



Analysis and Reflection on Sexuality and Disability: A Literature Review

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Statement of Authenticity:

"This dissertation is an original and authentic piece of work carried out by myself. I have fully acknowledged and referenced all secondary sources of information. It has not been presented in whole or in part for assessment elsewhere. I have read the assessment regulations and am fully aware of the potential consequences of any breach of them."

Signed:

A handwritten signature in blue ink that reads "Maritke Lehmann". The signature is written in a cursive style with a horizontal line underlining the name.

Date:

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Abstract

This study explores the topic of disability and sexuality, focusing on three objectives, namely, the experiences of people with disabilities in relation to sexuality, what barriers they may experience and what improvements could be made with regards to practice in supporting people with disabilities to develop sexual and intimate relationships. The dissertation is based on the research question as to how intimate citizenship has developed for people with disabilities in the last 20 year.

The study employs the secondary research approach of a literature review, using thematical analysis to organise themes occurring from the literature review. The research articles included in the literature review are contemporary going back no further than the year 2000. Furthermore, the literature originates in various countries, including Malta, Russia, Poland, United Kingdom, Ireland, United States, Canada, Portugal, Sweden, Ethiopia and the Netherlands. All literature used in the literature review relates to disability and sexuality.

The findings of this study highlight that people with disabilities often feel that they are not listened to and not taken seriously as adult people with adult needs and wishes. Furthermore, the findings underscore that people with disabilities still experience stigma and discrimination in relation to their sexuality. The findings also highlight that there are issues around practice due to the fact that people with disabilities feel restricted in exercising their rights and in making choices regarding their private lives.

The recommendations of this study include implications for further research, especially Scottish and participatory research. Regarding practice, the study suggests that people with disabilities should be more included in the decision-making process regarding policymaking and developing legislation in relation to sexuality.

Keywords: Learning Disability, Intellectual Disability, Disability, Intimacy, Sexuality, Rights, Romantic Relationships.

Chapter 1

Introduction

This dissertation discusses the relationship between disability and sexuality, using the methodological approach of a literature review. The dissertation is structured in 7 chapters, as outlined in the list of contents, starting with an introduction of the key issues, terminology and background of this study. The second chapter outlines the research question, rationale, aims and objectives. This is followed by a chapter explaining the methodology used in relation to this research project. The main parts of this dissertation are the chapters which contain the literature review and the discussion and analysis, accordingly, weighing more in terms of wordcount. The dissertation concludes with outlining the limitations of the study and a conclusion and recommendation chapter.

The study explores the experiences of people with disabilities in relation to developing intimate or sexual relationships. By researching this subject, I hope that the issues faced by people with disabilities with regards to developing intimate and sexual relationships will be highlighted, thereby raising awareness for the need to improve practice with regards to supporting people with disabilities to develop intimate and sexual relationships.

Terminology

Slesser (2018) explains that although 11,6 million people of the UK population in 2014 were registered as disabled, people with disabilities are a minority group and therefore subject to discrimination.

One discriminating factor can be the use of language and terminology regarding people with disabilities. Millar (2010) stresses that language can be utilised in an oppressive manner to identify, demean, and therefore oppress those that are different. Furthermore, power is often applied by categorising or naming groups to make them visible which promotes social marginalisation (Yuill et al. 2011). This is why I would like to avoid using labelling language when referring to people with disabilities. To further explain the terminology, the following definitions of disability will bring more clarity.

The Union of the Physically Impaired Against Segregation (UPIAS) (1976, p. 3-4) offers the following definition of impairment and disability:

- Impairment: Lacking part or all of a limb, or having a defective limb, organ or mechanism of the body.
- Disability: The disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities.

This means that essentially disability is not about impairment or physical difference, much rather it is about a power struggle that lies within a conjunction of relationships where people who possess an impairment are denied access to resources due to deeply engrained negative social attitudes (Slesser 2018).

Another definition is offered by the Convention on the Rights of Persons with Disabilities of the United Nations (2008), hereafter referred to as CRPD, which states in Article 1, p.4 that 'persons with disabilities include people

who have long term physical, mental, sensory or intellectual impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others’.

To avoid negative labelling of disability I would like to use the term ‘disabled person’ and ‘people with disabilities’ in this dissertation. According to Yuill et al. (2011, p.166) these terms maintain the ‘human or person aspect’ of disability while at the same time not dismissing the reason why this particular group of people is discriminated against.

Social Work Research

According to the Dissertation Handbook (Robert Gordon University 2020) the dissertation allows students to look critically and in-depth at a topic which is of special interest to them. The Dissertation Handbook (Robert Gordon University 2020) notes that it is expected that students are working independently on their dissertation whilst showing initiative and exhibiting self-motivation. Carey (2013, p.2) defines social work research as a ‘planned, cautious, systematic and reliable way of finding out or deepening our understanding of a selected topic or theme’.

Kiteley and Stogdon (2014) stress that there is an increasing demand for social work research to establish evidence-based findings to inform and improve social work practice. This is closely related to the term ‘evidence-based practice’, as it refers to the application of research knowledge to practice (Aveyard 2019). According to Carey (2013) social work research also has the benefit of supporting social workers to become better practitioners as it helps to understand and fully appreciate the social need that social workers aim to meet. Another benefit of doing research is that it helps the researcher to become more reflexive, because it encourages the researcher to look critically at his or her beliefs, values and practices in relation to principles and activities of related organisations, other professionals and colleagues (Carey 2013).

Background

I am working in a housing-support service for adults with disabilities. Therefore, I have developed an interest in exploring the issues around people with disabilities accessing certain rights. I have been working in this field for the last eight years and have experienced various examples of inequalities in relation to how people with disabilities struggle to exercise their rights regarding sexuality. One example in particular awoke my interest in relation to this topic. This example involves two of our residents with additional support needs, who decided to get married which resulted in one of them losing their disability benefits. This incident raised a lot of questions for me e.g. why do people with disabilities have to choose between keeping their benefits or the opportunity to marry the person they love? Does the social care system assume that people with disabilities have no additional support needs anymore after they get married? Most likely not. However, while the questions persist, this incident triggered a thinking process about disability and human rights, focusing on sexuality and intimate relationships.

In this context I would like to explain the term 'intimate citizenship' as it is central to the research question and will be discussed in more detail later on. Intimate citizenship involves the examination of rights, obligations and respect of the most intimate areas of life (Plummer 1995). The term relates to questions regarding all aspects of intimate issues such as relationships, living arrangements, gender and how to relate as a gendered being, raising children, how to handle one's own body and eroticism (Plummer 1995). I would like to stress that as Rogers (2016) explains, sexuality, intimacy, pleasure and relationships are an important part of human life and everyone should be able to experience these aspects of life. The underpinning idea of this dissertation is therefore based on equality as everyone should have equal opportunities to develop their abilities to their full potential (Thompson 2014). However, equality does not mean uniformity or the

assumption that everyone should be treated the same. Everyone is different and has different needs depending on their circumstances, including resources such as education or employment as well as the physical and social environment e.g. family and friends (Thompson 2014). Therefore, the term 'equality' refers more to treating everyone with equal fairness rather than treating everyone the same (Thompson 2014). The concept of equality therefore runs throughout the dissertation, focusing especially on the experiences of people with disabilities, implementations for practice and potential barriers as will be outlined in the next chapter.

Chapter 2

Rationale, Aims and Objectives

Rationale

Carey (2013) stresses that most research topics emerge from the identification of a recognised social work problem that needs to be improved or resolved. Dominelli (2002) argues that social workers should engage in researching equality and social justice issues, especially on behalf of less powerful and minority groups such as women, ethnic minority groups or people with disabilities. Therefore, my choice of research can make a valuable contribution in social work research considering it explores the inequalities that people with disabilities experience in relation to their private and intimate lives. Addlakha et al. (2017) stress that although people with disabilities have the same rights to sexual desires and hopes as non-disabled people, society has paid little attention to the sexuality of people with disabilities and has failed to recognise their aspirations and human rights in this area of life. Abbot and Howarth (2006) emphasise another important issue experienced by people with disabilities experience in this area of life, and that is the lack of support from services regarding

the development of a sexual identity and intimate relationships, as well as sexual experiences.

I hope that by undertaking this kind of research I can contribute to a vital discussion and fill a gap in the research around sexuality and disability. For, as Rogers (2016) stresses, not a lot of sexuality research has been conducted yet in relation to intellectual disability and relationships or the importance of friendships, including intimate friendships. Furthermore, my research in this area of practice has the potential to provide better understanding as to why the rights regarding sexuality of people with disabilities are not as recognised within society as the rights of people without disabilities.

Research Aims

The aim for this research project is to explore the relationship between disability and sexuality, how people with disabilities can exercise their rights with regards to sexuality and what barriers inhibit them from exercising those rights.

Objectives

- 1) Explore the views and experiences of people with disabilities regarding sexuality and the development of intimate relationships
- 2) Explore what, if any, barriers inhibit the development of intimate relationships or sexual experiences for people with disabilities
- 3) Explore what, if anything, needs to change in the area of practice to support people with disabilities to develop intimate relationships and to enable them to have sexual and intimate experiences

Research Question

How has intimate citizenship for people with disabilities developed in the last 20 years?

