that were not statistically significant in the logistic regressions were subsequently removed until we reached the final model selection (205). Residual deviance was checked for model fit (206). Given that responses were not obtained from repeated measures, the assumption related to independence of observations is cleared (207).

3.4 Objective 3: Evidence on legislation, health policy, and the use of sexual and reproductive health services by vulnerable populations in sub-Saharan Africa (1994-2019)

To conduct the systematic review, the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) approach (208) was followed. The systematic review protocol was registered in the PROSPERO database and can be retrieved from the following link: https://www.crd.york.ac.uk/PROSPERO/display_record.php?RecordID=106876&VersionID=1184126. The overall methodology is summarised in the following sections and is detailed in the published Manuscript 6 (Chapter 5).

3.4.1 Systematic review question

What are the relationships among health equity-focused legislation and policy, and the utilisation of SRH services by vulnerable populations in sub-Saharan Africa?

3.4.2 Search strategy, data extraction, and quality assessment

The following nine bibliographic databases were used: CINAHL, EBM Cochrane systematic Reviews, Embase, Global Health, MEDLINE, Popline, Proquest Dissertations and These Global, Scopus, and Web of Science. Search terms were developed using the Population, Intervention, Comparator, Outcome (PICO) methodology. These terms were piloted in CINAHL, refined, and transposed across the other databases, using thesaurus terms and appropriate truncation strategies as per specific database. The search strategy explored references from both the English and French languages, between 1994 and 2019. The year 1994 was chosen as the starting point for this search as it was the year of the launch of the International Conference on Population and Development (ICPD), convened by the United Nations to introduce and promote the SRH rights worldwide. The initial search strategies and keyword equations were validated by a public health librarian, designated to work with researchers, based at the School of Public Health of the Université de Montréal.

The following search strategy was used: (health equit* OR healthcare equit* OR “health care equit* OR health equalit* OR healthcare equalit* OR health care equalit* OR health inequit* OR healthcare inequit* OR health care inequit* OR health inequality* OR healthcare inequality* OR health care inequality* OR health disparit* OR healthcare disparit* OR health care disparit* OR pro-poor OR pro poor OR socioeconomic status OR socio-economic status OR socioeconomic factor* OR socio-economic factor*) AND (legislation OR law* OR regulation* OR health polic* OR health plan* OR health strateg*) AND (utilization of reproductive health OR sexual health OR sexual education OR family planning OR contracept* OR prenatal care OR antenatal care OR facility-based delivery OR facility based delivery OR postnatal care OR postpartum care OR hiv OR aids OR hiv/aids OR hiv testing and counselling OR hiv testing and counseling OR VCT OR sti* OR sexually transmitted infection* OR sexually transmitted disease* OR sexual abuse OR domestic violence OR intimate partner violence OR safe abortion OR post-abortion care OR post abortion care) AND (vulnerable population* OR vulnerable group* OR special population* OR special group* OR marginalized population* OR marginalized group* OR marginalised population* OR marginalised group* OR underserved population* OR underserved group* OR disadvantaged population* OR disadvantaged group* OR women OR woman OR youth OR adolescen* OR young adult* OR handicap* OR disabilit* OR disabled OR person* with disability* OR people with disability* OR “person* with a disability* OR lgbt* OR transgender OR sexual minorit* OR ethnic minorit* OR indigenous OR homeless OR illiterate OR unemployed OR rural population* OR poor OR street people OR street teen*) AND (Africa south of the Sahara OR sub-Saharan Africa OR west* Africa OR east* Africa OR central Africa OR south* Africa OR Angola OR Burundi OR Democratic Republic of Congo OR DRC OR Cameroon OR Central African Republic OR CAR OR Chad OR Republic of Congo OR Equatorial Guinea OR Gabon OR Kenya OR Nigeria OR Rwanda OR Sao Tome and Principe OR Tanzania OR Uganda OR Sudan OR South Sudan OR Djibouti OR Eritrea OR Somalia OR Botswana OR Comoros OR Lesotho OR Madagascar OR Malawi OR Mauritius OR Mozambique OR Namibia OR Seychelles OR South Africa OR Swaziland OR Zambia OR Zimbabwe

OR Benin OR Mali OR Burkina Faso OR Cape Verde OR Ivory Coast OR Gambia OR Ghana OR Guinea OR Guinea Bissau OR Liberia OR Mauritania OR Niger OR Senegal OR Sierra Leone OR Togo).

The inclusion criteria included the following items: original primary qualitative, quantitative, and mixed methods studies conducted and published between 1994 and 2019 in sub-Saharan Africa, from both English and French peer-reviewed and grey literature were screened. Studies needed to include the five key concepts of the research question: 1) equity, 2) legislation and health policy, 3) utilisation of SRH services (e.g. sexual health, sexual education, family planning/contraception, maternal health, STIs/HIV, safe abortion, sexual/gender-based violence protection services), 4) populations in vulnerable situations (e.g. women, youth/teenagers, people with disabilities, sexual minorities, people living with HIV, rural populations, illiterate and poor), and 5) countries in sub-Saharan Africa. Exclusion criteria were systematic reviews and studies which did not systematically include the five concepts of the research question.

Before data extraction and coding, the following phases were conducted: 1) identification of references based on the search strategy and uploaded in EndNote X9, 2) selection of titles and abstracts based on selection and exclusion criteria, and removal of duplicates, 3) review of manuscripts based on eligibility and removal of those which do not meet inclusion criteria, 4) quality assessment of eligible manuscripts and 5) inclusion of manuscripts, data extraction, and analysis. For each phase, at least two reviewers collaborated. In case of disagreement between reviewers, a consensus was sought. If consensus was not obtained, an additional reviewer was consulted for a final agreement. Data were extracted as per the following information: 1) publication year, 2) authors, 3) place of study in sub-Saharan Africa, 4) research design, 5) type of legislative and health policy instrument adoption/implementation, 6) type of populations in vulnerable situations, 7) type of SRH service utilisation, 8) qualitative and/or quantitative changes in utilisation of sexual and reproductive health services, and 9) timeline of changes in utilisation relative to the implementation of legislative and policy instruments.

Critical quality appraisal tools were used to assess different types of studies. For cohort, case-control, and cross-sectional studies, the2007 Strengthening the Reporting of Observational Studies in Epidemiology (STROBE)-Combined tool was used (209), and The Joanna Briggs Institute's Checklist for Quasi-Experimental Studies (210) was used to assess the quality of four types of quasi-experimental designs. The Mixed Methods Appraisal Tool (MMAT) was followed to assess mixed methods studies (211). Given that no qualitative studies were included in the final stage of the systematic review, no tool examining the rigour of qualitative research was used.

3.4.3 Data synthesis

Due to heterogeneity in study outcomes and findings, a meta-analysis was not considered. Rather, a narrative synthesis (212) was conducted to summarise the state of knowledge gathered from the literature included in the review.

3.5 Integration of results

Given the sequential nature of this mixed methods study, qualitative and quantitative data were analysed separately (178). First, we analysed the qualitative findings reported in Manuscripts 2 (perspectives of micro level policy actors – people with disabilities) and 3 (perspectives of meso and macro level policy actors – health service providers, disabled people's organisations, national and international organisations, and national policy-makers). We then proceeded with the quantitative analysis of three waves of secondary DHS data collected in the decade following the adoption of the Disability Act; this was informed by the qualitative findings (Manuscript 4). In parallel, we also analysed the systematic review findings of 32 studies at the regional sub-Saharan African level (Manuscript 5). In the discussion of this thesis (Chapter 7), all findings of the three phases are brought together and synthesised, in addition to a sixth manuscript which discusses the tensions between 'procedural ethics' and 'ethics-in-practice' (213) when conducting qualitative research in a global health context. The identification of remaining gaps is discussed and recommendations are proposed (Chapter 7) (178). The following table summarises the list of manuscripts in relation to research objectives and their corresponding chapter.

Tableau 8. – List of objectives, designs, manuscripts, and thesis chapters

Research objectives & design	**Manuscript**	**Chapter**
	▪ Manuscript 1 (meta-synthesis)	▪ Chapter 2 (literature review including meta-synthesis update)
Objective 1 on perceptions of policy actors of relationships in Uganda (qualitative multiple case study)	▪ Manuscript 2 (policy actors, people with disabilities, at micro level) ▪ Manuscript 3 (policy actors at meso/macro levels)	▪ Chapter 4 (qualitative results)
Objective 2 on associations between disability and other factors (repeated cross - sectional study, quantitative secondary analysis of DHS data)	▪ Manuscript 4 (Demographic and Health Surveys)	▪ Chapter 5 (quantitative results)
Objective 3 on pro-equity legislation, health policy, and the use of SRH services among vulnerable populations in sub-Saharan Africa (systematic review)	▪ Manuscript 5	▪ Chapter 6 (systematic review results)
	▪ Manuscript 6 (reflexive ethics paper)	▪ Chapter 7 (Discussion)

3.6 Ethics

Historically, people with disabilities, those with intellectual disabilities, in particular, have been either denied of their rights by being included in medical experiments as “guinea pigs” or excluded from research activities due to discrimination and overprotection (214). This research: 1) provided the opportunity to people with all types of impairments to participate in the study; 2) allowed them to express their own views and to be heard without the recourse to a proxy such as a family member or a health service provider (215); 3) consulted DPOs on disability-sensitive strategies to promote the participation of people with disabilities in research; and 4) ensured that the wording in interviews and focus groups with people with disabilities was disability-friendly. The consent form for people with disabilities was further translated in Luo. Language was simplified and pictogrammes were added to ease understanding (Appendix 4).

This research received ethics approval from four research ethics boards: the *Centre de recherche du Centre hospitalier de l'Université de Montréal* (CR-CHUM) (17.127-CÉR, 1 August 2017); the Research Ethics Committee in Sciences and Health of the Université de Montréal (CERCES-20-074-D, 13 May 2020), following a change of research affiliation in Canada; the Uganda National Council for Science and Technology (SS-4451, 14 November 2017); and the Lacor Hospital Institutional and Research Ethics Committee (LHIREC - 019/07/2017) (Appendix 3).

Chapter 4 – Results of Objective 1 on policy actors' perceptions

4.1 Preface to qualitative findings (Manuscripts 2 and 3)

In the qualitative phase of the research, I examined different policy actors' perceptions of the relationships among legislation, health policy, and the utilisation of SRH services by people with disabilities in the post-conflict northern region of Uganda. A research approach based on the Intersectionality-Based Policy Analysis framework puts equal weight on describing the problem and identifying potential solutions to reduce inequities. The qualitative data collected yielded three manuscripts. The first one (Thesis Manuscript 2) focused on hearing from one of the main policy actors, women and men with different types of impairments. I was interested to understand how they perceived the relationships among their use of SRH services, legislation, and health policy, and what they recommend to address the problems or barriers which were encountered. The second manuscript (Thesis Manuscript 3) examined the same questions among policy actors at the meso and macro levels to look for similarities and/or divergences in perceptions across levels and types of policy actors.

4.2 Manuscript 2: The intersectional jeopardy of disability, gender, and sexual and reproductive health: Experiences and recommendations of women and men with disabilities in Northern Uganda

Publication status: This manuscript was published in *Sexual and Reproductive Health Matters* in June 2020. I received official permission from the journal to reproduce it (149). It is open access and can be cited as:

Mac-Seing M, Zinszer K, Eryong B, Ajok E, Ferlatte O, Zarowsky C. The intersectional jeopardy of disability, gender and sexual and reproductive health: Experiences and recommendations of women and men with disabilities in Northern Uganda. Sexual and Reproductive Health Matters. 2020:1-27. doi: 10.1080/26410397.2020.1772654.

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Abstract

The 2030 Sustainable Development Goals committed to "Leave No One Behind" regardless of social identity. While access to sexual and reproductive health (SRH) services has improved globally, people with disabilities continue to face enormous barriers to SRH, infringing on their SRH rights (SRHR). Uganda adopted pro-disability legislation to promote the rights of people with disabilities. Despite these legal instruments, SRHR of people with disabilities continue to be violated and denied. To address this, we sought to understand and document how people with disabilities perceive the relationships between their use of SRH services, legislation, and health policy in three districts of the post-conflict Northern region of Uganda. Through an intersectionality-informed analysis, we interviewed 32 women and men with different types of impairments (physical, sensory, and mental), 12 hearing and non-hearing disabled people in two focus groups and we conducted non-participant observations at seven health facilities. We found that the access of people with disabilities to SHR services is shaped by the intersections of gender, disability, and violence and that individuals with disabilities experienced discrimination across both private-not-for-profit and public health facilities. Powered by ableism, they also encountered numerous physical, attitudinal, and communication accessibility barriers. Despite policy implementation challenges, people with disabilities expected to exercise their rights and made concrete multi-level recommendations to redress situations of inequity and disadvantages in SRH service utilisation. Intersectionality revealed blind spots in policy implementation and service utilisation gaps. Universal health coverage can be operationalised in actionable measures where its universality meets with social justice.

Keywords

Intersectionality, disability, gender, sexual and reproductive health rights, health equity, Uganda

Introduction

Access to sexual and reproductive health (SRH) services has improved globally; however, millions continue to have unmet SRH needs, particularly those living in poverty and rural areas, including people with disabilities (1). The SRH rights (SRHR) of people with disabilities remain violated and silenced (2). Approximately one billion people worldwide live with some form of disability (physical, sensory, intellectual, or mental) with 80% of disabled individuals living in low- and middle-income countries (3). The 2030 Sustainable Development Goals (SDGs), adopted in 2015 by the international community, underscore the need to "Leave No One Behind", regardless of gender, age, ability, wealth, or geographic location (4). Among these goals, at the intersection of SDG5, focusing on gender equality and the empowerment of women and girls, SDG3 promotes healthy lives, including SRH which is intertwined with and contributes to the attainment of universal health coverage (UHC) (1). When SRHR are examined from a disability and gender lens, pervasive SRHR violations have been reported to severely affect women and girls with disabilities, ranging from forced and/or coerced sterilisation, gender-based violence to lack of access to basic SRH services and information (5).

Twenty-five years after the recognition of SRHR at the First International Conference on Population and Development (ICDP) in Cairo, many governments, researchers, activists, coalitions of marginalised groups, and development partners reconvened in Nairobi in 2019. They reviewed ICDP progress related to SRHR and shared positive outcomes: global maternal mortality and HIV prevalence have both decreased, while access to family planning has increased (6). However, gender-based violence goes unabated and continues to disproportionally affect adolescents and young women, especially women who live in conflict and war zones as well as girls and young women with disabilities who "experienc[e] four times more violence than those without disabilities" (6). Compared to non-disabled people, women and men with disabilities experience multiple physical, attitudinal, and structural barriers infringing their SRHR, globally (3). They encounter additional obstacles to accessing maternal and reproductive health services (7, 8), are at increased risk of HIV (9) and of multiple forms of violence. People with intellectual disabilities and people living with mental health illnesses are particularly at risk of violence (10). In sub-Saharan Africa, people with disabilities have been reported to encounter all the above barriers, combined with poor access to basic SRH services and health system infrastructures (7, 8, 11, 12).

After years of debate among the United Nations Member States about how to promote and protect the rights of people with disabilities, the Convention on the Rights of Persons with Disabilities (CRPD) was adopted in 2006 and entered into force in 2008 (13). People with disabilities are referred to as "people who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (14). Legally, the CRPD seeks to compensate the historical disadvantages experienced by people with disabilities by providing guiding principles, such as non-discrimination and specific articles on rights, for example social participation, health, education, and employment (13). To date, more than 180 Member States have ratified the CRPD (15), including Uganda, which recently emerged from a 20-year armed conflict. The conflict largely affected its Northern region. The health system was severely weakened, health programmes had to be rebuilt, while gender-based violence and unwanted pregnancies were high and access to safe motherhood jeopardised, affecting most women and children (16, 17). Among sub-Saharan African countries, Uganda is cited as an example of a disability rights promoter (12, 18). The adoption of its Disability Act in 2006 and the ratification of the CRPD in 2008 are embedded in a legal space that dates from the promulgation of its Constitution in 1995 and its amendment in 2005, which enshrined the rights of people with disabilities (19). However, despite these legal tools, the presence of a National Council on Disability (20) and a representation of disabled elected officials at different governmental levels, concrete actions aimed at protecting the rights of people with disabilities are still lacking (12). People with disabilities in Uganda continue to have limited access to disability appropriate and sensitive SRH services and face high rates of discrimination when accessing services, coupled with structural barriers such as service costs (7, 11).

A comprehensive study of national policies helps better understand the trajectories of these policies and the interactions among agenda-setting, policy formulation, implementation, evaluation, and policy outcomes (21). The literature examining public policy and human rights, in the context of health, underscores the crucial role these play in anti-discrimination measures and in the provision of services by the State (22). While this is important and necessary, it is insufficient to analyse policy in a linear fashion when these interactions are complex and power structures influence policy and social outcomes. To address social inequities and multiple interconnected discriminations experienced by people with disabilities (5), Intersectionality-Based Policy Analysis (IBPA) offers a flexible framework to assist researchers and policy actors in bringing attention to intersecting social identities, diverse knowledges, multi-level factors, and a conscious exploration of complex policy issues for transformative policy solutions, beyond simply describing the problem (23). Intersectionality addresses the relationships between intertwined social identities, social inequities, power dynamics, social context, and complexity (24). Rooted in a long and deep history of Black, Indigenous and Third World Feminism as well as Queer and Postcolonial Theory, Intersectionality is a framework and research paradigm for understanding differences and resisting essentialization of differences (25). It was first coined in 1989 to address the multiple discriminations faced by Black American women workers who fell outside of the protection of anti-racism and anti-sexism legislation (26, 27).

The lack of data on the relationships between legislation, health policy and utilisation of SRH services by people with disabilities in sub-Saharan Africa is a major gap in the literature, in particular in post-conflict settings where access to and utilisation of services by affected populations are jeopardised (28). Framed within the conceptual and methodological context described above, the study reported here aimed to understand and document how people with disabilities perceive the relationships between their utilisation of SRH services, legislation, and health policy in the post-conflict Northern region of Uganda. We were interested in exploring their awareness of the pro-disability legislation and policy implementation, their perceptions of possible inequities related to SRH service utilisation and their recommendations on how to reduce these inequities. This paper reports the qualitative findings related to the perceptions of people with disabilities from a larger body of evidence of a study using mixed methods, which also involved other study participants, namely health service providers, local disabled people's organisations, international organisations, and national policy-makers.

Methods

Our study was conducted in the districts of Gulu, Amuru, and Omoro in the Northern region of Uganda. Through a multiple 'instrumental' case study design (29), our case was defined as the post-conflict Northern region, and the multiple cases include seven health facilities of two different types, the private-not-for-profit facilities (which are faith-based) and public health facilities, as shown in Table 7. Given the instrumental nature of the case study, the focus of this study was not to examine the intrinsic organisation of health facilities, but rather to use them as an 'instrument' to develop a better understanding of the perceptions of people with disabilities when they use SRH services. Field research, conducted from November 2017 to April 2018, consisted of three main phases. Phase 1 aimed at learning more about the local context and identifying key knowledge brokers. Phase 2 was dedicated to community mobilisation, recruitment of study participants, and data collection. Phase 3 focused on the dissemination of preliminary findings (Appendix 1 for detailed fieldwork activities). During the fieldwork, a methodological and reflexive logbook documented daily fieldnotes, methodological decisions as well as challenges and reflections on various emerging issues. Our research process was appraised using the Consolidated Criteria for Reporting Qualitative Research (COREQ), a widely used tool to assess rigor in qualitative research (30) (Appendix 2).

Tableau 9. – Health facilities included in the case study

	Private-not-for-profit health facilities	**Public health facilities**
Gulu district	Referral hospital (1)	Referral hospital (1)
Amuru district	Health centre level III (2)	Health centre level III (1)
Omoro district	Health centre level III (1)	Health centre level III (1)
Total	**4**	**3**

Positioning of researchers

The researcher MMS has worked for several years in sub-Saharan Africa with people with disabilities, advocating for their disability rights and SRHR within different international platforms and alongside disabled people's organisations. Prior to this study, MMS had not worked in Uganda. BE and EA are both Ugandans and speak English and several local languages. They are young social science undergraduates and have worked as research assistants in qualitative research and with people with disabilities. CZ and KZ are supervising the work of MMS in the context of her mixed methods study. Both have extensive research experience in Uganda and in working with vulnerable populations. OF is a queer scholar who works with populations marginalised because of their sexuality or gender identities and is one of the authors of the IPBA framework.

Study participants

Because of our commitment to include people with a diversity of experiences, we consciously opted to recruit people with different types of impairments (physical, vision, hearing, mental and intellectual) living in the catchment areas of the seven health facilities. The main selection criteria were adults with disabilities consenting to participate and answer the research questions on their own, without the presence of, nor the recourse to a third party. Purposive sampling sought maximum variation in disability and districts, while ensuring a gender-balanced sample. Village Health Teams (VHT) and disabled volunteers helped in community mobilisation and the identification of potential study participants. Recruitment of people with disabilities continued until saturation was reached (31). A total of 44 individuals with disabilities participated in the study: 32 took part in in-depth semi-structured interviews and 12 participated in two focus groups (one for hearing disabled people (n= 6) and one for non-hearing disabled people (n= 6)).

Data collection

We conducted in-depth semi-structured interviews, focus groups, and non-participant observations to triangulate findings (31). Data collection tools were first discussed among the core research team members (MMS, BE and EA), and field tested with a focus group of people with disabilities. We developed a glossary of key research and SRH vocabulary for consistency. Interview and focus group guidelines were informed by the IBPA framework and adapted for this research. The guidelines included the two sets of IBPA questions (23): 1) descriptive questions related to the problem of SRH utilisation by people with disabilities and information on policy implementation processes, and 2) transformative questions related to solutions aimed at reducing inequities and promoting social justice (Supplementary files 3-4). All interviews and focus groups were led in English by MMS and translated concurrently by BE and EA into Luo/Acholi. For participants with hearing impairments, a locally qualified Ugandan sign language interpreter, fluent in English and Luo/Acholi, was hired. Each interview and focus group lasted approximately one hour and was audio recorded with the permission of study participants. Both BE and EA were present during the interviews and focus groups and they cross-checked one another's translations. The following day, they transcribed the translated English parts of the recordings. MMS compared the recordings to the transcriptions for quality assurance. For non-participant observations, health managers were notified prior to this exercise. We spent at least half a day for initial visits in addition to follow-up visits. During our observations, we focused on various aspects of accessibility for each health facility. Daily debriefing sessions were conducted to improve the data collection process.

Analysis

We adopted a thematic analysis following specific steps (32). First, to become familiar with the qualitative dataset, all recordings were listened to, while noting preliminary impressions and thoughts related to data. Based on notes taken, selected recordings were listened to at least two times by MMS. All printed transcriptions were then read and re-read several times, noting additional impressions and initial ideas for codes. Second, using an inductive approach, we performed an initial round of coding to identify and organise data relevant to this research. Third, interview transcripts were imported in QDAMiner 5.0.31 (Provalis) and coding was performed. After all transcripts were coded, we used an iterative inductive-deductive approach, informed by intersectionality, to search for themes. As per the IBPA approach (23), when identifying themes, particular attention was paid to how study participants answered the two sets of questions (descriptive and transformative) asked during the in-depth interviews and focus groups. At this stage, connections between codes and broad themes were made. Fourth, MMS reviewed the data to check for the representativeness of themes. Fifth, the themes were reviewed and refined through discussion among the authors. Finally, the results were written up, guided by the IBPA's key principles (25): 1) intersecting social identities, 2) multilevel analysis (at micro, meso and macro levels), 3) power structures, 4) time and space (context), 5) diverse knowledges, 6) reflexivity, and 7) social justice and equity. Non-participant observations of health facilities related to accessibility were analysed in relation to emerging themes and compared with the narratives and experiences of study participants when accessing and using SRH services. To disseminate the preliminary findings and to seek feedback from the study's participants and stakeholders, we hosted five workshop presentations in Northern Uganda.

Ethical approval

This study received ethical clearance from three nationally approved research ethics committees: the Research Centre at the Hospital Centre of the University of Montreal (17.127-CÉR), the Uganda National Council for Science and Technology (SS-4451), and the Lacor Hospital Institutional and Research Ethics Committee (LHIREC 019/07/2017). All participants provided their consent through the support of a translated written consent form in Luo/Acholi and verbal translation by research assistants. Consent forms and support interview tools were made disability-friendly by using pictogrammes.

Results

Demographic data

Of the 32 people with disabilities who were individually interviewed, 53% were women. Eight people out of the 32 disclosed being HIV positive (25%); five out of the eight people living with HIV were women. Thirty-nine percent, 19%, 22% and 22% had physical, vision, hearing, and mental/intellectual impairments, respectively. Most had a source of income and were in a relationship. About one third had none to less than six years of formal education, while most had studied for more than six years. Almost all had children. Most had acquired their impairment after birth following illnesses or injuries, except for one person. In the two separate focus groups for hearing and non-hearing people with disabilities, half were women (Table 8).

Tableau 10. – Characteristics of participants

Characteristics	**In-depth semi-structured interviews N=32 (Percentage)***	**Focus groups** N=2 of 12 people (Percentage based on # people)**
Sex		
Women	17 (53)	6 (50)
Men	15 (47)	6 (50)
Impairment		
Physical	12 (38)	3 (25)
Vision	6 (19)	2 (17)
Hearing	7 (22)	7 (58)
Mental/Intellectual	7 (22)	
Onset of impairment		
At birth	1 (3)	
After birth	26 (81)	
Not specified	5 (16)	
HIV status (self-declared)		
HIV+	8 (25)	
Women among HIV+	5 (63)	
District		
Gulu	10 (31)	
Amuru	15 (47)	
Omoro	7 (22)	
Marital status		

Single	6 (19)	
Married/In union	17 (53)	
Separated / Divorced / Widow(er)	9 (28)	
Education (years)		
0-3	5 (16)	
4-6	6 (19)	
> 6	21 (66)	
Source of income		
Yes	27 (84)	
No	5 (16)	
Having children		
Yes	27 (84)	
No	5 (16)	

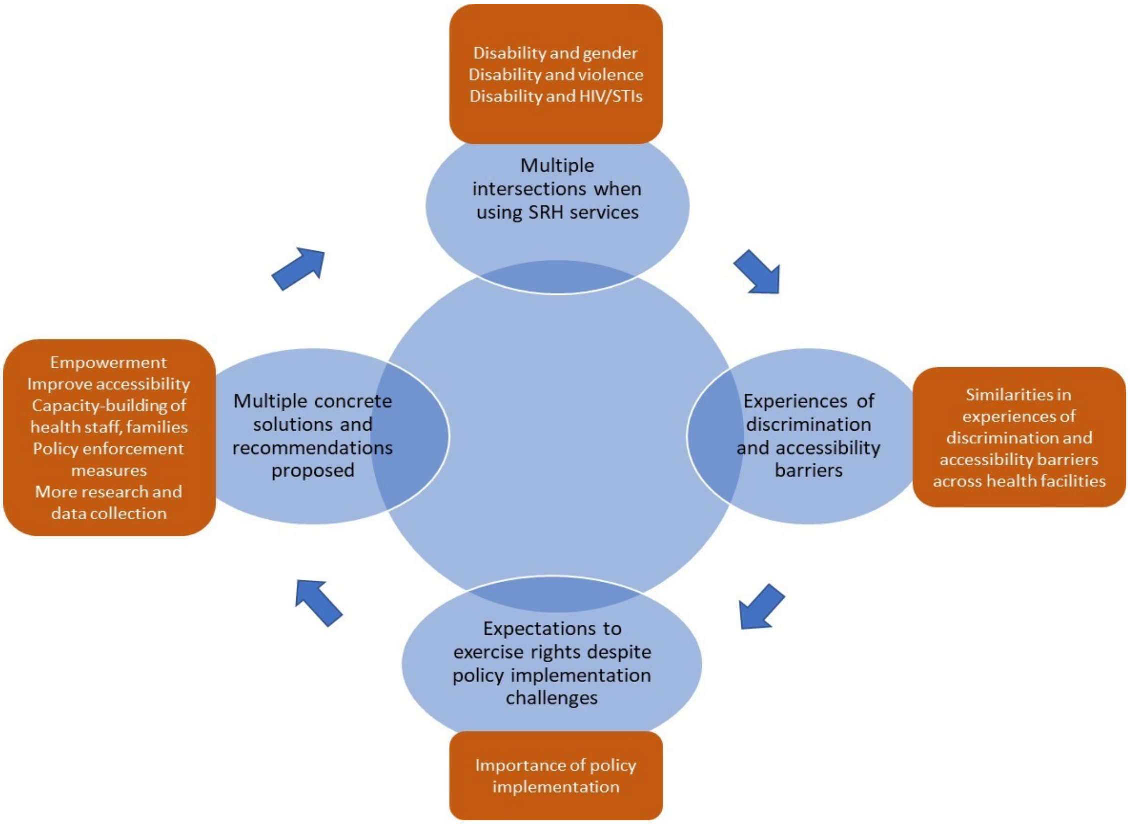
*Rounding might be slightly above or below 100%

** Only sex and disability data collected

Major themes

Embedded in the experiences of women and men with disabilities interviewed, the study identified four interrelated themes (in blue) and sub-themes (in brown) across disability, gender, health facility, and district (Figure 6). These main interrelated themes were as follows: 1) multiple intersections when using SRH services; 2) experiences of discrimination and accessibility barriers across health facility type; 3) expectations that people with disabilities exercise their rights despite policy implementation challenges; and 4) multiple concrete recommendations from people with disabilities. Themes and sub-themes are further developed in the following sections.

Figure 7. – Major themes identified



Multiple intersections when using SRH services

In discussing their experiences of and perspectives about SRH service utilisation, the connections between the participants' experiences of disability and other aspects of their identities were evident. People with disabilities, notably women, depicted complex intersections between gender, disability, and experiences of violence, often resulting in unwanted and unexpected health outcomes, such as HIV, sexually transmitted infections (STIs), or pregnancies. Underpinning these simultaneous intersections, the influence of ableism on the lives of women and men with disabilities shaped their struggles to use SRH services, beyond the stigma associated with a disability. While it is difficult to disentangle the various concomitant intersections jeopardising access to and use of SRH services, three main intersections were identified as important to people with disabilities: 1) disability and gender, 2) disability and violence, and 3) disability and HIV/STIs.

Disability and gender

When using SRH services, both women and men with disabilities divulged the burden that the service providers' and societal expectations created as well as of the control this created over their bodies. Health service providers and the community discriminated against people with disabilities, constantly challenging their basic sexual rights and capabilities to become pregnant or forge an intimate relationship. As people with disabilities, they were suddenly not expected to fulfill these gendered roles like any other women and men without disabilities. Study participants felt segregated from mainstream society by being denied of their right to use contraception or get married like anyone else.

> *In relation to getting a partner, a marriage partner, it is very hard for me as a person with disability to get a woman. People's perceptions are like, when you're disabled, you're not supposed to marry a non-disabled, you are supposed to get a fellow [who is] disabled, and you stay together*. (Man, physical impairment, Amuru)
>
> *They [health service providers] were saying "You who are personally dead, what do you want to space for? Men don't want you, why do you waste your time, why do you come for family planning, yet you even don't have men who love you?". I felt so bad, and then I was wondering, if I go for family planning, does it mean you should be with a man? Am not happy about it… And then, about women with disabilities who go for deliveries in the hospital…. Doctors use the wrong words like "These disabled legs are all paralysed, why do you get pregnant?".* (Focus group, hearing disabled people, Gulu)

Social norms and the perceptions of inadequacy of people with disabilities were also accompanied by the use of derogatory wording, such as "useless" (Focus group, hearing disabled people, Gulu), "lame" (Man, mental impairment, Gulu), "not normal" (Focus group, non-hearing people, Gulu) and “not fit” (Man, vision impairment, Amuru). These perceptions often led to the assumption that people’s impairment would lead to a complete state of inability to think or perform in society like everyone else and thus, resulting in surprise when this was proven otherwise. A woman and a man with a physical impairment, both from Gulu, reported respectively: “The nurses and doctors think that when you’re disabled, you’re disabled in your mind, everywhere, in all parts of your body” and “Most people thought that maybe the accident has spoilt my manhood. So, when they saw that my wife was pregnant, they were happy to see me going for antenatal [care with her]”.

In most cases, the social diktat to fit into traditional gender roles was detrimental to women with disabilities. Either they were reduced to their basic gender roles of conventional procreation or they were considered sexual objects. In both cases, women with disabilities were denied the full expression of their sexual and reproductive health rights. In addition, they were considered a burden, coupled with situations of stigmatisation and rejection, furthering their vulnerability through unstable relationships and single motherhood.

> *Many women are being left by men. You find that the man can come to me, that he loves me so much, but moment he made me pregnant, he can take off and disappear… People will start saying a lot of words “Why did you love that woman with disability, do you think she is going to help you?” For us who are blind, they will start saying “Do you think she can cook for you, she can wash for you, even if she produced [had a child], how is she going to take care of your baby?” So, when he leaves you, you start struggling with the baby alone*. (Focus group, hearing disabled people, Gulu)

Disability and violence

Compounded with the uneasy experiences based on gender and disability, participants disclosed direct and indirect examples of experiences of violence. Contradicting the belief that people with disabilities constitute a homogenous group, it was demonstrated that people with different types of impairments experienced various levels of violence and abuse, from being stigmatised and discriminated against to being raped and killed. Participants spoke of the heightened risk of sexual abuse and violence for women with sensory, mental, and intellectual impairments. In some communities, women with mental health problems, due to their psychotic episodes and most probably combined with a lack of adequate access to mental health care and psychosocial support in the region, were kept outside of the family home and left to themselves. These situations increased their vulnerability to multiple forms of violence. A woman with mental impairment, from Gulu, said: “I escaped from my mother, I went away, and I slept somewhere… They had to beat me, I came back naked, there was no clothe on me”. Other participants shared the followings:

> *There are some friends of mine, when we go at the centre… We can be there, and we take soda and there are some guys, some boys who come to them. They forced them to go somewhere and if they go, they abused them sexually… They have sex with them, they only buy them sodas and they don’t even give them any money.”* (Woman, intellectual impairment, Omoro)
>
> *In villages, you find that sometimes they [women with intellectual/mental impairments] are killed or strangled after being used [raped]… They are separated from the family members. You find the big family is here, and then, you find a disabled woman or man is given a home some distance away from the family members. They become a very good target to these people who are roaming around and who can easily rape them, grab them.* (Focus group, non-hearing disabled people, Gulu)

Although a response to address gender-based violence has been progressively put in place in Uganda, including in the Northern region, adapted services for people with disabilities remain limited and are not disability-sensitive (33). Non-participant observations revealed that health facilities, which are responsible for delivering the medical part of the response, were poorly accessible to people with various impairments. No disability desk nor signage for people with sensory impairments was available.

Disability and HIV/STIs

As illustrated above, the intersections between gender, disability, and violence are intricate and could result in health outcomes ranging from STIs to death. In various cases, violence seemed to be the mediating factor in contracting STIs, including HIV. Other mediating factors, such as lack of accessible HIV prevention and services for people with disabilities, may have also contributed to obstructing their full access to and utilisation of HIV-related information and services. Of the five disabled women who declared their HIV status, three lived with physical impairments, one with vision impairment and one with a mental impairment. All women expressed gendered vulnerabilities which further exacerbated their experience of disability intersecting with HIV/STIs and violence.

> *The doctors told me to take care of myself. I protect myself, because for us, women with disabilities, most men take advantage of us, they love having sex with us... Because they wait when we're not in good conditions [while experiencing a mental illness crisis], that was when they used the opportunity to abuse us sexually... I was infected with syphilis.* (Woman, mental impairment, Gulu)

> *When it reaches the time of having sex, he [a man living with HIV] will force on to you, because you don't have energy, he will force on to you… When you realise he has infected you, he will leave you, that is what is happening among women with disabilities.* (Focus group, hearing disabled people, Gulu)

Experiences of discrimination and accessibility barriers

Similarities in experiences of discrimination and accessibility barriers across health facilities

We observed two types of health facilities where people with disabilities sought SRH services: public health and private-not-for-profit facilities, with the latter mostly supported by faith-based organisations. Both types of health facilities provided similar healthcare service packages, ranging from maternal health to more specialised care at the level of referral hospitals. According to study participants, what distinguished both types of health facilities in service provision were modern contraception and mental health care services, which were provided by public health facilities but not private-not-for-profit facilities. Participants also reported that although health services were supposed to be free and available at all times in public health facilities, health staff were often absent, drugs were out of stock, and patients were referred to external clinics to get their medicine: “At times, the medicine is not there… You have to go and buy it from outside.” (Man, physical impairment, Omoro).

Contrary to common assumptions that private and faith-based services are of higher quality (34), we found that participants encountered similar obstacles in using SRH services, regardless of the type of health facility. Both private-not-for-profit and public health facilities showed unfriendliness toward users with disabilities, coupled with ableist and demeaning comments. Study participants also described being stigmatised as a result of physical (e.g. lack of assistive devices) and communication (e.g. sign language interpretation) barriers. Women with disabilities were particularly at risk of experiencing discrimination when seeking maternal health care and services, although men with disabilities were also affected.

> *When it comes to the time of birth, they [midwives] say “Have you seen? You! You climb on the bed!”. You cannot see where the bed is. You need to be directed [to where it is]. “You climb. Do it, as you were doing it when you were getting the child!”.* (Woman, vision impairment, Gulu)
>
> *When they [deaf women] are pregnant, it’s very hard to receive antenatal services and care. When they go to the hospital, on some occasions, they end up having a caesarian because there is a gap in communication between the person and the health service provider.* (Woman, hearing impairment, Gulu)
>
> *You know there are some people who are disabled, they just crawl and they’re unable to get from their places to the hospital. When they’re screened and they get that they’re HIV positive, they are supposed to come here and get medicine on a routine basis, but what they do is to send those who are able with their medical forms to come and get for them their medicine.* (Man, physical impairment, Omoro)

The non-participant observations (Table 3) corroborated what most participants shared in terms of inaccessibility of services, especially for health centres located further away from Gulu town, the major peri-urban area in Northern Uganda. Most health facilities were mostly not physically accessible, combined with the absence of adapted toilets and maternity beds. Further, none of the observed health facilities provided sign language interpretation. At the structural level, the Ministry of Health requires all health facilities to maintain a patient registry, which includes a specific column to collect disability data. However, this column was often left empty or was irregularly filled out by health service providers, therefore not identifying disabled people who sought treatment. Table 9 summarises the main observations of the seven health facilities visited.

Tableau 11. – Findings of non-participant observations

	Private-not-for-profit referral hospital	**Public referral hospital**	**Private-not-for-profit health centres level III**	**Public health centres level III**
Availability of accessible ramps and in acceptable condition	Yes	Yes	No	No
Availability of accessible toilets or separate toilets for people with disabilities	No	No	No	No
Availability of accessible maternity beds	No	N/A	No	No
Availability of accessible signage or sign language interpretation	No	No	No	No
Availability of a disability desk	No	No	No	No
Regular completion of Column 16 on Disability in the Ministry of Health's Patient Registry	No	N/A	No	No

Expectations to exercise rights despite implementation challenges

Despite diverse levels of knowledge about specific disability-related legislation and policy in relation to SRH, people with disabilities knew about the existence of policy implementation challenges. These included a lack of policy enforcement, limited budget allocation for disability issues, limited skills among health service providers to provide adapted services, lack of accessible mass education, and weaknesses among elected bodies, including disabled officials, to promote and protect the rights of people with disabilities. These policy implementation gaps had a direct impact on their experiences when using SRH services. People with disabilities clearly expressed that they expected to be able to exercise their rights, despite having a vague sense of what the pro-disability policies actually entailed. Most participants we interviewed expressed the idea of having the right to establish intimate relationships, become parents, use health services, work, study and simply be, despite powerful societal pressures to fit in and be "normal" (Woman, physical impairment, Amuru; Man, hearing impairment, Gulu).

> *I know that the rights of persons with disabilities are equal with others. What a normal person can do, a disabled person can do… someone with disability has the right to produce [have children], has the right to study, has the right to work, like any other person.* (Woman, physical impairment, Amuru)

Importance of policy implementation

In the view of many participants, the extension and translation of legislation and policy implementation would enable people with disabilities to use SRH services in which health service providers are culturally competent and provide high quality, respectful, and dignified care to people with disabilities. For others, policy implementation is operationalised through specific policy translation and accessibility measures, such as the provision of adapted maternity beds and ramps, necessary for them to access services. Without these facilitating factors, a gap is created between policy adoption and SRH service utilisation.

> *When you are pregnant, the laws [should] always take care of you when you come to the hospital, those nurses, those doctors, the laws always say they should give enough services without failure, without ignoring any person at all. This is what I know.* (Man, vision impairment, Amuru)

> *The thing is that these policies are just on paper!... When it comes to important documents like the Disability Act or the CRPD, nobody knows about it. People don't read, those laws are not promoted in the communities. They are in the hands of only those politicians and strong men, and strong organisations in Kampala. But ordinary people don't understand. Our leaders are a problem, but the policies are there. I have copies with me here. Am not a legislator, I cannot fight alone (laugh), you see. That's the problem. When you go to the health centre, it will be you alone, telling the nurse to do thing like this, construct a ramp there... They will just look at you. Our challenge is implementation.* (Man, hearing impairment, Gulu)

Multiple concrete solutions and recommendations proposed

To improve their sexual health and reduce experiences of discrimination regarding SRH services, people with disabilities expressed a range of recommendations. They went beyond identifying problems of policy implementation in the context of SRH service utilisation and clearly cited multi-level solutions that are motivated by social justice and equity which have the potential to improve the lives of people with disabilities. At the micro level, participants proposed that people with disabilities be empowered through education opportunities and community participation in awareness-raising activities. A woman with a physical impairment, from Amuru, recommended the following: "They should teach people with disabilities, because there are some that fear even to get pregnant. So, they should teach [people with] disabilities". Another study participant suggested more social participation.

> *The persons [people with disabilities] in the village should participate, they need to first understand these legislation and laws. And they themselves would see if it is truly being*

> *followed through. Then, they can start playing an active role in pushing for such services and advocating for such services.* (Man, hearing impairment, Gulu)

At the meso level, they insisted that family members and service providers be trained on the diversity of experiences of people with disabilities and on SRH rights, coupled with better accessibility of basic infrastructure (e.g. toilets and ramps) as well as information and services (e.g. provision of sign language interpretation). Specifically, a woman with vision impairment, from Gulu, recommended that “The family needs to be educated on how people with disabilities can be treated, so they are also able to help themselves”. Improvement in making communication more accessible was also recommended:

> *All these health service providers should learn sign language. It will be easy for anyone who is deaf to access services. For example, a pregnant woman would easily communicate to any person in maternity. She can be helped when a doctor knows simple signs.* (Man, hearing impairment, Omoro)

At the macro level, people with disabilities highlighted the necessity to move beyond a policy on “paper” toward the implementation of measures that will have a positive impact on the sexual rights of people with disabilities, such as allocating adequate budgets for the expansion and development of disability-sensitive services. Indeed, participants indicated that the lack of data on people with disabilities was a social justice challenge and recommended that more research be conducted to document and collect information on disabilities, such as impairment type.

> *For example, at the sub-county level, they don’t have the capacity of having transport to move deep down in the village there. But if you go at the sub-county to check on their budget, they don’t have a budget for that. That is if the government can put some budget, it would help them move to villages, to the grass root, to persons with disabilities.* (Man, vision impairment, Amuru)

> *I feel another thing is… to do research. A recommendation. One research about persons with disabilities and the differences [how] to help service providers and law makers to be able to understand how best to serve persons with disabilities, without just putting a law or a policy without doing a proper research to understand disability itself in relation to reproductive health service provision. A person who has experience in the difference in disabilities would serve people with disabilities the best way.* (Man, vision impairment, Amuru)

Discussion

This paper provides a novel contribution to the literature by examining how people with disabilities perceived their utilisation of SRH services in the context of legislation and policy implementation in Northern Uganda. We report three major findings. First, through an intersectionality-informed analysis, we were able to broaden the evidence base regarding the complexities of experience across the diversity of women and men with disabilities. People with disabilities, women in particular, experienced multiple concurrent intersections related to gender, disability, and violence when using various SRH services. These intersections were complex and multilayered, with disability interconnected with both gender and violence. It has been reported in the literature that the prevalence of all forms of violence, including sexual violence, is higher among people with disabilities relative to people without disabilities (10). A systematic review and meta-analysis conducted among adults with disabilities in sub-Saharan Africa found that people with disabilities were more at risk for HIV compared to non-disabled people, with an increasing gradient of risk for HIV based on gender and disability (9). The reasons cited for this heightened vulnerability to HIV were limited access to HIV prevention and a higher risk of sexual violence (35). Our study also complements the findings of a meta-synthesis on gender, disability, and reproductive health in sub-Saharan Africa which reported the exacerbation of gendered roles among women with disabilities who sought reproductive health services (36). People with disabilities, especially women, were considered “not normal” and were expected not to have children. The societal norm for “normalcy” conferred to abled-bodies highlighted the denigration of and the insidious impact of ableism, upon disabled bodies (37). According to intersectionality theory, power structures such as ableism shape the experiences of privileges for abled-bodied and penalties to those who are disabled (25).

