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Sexual Education for Adults with Intellectual Disabilities: A Critical Review of Policy and Practice in Four Service Providers in County Cork

Louise O'Sullivan

CARL Research Project

Name of student(s):	Louise O'Sullivan
Name of civil society organization/community group:	Down Syndrome Cork
Supervisor(s):	Dr. Máire Leane
Name and year of course:	Masters in Social Policy 2013/2014
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Declaration

I certify that all of this is my own. Where I have used the work of others it is acknowledged or referenced accordingly. The thesis has not been submitted for another degree at University College Cork or elsewhere.

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1. Introductory Chapter

1.1 Introduction

The research I am carrying out is on the policy and practice of sexual education for people with intellectual disabilities in Cork County in correlation with Down Syndrome Cork. The reason I am working with Down Syndrome Cork is because the dissertation is a Community Academic Research Link (CARL) project which will be discussed further in my methodology chapter. The topic I chose to do my research on was intellectual disability and sexuality with a focus on the provision of sexual education for people with intellectual disabilities. I decided on this topic as Irish legislation can be oppressive for people with intellectual disabilities who have the capacity to express their sexuality; in Ireland it is currently by law illegal for a person to have sexual relationships with a person with an intellectual disability outside of marriage. This is a large number of the Irish population to be targeted, in 2011 there were 57,709 people in Ireland said to have an intellectual disability (CSO, 2011).

I found this research topic of Sexual Education for People with Intellectual Disabilities interesting as in Ireland due to the current legislation there is no clear information on the extent of which sexual education is provided. It is an area that has been ignored in the past and is finally gaining attention due to self-advocacy e.g. 'Someone to Love' which aired on RTÉ 1 on the 17th February and another example is the Connect People Network (CPN) which was founded in 2002.

This research is important as there is no definite answer to what type of sexual education people with intellectual disabilities want or need. There is also the issue that adequate sexual education is not being provided to people with intellectual disabilities due to the issues of capacity and legislation (Irish Family Planning Association, 2012). This lack of sexual

education can also be due to the fear of facilitating crime by parents and service providers (LRC, 2005, 6.20). People with intellectual disabilities are blindfolded to the dangers and responsibilities of a sexual relationship. Through this research I wish to investigate the opinions of parents from Down Syndrome Cork on the sexuality of their children. The findings from my research can potentially be used to assist in changing the legislative context of people with intellectual disabilities and sexuality.

It is important to acknowledge that there is a minority of people with intellectual disabilities that are unable to make an informed decision on this issue of sexuality and in these circumstances there must be protective policies and legislation to stop exploitation or abuse.

1.1 Aims & Objectives

In this research my aims are:

- To explore views of parents from Down Syndrome Cork around sexuality of their children.
- To investigate policy and practice in relation to sexual education in four intellectual disability service providers in County Cork.
- To investigate service provider's opinions on sexual education for people with intellectual disabilities

My objectives to achieve these aims are to:

- Complete a policy review in terms of sexuality and intellectual disability to highlight the key policies and legislation affecting those with the capacity to have fulfilling relationships.

- Review the key pieces of literature on sexuality and relationships of people with intellectual disabilities as to gather a general perspective from public, services and parents of people with intellectual disabilities.
- Do a focus group in which parents from Down Syndrome Cork would feel comfortable to speak about their child sexuality.
- Complete one to one interviews with service providers to discuss in depth their attitude towards people with intellectual disabilities expressing their sexuality and the policies they have in place within the services on Relationships and Sexuality.
- To analyse and present the data and findings collected from the primary research.
- Conclude with a discussion of the key research questions and recommendations for future pieces of research.

1.2 Research Questions

From these aims I have devised questions I wish to ask parents from Down Syndrome Cork and services providers from around Cork County.

My overall research question for my parent focus group is; Exploration of Parental Attitudes and Knowledge of People with Intellectual Disabilities on the topics of Sexuality and Sexuality Education.