Chapter 3

Methodology and Ethical Issues

Methodology

For this research project I have chosen a literature-based research approach. Carey (2013) explains that literature-based dissertations are more time consuming, yet the researcher can go into more depth whereas empirical studies are perceived as more difficult to control and predict as they depend on other people to gain access to interview. A disadvantage of doing a literature review is that no new data will be collected (Carey 2013). Nevertheless, Aveyard (2019) stresses that literature reviews are equally as important as empirical research projects, because reviewing a body of research allows new conclusions to be made, providing reliable evidence for future policy developments. However, my decision regarding methodology was however based on the current situation arising from the COVID-19 pandemic, which made it impossible for me to undertake an empirical piece of research due to the fact that most of the potential interviewees were shielding.

In terms of inclusion and exclusion criteria, I have mainly included empirical research articles in this dissertation, with one exception. I have included one secondary research article by Block et al. (2012) because the authors have included two individuals with autism as co-authors in their article. By doing that the authors gave both individuals the opportunity to take initiative and to share their experiences around facilitated dating. The

literature chosen for the literature review has been peer-reviewed with one exception, that is a master's thesis by Greenwood (2019). I have included this thesis in the literature review because it is contemporary and relevant to my research question. Only research articles that have been published after the year 2000 have been included in this dissertation. Furthermore, only literature relating to the research question has been selected. The research studies that have been used in the literature review have been sourced in various countries including Malta, Russia, Poland, United Kingdom, Ireland, United States, Canada, Portugal, Sweden, Ethiopia and the Netherlands.

The keywords used in the search for relevant literature included 'disability or intellectual disability and sexuality', 'learning disability and sexuality', 'disability and intimacy', 'disability and sexuality', 'disability rights', 'disability and intimacy', 'disability and romantic relationships'. Appropriate Boolean operators such as 'AND' and 'OR' were used in the search for literature as well. The databases that have been used in the search for literature as follows: EBSCOhost, Google, Google Scholar, Oxford Academic Social Work Research, Research Gate, RGU Library Catalogue and Electronic Databases, Routledge, SAGE Journals Online, SOCIndex, Springer, Taylor and Francis, Wiley Online Library.

The literature review has employed a comprehensive and systematic approach rather than attempting it to be a systematic literature review, as according to Aveyard (2019) a systematic review is one of the most detailed and robust forms of reviews and therefore beyond the scope of a student-researcher. To achieve a systematic approach, one must consider a research question, a rationale, aims and objectives, a methods section, results and findings and recommendations for practice (Aveyard 2019). This is what I have attempted to do in my literature review.

With regards to appraising the literature, I have made use of the critical appraisal skills programme (CASP) which is a useful tool to screen literature for its rigour, methodology, relevance and credibility (Public Health Resource Unit 2006). According to Kiteley and Stogdon (2014) a literature review demands the same critical appraisal and logical analysis as any information processed in social work practice. According to Carey (2013) critical appraisal focuses very much on explaining social disadvantage, discrimination, forms of social injustice and inequality that are associated with race, gender, disability or class which appears to be appropriate for the research topic I have chosen.

In terms of data analysis, I have used thematic analysis to generate the main findings from the reviewed literature; I have organised it into different themes dependent on how directly the literature reflects the research question (Aveyard 2019).

Ethical Issues

Social work practice is based on interactions and structures which can have a positive impact on people, however, there is a potential for the outcome of these interactions and structures to be harmful (Thompson 2014).

According to the Code of Ethics by the British Association of Social Workers (2014), also referred to as BASW, the ethical awareness is fundamental to the social work profession because a lack thereof has a direct impact on the quality of service provision. Therefore, a commitment to promote social justice and respect human rights is at the core of social work practice (BASW 2014).

To promote ethical practice, it is important to consider questions of morality and values to ensure that we as professionals are clear about how our own personal bias and values as well as professional values of social work affect our practice (Banks 2006). In relation to social work research this means that before starting a research project all possible sources of harm have to be considered, especially when the research project involves a potentially

vulnerable group of people (Bell 2007). As required by the Research Ethics Policy of Robert Gordon University (2016), I have given consideration to all potential ethical issues. Also, by conducting a literature review I have prevented any potential social harm caused by the sensitivity of the research topic.

As well as protecting the participants of a research project, the codes of ethics also help researchers to be more accountable for their utilised research techniques and their dissemination of their findings, which reduces the risk of malpractice, dishonesty and abuse (Carey 2013). This is why I believe I have presented all data in an accurate and true manner as well as having ensured that all sources have been referenced appropriately.

I am aware that due to the fact that I am working with people with disabilities I have a personal and professional interest in this area of research. Furthermore, due to the fact that I feel quite connected to the research topic I have recognised that I have my own bias in this area of work. This is why it is important to remember to think critically when exploring and investigating any research problem as Carey (2013) suggests. It is important to be aware of how one's own bias can influence the direction of a research project and how it can undermine the project if the researcher is led too strongly by their own bias (Carey 2013). Therefore, I have attempted to be as open minded as possible throughout the research process.

Throughout the research process I recognised the value of critical reflection, which has helped me to recognise my bias and expectations regarding the research process. It has also helped me to deal with the challenge of working in the front-line through a pandemic while at the same time adhering to the expectations of the role as a researcher and student. The models I have used for critical reflection included Kolb and Fry's learning cycle (1975) to reflect on the different stages in my dissertation process

and Gibbs' model of reflection (1988) to reflect on my feelings and state of mental health (Bolton 2014).

Chapter 4

Literature Review

Introduction

This literature review explores the experiences of people with disabilities in relation to their sexuality and the barriers that many people with disabilities encounter in their sexual development. Three themes have been identified through thematic analysis, namely 1) views and experiences of people with disabilities regarding sexuality, 2) barriers that inhibit the development of intimate relationships or sexual experiences for people with disabilities, and 3) implementations for practice. Within the first theme two sub-themes have become apparent, namely 1) positive experiences and 2) negative experiences. The same applies to the third theme where the two sub-themes are 1) sociological barriers and 2) lack of sex education. Accordingly, the literature has been reviewed within the themes and sub-themes.

Experiences around disability and sexuality

Positive Experiences

Stoffelen et al. (2018) conducted a research project in the Netherlands, using Nominal Group Technique as a means of data collection. Nominal Group Technique employs both qualitative and quantitative measures which offers a structured form of group research. The research aims were to explore what is important to people with disabilities in relation to sexuality. The study involved 39 participants, both male and female, aged between 23 and 70 with an average age of 44 years. The participants were recruited

from a Dutch self-advocacy group. The study found that people with disabilities are capable of expressing what is important to them with regards to sexuality. Feeling comfortable and safe, lovemaking, sex education and the relationship between two people were aspects that featured as important to participants in this study.

Another participatory research study was undertaken by Richards (2017) in England. The study explored the perspectives of 30 local men with disabilities, aged between 28 and 65. The study was conducted in relation to health promotion and to explore what it means to be gay with disabilities, using visual methods like art, poetry, drama, sculpture and photography. The outcome of the artistic projects was that the participants felt the need to be listened to more as they have knowledge and experience to share in relation to health promotion. The artistic workshops provided a tool for the participants to express their views and feelings and to make their voices heard.

Callus (2016) undertook a small-scale research study in Malta to explore the meaning of friendship to people with disabilities and their experiences around friendship. Data for the study was extracted from focus groups. The researcher used purposive sampling to recruit the participants for the focus groups. The participants were people with disabilities and all of them came from the same self-advocacy group, which in total were 7 people. The researcher knew the participants beforehand through working together in previous self-advocate initiatives and the study took place in an environment with which both the researcher and the participants were familiar. The findings of the study showed a common theme of reciprocity in the relationships which the participants identified as friendships. The participants felt that friendships are the kind of relationships that make them feel valued and that enables them to interact and spend time with people they like.

Lafferty et al. (2013) conducted a research project in Ireland, using grounded theory in their study to explore the meaning and nature of close personal relationships of couples with disabilities. Eight heterosexual couples were recruited for the study via three different service providers. The researchers undertook 24 face-to-face semi-structured interviews. The research findings captured features of what close relationships mean to people with disabilities such as being together, experiencing happiness and contentment, the feeling of reciprocity and mutual support when going through ups and downs in the relationship and lastly, commitment and continuity. Further findings indicated that close relationships enhance the self-esteem, independence and self-confidence of people with disabilities.

An American article by Block et al. (2012) discusses the theoretical perspective of sexuality and disability and how these relate to occupational therapy research. The authors have involved Hope and Jacob, two autistic adults as co-authors in the process of this article. Block et al. (2012) describe Hope and Jacob's experiences with facilitated dating. Hope and Jacob communicate through an alternative way of communication, referred to as facilitated communication (FC) or facilitated typing. A certain level of contact is needed between the person who is typing and another supporting individual to facilitate this form of communication. Hope and Jacob expressed that without support they would never see each other. Both are of the view that facilitated dating is wonderful because it enables them to have a relationship, however it has some disadvantages as they are both dependent on other people to be together and that means that if staff is unavailable they cannot be together.