Second, women and men with disabilities experienced a wide range of attitudinal, communication, and physical barriers when accessing and using SRH services, irrespective of the type of health facilities being public or private-not-for-profit. While the finding related to barriers faced by people with disabilities is not new and supports what has already been reported in the literature (7, 8, 38), the finding related to the similarity of the challenges faced by people with disabilities across health facility type is novel. Past studies have described higher levels of satisfaction, a proxy to quality of care, among a wide range of users of faith-based (private-not-for-profit) health service providers, compared to public facilities in Africa (34). Across the continent, faith-based health service providers and organisations are seen as playing a key role in service provision in weakened health systems, such as in post-conflict settings (34). People with disabilities were not passive when discussing the discriminatory barriers to the use of SRH services. They insisted on their sexual rights in addition to their reproductive health rights, and that these rights be treated as equal to those of non-disabled people. This is in sharp contrast to the local social silence surrounding disability and sexuality (2).

Third, given the opportunity to express what they thought they knew about existing laws and policies promoting their rights, people with disabilities were consciously reflecting on their self-awareness of the relationships between policy and SRH service utilisation (25). This analysis also supports moving beyond individual risk factors and highlights the need to examine power structures, such as ableism, which gives unearned privileges to abled-bodies while oppressing people with diverse bodies and abilities (39, 40). As per the recommendations made by people with disabilities, a transformative shift is required in how society views and considers people with disabilities when insisting on their disability and SRH rights (25). They explicitly suggested means of being better empowered at the community level as well as implementable and enforceable actions in the health system and at a national level. The people with disabilities positioned themselves as active policy actors. This shows a desire and commitment to social justice and equity for people with disabilities within a larger system of sociopolitical structures (23) and is coherent with the transformative nature which the intersectional approach is promoting (25).

Limitations

The perspectives of other policy actors namely health service providers, disabled people's organisations, international organisations, and national policy-makers interviewed in the study were not included in this manuscript. Our goal was to present an in-depth analysis from the perspective of individuals with disabilities and we prioritised their voices as they are often ignored and silenced (2). As a result, the perspectives of other policy actors are absent from this manuscript and analysis, therefore not addressing any possible convergent or divergent findings at the micro level. Nonetheless, the rich accounts from the people with disabilities provided critical insight into their experiences and constitute the foundation for further differential analyses (41). We did not include the fully privatised health facilities among cases to contrast. Having this third group of health facilities could have provided a different understanding of SRH service utilisation. However, given that they are less numerous than PNFP and public health facilities in the three target districts (42) and that their services are generally costly, it is less likely that people with disabilities would use their services (34). Finally, we used translation and sign language interpretation during interviews and focus groups, and cross-cultural translation and interpretation may have added another level of meaning (43). To mitigate this risk, we piloted our interview tools, developed a bilingual glossary of key research and SRH vocabulary, followed by verifying the translations.

Conclusion and implications for policy and programmes

This study provided substantial evidence of the intersecting discrimination experienced by women and men with disabilities and the numerous barriers they face using SRH services. An intersectionality-informed analysis highlighted the complex relationships and interactions between gender, disability, the utilisation of SRH services, and the expectation that people with disabilities can exercise their rights despite policy implementation hurdles. The concrete multiple level recommendations put forth by people with disabilities, are already enshrined in the disability rights articulated in the CRPD, as ratified by Uganda in 2008. At the macro level, the findings presented here provide evidence-based arguments to the current national review process of the Ugandan Disability Act to ensure that both policy and its implementation align with the objectives, scope, and language promoted in the CRPD. People with disabilities recommended tighter enforcement of policy implementation through improved budget allocation for disability and more accountability from policy-makers and implementers. At the meso level, people with disabilities insisted that health professionals as well as family members be sensitised and trained on disability-sensitive SRHR to remove attitudinal, physical and structural barriers. The experiences and recommendations of people with disabilities should be used to inform the monthly and annual review meetings of District Health and Community Development Offices for further monitoring and follow-up. Within specific health facilities, recommendations pertaining to accessibility improvements can be integrated during two specific periods: 1) during annual strategic review and planning meetings, and 2) during decision-making processes for service and technical resource budget allocation. At the micro level, people with disabilities further stressed the importance of being empowered through social participation, education, and sensitisation on their SRHR. In conclusion, capitalising on the global objectives for universal healthcare access, “Leaving No One Behind” particularly matters for women and men with disabilities when seeking SRH services. Universal health coverage can be operationalised in actionable measures, where its universality meets with social justice (44).

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4.3 Manuscript 3: Policy implementation challenges and barriers to access sexual and reproductive health services faced by people with disabilities: An intersectional analysis of policy actors’ perspectives in post-conflict Northern Uganda

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Abstract

Background: Emerging from a 20-year armed conflict, Uganda adopted several laws and policies to protect the rights of people with disabilities, including their sexual and reproductive health (SRH) rights. However, the SRH rights of people with disabilities continue to be infringed in Uganda. We explored policy actors' perceptions of existing pro-disability legislation and policy implementation, their perceptions of potential barriers experienced by people with disabilities in accessing and using SRH services in post-conflict Northern Uganda, and their recommendations on how to redress these inequities.

Methods: Through an intersectionality-informed approach, we conducted and thematically analysed 13 in-depth semi-structured interviews with macro level policy actors (policy-makers, international organisations, and national non-governmental organisations); seven focus groups at meso level with 68 health service providers and representatives of disabled people's organisations; and a two-day participatory workshop on disability-sensitive health service provision for 34 healthcare providers.

Results: Through an intersectionality-informed approach, we conducted and thematically analysed 13 in-depth semi-structured interviews with macro level policy actors (national policy-makers and international and national organisations); seven focus groups at meso level with 68 health service providers and representatives of disabled people's organisations; and a two-day participatory workshop on disability-sensitive health service provision for 34 healthcare providers.

Conclusion: This study provides substantial evidence of the multilayered disadvantages people with disabilities face when using SRH services and the difficulty of implementing disability-focused policy in Uganda. Informed by an intersectionality approach, policy actors were able to identify concrete solutions and recommendations beyond the identification of problems. These recommendations can be acted upon in a practical road map to remove different types of barriers

in the access to SRH services by people with disabilities, irrespective of their geographic location in Uganda.

Keywords: Intersectionality-based policy analysis, people with disabilities, sexual and reproductive health, health equity, policy implementation, Uganda

Key Messages

Implications for policy-makers

- An intersectionality-informed analysis goes beyond describing a problem. It enables policy actors and researchers to examine intersecting social identities, diverse sources of knowledge, and multilevel factors, and to consciously explore complex policy issues for transformative policy solutions.
- Pro-disability policy implementation challenges are multiple and people with disabilities still experience physical, attitudinal, communication, and structural barriers to access to and use of SRH services in post-conflict Northern Uganda.
- Policy actors, including health service providers, disabled people's organisations, national and international organisations, and national policy-makers, proposed numerous recommendations and solutions which can be applied within the normative space created by the recent adoption of the 2019 Disability Act.
- The combination of these recommendations contributes to redressing situations of social inequity and injustice, and advances Uganda's progress towards the Sustainable Development Goals for universal health coverage.

Implications for the public

The fundamental rights of people with disabilities, including their SRH rights, continue to be violated despite the existence of many laws and policies adopted to promote the rights of people with disabilities in Uganda. The study found that multiple forms of barriers and policy implementation challenges still exist, preventing people with disabilities from accessing and using SRH services. Many actionable solutions at individual, community, and national levels exist and can be implemented to redress historic health inequities and injustice. People with and without disabilities, health service providers, civil society organisations, and policy-makers have a renewed opportunity to contribute to concretely ‘leave no one behind’, as promoted by the Sustainable Development Goals.

Background

More than 180 Member States have ratified the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD), which aims to promote, protect and ensure the fundamental human rights of people with disabilities.[1] The CRPD was adopted in 2006 and came into force in 2008 after two decades of negotiation among international organisations, activists, disabled people's organisations (DPOs), and governments.[2] According to the CRPD, people with disabilities are people "who have a long term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others".[3] Worldwide, one person in seven is estimated to live with some form of disability, with 80% of them living in low and middle resource income countries.[4] In 2019, the UN report on the realisation of the Sustainable Development Goals stated that despite improvement in development, people with disabilities continue to experience exclusion and face numerous barriers to their full participation.[5]

In sub-Saharan Africa, Uganda cited as an exemplary disability rights promoter,[6,7] was among the first countries to ratify the CRDP in 2008.[1] One fifth of its population was estimated to live with some disability.[8] In 1995, Uganda enacted its Constitution, and in 2005 it was amended, providing a legal space for the promotion of people with disabilities' rights. In the following years, several legal instruments that contain sections or articles related to the rights of people with disabilities were adopted. Among these, Uganda approved the Parliamentary Election Statute in 1996 and the Local Government Act in 1997. These laws, respectively, make provision for people with disabilities to be elected to Parliament, and at the district and sub-county levels.[6] In 2003, the National Council for Disability (NCD) Act was adopted and specified the role of this national body in the promotion, monitoring, and advocacy of equal opportunities for Ugandans with disabilities.[9] Three years later, Uganda further adopted a Disability Act with sections related to such as accessibility, social services, and health, including access to reproductive health and user-friendly health facility materials.[10]. In September 2019, Uganda updated this Act with a more comprehensive version, referencing the CRPD and using a similar definition of disability.[11]

Emerging from a 20-year armed conflict which most affected its Northern region, Uganda had to rebuild a weakened health system. It witnessed high levels of sexual and gender-based violence and unwanted pregnancies as well as poor access to safe motherhood[12,13] and reproductive health care.[14] Despite an arsenal of well-intentioned legal tools adopted over several years to promote and protect the human rights of people with disabilities, including their sexual and reproductive health (SRH) rights, people with disabilities continue to have limited access to routinely accessible SRH services in Uganda. Studies examining SRH service utilisation reported ongoing physical and costs barriers,[15,16] attitudinal challenges,[15] and multilayered discrimination and inequities[17] experienced by people with disabilities. The 2018 Guttmacher-Lancet Commission also highlighted that people with disabilities constitute a group 'with specific disadvantages' and are 'subjected to harmful stereotypes and myths' which contribute to their heightened risk of physical and sexual abuse.[18]

Intersectionality-Based Policy Analysis (IBPA) can critically address social inequities and multiple discriminations experienced by people with disabilities.[19] It provides a flexible framework to enable policy actors, researchers, and group advocates to examine diverse sources of knowledge, intersecting multiple social identities and multilevel factors, and to explore complex policy issues for transformative policy solutions, beyond describing the problem.[20] Intersectionality addresses the interrelationships among multiple social identities, social inequities, power dynamics, context, and complexity.[21] Principles promoted in the IBPA are the importance of acknowledging intersecting social categories, a multilevel analysis, power structures, the context, the diversity of sources of knowledge, reflexivity, and social justice and equity.[22] Before critical studies started to be interested in intersectionality to highlight inequality and multiple oppressions experienced by marginalised groups, [23-27] Black feminists and lesbians of the Combahee River Collective were already embracing core concepts of this framework and approach in their struggle in the 1970s.[28] Intersectionality was first coined in 1989 by Kimberlé Crenshaw to address the multiple discriminations faced by African American women workers who were protected by neither anti-racism nor anti-sexism legislation.[24,29]

The study reported here aimed to understand and document how policy actors perceive the relationships among legislation and health policy and the utilisation of SRH services by people with disabilities in the post-conflict Northern region of Uganda. We were interested in exploring policy actors' understanding of existing pro-disability legislation and policy implementation, their perceptions of possible discriminations experienced by people with disabilities in accessing and using SRH services, and their recommendations on how to redress these inequities. This paper reports the qualitative findings on the perceptions of policy actors at meso and macro levels, drawing from a larger body of evidence from a mixed methods study which also involved women and men with disabilities (micro level). Perspectives of women and men with disabilities have been reported previously.[17]

Methods

The qualitative study methods are reported in detail elsewhere and summarised here.[17] From November 2017 to April 2018, we conducted our study in the districts of Gulu, Amuru, and Omoro in the Northern region and in Kampala, the capital of Uganda. To assess the rigour of our qualitative research, we followed the Consolidated Criteria for Reporting Qualitative Research (COREQ).[30]

Study participants

A total of 115 people participated in the study: at the national level, 13 policy actors took part in in-depth semi-structured interviews; and at the community level, 68 health service providers and DPO representatives participated in seven focus groups of the Northern districts of Gulu, Amuru, and Omoro. Additionally, 34 health service providers and managers participated in a 2-day participatory workshop on disability-sensitive health service provision (Table 10). Participants were purposefully recruited, following a snow-ball approach in which initially recruited study respondents recommended other potentially relevant policy actors that could speak to the research objectives.[31] National policy actors based in the capital of Kampala were selected based on different types of organisations they belonged to and who were knowledgeable of disability and SRH related policy and programmatic processes in Uganda. Health service providers were recruited from seven health facilities, with a balance of gender and public and private-not-for-profit health facilities. Recruitment of study participants continued until saturation was reached.[32]

Tableau 12. – Sample characteristics

Source	Total	Women (%)	Men (%)	Disabled (%)
National level policy actors	**13**	**6 (46)**	**7 (54)**	**5 (39)**
Policy-makers from government	6	3	3	3
Representatives of international organisations/NGOs and national NGOs	7	5	2	2
Community level policy actors	**68**	**36 (53)**	**32 (47)**	**7 (9)**
Health service providers	60	34	26	1
Representatives of DPOs	8	2	6	6
Workshop participants	**34**	**19 (56)**	**15 (44)**	**0 (0)**
Health staff	27	16	11	0
Health managers	7	3	4	0
Total	**115**	**61 (53)**	**54 (47)**	**12 (10)**

Note: Due to rounding of percentage, the total might slightly be over or below 100.

Data collection

We used in-depth semi-structured interviews, focus groups, and a participatory workshop to triangulate findings.[32] These techniques were selected to further increase the trustworthiness of qualitative research process.[32] For fine-tuning of data collection tools, we first discussed them among the research team, and pre-tested each tool in focus groups and with sign language interpreters to improve comprehension. The IBPA framework informed this research and was adapted in our interview and focus group guidelines, which included two sets of questions: [20] The first set constituted descriptive questions related to the identification of problems related to SRH use among people with disabilities and information on policy implementation processes. The second set was composed of transformative questions related to solutions aimed at reducing inequities and addressing problems identified. Individual and group interviews were conducted in English, and research assistants translated concurrently questions and answers in Luo, when needed. For the few participants with hearing impairments, we hired locally qualified Ugandan sign language interpreters who were fluent in English, Luo and sign language. Each individual or group interview lasted around 60 minutes and was audio recorded with the permission of study participants.

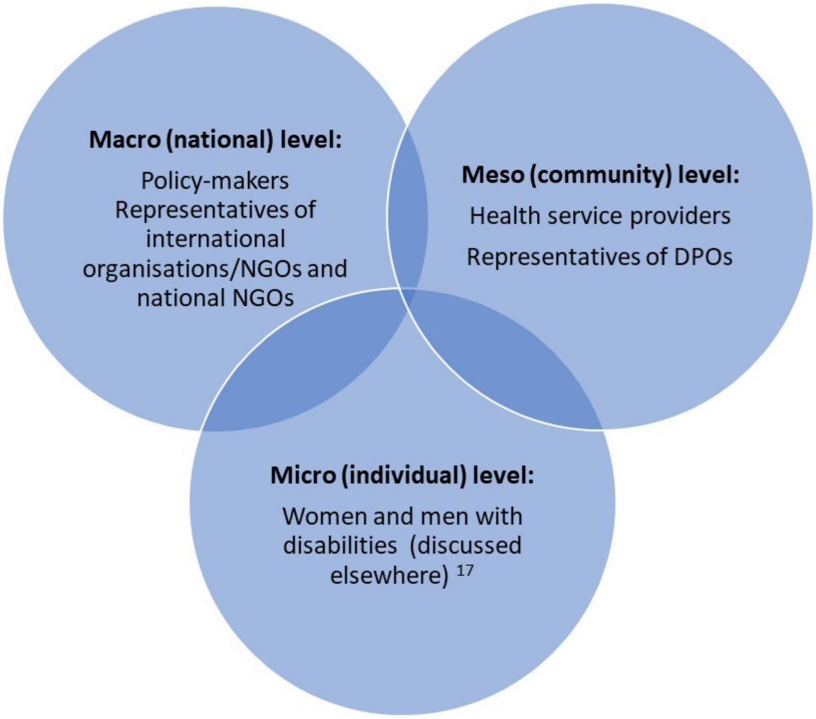
Consistent with the transformative component of the IBPA emphasising the search for solutions, we organised a 2-day participatory workshop on disability-sensitive service provision, following the numerous requests we received from interviewed health service providers. The workshop objective was to discuss the barriers people with disabilities encountered when seeking SRH services and the solutions to address concretely these problems. It was organised for health service providers and managers of seven health facilities of three districts. On the first day, the preliminary findings of the study and the existing pro-disability policies and legislation in Uganda were presented. Two women, one with a physical impairment and another with a mental impairment, and two men, one with a hearing impairment and the second with a vision impairment, were invited as experts to share their experiences and recommendations on how to improve accessibility and service delivery. On the second day, a deaf trainer and a hearing trainer who knew sign language facilitated a series of hands-on sessions for participants to learn the basics of Uganda sign language in relation to health and SRH services. With the permission of workshop participants, we documented the outcomes of group discussions and exchanges.

To ensure confidentiality, all citations from study respondents have been depersonalised and are referred to in this paper by their professional function only. For health service providers, the focus group (FG) number is specified.

Analysis

Informed by the intersectional framework, a thematic analysis was adopted due to its flexible approach as well as the opportunity this type of analysis provides us in managing “a large data set" in a more structured manner.[33] Our thematic analysis following specific steps which are described in detail elsewhere,[17] and briefly summarised here. Relevant themes emerged after a series of iterative activities which included listening to all recordings, reading a couple of times all interview transcripts, and writing down analytical memos along the process. Transcripts were coded through QDAMiner 5.0.31 (Provalis) following an inductive and deductive approach. Our analysis was guided by the key principles of the IBPA framework of intersecting social categories, multilevel analysis (Figure 7), power structures, time and space (context), diverse sources of knowledge, reflexivity, and equity and social justice.[22] Specifically, when identifying themes, we were attentive to how policy actors answered descriptive and transformative questions posed during individual and group interviews as well as during the workshop.[22]

Figure 8. – Multilevel analysis of policy actors



Results

We report here the findings of the perceptions of health service providers and representatives of DPOs, at meso level, and those of policy-makers and representatives of international organisations/NGOs and national NGOs, at macro level. They complement the findings of a larger body of evidence on the perceptions and recommendations of women and men with different types of impairments, at micro level, which highlighted the intersectional discriminations experienced by people with disabilities when using different types of SRH services.[17] Although we interviewed diverse policy actors at meso and macro levels, they shared several common narratives around the relationships between pro-disability legislation and policy and the use of SRH services by people with disabilities in the post-conflict Northern region of Uganda.

This study identified four major themes across policy actors, levels, and districts, as follows: 1) policy and legislation application challenges; 2) acknowledgment of the existence of multiple barriers faced by people with disabilities in accessing and using SRH services; 3) lingering impacts of the conflict on people with disabilities' access to services; and 4) multilevel recommendations to remove barriers.

Policy and legislation application challenges

Policy actors mentioned several challenges related to the implementation and enforcement of pro-disability policy and legislation in Uganda. Central to a lack of enforcement is a widespread lack of awareness and training on disability issues among policy executors, particularly health professionals, of existing key policy and laws which focus on the rights of people with disabilities. To some health service providers, this implementation gap was illustrated by inaccessible services and infrastructures.

> *"It's unfortunate that most of these things [policies] stop at Kampala or in offices. They [policy-makers] don't come to the ground…. Myself, I have even never seen the [Disability] Act… This is something that they should also consider if it must work out very well…*

> *because we should work with references… It was not availed….We also try to improvise. It is there, though it's not [up] to standard. But it is a requirement that we should at least create accessible [structures]… It's not very functional because some of our clients… are still crawling."* (Health service provider, FG9, Omoro)

Awareness was identified as essential in the pathway to policy implementation; however, a lack of prioritisation and budgeting were also identified as detrimental to an effective response to disability issues from ministry to local levels. The deficient financial capacity at governmental level was perceived to be influenced by policy-makers' worldviews and their lack of sensitivity towards disability issues.

> *"I mean the issue of mindset has affected most of our implementation. If I showed you the percentage for the [disability] budget… Like the law (…) it should be backed by resources, financially. If it is a government building, let's make sure it's accessible. That means you need money to change... Of the Ministry, I think it's 0.1, is it 1% or something less than 1%?"* (Government policy-maker, Kampala).

Although Uganda has adopted many policies promoting the rights of people with disabilities, policy actors insisted on the importance of supervision and monitoring: "*There is no committee in place to supervise the policies that have been approved, so it is upon the organisation to take it on or not.*" (Health service provider, FG4, Gulu). According to policy actors, the 2006 Disability Act was not substantial enough to hold the Government imputable to its policy intent: "*People have raised the issue that the Act has so many things missing… [The Act] doesn't hold the Government accountable*." (Government policy-maker, Kampala). They further mentioned that the NCD and the civil society organisations were not fully playing their role of advocacy for and monitoring of accessible services for people with disabilities: "*It's the role of disability unions and umbrellas to ensure that they engage institutions so that they can sign some memorandum of understanding… help push for disability-friendly services*." (National NGO representative, Kampala).

Acknowledgment of the existence of multiple barriers faced by people with disabilities in accessing and using SRH services

Irrespective of their background and function, policy actors at both community and national levels reported similar barriers regarding the access to and utilisation of SRH services experienced by people with disabilities. Four types of barriers were identified: physical, attitudinal, communication, and structural (related to systems, policies, and norms). According to respondents, the lack of accessible equipment and infrastructure, such as toilets, was prevalent and prevented people with disabilities, especially women, from having optimal access to maternal and reproductive health services. Health service providers were frank about the physical accessibility gaps that they observed in their health facility, prompting some of them to revisit their service delivery approach.

> *"Especially in our… maternity ward. You find that it is very hard to deliver them. Sometimes, we prefer to deliver them down on the floor. Sometimes, if you have the energy, you, as the medical person, you have to lift her up on the bed. She delivers. Again, you lift her down or you use a trolley to push her… In case of an operation….We don't have the equipment for people with [physical] disabilities like [involving] lower limbs. There is no way you can help her… [For] most of them, we deliver them on the floor. The delivery bed is made for normal people…. That is one of the challenges we're having ."* (Health service provider, FG4, Gulu)

At the attitudinal level, participants reported that for many health service providers in Uganda, people with disabilities were perceived to be sexually inactive and incapable of entertaining sexual activities or having children. This common perception lead health staff to believe that people with disabilities did not need to use any SRH services. This ableist attitude could deny people with disabilities the possibility of receiving SRH services like anyone else.

> *"[The] majority of them [health* service *providers] do not think disabled people are clients for reproductive health services… They imagine they might not need these services… I just asked them a question and I said: "If I come here with a wheelchair, rolling into your health*

> *centre, what will you see?", they told me: "We see a wheelchair"! "So, you don't see the person?!"... I said "It's just your work to check whether the baby is lying there [she was pregnant at that time], and not to look at my disability. It's the leg that is disabled… My womb is okay!"* (Government policy-maker with a disability, Kampala)

According to representatives of DPOs, most of whom were also people living with different impairments, the negative and discriminatory attitudes of health service providers were of concern. Often, these attitudes acted as deterrents among people with disabilities to seek care for health conditions that would necessitate medical attention. Moreover, DPO representatives questioned the professional ethics of health staff when they were providing SRH services.

> *"I don't know whether that is part of their code of conduct, but most of them are arrogant to clients at the hospital. This is a big barrier because most of our persons with disabilities would not want to go to [the] hospital where they are shouted at. In most cases, our health service providers do not know how to take care of [people with disabilities]. I think [that is] a very big barrier in accessing sexual health [and] reproductive services."* (DPO representative, Gulu)

When further probed, most policy actors mentioned the communication barriers which people with hearing impairments faced. In Uganda, sign language is officially recognised. According to the Disability Act, sign language should be "introduced into the curriculum of medical personnel".[10] Interviewed health service providers reported receiving no training in this regard during their professional training or continued education opportunities. The inability of health service providers to communicate health information or instructions to people with hearing impairments led to sub-optimal provision of SRH care. These situations could be detrimental to people with disabilities and frustrating to health service providers who needed to find alternatives to understand the needs of people with hearing impairments.

> *“Last week, we received one [patient who was a] deaf person. The problem was how to help? Because they use sign language… but none of us has been trained… I was trying to handle, doing signs… but I know [figured out] what she wanted because she came with a paper for HIV test… But when I wanted to talk to her, she cannot understand… I took her to the [HIV] counsellor, [but] I don’t know how they handled it.”* (Health service provider, FG6, Omoro).

At a structural level, one of the most important barriers policy actors reported was the lack of disability data collection and monitoring of service delivery. Although the Ministry of Health included a specific column on disability (Yes/No) in the patient registry book made available throughout health facilities in the country, this information was seldom or inconsistently collected. Most of health service providers did not receive any training on how to obtain and use data on disability nor did analyse the information collected when this was done.

> *“We realised that we are not capturing our data well. And if [it] is captured… we are not reporting… As you report something, you should be able to analyse, and you put in practice… At least, there should be a strategy where… even in the district level, [and at] the facility [level], we should be able to generate the number of people who are having disability, so… it can help with planning. We don’t know how many clients we have who are disabled.”* (Health service provider, FG9, Omoro)

During the workshop, participants had the opportunity to learn directly from people with disabilities who acted as experts in their SRH care trajectory. The four people with disabilities explained who they were in their community, what happened to them when seeking health services, and how they were often mistreated by health service providers. They also described the multiple barriers they faced. While sharing their stories, they also made sure that health staff recognised their strengths and resilience, beyond their impairments and the limitations they were facing due to systemic obstacles, at environmental, attitudinal, and communication levels.

According to workshop participants, this workshop helped them to be more reflexive and enabled them to better understand the situations of people with disabilities.

> *"I want to apologise. We have been working on people with different disabilities, but we didn't know what you people were going through. I want you to forgive me and us, the health workers… I would like to tell you that we shall see that we change the quality of care because disability can come to anyone, any time. So, I want you not to think that you are different from us. We shall make a change, I promise."* (Workshop participant, health manager, Gulu)

Lingering impacts of the conflict on people with disabilities' access to services

For many respondents, the impacts of the conflict were still vivid despite the end of the conflict through a signed agreement between the Government and the Lord's Resistance Army rebels in 2006.[34] According to them, the armed conflict contributed to "the breakdown of the formal system" (International NGO representative, Kampala), and generated widespread disabilities and trauma for Northern Ugandans. It affected family structure, with persisting sequelae to date. Others mentioned the high level of gender-based violence which occurred during the conflict. Many young women and girls became "*child mothers*", after being raped "*in the bush*", a term referencing the period in rebel captivity (Health service provider, FG3, Amuru). These situations were compounded by limited access to SRH services: "*Access to all health services or reproductive health services for people with disabilities is [was] not easily accessible. And it's worst in Northern Uganda. This is [was] due to war*." (National NGO representative, Kampala).

Policy actors believed that the impacts of the conflict were "*worse for people with disabilities*" (International NGO representative, Kampala), especially "*women with disabilities in the North [who] are still recovering from war*" (Government policy-maker, Kampala). In the context of insecurity due to armed conflict, families, in some instances, had to save their own lives amid the fighting, leaving their relatives with disabilities behind: "*So, if you're disabled and you have all* *these sorts of needs, and the family has to decide between running away to safety and helping you to access a service?*" (National NGO representative, Kampala). Paradoxically, while the conflict created different forms of hardship for people with and without disabilities, camps that were erected to cater for internally displaced Northern Ugandan populations also became a source of support considered as *"[one stop] shop centre[s]*" (Health service provider, FG9, Omoro) where all services such as food, education, and healthcare were provided for free, for all. However, as the conflict ceased, many NGOs stopped providing their humanitarian services, and people, including many with disabilities, had to fend for themselves and survive without any support.

> *"But after that [the conflict], people were dispersed… They are now coming from different places. [This situation has] created distance from points of service delivery. If a crippled person has to move for more than 10 km to seek for healthcare, that has become very hard. I would say that this is negative to them because it is not very easy for them now to access services, as it used to [be in the camps]."* (Health service provider, FG9, Omoro)

Based on the accounts of a few policy actors, a life spent in camps not only provided immediate benefits such as accessible and free services but also generated long-term social negative consequences. According to them, people lost their social compass and became dependent upon external sources to receive services. This situation might have created other social consequences given the lack of accessible services of proximity, including healthcare.

> *"The post-war effect in Northern Uganda has been there. [There] is still [a] dependency syndrome. We had so many NGOs which were supporting the household activities. Most NGOs have gone away, so people have [feel] the effects now. People resorted to drinking…. We have child-headed families because of… loss of parents… loss of dear ones."* (Heath service provider, FG3, Amuru).

Multilevel recommendations to remove barriers

At both community and national levels, policy actors described in detail the multiple barriers people with disabilities encountered when using health and SRH services. On the other hand, policy actors also identified specific recommendations to redress these barriers and better promote the rights of people with disabilities as enshrined in adopted policies and laws. Policy actors were reflective about their shortcomings, but they also went beyond listing problems. They felt the urgency to instill measures in their institution and capitalise on the strengths of people with disabilities to induce change.

> *"My recommendation goes to the Quality Assurance team [of the hospital]… Concerning people with disabilities, much has not yet been done. So, I would advise that we get a committee that looks at the welfare of persons with disabilities, to see that this kind of training should be continuous. And disabled who are doing good things like these ones [people with disabilities invited in the workshop as experts] should be used as role models to the other disabled persons."* (Workshop participant, health service provider, Gulu)

Given the intersectoral and multilayered nature of barriers to access SRH services and policy and legislation implementation challenges identified, policy actors acknowledged that solutions did not lie at a single location, nor could they be addressed by only one actor. Rather, respondents recommended solutions targeting specific policy actors. At the micro level, people with disabilities and their families were named, highlighting the importance of empowerment and the exercise of the basic rights of people with disabilities. At the meso level, both health service providers and local civil society organisations (CSOs) were mentioned as playing a crucial role in concretely removing barriers and in defending the rights of people with disabilities they served. Respondents argued that at the macro level, the Government and elected bodies held a prime position of being held accountable and responsible for putting in place actionable measures such as devoting financial and technical resources to mainstream disability in service delivery, including SRH services. The National Council for Disability was pinpointed as pivotal in monitoring the Government's policy and legislation focusing on the promotion and protection of disability rights.

National and international CSOs identified the need for more research and disability data collection and analysis for improved planning of services for people with disabilities.

The next table summarises the main recommendations made by policy actors at community and national levels during the interviews, focus groups, and participatory workshop, targeting the three levels of actors at micro, meso, and macro levels.

Tableau 13. – Main areas of recommendations proposed for and by policy actors to improve the access to and utilisation of SRH services by people with disabilities

Levels	**Recommendations**
At micro level People with disabilities and families	▪ Awareness-raising of people with disabilities and their families on disability rights: *"Awareness-raising is needed at all levels from family, health staff to policy-makers."* (Government policy-maker, Kampala ▪ Empowerment of people with disabilities and development of their leadership: *"Using people with disabilities themselves, train them. Use them to target their membership, that would be key."* (DPO representative, Gulu)
At meso level Health service providers and local authorities	▪ Improvement of accessibility for disability-sensitive health-related infrastructure, equipment, and services: *"The delivery beds... When I went to the Midwifery Day in Fort Portal, Karamoja district came with a bed that I have never seen… those are the beds [for] the use for people with disabilities… They [policy-makers] could come to the hospital, [and] find out if there are people who are interested in learning sign language… We wait for these things to be integrated into our curriculums."* (Health service provider, FG2, Omoro)
Local civil society organisations	▪ Advocacy for and representation of people with disabilities' rights: *"… to create a network of people working in the area of disability so that we can have a unified voice to address the issues, not only health issues but other social issues that affect people with disabilities."* (DPO representative, Gulu)
At macro level Government	• Monitoring and evaluation of policy processes: *"The Government needs to [have a] committee in action on the implementation of*

	the existing laws. The Government must ensure that the accessibility must be universal… to all… They should widen their scope of consultations when they are coming up with their policies and guidelines… so that you can be in position to intersect, and also ensure that the needs of all the categories of people, whom you have consulted, are taken care of." (DPO representative, Kampala)
National Council for Disability	▪ Disability mainstreaming with specific budget allocation: *"One priority is to mainstream disability at all levels of MCH [maternal and child health] and SRH, in all levels, but don't separate people with disabilities. It should be integrated, data collected, and with a budget!"* (International organisation representative, Kampala)
National and international civil society organisations	▪ Structural strengthening of the National Council for Disability: "*[There are] too many small disability organisations, and poorly coordinated. The NCD is not strong because too small…. Competition disadvantages, this decreases their bargaining power… If they are together at the same time, they have more power to ask for change. So, they need to be strong and give a united voice from all categories of people with disabilities for advocacy and lobbying."* (Government policy-maker, Kampala) ▪ More systematic research and data collection on disability issues: *"The role of research… is to make sure you collect the appropriate and relevant data [which can] inform the service institutions so that they create the demand of services for [people with] disabilities."* (National NGO representative, Kampala)

Discussion

This paper emphasises the plurality of voices, the exploration of both problems and solutions, and the triangulation of methods. An important finding of this study is the convergence of views collected from policy actors at community and national levels, who identified multiple policy implementation challenges and barriers to SRH service use experienced by disabled users. From the study findings, we highlight learnings which emerged from our approach of using both an intersectional analysis and a participatory workshop to validate and enrich study findings. Study respondents referred to the principles of intersectionality related to knowledge, power, multilevel analysis, and the importance of context, equity, and reflexivity. Specifically, we address the following three points of discussion: 1) how diverse sources of knowledge and the reflexivity of policy actors can lead to new insight about their privileges and the discrimination and barriers faced by people with disabilities; 2) the importance of the post-conflict context in understanding policy implementation challenges and the experiences of barriers to access among people with disabilities; and 3) the capacity of policy actors to propose transformative solutions to redress health inequities faced by people with disabilities.

First, through an intersectionality-informed analysis, we were able to analyse the different voices of different groups of policy actors. The study methodology capitalised on their distinctive social positions to shed light on their understanding of the relationships among legislation, policy and its implementation, and the use of SRH services by people with disabilities. Their views corroborated the perceptions of people with disabilities reported previously.[17] People with disabilities experienced multiple physical, attitudinal, communication, and structural barriers. In particular, the sister study to this paper identified inequitable access to SRH services in health facilities and numerous intersectional discriminations related to gender, disability, and experience of violence.[17] These barriers faced by people with disabilities have been discussed in the literature regarding Uganda[15,16,35], other sub-Saharan African countries,[36-39] and globally.[40] Furthermore, the interviewed policy actors were reflexive about their privilege, and the effects of oppression created by their inconsideration of the needs of people with disabilities. They recognised the effects that these internalised biases had on the experiences of access to and use of SRH services by users with disabilities.[41,42] According to the IBPA principles, acknowledging the diverse sources of knowledge and highlighting the reflexivity of policy actors enable them to reflect upon the power and privilege they own.[42] This realisation is a further step toward health equity and acts as a catalyst toward social justice.[42]

Second, the post-conflict context in Northern Uganda was considered in our analysis. Our findings showed that time spent in the camps during and after the armed conflict and the post-conflict period has heavily affected Ugandans. The post-conflict continues to disadvantage people with disabilities in the Northern region, up to the current day. In an intersectionality approach, time and space (context) are key components in analysis.[42,43] Literature has reported that the armed conflict in Uganda has caused limited access to and poor quality of maternal and reproductive health services,[14] while sexual and gender-based violence aggravated the physical and psychological health of women.[12] According to a systematic review on the long-term effects of armed conflicts, such as in Uganda, findings reported two types of effects, direct and indirect. Direct long-term effects included the experience of violence of all forms, disability, illnesses, injuries, and torture. The indirect long-term effects were characterised by limited access to healthcare and education as well as social marginalisation.[44] Specifically, a study conducted among people with disabilities in the Gulu region reported the negative effect the conflict had on the psychological and emotional health of people with disabilities who shared their traumatic experiences and difficult coping strategies.[45] These findings also reported difficulties in accessing healthcare services, including rehabilitation, such as assistive devices, and mental health services.[45] Literature further mentioned that people with disabilities, especially women, faced discrimination and lacked access to health facilities upon return home, coupled with economic challenges.[46]

Third, policy actors identified recommendations to the numerous barriers to SRH service utilisation experienced by people with disabilities, disability-focused policy implementation challenges, and multipronged recommendations addressed to policy actors at micro, meso, and macro levels. In an intersectionality-informed analysis, exploring alternatives and solutions is as important as identifying problems which need to be addressed.[20] Reflecting upon and consciously proposing solutions is integral to a transformative process and contributes to eventually reaching equity and social justice. For example, the recommendation made by policy actors to allocate more budget on disability issues and to reinforce the position of the NCD found an echo in the revised 2019 Disability Act.[11] Whereas the 2006 Disability Act did not include the scope of the NCD, the 2019 iteration of the Act specified its roles and funds, in addition to making the provision for representatives of the Council to work at the district level to enhance the presentation of people with disabilities in the community. Through the participatory workshop, health service providers and managers discovered the strengths of people with disabilities and that they could be experts in helping them devise health services to be more accessible and act as role models for others. While policy actors used to consider people with disabilities as weak and not capable, Intersectionality enabled them to acknowledge the multiple social categories a person/group may have, recognising that they may be simultaneously privileged in one context and be disadvantaged in another one.[42]

Limitations

Given the richness of information elicited from different groups of policy actors, we were not able to report them all in a single manuscript. Comprehensive description and analyses from people with disabilities at individual level have been reported elsewhere,[17] and the perceptions of policy actors at meso and macro levels are reported separately here. The contrasting of convergent or divergent views of policy actors will subsequently be discussed more in detail. We also did not include the views of policy actors located in other Northern districts which have been affected by the armed conflict. This inclusion may have expanded the depth of data collected and the richness of description to analyse. With more time and resources, this expansion would be possible. Given the convergence of problems and recommendations reported by study respondents, social desirability could have been a bias. However, respondents were clear about the observed multiple barriers faced by people with disabilities and the policy implementation challenges. They demonstrated the readiness to address these issues, collectively. Finally, to reduce the limitations of translation when it was used, we elaborated a glossary of research and SRH terms in English and Luo for consistency. Both research assistants were present during all interviews to support one another for translation when needed. At the end of each day of interviews, the research team met and debriefed about the interview process, including translation, for improvement purposes.

Conclusion

This study reveals the multilayered perceptions of policy actors at meso and macro levels of the relationships among pro-disability policy and legislation and the use of SRH services by people with disabilities in three post-conflict Northern districts of Uganda. The study findings intersect with and complement the perceptions and recommendations provided by people with disabilities at micro level. An intersectionality-informed analysis emphasised the importance of going beyond the identification of problems by concomitantly searching for solutions. With the recent adoption of the revised Disability Act in 2019, Uganda has renewed its commitment to remove barriers structurally and better protect the rights of people with disabilities. This creates a normative space for actions such as those recommended by the participants in our study. Concrete recommendations included empowering people with disabilities, families, and their organisations through awareness-creation and capacity-building, at micro level. At meso level, policy actors recommended training of health service providers on disability-sensitive services such as sign language, improving physical, attitudinal, and communication accessibility in health facilities, and collecting and analysing data on disability more systematically. At macro level, more accountability of policy-makers, active monitoring, and enforcing of policy implementation with disability budgeting were identified. The proposed solutions targeting three levels of policy actors, vertically, and various types of groups, horizontally, are within the reach and capacity of Government policy-makers, CSOs' managers, health decision-makers, DPO leaders, and people with disabilities. As suggested by the UN report on the Sustainable Development Goals for people with disabilities,[5] the recommendations can constitute the foundation for a hands-on road map to health equity by removing multiple barriers to access to and use of SRH services by people with disabilities, irrespective of their geographic location in Uganda.

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Mac-Seing has nothing to disclose.
Ochola has nothing to disclose.
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Zarowsky has nothing to disclose.

Ethical issues:

This study received ethics approval from the *Centre de recherche du Centre hospitalier de l’Université de Montréal* (CR-CHUM) (17.127-CÉR, 1 August 2017); the Research Ethics Committee in Sciences and Health of the Université de Montréal (CERSES-20-074-D, 13 May 2020), following a change of research affiliation in Canada; the Lacor Hospital Institutional and Research Ethics Committee (LHIREC - 019/07/2017); and the Uganda National Council for Science and Technology (SS-4451, 14 November 2017).

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Chapter 5 – Results of Objective 2 on associations between disability and sexual and reproductive health service use

5.1 Preface to quantitative findings (Manuscript 4)

This secondary quantitative analysis explored whether the findings on the perceptions of SRH service use inequities among people with disabilities obtained in the qualitative study can be observed at the population level. Specifically, the qualitative findings informed the selection of variables of interest, notably that related to the experiences of violence shared by both women and men with disabilities.

5.2 Manuscript 4: Disability and sexual and reproductive health service utilisation in Uganda: An intersectional analysis of Demographic and Health Surveys between 2006 and 2016

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Abstract

Background

Universal health coverage, including sexual and reproductive health (SRH), pledges to “leave no one behind”. However, people with disabilities continue to experience multiple barriers in accessing SRH services. Studies analysing the impacts of disability in conjunction with other social identities and health determinants reveal a complex pattern in SRH service use. Framed within a larger mixed methods study conducted in Uganda, we examined how disability, among other key social determinants of health (SDH), influenced the use of SRH services.

Methods

We analysed data from repeated cross-sectional national surveys, the Uganda Demographic and Health Surveys (DHS) of 2006, 2011, and 2016. The three outcomes of interest were antenatal care visits, HIV testing, and modern contraception use. Our main exposure of interest was the type of disability, classified according to six functional dimensions: seeing, hearing, walking/climbing steps, remembering/concentrating, communicating, and self-care. We performed descriptive and multivariable logistic regression analyses. Regression analysis was informed by the intersectional framework to highlight social and health disparities withing groups.

Results

From 2006 to 2016, 15.5-18.5% of study participants lived with some form of disability. Over the same period, the prevalence of at least four antenatal care visits, HIV testing, and modern contraception use improved significantly. The DHS year, highest education level attained, and wealth index were the most consistent determinants of SRH service utilisation. People with different types of disabilities did not have the same SRH use patterns. Interactions between disability type and wealth index were associated with neither HIV testing nor the use of modern contraception. Women who were wealthy with hearing (OR = 0.15, 95%CI 0.03 – 0.87) or with communication difficulty (OR = 0.17, 95%CI 0.03 – 0.82) had lower odds of having had optimal antenatal care visits compared to women without disabilities who were poorer.

Conclusion

This study provided evidence that SRH service use improved over time in Uganda and highlight the importance of studying SRH and the different disability types when examining SDH. The SDH are pivotal to the attainment of universal health coverage, including SRH services, for all people irrespective of their social identities.

Keywords

Determinants of health, disability, demographic and health surveys, sexual and reproductive health service utilisation, intersectionality, health equity, Uganda

Introduction

Heads of State at the United Nations (UN)'s 2019 High-Level Meeting reaffirmed their commitment to Sustainable Developmental Goal (SDG) 3.8 on universal health coverage (UHC), including equitable access for all to sexual and reproductive health (SRH) services and information [1]. Although UHC pledges to "leave no one behind", disability is not a focus of the UHC despite being an important dimension of inclusion for the SDGs [2]. Globally, 15% of the world's population is estimated to live with some form of disability (physical, sensory, intellectual, and mental), with 80% of these individuals residing in low- and middle-income countries (LMIC) [3]. According to several studies conducted in LMICs, women, men, and youth with disabilities continue to experience multiple barriers in accessing SRH services such as antenatal care, contraception, HIV testing, and SRH information [4-10]. Although there is limited literature documenting the situation of people with disabilities beyond the focus on "medical and rehabilitative provision for conflict-related direct physical impairment" [11], it is suggested that in conflict or post-conflict settings, women with disabilities can face an additional risk of violence from community members [12]. A recent systematic review conducted in 11 sub-Saharan countries reported that people with disabilities faced multiple barriers to accessing SRH services, spanning the individual to the community, healthcare system, and economic levels [13].