My overall research question for my one to one interviews with Service Providers is; An Investigation into the Policy and Practice of Sexuality Education of Services in Cork County with an Emphasis on the Attitudes of service Providers on the Sexuality of People with Intellectual Disabilities.

It had been intended I would do two focus groups with people with intellectual disabilities but unfortunately due to time restraints this was not achievable. If the focus groups had gone ahead

the research question I would have liked answered was; Exploration of the Opinions and Needs for Sexual Education.

The previous two research questions will be answered in my conclusion chapter along with recommendations for future research.

1.3 Contribution to Research

This research will be a contribution to research in many ways. By exploring issues relevant to people with intellectual disabilities it highlights the discrimination that arises for people with intellectual disabilities who have the capacity to have full sexual relationships. It also investigates parental and service provider attitudes to people with intellectual disabilities expressing their sexuality. This is an original piece of research on an issue that is under researched and not recognised in society. Although this is only a minor thesis I hope this research highlights the importance of providing sexuality education to people with intellectual disabilities.

1.4 Term Intellectual Disabilities

I would like to take a moment to explain the term Intellectual Disability that I will be using throughout my dissertation. In this research the term Intellectual Disability stands for those with mild to moderate intellectual disabilities that may have the capacity to have fully consenting relationships with people. Unfortunately as stated earlier there is a minority group of people with intellectual disabilities that are unable to make an informed decision on this issue of sexuality and in these circumstances there must be a form of protection to prevent exploitation. As stated this research is speaking of people with intellectual disabilities in the mild to moderate category.

1.5 Methodology

This is just a brief synopsis of the methodology approach; it will be discussed in-depth in chapter four of this dissertation.

The research took a qualitative approach to explore the views of service providers and parents on the issue of sexual education for people with intellectual disabilities in Cork area. This approach allows for conflicting views to be drawn out. An interpretive approach will be taken as this allows participants to describe their lived experiences from their point of view with the researcher making sense of these experiences (Kalof, 2008; Bryman, 2008). This approach is useful to my research topic as it allows me to have more in-depth conversation with the participants and to gain broader view of the issue.

The primary and secondary data collection methods are through focus group and semi-structured one to one interviews. A focus group is a group interview, focused on a topic set by myself. The group will interact and together construct answers or meanings in response to the questions or topics identified (Bryman, 2008). The Semi-structured interviews consist of a conversation with the interviewee on a pre-defined topic. (Fylan, 2005) This method is useful to my topic as I will be able to have in-depth discussion with the interview and delve deeper into issues that arise. A disadvantage that may arise from this method is the difficulty to not prompt or be judgemental of the replies. The secondary data collection will be carried out when doing the literature review and policy review for this research in which I will be doing an in-depth analysis of the key pieces of legislation and literature affected the sexuality of people with intellectual disabilities.

1.6 Chapter Outline

Chapter 1 Introduction – This chapter has identified the reasoning for this research report. I discussed the aims and objectives of the research and give a brief synopsis of the methodology that will be used to gather information and identify themes that will occur within the report.

Chapter 2 Literature Review – In this chapter I analysed the key pieces of literature related to intellectual disabilities and sexuality. I discussed this literature under the two main heading paternalism and empowerment

Chapter 3 Policy Review – I gave a historical overview of the key policies and legislation that relate to sexual education and capacity of people with intellectual disabilities under the main headings of protectionism, equality and rights.

Chapter 4 Methodology – The methodology chapter aimed to provide a detailed perspective of the methods used to gather the research findings. In this chapter I discussed the reasons for the research methods and why they were suited towards this report, the instrument used to gather the information and the difficulties that may arise when gathering the information.

Chapter 5 Research Findings – In the research findings chapter I provided an analysis of the data under such headings as sexuality and relationship policy within services, sexual education provisions and empowerment vs paternalism.

Chapter 6 – Conclusion – I will be restating the findings from the research answer the key research questions and discussed the recommendation for future research in this area.