Negative Experiences

Callus et al. (2019) conducted an inclusive research project in Malta with a group of disabled people to explore the notion of overprotection in the lives of people with disabilities. The researchers conducted focus groups, first with a group of people with disabilities who still live with their parents and afterwards with a group of representatives from various organisations working in the social care sector. The findings of the study showed that people with disabilities often experience being held back by their parents which hinders their ability to live an independent life and to make their own choices and decisions. The study also found that the experience of overprotection for people with disabilities also affects their ability to develop intimate relationships as either parents do not support their adult child to have intimate relationships or their relationships are viewed as something 'cute' and childlike (Callus et al. 2019, p.355).

Rogers with Tuckwell (2016) conducted a small-scale participatory research project in the UK, exploring emotional and socio-political questions in relation to what it means to be human. The study was about exploring how young disabled people make sense of their intimate, emotional and relationship experiences and how parents and carers engage with the sexual identities and relationships of their adult children. The outcome of the study was that the experience of intimacy and friendship for people with disabilities has been storied in a careless way, leaving people with disabilities without care, lonely and dehumanised. Furthermore, the study shows that people with disabilities do not always understand the cultural or social context within which they live in and that they need support to mediate such intimacies.

Fitzgerald and Withers (2011) have conducted a research project in the UK, to explore what women with disabilities think about sex, sexuality and themselves. The sample for this this project involved 10 women, all

identified as White British, with disabilities who were aged between 19 and 64. Data was collected through a semi-structured interview schedule. The study found that participants struggled to develop positive sexual identities and had mostly negative views and thoughts about sex and sexuality. Nevertheless, the experiences of women with disabilities shared in this study showed a huge variety which indicates the need for more research about how women conceptualise themselves as sexual women before looking at the development of sexual identities.

Another research study about experiences of lesbian, gay and bisexual (LGB) people with disabilities and the views of the staff was conducted by Abbot and Burns in England (2007). The research project aimed to give an insight into the lives of LGB people with disabilities in the UK. In the first stage of the study 71 staff from 20 different service settings were interviewed across the UK. In stage two of the study 20 people with intellectual disabilities were interviewed. The outcome of the second part of the study showed that LGB people with disabilities have a strong desire to experience intimate relationships and that they would want to be supported in realising this. However, the outcome of the staff interviews showed that supporting LGB people with disabilities in intimate relationships did not feature strongly in staff goals.

Rogers (2009) based in England, conducted a research study exploring the lived experience of her disabled daughter Sarah in relation to sexuality, using an auto ethnographical approach. In this study Rogers (2009) addresses issues such as disability, sexual experimentation, education, governance and responsibility. The study found that normalisation and infantilised identities influence the relationships of young women with disabilities, their health and their sexual identity. Furthermore, the study found that there is a paternal tension between giving young disabled people the liberty and autonomy they need to pursue an intimate and sexual life,

whilst at the same time parents feel they have the responsibility to protect their adolescent children from harm and exploitation.

Barriers that inhibit people with disabilities to develop intimate relationships or to experience sexuality and intimacy

Sociological Barriers

Iarskaia-Smirnova and Verbilovich (2020) explore how disability and sexuality are represented in the Russian media and how disabled people understand these representations. The article analyses how contemporary Russians with disabilities narrate their own lives in public forums, in combination with primary data from journalists and disability activists with and without disabilities. By telling stories about personal experiences regarding sexuality and disability, the voices of people are heard. Sharing these stories allows emancipation for people with disabilities. The article shows that even in conditions that to all intents and purposes silencing and where the sexuality of people with disabilities has become the object of social control and power manipulations, some people may speak up openly and share their experiences, providing the opportunity to reflect on cultural understandings of sexuality and disability in contemporary Russia.

Santos and Santos (2018) conducted a research project in Portugal, exploring the notion of what they describe as misfit sexual bodies through biographical interviews with disabled women. The article draws from feminist disability studies as well as empirical data from biographical narrative interviews with disabled Portuguese women. The women's stories give an insight into the struggle of sexual fulfilment and recognition. These stories call for a change in how society, mainstream literature, institutions and the state addresses sexuality and disability. Furthermore, the authors found that heteronormative, discriminatory and oppressive understandings

of sexuality and disability prevent disabled women from being recognised as sexual citizens.

Tefera et al. (2017) conducted a research study exploring the way disabled women contend with societal denial of intimacy, pregnancy and motherhood in Ethiopia. The authors employed an analytic qualitative approach, conducting inductive semi-structured, in-depth, face-to-face interviews with 13 female participants. The authors found that most of the interviewed women felt that society does not support them in having intimate relationships with someone, nor to become a wife and mother. Another research finding displayed the challenge of accessibility of health centres and the negative attitudes of health professionals towards women with disabilities. Nevertheless, the interview data did indicate that intimacy and becoming a mother or wife was an empowering experience for women with disabilities.

McCarthy (2016) undertook a research project in England with a group of people with different disabilities. The study focused on the relationship between disability and sexuality for people who receive informal care by family members or partners. McCarthy (2016) employed a methodology using case studies and semi-structured face-to-face interviews. The interviews were conducted between the years of 2012 and 2013. Participants were recruited through a 'gatekeeper' to enable trust and to reassure participants that the research process was legitimate. Other means of recruitment used in this study were online forums to enable people with mobility issues to partake in the research project. The study found that people with disabilities experience stigmatisation, a lack of independence and pressure of informal care; all of which have a limiting effect on the sexual self of people with disabilities.

Ignagni et al. (2016) conducted a dialogue about intimate citizenship between people from different backgrounds such as self-advocates labelled

as disabled, academics, students, Aboriginal leaders and artists. The authors share a Global North location, which is a platform where the rights and responsibilities of people who can call themselves citizens are being constantly contested. The authors wrote this paper from Canada and England. Inclusive workshops were facilitated around the themes of love, intimate work and consumption. The outcome of the workshops showed that people with disabilities found they are 'not allowed to love' (Ignagni et al. 2016, p.133). Further results showed that people with disabilities are often not seen as people who care but rather as people who are cared for. Lastly, people with disabilities shared that material deprivation is a limiting factor in relation to intimate citizenship, as intimate citizenship requires forms of consumption such as the things we buy, shop or consume in order to be intimate with ourselves or someone else.

Lack of sex education

Greenwood (2019) conducted a research project for her master's thesis, exploring intimacy and sexuality in people with Down Syndrome with a focus on assessing parental attitudes, sexual knowledge and romantic experiences. The study took place in California, USA, and used a questionnaire as means to collect data with selected questions from the Sexual Behaviour Scale by Ginevra et al. (2016). Data was analysed using statistical analysis. Ninety-four female participants took part in the survey. The results of the survey show variables in relation to age, gender and the level of development in a child with Down syndrome. The study found that mothers are somewhat willing to support their child in having intimate relationships, however they would rather not leave their child and romantic partner unsupervised. Greenwood (2019) suggests that not only people with Down syndrome should receive adequate sex education, but that it is equally important that health care professionals, parents and carers understand the issues regarding sex and romance faced by people with Down syndrome.

Kijak (2013) conducted a study in Poland with 133 people with disabilities aged between 18 and 25. The study took place in 11 schools and special institutions. The research aim was to explore the level of sexual development of people with a higher degree of disability, their level of understanding in relation to sexuality and what forms of sexual activity are taken up by those with a higher degree of disability. The methods of data collection in this study included interviews with health professionals according to J.M. Tanner's scale and interview questionnaires with participants. The qualitative results of the study showed that people with a higher degree of disability have sexual experiences but show a lack of knowledge of human sexual life. Kijak (2013) found that masturbation and petting were the most popular and common ways to experience sexuality for people with disabilities. Furthermore, the study showed that the lack of knowledge regarding sexuality and how to express sexual needs appropriately resulted in pathological forms of masturbation with serious consequences for health and life.

A two-year study was conducted by Bernart and Ogletree (2012) in Ohio, USA. The study explored how women with disabilities perceive sexuality and how it features in their lives. The researchers employed an ethnographic approach to their research project, using formal and informal observations and interviews as a source of data. Fourteen women with disabilities aged between 18 and 89 participated in the research project. The women were recruited from four different agencies in the Midwest of the United States. 20% of the population in this area is known to be living in poverty. The outcome of the study was that due to a lack of education and knowledge, most women associated sex with something negative e.g. fear of the first act, negative consequences, physical concerns and a perceived lack of pleasure. This resulted in most women having some, but very limited, sexual experiences.

Wright (2011) conducted a small-scale research project in North Tyneside, England, with young people with disabilities and their parents, healthcare professionals and teachers to explore the development of sexual relationships. Wright (2011) employed a purposive sampling strategy with regards to sampling young people with disabilities from one local authority team working with children with disabilities. Young people with disabilities aged between 11 and 16 were approached to participate because they were receiving sex education. The participants involved in this study were four young people with disabilities and their parents, two teachers and two nurses. Individual semi-structured interviews were conducted with the young people and their parents, whereas group interviews were held with the nurses and teachers. Information used in the interviews with the young people was produced in Communicate in Print which is a system that assists verbal communication. The study found that although professionals are committed to provide relevant and appropriate information and are convinced the delivery of sex education is adequate, young people with disabilities have a limited understanding about sex education and harbour misunderstandings about the information that has been given to them.