Due to the multiple challenges experienced, people with disabilities have been reported to have poorer health outcomes [3, 14]. The literature identifies numerous determinants that influence access to SRH services. They include women's age [15], education level [15, 16] and marital status [15] as well as the location of residence [15, 17], and level of household wealth [15, 16, 18, 19]. However, studies analysing the impacts of disability in conjunction with other key social identities [6, 20, 21] reveal a more nuanced pattern of associations with selected SRH utilisation outcomes. A cross-sectional study conducted in Sierra Leone found no significant difference between women with disabilities and those without disabilities when they sought maternal healthcare services, such as contraception use [20]. Using data from the Demographic and Health Survey (DHS), another study examined antenatal care among women with and without disabilities in Pakistan

[6]. It reported that the overall measure of disability showed no association with antenatal care, while women with any severe disability had higher odds of receiving advice on exclusive breastfeeding than non-disabled women. In Cameroon, a study that was conducted among people with and without disabilities, reported that although people with disabilities were at higher risk of poorer access to SRH services, disparities varied based on gender and disability [21]. The results of this study demonstrated that both women and men with disabilities had lower use of family planning and HIV testing that were not associated with access to SRH services, but were attributed to other factors associated with determinants related to respondents' childhood, such as poorer access to education and work opportunities [21].

The Northern region of Uganda was most affected by two decades (1987-2006) of armed conflict in Uganda, with persisting weakened socioeconomic and health systems [22]. In 2006, when the conflict ended, the Disability Act was also adopted in Uganda to protect and promote the rights of people with disabilities [23]. Framed within this background of conflict and access to health services, we were interested to examine how disability, among other social determinants of health, influences the use of SRH services. A parallel qualitative study found that adult women and men with disabilities living in Northern Uganda faced multiple challenges when using SRH services such as maternal care, contraception use, and HIV testing [24]. That study used an intersectionality-informed analysis to explore the co-existence of multiple social identities and social and health inequities experienced by vulnerable populations [25]. Major themes from the study included the complex intersections of disability with gender, HIV, and experience of violence [24]. The main objective of this present study was to investigate how disability was associated with selected SRH service utilisation in Uganda between 2006 and 2016. In addition, we looked at the interactions between disability type and sex, violence, education, and wealth.

Methods

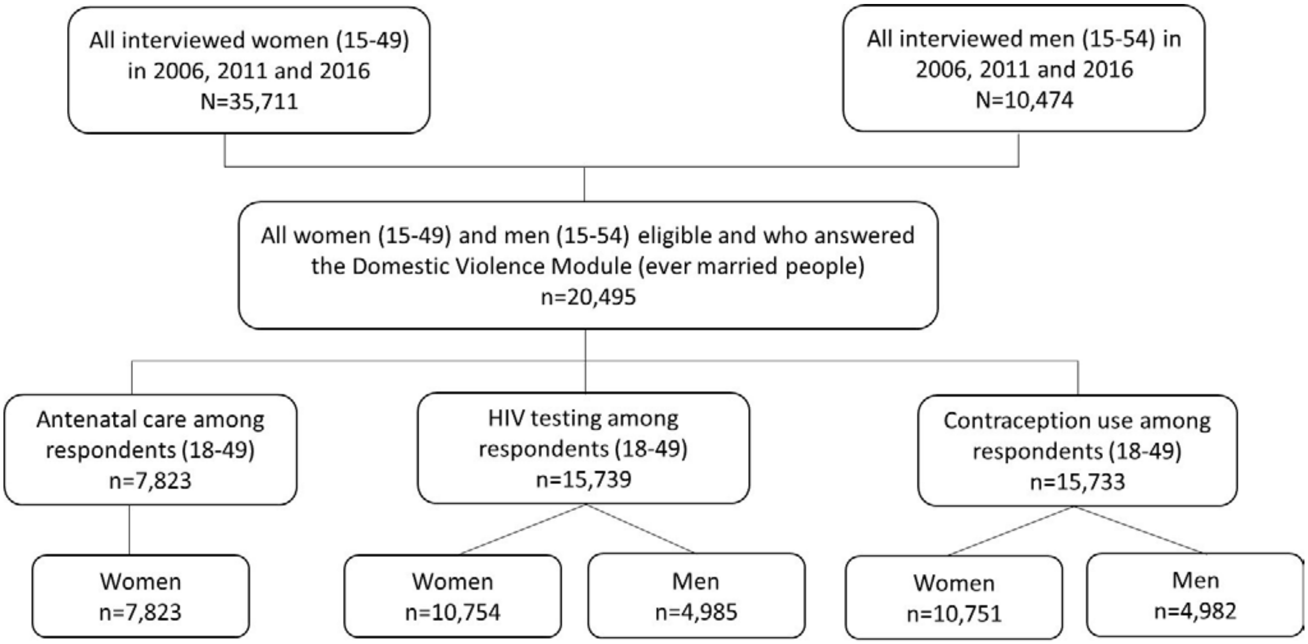
Study design and population

We analysed data from repeated cross-sectional surveys from Uganda DHS of 2006, 2011, and 2016. These three waves of national DHS were representative surveys at the regional level, using a stratified two-stage sample design [26-28]. Administratively, in the 2006 DHS, there were nine regions: Kampala (the capital), North, Central 1, Central 2, East Central, Eastern, West Nile, Western, and Southwest. In the 2011 DHS, the Northern region was split into two, adding a tenth region, Karamoja. In the 2016 DHS, these 10 regions were further divided into 15 regions, while keeping the outer geographical boundaries of 2006.

Given the importance of the experience of violence expressed by people with disabilities in our qualitative study [24], this study included participants who answered the Domestic Violence Module within each DHS which focused on adult women and men, aged 18 to 49 years old. In the 2006 DHS, one female participant in every three households responded to the Module questions, while one male respondent was selected among the remaining two households [26]. In the 2011 DHS, one woman per household was selected among the two-third of the households, while one man per household was selected in the one-third of the households [27]. In the 2016 DHS, all households were invited to participate in the Module: one woman per household was randomly selected in two-thirds of the households, and in the remaining one-third of the households, a man per household responded to the questions [28]. In all three DHS, ever-married people were eligible for the Domestic Violence Module. Among these, when privacy was ensured during the interviews, they answered questions related to emotional, physical, and sexual violence, as part of the Module [26-28]. The participation rate was 96.2%, 99.3%, and 99% among eligible women and 98.2%, 98.8%, and 99% among eligible men, in 2006, 2011, and 2016, respectively [26-28]. The main reason reported for the non-participation of eligible people was the lack of privacy to complete the Domestic Violence Module [26-28].

The study population included ever-married people aged 18-49 years old for a total of 7,823 women for antenatal care visits, 10,754 women and 4,985 men for HIV testing, and 10,751 women and 4,982 men for contraception use over the three waves of data collection (Figure 8).

Figure 9. – Study population



Variables

The three outcomes included: 1) antenatal care visits for the last pregnancy, 2) HIV testing during the past year, and 3) use of current type contraception type. The total number of antenatal care visits during their last pregnancy was recategorized as a binary variable based on the World Health Organization's recommendation of at least four antenatal care visits for a positive pregnancy [29]: 0 for "0-3 antenatal care visits", and 1 for "4 or more antenatal visits". The HIV testing variable, which asked whether respondents have ever been tested for HIV during the past year of the survey, kept its binary form (0=no, 1=yes). For the current use of contraception method variable, participants were asked which method they were currently using at the time of the survey. Modern types of contraception (such as pills, injectables, male/female condoms, and sterilisation, intrauterine devices, hormonal implants, and emergency contraception) were grouped together versus other methods (No use/use of traditional or folkloric contraception).

The main exposure variable of interest was the disability status, captured in the DHS as a ‘difficulty’ and following the Washington Group Short Set of Disability (WG) Questions [30]. The WG disability questions examined six functional dimensions: 1) seeing, 2) hearing, 3) walking or climbing steps, 4) remembering or concentrating, 5) self-care, and 6) communication, and according to four main levels of difficulty for each functional dimension: “No difficulty”, “Some difficulty”, “A lot of difficulty”, and “Cannot do it at all”. Disability type was recoded in a binary variable: 0 as “No difficulty”, and 1 as “At least some difficulty and above” which also included people who were reported to have severe difficulties in any of the functional dimensions.

Sensitivity analyses were conducted for antenatal care visits and disability, to examine if and how their categorization influenced the estimated effect measures. Other variables of interest included sex, age, marital status, region, highest education level attained, wealth index, religion, and year of DHS. In addition, the experience of emotional, physical, and sexual violence was included as women and men with disabilities reported being at risk of and/or having experienced different forms of violence [24].

Statistical analysis

DHS datasets were publicly available after the Uganda Bureau of Statistics processed and cleaned the data [26-28]. Data management, descriptive analyses, and multiple variable logistic regressions were conducted in R software (version 3.6.3) [31] and QGIS software (version 3.14) was used to produce bivariate choropleth maps [32]. Less than 1% of responses for outcomes were missing (respondents did not answer or did not know the answer) and were excluded from analyses. Descriptive analyses examined outcomes and exposure variables of interest at each time point. Bivariate choropleth maps were generated to examine how the overall disability status and outcomes of interest evolved by region between 2006 and 2016. Multivariable logistic regressions were created for each outcome of interest whereas a regional variable was created as well as survey year. Variables with a Variance Inflation Factor (VIF) higher than 10, indicating the presence of multicollinearity, were excluded from analyses [33]. Given the intersectional approach adopted in our larger mixed methods study, key interaction terms ('intersections') informed by the qualitative findings were explored, emphasising the 'multiplicative' nature of people's identities [34]. Specifically, we looked at interaction terms between disability type and each of the following: sex, education, wealth index, and experience of emotional, physical, and sexual violence. The selection of final models was based on the Akaike Information Criterion (AIC) and the residuals were examined for model fit [35]. In the three outcome models, we present final outputs and interaction terms of interest.

Results

Table 12 summarises the socioeconomic characteristics of the study populations for selected SRH service use for the period between 2006 and 2016 in Uganda. The majority of respondents were women, ranging from 68.3% for HIV testing and use of modern contraception to 100% of respondents for antenatal care visits since direct maternal care only targeted women. Among the ever-married adult respondents of reproductive age (18-49 years old), approximately 11% were separated/divorced/widowed. Across SRH service use, 15.5-18.5% lived with some form of disability in at least one of the functional dimensions. Regarding difficulty type, 7.1-8.6% of respondents were reported having at least some difficulty in walking or climbing steps, and 7.6-8.6% had at least some difficulty in remembering or concentrating. People were also reported to have had at least some difficulty in seeing (2.7-4.0%), in hearing (1.2-1.4%), and in self-care (0.5-1.3%). Approximately 80% people lived in rural areas, had primary education (60.1-61.2%), and were of Anglican, Catholic, or Muslim faith. Approximately two-thirds of respondents were situated in the three lowest wealth quintiles. Approximately 40% of respondents experienced emotional violence, 35.8-42.8% faced physical violence, and 19.4-25.1% reported sexual violence.

Tableau 14. – Characteristics of population by SRH service in Uganda (2006-2016)

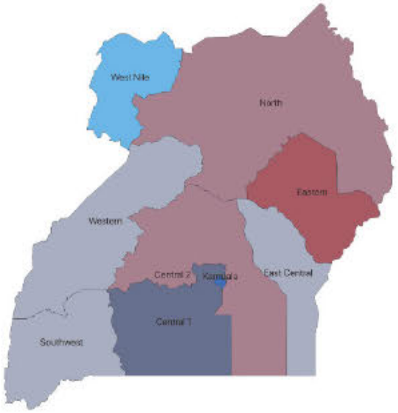
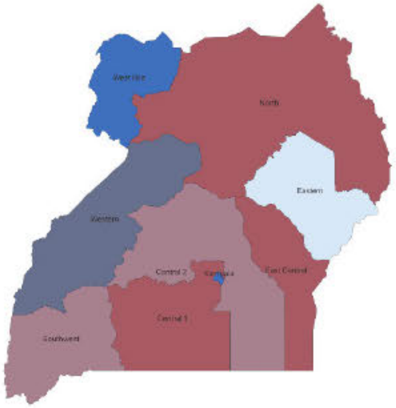
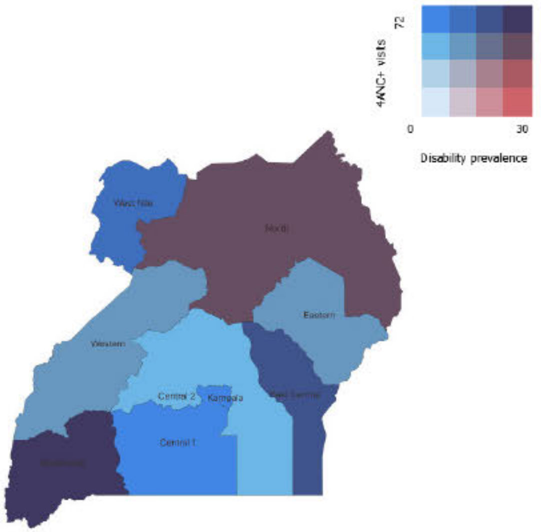
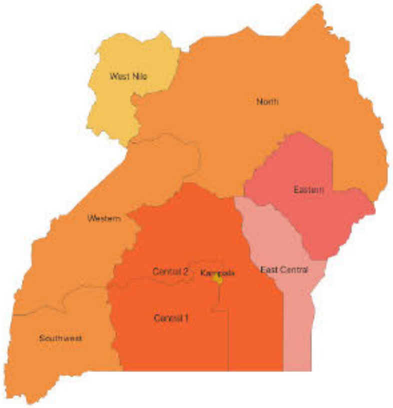
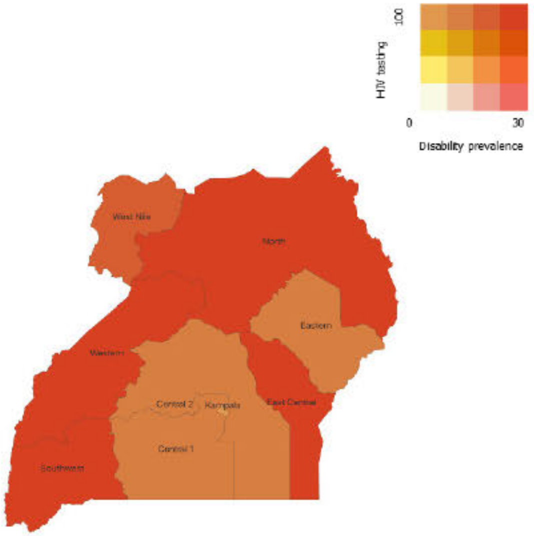
	Antenatal care visits (N=7,823)	HIV testing and use of modern contraception type (N=15,739[a])
Sex		
Women	100	68.3
Age in years		
18-19	5.4	3.9
20-24	26.2	18.4
25-29	26.5	21.4
30-34	20.8	20.4
35-39	13.1	15.7
40 and >	8.0	20.1
Marital status		
Married/in union	89.3	87.1
Separated / divorced / widowed	10.7	12.9
Disability		
Overall	15.5	18.5
Difficulty seeing	2.7	4.0
Difficulty hearing	1.2	1.4
Difficulty walking / climbing steps	7.1	8.6
Difficulty remembering / concentrating	7.6	8.6
Difficulty with self-care	0.8	1.1
Difficulty communicating	0.9	1.2
Highest education level attained		
No education	15.9	13.6
Primary	61.2	60.1
Secondary	18.2	19.3
Higher	4.7	7.0
Wealth index		
Quintile 1 (poorest)	26.1	23.3
Quintile 2 (poorer)	22.1	21.1
Quintile 3 (middle)	18.2	18.4
Quintile 4 (richer)	16.8	18.0
Quintile 5 (richest)	16.7	19.2
Religion		
Anglican	35.5	36.5
Catholic	37.3	38.2
Muslim	12.7	11.9
Seven Day Adventist /	12.5	11.5

Pentecostal / Born Again / Evangelical		
Other	2.0	1.9
Place of residence		
Rural	81.7	79.9
Region		
Kampala	5.4	6.2
North	19.0	18.0
Central 1	8.4	8.8
Central 2	8.5	8.9
East Central	9.4	9.3
Eastern	16.5	16.0
West Nile	8.3	7.9
Western	12.0	12.2
Southeast	12.5	12.5
Experience of violence		
Emotional	42.1	40.8
Physical	42.8	35.8
Sexual	25.1	19.4

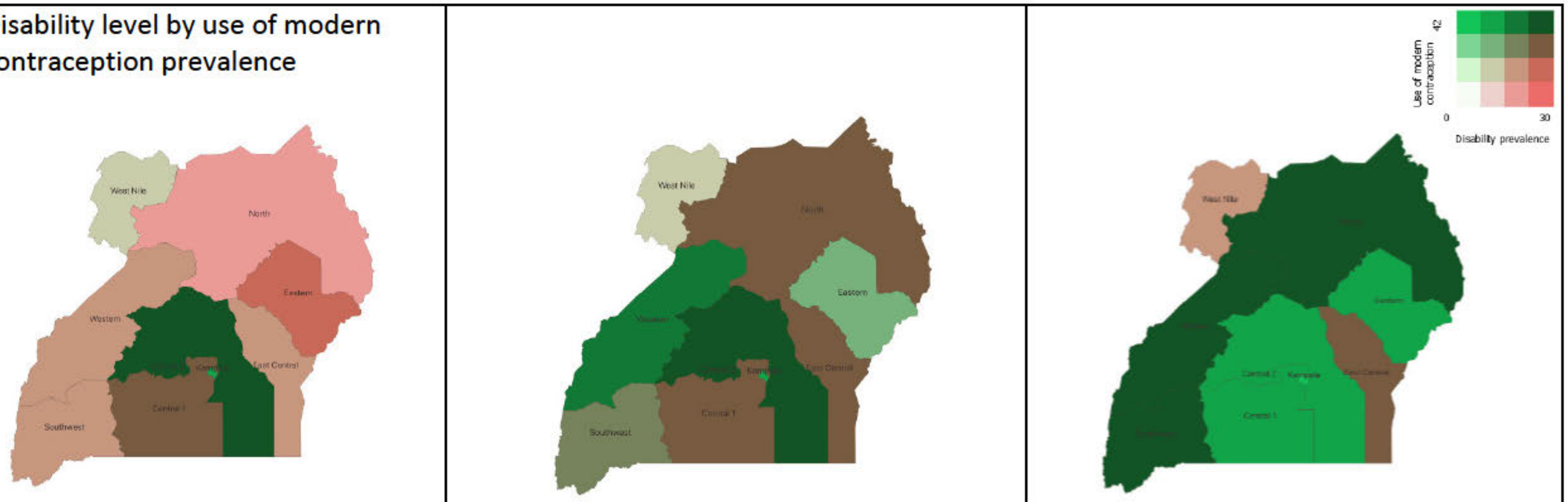
[a] For the use of modern contraception type, there are six people less, N= 15,733

Regarding the three selected SRH services used over the years, between 2006 to 2016, the prevalence of at least four antenatal care visits increased from 48.3% to 61.0%, while HIV testing prevalence rose from 30.8% to 92.4% and the prevalence of use of modern contraception increased from 18.6% to 34.2%. As per region and DHS year, the disability prevalence ranged from 4.9 to 32% (Figure 9). Across the regions, the prevalence of at least four antenatal care visits among people with disabilities increased most from 2011 to 2016 (Figure 9a). HIV testing in 2006 was low among people with disabilities with the exception in Kampala, where more than 60% of respondents with disabilities reported having been tested for HIV (Figure 9b). It increased from 2011 to 2016 where most of the regions recorded more than 80% of HIV testing among people with disabilities. Regarding the use of modern contraception (Figure 9c), slight changes were observed from 2006, in the regions of Kampala, Central 1, and Central 2 in 2011 and then in the North, Western, and East Central regions as reported in 2016.

Figure 10. – Disability level by SRH service use prevalence in Uganda (2006 to 2016)

2006^{a}	2011	2016
a. Disability level by at least four antenatal care visits 		
b. Disability level by HIV testing prevalence 		

c. Disability level by use of modern contraception prevalence



[a] For comparability, the 2006 boundaries of Uganda were used for the 2011 and 2016 maps.

Determinants of sexual and reproductive health service utilisation

In Table 13, the disability type was not associated with the SRH service use, except for people with difficulty in communicating who had lower odds of having used modern contraception compared to people without disabilities (OR = 0.51, 95%CI 0.29 – 0.90). Women had higher odds of being tested for HIV (OR = 2.76, 95%CI 2.38 – 3.21), while sex was not associated with the use of modern contraception. People who were separated, divorced, or widowed had lower odds of having had the optimal number of antenatal care visits (OR = 0.76, 95%CI 0.63 – 0.90) and to have used modern contraception (OR = 0.76, 95%CI 0.67 – 0.86) relative to married/in union participants. Violence of any type was not associated with either the use of antenatal care or HIV testing. However, participants who experienced emotional (OR = 1.22, 95%CI 1.11 – 1.34) and physical violence (OR = 1.15, 95%CI 1.04 – 1.27) were more likely to have used modern contraception.

There were three covariates that showed a consistent association with the SRH service use: the DHS year, education level, and wealth index. Compared to 2006, the year 2016 showed higher odds of having had at least four antenatal care visits (OR = 1.62, 95%CI 1.38 – 1.89), of being tested for HIV (OR = 29.31, 95%CI 24.93 – 34.35), and having used modern contraception (OR = 2.29, 95%CI 1.99 – 2.63). Having at least a primary education led to higher odds of being tested for HIV (OR = 1.82, 95%CI 1.53 – 2.15) and having used modern contraception (OR = 1.88, 95%CI 1.60 – 2.21), while having at least a secondary education increased the likelihood of having had the optimal number of antenatal care visits (OR = 1.43, 95%CI 1.18 – 1.87). Regarding the wealth index, the increasing wealth quintiles were positively associated with utilisation of all three SRH services: participants who were richer had higher odds than those who were among the poorest to have had at least four antenatal care visits (OR = 1.81, 95%CI 1.41 – 2.33), tested for HIV (OR = 2.80, 95%CI 2.10 – 3.73) or used modern contraception type (OR = 2.09, 95%CI 1.73 – 2.52).

Tableau 15. – Multiple logistic regression models on sexual and reproductive health use

	Model I[a]: At least four antenatal care visits		**Model II[b]: HIV testing**		**Model III[c]: Modern contraception type use**	
	OR	95% CI	OR	95% CI	OR	95% CI
Disability (Ref[d]: No difficulty)						
Difficulty seeing	1.09	0.76 – 1.57	1.17	0.82 – 1.66	0.98	0.70 – 1.39
Difficulty hearing	0.60	0.19 – 1.89	1.64	0.89 – 3.03	1.19	0.66 – 2.17
Difficulty walking / climbing steps	1.22	0.99 – 1.49	0.90	0.63 – 1.29	1.29	0.98 – 1.71
Difficulty remembering / concentrating	0.85	0.70 – 1.05	0.94	0.68 – 1.30	1.05	0.82 – 1.34
Difficulty in self-care	1.32	0.75 – 2.32	0.45	0.15 – 1.37	1.37	0.67 – 2.80
Difficulty in communicating	1.54	0.34 – 6.90	0.62	0.20 -1.96	0.51*[e]	0.29 – 0.90
Year (Ref: 2006)						
2011	1.03	0.85 – 1.25	8.78***	7.37 – 10.46	1.41***	1.21 – 1.65
2016	1.62***	1.38– 1.89	29.31***	24.93 – 34.45	2.29***	1.99 – 2.63
Sex (Ref: Man for Models II and III)						
Woman	-	-	2.76***	2.38 – 3.21	0.93	0.84 – 1.04
Marital status (Ref: Married / in union)						
Separated / divorced / widowed	0.76**	0.63 – 0.90	0.88	0.74 – 10.4	0.76***	0.67 – 0.86
Religion (Ref: Anglican)						
Catholic	-	-	-	-	0.92	0.84 – 1.02
Muslim	-	-	-	-	0.81**	0.70 – 0.94
Seven Day Adventist / Pentecostal / Born Again / Evangelical	-	-	-	-	0.76***	0.66 – 0.86
Other	-	-	-	-	0.63**	0.45 – 0.88
Highest education (Ref: No education)						
Primary	1.10	0.93 – 1.30	1.82***	1.53 – 2.15	1.88***	1.60 – 2.21
Secondary and higher	1.43***	1.18 – 1.87	3.46***	2.75 – 4.34	2.32***	1.92 – 2.81

Wealth index (Ref: Quintile 1 Poorest)						
Quintile 2 (poorer)	1.20*	1.01 – 1.42	1.14	0.96 – 1.35	1.41***	1.22 – 1.61
Quintile 3 (middle)	1.22	1.00 – 1.48	1.39***	1.15 – 1.69	1.58***	1.37 – 1.84
Quintile 4 (richer)	1.48***	1.22 – 1.83	1.66***	1.33 – 2.06	1.99***	1.70 – 2.33
Quintile 5 (richest)	1.81***	1.41 – 2.33	2.80***	2.10 – 3.73	2.09***	1.73 – 2.52
Region (Ref: Urban)						
Rural	1.02	0.84 – 1.22	0.95	0.71 – 1.21	0.86*	0.74 – 0.996
Region (Ref: Kampala)						
North	1.13	0.82 – 1.57	1.50	0.99 – 2.30	0.95	0.74 – 1.22
Central 1	0.88	0.63 – 1.24	0.76	0.50 – 1.16	0.83	0.65 – 1.07
Central 2	0.75	0.54 – 1.03	0.85	0.57 – 1.28	1.15	0.91 – 1.45
East Central	1.02	0.73 – 1.43	0.62*	0.41– 0.93	0.75*	0.57 – 0.97
Eastern	0.79	0.57 – 1.09	0.75	0.50 – 1.14	0.96	0.76 – 1.20
West Nile	1.52*	1.05 – 2.21	1.36	0.88 -2.10	0.50***	0.38 – 0.67
Western	0.94	0.67 – 1.31	0.86	0.58 – 1.28	0.89	0.70 – 1.13
Southeast	1.04	0.75 – 1.43	0.79	0.53 – 1.18	0.80	0.63 – 1.02
Experienced violence (Ref: No)						
Emotional violence	1.11	0.98 – 1.25	1.06	0.93 – 1.21	1.22***	1.11 – 1.34
Physical violence	0.90	0.78 – 1.02	0.92	0.80 – 1.06	1.15**	1.04 – 1.27
Sexual violence	0.93	0.81 – 1.06	0.91	0.79 – 1.05	-	
Disability type*Sex (Ref: Man and without any type of difficulty)						
Difficulty seeing*Sex	-	-	0.56*	0.35 – 0.90	1.33	0.85 – 2.09
Difficulty in self-care*Sex	-	-	3.58*	1.23 – 10.38	0.41	0.17 – 1.01
Disability type*Education (Ref: Without disability and no education)						
Difficulty hearing*Primary education	2.91	0.80 – 10.53	-	-	-	-
Difficulty hearing*Secondary education and higher	10.84*	1.67 – 70.54	-	-	-	-
Disability type*Wealth index (Ref: Without any type of difficulty and poorer)						
Difficulty hearing*Poor	0.37	0.10 – 1.37	-	-	-	-
Difficulty hearing*Middle	1.01	0.24 – 4.16	-	-	-	-
Difficulty hearing*Rich	0.15*	0.03 – 0.87	-	-	-	-

Difficulty hearing*Richer	0.16*	0.03 – 0.89	-	-	-	-
Difficulty in communicating*Poor	0.23	0.05 – 1.15	-	-	-	-
Difficulty in communicating*Middle	0.48	0.07 – 3.42	-	-	-	-
Difficulty in communicating*Rich	0.17*	0.03 – 0.82	-	-	-	-
Difficulty in communicating*Richer	0.90	0.07 – 12.32	-	-	-	-

[a] Adjusted for disability type, year, marital status, residence, region, education, wealth index, age and violence

[b] Adjusted for disability type, year, sex, marital status, residence, region, education, wealth index, age and violence

[c] Adjusted for disability type, year, sex, marital status, religion, residence, region, education, wealth index, age and violence

[d] Reference group

[e] *p < 0.05, **p < 0.01, ***p < 0.001 in two-tailed tests of significance

Religion and region of residence were also significantly associated with SRH service use. Muslims (OR = 0.81, 95%CI 0.70 – 0.94) or the Seven Day Adventist/Pentecostist/Born Again/Evangelical (OR = 0.76, 95%CI 0.66 – 0.86) faith were less likely to have used modern contraception compared to Anglicans, while the Catholic faith did not show any significant association with any of the SRH service use. Women living in West Nile had higher odds of having had at least four antenatal care visits (OR = 1.52, 95%CI 1.05 – 2.21), while they had lower odds of having used modern contraception (OR = 0.50, 95%CI 0.38 – 0.67) compared to people living in the capital. People in East Central were less likely to be tested for HIV (OR = 0.62, 95%CI 0.41 – 0.93) and having used modern contraception (OR = 0.75, 95%CI 0.57 – 0.07). People living in rural areas were less likely to have used modern contraception (OR = 0.86, 95%CI 0.74 – 0.996).

The sensitivity analyses did not reveal any significant differences in the measures of association. The categorization of disability, antenatal care visits, and the use of modern contraception type did not influence the measures of association.

Effects of interaction terms

In the final models (Table 2), a few interaction terms were statistically significant. Among interactions between disability type and sex, women with difficulty in seeing were less likely to have had HIV testing (OR = 0.56, 95%CI 0.35 – 0.90) compared to men without seeing difficulty, while women with difficulty with self-care had higher odds to have been tested for HIV (OR = 3.68, 95%CI 1.23 – 10.38). Among interactions between disability type and education, only women with hearing difficulty and who had a least secondary education were more likely than women without education to have had at least four and more antenatal care visits (OR = 10.84, 95%CI 1.67 – 70.54). For interactions of disability type and wealth index, women with difficulty reading in the fourth (OR = 0.15, 95%CI 0.03 – 0.87) and fifth (OR = 0.16, 95%CI 0.03 – 0.89) quintile of wealth index and women with difficulty in communicating in the fourth wealth index quintile (OR = 0.17, 95%CI 0.03 – 0.82) had lower odds of having had at least four antenatal care visits compared to women without any type of disability.

Discussion

This study found that SRH service use increased among the study population between 2006 and 2016, notably for HIV testing, and that the association of disability type and SRH service use was nuanced. Our results also demonstrate the importance of considering the intersectionality of vulnerabilities, such as disability, wealth, and sex, in quantitative analyses when examining social determinants of health.

Across all three SRH outcomes, the likelihood of service use increased from 2006 to 2016. The years included in our analyses coincided with the 2000-2015 Millennium Development Goals (MDG) which focused on maternal health improvement (MDG 5) including contraception use and the fight against HIV and AIDS (MDG 6) [36]. Among the three outcomes, HIV testing recorded the sharpest increase in 2016 compared to previous years. This can likely be explained by additional HIV financing by The Global Fund in Uganda from 2001 to 2007 [37], and the continuous HIV and AIDS funding by the President's Emergency Plan for AIDS Relief (PEPFAR) from 2003 to date in sub-Saharan African countries, including Uganda [38]. However, disparities were observed among regions and across the different types of SRH services. Unequal healthcare coverage could potentially have contributed to these regional disparities coupled with slower performance in maternal health outcomes across the country and possibly reflecting a rural-urban divide [39].

Our findings showed that social determinants of health, such as education level [15, 16] and wealth [15, 16, 18, 19] were important determinants of SRH service use, with other studies having found that being religious [40, 41] and living in rural areas [15, 17] decreased the likelihood of using some types of SRH services, such as the use of modern contraception. Furthermore, our findings suggest the need to explore beyond individual social determinants of health and consider the multiple layers of coexisting factors. We found that including an interaction between the type of disability and other factors such as sex, education level and wealth was important to detect associations and health inequities that would have otherwise been missed. Other quantitative research on intersectionality highlighted the "danger of misunderstanding the nature of social experiences and identities manifested in specific contexts" [34] and the importance of adopting the "intersectionality [framework]'s core ideas of social inequality, power, relationality, social context, and complexity" into quantitative population health research drawing from the social sciences [42]. Based on our qualitative study, we learned from women and men with disabilities that they experienced multiple barriers and layers of discrimination in accessing and using SRH services in Northern Uganda [24].

Specifically, to better understand marginalised people's realities, the literature on intersectionality has further stressed the need to consider multiple level analysis, from the individual to the populational level [43]. In one of her seminal papers, "When Black + Lesbian + Woman ≠ Black Lesbian Woman" [44], Bowleg recommended examining the non-additive aspects of social identities and power dynamics such as racism, heterosexism, and sexism [43]. In other words, according to the context, vulnerable and marginalised people may simultaneously experience privileges on one hand (for example, based on their gender), and disadvantages on another hand (for example, based on their ethnic background), hence looking beyond the additive aspects of social experiences. Our findings suggest that a 'rich + woman + hearing impairment' in the context of antenatal care services in Uganda cannot be automatically equated to being a 'rich woman with hearing impairment'. A 'rich + woman + hearing impairment' may not have benefited from all the privileges of wealth, possibly due to the forces of ableism, sexism, and other discriminatory power dynamics that could have prevented her to have used the services at the same frequency compared to other women with other impairments or non-disabled women.

Regarding the experience of violence, although emotional and physical violence were associated with an increased likelihood of using modern contraception, there was no significant interaction between disability and violence. This finding is in contrast to a recent study conducted in Uganda which showed that women with disabilities were significantly more likely to have experienced all forms of violence compared to women without disabilities [45]. Our study may have underestimated the association of the experience of any type of domestic violence on the use of

SRH services, due to reasons such as fear of stigma [46] and also given that our study population included only ever-married people over the age of 18 years old. A systematic review on gender-based violence victimization in adolescent girls in LMICs reported that young people who were unmarried or married experienced different forms of violence, such as sexual violence, intimate partner violence, and child marriage [47].

Limitations

Our study has several limitations. The DHS data were collected through self-reporting from participants. However the information related to disability was obtained from the household head for all household members which might have introduced a bias in reporting each household member's type and level of difficulty in functional dimensions. Moreover, underlying power structures, such as ableism, were not examined in this study, which likely played a critical role in SRH service use, potentially due to multiple discriminatory barriers hindering the effective use of services among people with disabilities [24]. Intersectional scholarship posits that power systems both structure and reinforce social identities and could be better understood through mixed methods [43], although qualitative data collection was not a methodological dimension included in the DHS. Finally, structured questionnaire designed for quantitative research, such as the DHS, is that these types of questionnaires are not designed to capture diverse societal interactions in various groups, such as people located at the margin of the society [48].

Conclusion

This study provided evidence that SRH outcomes improved over time in Uganda and highlight the importance of examining the social determinants of health when studying SRH and the different types of disability. Social determinants of health are pivotal to the attainment of the SDGs, notably SDG 3 which emphasises universal health coverage, including SRH services, for all people irrespective of their social identities. According to the United Nations' Convention on the Rights of Persons with Disabilities, disability results from the interactions between people with impairments (physical, sensory, intellectual, and mental) and barriers (physical, attitudinal and structural) in society that hinder their social participation [49]. Provided that accessible environments and/or enabling social determinants of health are present and that barriers are removed [3], people can fully exercise their rights and enjoy more positive health outcomes.

Abbreviations

AIC	Akaike Information Criterion
AIDS	Acquired Immunodeficiency Syndrome
DHS	Demographic and Health Survey
HIV	Human Immunodeficiency Virus
LMIC	Low- and Middle-Income Country
MDG	Millennium Development Goals
PEPFAR	President's Emergency Plan for AIDS Relief
SDG	Sustainable Development Goals
SRH	Sexual and Reproductive Health
UHC	Universal Health Coverage
UN	United Nations
VIF	Variance Inflation Factor

Declarations

Ethics approval and consent to participate

This study received ethics approval from the Centre de recherche du Centre hospitalier de l'Université de Montréal (CR-CHUM) (17.127-CÉR, 1 August 2017); the Research Ethics Committee in Sciences and Health of the Université de Montréal (CERCES-20-074-D, 13 May 2020), following a change of research affiliation in Canada; the Lacor Hospital Institutional and Research Ethics Committee (LHIREC - 019/07/2017); and the Uganda National Council for Science and Technology (SS-4451, 14 November 2017).

Consent for publication

Not applicable

Availability of data and materials

The datasets used in this study are available online from the DHS Program at: https://dhsprogram.com/data/Using-Datasets-for-Analysis.cfm

Competing interests

None to declare

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Authors' contributions

MMS conceptualised the manuscript. MMS, MY and KZ analysed the data. All authors reviewed, read, and approved the final manuscript.

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Chapter 6 – Results of Objective 3 on policy, sexual and reproductive health service use, and vulnerable populations in sub-Saharan Africa

6.1 Preface to systematic review findings (Manuscript 5)

In addition to the previous qualitative and quantitative studies conducted in Uganda, I was interested to better understand the regional patterns of the relationships among legislation, health policy, and the use of SRH services among vulnerable populations in sub-Saharan Africa. A systematic review examined primary research in the literature from 1994, the year when the first International Conference on Population and Development was held and during which important SRH global orientations were discussed, and 2019. This systematic review is placed after the three empirical papers related to Uganda to contextualise evidence reported at the national level in light of findings generated at the sub-Saharan African regional level. An inductive approach in presenting research findings in this order aims to highlight the importance of a constant 'conversation' between data generated at the local level and those obtained at the regional level. Findings might converge, diverge, or highlight policy and practice gaps to bridge both levels of body of knowledge. The systematic review was carried out in parallel with the primary research reported in the previous chapters, allowing this ongoing 'conversation' to occur. In line with the commitment to contextually anchored and locally-driven global health research and practice in a decolonising approach (217), we privilege the local voices in beginning this conversation.

6.2 Manuscript 5: Pro-equity legislation, health policy and utilisation of sexual and reproductive health services by vulnerable populations in sub-Saharan Africa: A systematic review

Publication status: This manuscript was published in *Global Health Promotion* in August 2020 (218). It is open access and can be cited as:

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Abstract

Twenty-five years ago, the International Conference on Population and Development highlighted the need to address sexual and reproductive health (SRH) rights on a global scale. The sub-Saharan Africa region continues to have the highest levels of maternal mortality and HIV, primarily affecting the most vulnerable populations. Recognising the critical role of policy in understanding population health, we conducted a systematic review of original primary research which examined the relationships between equity-focused legislation and policy and the utilisation of SRH services by vulnerable populations in sub-Saharan Africa. We searched nine bibliographic databases for relevant articles published between 1994 and 2019. Thirty-two studies, conducted in 14 sub-Saharan African countries, met the inclusion criteria. They focused on maternal health service utilisation, either through specific fee reduction/removal policies, or through healthcare reforms and insurance schemes to increase SRH service utilisation. Findings across most of the studies showed that health-related legislation and policy promoted an increase in service utilisation, over time, especially for antenatal care, skilled birth attendance, and facility-based delivery. However, social health inequalities persisted among sub-groups of women. Neither the reviewed studies nor the policies specifically addressed youth, people living with HIV, and people with disabilities. In the era of the Sustainable Development Goals addressing health inequities in the context of social determinants of health becomes unavoidable. Systematic and rigorous quantitative and qualitative research, including longitudinal policy evaluation, is required to understand the complex relationships between policy addressing upstream social determinants of health and health service utilisation.

Keywords

Determinants of health, equity/social justice, maternal health, policy/politics, reproductive health, sub-Saharan Africa, systematic review

Introduction

At the 1994 International Conference on Population and Development (ICDP), the international community adopted the Programme of Action (PoA) which recognised sexual and reproductive health (SRH) as a fundamental right (1). This commitment was further renewed during the 2019 Nairobi Summit (2). Building on the Millennium Development Goal (MDG) 5 which focused on improving maternal health (2000-2015), the health-focused Goal 3 of the Sustainable Development Goals (SDG) (2015-2030) reaffirms the importance of “universal access to sexual and reproductive health services, including […] family planning, information and education, and the integration of reproductive health into national strategies and programmes”(3). The SDG agenda on SRH rights (SRHR) catalyses both SDG 3 on health and SDG 5 on gender equality, beyond the MDG 5 objectives (3). Typically, SRHR not only focus on information and services related to contraception, maternal health, and HIV/AIDS, but also on the sexual health of adolescents, abortion, and gender-based violence (4). Despite notable improvements in several health outcomes from maternal mortality to HIV survival globally, the sub-Saharan African region did not see the same magnitude of change in these indicators. Compared to other regions worldwide, sub-Saharan Africa has the highest average of maternal mortality ratio in 2017 (5) and HIV prevalence in 2018 (6).

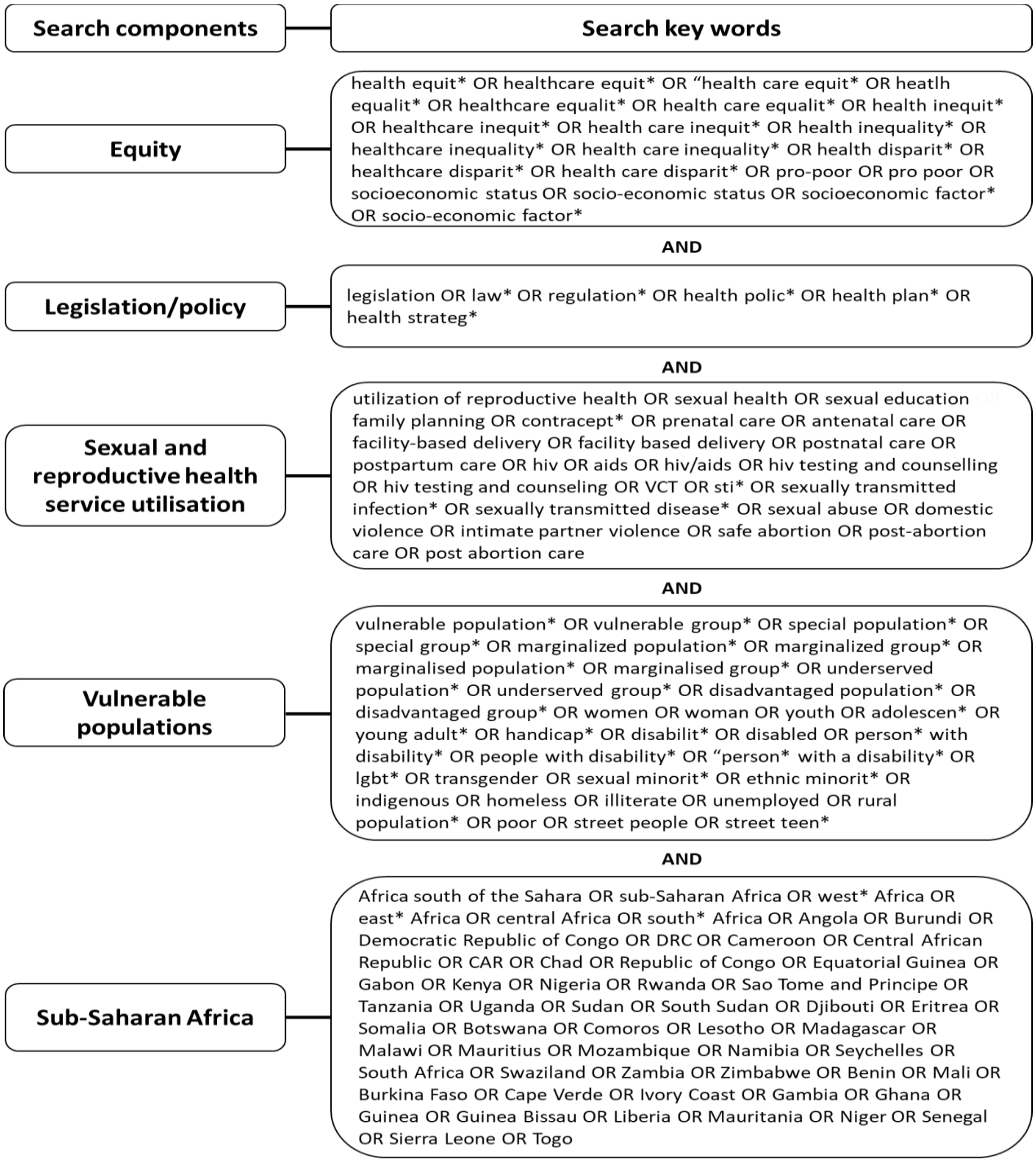
Social determinants of health such as gender, wealth, and place of residence are reported to influence the unequal access to SRH services, while evidence has shown that structural determinants such as laws and policies, driven by socio-cultural values, can both promote SRHR and restrict the use of specific SRH services such as safe abortion (4). The Commission on Social Determinants of Health (CSDH) report (7) reminds us that social health inequities result from unjust distribution of power and resources as well as inadequate social policies which can worsen people’s health (8), most affecting vulnerable populations. Despite the challenges of defining vulnerability and how best to measure it (9), there is an agreement that vulnerable populations share a complex confluence of common characteristics based on factors such as age, sex, ethnicity, education, and wealth, which put them at a heightened disadvantage relative to other populations (10). One of the key CSDH recommendations was the promotion of a systematic contextual analysis of health disparities among populations (7). Policy approaches to reducing health inequities have been identified to include such as “targeting disadvantaged populations, closing the gaps between worse-off and better-off groups, and addressing the social health gradient across the whole population” (11). Considering the above conceptual and methodological context, we were interested in learning more about how the empirical literature addresses the interplay between legislation and policy adoption aimed at reducing health disparities between groups and health service utilisation among vulnerable populations. This paper reports a systematic review which aimed at examining the relationships between health equity-focused legislation and policy and the utilisation of SRH services by vulnerable populations in sub-Saharan Africa.