2. Literature Review

2.1 Introduction

This chapter aims to discuss in depth the research and literature done around the area of intellectual disabilities and sexuality. Perspectives that will be analysed in this chapter include those of service providers; parents; the community and people with intellectual disabilities themselves. The concepts of empowerment and paternalism which were discussed in the previous chapter also proved relevant here. But firstly, a general overview of the perspectives Irish society has of people with intellectual disabilities in terms of sexuality will be undertaken. It will be shown how they help frame responses to Intellectual disability and sexuality in the literature.

An issue for people with intellectual disabilities is that the Irish society views intellectual disabilities as homogenous when there are actually many different types of intellectual disability. It doesn't seem fair that people with intellectual disabilities are all put under one umbrella as Irish legislation currently categorises them. Another issue that arises is that people with intellectual disability are often infantilised and so parents and service providers see the person with an intellectual disability as asexual. This can result in there being an inadequate provision of sexual education for people with intellectual disabilities and possibly a lack in promoting such groups to have relationships.

Thanks to self-advocacy groups such as *Connect People Network*, there has been a growing acknowledgement of the issue of the sexuality of people with Intellectual Disability. This chapter gives a review of data and published works that are contributing to providing people with intellectual disabilities sexual education. The chapter will be broken into two reoccurring themes throughout; these themes are paternalism and empowerment. There are

groups within society who feel people with intellectual disabilities should be empowered to have relationships as every person has the right to receive sexual education and participate in consenting sexual relationships. These groups would consist mainly of progressive parents, service providers and self-advocates. Conversely, there are also groups of people in society who take a paternalistic perspective. The more conservative parents and service providers would believe that it is more beneficial for people with intellectual disabilities to be uneducated in relation to their sexuality and sexual health. It is important to acknowledge that the research I am conducting primarily focuses on people with mild to moderate intellectual disabilities as there are a minority group of people with intellectual disabilities who unfortunately do not have the capacity to consent to such an act and so must be protected.

2.2 Perspectives

Paternalism and empowerment are two concepts which underpin many responses to people with intellectual disability and they are certainly influential in shaping decision making on the methods of teaching sexual education to people with intellectual disabilities. Paternalism is needed in sexual education to teach a person what is deemed appropriate when it comes to friendships and relationships. Empowerment gives a voice to those marginalised within society.

2.2.1 Paternalism

Allan & Seery (2007) carried out research which aimed "capture the current provision of relationships and sexuality education for people with intellectual disabilities" in Ireland (Allan & Seery, 2007. pp, 5). They gathered this information through surveys sent out to 244 individuals in 152 agencies working in the area of intellectual disabilities and also had 14 in

depth telephone interviews. People with intellectual disabilities are often perceived as asexual as mentioned earlier in the essay. If a person with intellectual disabilities shows interest in expressing their sexuality they are often seen as either incapable of understanding or acting on these feelings or "unable to control their sexual urges" (Allan & Seery, 2007, pp. 9). If services were to provide "appropriate and accurate information" (Allan & Seery, 2007, pp. 9), then a person with intellectual disabilities would be more likely to "develop appropriate sexual behaviour" (McCarthy & Thompson, 2001 cited by Allan & Seery, 2007, pp. 9). It was found in this piece of research that "staff attitudes may be tempered by the organisations ethos, which can often be 'play it safe' attitude" (Allan & Seery, 2007, pp. 27) Aside from these barriers there is also "no cohesive or national approach" to sexual education for people with intellectual disabilities (Allan & Seery, 2007, pp.43). Not only is there no appropriate sexual education for service users but "staff and carers are ill prepared or reluctant to address issues of sexuality" (Allan & Seery, 2007, pp.43).

Evans et al. (2009) found there was a preference by staff and carers for people with intellectual disabilities to have platonic relationships rather than a sexual one. The sexual education or knowledge that the person with intellectual disabilities receives or has is very much dependent on how liberal in thinking their carer or support staff are on the issue of sexuality (Evans et al. 2009). Having inappropriate attitudes and teaching methods of sexuality can cause ill effect on developing sexual knowledge for people with intellectual disabilities. This brings about the discussion on the paternalistic perspective and whether or not there are still a large percentage of people who have this perspective in terms of sexual education for people with intellectual disabilities. Oliver (2009) states that society and the state almost view disabled people as "somehow less than whole and, at worst, not quite human" (Oliver, 2009. pp.127), taking away their human right to having a fulfilling relationship.