A research study conducted in Canada by Esmail et al. (2010), explores the societal perceptions and attitudes towards sexuality and disability, using a qualitative approach. The researchers conducted focus groups involving people with visible disabilities, people with invisible disabilities, service providers and the general public. As a tool to help stimulate conversation the researchers used a documentary called 'Sexuality'. The research findings highlighted that people with disabilities experience stigma due to a lack of education and information around disability and sexuality, resulting in a common view of people with disabilities as asexual. The researchers have indicated the need for further research as to how to best inform and educate all members of society.

Kelly et al. (2009) undertook a research project in Ireland exploring the views of people with disabilities on relationships and sexuality and what sort of support they would like in this area of their lives. In total 15 adults with disabilities, both women and men, participated in the project. Data for the study was contracted from focus groups. The study found that people with disabilities have a limited sexual understanding due to a lack of sex education. Furthermore, the study found that the lack of sexual knowledge puts people with disabilities in a disadvantaged position to negotiate their sexuality. Participants in this study expressed their need for assistance in this area of their lives and their wish to be trusted to form intimate relationships.

Implementations for Practice

Vehmas (2019) conducted a research study in Sweden to explore sexuality and rights for people with profound and multiple disabilities. The study is based on fieldwork data from ethnographic observations and interviews between the years of 2015 and 2016, carried out by Dr Mietola and Dr Miettinen. The study by Vehmas (2019) found that sexuality should be included in the care of people with profound and multiple disabilities just as any other matter considered necessary to enhance human growth. The study furthermore found that the only ethically feasible way of experiencing intimacy and sexuality for people with profound and multiple disabilities would be masturbation and as a matter of fact some of the participants would need assistance in doing so.

A research project conducted by Linton and Williams (2019) explored how to sustain an intimate and sexual relationship with a disability in older adulthood from a social work perspective. The study used convenience and snowball sampling to recruit participants from three different metropolitan cities in America. All participants were social workers working with older people with disabilities. Inductive semi-structured interviews were used to collect data about lived professional experiences of working with older

couples with disabilities. The authors of the study found that the role of social workers included supporting clients to learn about their sexual abilities, consenting to sex and finding appropriate accommodation for intimate and sexual experiences.

Turner and Crane (2016) conducted a qualitative case study in America to explore how people with mild disabilities experience their social-sexual lives. The method used by the authors involved a qualitative case study which was informed by heuristic inquiry. Participants included three men and two women between the ages of 21 and 54, all of them identified as heterosexual. The authors used semi-structured interviews and observations to collect data. The research findings displayed two main themes which were pleasure and sexual voice. Participants expressed that pleasure is important to them and that often they are not asked about matters relating to their sexuality. Furthermore, the study suggests implications for disability professionals and sexual health professionals, stressing the need to include sexuality in clients' annual planning meetings and to recognise that there is a need for increased support to promote quality of life.

Hollomotz and the Speakup Committee (2008) have conducted a participatory research project in England with a group of 15 self-advocates with disabilities. The research aimed to explore how privacy is pursued in residential group settings. The research project was conducted courtesy of an alliance between the researcher and people with disabilities, involving participants in all stages of the research process. The research found that participants were not allowed to invite other people to their bedrooms and therefore experienced a lack of privacy in their bedrooms. The study further showed that there was a discrepancy between the service priorities and the priorities of people who use services. Therefore, the study suggests that certain points should be considered, namely, the contractual agreement between service provider and service users, using independent advocates,

the role of staff who support service users, the facilities and implementing possible safeguards and how services can support people with learning disabilities to use their private spaces to see other people privately.

Conclusion

The 11 research articles which have been reviewed within the first theme have been sourced from England, Ireland, the Netherlands, Malta and the United States. Nevertheless, the research from English sources appear to dominate this theme with five articles originating in England. This indicates a need for more research regarding sexual experiences of people with disabilities across the world.

Regarding the second theme, the narrow range of research articles being reviewed in this theme may indicate a research gap with regards to practice implementations in relation to supporting people with disabilities to develop intimate and sexual relationships.

Finally, it has become apparent that a range of research from various countries and institutions has been conducted on potential barriers that inhibit people with disabilities from developing intimate and sexual relationships. Furthermore, the literature review has shown that although research regarding sexuality and disability has been conducted in the UK, as yet no Scottish research has been conducted in relation to this subject. The findings of the literature review will be discussed in detail in the following chapter.

Chapter 5

Discussion and Analysis

Introduction

This section provides an analysis and discussion of the findings of the studies that have been reviewed in the previous chapter. The studies have been brought together in three main themes, namely 1) views and experiences of people with disabilities on sexuality, 2) implementations for support and practice, and 3) barriers that inhibit people with disabilities from experiencing sexuality and developing intimate relationships. As mentioned previously in the literature review, a few sub-themes have become apparent after reviewing the literature. Therefore, the discussion and analysis will be structured according to the three main themes and sub-themes. The analysis will address the objectives of this study which have been outlined in chapter two.

Views and Experiences of people with disabilities on and around sexuality

Positive Experiences

The literature has found that there is a strong wish amongst people with disabilities to experience sexuality and intimacy and that relationships are important to people with disabilities (Stoffelen et al. 2018, Richards 2017, Callus 2016, Lafferty 2013, Block et al. 2012). Furthermore, the literature has found that friendships and sexual or intimate relationships have a positive impact on the self-esteem and self-confidence of people with disabilities (Callus 2016, Lafferty 2013).

Despite the paper by Block et al. (2012) not being a primary research article, the experiences by Hope and Jacob are valuable in this context as they give an insight of the challenges around dating that people with autism and communication issues encounter in their daily lives. Facilitated communication and dating enables people with communication issues to express themselves and build relationships as it enabled Hope and Jacob to build a real relationship, sharing intimacy and love (Block et al. 2012). The disadvantage with facilitated dating however is that people like Hope and Jacob are completely reliant on others to help them develop and sustain a relationship, especially challenging when staff is unreliable or does not recognise the importance of facilitated meetings for the people involved (Block et al. 2012).

Particularly valuable are the studies by Stoffelen et al. (2018) and Richards (2017), because people with disabilities were included in the whole research process and were able to actively promote their views and experiences. Inclusive research projects are therefore an example of providing opportunities for people with disabilities to actively make a difference in potential future social work practices and service provision, as Mackay (2010, p. 178) stresses, 'having a say' is what can influence change and improvement.

Promoting positive experiences in the lives of people with disabilities is one of the main focuses in the Keys to Life Strategy as it recognises the importance of social interactions and building relationships to encourage the development of social skills and to prevent social isolation (Scottish Government 2013). The Keys to Life Strategy furthermore acknowledges that people with disabilities have a right to choose their friends and to be in control in relationship situations (Scottish Government 2013). Making meaningful connections and building friendships can help people with disabilities to feel included in the local community, to be socially accepted and to achieve an ordinary life (Williams and Evans 2013).

Negative Experiences

Other experiences that people with intellectual and learning disabilities shared included dehumanising, infantilising experiences, overprotection and a lack of support to realise intimate relationships. These findings featured in the studies of Callus et al. (2019), Rogers and Tuckwell (2016), Fitzgerald and Withers (2011), Abbot and Burns (2007) and Rogers (2009).

Thompson (2003, p.87) stresses that infantilisation involves the differential allocation of power, rights, resources and life chances. The experiences people with disabilities shared in the reviewed research can thereby be explained by this, as society ascribes people with disabilities a childlike status due to their disability, causing disempowerment and a denial of rights and citizenship (Thompson 2003). According to Dominelli and Campling (2002) it is central to power relations of inequality that difference is devalued which underpins the dynamics of oppression and explains the derogatory treatment of the people who are excluded – in this case people with disabilities. Banks (2006) explains that the development of seeing service users as consumers rather than as persons with basic moral rights has resulted in downplaying features of the social context in which any relationship takes place which legitimises the paternalistic treatment of people who are judged to be less rational – e.g. people with learning disabilities – because it contains within it the seeds of professional control and parentalism (Banks 2006).

To understand the desexualisation of people with disabilities McRuer and Wilkerson (2003) explain that one must meet certain criteria to have a sexuality that is socially intelligible. That is, the norm of mental and physical ability and heteronormativity (McRuer and Wilkerson 2003). This leads to sexual exclusion for people with disabilities, which De Boer (2015) explains can be due to the fact that often people with disabilities are perceived as asexual or third gender. Therefore, it appears to be common practice not

to talk about sex or sexuality with a disabled person. De Boer (2015, p.74) explains that the reason for this may be that people with disabilities are either seen as not sexual persons or they are seen as being sexual but not in the 'right way' because their disability implies dependency and helplessness, whereas masculinity and sex is associated with power and autonomy. Another issue associated with disability and sexuality is that historically society has been averse to what Rogers (2010, p.64) describes as 'difficult' bodies, especially bodies that include intellectual impairment. According to Rogers (2010), this aversion was often and still is associated with the fear of the unknown. The unknown can be scary, and this may be an explanation for why disabled and queer people have been perceived as a threat to society in the past (Loeser et al. 2018). Another aspect according to Rogers (2016, p.620) is that people with disabilities who have higher support needs are considered vulnerable and dangerous and their vulnerability is often used as a regulatory tool to exert power over their 'difficult behaviour' to prevent any sexual interactions between them. And for some people with disabilities the consequence of expressing sexual needs and desires is to be considered promiscuous, often resulting in the need to undergo therapy to solve these issues (Rogers 2016). However, Callus et al. (2019) shares another view on overprotection which is that parents and others wish to safeguard the well-being of their children in a world that unfortunately does not meet the support needs of people with disabilities and therefore complex processes and practices which are taken for granted by others are difficult and often impossible to manage independently, such as using public transport or checking the change in a shop.