Methods

We followed the structure of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Statement and used the PICO methodology: Population, Intervention, Comparator (when available), and Outcome (12) (Appendix 1). The systematic review protocol was registered in the PROSPERO database and can be retrieved at the following link: (https://www.crd.york.ac.uk/PROSPERO/display_record.php?RecordID=106876&VersionID=1184126). We searched the following nine bibliographic databases: CINAHL, EBM Cochrane Systematic Reviews, Embase, Global Health, MEDLINE, Popline, Proquest Dissertations, and Theses Global, Scopus, and Web of Science. Search terms were developed based on the key concepts related to the research objective: 1) equity, defined as “the absence of avoidable or remediable differences among groups of people, whether those groups are defined socially, economically, or geographically” (13); 2) legislation, defined as any preparation and enactment of laws (14) and/or health policy, defined as any “decisions, plans, and actions that are undertaken to achieve specific health care goals within a society” (15); 3) SRH service utilisation (1) referred to such as antenatal care, facility-based delivery, contraception, safe abortion and prevention of mother to child transmission of HIV (PMTCT); 4) vulnerable populations, defined as “groups who, because of their position in the social strata, are commonly exposed to contextual conditions that distinguish them from the rest of the population” (10) such as women, youth and the poor; and 5) countries in sub-Saharan Africa (Figure 10). Inclusion criteria were original primary qualitative, quantitative, and mixed methods studies which addressed the above research concepts, conducted, and published between 1994 (year of the ICPD) and 2019 in sub-Saharan Africa, from both English and French peer-reviewed and grey literature. Search records were independently screened by authors (MMS, COO, and KZ).

One author (MMS) extracted data from included studies and another (FM) reviewed them as per the following information: publication year, authors, countries in sub-Saharan Africa, research methods and design, type of legislation/policy adoption/implementation, population and number, type of SRH service utilisation, quantitative and/or qualitative results in SRH service use, and number of years before/after legislation/policy adoption. We analysed the study findings as per the type of legislation/policy which promoted SRH service utilisation per year and country; groups of population that can be in situations of vulnerability; direction and significance of the SRH results in quantitative research designs, such as quasi-experimental designs which warrant such an analysis related to causal inferences (16); and quality of reporting in studies. Due to heterogeneity in study outcomes and findings, a meta-analysis was not considered. Rather, we conducted a narrative synthesis (17).

Figure 11. – Search strategy



Search components	Search key words
Equity	health equit* OR healthcare equit* OR “health care equit* OR heatlh equalit* OR healthcare equalit* OR health care equalit* OR health inequit* OR healthcare inequit* OR health care inequit* OR health inequality* OR healthcare inequality* OR health care inequality* OR health disparit* OR healthcare disparit* OR health care disparit* OR pro-poor OR pro poor OR socioeconomic status OR socio-economic status OR socioeconomic factor* OR socio-economic factor*
	AND
Legislation/policy	legislation OR law* OR regulation* OR health polic* OR health plan* OR health strateg*
	AND
Sexual and reproductive health service utilisation	utilization of reproductive health OR sexual health OR sexual education OR family planning OR contracept* OR prenatal care OR antenatal care OR facility-based delivery OR facility based delivery OR postnatal care OR postpartum care OR hiv OR aids OR hiv/aids OR hiv testing and counselling OR hiv testing and counseling OR VCT OR sti* OR sexually transmitted infection* OR sexually transmitted disease* OR sexual abuse OR domestic violence OR intimate partner violence OR safe abortion OR post-abortion care OR post abortion care
	AND
Vulnerable populations	vulnerable population* OR vulnerable group* OR special population* OR special group* OR marginalized population* OR marginalized group* OR marginalised population* OR marginalised group* OR underserved population* OR underserved group* OR disadvantaged population* OR disadvantaged group* OR women OR woman OR youth OR adolescen* OR young adult* OR handicap* OR disabilit* OR disabled OR person* with disability* OR people with disability* OR “person* with a disability* OR lgbt* OR transgender OR sexual minorit* OR ethnic minorit* OR indigenous OR homeless OR illiterate OR unemployed OR rural population* OR poor OR street people OR street teen*
	AND
Sub-Saharan Africa	Africa south of the Sahara OR sub-Saharan Africa OR west* Africa OR east* Africa OR central Africa OR south* Africa OR Angola OR Burundi OR Democratic Republic of Congo OR DRC OR Cameroon OR Central African Republic OR CAR OR Chad OR Republic of Congo OR Equatorial Guinea OR Gabon OR Kenya OR Nigeria OR Rwanda OR Sao Tome and Principe OR Tanzania OR Uganda OR Sudan OR South Sudan OR Djibouti OR Eritrea OR Somalia OR Botswana OR Comoros OR Lesotho OR Madagascar OR Malawi OR Mauritius OR Mozambique OR Namibia OR Seychelles OR South Africa OR Swaziland OR Zambia OR Zimbabwe OR Benin OR Mali OR Burkina Faso OR Cape Verde OR Ivory Coast OR Gambia OR Ghana OR Guinea OR Guinea Bissau OR Liberia OR Mauritania OR Niger OR Senegal OR Sierra Leone OR Togo

Two authors (MMS and FM) assessed the quality of studies through quality appraisal tools for different study designs, and a third author (KZ) spot-checked. The Joanna Briggs Institute’s Checklist for Quasi-Experimental Studies (18) was used to assess the quality of four types of quasi-experimental designs: Category A - without control groups, Category B - with control groups but without pretests, Category C - with control groups and pretests, and Category D - interrupted time-series (19). For cross-sectional studies, the Strengthening the Reporting of Observational Studies in Epidemiology-Combined tool was used (20). For mixed methods studies, the Mixed Methods Appraisal Tool was selected (21). Given the recommendations of the Cochrane Collaboration's tool for assessing risk of bias, quality scores were not used as they are not deemed appropriate (22). Since no primary qualitative studies were included in the review, no checklist assessing the rigour of qualitative studies was used.

Results

The initial search produced a total of 5,414 references. Of those, 818 duplicates were removed. We then reviewed 4,596 references of which 4,538 references were discarded based on the inclusion criteria. At the eligibility phase, 58 studies were fully reviewed, of which 32 were finally included (Figure 11), involving 14 countries in sub-Saharan Africa where the effects of adopted equity-focused SRH-related legislation and policy were examined. Ghana (n=11) was the country mostly studied, followed by Kenya (n=5), Burkina Faso (n=4), and Mali (n=4). Most studies focused on maternal health service utilisation, and a few examined abortion services, PMTCT, and postnatal care (Figure 12). Of these 32 studies, 30 adopted quantitative designs and two studies employed mixed methods. No primary qualitative studies were included in the final phase as they did not meet the combination of inclusion criteria. Among the quantitative studies, there were 26 quasi-experimental studies, with the following study design categories: 11 were in Category A (without control groups) (23-33), four in Category B (with control groups but without pretests) (34-37), eight in Category C (with control groups and pretests) (38-45), and three in Category D (interrupted time series) (46-48). Four studies were cross-sectional (49-52). Among the two mixed methods study designs, one used a quasi-experimental of Category C design along with key informant interviews (53), and the second used a cross-sectional design combined with qualitative interviews (54). Table 14 summarises the study characteristics.

Figure 12. – Flow chart

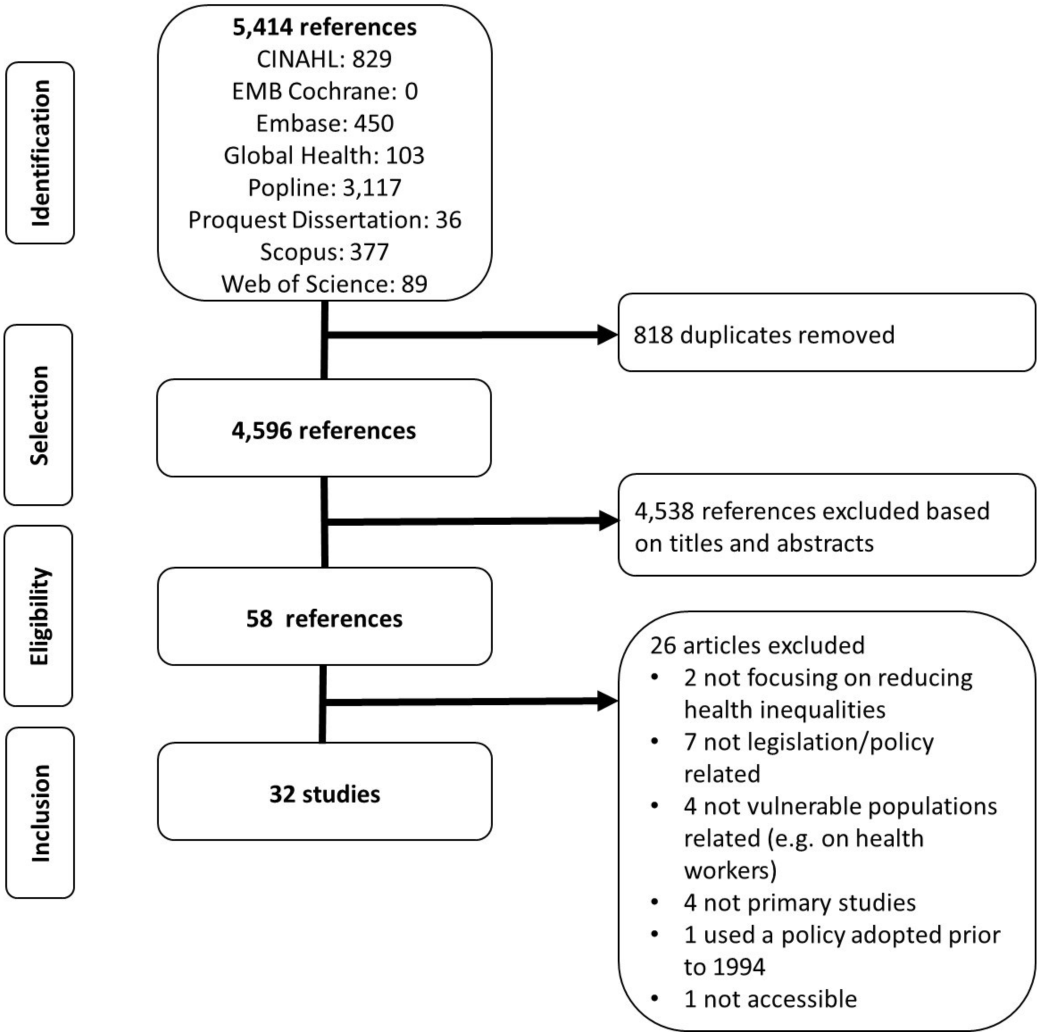
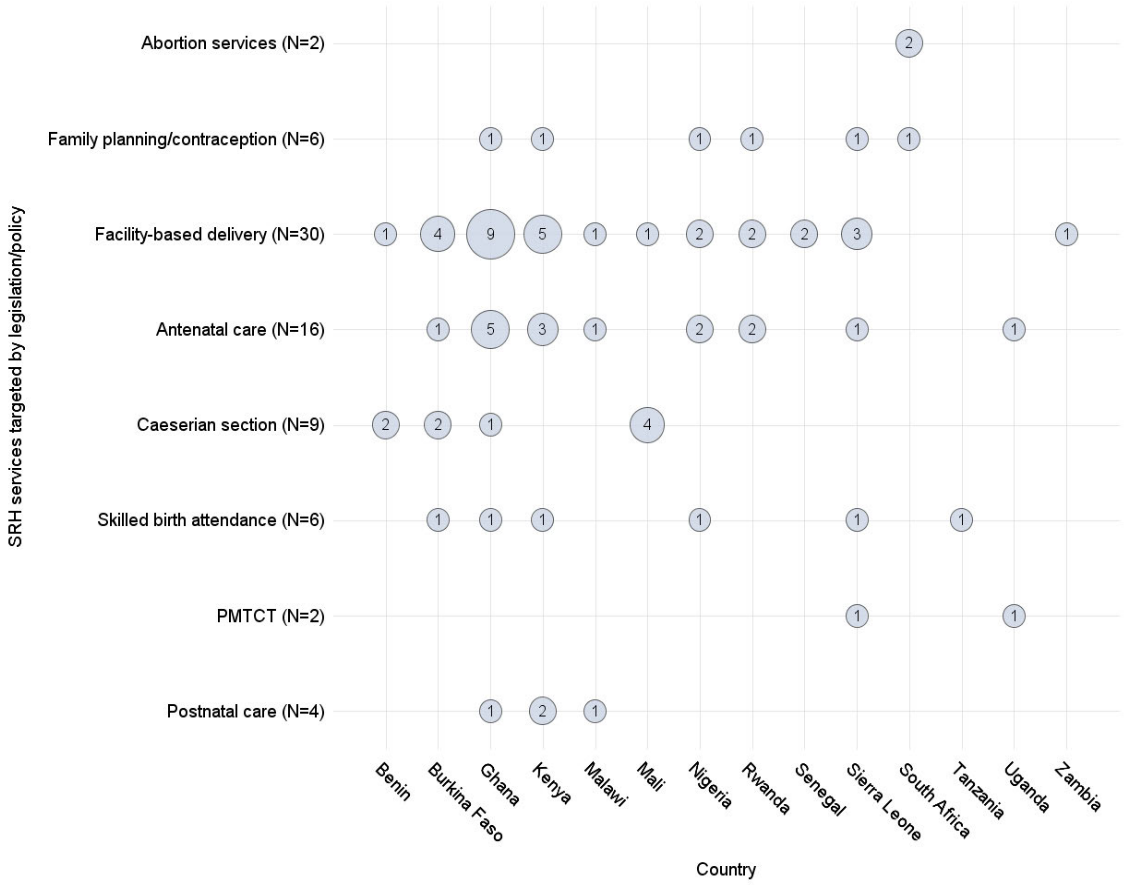


Figure 13. – SRH services targeted by legislation/policy per country



Note

Studies conducted in a country can look at more than one type of legislation/policy in relation to SRH service utilisation. Hence, one study can examine several countries, policies, and the utilisation of SRH services at the same time.

Tableau 16. – Summary of studies included

First author (Year) **Countries**	**Research design and methods** **(Period)**	**Legislation and policy**	**Type of SRH service utilisation**	**Population and number**	**Main results**	**Difference between the beginning of policy and beginning of study (year)**
Dickson (2003) South Africa	Cross-sectional Survey (September to December 1999)	The Choice on Termination of Pregnancy Act of 1996 – adopted in 1997	1st and 2nd trimester abortion services	Women 16-50 years old from 292 health facilities	▪ 32% of 292 health facilities providing abortion services in country ▪ 3,112 (78%) terminations out of a mean of 3,996 abortions/month in the 1st semester ▪ 884 (22%) out of a mean of 3,996 abortions/month in 2nd semester ▪ 2 urbanised provinces with more access to abortion services	2 years after
Ehlers (2003) South Africa	Cross-sectional Exploratory descriptive survey (1999-2000)	The Choice on Termination of Pregnancy Act of 1996 – and contraceptives and emergency contraceptives made free	Knowledge and utilisation of contraceptives	250 adolescent mothers aged 19 years old and younger who delivered during	▪ Out of 250 mothers, 139 knew about contraceptives; 117 (46.8%) ever used contraception ▪ 94% of 250 used contraceptives after delivery; 65.2% used injections so that family and boyfriends do not need to know about it ▪ Only 34 (13.6%) mothers with planned pregnancy	3 years after
Penfold (2007) Ghana	Quasi-experimental with control groups and pretests Pre and post intervention implementation cluster-sampled household survey	Delivery Fee Exemption Policy in 2003	FBD	2,922 women aged 15-58, of 2 regions, who delivered during the exemption fee period	▪ 2,922 women had 3,035 deliveries: 43% before the exemption and 57% after the intervention period ▪ Increased adjusted OR 1.83 [95%CI 1.44-2.32] ($p<0.001$) and 1.34 [95%CI 1.02-1.76] ($p<0.05$) of delivering in a health facility in Central and Volta regions, respectively; except women with no education in Volta region	1 year before and 1 year after

	(2002-2003, 2004-2005)					
Byamugisha (2010) Uganda	Quasi-experimental with control groups and pretests Retrospective analysis of hospital records (2002-2006 and 2006-2009)	Routine Opt-out HIV testing in ANC visits in 2006	HIV testing during ANC visits	54,429 ANC attendees and 469 male partners who were tested for HIV (2002-2009)	▪ From May 2002 to May 2006, 6,570/29,834 (22%) new ANC attendees tested for HIV vs 21,538/24,595 (87.6%) (2-tailed p=0.002) tested for HIV from June 2006 to 2009 ▪ Before policy, 87.5% of men tested for HIV, and 100% of them after (2-tailed p=0.01) ▪ 316/566 (55.8%) of HIV infected pregnant women used ARV for PMTCT before policy vs 855/1,147 (77.2%) after policy (2-tailed p=0.015) ▪ 172/566 (30.4%) of HIV infected pregnant women delivered in hospital before policy vs 464/1,147 (40.5%) after policy (2-tailed p=0.042)	4 years before and same year
De Allegri (2011) Burkina Faso	Cross-sectional Three-stage cluster household survey (Feb-March 2009)	Abolition of ANC user fees, 2002 Hospital admission without pre-payment for all emergency cases, 2006 Subsidy for C-section, 2006 Subsidy for all deliveries 2007	ANC, DEL	435 women who reported a pregnancy 12 months prior to interview date (Feb-March 2009)	▪ OR of 4.3 among women with at least 3 ANC visits to deliver in health facility (p=0.001) ▪ OR of 28.42 among women living ≤ 5 km from health facility to delivery in facility (p=0.001) ▪ OR of 17.20 among Mossi pregnant women and OR of 8.32 among Peuhl women to deliver in facility (p=0.001) ▪ But lack of associations between age, parity, education, and household head characteristic and ANC seeking	2-3-7 years after
De Allegri (2012)	Quasi-experimental without control groups	Abolition of 80% user fees for FBD,	FBD	1934 women who has completed a pregnancy 12	▪ Increase of FBD from 49% in 2006 to 84% in 2010 (p<0.001)	1 year before and 0-1-2-3 years after

Burkina Faso	Five repeated cross-sectional surveys (2006-2010)	2006 (effective in January 2007)		months before interview	▪ Concentration index >1, favouring women with higher SES, 2 years before policy implementation (p=0.05) and 3 years after (p<0.001)	
Dzakpasu (2012) Ghana	Interrupted time-series Time-series methods (DHS and cluster RCT) (2004-2009)	Free delivery care, 2005 Free National health Insurance for pregnant women, 2008	FBD (and health insurance coverage)	Out of 92,462 deliveries, 91,015 (98.4%) women with complete data (2004-2009) 27,841 (90%) who delivered (2008-2009) with complete insurance enrolment data	▪ Increase of 2.3% (p=0.015) and 7.5% (p<0.001) after the 2005 free delivery care and 2008 free NHIS policies (after adjusting for month of delivery and temporal trend) ▪ Concentration index for FBD of -0.0086 after the 2005 free care (period 1) and -0.0478 after the 2008 NHIS policies (period 2), favouring poorest women (p<0.001) ▪ Concentration index for FBD of 0.016 from period 1 to period 2, favouring richer women (p<0.001) ▪ Concentration index for FBD of -0.018 after the 2005 free delivery and after the 2008 NHIS policies, favouring poorer women (p<0.001)	1 before and 1 year after
El-Khouri (2012) Mali	Quasi-experimental with control groups and no pretest Nationally representative facility-based patient survey (of 16 public health sector centres and 9 hospitals that offer C-sections in 2010); comparing to DHS 2006)	Fee exemption policy for caesareans, 2005	C/S	2,477 women who had C-sections over 8-month period	▪ Richest 40% women with 1.67 times more to get a C-section in 2010 compared to those with a C-section in 2006 [95% CI 1.43-1.91] ▪ Poorest 40% women with 0.59 times more to get a C-section in 2010 compared to those with a C-section in 2006 [95% CI 0.47-0.71] ▪ Transport costs and road conditions as barriers to accessing C-section services in health facilities	5 years after

Bellows (2013) Kenya	Quasi-experimental without control groups Two cross-sectional household surveys (2004-2005 and 2006-2008)	Maternal Health Voucher Programme, 2006	FBD, SBA	4,362 women aged 12-54 years old 1,914 in 2004-2005, before the programme 2,448 in 2007-2008, after the programme	▪ Increased OR of 1.4 [95% CI 1.19-1.58; p<0.001] for FBD and OR of 1.2 [95% CI 1.02-1.36; p<0.01] for SBA after the programme implementation ▪ Variables associated with a statistically significant increased odds of having a FBD include: being aged 24-34 years old, having completed secondary education and being among the least poor ▪ The 'least poor' and women with ≥4 children, less likely to purchase voucher	2 years before and same year
Kengia (2013) Tanzania	Quasi-experimental without control groups Four cross-sectional surveys (DHS) (1992, 1996, 1999, 2004/5)	Health sector reform Plan of Action 1996-1999 Health sector reform Programme of Work 1999-2002	SBA	14,752 women aged 15-49 years old	▪ Overall % of SBA utilisation rate decreased from 1992-1999 and increased in 2004-2005 ▪ Poorest and poor women's SBA utilisation decreased from 1992-1999, while that of middle income, rich and richest women increased ▪ From 1999-2004, it increased among poorest and poor women, and decreased among the other wealth quintile women	4 years before and 0-3 years after (first policy) 3-7 years before and 5 years after (second policy)
Obare (2013) Kenya	Quasi-experimental with control groups and no pretest Household survey comparing women exposed to the programme (since 2006) and those who are not (2006-2010)	Reproductive Health Vouchers, 2006-2011	ANC services, FP, DEL, PNC	2,527 women aged 15-49 years old • Step 1: 2006-2008 • Step 2: 2008-2011	▪ OR of 1.5 [95% CI 1.0-2.1; p<0.05] among women exposed to the programme since 2006 to ever use family planning compared to those not exposed at all ▪ OR of 3.6 [95% CI 1.2-11.2; p<0.05] among Muslim/other/no religion to ever use family planning in past 12 months compared to those with Catholic religion ▪ OR of 2.1 [95% CI 1.5-3.1; p<0.01] for FBD and OR of 2.0 [95% CI 1.4-2.8; p<0.01] for SBA among women who are exposed to the programme since 2006 compared to those not exposed at all	Same year

					▪ No difference in ANC services among the women of the 2 groups ▪ Poor women significantly less likely to have delivered in a facility, have been assisted by SBA or received postnatal services compared to non-poor among women exposed to the programme since 2006, those not exposed in 2006-2010 and those not exposed at all ▪ Significantly higher proportion of poor women who have been exposed to the programme since 2006 compared with poor women who have not been exposed at all to the programme	
Skiles (2013) Rwanda	Quasi-experimental with control groups and pretests Cross-sectional survey (DHS): 2005: pre-intervention; 2007-2008: post intervention	Performance-based Financing, 2005	CTN, ANC, FBD	4,477 women aged 15-49 years old from intervention districts and 3,422 women in control districts	▪ In 2007, FBD improved significantly in all income groups ($p<0.001$) except for the poorest and the least poor ▪ In 2007, modern contraceptive use significantly increases in all income groups (with at $p<0.01$) ▪ No change over time in ANC≥4 among all income groups except for the middle-income group ($p<0.01$) and the less poor ($p<0.05$)	0-3 years after
Abrokwah, (2014) Ghana	Quasi-experimental with control groups and no pretest Cross-sectional survey (2005-2006)	Social Health Insurance, 2005	ANC	1,012 women aged 15-49 years old and who were pregnant	▪ Women who had access to insurance are more likely to seek (and spend at least 1 cent) on prenatal care compared to uninsured pregnant women ($p=0.05$ at baseline, and $p=0.001$ with interaction) ▪ Women who were in an area with health insurance actually spend less out-of-pocket on any spending compared to women in areas without health insurance	Same year

Fournier (2014) Mali	Interrupted time series Pre-intervention period of 30 months (January 1, 2003 to June 30, 2005) Post-intervention period of 83 months (July 1, 2005 to May 31 2012)	Fee exemption for C-sections, 2005	C/S	5,375 women (of reproductive age)	▪ There has been an increase among all women living in villages with no healthcare facility, villages with healthcare facilities and in cities with a district hospital ▪ However, after policy implementation, there has been statistically significant (p<0.001) increase of 1% in C/section among women in villages with no healthcare facility and of 5.7% increase among those living in cities with a district hospital, but not among those living in villages with a healthcare centre	30 months before and up to 83 months after
Frimpong (2014) Ghana	Quasi-experimental without control groups Retrospective cohort (January 2008 and August 2010)	National Health Insurance Scheme (2003) Premium exemption for pregnant women, July 2008	ANC	1,411 women who conceived and delivered after the exemption policy	▪ Among women who conceived after the premium exemption, NHIS registration increased significantly to 71-73% among pregnant women in 2008-2009 and to more than 90% among women who delivered in 2009 (p<0.01) ▪ In hospitals and health centres, women registrants were more likely to receive extensive safe motherhood counseling during ANC vs those who are not registered ▪ In hospital and health centres, health insurance did not affect place of delivery ▪ Clients from CHC who are registered were significantly more likely to deliver at a health facility than others	5-7 years after
Ganle (2014) Ghana	Cross-sectional Retrospective cross-sectional	User fee exemption for maternal healthcare policy, 2003-2005	ANC, DEL, PNC	10,370 women aged 15-49 years old	▪ ANC more common among women with live birth (98%) vs women with stillbirths (88%) ▪ The frequency of ANC higher among women with high school and higher education (7.9) vs women with no	4 years after

	Maternal Health Survey (2007)				education (5.3), and among highest wealth quintile (8.3) vs lowest quintile (4.9) ▪ 88% of births of women with at least secondary education in health facility vs 31% of births of women with no education ▪ 92% women in the highest wealth quintile delivered institutionally vs 27% of women in lowest quintile ▪ More women living in urban areas delivered in health facilities vs women in rural areas	
McKinnon (2015) Ghana Senegal Sierra Leone Control: Cameroon Congo (Brazzaville) Ethiopia Guinea Mozambique Tanzania	Quasi-experimental with control groups and pretests Representative household surveys (DHS) in 3 countries with user fee exemption implementation of policy and 3 control countries without policy implementation	User fee exemption for pregnant women September 2003 in Ghana (for poorest regions first) January 2005 in Senegal (in most deprived provinces first) April 2010 in Sierra Leone for all women and children under 5	FBD	All women aged 15-49, between 2000 and 2012, totalling 150,541 live births	▪ Increased proportion of women delivering in health facilities across SES (wealth quartile, number of assets and maternal education) - But no difference in FBD increase after user fee removal among women in the poorest quartile and richest women ▪ Little evidence that trends in the prevalence of facility delivery by any SES measures differed between the intervention and control countries ▪ Women in most materially deprived women with greater FDB prevalence, though not statistically significant ▪ Increased FBD prevalence among women with secondary education (p=004) vs those with no education	Pre-assessment for control countries and post-assessment for intervention countries with policy adoption
Singh (2015) Ghana	Mixed methods Quantitative household and community leader surveys and	NHIS in 2003-2005, with fee exemption for women and children under 3 months in 2008	ANC, FBD	969 women with children under 5	▪ Having insurance during the exact time of pregnancy was significantly associated with FBD (OR=2.5; CI: 1.3-4.5; p<0.01), but not with ANC visits	4-9 years after

	qualitative interviews (May-June 2012)				▪ Qualitative findings show a lack of understanding among women of who and what are covered ▪ Wealthier (X^2=17.0; df=4; p<0.002) and more educated women (X^2=40.3; df=4; p<0.000) more likely to have some insurance coverage ▪ Insurance did not address costs related to transport and extreme poverty experienced by some women	
Chama-Chiliba (2016) Zambia	Quasi-experimental with control groups and pretests Cross-sectional DHS (May 2002-September 2007)	Abolition of user fees in public health facilities, April 2006	FBD (in rural areas)	7,146 women aged 15-49, 5,410 children born between May 2002 and September 2007 1,500 women in 54 rural districts (fees abolished) in treatment group in specific region and 2,118 women in (fee paying) control regions	▪ Fee abolition with no significant effect on delivery location for home or public deliveries among women living in rural areas – But significant positive effect on deliveries in private or faith-based health facilities for rural women ▪ No significant difference in ANC between treatment and control groups ▪ Factors: distance and drugs availability in health facilities	4 years before and 1 year after
Johnson (2016) Ghana	Quasi-experimental without control groups Four rounds of DHS (1993, 1998, 2003, 2008)	Cash and carry policy, before 1998 Free ANC policy (1998-2003)	SBA	Thousands of women giving birth, depending on each wave of DHS	▪ Overall increased percentage of SBA over different periods of policy implementation among different sub-groups (p<0.01): women with no formal education and those with secondary/higher education; no formal education, primary education and secondary/higher education among women's partner; women from all wealth	5 years before and 3 years after

		Free delivery care policy (2003-2005) and abolished in 2007 NHIS in 2005, with integration of exemption fees for pregnant women in 2008			quintiles; and women in urban and rural residence ▪ But: Northern and Southern district divide persist, maybe explained by the North being poorer and with women with low education (less aware of the policies?), as SES variables do not explain it all	
Langlois (2016) Burkina Faso	Quasi-experimental without control groups Quasi-experimental (2008 and 2010)	National policy to subsidize SBA, 2006-2007	SBA	1,260 women aged 15-49 (pre-subsidy) and 1,395 women aged 15-49 (post subsidy) 1st survey in 2008 2nd survey in 2010	▪ Increase in adjusted rate of SBA among all SES strata of women, strongest among lowest SES women with increased rate of SBA sustained over time: 45% (95% CI=19-77%) immediately upon subsidy policy introduction; 46% (95% CI=20-78%) higher at 6 months; 47% (95% CI=20-78%) higher at 1 year; and 48% (95% CI=21-81%) higher 2 years after policy introduction ▪ Apparent decline in SES inequities in accessible obstetric care in Burkina Faso?	2-4 years after
Leone (2016) Ghana Burkina Faso Control: Cameroon Nigeria Zambia	Mixed methods Quasi-experimental intervention countries, with last survey conducted at least 3 years after policy: Burkina Faso (circa 2010) and Ghana (circa 2006)	Burkina Faso: 80% reduction in user fees, 2007 Ghana: Institutional birth fee exemption, 2003-2005 No user fee policy in control countries	C/S, FBD	187,310 women	▪ Increase FBD from 40% to 70% and from 45% to 60% in Burkina Faso and Ghana, respectively ▪ In Burkina Faso and Ghana, women from no to higher education more likely to have FBD, whereas those with no and primary education were more likely to have C/section (p=0.000 and p=0.017); women living rural and urban areas more likely to have FBD, whereas it is only those living in urban areas more likely to have C/section (p=0.000)	At least 3 years after

	Control countries: Cameroon, Zambia and Nigeria Key informant interviews				▪ Compared to poorest women in all 5 countries, women who are of average wealth, rich and richest are more likely to have C/sections (p=0.000)	
Manthalu (2016) Malawi	Quasi-experimental with control groups and pretests Yearly panel data (2003-2010)	Exemption fees for health care policy, with mission health facilities, 2006	ANC, DEL, PNC	Women receiving maternal health services from 142 mission health facilities which signed service level agreements (SLA)	▪ Significant difference between women receiving services from SLA and no SLA health facilities in at least 1 ANC during pregnancy and FBD (p<0.01), but no difference in 1ANC during 1st trimester and postpartum care visits	3 years before and 4 years after
Vallières (2016) Sierra Leone	Quasi-experimental without control groups Cross-sectional survey (October-November 2011)	Free Health Care Initiative (FHCI) for pregnant and lactating mothers, 2010	FP, ANC, SBA FBD, PMTCT, Child health	205 pregnant women from villages in the riverine area, and 136 pregnant women from villages in the mainland area	▪ Significant difference in SBA % post-FHCI among riverine (44.3%) and mainland (64.9%) women (p=0.000) ▪ Significant difference in TBA in post-FHCI in riverine (55.7%) and mainland (33.9%) women (p=0.000), whereas there was no significant difference in pre-FHCI (50.8% in riverine women and 44.4% in mainland women) ▪ Significant difference in FBD % in post-FHCI among riverine (41.3%) and mainland (61.2%) women (p=0.000) ▪ Significant difference in FP % in post-FHCI among riverine (28.4%) and mainland (44.8%) women (p=0.000) ▪ No difference in PMTCT in women in the riverine and mainland region ▪ Factors related to transport and more difficult terrain in the riverine area, as well as poor working and living conditions of	1 year after

					health workers (worse in remote areas like in the riverine areas?)	
Ajayi (2017) Nigeria	Quasi-experimental without control groups Cross-sectional surveys (DHS 2008, 2013) and survey (2016)	National free maternal and child healthcare programme, 2012	ANC, FBD, SBA	1,227 women aged 15-49 in 3 states	▪ 33.6% of all women benefited from free maternal health services, those from middle SES (38.3%, p<0.001) and who lived in a community where a health facility was available (37.2%, p<0.001) benefited most ▪ No clear trends in ANC and FBD from 2008, 2013 and 2016 in 3 states ▪ Increase in SBA in 3 states from 2013 to 2016	4 years before and 1-4 years after
Wang (2017) Ghana Rwanda Indonesia N.B. Only data from sub-Saharan Africa reported here	Quasi-experimental with control groups and no pretest DHS in Ghana (2008) and Rwanda (2010)	NHIS: 2003 in Ghana, 2004 in Rwanda	ANC1, ANC4, ANC during 1st trimester, FBD	Women aged 15-49 who are insured and those not insured (matched)	▪ 40.1% in Ghana and 73.1% in Rwanda of total women covered by health insurance ▪ Health insurance coverage positively associated with employment and richest households in Ghana, and unemployment and poorest household in Rwanda ▪ Before matching, significant difference between uninsured and insured women in terms of ANC1, but not after matching in Ghana. Significant difference of ANC1 before and among matching between both groups in Rwanda, favouring those with insurance ▪ Before matching, ANC in the 1st trimester positively associated with health insurance coverage in Ghana and Rwanda, but not after matching ▪ Significant differences before and after matching for FBD between insured and not insured in Ghana and Rwanda	5-6 years after
Calhoun (2018)	Quasi-experimental without control groups	Removal of delivery fees in	FBD in public facilities	2,793 women at baseline and 1,232 women at	▪ Women more significantly likely to deliver in a public health facility than at home or a private facility post policy	3 years before and 1 year after

Kenya	Longitudinal survey, baseline (2010) and endline (2014)	public facilities policy, 2013		endline (15-49 years old, unweighted)	▪ Among the poor women, increase in public health sector delivery (from 40 to 46%) and in private sector (from 36 to 45%), and decrease in home delivery (from 24 to 10%)	
Dennis (2018) Kenya	Quasi-experimental with control groups and pretests Repeated cross-sectional in 4 intervention and 3 comparison counties, looking at three periods: 2005-2009, 2010-2013 and 2013-2016	Maternal health voucher programme (2006-2016), Free Maternal Services Policy, 2013	ANC4+, FBD, PNC, complete care	5,323 women aged 15-49 who gave birth or was pregnant in the past 12 months	▪ ANC4+ increased for women living in both voucher and comparison counties in pre- and post-policy implementation period; OR 1.46 among women in voucher counties to have ANC4+ vs comparison during free maternal service period (p=0.006) ▪ No difference in FBD during pre- and post-policy combined with voucher programme period, but OR 1.65 among women in voucher counties to have FBD vs comparison, following the post-policy implementation period (p=0.008) ▪ OR 1.73 among women in voucher counties to have PNC vs comparison following the post-policy implementation period (p=0.001) ▪ In all periods, more than 60% of maternal services utilised in the public sector (vs private), with a decline of service utilisation in private sector during post-policy period combined with free maternal service period	1 year before and 4-7 years after
Obare (2018) Kenya	Quasi-experimental: interrupted time-series Repeated cross-sectional survey	User fee policy shifts: 2004 “10/20 policy”, 2007 “user fee removal of 10/20 policy in public facilities” and 2013 “free	ANC, FBD	8,195, 8,444 and 31,079 women who had ever given birth in 2003, 2008-9 and 2014 respectively	▪ ANC and FBD steadily increased between 2003 and 2014 ▪ Women with ANC from public health facilities increased from 71% in 2003 to 83% in 2008-9, while services from private facilities decreased over the same period ▪ No significant changes in public FBD following the 2004 10/20 and 2014 free	1 year before 1st policy and 1 year after for last 2nd and 3rd policies

	(DHS): 2003, 2008-9, 2014	maternity services”			maternity policies among poor or rural women ▪ After the 2004 10/20 policy, there was a statistically significant increase in home deliveries among all women ▪ A statistically significant increase in public FBD among richer women, accompanied by a decrease in home deliveries after 2007 policy	
Ogundele (2018) Ghana Nigeria	Quasi-experimental without control groups Three series of cross-sectional surveys (DHS): in 2003, 2008 and 2014 in Ghana, and in 2003, 2008 and 2013 in Nigeria	Ghana fee exemption for maternity care policy, 2005 (initiated in 2003) Nigeria NHIS, 2005 (initiated in 1999)	FP, ANC and delivery	Women aged 15-49 who gave at least one birth in the 5 years prior to survey, in both countries	▪ Regarding SRH service utilisation examined, there is a decline of inequality between richer and poorer in Ghana, while it is non-pro-poor in Nigeria ▪ The use of FP information is significantly favouring poorer women in Ghana and pro-rich in Nigeria ($p \le 0.01$) ▪ The use of ANC services at government health facility is pro-poor in both countries ($p \le 0.01$), while delivery at home is also mostly used by poorer women in both countries ($p \le 0.01$) ▪ C/S is pro-rich in both countries ($p \le 0.01$)	Ghana: 0-5-11 years after Nigeria: 4-9-14 years after
Ravit (2018) Benin Mali	Quasi-experimental without control groups Repeated cross-sectional surveys (DHS): in Benin in 2001, 2006 and 2011-12, and in Mali in 2001, 2006 and 2012-13	User fee policy exemption for C/S in selected public and private health facilities in Benin, 2009, and user fee removal reform, including C/S in Mali, 2005	C/S	23,266 and 24,036 women aged 15-49 who delivered a live-born child in the past 5 years prior to interview, in Benin and Mali, respectively	▪ In Benin, no significant difference in C/S between urban and rural or educated and non-educated women; there is a difference favouring richer women vs poorer women having access to C/S ($p \le 0.001$), and no difference between rich/poor before and after policy adoption ▪ In Mali, significant difference between educated and non-educated in accessing C/section before and after policy implementation ($p=0.043$); no difference	1-8 years before and 2-8 years after

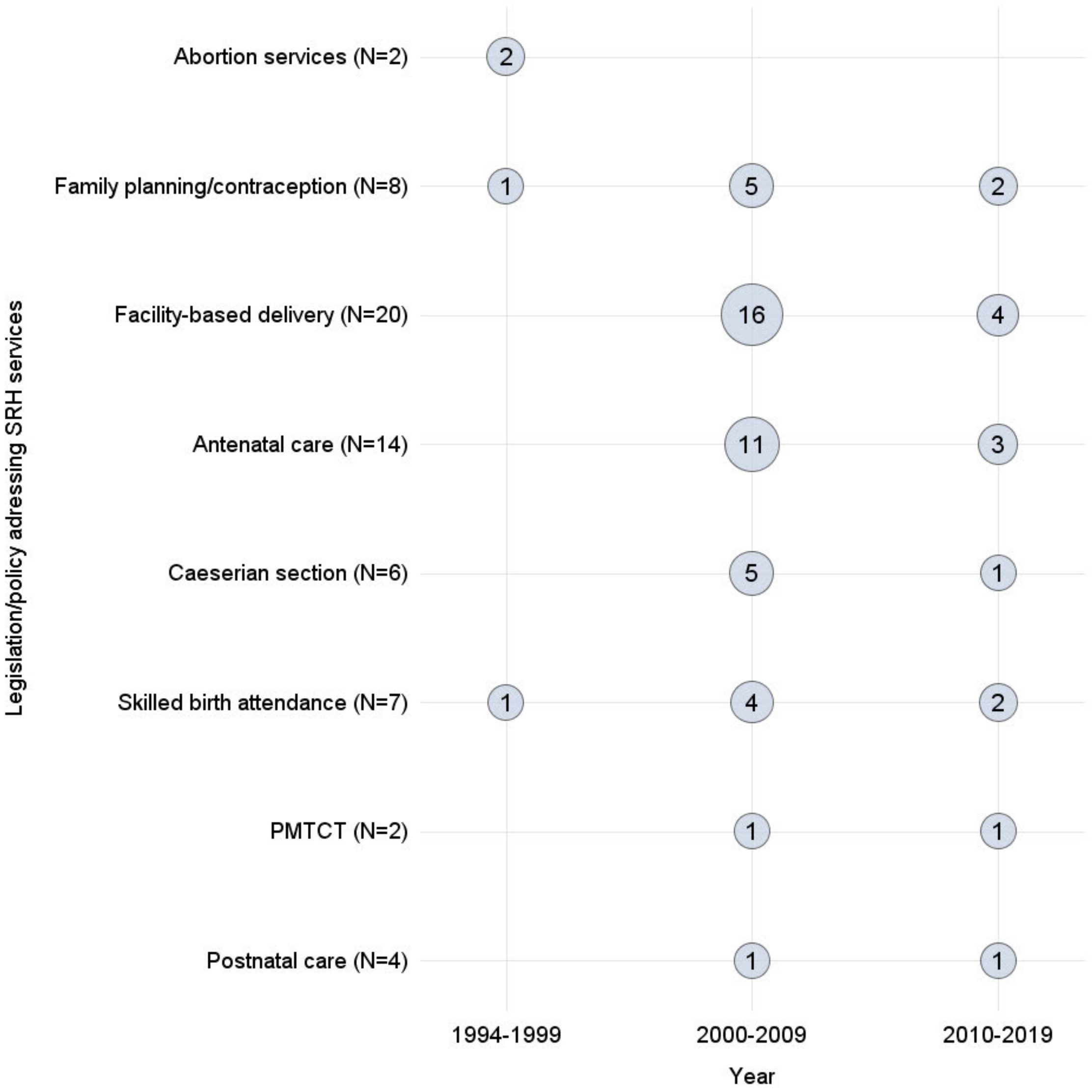
					between rich and poor between before and after policy implementation	
Ravit (2018) Benin Mali Control: Cameroon Nigeria	Quasi-experimental with control groups and pretests Repeated cross-sectional surveys (DHS): Intervention countries: Benin: 1996, 2001, 2006, 2011-12 Mali: 1995-96, 2001, 2006, 2012-13 Control countries: Cameroon: 1991, 1998, 2004, 2011 Nigeria: 1990, 2003, 2008, 2013	User fee policy exemption for C/S in selected public and private health facilities in Benin, 2009, and user fee removal reform, including C/S in Mali, 2005	C/S and FBD	46,362 women who delivered a live child in the last 3 years before the interview in the policy group, and 53,438 women in the non-policy group	▪ Adjusted OR=1.36 (95%CI 1.11 to 1.66; (p≤0.01) to have access to C/S; adjusted OR=2.71 (95%CI 1.70 to 4.32; (p≤0.001) among non-educated women; adjusted OR=2.02 (95%CI 1.48 to 2.76; (p≤0.001) among women living in rural areas; and adjusted OR=3.88 (95%CI 1.77 to 4.72; (p≤0.001) among middle-class wealth index ▪ The policy contributes to adjusted OR=1.68 (95%CI 1.48 to 1.89; (p≤0.001) in FBD	3-13 years before and 2-8 years after

Legend
ANC: Antenatal check-up
CTN: Contraception
C/S: Caesarian section
DEL: Delivery
FBD: Facility-Based Delivery
FP: Family Planning
NHIS: National Health Insurance Scheme
PMTCT: Prevention of Mother to Child Transmission
PNC: Postnatal Care
SBA: Skilled Birth Attendants

Type of legislation and SRH services used

Among included studies, national legislation or policy adoption promoting the access to and utilisation of SRH services spanned the period from 1996 to 2013, with a concentration of studies conducted between 2000 and 2009 (Figure 13).