According to Brown (1994), for people with disabilities to lead a healthy life there needs to be basic acceptance, optimism and technologies to enable them to develop their potential and competence and to assume autonomy over their own lives. A healthy life presumably includes wellbeing and according to Simpson (2012) there are two particular aspects of relevance,

namely subjective wellbeing and environmental indicators for wellbeing. According to Bourdieu (1984) and Putnam (2000), subjective wellbeing involves an individual's own sense of happiness and social relationships which is also referred to as social capital and general health. Environmental wellbeing on the other hand refers to the subjective state of the social and physical environment (Simpson 2012). However, looking at the experiences shared by people with disabilities in the literature that has been reviewed, the experience of subjective wellbeing seems to still be restricted for people with disabilities. As mentioned earlier, the Keys to Life Strategy stresses the importance of acknowledging that having meaningful relationships is a priority for people with disabilities (Scottish Government 2013). Prioritising meaningful, safe and healthy relationships for people with disabilities has been included in the Keys to Life Implementation Framework and Priorities 2019-2021 to ensure that the needs of people with disabilities are reflected in new governmental guidelines, strategies and frameworks by working with the local authorities and other providers (Scottish Commission for Learning Disability 2019). One further example of legislative implementations that theoretically promote sexuality and intimacy for people with disabilities there is for example the Human Rights Act 1998 (HRA). Amongst other articles, the Act refers to the right to a private and family life in part one Article 8, and in part one Article 12 it states that everyone of a marriageable age has a right to marry. These articles are also reflected in the CRPD of the United Nations (2008) and Article 4 of this document states that the full realisation of all human rights and fundamental freedoms must be promoted. Although the HRA 1998 does not specifically talk about a right to sex, Article 8 of the HRA 1998 implies that some sort of sexual relationship must be in place to start a family (Evans and Rodgers 2000). With regards to human rights and how these rights should apply to everyone, people with disabilities often do not seem able to exercise the rights in relation to sexuality and intimacy. One reason might be a question of capacity. This is further explained in the Adults with Incapacity (Scotland) Act 2000, section 6, where an adult is defined as incapable when they are

not able to act, make decisions, communicate decisions, understand decisions or retain the memory of decisions. Nevertheless, the Act starts with the assumption that every individual has the capacity to consent to sexual relations, to form a family and to marry; therefore, any interference with these rights must be lawful and necessary (Mental Welfare Commission 2011).

Barriers that inhibit people with disabilities to develop intimate relationships or to experience sexuality and intimacy

Sociological Barriers

Various studies have found that there are still sociological barriers that inhibit people with disabilities to have intimate relationships and sexual experiences. Studies by Iarskaia-Smirnova and Verbilovich (2020), Santos and Santos (2018), Tefera et al. (2017), McCarthy (2016) and Ignagni et al. (2016) have found that in relation to their sexuality people with disabilities still feel stigmatised, discriminated against, not supported by society and not included as sexual citizens.

The concept of sexual citizenship or intimate citizenships is about exercising human rights with regards to one's own body, feelings, identities, sexuality, genders, relationships, eroticism and representations without justification (Plummer 1995). The concept of intimate citizenship should be accessible to all individuals and everyone should be in control over their own private lives, intimacy, sexuality and personal relationships (Hough 2012). However, the reality for people with disabilities is different as shown in the literature review. Common barriers for people with disabilities to exercise their rights with regards to intimate citizenship include the social construction of disability and sexuality, attitudes of staff in residential settings, lack of access to places where one can meet a potential partner etc. (Hough 2012). In relation to this, it is society's inability to accommodate human differences that causes disability and not the outcome of physical or mental impairments (Priestly 2003). Putnam (2005) explains

that if a person's abilities match the environment's attributes, there is no disability. However, if this is not the case then disability is present (Putnam 2005). That means, disability resides within society, not within the person (Yuill et al. 2011). According to Slesser (2018) there are several social attitudes and approaches or cultural practices that devalue people with disabilities and place them in a secondary position to people without disabilities. Millar (2010) stresses that people with disabilities, especially children, women and people from ethnic minorities are still amongst the poorest members of society. To therefore achieve meaningful and positive change in the lives of disabled people means to transform society and its negative social attitudes (Slesser 2018). In this context, it makes sense to look at the concept of normalisation, which aimed to reintegrate people with disabilities into society (Thompson 2006). The term 'normalisation' refers to a concept that is based on a set of principles and values that are held by most people in society and which apply to everyday activities that most people in society are free to experience (Williams and Whittaker 2013). Basically, the aim was to make mainstream society available to people with disabilities (Williams and Whittaker 2013). Nevertheless, the concept was based on directing attempts of normalisation predominantly at people with disabilities rather than resolving the issues within society that caused people with disabilities to be excluded in the first place (Thompson 2006).

Another obvious barrier for people with disabilities is stigma. As McCarthy (2016) found, people with disabilities experience the stigma of being labelled as a disabled person in daily life. Goffman (1963, p.3) defines stigma as 'an attribute that is deeply discredited'. Within social work the term 'stigma' is used to refer to members of society who are labelled as different (Evans and Whittaker 2010). There are certain attributes that are particularly discredited by society e.g. disability, sexuality, substance misuse, mental illness or a criminal record (Yuill et al. 2011). For someone who possesses an attribute that is considered discredited, in this case disability, the consequence can be social exclusion and marginalisation, as

described by McCarthy (2016). In relation to how stigma affects people with disabilities and their private lives, Hahn (1981) explains that stigmatisation can cause severe psychological barriers such as low self-esteem or anxiety, which can create difficulties for people with disabilities in relation to love and intimacy. Looking back at McCarthy's findings, the occurrences of discrimination against people with disabilities are likely to be due to a lack of awareness and poor policies and practice (Evans and Whittaker 2010). This is why Evans and Whittaker (2010) argue that the reason people with disabilities are discriminated against may be due to a lack of awareness, resulting in ineffective practice.

Lack of Sex Education

According to Priestley (2003), people with disabilities have often been either excluded from sex education or have received inferior levels of sex education due to sexual activities being frowned upon by service providers and therefore actively discouraged by sex segregation or adult surveillance. Similar views have been reflected in the findings of the studies by Greenwood (2019), Kijak (2013), Bernart and Ogletree (2012), Wright (2011), Esmail et al. (2010) and Kelly et al. (2009). These findings revealed a lack of knowledge and education regarding sexuality and sexual activity often results in limited sexual experiences for people with disabilities. Research has shown as well, that although sex education is provided in schools, the information that is given to people with disabilities does not seem to match their level of understanding and therefore creates misunderstandings rather than a better comprehension of sex (Wright 2011).

Rohleder (2010) stresses that sex education brings up ambivalent feelings amongst carers and professionals due to the dilemma of caring for and supporting people with disabilities whilst recognising their rights with regards to sexuality and at the same time protecting them from potential harm and abuse. Therefore, it is important to balance concerns for safety with the notion of sex is natural and pleasurable rather than providing sex

education that demonises and pathologises sex, just like sexuality for people with disabilities was constructed in the past (Rohleder 2010). Furthermore, the apparent denial of disabled people's sexuality contradicts the preconception that people with disabilities are more vulnerable towards sexual harm than people without disabilities (Priestley 2003). As Hough (2012) stresses, society needs to start seeing people with disabilities as individuals who are not always vulnerable and who have rights to intimacy, sexuality and relationships (Hough 2012).

According to the World Health Organisation (2002), also referred to as WHO, an understanding of the complexity of factors that shape human sexual behaviour and a positive approach to human sexuality determine whether expressing sexuality leads to sexual health and well-being or whether it causes sexual behaviours that put people at risk and make them vulnerable towards sexual and reproductive ill-health. This means that professionals and services have to listen to people with disabilities and their needs as regards sexuality and relationships (Harflett and Turner 2016). Furthermore, Kelly et al. (2009) stress the importance of going beyond the biological facts and include discussions about the social and emotional aspects of sexuality to address the needs that people with disabilities have in this area of life. This is further researched by Schaafsma et al. (2017) who explain that sex education should be goal-oriented and comprehensive, specifying what people with disabilities do know and want to know. Additionally, these programmes should include the teaching of skills in relation to sexuality as well as knowledge (Schaafsma et al. 2017). To ensure the maintenance of these programmes, multiple sessions and boosters should be provided (Schaafsma et al. 2017).

Implementations for Support and Practice

A number of studies have revealed what needs to change with regards to supporting people with disabilities developing and having intimate and sexual relationships. The findings of the reviewed literature included a number of issues: namely, Vehmas (2019) found that for people with disabilities, the only ethically feasible way of experiencing sexuality is masturbation; Turner and Crane (2016) found that people with disabilities are often not asked about their intimate wishes and desires, hence their suggestion for including these questions in their annual planning meetings; Hollomotz and the Speakup Committee (2008) have found that certain areas of service provision should be reviewed, as they found a discrepancy of priorities between service users and the service providers. On the other hand, Linton and Williams (2019) have found that sustaining intimate and sexual relationships between people with disabilities or between couples where at least one individual has a disability, is possible with the support provided by social work.

The findings discussed above confirm what Williams and Evans (2013, p.55) stressed in their discussion about the role of the social worker, namely 'that people with disabilities need support, advice and teaching in understanding emotional and sexual relationships'. This support may include advocacy, to help people with learning difficulties gain privacy and opportunities to develop relationships (Williams and Evans 2013). Furthermore, the support may also include counselling to help people with disabilities process disappointments, rejections and to reflect on appropriate or inappropriate behaviour (Williams and Evans 2013). Individuals with disabilities do not necessarily share the same level of vulnerability and therefore, individuals should not be assumed to lack the capacity to make decisions regarding their sexual and intimate life without an opportunity to access appropriate information, and education and assistance in processing this information and its relevance to them (MWC 2011).

The other side to this matter according to section 3 (1) of the Adult Support and Protection (Scotland) Act 2007 is that people with disabilities need protection from abuse and exploitation because they are more vulnerable to being harmed due to their disability, mental disorder, illness or physical or mental infirmity. Mackay (2008) stresses that in order to define a person as an adult at risk of harm three parts of the definition have to be met. One of them is vulnerability due to e.g. disability, as mentioned above; the second definition is the inability to safeguard one's own well-being, property and interests, and the third part is that the person is at risk of harm (Mackay 2008). Brannan (2018) explains that when an individual is considered to be at risk of harm due to the fact that their needs are not met or because they are considered vulnerable, the focus of a social work intervention would be to assess any risks of harm, leading to measures of protection. This is why quite often when working with people with disabilities, protection overrules intimate and sexual choices of service users with the result that their private life is rather restricted (Evans and Whittaker 2010). Obviously, there is a need to protect people with disabilities due to the risk of financial or sexual abuse as shown in reports such as the Report of the Inspection of Scottish Borders Council Social Work Services for People Affected by Learning Disabilities (Scottish Executive and Mental Health Commission 2004). Nevertheless, any intervention that restricts the life of people with disabilities should be the least restrictive option and of benefit for the individual (Mackay 2008). Considering the least restrictive option in line with the Codes of Practice by the Scottish Social Services Council (SSSC) (2016), the focus should be very much on promoting the views, wishes and independence of service users, empowering them to exercise their rights and enabling them to take positive risks in life. Nonetheless, people with disabilities feel that they are not listened to with regards to sexuality and intimacy, or not even asked about their wishes and desires in this area of their life (Turner and Crane 2016, Hollomotz and the Speakup Committee 2008). People with disabilities are persons with basic human needs and

rights as well and service providers should recognise that every human being needs intimacy and love and should be able to exercise their rights accordingly. This is also reflected upon in the Equality Act 2010 which names disability as one of the protected characteristics under section 4. Therefore, service providers should treat people with disabilities no differently in this respect than people with no disabilities. However, most staff do not feel comfortable or confident to support people with disabilities with issues regarding their sexuality and therefore staff would require adequate training (Abbot and Howarth 2006).

In relation to care planning, Maestri-Banks (2013) suggests that people with disabilities often need help to feel empowered, so involving people with disabilities in the process of care planning and thereby enabling them to speak about their needs and wishes, a space and opportunity may be provided to raise an awareness of other care needs e.g. intimate and personal care needs, involving sexuality. Regarding social work practice, service user involvement is particularly important because it promotes inclusion and challenges structural oppression, therefore reflecting anti-oppressive and anti-discriminatory practice (Ward et al. 2016). In this context, person-centred practice comes to mind which is a key feature in the approach of person-centred planning, as it is based on an inclusive agenda, promoting the rights of people with disabilities (Gibson 2018).

Chapter 6

Limitations of Study

Choosing to conduct a literature review has brought certain limitations to this study. Firstly, due to the fact that literature reviews rely on other authors to provide empirical research (Aveyard 2019), this study was dependent on the research of others. With regards to the chosen topic for this study, there was a limited number of empirical research articles available and most of these articles have been included in previous literature reviews (see NDTI Report by Harflett and Turner 2016). This means that there is a likelihood that my findings are not new findings. Additionally, the limited number of research available created a challenge to appropriately address the second objective of this study.

Also, due to the fact that in a number of studies reviewed the participants were female, the findings regarding a male perspective may have been limited.

Another limitation to this study is the fact that although the literature review has shown that there is a variety of research available on disability and sexuality across the world, no Scottish research articles were found. As a first-time researcher, my skills and knowledge are still developing and that may have led to some limitations in gathering and assimilating resources. One notable gap has been the lack of Scottish research articles. This may have influenced the research process in terms of identifying, critiquing and synthesising literature as it may not have been done as comprehensibly as that of a more experienced researcher.

Furthermore, due to the fact that I was dependent on previously conducted research, according to Carey (2013) there may be a likelihood of repeating the bias which were existent in the original research articles. Additionally, although I have made every effort to present the reviewed data as objectively as possible, my work with people with disabilities may have

influenced the discussion of my findings. This means, as well as the bias of other authors, it is likely that my own bias has influenced this study.

Nonetheless, the findings of this study have influenced my work, enhanced my understanding and made me more compassionate regarding the sexuality and needs of your clients.

Chapter 7

Conclusion and Recommendations

Conclusion

Within this study a range of literature has been reviewed in relation to sexuality and disability. The study has explored this literature in regards to the three main objectives of this study, namely, exploring the experiences of people with disabilities in relation to developing sexual and intimate relationships, the potential barriers that people with disabilities experience in relation to developing intimate and sexual relationships, and what needs to change in practice to support people with disabilities to develop intimate and sexual relationships.

Regarding the first objective and with reference to the literature review, research has shown that relationships are important to people with disabilities and in particular participatory research has shown that people with disabilities are perfectly able to express their needs and wishes regarding sexuality and intimacy. However, research has also shown that often parents and practitioners do not listen to or acknowledge these needs and wishes for the sake of protection, which leads to people with disabilities having dehumanising experiences of overprotection and infantilisation. Although parents and carers do not necessarily intend to restrict people with disabilities in their rights regarding sexuality, research has shown that parents and carers feel torn between enabling people with disabilities to

have the freedom and autonomy they need to experience sexuality and intimacy and protecting them from emotional and physical harm. Nonetheless, it became apparent in the literature review, that particularly inclusive and participatory research projects are important as they empower people with disabilities to voice their opinions and concerns. By including people with disabilities in research matters that directly affect them, such as matters of sexuality and intimacy, it is likely that the outcome of these research projects will actually benefit people with disabilities, which increases the level of relevance when it comes to improving policies and legislation regarding these matters.

Looking at the second objective of this study (potential barriers that people with disabilities experience), the literature review has shown that there are still a number of barriers that inhibit people with disabilities to develop or experience sexual and intimate relationships. These barriers include discrimination, stigmatisation, social marginalisation and a lack of sex education. Although these are not necessarily new barriers, they still need to be addressed. Considering that a lot of effort has been put into addressing issues of stigma and discrimination already e.g. policies and legislation as well as implementations of anti-discriminatory practice, there is not any ground-breaking conclusion that I can draw regarding these issues. Nevertheless, I think it is important that we educate and inform ourselves in relation to why stigma and discrimination exist and why it keeps perpetuating. Studies like I have undertaken here encourage ongoing reflection on the behaviours, prejudices and thinking processes of future social workers and will help to challenge any unconscious stigmatising or discriminating attitudes that we may have acquired. Furthermore, conversations about the origins of potential stigmatising and discriminating attitudes with colleagues, friends and family would be necessary to change our own thinking processes and behaviours. I think it would be beneficial to include people with disabilities who are stigmatised and discriminated against in these conversations, if they feel comfortable to do so. A good

place to start would be inclusive and participatory qualitative research which would provide a safe environment for those who are discriminated against and stigmatised to share their experiences. With regards to addressing the issue of the lack of sex education, I think inclusive and participatory research would be beneficial as well because it helps to uncover the lack of knowledge with specific indication as to what people with disabilities do not know but would like to know. Considering the fact that some research of this sort is already available as shown in the literature review, it would be beneficial for the government and policymakers to take these outcomes into account when developing new policies and legislation. Sufficient sex education would be in the best interest of policymakers as well as people with disabilities as it may resolve issues arising from inadequate sex education such as indecent exposure, pathological masturbation or other issues that research has uncovered. Generally, sex education should be made accessible and comprehensible to everyone and forms of execution thereof may have to be adapted depending on the needs of the audience.