Figure 14. – Legislation/policy addressing SRH service utilisation per year



Most studies analysed SRH service utilisation from 1-8 years before and 1-8 years after legislation/policy adoption (23, 25, 27, 30, 31, 33, 38, 42-48) and between 1-14 years after legislation/policy adoption (26, 28, 29, 32, 34, 37, 40, 41, 49-54). Two studies examined service utilisation 2-4 years before legislation/policy adoption at time point 1 and the same year at time point 2 (24, 39). Two others assessed service use the same year as legislation/policy adoption (35, 36). Twenty studies out of 32 examined maternal health-related policies which focused on eliminating or subsidising facility-based delivery (23, 24, 29-31, 38, 41, 42, 44, 45, 48, 51, 53) and skilled birth attendant use (24, 27-30), either through specific policies promoting these services or through national health care reforms (25), national health insurance schemes (27, 37, 46, 54), and performance-based financing (40). Fourteen studies examined the effects on antenatal care service utilisation from the influence of maternal health fee exemptions or abolition (29, 30, 32, 43, 48, 51, 52), performance-based financing (40), specific reproductive health voucher programmes (35, 44) and health insurance schemes (26, 36, 37, 54). Two studies looked at the impact of abortion legislation on the use of safe abortion service (49) and contraception (50). Four other studies examined the effects of a reproductive health programme (35), performance-based financing (40), national health insurance (32), and exemption fees (32) or free health care (29) for pregnant women and lactating mothers on family planning and contraception. Five studies considered policy pertaining to caesarian section (33, 34, 45, 47, 53). To a lesser extent, postnatal care (35, 43, 44, 52) and PMTCT (29, 39) were studied.

Changes in SRH service utilisation

Most studies (27/32) used the four types of quasi-experimental designs. They examined a large range of multiple SRH outcomes (n=46), and their findings varied in significance (Table 15). Sixty percent (28/46) of the results found statistically significant positive increases following policy implementation in service utilisation, ranging from family planning and contraception (32, 35, 40), antenatal care (32, 36, 37), facility-based delivery (23, 24, 29, 35, 37, 38, 40, 43, 45, 46, 53), skilled birth attendant use (24, 27-29), caesarian section (32, 34, 45, 47, 53), postnatal care (44) and PMTCT (39). Among these studies with positive results (statistically significant and improved outcomes), several examined the effects of abolition/reduction of service fees (23, 29, 32-34, 38, 43, 45-47, 53) and the implementation of national health insurance schemes (32, 36, 37). Eight studies found mixed results (i.e. a mixed of positive, negative, statistically significant, and not statistically significant outcomes) on the use of antenatal care (40, 43), facility-based delivery (26, 42, 44, 48), skilled birth attendant use (25) and caesarian section (33). Ten others showed no significant results on the use of antenatal care (26, 30, 35, 48), facility-based delivery (30, 31, 41, 53), skilled birth attendants (30), and HIV testing during pregnancy (29). From all quasi-experimental study designs, no specific reporting on safe abortion care service utilisation was made.

Tableau 17. – SRH service utilisation results by quasi-experimental design and significance of results

	Positive results[1]				**Mixed results[2]**				**No significant results[3]**				**Total**
Quasi-experimental design	A	B	C	D	A	B	C	D	A	B	C	D	
Abortion services													-
Family planning / contraception	**1** Ogundele (2018)	**1** Obare (2013)	**1** Skiles (2013)										**3**
Antenatal care	**1** Ogundele (2018)	**2** Abrokwah (2014) Wang (2017)					**2** Skiles (2013) Manthalu (2016)		**2** Frimpong (2014) Ajayi (2017)	**1** Obare (2013)		**1** Obare (2018)	**9**
Facility-based delivery	**3** De Allegri (2012) Bellows (2013) Vallières (2016)	**2** Obare (2013) Wang (2017)	**5** Penfold (2007) Skiles (2013) Leone (2016) Manthalu (2016) Ravit (West Africa, 2018)	**1** Dzakpasu (2012)	**1** Frimpong (2014)		**2** Chama-Chiliba (2016) Dennis (2018)	**1** Obare (2018)	**2** Ajayi (2017) Calhoun (2018)		**2** McKinnon (2015) Leone (2016)		**19**
Skilled birth attendants	**4** Bellows (2013) Johnson (2016) Langlois (2016)				**1** Kengia (2013)				**1** Ajayi (2017)				**6**

	Vallières (2016)												
Caesarian section	**1** Ogundele (2018)	**1** El-Khouri (2012)	**2** Leone (2016) Ravit (West Africa, 2018)	**1** Fournier (2014)	**1** Ravit (Benin, Mali, 2018)								**6**
Postnatal care			**1** Dennis (2018)										**1**
HIV testing during ANC			**1** Byamugisha (2010)						**1** Vallières (2016)				**2**
Total	**10**	**6**	**10**	**2**	**3**	**-**	**4**	**1**	**6**	**1**	**2**	**1**	**46**[a]
Total	**28**				**8**				**10**				**46**[a]

[a] 27 studies analysed multiple SRH results (including one of the mixed methods studies which used a quasi-experimental design for its quantitative component).

Notes

[1] Positive results: If all results are reported to be statistically significant and improved outcomes.

[2] Mixed results: A mixed of positive, negative, statistically significant and not statistically significant outcomes.

[3] Negative results: Not statistically significant or significance not reported.

Legend

A: Quasi-experimental designs without control groups
B: Quasi-experimental designs that use control groups but no pretest
C: Quasi-experimental designs that use control groups and pretests
D: Interrupted time-series designs

Differential vulnerability in the utilisation of SRH services among population sub-groups

Despite the general trend of increased utilisation of SRH services following the adoption of legislation or health policy, disparities in service utilisation remained among sub-groups of women or vulnerable women. Women with no education and within the lowest wealth quintile were less likely to use antenatal care in Ghana even after fee exemption (52). Concerning the uptake of facility-based delivery, women who had some education (38), high school or higher education (24), those who were wealthier (24, 35, 40, 41, 46), residing less than 5 km away from a health facility (51) or living in less difficult terrain (29) tended to give birth in health facilities more often than the other groups of women. Related to caesarian section use, in some studies, less disadvantaged women benefited more from services (34, 47, 53), while one study in West Africa showed that non-educated women and those living in rural areas benefited most after policy adoption (45). A study conducted in Kenya found that women who were of Muslim/Other/No religion were more inclined to use family planning compared to women of the Catholic faith (35). Besides sub-groups of women of reproductive age studied, a South African study examined the utilisation of contraception among adolescent mothers (50) and an Uganda study focused on HIV testing among pregnant women and their male partners (39). Included studies did not address other vulnerable populations as their primary targets or in explicit sub-analyses.

Quality of reporting in studies

Among the two mixed methods studies, only one of the five quality assessment criteria was addressed, which was related to the rationale for why a mixed methods design was important. Despite having reported the use of qualitative data collection techniques, both studies heavily focused on their quantitative results and interpretation. The other criteria on mixed quantitative and qualitative methods data integration, interpretation and management were not reported. Regarding the assessment of 27 quasi-experimental study designs, three main observations emerged. First, in eight studies, mostly using repeated cross-sectional surveys (23, 29, 30, 32, 34, 38, 42, 53), there was no indication that the independent variables occurred in time before the dependent variables (18), even though the year of legislation/policy adoption was known in all studies. Second, 14 studies did not include any control groups (23-33, 46-48). Third, on a more positive side, six studies added multiple measurements at different time points before and after the intervention (23, 39, 43, 46-48). Concerning the five cross-sectional studies, none clearly reported efforts to address potential sources of bias such as controlling for confounding factors. Further, three studies (49, 50, 52) out of five did not clearly report how quantitative variables were handled in the analyses nor statistically control for confounding factors. All cross-sectional studies acknowledged methodological limitations.

Discussion

To the best of our knowledge, this is the first systematic review to assess the scientific literature which examined the relationships between legislation or health policy and the utilisation of SRH services by vulnerable populations in sub-Saharan Africa. We found that the adoption of equity-focused legislation and policy promoted SRH service utilisation over time, mainly related to maternal health services among vulnerable populations of women, corroborating what has been reported in the literature (55-57). However, despite the passage of time since the ICPD promoting a wide range of SRH rights and services for all, a narrow scope of SRH focusing on maternal health service utilisation is observed. This may be explained by the emphasis of the MDG 5, from 2000 to 2015, to prevent and manage the “clustering of mortality around delivery” and save women’s lives (58).

Promising pro-equity policy influence over SRH service utilisation

We found that policies promoting fee abolition or reduction and national health insurance schemes seemed to lead to increased trends in various types of SRH service utilisation and across groups of populations, including those less educated, less better-off and living in rural areas. These policies addressed social determinants such as education, wealth and place of residence across different groups and social gradients in the population (11). Despite promising improvements over time, social health inequities persisted within vulnerable populations based on the rich/poor, educated/non-educated and urban/rural divides. A systematic review of differences in maternal health service utilisation in low- and middle-income countries (LMIC) showed that living in urban areas and being better off economically positively influenced the use of skilled birth attendants and likelihood of delivering in a health facility, while economic status did not influence antenatal care uptake (59). The age and parity of mothers, as well as women's education and that of her husband's, have been described in the literature as factors for divergent outcomes in relation to antenatal care uptake (60), while societal norms and values (7), such as religion were reported as potential barriers for family planning use (61). Further, abortion laws remain very restrictive in most of the African continent with only South Africa and Cape Verde legally allowing women to request an abortion, under specific conditions (62). As for the utilisation of PMTCT services, barriers to policy translation into concrete changes could be partly explained by stigma and fear of HIV status disclosure to partners and family.

Important populations left behind

Studies included in this review excluded specific vulnerable populations. Sub-Saharan Africa is home to three of the world's largest vulnerable populations, notably youth, people living with HIV and people with disabilities. Firstly, though several studies included various sub-groups of women in their reproductive age, the majority did not report any specific analysis pertaining to young people. Among young women, 37% and 45% are married before they reached 18 years old in Eastern and Southern Africa and Western and Central Africa, respectively (63). Over the past decades, single young women in sub-Saharan Africa have become more sexually active; this has important practical implications for SRH service utilisation by youth (64).

Secondly, the majority of people living with HIV worldwide live in sub-Saharan Africa, with women aged 15 and older representing 59% of new adult HIV infections in 2017 (65). Facing multiple challenges such as stigma and discrimination at family and community levels, the SRHR of people living with HIV are curtailed by laws criminalising the transmission or non-disclosure of HIV transmission, which jeopardise their SRH service utilisation (65). According to development aid assistance analyses from 2000 to 2013, HIV/AIDS has received the majority of external funding relative to other health sectors (66). The high level of foreign assistance to many sub-Saharan African countries where HIV was prevalent might have shrunk the domestic policy space for policy formation because of aid dependence (67).

Thirdly, people with disabilities represent approximately one billion people of the world's population, and 80% live in LMICs, including in sub-Saharan Africa (68). Literature has shown that people with disabilities experience barriers related to physical and communication accessibility, negative attitudes of health professionals, and financial costs when accessing SRH services (69, 70). A systematic review and meta-analysis reported that adults with disabilities in sub-Saharan Africa, especially women, were at heightened risk for HIV (71). A recent study on the intersection between gender, disability, and poverty in Kenya reported that despite pro-poor policy promoting free maternal healthcare, women with disabilities were left behind (72). Although these three large groups stood out by their absence in this review, other vulnerable groups such as people living on the streets and sex workers were also missing. The use of conventional surveys, measuring health disparities might not reach them nor address their specific characteristics, may explain this gap (4).

Limitations of the literature, PICO methodology and the study

This review highlighted limitations in the literature and the use of a classic PICO systematic review methodology to explore complex questions. The study itself also has several limitations. First, despite having adopted a systematic review process covering a 25-year period (1994-2019), our literature search resulted in only 32 studies. This demonstrates that the relationships between pro-equity legislation or health policy and the utilisation of SRH services by people in situations of vulnerability are largely unexplored in sub-Saharan Africa. Second, the positivist nature of the PICO methodology requiring a specific relation between various research question components could have precluded the inclusion of qualitative research studies. The standardised PICO requirements are often in contradiction with the more inductive nature of qualitative research. Third, our choice to review primary empirical research meant that we did not include realist and systematic reviews which may have led to other angles of analysis. Fourth, while most studies focused on the “impact” aspect of the CSDH recommendation to evaluate health policy more effectively (7), none of the included studies looked at the effects of, for example, pro-poor tax policy, gender equality policy, or disability laws on the utilisation of SRH services among vulnerable populations. Finally, the quality assessment of studies suggested methodological weaknesses such as ambiguous temporality between independent and dependent variables in cross-sectional surveys (not related to when a legislation/policy was adopted versus when a study was implemented), selection and history, which potentially threaten the internal validity of studies (19).

Conclusion and implications for policy and research

In the SDG era with the motto “leave no one behind”, policy- and decision-makers need to revisit national legislation and policy implementation more critically and address a broader scope of SRH services beyond maternal health care to reach the SRHR targets of 2030 (4). In terms of policy, not only is it essential to remove financial barriers and reduce SRH service utilisation disparities among groups, but there is also an urgency to consider social determinants of health (7) so as to address the unequal distribution of socioeconomic factors such as income, education and place of residence (11). This calls for more integrated intersectoral action between the health, finance and economy, education, and infrastructure sectors, for instance (11, 73). The attainment of SRH universal coverage is multifaceted and depends upon the interplay of power structures (e.g. sexism, classism, etc.) which produce and perpetuate unequal health outcomes. An intersectional analysis can make health inequities more visible in relation to these power dynamics (74). Regarding research, this review also confirmed the need for more rigorous quantitative, qualitative, and mixed methods research designs to answer to research questions emanating from complex policy and health system related contexts. Specifically, research strategies such as the case study approach, advances in impact evaluation, investigating policy and system change over time, cross-national analysis and action research are suggested for policy analysis and systems strengthening (75). Research should further examine prospectively or retrospectively the impacts of legislation/policy implementation on SRH service utilisation, over a period of at least 10 years (75). In conclusion, health policy and systems research should also be more "people-centred", in particular focusing on the most vulnerable, in developing recommendations for policy- and decision-makers "to address equity and social justice" more systematically (76).

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To contemplate disability is to scrutinise inequality.

Disability is both a signifier of inequity and the promise of something new and affirmative.

– Goodley, Lawthon, Liddiard & Runswick-Cole (219)

Chapter 7 – Overall Discussion

Anchored in the field of global health, this doctoral research aimed to examine the relationships among legislation and health equity (at the macro level) and the use of SRH services of people with disabilities (at the meso and micro levels) in the post-conflict Northern region of Uganda, between 2006, the year of the 'end' of the armed conflict and adoption of the Disability Act in Uganda, and 2019. Through a transformational sequential mixed methods study with a qualitative predominance (178), the intersectional approach (16) was adopted to guide successive analyses and interpretation of a series of studies' findings. Intersectionality brings critical attention to the complex relationships among societal power systems and dynamics (such as sexism, patriarchy, ageism, racism, ableism, and classism) and the interplay of people's multiple categories/identities (based on sex, age, race, ability, education, wealth, and others), within a specific social, political, and historical context embedded in space and time (16). Committed to social justice and equity, intersectionality promotes the recognition and amplification of marginalised voices and the emergence of different sources of knowledge; an intersectional approach fights against a "hegemonic production of knowledge" (79).

Specifically, my doctoral research applied an Intersectionality-based policy analysis (IBPA), an approach mostly used in public health policy contexts (96). The IPBA framework theorised and proposed by Olena Hankivsky and colleagues (17, 84, 90, 91, 96, 97, 220, 221) is a relatively new approach to analysing public policy by relating seven key concepts or principles: 1) social justice and equity, 2) intersecting categories, 3) multi-level analysis (micro, meso and macro), 4) power structures and dynamics, 5) diverse sources of knowledge, 6) context (time and space), and 7) reflexivity. These principles should not only be analysed iteratively but should also be taken into account in policy analysis, including how the problem is perceived by different policy actors and in the analysis of groups/populations that are differently affected by the problem (IBPA descriptive questions), as well as concerning the solutions that are envisaged to address the problem (IBPA transformative questions) while considering reflexivity in the policy analysis process. Olena Hankivsky, a professor at Simon Fraser University, and her Canadian and international colleagues (such as Olivier Ferlatte and Bilkis Vissandjee at Université de Montréal, and early intersectional theorists Patricia Hill Collins, Ange-Marie Hancock, and Nira Yuval-Davis) have devoted two recent books to describing, promoting, and explaining this new approach to policy analysis. The first book edited by Hankivsky, *An Intersectionality-Based Policy Analysis Framework,* highlights seven Canadian case studies which have adopted the IPBA framework to analyse policies related to issues such as maternal care policy in British Columbia, palliative care, Aboriginal community health, and funding for HIV prevention for gay men (96). In 2019, Hankivsky expanded the body of knowledge on intersectionality and the IBPA framework by publishing a second major book, *The Palgrave Handbook of Intersectionality in Public Policy*, this time collaborating with more than thirty theorists and experts using the intersectional framework in public policy analysis (97).

Contrary to existing and more conventional frameworks and models to analyse policy, such as the Linear Model of Grindle and Thomas (103), Multiple Streams Framework of Kingdon (problem, policy, politics, window of opportunity, and policy entrepreneurs) (98), the Policy Triangle Model (content, process, context, and actors) of Walt and Gilson (100), or the Sex- and Gender-based Analysis framework of the Canadian government (101), the IBPA framework provides a flexible and innovative approach to analysing policy, especially its blind spots. It highlights equity issues while consciously considering the multiple identities of groups, including vulnerable populations such as people with disabilities (17, 91). The IBPA framework allows us to question more deeply the state of existing policies, notably how they promote (or not) social justice and health equity while recognising the processes of discrimination, power, and oppression (such as ableism, patriarchy, and sexism) borne by vulnerable and marginalised populations. Through the transformative questions, this framework encourages us to analyse policies differently. It challenges us to be attentive to the processes of marginalisation that policies may engender and to issues of social inequities, as well as to identify concrete solutions to change the problematic situation around a public policy already adopted or being formulated (96). Furthermore, it is one of the first frameworks that systematically considers the importance and voices of diverse sources of knowledge, especially those on the margins of society (17, 91, 220). The IBPA framework is not (yet) a conventional approach, framework, or model of policy analysis, but it proposes a new multi-factorial, multi-directional, and multi-relational lens to policy analysis (17, 221).

In this chapter, I integrate and synthesise the overall thesis findings (Section 7.1) and knowledge translation activities (Section 7.2). I discuss the thesis' contributions (Section 7.3) to global health scholarship (Section 7.3.1) and intersectionality through its comprehensive application and contribution to global health (Section 7.3.2). Section 7.3.3 discusses the thesis contributions to theory and its methodological strengths and challenges in Section 7.3.4), including those related to applying ethics norms in a context of global health qualitative research conducted with people with disabilities (Thesis Manuscript 6). In Section 7.4, I discuss the dissertation's limitations and propose recommendations for future perspectives (Section 7.5). I close this chapter with my reflexive notes (Section 7.6).

7.1 Synthesis of mixed methods results

In the previous chapters, each of the manuscripts discusses the study findings in relation to existing literature. Here, I focus on the three main findings of this doctoral research: 1) the situated understanding and perceptions of five groups of policy actors of the relationships among legislation, health policy, and the utilisation of SRH services by people with disabilities in post-conflict Northern Uganda, 2) the perceptions of the inequitable access to and use of SRH services among people with disabilities in Uganda, and 3) the (in)visibility of disability in mainstream SRH-related policy analysis.

This mixed methods study examined perceived and empirical relationships among legislation, health policy, and the actual use of SRH services by people with disabilities in the post-conflict Northern region of Uganda, between 2006 and 2019. To address the first objective (first phase: qualitative study), I examined how five key groups of policy actors – women and men with disabilities, service providers, disabled people's organisations, national and international organisations, and national policy-makers – perceived the relationships among legislation, health policy, and the utilisation of SRH services by people with disabilities in the post-conflict Northern region of Uganda.

For the second objective (second phase: quantitative secondary study), I examined whether and how disability was associated with selected SRH service utilisation in Uganda between 2006 and 2016, the decade following the adoption of the country's first Disability Act. The selection of variables for the second quantitative phase was informed by the qualitative findings of the first phase.

For the third objective (overlapping phase: systematic review), I systematically reviewed the existing body of evidence on pro-equity legislation, health policy, and the utilisation of SRH services by vulnerable populations in sub-Saharan Africa from 1994 to 2019. This overlapping phase aimed to further understand whether the evidence found at the country level can also be observed at the regional level. The IBPA approach guided our analyses and interpretation through the following key principles (Table 18): 1) social justice and equity, 2) intersecting categories/identities, 3) multilevel analysis, 4) power structures and dynamics, 5) different sources and production of knowledge, 6) time and space (the context), and 7) reflexivity (96).

Tableau 18. – Key IBPA principles examined in the thesis manuscripts

Key principles in the IPBA	Manuscript 1: Meta-synthesis	Manuscript 2: Qualitative paper 1	Manuscript 3: Qualitative paper 2	Manuscript 4: Quantitative paper	Manuscript 5: Systematic review	Manuscript 6: Ethics paper
Social justice and equity		x	x		x	
Intersecting categories	x	x		x		
Multilevel analysis (micro, meso, macro)		x	x	x	x	
Power dynamics and structures	x	x	x			x
Diverse knowledges	x	x	x			
Time and space (context)		x	x	x	x	x
Reflexivity		x	x			x

7.1.1 Situated understanding and perceptions of policy actors of the relationships among legislation, health policy, and use of sexual and reproductive health services

Among the five groups of policy actors at the micro (people with disabilities, Manuscript 2), meso (health service providers and representatives of disabled people's organisations), and macro levels (national and international organisations and national decision-makers) (Manuscript 3), perceptions of the relationships among legislation and health policy implementation and the use of SRH services by people with disabilities in the post-conflict Northern region of Uganda converged. The five groups of policy actors recognised the existence of numerous technical and financial challenges in the implementation of adopted disability-focused legislation and policy for people with disabilities to fully exercise their SRH rights without discrimination and stigma. Despite being situated at different levels, the five groups of policy actors put forward complementary recommendations to address the inequitable access to and use of SRH services by people with disabilities and remove physical, attitudinal, and structural barriers, in addition to the necessity of empowering people with disabilities. To date, published studies (130, 222, 223) have focused largely on removing barriers related to the inaccessible and non-disability-friendly nature of SRH services. In contrast, our study findings emphasised the importance of removing structural barriers such as the limited collection and monitoring of disability-disaggregated data or the lack of prioritisation of disability budgeting for legislation and health policy measures to be enforced. This finding aligns with conclusions in the literature that it is vital to plan for and capture disability-related data for people with disabilities to exercise fully their human rights, including health (192, 224).

According to policy actors at the meso and macro levels, especially health service providers and national policy-makers (Manuscript 3), the post-conflict context further shaped the experience of additional barriers to access and use of services by people with disabilities beyond disability-related policy implementation issues. They perceived that the Northern region of Uganda which was most affected by the 20-year armed conflict still bears persisting challenges for people with disabilities to access and use SRH services. Research reported that the conflict has engendered limited access to and poor quality of reproductive and maternal health services (59, 222). Policy actors' narratives and reflections on the relationships among legislation, health policy, and use of SRH services by people with disabilities in a post-conflict setting were intertwined with their reports of the underlying intersections of gender, disability, HIV, and experiences of violence, especially faced by women with different types of impairments. Some of these findings corroborate existing systematic reviews that report close relationships between disability and gender (5, 142, 225), disability and HIV (138, 226), and disability and experiences of different forms of violence (227, 228). However, none of the reported studies addressed the concomitant intersections among disability, gender, HIV and other STIs, and violence. These intersections emphasise the multilayered experiences of marginalised populations, notably people with disabilities, whose lives occur at the junction of multiple indivisible identities and within specific contexts (96, 229).

7.1.2 Perceived inequitable access to and use of sexual and reproductive health services among people with disabilities and their actual service use in Uganda

In the qualitative study, policy actors, irrespective of the level of analysis, were unanimous in reporting multiple barriers women and men with different impairments experienced in accessing and using SRH services. The intersectional analysis of quantitative secondary data of repeated Demographic and Health Surveys (DHS), however, showed a more nuanced pattern of the use of SRH services among people with different types of impairments. To date, literature and systematic reviews concur with the widespread understanding and recognition that SRH services are mostly inaccessible and disability-unfriendly (223, 230). However, most cross-sectional studies examining the access to and use of SRH services among people with disabilities did not report differences in contraception use (231), access to maternal health services (231, 232), or use of any SRH service relative to people without disabilities (233). Inequitable SRH service use was only highlighted when additional analyses were performed based on people's type of impairments, beyond the status of people 'with' or 'without' disabilities (234) and sociodemographic factors such as wealth and education (233). Based on interaction term analyses, my quantitative findings revealed that wealthier women with sensory impairments were less likely to have had the optimal antenatal care visits despite their wealth level relative to the poorest group of women without disabilities. Similarly, a cross-sectional study conducted in Cameroun among people with and without disabilities reported that people with physical or hearing impairments were at higher risk of having difficulties with SRH care and that socioeconomic differences partly influenced the use of SRH services among people with and without disabilities (233).

The seemingly divergent qualitative and quantitative findings emphasise the need to explore the specific issues related to disability data sources and underlying power dynamics which are not captured in cross-sectional surveys, such as the DHS. Casebolt argues that having disability questions in the DHS household questionnaire requiring one household member, often the household head, to qualify the type and level of difficulties on behalf of other household members is not optimal (235). Ideally, each household member should answer the disability questions individually, hence decreasing the potential for information bias; however, this requires the DHS programme to adjust and standardise the DHS training and roll-out procedures throughout countries worldwide where the programme is implemented (235). Furthermore, the intersectional approach postulates that power systems and dynamics, such as ableism, not only structure the interplay of social identities but also reinforce them (236), while structured questionnaires such as the DSH are often not designed to capture complex societal interactions between multiple identities and societal structures and dynamics (229, 237, 238). More transformative actions and research based on disability rights are better suited to address the tensions between the perceptions of ableist discrimination and stigma experienced by people with disabilities and their actual utilisation of SRH services (239).

7.1.3 (In)visibility of disability in mainstream sexual and reproductive health-related policy analysis

In line with the IBPA framework's recommendation for a multilevel analysis of any research focus (96), my doctoral research aimed to understand and document the perceptions of the relationships among legislation, health policy, and the use of SRH services by people with disabilities in post-conflict Northern Uganda among policy actors at the micro, meso, and macro levels. It also examined the associations of disability and other factors with the use of SRH services throughout Uganda, between 2006 and 2016. Concurrently, it was important to ensure that the evidence produced at the country level be interpreted in light of evidence at the regional sub-Saharan African level. The findings of the empirical studies reported in Manuscripts 2-4 reported rich information regarding the complex interplay of these relationships, highlighting the diverse situated voices of people with disabilities and those of other policy actors in Uganda (149). However, the strict and standardised PICO methodology prescribed for the conduct of systematic reviews (208) resulted in the exclusion of qualitative studies from the systematic review (Manuscript 5), thus excluding diverse views and sources of knowledge from the analyses (218). Nevertheless, this systematic review covering 25 years of research about the relationships among pro-equity legislation, health policy, and the use of SRH services among vulnerable populations in sub-Saharan Africa confirmed that people with disabilities are often excluded as an important marginalised group; this is symptomatic of the hegemonic post-positivist production of knowledge (79). The IBPA framework enables multilevel dialogue and highlights the presence of invisible groups and hidden social inequities that otherwise would have been missed in policy analysis (220). This finding further supports the use of intersectional analyses to identify and illuminate blind spots in global health equity (93, 240) and public policy analysis research (221).

7.2 Knowledge translation

At several stages of my doctoral research, study findings were shared with different audiences and under various formats. As a researcher attentive to the research process, particularly the feedback on the relevance of information shared among presentation participants and conference attendees, I sought to diversify the type and background of the audiences. I also ensured that knowledge exchanges occurred not only during international scientific conferences but also in Uganda among local health and administrative authorities as well as people with disabilities, their representatives, and elected officials with disabilities. In the following table, I only focus on the knowledge exchange activities which directly resulted from this doctoral research and which were conducted between March 2016 and January 2021, in Canada, Uganda, and internationally.

Tableau 19. – Summary of knowledge translation activities

Publications as first author (not including commentaries and editorials)	
Peer-reviewed articles published	4
Other articles submitted (under review) to refereed journals	2
Total number of publications	**6**
Conferences and oral scientific publications	
At the host university or research institute	3
In other universities in the province	5
National scale	3
International scale	6
Total number of conferences and oral presentations	**17**
Poster presentations	
At the host university or research institute	1
Total number of poster presentations	**1**
Knowledge exchange in Uganda	
Presentations to stakeholders, people with disabilities, and health managers and providers	3
Workshop and presentation to hospital health staff of six health facilities	1
Meeting with health and administrative officials	2
Dissemination email of a qualitative evidence brief	1
Total number of dissemination activities	**7**
Total	**31**

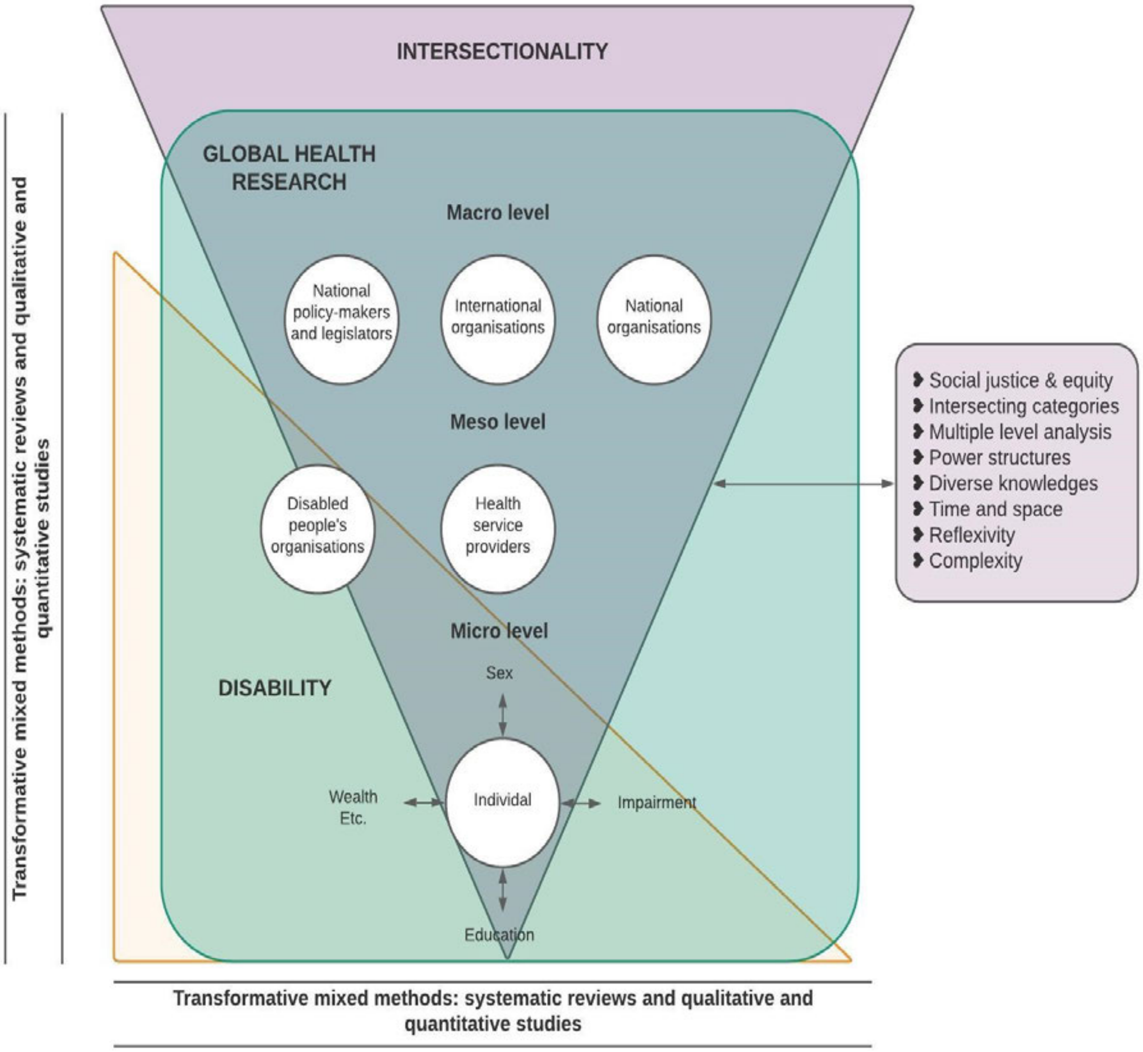
At the beginning of the fieldwork phase, I met relevant district administrative and health officials to explain the research objectives and data collection plan and to seek their official permission to conduct the study in Uganda. Without exception, officials complained that most 'Western' researchers whom they had met before collected their data without returning to let these key local stakeholders know about their study findings. Their feedback was important and factored into my subsequent research process and activities. By respecting their wishes to learn more about the study findings, the research assistants and I were received with great surprise when we went back to share the research evidence brief and how the study went during the past few months. They asked, "you're not gone yet?!". Specifically, at the end of the qualitative data collection phase and before leaving Uganda, I organised a series of dissemination and exchange activities to present and discuss the preliminary qualitative findings with people with disabilities, disabled people's organisations, elected disabled officials, as well as healthcare providers, managers, and administrative officials of the districts of Gulu, Amuru, and Omoro. These activities aimed to honour my commitment to sharing evidence collected and discussing together with local stakeholders, recommendations on how to move ahead from these research findings. Moreover, when presentations were prepared for people with disabilities, I ensured that sequential English-Luo translation and Ugandan sign language interpretation were provided to promote understanding and exchanges with people with different impairments and levels of education. The exchanges required more resources, but the additional time allotted and efforts deployed were necessary to initiate further dialogue in the long run.

7.3 Dissertation's contributions to the field of global health: Recognition of disability in global health research through intersectionality

I will discuss the contributions of this thesis on two fronts: 1) the study of disability in global health scholarship, and 2) the comprehensive application of intersectionality in policy analysis and global health fields, and across a multilevel analysis of five groups of actors. I will also discuss the methodological strengths and challenges of this thesis.

The implementation of my doctoral research lay at the interface of different research fields and methods. My thesis is primarily embedded in the field of public health, and in particular in global health, both of which aim for health equity and social justice (241). Global health has been defined as "an area for study, research, and practice that places a priority on improving health and achieving health equity for all people worldwide" (241). It has been also referred to as "collaborative transnational research and action for promoting health for all" (242). Through sexual and reproductive health, still a major public health issue globally and in sub-Saharan Africa (134), I explored disability in global health using an intersectional approach (243, 244). I focused on both women and men with disabilities, 'placing disability' (245) at the heart of global health scholarship through the intersectionality-based policy analysis (IBPA) of SRH service utilisation though the perspectives of a marginalised and vulnerable group of people with disabilities in post-conflict Uganda (243, 244, 246). To connect these fields, the IBPA framework was adopted throughout the different phases of the research (96). Intersectionality is a useful theoretical and analytical framework to highlight less researched social inequities (221). It enabled me to test the complex contours of the linkages among legislation and health policy, societal oppressive power systems such as ableism, and the situated views of a diverse group of policy actors including women and men with different impairments in the Global South. Schematically (Figure 14), I conceptualise intersectionality (purple triangle) as the cementing tool which bridges, at the theoretical, analytical, and empirical levels, disability (yellow triangle) in global health research (green rectangle) through the specific study and application of key principles promoted by the IPBA framework. The connecting operational exercise was made possible by adopting a multiple mixed methods approach.

Figure 15. – Relationships among intersectionality, disability, and global health research



7.3.1 Disability in global health scholarship

At the macro level, ableism (247) is a powerful societal system of inequality that provides 'unearned privileges' to non-disabled people (248). Ableism is characterised by negative discriminatory biases and prejudice against people with disabilities and can lead to the invisibility and exclusion of *people with disabilities* in global development issues, including global health (246, 249). Coupled with a globalised neo-liberal paradigm which emphasises economic growth and development, often at the expense of inclusion and human rights (249), ableism fosters a view of people with disabilities as ‘unproductive bodies’, uninteresting and meriting neither attention nor investment (249). Critical political economy reminds us that societal, political, economic, and historical processes shape people’s health through hegemonic worldviews and power asymmetries (250). When ‘disability’ is further examined in global health, the Disability-Adjusted Life Year (DALY), a measure of the overall burden of disease, is used to allocate resources for health programmes and services (250). The use of this metric has been challenged as DALYs use a subjective disability weight attributed by health economists to diseases or health problems and fails to consider people’s feelings and perceptions of their health status and the contextual environment in which people’s lives are evolving (251). A core critique of the DALY approach to disability is that a person with disabilities is not necessarily a person who is sick. Groce argued that unless people with disabilities are included in mainstream global health research initiatives and their rights are considered, their socioeconomic development, including their health, will remain unchanged (244). Acknowledging and addressing the existence of ableism and other oppressive societal forces, this thesis has recentered disability and the views of women and men with disabilities within and across the research processes.

Guided by the principles of empowerment, non-discrimination, and accessibility promoted by the Convention of the Rights of Persons with Disabilities (107) and the social model of disability which emphasises the interactions between barriers in society and the participation of people with disabilities (243), the thesis findings highlighted the SRH rights of women and men with disabilities in post-conflict Northern Uganda. I situated the production of knowledge as a co-generation of ideas and evidence that was multilevel – five groups of policy actors, including women and men with disabilities – and that was intertwined with the analysis of the context, power structures, and critical reflexive considerations. Asserting who is acknowledged characterises the intersectional approach to its fundamental epistemic core (79). The conduct of in-depth interviews and focus groups seeking the diverse perspectives of people with disabilities in various catchment areas in Northern Uganda was not a trivial methodological decision. It stemmed from an “epistemic and political recognition of different ways of knowing” (252). The study participant recruitment strategy deliberately focused on looking for and hearing the voices of women and men with physical, hearing, vision, and cognitive impairments, beyond interviewing certain groups of people with disabilities and other policy actors who could be more easily recruited. From the overall research conception and throughout the multiple data collection techniques, this research insisted that both *disability data* and *people with disabilities* be made visible in mainstream global public health scholarship (253). Not only were specific intersections of SRH rights violations identified by different groups of policy actors, but specific measures to redress the situation and enable women and men with disabilities to fully exercise their basic human and disability rights were put forward.

Informed by iterative review and synthesis of the literature, my mixed methods research not only broadened the disability-related evidence in a global health context, but also engaged closely with the national Ugandan administrative and health authorities by providing new information to act upon and remove the multiple SRH service access and use barriers faced by people with disabilities. Integrated knowledge translation is a practice embedded in research activities that promotes the uptake of evidence generated (254). Through several person-to-person knowledge exchange activities outlined above, Ugandan health authorities and local staff were confronted with their responsibility to provide more accessible and disability-friendly SRH services. In response to recurrent requests from health service providers for more training on disability and the Ugandan sign language (USL), a two-day thematic disability orientation training workshop was co-organised with a deaf trainer, four people with disabilities (two women and two men), and a trilingual (English, Luo, and USL) community disability worker for the health staff and managers of six northern health facilities, including two referral hospitals. This event allowed us to exchange ideas and strategies on how to make health and SRH services accessible to people with different impairments, starting from collecting data on disability as inscribed in the Ministry of Health's patient registry, a practice rarely done or not properly completed. The workshop participants had the opportunity to link the preliminary study findings (in April 2018) to the existing Ugandan disability-focused legislation and policy landscape and their current practice of mostly ignoring the health rights and needs of people with disabilities who use their services. They recognised and reflected upon the lack of focus on disability in their professional training and ongoing in-service continuing education. For the first time, according to their accounts, they exchanged with and learned directly from people with disabilities who acted as training co-facilitators. Health staff realised the multiple identities of people with disabilities, which included being community leaders, business entrepreneurs, and experts in knowing what concrete accessibility measures entail. Health facility managers exchanged phone numbers with the co-facilitators with disabilities for future potential training on disability-sensitive health/SRH service provision that would be organised in their health facility to better align their service provision with existing disability-related policies and health services accessibility standards (255).

This research not only focused on the perspectives of women and men with disabilities in a sub-Saharan African country but also critically examined the relationships of disability with policy implementation processes and the SRH service utilisation by people with disabilities through the situated views of five groups of policy actors. In contrast, most disability-related global health research has traditionally either focused on the subjective experiences of people with disabilities (256), such as their perceived barriers and facilitators related to SRH service access (142), or the quantitative disadvantages of people with disabilities in health (4), HIV and AIDS (138, 226), education (257), and economic (258) outcomes. While disability has been studied through the human rights angle (259) and in national AIDS strategic plans in sub-Saharan Africa (260), global health scholarship has not to date concomitantly addressed in the same research initiative the diverse voices of people with disabilities as one of the key policy actors among other policy actors at meso and macro levels. Moreover, disability was mostly examined either in SRH-related qualitative (130, 144, 261-266) or quantitative (139, 231, 233, 267-269) studies but rarely through multiple mixed methods together. Informed by intersectionality theory, this thesis emphasised the multilayered interfaces among disability, gender, and the experiences of violence in the context of SRH, on one hand, and the nuanced quantitative interplay of social determinants of health among people with disabilities, on the other hand. Through this research, we were able to address the issue of invisibility by clearly asserting the relevance and place of disability and people with disabilities in global health research. Additionally, I addressed the issue of SRH service use disparities between people with and without disabilities in Uganda by providing more nuanced observations through the analysis of secondary DHS data over a period of 10 years. Throughout the interpretation of results, I considered the multiple identities of people with disabilities, the context, an analysis at multiple levels, and the prevailing power relations that play an important role in understanding people with disabilities' experiences and realities.

Anchored in the intersectional perspective, as further discussed below, mainstreaming disability into research contributes to overcoming invisibility and empowers people with disabilities as a community (253). In the 2000-2015 Millennium Development Goals, disability was not reported, while the 2015-2030 Sustainable Development Goals explicitly included people with disabilities in 11 of the indicators to ensure accountability among the United Nations Member States that adopted the goals (270). Including disability in global health scholarship informs global health governance (243), which advances global health goals such as health equity, access to care and medicine, and social justice (271). It also further contributes to accountability to the community of people with disabilities with whom we are working (272). This study offered concrete examples of alternative ways of conducting research and knowledge exchanges to the hegemonic research and practice approaches which make invisible what should be visible.

7.3.2 Intersectionality: Critiques and relevance

In the past three decades, intersectionality has been engaged as a theory, in different applications, or as a praxis demanding greater social justice (75). It has emerged as a major critical inquiry and praxis that stemmed from social movements of African Americans, women, LGBTQ+ communities, and different groups of social minorities outside of academia (16, 273) to become an approach that has found a certain space in various academic disciplines (273). Although intersectionality as a theory and praxis was first articulated by Kimberlé Williams Crenshaw, an Afro-American scholar, critical race theorist, feminist, and activist, some White European feminists have characterised intersectionality as a North American import which is too preoccupied with the intersection of race and gender (274) and as the "brainchild" of feminism

(275). For Sirma Bilge, an intersectionality scholar and sociology professor at the Université de Montréal, this reappropriation and (mis)labeling of intersectionality represents a process of “whitening” intersectionality (275), similar to the one that is stripping intersectionality of its radical grassroot origins to be considered only as a disciplinary strand of feminism in academia, where recognised knowledge is produced (79). An intersectional feminist positioning recognises the diversity of the feminist movement and that unless the feminist voices at the margins of the ‘table of feminists’ are included, the struggles among less-heard groups for recognition will persist (276).

Although intersectionality has grown in popularity in public policy (221), health systems research (238), and global health (93, 94) literature, the following issues merit discussion: 1) the claim of its excessive focus on ‘diversity’ (76, 79, 277), 2) the claim of its lack of focus on power structures (278), and 3) its difficult operationalisation at the methodological level (83). The first point related to the ‘diversity’ issue of intersectionality posits that because of the emphasis on people’s multiple social identities of sex, age, race, class, sexuality, ability, indigeneity, etc., intersectionality has been equated to the culture of diversity as a ‘marketable’ neoliberal feature to look good and professional (79, 275). Its ‘catch-all’ approach has been widely reproached by the academic feminist opponents of intersectionality (277). On the contrary, according to one of the seminal texts of Crenshaw, intersectionality can and should be used to demarcate structural inequalities faced by marginalised populations, often women, who live at the intersection of concomitant social identities (76, 80). At the same time, one needs to temporarily zoom in and analyse these inequalities through relevant social categories and in constant relation to the underlying power structures and existing and past socio-political contexts (76, 80). In this perspective, focusing on specific intersections becomes necessary while resisting essentialism and over-stereotyping a marginalised population as being monolithic and representative of each and everyone in this group (237).

Despite the criticisms of intersectionality as excessively focused on “diversity”, this thesis demonstrates that the theoretical underpinnings of intersectionality and the mixed methods application of the IBPA framework were both conceptually and practically useful to answer a complex research question that looks at multiple levels of perspectives and analyses. The application of intersectionality in global health research involving policy analysis and women and men with different impairments demanded a different set of paradigms, lenses, and positionalities. The IPBA approach drew on the situated and diverse sources of knowledge of both policy actors and researchers to develop a better understanding of policy processes and challenges, especially by highlighting the voices of a marginalised and vulnerable population, people with disabilities (93, 96). Although the perceptions of the different policy actors were often convergent, each has contributed to a specific aspect of the understanding and analysis. The IPBA further highlighted the search for solutions through the adoption of transformative questions beyond developing a thick description of the problems (96). Not only did policy-makers, international and local organisations, and representatives of disabled people’s organisations report recommendations to remove barriers, but people with disabilities also suggested several concrete strategies to exercise their SRH rights. The intersectional perspective argues that this conscious exercise critically repositions the roles of equity-seeking populations and their advocates in the policy implementation processes, including the monitoring and evaluation phases (220).

The second issue related to intersectionality purports that it lacks attention to power systems and dynamics, staying too close to the multiple struggles marginalised and vulnerable populations are experiencing at the individual level (278). It has further been argued that intersectionality’s focus on issues such as race, gender, and class are “antisystemic” (278) and that Foucault’s notion of biopower or the theory of symbolic power of Bourdieu (279, 280) are better theoretical approaches if one is ‘really’ serious about examining power. Although the theoretical contributions of Foucault and Bourdieu are not disputed here, these critiques are problematic as most critical intersectionality scholars have emphasised the study of power structures, not in silo, but in conjunction with the multiple categorisation of social identities among concerned populations and in relation with the context (16, 38, 75, 80, 237, 273). To highlight social inequities and address social justice, the IBPA enabled – and forced – me to pay greater attention not only to what the problem is and who is excluded/included as previously discussed, but also to the why and how (93). The manner in which the IPBA framework was designed enables us, researchers, to address these underlying questions related to the 'what', 'who', 'why', and 'how' (96).

In the global Sustainable Development Goals, the international community and world governments have pledged to "leave no one behind", and that they would account for all individuals in the global development processes and initiatives, irrespective of their social identities and backgrounds (270). The intersectional approach contributes to a better understanding of how social health inequities "are shaped by interactions between multiple sites and levels of power: institutions such as families, governments, laws, and policies; structures of discrimination such as sexism, ableism, and racism; and broader processes of globalisation and neoliberalism" (93). Through intersectionality, we highlighted how gendered ableism was intertwined with the different aspects of the lives of people with disabilities, such as access to health and SRH services, education, or decisions related to their own body and intimate relationships. By examining the policy implementation processes related to disability in the context of SRH service utilisation, we further learned that policy implementation challenges were interconnected with resources, notably technical and financial resources, but also with the lack of the leveraging power of the line ministry entrusted to promote and protect the rights of people with disabilities in Uganda. Coupled with this was the marginal prioritisation of people with disabilities in an ableist society despite the adoption of legislation and policies supposed to advance their rights.

Reflecting a perception that intersectionality is too complex, the third critique stems from this theory's apparent lack of methodology. The definition of intersectionality in Chapter 2 (16) mentions the following:

> *Intersectionality is a way of understanding and analyzing the complexity in the world, in people, and in human experiences. The events and conditions of social and political life and the self can seldom be understood as shaped by one factor. They are generally shaped by many factors in diverse and mutually influencing ways. When it comes to social inequality, people's lives and the organization of power in a given society are better understood as being shaped not only by a single axis of social division, be it race or gender or class, but by many axes that work together and influence each other. Intersectionality as an analytic tool gives people better access to the complexity of the world and of themselves*. (p.2)

This definition demands that we pause and reflect upon how to operationalise intersectionality so that it can be used practically in a global health research context with people with disabilities. Leslie McCall proposed a methodology to understand and address this complexity by suggesting three types of analyses: anticategorical, intracategorical, and intercategorical complexity (281, 282). Embedded in post-structuralist feminism, anticategorical complexity analysis rejects and deconstructs social categories as "social life is considered too irreducibly complex" (282). Intracategorical complexity analysis focuses on a specific category within a group of people, for example, Black women, while the analysis of intercategorical complexity highlights the relationships among multiple social groups within and across social categories and identities (281, 282). McCall's preference and research focus led her to adopting the third approach of intercategorical complexity through quantitative analyses. This is a first step in unpacking the different types of categorical analyses. However, McCall's recommendations do not provide sufficient operational guidance on how to translate the above definition into an actual application of the relations among the key concepts and principles of intersectionality of social justice and equity, complexity, multiple social categories, time and space, different sources of knowledge, power, and reflexivity (16, 17, 91).

Although still complex due to the multiple principles put forward, the IPBA framework provides more concrete guidance on how to analyse policy and data considering these principles through two specific sets of questions, descriptive and transformative (84, 96). These questions enabled me to apply the intersectionality principles more systematically by adapting: 1) the five descriptive questions related to the policy problem identification, how it is represented, and what are the current responses to the problem, and 2) the seven transformative questions which focus on the inequities that exist in relation to the problem, how interventions can be made to improve the problem, and how to know that inequities will be reduced, by simultaneously taking into account one's biases and the effects of power structures in the everyday world (17). Jones, Gautier, and Ridde argue that conceptual frameworks, such as the IPBA, can be useful analytical tools to operationalise the 'fuzzy boundaries' of complex relations among concepts and policy actors in a global health context (283). In a very recent systematic review of the various definitions of global health reported in the literature, global health is characterised as "an area of research and practice committed to the application of overtly multidisciplinary, multisectoral and culturally sensitive approaches for reducing health disparities that transcend national borders" (284). The IPBA framework provides a practical roadmap which aligns with the practical nature of global health scholarship. Furthermore, making abstract concepts of intersectionality accessible as workable questions promotes knowledge translation among a diverse groups of global and public health policy actors, including people with disabilities and decision-makers (285).

Specifically, intersectionality helped me address the complex relations among the various IBPA key principles and across SRH-related policy analysis and global health research. In this thesis, I examined the relationships among legislation, health policy, and the use of SRH services by people with disabilities in Northern Uganda through a mixed methods study based on concurrent multilevel analysis of policy actors at the micro (women and men with different impairments), meso (health services providers and disabled people's organisations), and macro (national and international organisations, and national policy-makers) levels. This approach enhanced the extent and depth of understanding of the research object and subject (96). In addition to explicating their situated knowledge, policy actors also brought a contextual understanding and analysis to the relationships among legislation, health policy, and the utilisation of SRH services by people with disabilities in Northern Uganda. At the macro level, national policy-makers and representatives of national and international organisations shared their perspectives as decision-makers, funders, and executive decision-makers, and implementers of national and international health-related decisions. At the meso level, disabled people's organisations played a critical role in both defending and monitoring the rights of their constituencies with disabilities, while health service providers followed the norms and standards dictated by the central level. At the micro level, women and men with disabilities not only used the services provided but also were influenced by the policy implementation processes, successes, and pitfalls. Studying the different social locations of a variety of policy actors contributed to a deeper and broader understanding of the 'problem', and how it could be addressed critically (96).

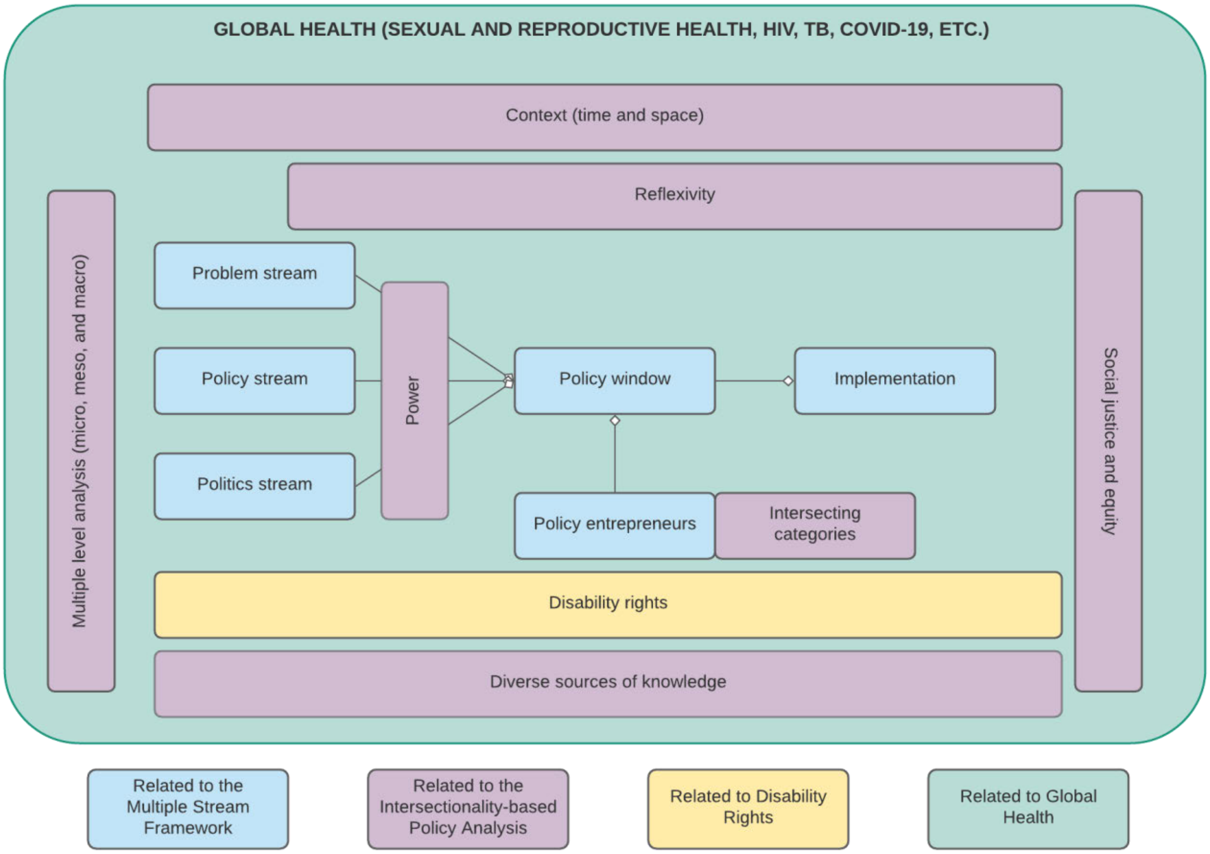
7.3.3 Contribution to theory: Proposal of two adapted conceptual frameworks

This thesis addressed the invisibility of disability and people with disabilities in the mainstream global SRH related literature and health policy and systems scholarship (41, 218, 244). This was realised by adopting the principles of intersectionality promoted by the IPBA framework (17, 91, 220) to better understand and document the relationships among legislation, health policy, and the use of SRH services by people with disabilities in post-conflict Northern Uganda. I was interested both in policy actors' perspectives and lived experience, and at exploring empirical associations, over time, between disability and SRH service utilisation in the decade following Uganda's adoption of the Disability Act. Framed within this critical conceptual and pragmatic context, the more classical policy analysis models and frameworks were not adopted. Two of the most frequently used theories and frameworks in the global universal health coverage context to analyse health financing policy processes in sub-Saharan Africa (283) are the Multiple Streams Framework developed by Kingdon (98) and the Policy Triangle Model of Walt and Gilson (100, 109). The Multiple Streams Framework posits that policy agenda-setting evolves through the combination of three 'streams', namely the problem, policy, and politics, with policy emerging when a window of opportunity is captured by policy advocates or entrepreneurs (98). According to Kingdon, when all streams meet, "a problem is recogni[s]ed, a solution is available, the political conditions are right, and the three streams get joined together. So advocates develop their ideas over a long period of time" (98). Although this framework is widely used in public policy analysis, it does not examine equity issues (99) nor explicitly analyse underlying structural power dynamics. On the other hand, the Policy Triangle Model, elaborated by Walt and Gilson, addresses the positions of actors in power structures along with the analysis of policy content, process, and context, whereby the actors both influence and are influenced by the main elements of the model (100). However, the Policy Triangle Model does not consider the diversity of interlocking inequities experienced by different population groups and sub-groups of women and men such as people with disabilities nor addresses explicitly equity issues (96).

According to the 2019 Global Burden of Disease study, the impacts of disabilities and non-communicable diseases including those related to SRH are rising; unless health systems and policy actors pay greater attention to global public health disparities and risk factors through dynamic policy dialogues and government commitments, an explosion of global health issues will persist (286). Addressing these global health disparities requires a conscious and deeper examination of structures and processes of power which produce and perpetuate inequitable health outcomes among and across populations (93). A 2021 systematic review of the literature examining how global health was defined reiterates the ethical nature and intent of global health to address health inequities through modes of governance and a multiplex approach guided by justice principles (284). In 2009, Koplan and colleagues were among the first to define global health as "an area of study, research and practice that places a priority on improving health and achieving equity in health for all people worldwide" (241, 284).

Given that no single definition of global health nor unique conceptual framework or model of policy analysis can simultaneously address the complex multifaceted relations among global health, policy analysis and critical studies such as intersectionality, all the while leaving no one behind, I propose two 'theoretical bricolages' (283) by combining the IPBA framework principles (17, 91) with the Multiple Streams Framework of Kingdon (98) on one hand (Figure 16), and with the Policy Triangle Model of Walt and Gilson (100) on the other hand (Figure 17). Both proposed conceptual frameworks take into account the rights of people with disabilities so that policy analyses no longer exclude 15% of the world's population nor sustain, even unintentionally, structural social health inequities. Addressing the invisibility of more than 15% of the world's population in development and research discourses (37-40) has become one of the most pressing problems contemporary research, including policy analysis, is facing concerning access to health services, health equity (41-43), and global health governance (44).

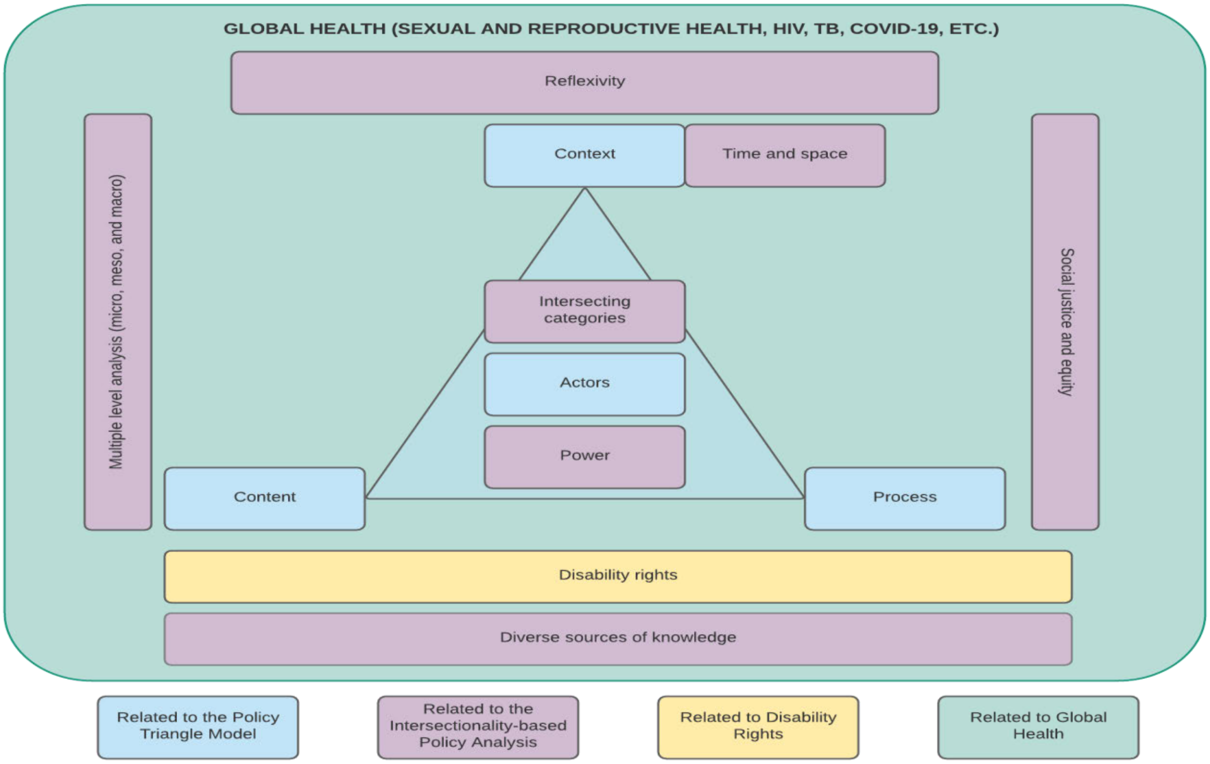
Figure 16. – Intersectionality-based 'Multiple Streams' policy analysis framework in global disability health scholarship



Note: Framework developed by the author based on the Multiple Streams Framework of Kingdon (98) and the Intersectionality-based Policy Analysis Framework of Hankivsky and colleagues (91).

Specifically, the combination of the Multiple Streams and IPBA frameworks enables global health and policy analysis researchers to appreciate the strengths of considering the power dynamics and structures in a multilevel analysis of the three *problem*, *policy,* and *politics streams*, while constantly taking into account both the potential biases and advantages of the intersecting categories of *policy entrepreneurs* and the different sources of knowledge mobilised to understand the emergence of a *policy window* towards *implementation*. Policy implementation cannot be undertaken in a vacuum without aiming for social justice and equity as long-term objectives. This also requires the practice of reflexivity emphasising disability – and human – rights over time and across space (geography) to ensure equitable policy outcomes. This first adapted conceptual framework can be tested in understanding how and within which contexts existing or future global and public health policies impact on various sub-groups of population's health. For example, one might ask how emerging national health policies affect the social participation of survivors of sexual and gender-based violence in the context of the COVID-19 pandemic response.

Figure 17. – Intersectionality-based 'Policy Triangle' policy analysis framework in global disability health scholarship



Note: Framework developed by the author based on the Policy Triangle Model of Walt and Gilson (100) and the Intersectionality-based Policy Analysis Framework of Hankivsky and colleagues (91).

This second 'theoretical bricolage' combining the Policy Triangle Model and IPBA framework further clarifies the intersecting identities of policy actors and the underlying power structures and dynamics intertwined in the emergence of policy content and processes. This conceptual juxtaposition also emphasises the importance of analysing the policy context, content, and processes at the micro, meso, and macro levels from diverse sources of knowledge and through disability-sensitive reflexive practices for long-term objectives of social justice and equity. One example of application can be the analysis of national safe abortion policy in sub-Saharan Africa.

In summary, these proposed frameworks enhance the equity sensitivity of the Multiple Streams Framework and the sensitivity to multiple, intersecting dimensions of (in)equity of the Policy Triangle Model. In addition, they strengthen IBPA's fit with global health policy and practice challenges and facilitate engagement of IBPA with the major approaches to global health policy analysis.

7.3.4 Methodological strengths and challenges

One of the major strengths of this thesis was the adoption of a mixed methods approach characterised as the 'third' paradigm which combines and catalyses both qualitative and quantitative research traditions (287). Through multiple types of data, such as from the systematic reviews, in-depth interviews, focus groups, non-participant observations, and secondary data analyses of multiple waves of the nationally representative Demographic and Health Surveys, I was able to triangulate evidence, while "maximi[zing] the strengths and counterbalan[cing] the weaknesses of each data type" (288). A mixed methods approach was necessary to answer a complex research question which could not have been answered by either of the qualitative or quantitative methods alone (178). It integrated "the power of stories and the power of number" (289). A mixed methods design enabled our research team, including both my thesis directors, Christina Zarowsky, a medical doctor and anthropologist, and Kate Zinszer, an epidemiologist, to combine both qualitative and quantitative epistemologies and openly engage over misunderstandings and epistemological tensions (289). As a team, I/we became methodologically more "bilingual" (290) and we were able to operationalise intersectionality through various methodological methods, study analyses, and to address critical questions related to social and health inequities (291). Another strength was that I was able to collect sufficiently rich and rigorous data on a complex issue in a challenging context. This would not have been possible without the financial resources I was able to mobilise through a series of doctoral training, fieldwork, and publication support scholarships and travel grants that allowed me to pursue the overall and specific research objectives. The access to financial resources throughout any doctoral processes, especially in global health, is crucial in succeeding (or failing) envisaged research plans and activities, reducing the financial burden while not compromising focus, time, and energy for productivity and completion of the thesis (292).

Although this methodological choice in adopting a mixed methods approach was a strength, two specific challenges were also associated with this decision. First, epistemologically, this meant that I/we needed to be flexible enough to dance between and across two research paradigms that often do not talk to one another on a deeper level (178). Second, methodologically, this choice also meant the necessity and capacity to understand the methodological underpinnings of and correctly apply the criteria of rigour for each research tradition coupled with that of mixed methods research. Conducting mixed methods research, including two reviews, a multiple case qualitative study, and quantitative secondary analysis within a doctoral research timeframe was challenging. As a team, coming from different disciplinary and professional backgrounds and having three different reporting and linguistic styles, we had to find common grounds that would cut across our differences while keeping the gist of key ideas and messages. The language, methodology, and explanations reported needed to be understandable to both 'number-sensitive' (quantitative) and 'meaning-sensitive' (qualitative) researchers.

7.3.4.1 Challenges and reflections related to ethics norms application

7.3.4.2 Preface to ethics norms application challenges and reflections (Manuscript 6)

In addition to the methodological challenges exposed in conducting mixed methods, this study revealed important ethical challenges. The sixth paper (Thesis Manuscript 6) addressed ethical issues in the conduct of a qualitative study with people with disabilities in the Global South. Although all ethical clearances and renewals were obtained to implement this study following the Canadian and Ugandan normative tools and formal requirements of research ethics boards, specific aspects such as privacy and the availability and management of financial resources still emerged as important findings of this study. In Manuscript 6, we share the challenges related to global health qualitative research ethics norms application, in particular our reflections concerning the potential tensions between 'procedural ethics' in the application of ethics norms and 'ethics-in-practice' while conducting research in the field (213, 293). These issues merit further attention among current and future global health researchers. Suggestions are made to address these challenges in the context of global health research with people with disabilities in a low- and middle-income country.

7.3.4.3 Manuscript 6: How to navigate the application of ethics norms in global health research: Reflections based on qualitative research conducted with people with disabilities in Uganda

Publication status: This manuscript was submitted to *BMC Medical Ethics* in 2020 and is under review.

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Abstract

Background: As Canadian global health researchers who conducted a qualitative study with adults with and without disabilities in Uganda, we obtained ethics approval from four institutional research ethics boards (two in Canada and two in Uganda). In Canada, research ethics boards and researchers follow the research ethics norms of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2), and the National Guidelines for Research Involving Humans as Research Participants of Uganda (NGRU) in Uganda. The preparation and implementation of this qualitative research raised specific ethical issues related to research participant privacy and the importance of financial availability and management.

Main body: Our field experience highlights three main issues for reflection. First, we argue that, in a global health research context, methodological and logistic adjustments were necessary throughout the research implementation process to ensure the protection of study participants' privacy, especially that of people with disabilities, despite having followed the prescribed Canadian and Ugandan ethics norms. Data collection and management plans were adapted iteratively based on local realities. Second, securing financial support as a key aspect of financial management was critical to ensure privacy through disability-sensitive data collection strategies. Without adequate funding, the recruitment of research participants based on disability type, sex and region or the hiring of local sign language interpreters would not have been possible. Third, although the TCPS2 and NGRU underscore the significance of participants' privacy, none of these normative documents clearly express this issue in the context of global health research and disability, nor broadly discuss the ethical issue related to financial availability and management.

Conclusion: Conducting research in resource limited settings and with study participants with different needs calls for a nuanced and respectful implementation of research ethics in a global health context. We recommend a greater integration in both the TCPS2 and NGRU of global health research, disability, and responsible conduct of research. This integration should also be accompanied by adequate training which can further guide researchers, be they senior, junior or students, and funding agencies.

Keywords

Global health research, research ethics norms, privacy, financial availability and management, disability, Uganda

Background

In Canada, researchers, be they senior, junior or students, and research ethics board (REBs) must follow the research ethics norms of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS2) [1], when addressing the expected ethical issues for a research project evaluation. Following this normative document is required by the Canadian research granting agencies, namely the Canadian Institutes of Health Research, Research Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council, in order to receive and administer research project's funds. When a research project is undertaken in another country, which is often the case in global health research, researchers need to further secure ethics approval from in-country REBs at national and/or regional levels [2]. Specific ethical issues emerge from global health research, such as resource limitations, population vulnerability, lack of human rights protection, and in relation to the status of researchers when they are doctoral and postdoctoral fellows [3]. Studies have also highlighted the importance of understanding the practical realities of applying ethical principles and norms in "real world contexts" such as in Africa to optimise health research collaboration [4].

We are Canadian researchers residing in the province of Québec who conducted a qualitative study in Uganda, from November 2017 to the end of April 2018. The qualitative research, reported in detail elsewhere [5], was part of a broader mixed methods project which examines the relationships among legislation, health policy, and the utilisation of sexual and reproductive health (SRH) services by people with disabilities in Uganda. The qualitative research included in-depth semi-structured interviews (n=45) with people with different types of disabilities (physical, vision, hearing, mental and intellectual), national organisations and decision-makers, focus groups (n=9) with health service providers, disabled people's organisations and people with disabilities, as well as non-participant observations of health facilities (n=7), in three northern districts (Gulu, Amuru and Omoro) and Kampala, the capital of Uganda.

We sought ethics approval from our Canadian institutional REB, which followed the principles and ethics norms of the TCPS2 [1]. Based on three core principles – respect for persons, concern for welfare, and justice (TCPS2, article 1.1) – the TCPS2 recommends a proportional approach when evaluating projects, which considers the vulnerability of study participants, such as pregnant women, people with disabilities and minors, and the risks related to the implementation of any research project [1]. We sought two additional ethics approvals from the Uganda national and regional REBs, which followed the principles and norms stipulated in the *National Guidelines for Research Involving Humans as Research Participants* of Uganda (NGRU) [6]. The NGRU provide mechanisms to protect the rights and welfare of research participants, promote ethical standards and procedures, and ensure that researchers consider the social and cultural values of participating communities [6].

In the preparation phase in Canada and after, we diligently responded to REBs' request forms and received clearance from the *Centre de recherche du Centre hospitalier de l'Université de Montréal* (CR-CHUM) (17.127-CÉR, 1 August 2017); the Research Ethics Committee in Sciences and Health of the Université de Montréal (CERSES-20-074-D, 13 May 2020), following a change of research affiliation in Canada; the Uganda National Council for Science and Technology (SS-4451, 14 November 2017); and the Lacor Hospital Institutional and Research Ethics Committee (LHIREC - 019/07/2017). Throughout the study implementation process in Uganda, we constantly attempted to address and critically reflected on how we were applying the prescribed ethics norms in a "real world" context. We were confronted with two main ethical issues related to privacy and another important issue related to the availability and management of financial resources. These issues assume a heightened significance for the following reasons: 1) respect for privacy is a key ethical issue in both TCPS2 and NGRU, and is a fundamental right in Québec [7], Canada [8], Uganda [9] and internationally [10]; and 2) securing adequate financial support and managing finances responsibly were crucial to being able to deploy various strategies to optimise the research including respecting research participants' privacy, particularly for people with different disabilities.

Privacy encompasses three concepts: privacy, confidentiality, and protection of personal data. Privacy specifically refers as "[…] the right to be let alone" [11], and "an individual's right to be free from intrusion or interference by others" [1]. In the TCPS2, confidentiality is defined as an "ethical and/or legal responsibility of individuals or organizations to safeguard information entrusted to them, from unauthorized access, use, disclosure, modification, loss or theft" [1]. In the Québec legislation on the protection of personal information [12], privacy mainly refers to the protection of personal data such as those collected during and after study implementation. In Uganda, privacy and confidentiality are mentioned in the NGRU but are not defined [6]. In the 2019 Uganda Data Protection and Privacy Act, privacy is further understood among a list of principles which stipulate that people who collect, process, hold or use personal data "shall be accountable to the data subject for data collected, processed, held or used" and "observe security safeguards in respect of the data" [9].

Since neither the TCPS2 nor NGRU specifically address ethical issues related to finances and their management, financial management is understood according to the Canadian and Québec policies on responsible conduct of research. Based on the Canadian policy, « Researchers are responsible for using grant or award funds in accordance with the policies of the Agencies […] and for providing true, complete and accurate information on documentation for expenditures from grant or award accounts » [13] (p.4). In the Québec policy, « Individuals and organizations at all levels should ensure the responsible allocation and management of research funds in accordance with sound academic and financial principles. This includes ensuring an efficient use of resources » [14] (p. 12).

We wish to share our reflections regarding the application of ethics norms to global health qualitative research conducted with people with disabilities in Uganda, with an emphasis on participants' privacy and the availability and management of finances.

Main text

Management of participant privacy

Prior to leaving for Uganda, we received ethics approval from REBs. The study protocol contained information on data collection and analysis, interview recordings and transcriptions, and the duration of data and research records storage. In the consent forms, the importance of confidentiality and privacy was underscored for people with disabilities and other study participants. To promote the understanding of participants with disabilities, the language in the consent form was simplified, pictogrammes were added, and the content was translated in Luo/Acholi (local languages). Research participants were also informed that the collected information would be kept confidential and protected from any unauthorised disclosure or damage. The term « anonymity » was used to further inform participants about the storage of recordings and depersonalised transcripts in a safe and locked facility, until their destruction would occur after a period of 10 years, as requested by the first Canadian REB (CR-CHUM).

Once in the data collection phase in Uganda, in accordance with the ethical principles of the respect for persons, their dignity and autonomy, all participants were solicited to give their informed consent to participate in the study [1, 6] in the language of their preference, either in Luo/Acholi, sign language or English. They were informed about the voluntarily aspect of their consent, of the possibility to withdraw from the study at any time, and about the confidentiality of their personal data. When interviewing people with disabilities at their home or at the health facility, it was ensured that they were alone with the research team. However, when it was not feasible to find a private and closed space, we were sometimes seen from afar, under a mango tree in the garden or at the back of a health facility compound improvising a quiet space with two or three chairs. While the scene might look bucolic, confidentiality was sub-optimal. We had to adapt to the local realities related to lack of private spaces. In and of itself, this was not a problem for several participants with disabilities who suggested to be interviewed outside and who felt comfortable with this alternative. Interviews with national actors such as policy-makers were held privately in their office. All focus groups were also conducted in separate rooms, either in a health facility examination room or in the premise of a local disabled people's organisation. For participants with hearing disabilities (7/32 people interviewed individually, and 6 people of two focus groups), we hired local sign language interpreters. Given the double linguistic barriers of the researcher MMS not knowing either the Ugandan sign language or Luo/Acholi, hiring sign language interpreters was necessary to communicate with and promote the autonomy of participants who were deaf and who wanted to express their own experience. To ensure confidentiality, research assistants who were recruited for a five-month period were requested to sign a confidentiality clause in their contract, while sign language interpreters, who were hired to provide an occasional service, verbally agreed to honour participants' confidentiality.

Concerning data storage, we stated in the consent forms that data transcripts would be kept for a period of 10 years although we are not certain how this would be managed. Upon completion of data collection and before leaving Uganda, the regional Ugandan REB requested to keep the original of all consent forms in their locked offices, while the Canadian REB (at the CR-CHUM during the qualitative study implementation) also requested the same. As a result, MMS made photocopies of the original consent forms and brought them back to Canada to partially fulfill the Canadian REB requirement. The forms are stored at MMS home given a lack of access to locked cabinets provided by the Université de Montréal. Given that the original consent forms are in Uganda, it would be difficult to monitor whether they are currently still there and will be kept safely for a period of 10 years, as requested. Another issue related to data storage was the lack of clarity in how to safely store the interview and focus group recordings and transcriptions. Passwords were assigned to the recordings and transcriptions, with minimal access given, and the recordings and transcriptions were saved on an online institutional cloud (of the Université of Montréal), that requires a two-level authentication. The three Canadian funding agencies conducted an online consultation on the development of a policy on research data management in September 2018 [15]. The consultation findings also emphasised a lack of guidance from the TCPS2, coupled with a confusion among respondents on whether the researchers or research institution should be responsible for personal data management [16].

Research financing and its management

Securing the necessary funds to implement field research activities in Uganda was pivotal to ensuring many ethics norms, particularly related to the inclusion of the diverse voices of women and men with different types of disabilities. Obtaining the appropriate funds enabled us to recruit sign language interpreters and two research assistants who also acted as translators. We also travelled on *boda-boda* (moto-taxi) to villages to meet and interview study participants or discuss with study stakeholders, as these villages are often inaccessible for larger vehicles. The deliberate decision to conduct these activities had concrete logistical and ethical impacts: 1) people with and without disabilities who did not speak English (one of the official languages in Uganda) and those who used the Uganda sign language (also listed among one of the official languages) were included and participated in the research; and 2) we did not restrict the interviews and focus groups to three district headquarters (which were the most 'accessible') or in the Ugandan capital – we were able to invest in efforts to reach more remote individuals over the course of several weeks. Without the proper financial resources, none of these accommodations would have been possible and we would have been unable to fully respect the principle of justice as described in the TCPS2 [1] and the literature [17]. Decisions on how to spend research funding, such as on inclusion, and on how to practice responsible management of finances are not explicitly stated in TCPS2 or NRGU. Neither the NGRU nor the TCPS2, both of which have a section on conflicts of interest, address research financing and management of funds. This specific aspect is rather addressed in the *Canadian Tri-Agency Framework on Responsible Conduct of Research* [13] and the *Policy for the Responsible Conduct of Research* of the *Fonds de recherche du Québec*, the provincial research funding agency. Hence, a better alignment and connection between all these guiding and normative documents would be extremely useful for researchers.

How can ethics norms be better addressed when conducting global health research with people with disabilities?

It is important to note that several of the methodological and logistic adaptations made throughout the qualitative study implementation were based on MMS' experience of working for several years with people with disabilities in sub-Saharan Africa. These accommodations included simplifying the language in the consent form coupled with the use of pictogrammes, hiring sign language interpreters, and budgeting for these activities accordingly to ensure disability-sensitive data collection and inclusion of people with different types of disabilities. This prior knowledge of the communication and accessibility needs of people with disabilities was required in order to appropriately address certain 'real world' ethical issues, which would not have been possible by simply following the broad principles and ethics norms of privacy stipulated in normative documents and REBs' official requirements. Historically, people with disabilities, those with intellectual disabilities in particular, have been either denied their rights by being included in medical experiments as "guinea pigs" or excluded from research activities due to discrimination and overprotection [18]. To reach the principles of fairness and equity in research participation [1], previous experience taught us that budget planning was necessary to reach these objectives. By doing so, it provided the opportunity to people with all types of disabilities to participate in the study, allowed them to express their own views and to be heard [19]. According to the Canadian Coalition for Global Health Research, inclusion of historically marginalised groups is a key principle for sound global health research [20]. The exclusion of a certain group is compounded by power dynamics which can be addressed by not only acknowledging marginalised groups, but by actively promoting their voices and knowledges [21]. Global health scholars advocate for more equity in global health research by embracing an epistemic positionality that further promotes the conduct of research toward social justice [22].

Considering the above, we make three suggestions. First, we suggest a greater consideration of global health research and disability in the updated 2018 TCPS2 [23] in the same way qualitative research or indigenous communities have been considered. Although global health research and ethics have been widely discussed [24-26], and disability in global health research to a lesser extent due to under-prioritisation [27], global health research and disability have not received the same attention in the TCPS2 and NGRU. Additional information on these topics can help researchers, funding agencies, and institutional REBs to better address the ethical issues of privacy in a more comprehensive manner. Literature has reported that some REBs lacked training on the full scope of what privacy entails [28]. This specific issue deserves further reflection and discussion at provincial and national levels, both in Canada and Uganda. Second, given the importance of adequate financing and how the funding is spent to achieve the research objectives and ethics norms, information on availability and management of financial resources should be made more explicit in both the TCPS2 and NGRU. Finally, we suggest that a greater consideration of global health and disability as well as responsible conduct of research in normative documents be accompanied with more training on ethical issues for global health researchers and trainees. This last recommendation is also echoed in the literature on qualitative research and the importance of privacy [29]. For example, training can be offered before or during the research protocol development, with an emphasis on legal and ethical issues related to each step of the privacy cycle (data collection, utilisation, conservation, and destruction) [30]. Understanding and applying the full scope of ethics norms such as related to privacy and financial management, needs to go beyond theory and be closely linked to practice in the "real world".

Conclusion

Conducting research in resource-limited settings and with study participants with different needs calls for a nuanced and respectful implementation of research ethics in a global health context. Based on praxis and the local reality in Uganda, we had to iteratively adapt our approach to respect the privacy of research participants and research objectives. More importantly, without the adequate financial resources, key accommodations would not have been possible. To promote a more comprehensive understanding of ethics norms, we recommend a greater integration of global health research, disability, and responsible conduct of research in normative documents such as the TCPS2 and NGRU. This integration should also be accompanied by adequate training, such as online modules, which can further guide researchers and practitioners in how to prepare a more detailed data management plan and better understand the necessary steps to be taken to manage finances responsibly.

Abbreviations

CERSES	Research Ethics Committee in Sciences and Health of the Université de Montréal
CR-CHUM	*Centre de recherche du Centre hospitalier de l'Université de Montréal*
LHIREC	Lacor Hospital Institutional and Research Ethics Committee
NGRU	National Guidelines for Research Involving Humans as Research Participants of q Uganda
REB	Research Ethics Board
SRH	Sexual and Reproductive Health
TCPS2	Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans

Declaration

Ethics approval and consent to participate

Not applicable

Consent for publication

Not applicable

Availability of data and materials

Not applicable

Competing interests

LR is a PhD student and an analyst at the *Commission d'accès à l'information du Québec,* the office of the Privacy Commissioner in the Province of Québec. She is on leave without pay to complete her doctoral studies. BG is the Co-Head Section Editor for the 'Ethics in Biomedical Research' section of the BMC Medical Ethics Journal. The content of this article reflects the opinion of the authors and not that of any organisation or institution.

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Authors' contribution

MMS and LR conceptualised the manuscript. All authors contributed, reviewed, read, and approved the final manuscript.

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7.4 Dissertation’s limitations

Besides the limitations discussed separately in each of the six manuscripts, this thesis research has three main overarching limitations. First, I was not able to go back to Uganda in July 2020 as planned to present the overall findings of my doctoral research nor further exchange with local stakeholders and decision-makers. The objective of that trip was to meet, once again, post data collection phase, stakeholders at the district, regional and national levels, and seek their feedback, validation, and their knowledge utilisation plans of the research findings. Scientific dissemination during international conferences and in peer-review publications is important, but sharing the results back with local stakeholders, in particular people with disabilities and their representatives, is equally, if not more important to me. From December 2019, I started to plan and explore funding opportunities for two-week dissemination activities among stakeholders of the three Northern districts, and the ministries of Health, and Gender, Labour, and Social Development in Uganda. Through competition, I was awarded a 3,000 CAD field dissemination scholarship from the *Réseau de recherche en santé des populations du Québec*. Additionally, the Teasdale-Corti Foundation (Milano) offered to cover my food and lodging during that period. Also, we jointly planned that I would share the research findings during the St-Mary’s Hospital Lacor’s Annual General Meeting where more than 500 stakeholders and participants were expected to attend. Furthermore, I was expected to provide another disability-related training to the health staff of the hospital and its affiliated health centres as well as to the hospital’s partners to further the policy dialogue and knowledge exchange we started in 2018. Unfortunately, this planned dissemination activity in Uganda was cancelled due to the COVID-19 pandemic, forbidding any ‘non-essential’ research activities overseas. Future opportunities will be explored to reconnect with Ugandan policy actors, people with disabilities, and disabled people’s organisations.

Second, although this research attempted to capture the views from five groups of policy actors, including people with disabilities, their representatives, health service providers, local and international organisations as well as national policy-actors, we did not include the views of people with disabilities outside of the Northern region, and non-disabled health service users.

Adding these two additional groups would have enhanced the breadth and depth of qualitative evidence in understanding and documenting the perceptions of policy actors of the relationships among legislation, health policy, and the utilisation of SRH services by people with disabilities in post-conflict Northern and other regions of Uganda. Examining the contrasted perspectives of the disabled and non-disabled health service users throughout the country would also have provided a more complete picture and richer intersectional analysis of barriers and facilitators to SRH service access and utilisation in Uganda (186). However, due to practical reasons, this approach was not implemented. A purposive decision was taken to focus on the Northern region which was most affected by the armed conflict and where St Mary's Hospital Lacor, the research partner of my thesis Director, was located. Nonetheless, with the combination of the quantitative secondary analysis and systematic literature reviews, a different type of data triangulation was ensured, looking at the evidence at the populational level between 2006 and 2016.

Finally, although the findings of this transformative exploratory sequential mixed methods study are diverse and rich, they cannot be directly generalised to other contexts given its multicomponent features of the study of a complex research issue. The qualitative findings, however, can be transferable to other contexts in sub-Saharan Africa, provided that the experiences of people with disabilities and policy implementation challenges were similar (186).

7.5 Recommendations

In light of the overall research findings and discussion, I make the following recommendations to inform future interventions and research. Although they are not revolutionary, they are necessary to remove the systemic barriers that are repeatedly experienced by people with disabilities when accessing and using SRH services.

For policy actors in Uganda:

- For national policy-makers and local healthcare providers:
    - Understand ableism, recognise its negative health, socioeconomic, and emotional impacts on women and men with disabilities and their families, and act upon the multiple physical, attitudinal, communication, and structural barriers to health/SRH service access and use through transformative actions as recommended by all five groups of policy actors.
    - Systematically collect disability-related data in the existing Ministry of Health Patient Registry (Column 16) and compile the data at the regional and national levels. Analyse and incorporate collected data into the budgeting and decision-making processes of health/SRH services for people with disabilities throughout the different regions of Uganda. These data will inform the type of reasonable accommodation and disability-sensitive policy, information, and services needed to be implemented for people with disabilities to exercise their right to health/SRH.
    - Engage with disabled people's organisations in devising disability-friendly and accessible health/SRH services as well as training on disability-sensitive service delivery and rights for both health service providers and policy-makers. Disabled people's organisations are present nationally and regionally, they are well-positioned to play an active role as training partners and monitoring collaborators for enhanced accountability.
- For disabled people's organisations and women and men with disabilities:

  - Capitalise on the results of this research to lobby local elected officials with and without disabilities for the enhanced exercise of disability rights and accessible health/SRH services as per the revised Disability Act adopted in 2019 and the binding Convention on the Rights of Persons with Disabilities ratified by Uganda in 2008.
  - Empower women and men with different impairments as a counter-force to the status quo to create demand for improved accountability among policy-makers and enforcement of disability-focused policy and legislation adopted in Uganda, accompanied with the associated technical, financial, and human resources.

For researchers interested in disability, intersectionality, and global health:

- Expand on the evidence found in this research and conduct a participatory multi-phase transformative mixed methods study to comprehensively understand the SRH service use among people with and without disabilities in Uganda and similar contexts in sub-Saharan Africa. Based on the availability of data sources, one can envision the following phases: qualitative-quantitative-qualitative or quantitative-qualitative-quantitative studies, using the IBPA key principles for analysis and interpretation. In the qualitative phases, involve youth and adults with and without disabilities across more than one region of Uganda. For the quantitative phase(s), conduct a quasi-experimental comparative study involving countries that adopted national disability-related policy and those that did not to examine their impacts on the utilisation of SRH service use among people and without disabilities for a period of at least 10 years.
- Plan to have an advisory committee composed of at least one woman and one man with disabilities who can counsel the research team. This approach would provide the awareness needed to understand complex issues related to SRH rights for people with disabilities and optimise the research relevance and implementation as well as uptake of evidence generated.
- From the research inception onward, design an iterative integrated knowledge translation plan with the advisory committee and disabled people’s organisations to promote knowledge exchange and generated evidence uptake among key knowledge users such as national policy-

makers, regional decision-makers, and local health managers and clinical staff. Ensure authentic working partnership with knowledge users from the onset, and not as an after-thought (294).