With regards to the third objective, it transpired from the literature review that there are quite a lot of discrepancies between legislation, policy developments and practice when it comes to supporting people with disabilities to develop intimate relationships. The measures of support implemented by law and policy for people with disabilities are focused mainly on protection e.g. Adult Support and Protection (Scotland) Act 2007, side-lining the intimate and sexual wishes and needs of people with disabilities. This leaves people with disabilities feeling ignored and not listened to, as shown in the literature review. As mentioned in the discussion chapter, there is a need to protect people with disabilities from harm such as sexual and financial abuse. However, I do think people with disabilities should be able to exercise their rights in relation to sexuality and intimacy as they would like to, and their disability should not be the barrier. Therefore, I think the involvement of people with disabilities in policymaking and the development of legislation would be beneficial. This way of including

people with disabilities in the process of policymaking would reflect the social work approach of person-centred planning.

The literature review has also shown that staff did not feel comfortable or confident to deliver adequate support in relation to supporting people with disabilities to develop intimate and sexual relationships. Therefore, service providers should offer adequate training opportunities for staff in this area of practice. Families with children with disabilities are likely to benefit from such training opportunities as well, because it would provide parents with a more confident approach to parenting and on the other hand issues such as over-protective parenting and infantilising adults with disabilities would be addressed.

Further research is required in relation to disability and sexuality, especially Scottish research, as according to the findings of the literature review revealed a gap in this area. The availability of Scottish research would be especially useful in terms of developing new policies and legislation, because Scottish research would be easy to apply to policies and legislation in the Scottish context. The disadvantage of research from other countries is that it bears the issue of transportability in relation to cultural differences, other value bases and legal systems.

Recommendations

- The need for Scottish research in relation to disability and sexuality
- The need for more participatory research regarding disabled people's experiences in relation to sexuality and intimacy
- The need for more participatory research regarding the lack of sex education

- The Scottish government and policymakers should take into account the findings of already existing research in relation to disability and sexuality
- Sex education should be accessible and comprehensible for everyone
- A more inclusive and person-centred approach with regards to policymaking and developing legislation in Scotland
- Training in relation to sex education and delivering appropriate support to help people with disabilities to develop sexual and intimate relationships for staff and parents
- People with disabilities should continue to be encouraged to share and voice their opinions about issues regarding their sexuality
- Ongoing reflection on personal thinking processes that may include unconscious stigmatising or discriminating content

References

ABBOT, D. and BURNS, J., 2007. What's love got to do with it?: Experiences of Lesbian, Gay and Bisexual People with Intellectual Disabilities in the United Kingdom and Views of Staff who support them. *Sexuality Research and Social Policy: Journal of NSRC*, **4**(1), pp. 27-39.

ABBOT, D. and HOWARTH, J., 2006. Still off Limits? Staff Views on Supporting Gay, Lesbian and Bisexual People with Intellectual Disabilities to Develop Sexual and Intimate Relationships. *Journal of Applied Research in Intellectual Disabilities*, **20**, pp. 116-126.

ADDLAKHA, R., PRICE, J. and HEIDARI, S., 2017. Disability and Sexuality: Claiming Sexual and Reproductive Rights. *Reproductive Health Matters*, **25**(50), pp. 4-9.

Adult Support and Protection (Scotland) Act 2007. a.s.p. 10. <http://www.legislation.gov.uk/asp/2007/10/contents> {Accessed last 13th September 2020}

Adults with Incapacity (Scotland) Act 2000. a.s.p. 4. <http://www.legislation.gov.uk/asp/2000/4/contents> {Accessed last 13th September 2020}

AVEYARD, H., 2019. *Doing a literature review in health and social care: a practical guide*. London: Open University Press.

BANKS, S., 2006. *Ethics and values in social work*. 3 edn. Basingstoke: Palgrave Macmillan.

BELL, J., 2007. *Doing your research project: a guide for first-time researchers in education and social science*. 4 edn. Maidenhead: Open University Press.

BERNERT, D.J. and OGLETTREE, R.J., 2013. Women with intellectual disabilities talk about their perceptions of sex. *Journal of Intellectual Disability Research*, **57**(3), pp. 240-249.

BLOCK, P., SHUTTLEWORT, R., PRATT, J., BLOCK, H. and RAMMLER, L., 2012. Disability, Sexuality and Intimacy. In: N. POLLARD and D. SAKELLARIOU, eds. *Politics of Occupation-Centred Practice: Reflections on Occupational Engagement across Cultures*. pp. 162-179.

BOLTON, G., 2014. *Reflective practice: writing and professional development*. Los Angeles: SAGE.

BOURDIEU, P., 1984. *Distinction: A Social Critique of the Judgement of Taste*. London: Routledge and Kegan Paul.

BRANNAN, J., 2018. Generic Issues in Practice Context. In: J. LISHMAN et al., eds. *Social work: an introduction*. 2nd ed. Los Angeles: SAGE. pp. 427-434.

BRITISH ASSOCIATION OF SOCIAL WORKERS, 2014. *The Code of Ethics for Social Work*. {Online} Available from: <https://www.basw.co.uk/about-basw/code-ethics> {Accessed last 13th September 2020}

BROWN, H., 1994. 'An Ordinary Sexual Life?': A Review of the Normalisation Principle as It Applies to the Sexual Options of People with Learning Disabilities. *Disability & Society*, **9**(2), pp. 123-144.

CALLUS, A., 2017. 'Being friends means helping each other, making coffee for each other': reciprocity in the friendships of people with intellectual disability. *Disability & Society*, **32**(1), pp. 1-16.

CALLUS, A., BONELLO, I., MIFSUD, C. and FENECH, R., 2019. Overprotection in the lives of people with intellectual disability in Malta: knowing what is control and what is enabling support. *Disability & Society*, **34**(3), pp. 345-367.

CAREY, M., 2013. *The social work dissertation using small-scale qualitative methodology*. 2 edn. Maidenhead: McGraw-Hill Education.

DE BOER, T., 2015. Disability and Sexual Inclusion. *Hypatia*, **30**(1), pp. 66-81.

DOMINELLI, L. and CAMPLING, J., 2002. *Anti-oppressive social work theory and practice*. New York: Palgrave Macmillan.

DOMINELLI, L., 2002. *Feminist Social Work Theory and Practice*. Basingstoke: Palgrave.

Equality Act 2010. C.15.
<http://www.legislation.gov.uk/ukpga/2010/15/contents> {Accessed last 13th September 2020}

ESMAIL, S., DARRY, K., WALTER, A. and KNUPP, H., 2010. Attitudes and perceptions towards disability and sexuality. *Disability and rehabilitation*, **32**(14), pp. 1148-1155.

EVANS, A. and RODGERS, M.E., 2000. Protection for Whom?: The Right to a Sexual or Intimate Relationship. *Journal of learning disabilities*, **4**(3), pp. 237-245

EVANS, M. and WHITTAKER, A., 2010. *Sensory awareness and social work*. Exeter: Learning Matters.

FITZGERALD, C., and WITHERS, P., 2011. 'I don't know what a proper woman means: what women with intellectual disabilities think about sex, sexuality and about themselves.' *British Journal of Learning Disabilities*, **41**, pp. 5-12.

GIBSON, N. 2018. Person-Centred Planning and Personalisation. In: J. LISHMAN et al., eds. *Social work: an introduction*. 2nd ed. Los Angeles: SAGE. pp. 339 – 352

GOFFMAN, E., 1963. *Stigma: notes on the management of spoiled identity*. New York: Simon & Schuster.

GREENWOOD, J.A., 2019. *Sexuality and Romance in Individuals with Down Syndrome: Assessing Parental Attitudes, Sexual Knowledge and Experiences with Romance*. Unpublished MSc Thesis. University of California, Irvine.

HAHN, H., 1981. The social component of sexuality and disability: Some problems and proposals. *Sex Disabil*, **4**, pp. 220–233.

HOLLOMOTZ, A., and THE SPEAKUP COMMITTEE, 2008. 'May we please have sex tonight?' – people with learning difficulties pursuing privacy in residential group settings. *British Journal of Learning Disabilities*, **37**, pp. 91-97.

HOUGH, R.E., 2012. Adult protection and 'intimate citizenship' for people with learning difficulties: empowering and protecting in light of the No Secrets review. *Disability & Society*, **27**(1), pp. 131-144.

Human Rights Act 1998. C.42.
<http://www.legislation.gov.uk/ukpga/1998/42/contents> {Accessed last 13th September 2020}

IGNAGNI, E., FUDGE SCHORMANS, A., LIDDIARD, K. and RUNSWICK-COLE, K., 2016. 'Some people are not allowed to love': intimate citizenship in the lives of people labelled with intellectual disabilities. *Disability & Society*, **31**(1), pp. 131-135.

KIJAK, R., 2013. The Sexuality of Adults with Intellectual Disability in Poland. *Sexuality and Disability; A Journal Devoted to the Psychological and Medical Aspects of Sexuality in Rehabilitation and Community Settings*, **31**(2), pp. 109-123.

KITELEY, R. and STOGDON, C., 2014. *Literature reviews in social work*. Los Angeles: SAGE.

LAFFERTY, A., MCCONKEY, R. and TAGGART, L., 2013. Beyond friendship: the nature and meaning of close personal relationships as perceived by people with learning disabilities. *Disability & Society*, **28**(8), pp. 1074-1088.

LINTON, K.F. and WILLIAMS, L.R., 2019. Sustaining an intimate and sexually fulfilled marriage or partnership in older adulthood with a disability: Perspectives of social workers. *Journal of Human Behavior in the Social Environment*, **29**(8), pp. 1026-1035.

LOESER, C., PINI, B. and CROWLEY, V., 2018. Disability and sexuality: Desires and pleasures. *Sexualities*, **21**(3), pp. 255-270.

MACKAY, R., 2010. Social Policy perspectives on empowerment. In: S.J. HOTHERSALL, and J. BOLGER. *Social policy for social work, social care and the caring professions Scottish perspectives*. Farnham: Ashgate. pp 175 – 201

MACKAY, K., 2008. The Scottish adult support and protection legal framework. *The Journal of Adult Protection*, **10**(4), pp. 25-36.

MAESTRI-BANKS, A., 2013. Learning Disability, Education and Empowerment: Learning from Individuals who live with a Learning Disability. *Health and Social Care Education*, **2**(1), pp. 21-24.

MCCARTHY, A., 2016. Understanding and exploring the Effects of Informal Care on the Sexual Self: A Disability Perspective. *Graduate Journal of Social Science*, **12**(1), pp. 96-117

MCRUER, R. and WILKERSON, A., 2003. Introduction. Desiring Disability: Queer Theory Meets Disability Studies. *GLQ: A Journal of Lesbian and Gay Studies*, **9**(1-2), pp. 1-24.

MENTAL WELFARE COMMISSION, 2012. *Consenting Adults*. {Online} Edinburgh: The Mental Welfare Commission. Available from: https://www.mwscot.org.uk/sites/default/files/2019-06/updated_consenting_adults.pdf {Accessed last 13th September 2020}

MILLAR, J. 2010. Disability: A Question of Perception. In: S.J. HOTHERSALL, and J. BOLGER. *Social policy for social work, social care and the caring professions Scottish perspectives*. Farnham: Ashgate. pp. 271 – 292

PLUMMER, K., 1995. *Telling sexual stories: Power change and social worlds*. London: Routledge.

PRIESTLEY, M., 2003. *Disability: a life course approach*. Oxford: Polity.

PUBLIC HEALTH RESOURCE UNIT., 2006. *Critical Appraisal Skills Programme*. England: Public Health Resource Unit.

PUTNAM, R., 2000. *Bowling Alone: The Collapse and Revival of American Community*. New York: Simon and Schuster.

PUTNAM, M., 2005. Developing a framework for political disability identity (Conceptualizing Disability). *Journal of Disability Policy Studies*, **16**(3), pp. 188-198.

RICHARDS, M., 2017. 'Angry, when things don't go my own way': what it means to be gay with learning disabilities. *Disability & Society*, **32**(8), pp. 1165-1179.

ROBERT GORDON UNIVERSITY., 2020. *Dissertation module handbook*. Aberdeen: Robert Gordon University

ROBERT GORDON UNIVERSITY., 2016. *The Robert Gordon University research ethics policy*. Aberdeen: The Robert Gordon University.

ROGERS, C., 2010. But it's not all about the sex: mothering, normalisation and young learning-disabled people. *Disability & Society*, **25**(1), pp. 63-74.

ROGERS, C., 2016. Intellectual disability and sexuality: On the agenda? *Sexualities*, **19**(5-6), pp. 617-622.

ROGERS, C., 2009. (S)excerpts from a Life Told: Sex, Gender and Learning Disability. *Sexualities*, **12**(3), pp. 270-288.

ROGERS, C. and TUCKWELL, S., 2016. Co-constructed caring research and intellectual disability: An exploration of friendship and intimacy in being human. *Sexualities*, **19**(5-6), pp. 623-640.

ROHLEDER, P., 2010. Educators' ambivalence and managing anxieties in providing sex education for people with learning disabilities. *Psychodynamic Practice*, **16**(2), pp. 165-182.

SANTOS, A.C. and SANTOS, A.L., 2018. Yes, we fuck! Challenging the misfit sexual body through disabled women's narratives. *Sexualities*, **21**(3), pp. 303-318.

SCHAAF SMA, D., KOK, G., STOFFELEN, J.M.T., and CURFS, L.M.G., 2017. People with Intellectual Disabilities Talk about Sexuality: Implications for the Development of Sex Education. *Sex Disabil*, **35**, pp. 21-38.

SCOTTISH COMMISSION FOR LEARNING DISABILITY, 2019. *The Keys to Life: Unlocking Futures for People with Learning Disabilities – Implementation Framework and Priorities 2019-2021*. {Online} Available from: <https://keystolife.info/wp-content/uploads/2019/03/Keys-To-Life-Implementation-Framework.pdf> {Accessed last 13th September 2020}

SCOTTISH EXECUTIVE AND MENTAL HEALTH COMMISSION, 2004. *Report of the Inspection of Scottish Borders Council Social Work Services for People Affected by Learning Disabilities*. {Online} Available from: <http://docs.scie-socialcareonline.org.uk/fulltext/reportaffectlearningdisabilities.pdf> {Accessed last 13th September 2020}

SCOTTISH GOVERNMENT, 2008. *Communication and Assessing Capacity*. {Online} Edinburgh: The Scottish Government. Available from: <https://www.gov.scot/binaries/content/documents/govscot/publications/advice-and-guidance/2008/02/adults-incapacity-scotland-act-2000-communication-assessing-capacity-guide-social-work-health-care-staff/documents/0055759-pdf/0055759-pdf/govscot%3Adocument/0055759.pdf> {Accessed last 13th September 2020}

SCOTTISH GOVERNMENT, 2013. *The keys to life*. {Online} Edinburgh: The Scottish Government. Available from: <https://www.gov.scot/binaries/content/documents/govscot/publications/strategy-plan/2013/06/keys-life-improving-quality-life-people-learning-disabilities/documents/keys-life-improving-quality-life-people/keys-life-improving-quality-life-people/govscot%3Adocument/00424389.pdf> {Accessed last 13th September 2020}

SCOTTISH SOCIAL SERVICES COUNCIL, 2016. *Codes of Practice*. Dundee: SSSC.

SIMPSON, G., 2012. Developing Wellbeing as a Critical Tool in Social Work Education: An Example from the Field of Learning Disability. *Social Work Education*, **31**(5), pp. 622-636.

SLESSER, S., 2018. Working with adults: disability and sensory impairment. In: J. LISHMAN et al., eds. *Social work: an introduction*. 2nd ed. Los Angeles: SAGE. pp. 489 – 501

STOFFELEN, J.M.T., SCHAAFSMA, D., KOK, G. and CURFS, L.M.G., 2019. Views on Sex Using the Nominal Group Technique to Explore Sexuality and Physical Intimacy in Individuals with Intellectual Disabilities. *Sexuality and Disability; A Journal Devoted to the Psychological and Medical Aspects of Sexuality in Rehabilitation and Community Settings*, **37**(2), pp. 227-244.

TEFERA, B., VAN ENGEN, M., VAN DER KLINK, J. and SCHIPPERS, A., 2017. The grace of motherhood: disabled women contending with societal denial of intimacy, pregnancy, and motherhood in Ethiopia. *Disability & Society*, **32**(10), pp. 1510-1533.

THOMPSON, N. 2014. *Understanding Social Work: Preparing for Practice*. Basingstoke: Palgrave Macmillan.

THOMPSON, N., 2006. *Anti-discriminatory practice*. 4 edn. Basingstoke: Palgrave Macmillan.

THOMPSON, N., 2003. *Promoting equality: challenging discrimination and oppression*. 2 edn. Basingstoke: Palgrave Macmillan.

TURNER, G.W. and CRANE, B., 2016. Pleasure is paramount: Adults with intellectual disabilities discuss sensuality and intimacy. *Sexualities*, **19**(5-6), pp. 677-697.

UNITED NATIONS., 2008. *United Convention on the Rights of Persons with Disabilities*. New York: UN

- UPIAS, 1976. *Fundamental Principles of Disability*. London: UPIAS
- VEHMAS, S., 2019. Persons with profound intellectual disability and their right to sex. *Disability & Society*, **34**(4), pp. 519-539.
- YUILL, C., KEENAN, C. and MCLEAN, F., 2011. Disability. In: C. YUILL and A. GIBSON. *Sociology for social work: an introduction*. London: SAGE Publications. pp. 164-184.
- YUILL, C., MACKAY, R. and MUTCH, A., 2011. Health. In: C. YUILL and A. GIBSON. *Sociology for social work: an introduction*. London: SAGE Publications. pp. 138-163.
- WARD, N., RAPHAEL, C., CLARK, M. and RAPHAEL, V., 2016. Involving People with Profound and Multiple Learning Disabilities in Social Work Education: Building Inclusive Practice. *Social Work Education*, **35**(8), pp. 918-932.
- WILLIAMS, P. and EVANS, M., 2013. *Social Work with People with Learning Difficulties*. 3 edn. London: SAGE Publications Ltd.
- WORLD HEALTH ORGANISATION, 2002. *Defining Sexual Health: Report of A Technical Consultation on Sexual Health*. Geneva: World Health Organization.
- WRIGHT, R., 2011. Young People with Learning Disability and the Development of Sexual Relationships. *Mental Health and Learning Disability Research and Practice*, **8**(1), pp. 63-77