7.6 Reflexivity

My doctoral studies started as a deliberate action to step back from field interventions and, as a result, to act differently in the pursuit of contributing to the visibility and inclusion of disability issues in global health research. The journey has been difficult. However, adversity, openness, and endurance have been what I got the most out of this unique experience. As a non-disabled woman, of Chinese origin, a native of Madagascar, and whose sociopolitical references are embedded in the Western world, mostly from Québec in Canada, I acknowledge the privileges from which I have benefited thus far to be able to conduct this research. Working with and for women and men with disabilities in countries such as Kenya, Rwanda, Burundi, Ethiopia, Mozambique, Senegal, Cambodia, Vietnam, and Laos helped me gain more insight into my own intersectional identities, and what could be envisioned in terms of the type of research I wanted to conduct to close a small portion of a huge gap in bringing to light what is meant to "leave no one behind". A few lessons I learned from my professional experience working with people with disabilities and various types of stakeholders, and which I have attempted to follow during my doctoral process, are the importance of calculated patience, the acknowledgment of our situated differences and strengths, and the consideration of local structures and cultures in devising and implementing any project strategies, including research activities. A necessary period of investment in the country to know, be trusted, and respect one another was crucial. Concretely, this meant being immersed in the Northern Ugandan way of life, exchanging on what was important in life (for example, religion was of utmost importance for any Ugandan irrespective of their faith), sharing meals with people, going to the local market daily, using local transportation, such as *boda-bodas* or public vans, and meeting and interviewing several knowledge brokers (around 30 people) before I started to collect data. Moreover, nurturing a trust-building relationship with Dr. Emmanuel Ochola, the head of the Research Department, Sisters Rose Grace

Ayoo and Aber Sharon, senior nursing managers, or the administrative staff and security guards, was key to navigate within and out of the St-Mary's Hospital Lacor.

Over the years, people with disabilities taught me that where obstacles stood, solutions can be found to remove barriers, as long as individual ingenuity and collective will coexisted, side by side, and throughout the process. My previous professional work with policy- and decision-makers at the community and national levels, or the United Nations and donor agencies made me realise the significance of the availability of 'good and hard' evidence to inform policy- and decision-making. Not only that, but the way the project and research findings were conveyed was equally crucial so that people taking policy and programmatic decisions would remember the stories we would tell. This doctoral process has further taught me the need to generate robust evidence through a delicate mix of theoretical foundations and rigorous methodological applications for 'numbered stories' to be remembered and acted upon. I also learned the value of purposefully constituting a team composed of people from diverse backgrounds and experiences. In addition to working closely with my two thesis supervisors, once in the field, I took the time to recruit research assistants, sign language interpreters as well as well-trusted *boda-boda* drivers to get us to the different villages and communities of the three target northern districts. After a few days of consultation and recruitment interviews, I selected Bryan Eryong and Emma Ajok, both living in Gulu, speaking the local northern languages, and who were sensitive to the experiences of people with disabilities. Recommended by the administrative team of the St-Mary's Hospital Lacor, two main *boda-boda* drivers were hired based on their knowledge of the many unmarked mud roads that we used to reach participants with disabilities. Mr. Patrick Ojok, the Coordinator of the Gulu Disabled People's Union, was one of the first disability knowledge brokers I met. He was very generous in sharing information and the contacts of subsequent disability-related knowledge brokers in Uganda, as well as availing his organisation's open hall to our team to meet and interview study respondents who were living in the neighbourhood.

Five years ago, I was not interested in generating data or publishing for the sake of either. Rather, I was interested in the utility of research findings for people with disabilities and their representatives, decision-makers, government officials, and health service providers. My position has evolved. To make 'invisible' disability-related data visible, it is necessary to generate and diffuse such data. I have participated in an exclusive academic system, while including the intersectional lens and ensuring women and men with different impairments were included in the research project as themselves, and not using a proxy such as their family members or health service providers, to hear their perspectives. This brought me to connect with the disabled people's organisations and communities of people with disabilities in the Northern region, and the capital of Uganda, a country where I had never set foot before the Ph.D. The decision to use intersectionality as a theoretical and analytical framework represented additional challenges. The decision to use the IBPA framework made a lot of sense, and that from the beginning. However, how to do it was far from clear. I had to learn how to apply the intersectional lens as I went along, discovering its various contours and nuances throughout each manuscript elaboration and ensuring that the language adopted was as limpid as possible to all team members and readers. Furthermore, I needed to be mindful of the use of some specific intersectional concepts during exchanges among team members. For example, a 'multilevel analysis' in intersectional terms means examining a research object or understanding the reality of a specific group based on different levels of perspectives (micro, meso, and macro) (96), while it calls for specific statistical analyses and data structures in statistical terms. Moreover, the analysis of the context through the intersectional notions of time and space was particularly critical as privileges and disadvantages experienced by individuals may change over time and space, and according to different societal power dynamics present at the time of data collection and analysis (142). However, in statistical analyses, time and space are variables like any other others that need to be considered and controlled for in regression analyses.

For me, the realisation of a thesis and the generation of both qualitative and quantitative evidence is an extension of my social engagement's greater aim, social justice. Through research, my commitment to social justice grew further when I realised that disability and research involving people with disabilities were little discussed in mainstream global health scholarship, despite people with disabilities' representing one-seventh of the world's population. As argued by researchers and activists working on intersectionality and disability, one cannot find out anything about a vulnerable or marginalised group, unless their voices are directly heard in research activities (253, 295). Although it took more time and resources, I interviewed women and men with different impairments myself, in their community, in addition to meeting with their disabled people's organisations, health service providers, and policy-makers. This decision was informed by my epistemological stance that sources of knowledge stem from both people's stories and the quantifiable observations associated with them, and not by either of them alone. This commitment was further translated into learning additional skills and applying different research data collection and analysis strategies, and it was a privilege to have been able to do that. It was also key to not only collect data but in return, to contribute to the knowledge transfer and the mentoring of both research assistants on qualitative research methods and ethics norms. Although original pieces of evidence have been generated, I remain realistic about the scope of its influence. As the disability scholar, Leslie Swartz, of Stellenbosch University highlighted, I/we need to acknowledge that "[e]ven where good research is carried out, the expectation that research will change the world also needs to be tempered with realism" (296).

For the past year, I attempted to finish my thesis during a unique moment in history: the COVID-19 pandemic which has disrupted the global political, health, and socio-economic systems worldwide, myself included. Struck by the unjust COVID-19 related health outcomes among the elderly, people with disabilities, women, and children (as victims of violence), or the homeless in Canada, and other countries – I decided to write about it. In collaboration with a colleague completing his post-doctoral fellowship in public health, we submitted a commentary, which has recently been published by *Global Health Promotion* (297). It discusses the complex intersections between the responses to the pandemic and public health priorities, the exacerbation of health inequities faced by different groups of vulnerable populations, including people with disabilities, and the need for responsible innovation and technological solutions to address the crisis (297). As junior researchers, I/we wanted to reaffirm our commitment to health equity. Although it is not a new concept in global and public health, health equity can never be ignored, even unintentionally. The COVID-19 pandemic has brutally reminded us that our attention to health equity cannot loosen and must be maintained throughout our endeavours in global public health, now and in the future.

Chapter 8 – Conclusion

More than five years into the Sustainable Development Goals' implementation, sexual and reproductive health, and the rights of people with disabilities remain major global health issues. People with disabilities represent 15% of the world's population, or one billion people. In Uganda, one person in five lives with some form of disability. To date, more than 180 Member States of the United Nations have ratified the Convention on the Rights of Persons with Disabilities. Uganda did so in 2008. This thesis presents an original mixed-methods policy-based intersectional analysis which examined sexual and reproductive health service use among one of the most marginalised and vulnerable populations: people with disabilities in a conflict-affected setting in a low-income country. It broadened our understanding of the complex relationships among legislation, health policy, and the utilisation of sexual and reproductive health services by people with disabilities in the post-conflict Northern region of Uganda. This research enabled the documentation, analyses, and triangulation of information collected at different stakeholder levels (micro, meso, and macro) and among different policy actors. It provided insight into social and health inequities experienced by people with disabilities who are at the intersections of multiple social identities and disadvantages. This study also demonstrated the strength of adopting a mixed methods approach to examine the intricate relationships between the complex and non-linear policy implementation process and sexual and reproductive health service use among women and men with different impairments in a post-conflict setting.

A critical examination of the relationships among context, social identities, power dynamics, diverse sources of knowledge, multilevel analysis, and reflexivity was necessary to make visible the unrecognised and undocumented. This thesis contributed to placing disability and people with disabilities at the centre of global health scholarship, through the use of an intersectional lens and its key principles. The perspectives of women and men with disabilities were actively sought, listened to, and acknowledged. The extent and nature of their use of sexual and reproductive health services were measured. This work supported and encouraged other key policy actors – healthcare providers, managers, policy-makers, NGOs, politicians – to fully recognise the presence, strengths, and challenges of people with disabilities, and the need to protect their right to health.

The Sustainable Development Goals underscore the importance of inclusivity and accountability. The study findings provide evidence and insight for policy and decision-makers, managers, and funding partners to address systemic health inequities. “Leaving no one behind” must include the removal of physical, attitudinal, communication, and structural barriers; collecting disability-disaggregated data; allocating consequent financial, technical, and human resources to enforce disability and human rights-focused policy and legislation; empowering people with disabilities and their families; changing the mindsets of policy- and decision-makers, and training healthcare personnel to provide disability-sensitive and accessible health services including sexual and reproductive health. Universal health coverage *for all* is possible through transformative action and research to fill the knowledge and programmatic gaps. We can and must do better when addressing health equity by including people with disabilities. It is not a question of diversity but rather an issue of human rights and social justice.

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Appendices

Chapter 2

Appendix 1: Liste de contrôle COREQ

Appendix 2 : Liste de contrôle ENTREQ

Chapter 3

Appendix 1: Guidelines for in-depth semi-structured interviews, focus groups, and non-participant observations

Appendix 2: Glossary of key research and SRH vocabulary in Luo and English

Appendix 3: Ethics certificates

Appendix 4: Consent forms

Chapter 4

Appendix 1: Detailed fieldwork activities

Appendix 2: COREQ Checklist

Chapter 6

Appendix 1 : PRISMA Checklist

Chapter 2 : Appendix 1: Liste de contrôle COREQ

Évaluation des recherches qualitatives selon les 32 critères de COREQ

Items[7] / Numéro des articles	**(1)**	**(2)**	**(3)**	**(4)**	**(5)**	**(6)**	**(7)**	**(8)**	**(9)**	**(10)**	**(11)**
Domaine 1 : Équipe de recherche et de réflexivité											
Caractéristiques personnelles											
1. Enquêteur/animateur	-	-	-	Oui	Oui	Oui	Oui	Oui	Non	-	Non
2. Titres académiques	Oui	-	-	-	Oui	Oui	Oui	-	-	-	Oui
3. Activité	Oui	-	-	-	Oui	Oui	Oui	-	-	-	Oui
4. Genre	Oui	Oui	Oui	Oui	Oui	Oui	Oui	-	Oui	-	Oui
5. Expérience et formation	Oui	-	-	-	Oui	Oui	Oui	-	-	-	Oui
Relations avec les participants											
6. Relation antérieure	-	-	-	-	-	-	-	-	-	-	-
7. Connaissances des participants au sujet de l'enquêteur	Oui	Oui	Oui	Oui	Oui	Oui	Oui	-	-	-	-
8. Caractéristiques de l'enquêteur	-	Oui	-	-	-	-	Oui	-	-	-	-
Domaine 2 : Conception de l'étude											
Cadre théorique											
9. Orientation méthodologique et théorie	-	Oui	Oui	-	-	-	Oui	-	-	-	-
Sélection des participants											
10. Échantillonnage	BN[8]	BN	DC[3]	DC	DC	-	DC	DC	DC	DC	DC
11. Prise de contact	OPH[9]	LH[4]	-	DR[4]	EP[4]	OPH	EP	-	EP	-	-
12. Taille de l'échantillon	50	8	19	5	16	58	1	59	21	88	12

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[7] Aux questions/items, soit un « oui » ou un « non » sera inscrit. Sinon un tiret sera inscrit lorsqu'aucune information n'a été donnée.

[8] BN : boule de neige DC : de convenance

[9] OPH : organisation de personnes handicapées LH : leaders handicapés DR : directeur d'un centre de réadaptation EN : en personne AT : au travail

13. Non-participation	1	-	-	-	-	-	-	-	-	-	-
Contexte											
14. Cadre de la collecte des données	-	-	HP[10]	CR[5]	AD[5]	-	AD	OPH AT[5]	EC[5]	-	EC
15. Présence de non-participants	-	-	-	-	-	-	-	-	-	-	-
16. Description de l'échantillon	Oui	Oui	Oui	Oui	Oui	-	Oui	Oui	Oui	Oui	Oui
Recueil des données											
17. Guide d'entretien	-	Oui	Oui	-	-	-	-	-	-	-	Oui
18. Entretiens répétés	-	-	-	-	-	-	Oui	-	-	-	-
19. Enregistrement audio/visuel	Oui	Oui	Oui	Non	Oui	-	Oui	Oui	Oui	Oui	Oui
20. Cahier de terrain	-	-		Oui	Oui	-	Oui	-	-	Oui	-
21. Durée	-	45-60[11]	-	60	30-60	-	60-140	-	-	-	-
22. Seuil de saturation	NA[12]	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA
23. Retour des transcriptions	-	Oui	-	-	-	-	-	-	-	-	-
Domaine 3 : Analyse et résultats											
Analyse des données											
24. Nombre de personnes codant les données	2	1	2	-	-	-	-	1	2	-	1
25. Description de l'arbre de codage	-	-	-	-	-	-	-	-	-	-	-
26. Détermination des thèmes	PD[13]	ND[7]	PD	PD	ND	ND	ND	ND	ND	ND	PD
27. Logiciel	Non	Non	Oui	Non	Non	Non	Non	Oui	Oui	-	-
28. Vérification par les participants	-	Oui	-	-	-	-	-	-	-	-	-
Rédaction											
29. Citations présentées	Oui	Oui	Oui	Oui	Oui	Oui	Oui	Oui	Oui	Oui	Oui
30. Cohérence des données et des résultats	Oui	Oui	Oui	Oui	Oui	Oui	Oui	Oui	Oui	Oui	Oui

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[10] HP: hôpital CR : centre de réadaptation AD : à domicile EC : endroit choisi par les participants

[11] La durée en minutes

[12] NA : non applicable

[13] PD : prédéterminé ND : non-déterminé

31. Clarté des thèmes principaux	Oui	Non	Oui	Oui	Oui	Oui	Oui	Oui	Oui	-	Oui
32. Clarté des thèmes secondaires	-	-	-	-	Oui	Oui	-	-	-	-	-
Total sur 32 items	**19**	**20**	**17**	**18**	**21**	**15**	**23**	**14**	**15**	**9**	**17**

Chapter 2 : Appendix 2 - Liste de contrôle ENTREQ

Évaluation de la méta-synthèse selon la liste de contrôle ENTREQ

Items	Justification
1. But	En quoi la recherche qualitative nous informe-t-elle sur les intersections entre le genre et le handicap en matière de santé reproductive en Afrique subsaharienne?
2. Méthodologie de synthèse	Une méta-synthèse avec une analyse taxonomique.
3. Stratégie de recherche	La stratégie de recherche a été initialement menée pour réaliser un *review exploratoire* à partir de mots-clés des notions d'une première question (« What is known from the existing literature about gender and disability in relation to reproductive health in Sub-Sahara Africa?») quant à un *review exploratoire* mené début mai 2016. Ainsi pour la méta-synthèse, une nouvelle stratégie n'a pas été réalisée.
4. Critères d'inclusion	Les critères d'inclusion initiaux pour le *review exploratoire* étaient : " 1) primary and secondary studies using qualitative, quantitative or mixed methods designs; 2) studies which included the main four notions of the research question, with reproductive health comprising of sexual health and education, family planning/contraception, maternal health, HIV and AIDS, sexually transmitted infections, sexual violence and abortion care, based on the United Nations Population Fund's definition; and 3) studies published after 2001, as the World Health Organization launched its revised version of the International Classification of Functioning, Disability and Health (ICF) that year." Quant aux critères d'inclusion de la méta-analyse, ceux-ci sont : 1) des études originales qualitatives et 2) ayant un score d'au moins d'un tiers des items sur 32 de la liste de contrôle COREQ.
5. Sources des données	Medline, Global Health et Web of Science (semaine du 4 mai 2016).
6. Stratégies de recherche[14] électronique	Each strategy included the main four concepts of the research question, i.e. 1) gender, 2) disability, 3) reproductive health and 4) Sub-Sahara Africa, using medical sub-headings (MeSH) when these were available (e.g. in Medline and Global Health). Additionally, the following key words were also included in search strategies: ["gender" or "gender identity" or "gender role*" or "sex*" or "sex role*" or "sex difference*" or "masculin*" or "feminin*" or "woman" or "women" or "girl*" or "man" or "men" or "boy*"] and ["disabled person*" or "disabled people" or "person* with disability*" or "people with disability*" or "disabilit*" or "handicap*" or "deaf*" or "hard of hearing" or "blind*" or "impair*" adj1 ("vision" or "visual"

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[14] Selon les termes originaux utilisés en anglais lors de la revue exploratoire.

	or “physical” or “motor” or “learning” or “development*” or “intellectual” or “mental)] and [“reproductive health” or “sex* health” or “sex* education” or “family planning” or “maternal health” or “mother* health” or “pregnanc*” or “reproduct*” or “contracept*” or “HIV” or “AIDS” or “STI*” or “sexually transmitted infection*” or “sex* violence” or “abortion” or “safe abortion” or “post abortion care” or “women* health”] and [“africa” or “west* africa*” or “east* africa*” or “centr* africa*” or “south* africa*” or “Angola” or “Burundi” or “Democratic Republic of Congo” or “DRC” or “Cameroon” or” Central African Republic” or “CAR” or “Chad” or “Republic of Congo” or “Equatorial Guinea” or “Gabon” or “Kenya” or “Nigeria” or “Rwanda” or “Sao Tome and Principe” or “Tanzania” or “Uganda” or “Sudan” or “South Sudan” or “Djibouti” or “Eritrea” or “Somalia” or “Botswana” or “Comoros” or “Lesotho” or “Madagascar” or “Malawi” or “Mauritius” or “Mozambique” or “Namibia” or “Seychelles” or “South Africa” or “Swaziland” or “Zambia” or “Zimbabwe” or “Benin” or “Mali” or “Burkina Faso” or “Cape Verde” or “Ivory Coast” or “Gambia” or “Ghana” or “Guinea” or “Guinea Bissau” or “Liberia” or “Mauritania” or “Niger” or “Senegal” or “Sierra Leone” or “Togo”].
7. Méthode de sélection des recherches	Pour la revue exploratoire, la première sélection s’est faite à partir des titres et des résumés. La deuxième sélection a été menée en lisant les articles au complet. Quant à la méta-synthèse, seulement les recherches qualitatives, soit 11 sur 21 études des études retenues lors de la revue exploratoire sont incluses dans un premier temps. Les études quantitatives ont été exclues.
8. Caractéristiques des études incluses	Voir les tableaux inclus dans le manuscrit
9. Résultats de la sélection des études	Voir la figure incluse dans le manuscrit
10. Raison de l’évaluation	Les études retenues ont été évalué pour leur qualité selon la liste de contrôle COREQ.
11. Items d’évaluation	32 items de COREQ regroupés selon trois grands domaines : 1) l’équipe de recherche et de réflexivité, 2) la conception de l’étude, et 3) l’analyse et les résultats.
12. Processus d’évaluation	L’évaluation a été faite par l’étudiante seule.
13. Résultats de l’évaluation	Voici le tableau des résultats (Tableau 1). Les études ayant un score de moins du tiers sur 32 items sont exclues de la méta-synthèse étant un nombre plus élevé d’items manquants quant à la qualité d’une recherche qualitative.
14. Extraction des données	Les textes sous la section des résultats ont été extraits électroniquement et saisis à travers un logiciel informatique.
15. Logiciel si utilisé	NVivo 11 Plus avec NCapture
16. Nombre de réviseurs	Une personne seulement sous supervision
17. Codage	Arbre des nœuds selon les thématiques existantes.
18. Comparaison des études	Cette approche n’a pas été adoptée.

19. Dérivation thématique (*thematic derivation*)	L'analyse thématique n'a pas utilisé aucun cadre conceptuel, donc a été inductive du début jusqu'à la fin.
20. Citations	Prises en compte dans l'analyse finale.
21. Résultats (*outputs*) de la synthèse	Deux principales thématiques avec des sous-thématiques.

Chapter 3: Appendix 1 - Guidelines for in-depth semi-structured interviews, focus groups, and non-participant observations

Semi-structured interview guide with people with disabilities

Date:	Location:
Interviewer(s):	Presence of a local sign language interpreter? Y / N
Interviewee's title and/or organisation:	Membership of interviewee to a disabled people's organisation? Y / N
Sex of interviewee: F / M Age:	Which disability the interviewee identify her/himself to? ▪ Physical? ▪ Vision? ▪ Hearing? ▪ Communication? ▪ Concentration and remembering? ▪ Self-care? ▪ Multiple?

Introduction

Thank you for accepting to talk to us today. This interview will take approximately one hour of your time. We can take breaks in between if needed, please let us know. The information that you will provide will be kept confidential. Your answers will not be associated with your name, unless you want to be identified. Your answers will only be shared with other research team members and will be compiled with other answers from various participants with disabilities.

I am going to ask you questions about your perceptions (i.e. ideas, point of views) on how laws, health policies are related to the use of sexual and reproductive health services by women and men with disabilities, in particular in the post-conflict Northern region of Uganda. At any time, you may ask for clarification if questions are not clear to you.

Anonymity

Despite being recorded, I would like to assure you that the discussion will be anonymous. The tapes will be kept safely in a locked facility until they are transcribed word for word, then they will be destroyed. The transcribed notes of the interview will contain no information that would allow individual subjects to be linked to specific statements. You should try to answer and comment as accurately and truthfully as possible. If there are any questions or discussions that you do not wish to answer or participate in, you do not have to do so; however please try to answer and be as involved as possible.

Guiding questions

1) Descriptive questions in relation to the IBPA

- Tell us a bit more about yourself, age, marital status, disability, education, employment, etc.?
- What do you know about sexual and reproductive health services available in Uganda?
- Which ones are you using?
- What kinds of challenges are you facing as a person with disabilities, or other people with disabilities, are facing in the utilisation of these sexual and reproductive health services?
- Are there any differences in the utilisation of these services with other groups of people in Uganda, for example those who are not disabled and/or who are living in other regions that were not so affected by the last armed conflict?
- How do you think the use of sexual and reproductive health services can be influenced by Ugandan legislation and health policy?
- Are you aware of any legislation and health policy that are supposed to protect and promote the rights of people with disabilities in Uganda?
- If yes, which ones?
- If not, why?
- So if we look back at the question of this study, what could be the linkages or the relationships between legislation, health policy and sexual and reproductive health services by people with disabilities, in the post-conflict Northern region of Uganda?

2) Transformative questions in relation to the IBPA

- How can we improve the access to and utilisation of sexual and reproductive health services by people with disabilities in Uganda and especially in the Northern post-conflict region?
- What are the roles of people with disabilities - service providers - local NGOs – international organisations – national policy-makers, in promoting transformative action for improved access to and utilisation of SRH services by people with disabilities?

Follow-up during focus groups

Before we depart from one another, if needed, would you be interested to be part of a focus group with other people with disabilities to deepen our understanding of what we just talked about?

Y / N

Conclusion

- Thank you for participating. This has been a very successful discussion
- Your opinions will be a valuable asset to the study
- We hope you have found the discussion interesting
- I would like to remind you that any comments featuring in this report will be anonymous
- If you would like to review some of the accuracy of your statements when we will write the report, please let me know if you would like to be contacted. If yes: email or local phone number

Semi-structured interview guide with national policy-makers and international organisations

Date:	Location:
Interviewer(s):	Presence of local sign language interpreter: Y / N
Interviewee's title and organisation:	
Sex of interviewee: F / M Age:	Do the interviewee identify her/himself as a person with disability? If yes, which disability: ▪ Physical? ▪ Vision? ▪ Hearing? ▪ Communication? ▪ Concentration and remembering? ▪ Self-care? ▪ Multiple?

Introduction

Thank you for agreeing to be interviewed today. This interview will take approximately one hour of your time. The information that you will provide will be kept confidential. Your responses will be anonymized, unless you want to be identified. Your responses will only be shared with other research team members and will be compiled with other answers from various participants.

I am going to ask you questions about your involvement in policy-making in terms of the relationships between legislation, health policy and utilisation of sexual and reproductive health services by people with disabilities, in particular in the post-conflict Northern region of Uganda. At any time, you may ask for clarification if questions are not clear to you.

Anonymity

Despite being recorded, I would like to assure you that the discussion will be anonymous. The tapes will be kept safely in a locked facility until they are transcribed word for word, then they will be destroyed. The transcribed notes of the interview will contain no information that would allow individual subjects to be linked to specific statements. You should try to answer and comment as accurately and truthfully as possible. If there are any questions or discussions that you do not wish to answer or participate in, you do not have to do so; however please try to answer and be as involved as possible.

Guiding questions

1) Descriptive questions in relation to the IBPA

- What is your awareness of the formulation and implementation processes of legislation and health policy that promote the rights of people with disabilities *in Uganda and/or in the Northern region? Can you give examples?
- What knowledge, values and experiences do you bring to these legislation and health policies in Uganda?
- What are your perceptions on the utilisation of SRH services by people with disabilities in the post-conflict Northern region of Uganda, in comparison to other groups of the population and also in other regions?
- What are your perceptions on how legislation, health policy and SRH service utilisation by people with disabilities are related with one another, in the post-conflict Northern region of Uganda?
- How groups are differently affected by these legislation and health policies?
- How would the utilisation of SRH services by people with disabilities differ between types of health facilities, i.e. charity-based or public-based and why?

2) Transformative questions in relation to the IBPA

- According to you, are there any inequities that exist in relation to the utilisation of sexual and reproductive health services among people with disabilities and people without disabilities, in the context of those legislation and health policies in Uganda?
- When and how can interventions be made to improve these inequities? Can you give examples?

Conclusion

- Thank you for participating. This has been a very successful discussion
- Your opinions will be a valuable asset to the study
- We hope you have found the discussion interesting
- I would like to remind you that any comments featuring in this report will be anonymous
- If you would like to review some of the accuracy of your statements when we will write the report, please let me know if you would like to be contacted. If yes: email or local phone number

Focus group interview guide with people with disabilities

Date:			Location:	
Interviewer(s):			Presence of local sign language interpreter: Y / N	
Interviewee's title and/or organisation:	Sex of participants:	Age:	Disability type: ▪ Physical? ▪ Vision? ▪ Hearing? ▪ Communication? ▪ Concentration and remembering? ▪ Self-care? ▪ Multiple?	Membership to any disabled people's organisations: Y /N Which one?
Notes (e.g. if anyone came accompanied, etc.):				

Welcome and introduction of researcher/research assistant (and local sign language interpreter, if needed).

Overview

We have met during individual interviews. Today, we are meeting as you have accepted to be interviewed in a group. Again, the objective of this study is to look at the relationships between laws, health policies and utilisation of sexual and reproductive health services by people with disabilities in the post-conflict Northern region of Uganda.

Anonymity

Despite being taped, I would like to assure you that the discussion will be anonymous. The tapes will be kept safely in a locked facility until they are transcribed word for word, then they will be destroyed. The transcribed notes of the focus group will contain no information that would allow individual subjects to be linked to specific statements. You should try to answer and comment as accurately and truthfully as possible. I and the other focus group participants would appreciate it if you would refrain from discussing the comments of other group members outside the focus group. If there are any questions or discussions that you do not wish to answer or participate in, you do not have to do so; however please try to answer and be as involved as possible.

Warm-up

First, I would like everyone to introduce themselves. Can you tell us your name and where do you come from?

Guiding questions

- What are the types of sexual and reproductive health services you have tried to use or have used?
- Where did you go for these services?
    - Probe: type of health facility, i.e. charity or public-based?
- What are the facilitating factors and barriers in accessing and utilising sexual and reproductive health services in the Northern region and why?
- Have you, or anyone you know, been treated differently because of age, sex, disability, place of residence, etc.?
    - Probe: Can you explain?
- Have these treatments been always the same/different, for example since the adoption of disability laws and policies in Uganda?
    - Probe: Have you seen any changes in time, for example, since 2006, the year of the adoption of the Disability Act in Uganda?
- How do you think can these facilitators be enhanced and these barriers be handled by yourselves as people with disabilities, health facilities (which type?), service providers, community leaders and national policy-makers?

Conclusion

- Thank you for participating. This has been a very successful discussion
- Your opinions will be a valuable asset to the study
- We hope you have found the discussion interesting
- I would like to remind you that any comments featuring in this report will be anonymous
- If you would like to review some of the accuracy of your statements when we will write the report, please let me know if you would like to be contacted. If yes: email or local phone number

Focus group interview guide with health service providers

Date:			Location:
Interviewer(s):			Presence of local sign language interpreter: Y / N
Interviewee's title and/or organisation:	Sex of participants:	Age:	Disability type: ▪ Physical? ▪ Vision? ▪ Hearing? ▪ Communication? ▪ Concentration and remembering? ▪ Self-care? ▪ Multiple?
Notes and observations:			

Welcome and introduction of researcher/research assistant (and local sign language interpreter, if needed).

Overview

Today, we are meeting as you have accepted to be interviewed in a group. Thank you. The objective of this study is to look at the relationships between laws, health policies and utilisation of sexual and reproductive health services by people with disabilities in the post-conflict Northern region of Uganda.

Anonymity

Despite being recorded, I would like to assure you that the discussion will be anonymous. The tapes will be kept safely in a locked facility until they are transcribed word for word, then they will be destroyed. The transcribed notes of the focus group will contain no information that would allow individual subjects to be linked to specific statements. You should try to answer and comment as accurately and truthfully as possible. I and the other focus group participants would appreciate it if you would refrain from discussing the comments of other group members outside the focus group. No personal questions will be asked. If there are any questions or discussions that you do not wish to answer or participate in, you do not have to do so; however please try to answer and be as involved as possible.

Warm-up

First, I would like everyone to introduce themselves. Can you tell us your name and where do you come from?

Guiding questions

- How would you qualify the type of health facility at which you are working?
- What are the types of sexual and reproductive health services that you are providing to users?
- What type of users that you mostly serve?

    - Probe: Sex, age, disability, place of residence, etc.?
- What are the facilitating factors and barriers different groups of users in accessing and utilising sexual and reproductive health services in the Northern region and why?
- What are some of the specific barriers some of the most vulnerable potential users might have in accessing and utilising sexual and reproductive health services in the Northern region and why?
- Have these barriers/obstacles been always the same/different, for example since the adoption of disability laws and policies in Uganda?
    - Probe: Have you seen any changes in time, for example, since 2006, the year of the adoption of the Disability Act in Uganda?
- How do you think can these facilitators be enhanced and these barriers be handled by yourselves as service providers, the different users themselves, community leaders and national policy-makers?

Conclusion
- Thank you for participating. This has been a very successful discussion
- Your opinions will be a valuable asset to the study
- We hope you have found the discussion interesting
- I would like to remind you that any comments featuring in this report will be anonymous
- If you would like to review some of the accuracy of your statements when we will write the report, please let me know if you would like to be contacted. If yes: email or local phone number

Focus group interview guide with local non-governmental organisations, including disabled people's organisations

Date:			Location:
Interviewer(s):			Presence of local sign language interpreter: Y / N
Interviewee's title and/or organisation:	Sex of participants:	Age:	Disability type: ▪ Physical? ▪ Vision? ▪ Hearing? ▪ Communication? ▪ Concentration and remembering? ▪ Self-care? ▪ Multiple?
Notes and observations:			

Welcome and introduction of researcher/research assistant (and local sign language interpreter, if needed).

Overview

Today, we are meeting as you have accepted to be interviewed in a group. Thank you. The objective of this study is to examine at the relationships between legislation, health policies and utilisation of sexual and reproductive health services by people with disabilities in the post-conflict Northern region of Uganda.

Anonymity

Despite being recorded, I would like to assure you that the discussion will be anonymous. The tapes will be kept safely in a locked facility until they are transcribed word for word, then they will be destroyed. The transcribed notes of the focus group will contain no information that would allow individual subjects to be linked to specific statements. You should try to answer and comment as accurately and truthfully as possible. I and the other focus group participants would appreciate it if you would refrain from discussing the comments of other group members outside the focus group. No personal questions will be asked. If there are any questions or discussions that you do not wish to answer or participate in, you do not have to do so; however please try to answer and be as involved as possible.

Warm-up

First, I would like everyone to introduce themselves. Can you tell us your name and where do you come from?

Guiding questions

- What is your awareness of the formulation and implementation processes of legislation and health policies that promote the rights of people with disabilities in the post-conflict Northern region of Uganda?
    - Probe: Has anyone among you have been involved in such policy/law formulation? If yes, please explain
- According to you, what are the main sexual and reproductive health services that you are provided to users?
    - Probe: Which type of uses (sex, age, disability, place of residence, etc.)?
- What are the facilitating factors and barriers different groups of users in accessing and utilising sexual and reproductive health services in the Northern region and why?
- What are some of the specific barriers some of the most vulnerable potential users might have in accessing and utilising sexual and reproductive health services in the Northern region and why?
- Have these barriers/obstacles been always the same/different, for example since the adoption of disability laws and policies in Uganda?
    - Probe: Have you seen any changes in time, for example, since 2006, the year of the adoption of the Disability Act in Uganda?
- How do you think can these facilitators be enhanced and these barriers be handled by yourselves as service providers, the different users themselves, community leaders and national policy-makers?

Conclusion

- Thank you for participating. This has been a very successful discussion
- Your opinions will be a valuable asset to the study
- We hope you have found the discussion interesting
- I would like to remind you that any comments featuring in this report will be anonymous
- If you would like to review some of the accuracy of your statements when we will write the report, please let me know if you would like to be contacted. If yes: email or local phone number

Non-participant observation guide

The following non-participant observation tool will play the role as a guide in order to keep detailed notes of visits to health facilities. Drawings can also be made to highlight observations.

- During the observations, detailed attention will be paid on the "who, what, where and when" of the different activities taking place at health facilities, as well as "how" these are handled in relation to women and men with disabilities seeking sexual and reproductive health services, if any. The "what, who, where, when and how" will be derived from observing several people with disabilities. This will be summarised.
- More specifically, observations will focus on key principles of intersectionality, when possible and applicable, i.e. in relation to:
    - Who in terms of social identifies of users of health facilities
    - Time and space (e.g. location and accessibility features)
    - Different actors involved
    - Type of power that can be observed that actors are exercising (or not)
    - Whose knowledge and what type of knowledge is observed
    - Equity/social justice in terms of access, accessibility/barriers
    - Reflexivity
    - Other issues

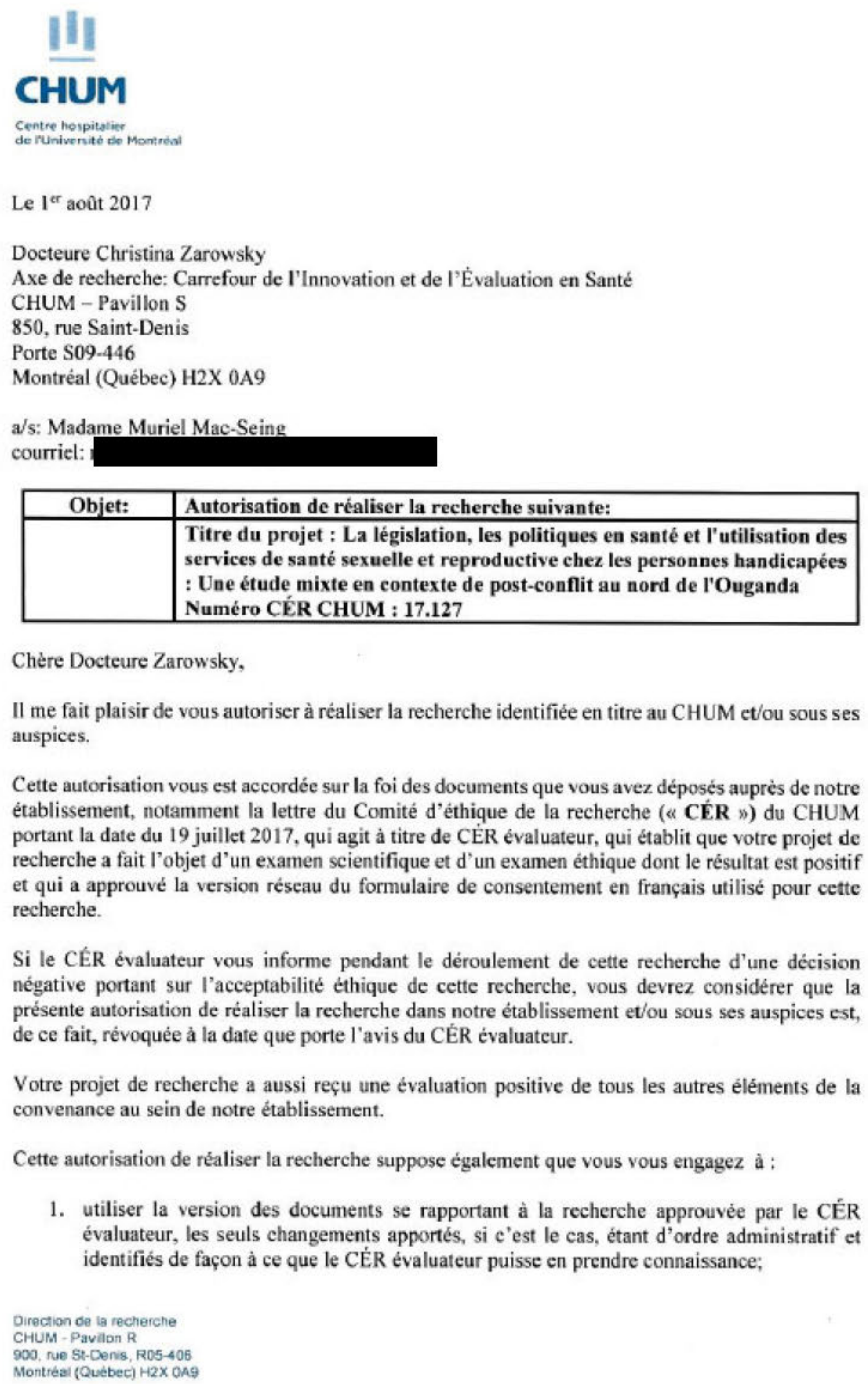
Items	**Observations**
Where (Location) **Attention to accessibility features (physical and communication)**	
When (Date and time)	
What (Activities)	
Who (People and social identities)	
How (Attitudes, facilitators, attitudes, etc.)	

Appendix 2: Glossary of key research and SRH vocabulary in Luo and English

English	Luo
Research, Study	Kwed, kwan
Researcher	Lakwed
Research assistant	Lakony koro Lakwed
Legislation	Pen Cik
Law	Cik
Health policy, Health plan	Cik me doro yot kum, Tam me yot kum
Sexual and reproductive health	Yot kum makubbe ki butu ki nywal
Sexual and reproductive health rights	Twero makubbbe yot kum me butu ki nywal
Utilisation of services	Tec ki kony
Women, men, people with disabilities	Mon, coo, ki dano ma tye ki ngolo
Disabled people	Dano me tye ki ngolo
Physical disability	Ngolo me nen
Visual disability	Ngolo me too wang
Hearing disability, Deaf	Ngolo me dingit
Speech (or communication) disability or speech (or communication) impairment	Ngolo me too lep
Intellectual disability	Ngolo me two wic
Mental health illness, Mental health problem	Two wic, Peko me two wic
Relationships between legislation and utilisation of sexual and reproductive services	Wat iken Pen cik ki tic ki kony ma yot kum makubbe ki butu ki nywal
Disparities (as in inequities, differences)	Apokapoka
Confidentiality, Anonymity, Privacy	Mug
Potential risks in participating in the research	Peko ma romo bedo ikwed
Potential benefits in participating in the research	Kony ma romo bino Ikwed
Consent form	Karetac ma moko tam

Are you aware? Do you know?	Itye ki ngec? Ingeyo?
What are your perceptions about xxx?	Ngo ma ineno ikom xxx?
What are your ideas about xxx?	Ngo ma itamo ikom xxx?
Disabled people's organisations (DPO)	Dul palungolo
Membership with disabled people's organisations?	Itye dan ma dul palungolo
Interviews	Penyo lapeny
Focus groups	Nywako tam idul
Observations	Neno
Recording of interview	Coko dwan
Recording of focus group	Coko dwan idul
Access	Oo-kunu
Getting	Gamo
Giving	Miyo
Delivery	Miyo
Health facility	Ot yat
Referral hospital	Ot yat madit
Societal attitude	Kit dano
Health service delivery	Miyo kony me yot kum
Inaccessible	Pe none

Appendix 3: Ethics certificates



CHUM
Centre hospitalier
de l'Université de Montréal

Le 1er août 2017

Docteure Christina Zarowsky
Axe de recherche: Carrefour de l'Innovation et de l'Évaluation en Santé
CHUM – Pavillon S
850, rue Saint-Denis
Porte S09-446
Montréal (Québec) H2X 0A9

a/s: Madame Muriel Mac-Seing
courriel: [redacted]

Objet:	**Autorisation de réaliser la recherche suivante:**
	Titre du projet : La législation, les politiques en santé et l'utilisation des services de santé sexuelle et reproductive chez les personnes handicapées : Une étude mixte en contexte de post-conflit au nord de l'Ouganda **Numéro CÉR CHUM : 17.127**

Chère Docteure Zarowsky,

Il me fait plaisir de vous autoriser à réaliser la recherche identifiée en titre au CHUM et/ou sous ses auspices.

Cette autorisation vous est accordée sur la foi des documents que vous avez déposés auprès de notre établissement, notamment la lettre du Comité d'éthique de la recherche (« **CÉR** ») du CHUM portant la date du 19 juillet 2017, qui agit à titre de CÉR évaluateur, qui établit que votre projet de recherche a fait l'objet d'un examen scientifique et d'un examen éthique dont le résultat est positif et qui a approuvé la version réseau du formulaire de consentement en français utilisé pour cette recherche.

Si le CÉR évaluateur vous informe pendant le déroulement de cette recherche d'une décision négative portant sur l'acceptabilité éthique de cette recherche, vous devrez considérer que la présente autorisation de réaliser la recherche dans notre établissement et/ou sous ses auspices est, de ce fait, révoquée à la date que porte l'avis du CÉR évaluateur.

Votre projet de recherche a aussi reçu une évaluation positive de tous les autres éléments de la convenance au sein de notre établissement.

Cette autorisation de réaliser la recherche suppose également que vous vous engagez à :

1. utiliser la version des documents se rapportant à la recherche approuvée par le CÉR évaluateur, les seuls changements apportés, si c'est le cas, étant d'ordre administratif et identifiés de façon à ce que le CÉR évaluateur puisse en prendre connaissance;

Direction de la recherche
CHUM - Pavillon R
900, rue St-Denis, R05-406
Montréal (Québec) H2X 0A9

2. vous conformer aux demandes du CÉR évaluateur, notamment pour le suivi éthique continu de la recherche ainsi que pour lui rendre compte du déroulement du projet et des actes de votre équipe de recherche ainsi que du respect des règles de l'éthique de la recherche;
3. conserver les dossiers de recherche pendant la période fixée par le CÉR évaluateur après la fin du projet, selon les règles de conservation de l'établissement, afin de permettre leur éventuelle vérification;
4. respecter le cadre règlementaire de l'établissement, notamment, s'il y a lieu, les modalités arrêtées au regard du mécanisme d'identification des participants à la recherche dans notre établissement, à savoir, la tenue à jour et la conservation de la liste à jour des participants de recherche recrutés sous les auspices de notre établissement. Cette liste devra nous être fournie sur demande.

L'autorisation qui vous est donnée ici de réaliser la recherche sous les auspices de notre établissement sera renouvelée sans autre procédure à la date indiquée par le CÉR évaluateur dans sa décision de renouveler son approbation éthique de cette recherche.

La présente autorisation peut être suspendue ou révoquée par le CHUM en cas de non-respect des conditions établies lors de notre examen de la convenance. Le CÉR évaluateur en sera alors informé.

Vous consentez également à ce que le CHUM communique aux autorités compétentes des renseignements personnels qui sont nominatifs au sens de la loi en présence d'un cas avéré de manquement à la conduite responsable en recherche de votre part lors de la réalisation de cette recherche.

Toute communication avec le soussigné concernant la présente autorisation à réaliser la recherche doit être acheminée ainsi :

- par courriel : convenance.recherche.chum@ssss.gouv.qc.ca
- par téléphone : (514) 890-8000, poste 15213.

Pour toutes questions, conseils ou soutien relativement aux aspects éthiques de votre projet de recherche, vous pouvez aussi solliciter l'appui du CÉR de notre établissement en vous adressant aux coordonnées suivantes :

- par courriel : ethique.recherche.chum@ssss.gouv.qc.ca
- par téléphone : 514 890-8000, poste 14485.

En terminant, je vous demanderais de toujours mentionner dans votre correspondance au sujet de ce projet de recherche le numéro attribué à votre demande par le CHUM, soit **17.127**.

En vous remerciant de votre contribution à la mission de recherche de notre établissement, je vous prie d'agréer, Chère Docteure Zarowsky, l'expression de mes sentiments les meilleurs.

[redacted]

Vincent Poitout, D.V.M., Ph.D, FCAHS
Personne mandatée par le CHUM
pour autoriser la réalisation des recherches

c.c. :

- Me Marie-Josée Bernardi, Présidente par intérim du CÉR du CHUM

Tel. +256 - 471 - 432310, Fax. +256 - 471 - 432
Email: info@lacorhospital.org Website: lacorhospital.org

10th October 2017

To Muriel **Mac-Seing**
[redacted]

LHIREC 019/07/2017: **Study Title:** Legislation, health policy and utilization of SRH services by people with disabilities: a mixed methods study in the post-conflict Northern region of Uganda

Type: [√] **Initial Review**
[ ] Protocol Amendment
[ ] Letter of Amendment (LOA)
[ ] Continuing Review
[ ] Material Transfer Agreement
[ ] Other, Specify: _______________

I am pleased to inform you that at the LHIREC has approve the above referenced application. Approval of the research is for the period of **07th September 2017** to **07th August 2018**

As Principal Investigator of the research, you are responsible for fulfilling the following requirements of approval:

1. All co-investigators must be kept informed of the status of the research.
2. Changes, amendments, and addenda to the protocol or the consent form must be submitted to LHIREC for re-review and approval **prior** to the activation of the changes. The REC application number assigned to the research should be cited in any correspondence.
3. Reports of unanticipated problems involving risks to participants or other must be submitted to the LHIREC. New information that becomes available which could change the risk: benefit ratio must be submitted promptly for LHIREC review.
4. Only approved consent forms are to be used in the enrollment of participants. All consent forms signed by subjects and/or witnesses should be retained on file. The LHIREC may conduct audits of all study records, and consent documentation may be part of such audits.

5. Regulations require review of an approved study not less than once per 12-month period. **Therefore, a continuing review application must be submitted to the LHIREC eight weeks prior to the above expiration date of 07th August 2018 in order to continue the study beyond the approved period.** Failure to submit a continuing review application in a timely fashion may result in suspension or termination of the study, at which point new participants may not be enrolled and currently enrolled participants must be taken off the study.

6. You are **required** to register the research protocol with the Uganda National Council for Science and Technology (UNCST) for final clearance to undertake the study in Uganda.

The following is the list of all documents approved in this application by LHIREC.

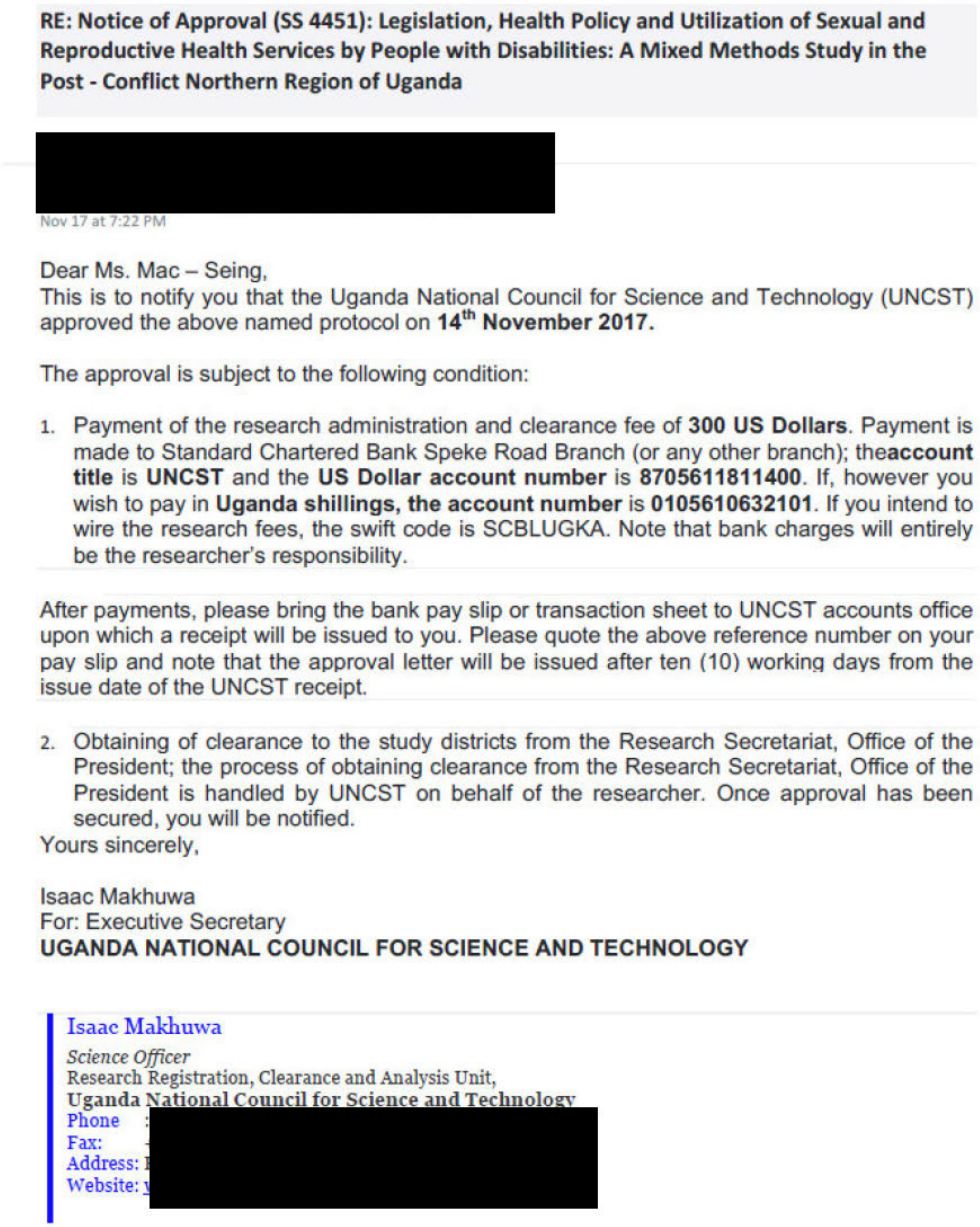
No	Document Title	Language	Version	Version date
1.	Proposal	English	2.0	October 2017
2.	Informed Consent forms	English / Luo	2.0	October 2017

Thanks [redacted]

OGWANG DAVID MARTIN Date 10/10/2017

Names:

For LHIREC Chairman



RE: Notice of Approval (SS 4451): Legislation, Health Policy and Utilization of Sexual and Reproductive Health Services by People with Disabilities: A Mixed Methods Study in the Post - Conflict Northern Region of Uganda

[redacted]

Nov 17 at 7:22 PM

Dear Ms. Mac – Seing,
This is to notify you that the Uganda National Council for Science and Technology (UNCST) approved the above named protocol on **14th November 2017.**

The approval is subject to the following condition:

1. Payment of the research administration and clearance fee of **300 US Dollars**. Payment is made to Standard Chartered Bank Speke Road Branch (or any other branch); the**account title** is **UNCST** and the **US Dollar account number** is **8705611811400**. If, however you wish to pay in **Uganda shillings, the account number** is **0105610632101**. If you intend to wire the research fees, the swift code is SCBLUGKA. Note that bank charges will entirely be the researcher's responsibility.

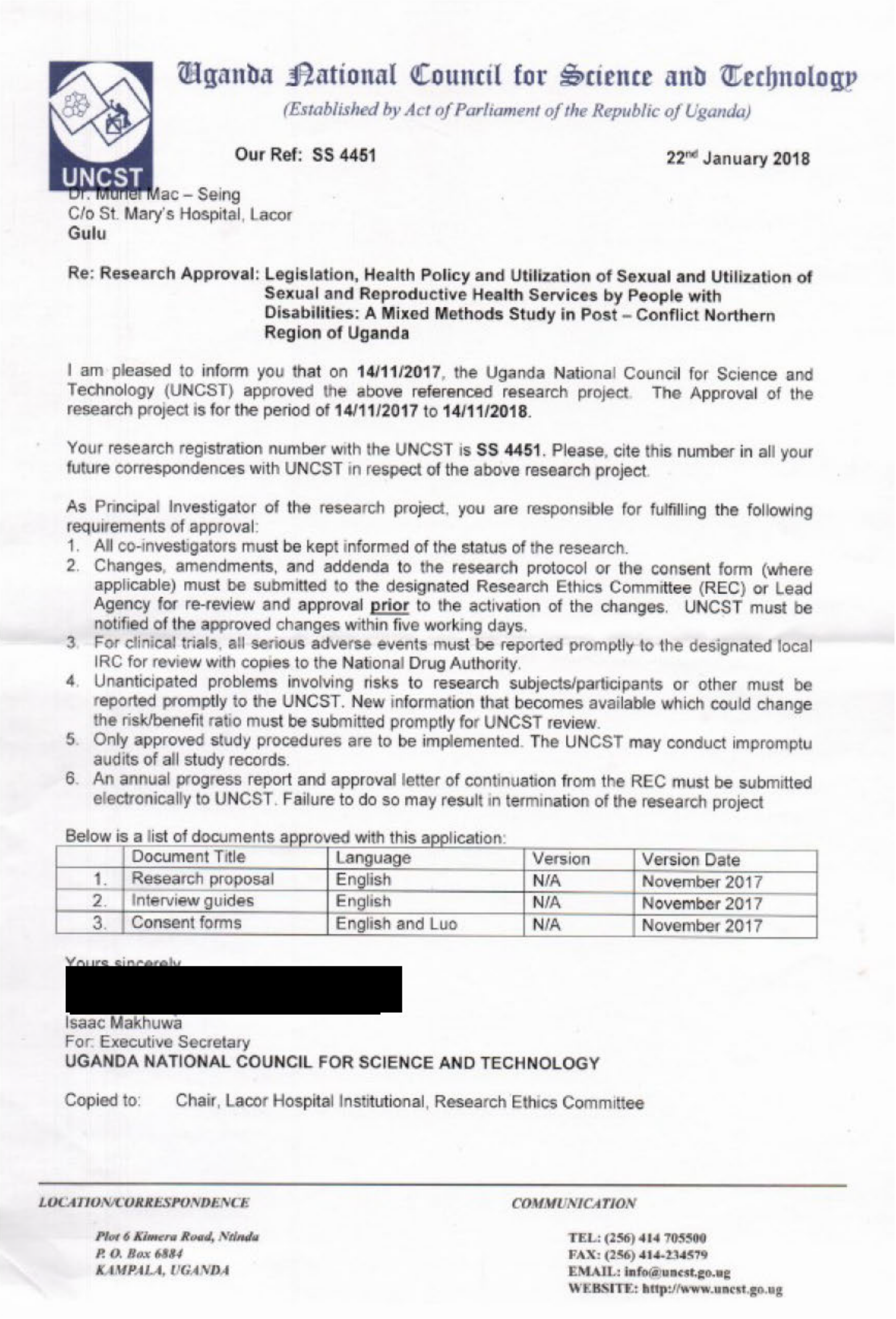
After payments, please bring the bank pay slip or transaction sheet to UNCST accounts office upon which a receipt will be issued to you. Please quote the above reference number on your pay slip and note that the approval letter will be issued after ten (10) working days from the issue date of the UNCST receipt.

2. Obtaining of clearance to the study districts from the Research Secretariat, Office of the President; the process of obtaining clearance from the Research Secretariat, Office of the President is handled by UNCST on behalf of the researcher. Once approval has been secured, you will be notified.

Yours sincerely,

Isaac Makhuwa
For: Executive Secretary
UGANDA NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY

Isaac Makhuwa
Science Officer
Research Registration, Clearance and Analysis Unit,
Uganda National Council for Science and Technology
Phone
Fax:
Address:
Website:
[redacted]



UNCST

Uganda National Council for Science and Technology

(Established by Act of Parliament of the Republic of Uganda)

Our Ref: SS 4451 **22nd January 2018**

Dr. Muriel Mac – Seing
C/o St. Mary's Hospital, Lacor
Gulu

Re: Research Approval: Legislation, Health Policy and Utilization of Sexual and Utilization of Sexual and Reproductive Health Services by People with Disabilities: A Mixed Methods Study in Post – Conflict Northern Region of Uganda

I am pleased to inform you that on **14/11/2017**, the Uganda National Council for Science and Technology (UNCST) approved the above referenced research project. The Approval of the research project is for the period of **14/11/2017** to **14/11/2018.**

Your research registration number with the UNCST is **SS 4451.** Please, cite this number in all your future correspondences with UNCST in respect of the above research project.

As Principal Investigator of the research project, you are responsible for fulfilling the following requirements of approval:

1. All co-investigators must be kept informed of the status of the research.
2. Changes, amendments, and addenda to the research protocol or the consent form (where applicable) must be submitted to the designated Research Ethics Committee (REC) or Lead Agency for re-review and approval **prior** to the activation of the changes. UNCST must be notified of the approved changes within five working days.
3. For clinical trials, all serious adverse events must be reported promptly to the designated local IRC for review with copies to the National Drug Authority.
4. Unanticipated problems involving risks to research subjects/participants or other must be reported promptly to the UNCST. New information that becomes available which could change the risk/benefit ratio must be submitted promptly for UNCST review.
5. Only approved study procedures are to be implemented. The UNCST may conduct impromptu audits of all study records.
6. An annual progress report and approval letter of continuation from the REC must be submitted electronically to UNCST. Failure to do so may result in termination of the research project

Below is a list of documents approved with this application:

	Document Title	Language	Version	Version Date
1.	Research proposal	English	N/A	November 2017
2.	Interview guides	English	N/A	November 2017
3.	Consent forms	English and Luo	N/A	November 2017

Yours sincerely

[redacted]

Isaac Makhuwa
For: Executive Secretary
UGANDA NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY

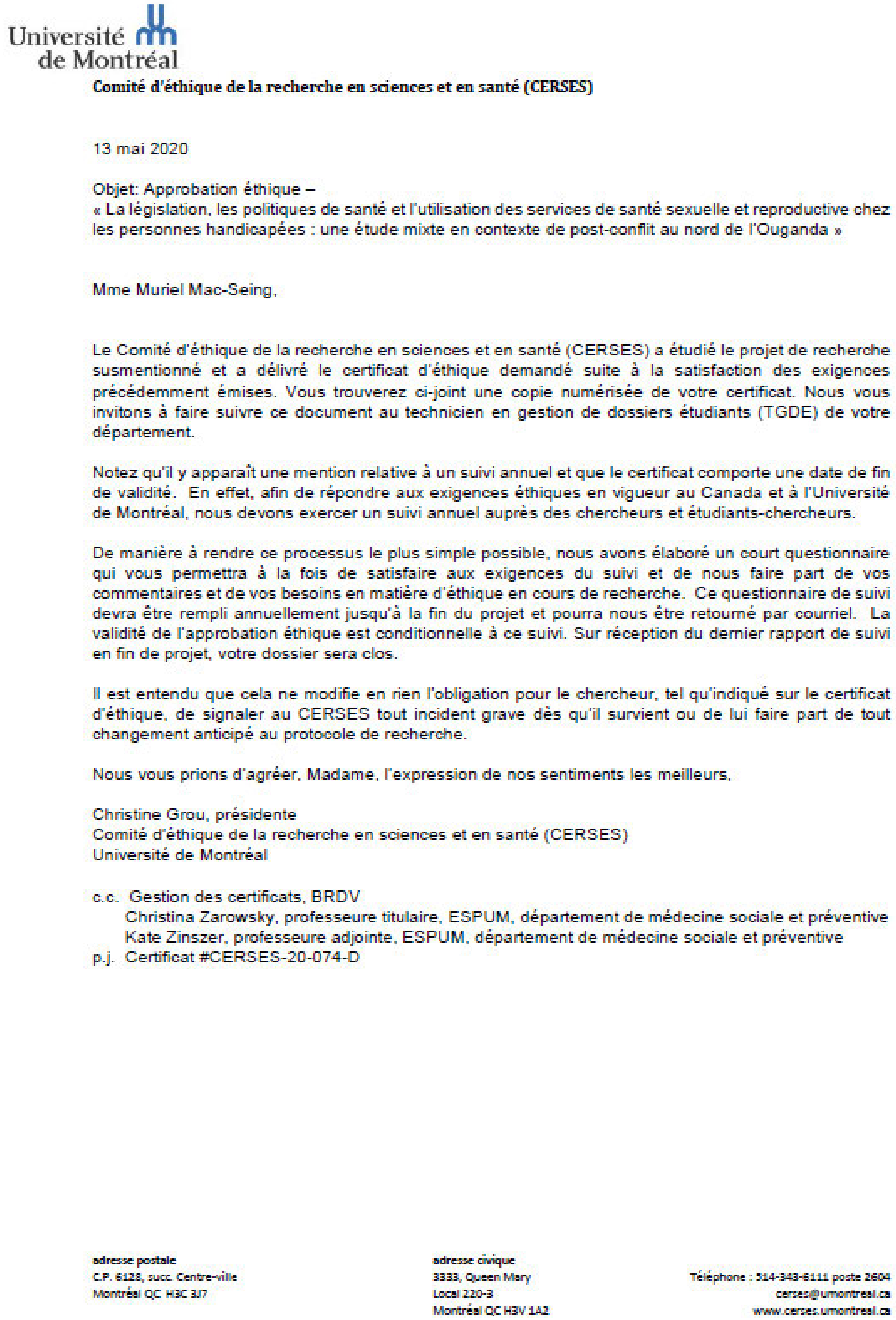
Copied to: Chair, Lacor Hospital Institutional, Research Ethics Committee

LOCATION/CORRESPONDENCE

Plot 6 Kimera Road, Ntinda
P. O. Box 6884
KAMPALA, UGANDA

COMMUNICATION

TEL: (256) 414 705500
FAX: (256) 414-234579
EMAIL: info@uncst.go.ug
WEBSITE: http://www.uncst.go.ug



Université de Montréal
Comité d'éthique de la recherche en sciences et en santé (CERSES)

13 mai 2020

Objet: Approbation éthique –
« La législation, les politiques de santé et l'utilisation des services de santé sexuelle et reproductive chez les personnes handicapées : une étude mixte en contexte de post-conflit au nord de l'Ouganda »

Mme Muriel Mac-Seing,

Le Comité d'éthique de la recherche en sciences et en santé (CERSES) a étudié le projet de recherche susmentionné et a délivré le certificat d'éthique demandé suite à la satisfaction des exigences précédemment émises. Vous trouverez ci-joint une copie numérisée de votre certificat. Nous vous invitons à faire suivre ce document au technicien en gestion de dossiers étudiants (TGDE) de votre département.

Notez qu'il y apparaît une mention relative à un suivi annuel et que le certificat comporte une date de fin de validité. En effet, afin de répondre aux exigences éthiques en vigueur au Canada et à l'Université de Montréal, nous devons exercer un suivi annuel auprès des chercheurs et étudiants-chercheurs.

De manière à rendre ce processus le plus simple possible, nous avons élaboré un court questionnaire qui vous permettra à la fois de satisfaire aux exigences du suivi et de nous faire part de vos commentaires et de vos besoins en matière d'éthique en cours de recherche. Ce questionnaire de suivi devra être rempli annuellement jusqu'à la fin du projet et pourra nous être retourné par courriel. La validité de l'approbation éthique est conditionnelle à ce suivi. Sur réception du dernier rapport de suivi en fin de projet, votre dossier sera clos.

Il est entendu que cela ne modifie en rien l'obligation pour le chercheur, tel qu'indiqué sur le certificat d'éthique, de signaler au CERSES tout incident grave dès qu'il survient ou de lui faire part de tout changement anticipé au protocole de recherche.

Nous vous prions d'agréer, Madame, l'expression de nos sentiments les meilleurs,

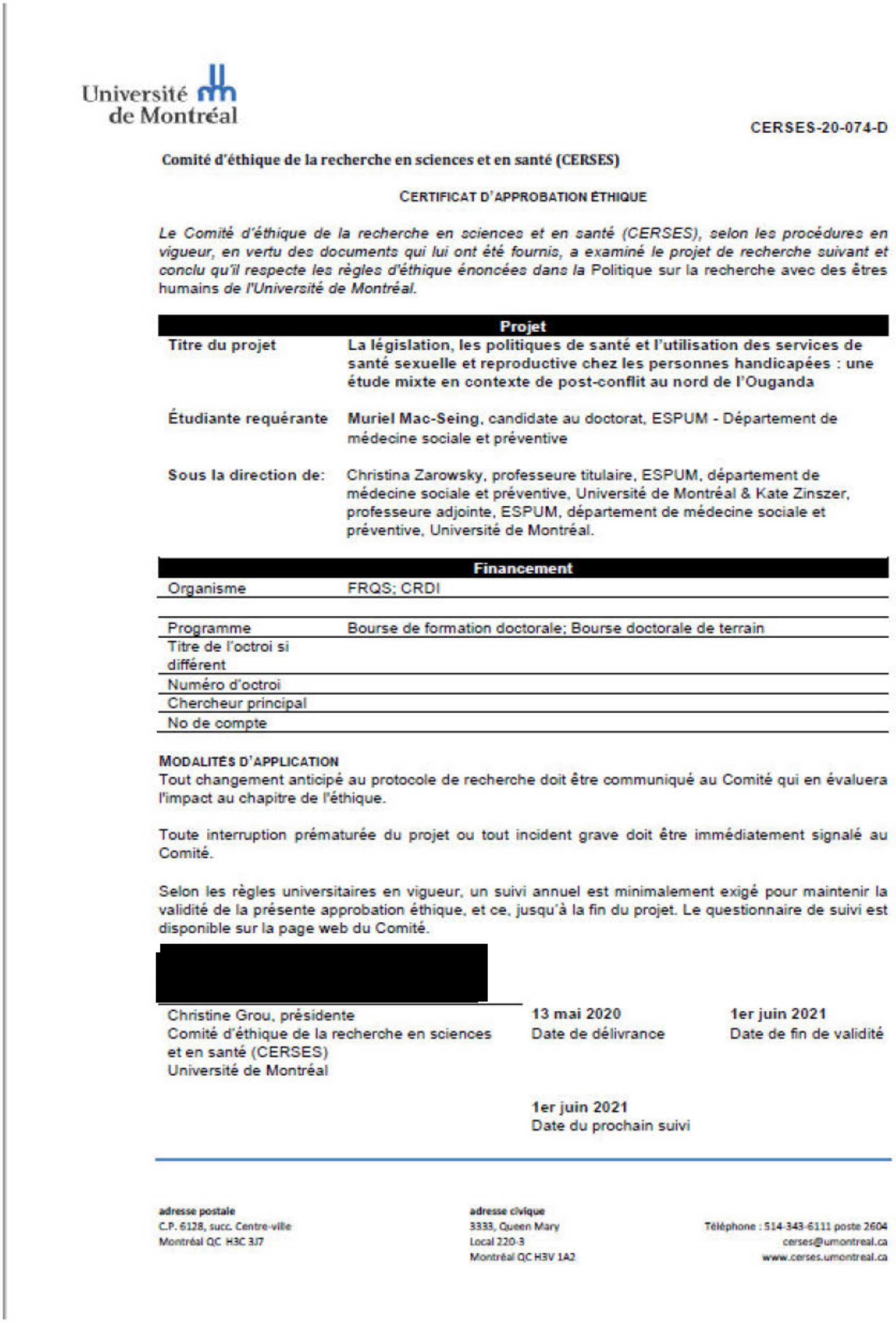
Christine Grou, présidente
Comité d'éthique de la recherche en sciences et en santé (CERSES)
Université de Montréal

c.c. Gestion des certificats, BRDV
Christina Zarowsky, professeure titulaire, ESPUM, département de médecine sociale et préventive
Kate Zinszer, professeure adjointe, ESPUM, département de médecine sociale et préventive
p.j. Certificat #CERSES-20-074-D

adresse postale
C.P. 6128, succ. Centre-ville
Montréal QC H3C 3J7

adresse civique
3333, Queen Mary
Local 220-3
Montréal QC H3V 1A2

Téléphone : 514-343-6111 poste 2604
cerses@umontreal.ca
www.cerses.umontreal.ca



Université de Montréal

CERSES-20-074-D

Comité d'éthique de la recherche en sciences et en santé (CERSES)

CERTIFICAT D'APPROBATION ÉTHIQUE

Le Comité d'éthique de la recherche en sciences et en santé (CERSES), selon les procédures en vigueur, en vertu des documents qui lui ont été fournis, a examiné le projet de recherche suivant et conclu qu'il respecte les règles d'éthique énoncées dans la Politique sur la recherche avec des êtres humains *de l'Université de Montréal.*

Projet	
Titre du projet	**La législation, les politiques de santé et l'utilisation des services de santé sexuelle et reproductive chez les personnes handicapées : une étude mixte en contexte de post-conflit au nord de l'Ouganda**
Étudiante requérante	**Muriel Mac-Seing**, candidate au doctorat, ESPUM - Département de médecine sociale et préventive
Sous la direction de:	Christina Zarowsky, professeure titulaire, ESPUM, département de médecine sociale et préventive, Université de Montréal & Kate Zinszer, professeure adjointe, ESPUM, département de médecine sociale et préventive, Université de Montréal.

Financement	
Organisme	FRQS; CRDI
Programme	Bourse de formation doctorale; Bourse doctorale de terrain
Titre de l'octroi si différent	
Numéro d'octroi	
Chercheur principal	
No de compte	

MODALITÉS D'APPLICATION

Tout changement anticipé au protocole de recherche doit être communiqué au Comité qui en évaluera l'impact au chapitre de l'éthique.

Toute interruption prématurée du projet ou tout incident grave doit être immédiatement signalé au Comité.

Selon les règles universitaires en vigueur, un suivi annuel est minimalement exigé pour maintenir la validité de la présente approbation éthique, et ce, jusqu'à la fin du projet. Le questionnaire de suivi est disponible sur la page web du Comité.

[redacted]

Christine Grou, présidente
Comité d'éthique de la recherche en sciences et en santé (CERSES)
Université de Montréal

13 mai 2020
Date de délivrance

1er juin 2021
Date de fin de validité

1er juin 2021
Date du prochain suivi

adresse postale
C.P. 6128, succ. Centre-ville
Montréal QC H3C 3J7

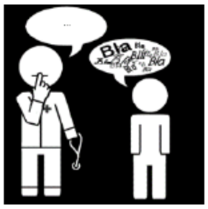
adresse civique
3333, Queen Mary
Local 220-3
Montréal QC H3V 1A2

Téléphone : 514-343-6111 poste 2604
cerses@umontreal.ca
www.cerses.umontreal.ca

Appendix 4: Consent forms

Consent form with people with disabilities and its translated version in Luo

Project title Legislation, health policy and utilisation of sexual and reproductive health services by people with disabilities: A mixed methods study in the post-conflict Northern region of Uganda **Investigators**: Muriel Mac-Seing, Christina Zarowsky, Kate Zinszer, University of Montreal	
Introduction You are invited to join this research study based on your experience of disability in Uganda. Muriel Mac-Seing, a PhD candidate in public health at the University of Montreal is going to conduct this research. In the description of the study, you will be given information about potential benefits and risks that you may experience in relation to the study as well as confidentiality issues. Please take whatever time is needed for you to discuss this research with your family members or anyone else you wish to. The decision to join this research is up to you. **Research objective** In this research study, we are going to look at the relationships between legislation, health policy and utilisation of sexual and reproductive health services by people with disabilities, in the post-conflict Northern region of Uganda.	  
What is involved in this research If you decide to participate, you will be asked to be interviewed and/or participate in a focus group discussion. It will take about 60 minutes for each interview or focus group. We can take breaks during the interview/focus group if needed. You may stop participating at any time you wish. With your permission, the interview will be recorded and transcribed. You will have the opportunity to verify the transcription of the interview in which you have participated. The transcriptions of interviews as well as personal notes will be analysed by Muriel Mac-Seing to find common themes in what you say. The study results will be presented in international conferences and a thematic workshop will be organised in Uganda to share preliminary results. A local research assistant will support Muriel Mac-Seing in the translation. In cases where a local sign language interpreter is needed, this will also be provided to facilitate your participation in the research. Given the invaluable time you are going to provide to answer to the questions, we will compensate you for the expenses related to	  

transportation and time used. Refreshments will be for focus group meetings.	
Potential risks The research could involve minimal risks for participants. There could be some emotional discomfort in recalling some aspects of your own experience. If there are questions to which you wish not to answer, we will not be offended and there will be no negative consequences.	👎
Potential Benefits in taking part of this research This research will give you, as a person with disabilities, the opportunity to share your perceptions on how legislation and health policy are related to the use of sexual and reproductive health by people with disabilities, like you, in the Northern region of Uganda. It will be an opportunity for you to contribute to better understand these relationships and inform national policy-makers and health decision-makers about the research results.	👍
Confidentiality All information you will share with us will be kept confidential (i.e. secret) and protected from any unauthorised disclosure or damage. Your name will be removed from data collected, so we cannot identify you, unless you want your identity to be disclosed. Interview recordings will be transcribed and used by Muriel Mac-Seing. Transcriptions will be kept for 10 years in a locked cabinet in a secured office. Only Muriel Mac-Seing will have access to the office and know your name.	
Your rights as a research collaborator/participant Your participation in this research is voluntary. You have the right to not participate or to leave it at any time. Deciding to not participate or choosing to leave the research midway will not penalise you or harm your relationships with others.	
Contacts for questions or problems If you have any questions or problem about the research, please contact Muriel Mac-Seing [redacted] any time, as needed. For any suspected cases of violation of participants' rights, please feel free to contact Dr. Martin Ogwang, the Chair of the Lacor Hospital Institutional [redacted] email at: [redacted]	?

Consent certificate
I have read the information related to the research or it has been read and explained to me. I voluntarily accept to be a participant of this research.

Name of participant:
………………………………………………………………………………………………

Signature of participant:
………………………………………………………………………………………………

Date:
………………………………………………………………………………………………

Or, a digital (e.g. thumb) print, if the participant cannot sign, with the signature of a witness.

Name of witness:
………………………………………………………………………………………………

Signature of witness:
………………………………………………………………………………………………

Date:
………………………………………………………………………………………………

Statement by the researcher/person taking the consent
I have accurately read out the research related information to the potential participant.

A copy of this information consent form is provided to the participant.

Name of researcher/person taking the consent:
………………………………………………………………………………………………

Signature of researcher/person taking the consent:
………………………………………………………………………………………………

Date: ....

Translation of the consent form for people with disabilities in Luo

Yee me bedo ikwed pi dano ma tye ki goro

Wi lok me kwed

Pen Cik, moko tam me doro yot kum, ki kit ma jo ma gitye ki goro gitiyo kede ki kony me yot kum makubbe ki butu wa ki nywal: Kwed ma kirubu dirone I Kumalo me Uganda inge lweny

Lutim Kwed: Muriel Mac-Seing, Christina Zarowsky, Kate Zinszer, me univasiti me Montreal.

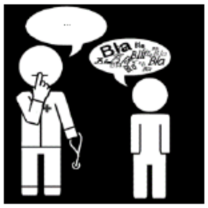
Acaki
Kitye ka lwongi me bedo i kwed man malubbe ki jami ma ikato ki iiye I Uganda macalo ngat ma tye ki goro. Muriel Mac-Seing, ma tye ikwanne me digrii mamalo, onyo PhD ikum yot kum pa lwak i University me Montreal (I Canada) en aye obitimo kwed man. Kibimiini ngec ikum kwed man, lok kum berre wa racce ma itwero nongone macalo ngat muyee bedo ikwed, wa kit ma kibigwoko mung ikumi. Tim ber, ka lok mot ye ma imito nywakone ki lugangwu onyo ngat mo, kwany kareni inywaki. Moko tam me bedo ikwed man, obedo moko tam ma megi.

Tyen lok me kwed man
I kwed man, wabingiyo kit wat matye ikin Pen Cik, cik ma doro yot kum, kimoko, ki kit ma jo ma gitye ki goro gitiyo kede ki kony me yot kum makubbe ki butu wa ki nywal pi jo ma tye ki goro i kumalo me Uganda inge lweny/kukukuku.

Ngo ma bitimme ikwed man?
Ka iyee me bedo i kwed man, wabipenyi lapeny mogo onyo wapenyi me bedo ilwak me nywako lok, matero kine cawa acel. Watwero nongo yweyo ka dano ool Itye agonya me giko gamo lapeny nyo me weko kweda man cawa mo keken
Ka iyee, wabimako dwani, dok wacoyo coc mogo. Ibibedi ki kero me neno ke gin ma kicoyo aye gin ma iwaco. Coc ikum lok ma iwaco, Muriel Mac-Seing aye obingiyo tere me niang ka tye wat mogo ikin lok ma ibedo ka wacone. Adwogi me kwed man kibityerone iguure madito me wilobo pa lukwedkwed, dok guure mogo kibiyubune I Uganda me nywako wiyewiye me adwogi man.

Latim kwed ma latedero obikonyo kor Muriel Mac-Seing ki gonyo leb. Ka inen mitte lagony leb pi luding it, man wabinongone wek okony Bedoni ikwed man.

Kit ma cawa ma ibimiyo pire tek tutwal pi gamo lapeny magi, wabiculi pi acara ma inongo me gin wot wa pi cawa ma watiyo kede. Wabimiyo pii amata mo pi guure me dul.

Peko ma iromo nongone Peko ma kwed man twero kelo ne nok mada pi lubed ikwed. Gwok cwinyi bicwer ka wii opo jami mogo ma ikato ki iiye. K ace inen tye lapeny mo ma pe imito gamone, cwinywa pe bicwer k ape igamo, dok pe bikelo adwogi mo marac.	👎
Ber onyo magoba me bedo ikwed man Kwed man obimiini, macalo ngat ma tye ki goro, kero me nywako nenoni ikum kit ma pen cik ki cik me youtkum gikemo tic ki kony me yot kum makwako yot kum me butu ki me nywal/ot nyodo pi jo ma tye ki goro calo in itumg kumalo me Uganda. Ibibedo ki kero me konyo kor niang matut ikum wat metye ikin-gi, dok bimiyo ngec bot limok cik ki lumok tam pi yotkum makemme ki adwogi me kwed man.	👍
Gwoko mung Wabigwoko imung jami ducu ma inywako kwedwa, dok wabigwokone wek pe giballe dok pe kiwac ata. Nyingi kibikwanyone woko ki ikum lok makatti, wek pe kirom ngeyo ni ibedo ngadi, nikwanyo ka in imito ni dano ongee ni obedo in. Dwan ma wamako ducu lakwed Muriel Mac- Seing aye bikobo ka bigwokone. Coc magi kibigwokogi pi mwaka apar kama kifungu I kabat I opic mo ma Muriel Mac-Seing keken aye room nongone ki ngeyo nyingi.	
Twero ni macalo labed ikwed Bedoni ikwed man tye keekn pien iyee/ijalle me bedo iiye labongo dic. Itye ki twero me bedo iiye onyo me wekone cawa mo keken. Kwero bedo okwed man onyo wekone ki ikor yoo pe kibicimo iye wangi, dok adwogine mo marac peke, pe bibalo watti ki jo mukene.	
Jo ma itwero kubbe kwedgi pi lapeny onyo peko mo Ka itye ki lapeny onyo peko mo ikum kwed man, kubbe ki Muriel Mac- [redacted] Ka itye ki peko mo ma kemo kwed man ma imito titone, itwero kubbe ki Professor Christina Zarowsky, University me Montreal ki Kabedo me kwed iot yat me university me montreal (CRCHUM) ki email bot: [redacted] Ka ibyeko ni kituru twero pa labed ikwed man, bed agonya me kubbe ki Dr. Martin Ogwang, wonkom laloyo Ludor kwed ii ot yat Lacor (Lacor [redacted] onyo Dr. Peter [redacted]	❓

Nyutu atyer yee me bedo ikwed

An dong atyeko kwano ngec makemo kwed man, onyo kikwano, kitito ira. An aye labongo dic mo me bedo ikwed man.

Nying Labed ikwed: ……………………………………………………………………………………………

Keto cing labed ikwed: ……………………………………………………………………………………………

Nino dwe: ……………………………………………………………………………………………

Or, a digital (e.g. thumb) print, if the participant cannot sign, with the signature of a witness.

Nying lacaden: ……………………………………………………………………………………………

Keto cing pa lacaden: ……………………………………………………………………………………………

Nino dwe: ……………………………………………………………………………………………

Lok pa latim kwed onyo ngat ma ojolo yee/jalle pa labed ikwed

An dong atyeko kwanno mabed dok maleng ngec makubbe ki kwed man bot ngat man ma romo bedo ikwed man

Kopi me ngec ki yeyo man limiyo bot labed ikwed.

Nying latim kwed onyo ngat ma ojolo yee me bedo ikwed ki bot labed ikwed: ……………………………………………………………………………………………

Keto cing ngat ma ojolo yee me bedo ikwed ki bot labed ikwed: ……………………………………………………………………………………………

Nino dwe: ....

Consent form with national policy-makers, international organisations, local non-governmental organisations, and health service providers

Project title

Legislation, health policy and utilisation of sexual and reproductive health services by people with disabilities: A mixed methods study in the post-conflict Northern region of Uganda

Investigators: Muriel Mac-Seing, Christina Zarowsky, Kate Zinszer, University of Montreal.

Introduction

You are invited to join this research study based on your involvement and/or contribution to legislation and health policy and/or delivery of sexual and reproductive health services for people with disabilities in Uganda, and in particular in the post-conflict Northern region of Uganda. Your participation to the study is voluntary and you can withdraw from it at any time. Muriel Mac-Seing, a PhD candidate in public health at the University of Montreal is going to conduct this research. In the description of the study, you will be given information about potential benefits and risks that you may experience in relation to the study, as well as confidentiality issues.

Research objective

In this research study, we are going to examine the relationships between legislation, health policy and utilisation of sexual and reproductive health services by people with disabilities, in the post-conflict Northern region of Uganda.

What is involved in this research

If you decide to participate, you will be asked to be interviewed and/or participate in a focus group discussion. It will take about 60 minutes for each interview or focus group. You may stop participating at any time you wish. With your permission, the interview will be recorded and transcribed. You will have the opportunity to verify the transcription of the interview in which you have participated. The transcriptions of interviews as well as personal notes will be analysed by Muriel Mac-Seing to find common themes in what you say. The study results will be presented in international conferences and a thematic workshop will be organised in Uganda to share preliminary results. A local research assistant will support Muriel Mac-Seing in the translation, when needed. In cases where a local sign language interpreter is needed, this will also be provided to facilitate your participation in the research.

Potential risks

The research could involve minimal risks for participants. There could be some emotional discomfort in recalling some aspects of your own experience. If there are questions to which you wish not to answer, we will not be offended and there will be no negative consequences.

Potential benefits in taking part of this research

This research will give you, as a national policy-maker or a representative of international/local organisation or a service provider, the opportunity to share your perceptions on the relationships between legislation, health policy and utilisation of sexual and reproductive health services by people with disabilities in the post-conflict Northern region of Uganda. It will be an opportunity for you to contribute to better understand these relationships, and inform the policy-making process, as well as the service delivery mechanism processes about the research results.

Confidentiality

All information you will share with us will be kept confidential and protected from any unauthorised disclosure or damage. Your name will be removed from data collected so we cannot identify you, unless you want your identity to be disclosed. Interview recordings will be transcribed and used by Muriel Mac-Seing. Transcriptions will be kept for 10 years in a locked cabinet in a secured office. Only Muriel Mac-Seing will have access to the office and know your name.

Your rights as a research collaborator/participant

Your participation in this research is voluntary. You have the right to not participate or to leave it at any time. Deciding to not participate or choosing to leave the research midway will not penalise you.

Contacts for questions or problems

If you have any questions or problem about the research, please contact Muriel Mac-Seing at: +1 [redacted] at [redacted] as needed. For any suspected cases of violation of participants' rights, please feel free to contact Dr. Martin Ogwang, [redacted]

Consent certificate

I have read the information related to the research or it has been read to me. I voluntarily accept to be a participant of this research.

Name of participant:

…………………………………………………………………………………………………

Signature of participant:

…………………………………………………………………………………………………

Date:

…………………………………………………………………………………………………

Statement by the researcher/person taking the consent

I have accurately read out the research related information to the potential participant.
A copy of this information consent form is provided to the participant.

Name of researcher/person taking the consent:

…………………………………………………………………………………………………

Signature of researcher/person taking the consent:

…………………………………………………………………………………………………

Date:

…………………………………………………………………………………………………

Chapter 4:

Appendix 1: Detailed fieldwork activities

Phase 1: Phase-in	▪ Settling down in a temporary accommodation ▪ Introduction to the local stakeholders and exploration of the Lacor Hospital compound ▪ Identification of and exchanges with key knowledge brokers (n=30) ▪ Recruitment process interviews of potential Research Assistant (RA) candidates (n=11) ▪ Research team recruitment: o The orientation of two RAs: one woman and one man, with experience in qualitative data collection and working with people with disabilities o Identification of reliable *boda-boda* (moto-taxi) drivers (n=2) to drive to villages o Identification of qualified local sign language interpreters (n=3) ▪ Elaboration with RAs of a glossary of key research and SRH vocabulary in English and Luo/Acholi languages ▪ Field testing of the interview and focus group guidelines for people with disability, with people with different types of impairments ▪ Start and maintenance of a methodological and reflexivity logbook
Phase 2: Data collection	▪ Courtesy visits to all District Commissioners, Medical Officers (DHO), and Community Development Officers (DCDO), and obtention of official permissions to collect data in target districts ▪ Meeting with local disabled people's organisations (DPOs) and organisations working for people and children with disabilities (n=6) ▪ Community mobilisation by Village Health Teams (VHT) of health facilities and volunteers with disabilities ▪ In-depth semi-structured interviews of people with disabilities (n=32) and focus groups (n=2) ▪ 50.2 hours of recording and 956 pages of transcription completed ▪ Preliminary visits and non-participant observations of health facilities (n=7)
Phase 3: Phase-out	▪ Courtesy follow-up visits to all DHO, DCDO, and Commissioners to provide feedback and present preliminary findings ▪ Organisation of preliminary finding presentations (n=5), including to the community of DPOs ▪ Organisation of a 2-day orientation training on disability-friendly health service provision to more than 30 health staff and managers of health facilities (n=6). Co-facilitators were four people with disabilities and two sign language trainers (one of whom is deaf) ▪ Farewell to partners and stakeholders, and host community at the Lacor Hospital

Appendix 2: COREQ Checklist

Domain 1: Research team and reflexivity	
Personal characteristics	
1. Interviewer/facilitator	Yes
2. Credentials (of researchers)	Yes
3. Occupation (of researchers at the time of the study)	Yes
4. Gender	Yes
5. Experience and training	Yes
Relationship with participants	
6. Relationship established	Yes
7. Participant knowledge of the interviewer	Yes
8. Interviewer characteristics	Yes
Domain 2: Study design	
Theoretical framework	
9. Methodological orientation and theory	Yes
Participant selection	
Sampling	
10. Method of approach	Yes
11. Sample size	Yes
12. Non-participation (from selected sample)	None
13. Setting of data collection	Yes
14. Presence of non-participants	No
15. Description of sample	Yes
Data collection	
16. Interview guide	Yes
17. Repeat interviews	No
18. Audio/visual recording	Yes
19. Field notes	Yes
20. Duration	Yes
21. Data saturation	Yes
22. Transcripts returned	No
Domain 3: Analysis and findings	
Data analysis	
23. Number of data coders	Yes
24. Description of the coding tree	No but available
25. Derivation of themes	Yes
26. Software used	Yes
27. Participant checking	Yes
Reporting	
28. Quotations presented	Yes
29. Data and findings consistent	Yes
30. Clarity of major themes	Yes
31. Clarity of minor themes	Yes

Chapter 6:

Appendix 1 : PRISMA Checklist

PRISMA Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	1
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	2-4
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	4-5
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	4
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	5
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	5
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	5
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	5
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	6

Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	5
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	5
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	N/A
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	5

Section/topic	**#**	**Checklist item**	**Reported on page #**
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	5
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	7
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	7-10
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	10-11
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	N/A
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	N/A
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	N/A
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	N/A
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	11-15

Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	15-16
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	17-18
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	Title page

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