Kelly et al (2009) in this piece of research the researchers were focusing on the service user's perspectives. The research was carried out in a service for people with intellectual disabilities located in the midlands. There were 15 participants, 7 women and 8 men, from a range of different intellectual disabilities aged 23 to 41. The research aimed to discover the experiences of people with intellectual disabilities in terms of relationships and sexuality (Kelly et al. 2009). The method used to interview was a focus group. This research has been placed under the paternalism heading as it shows what affects society has had on sexual education for people with intellectual disabilities and the barriers the participants of the research are facing due to their service providers ethos. It was stated in the article that "service providers are afraid that in supporting people with intellectual disabilities in this area, they may be endorsing or promoting illegal conduct" (Foley 2009 cited in Kelly et al 2009). A question that arises from this statement is that, is the real fear a relationship becoming serious? It raises the question of the possibility of staff becoming over protective and may suggest that the relationship should end if the relationship was no longer 'cute'. In the interviews it was stated that even people with intellectual disabilities that were considered capable of having a relationship were being kept restricted from sexual expression. Just because the service does not educate people with intellectual disabilities on sexuality it does not mean that the urges do not exist. Kelly et al. (2009) state that "voices remain oddly absent" up until recently in research on people with intellectual disabilities. There is beginning to be more self-advocacy on the issue of intellectual disabilities and sexuality. The findings from this research were "that people with intellectual disabilities in Ireland want to experience intimate relationships but encounter many barriers in their quest for a full sexual life" (Kelly et al. 2009. pp, 314).

Staff members may have "positive attitudes towards the sexuality of persons with intellectual disabilities but this does not always influence their willingness to provide education" (Foley & Kelly, 2009, pp.9). Why is this the case? What has made these people unwilling to provide sexual education to their clients? Is it because of the service providers' ethos as discussed earlier? Or is it because of parent's attitudes to their child receiving sexual education? Many parents of people with intellectual disabilities are "resistant to their child's sexuality believing that their children are permanent children and thus asexual" (Foley & Kelly, 2009, pp. 9). This could be a reason why some staff who are positive regarding the sexuality of people with intellectual disabilities feel they cannot advocate this positivism due to the parent's paternal attitude. Another issue is that most parents don't want to consider their child to have sexual urges, but there is still the need to provide sexual education to disabled and non-disabled children as to inform them of the dangers and realities of a sexual relationship. It is easy for families to keep sexual education from people with intellectual disabilities as such people are so commonly seen as not knowing what is in their best interest and so "it is the guardians who have the most to say in determining the service the person receives" (Kelly, 2013, pp.369). The reality is that this restriction is putting their child at risk of secretly having relationships outside of service hours or without the knowledge of their family and especially without the appropriate knowledge of the dangers and realities of a relationship.

Kelly (2013) researched the difficulties that can arise for people with intellectual disabilities when they attempt to express their sexuality. As stated by one author "just as children are assumed to have no sexuality, so disabled people are similarly denied the capacity for sexual feeling or expression" (Shakespeare, 1996, pp.199). The research consisted of "four focus groups carried out in an intellectual disability service in the Irish midlands" (Kelly, 2013, pp. 355). Two of the focus groups were with staff members, another was with the 'sexuality

committee' within the service and the fourth was with parents of the service users (Kelly, 2013). The duration of the focus groups were an hour long in which the participants loosely covered topics such as "attitudes towards sexuality and intellectual disability, experience with regards to relationships and sexuality of people with intellectual disabilities, and supports that might help parents or staff in this area" (Kelly, 2013, pp. 355). Difficulties that arose for Kelly (2013) in her research included broadening the views of parent and support staff of people with intellectual disabilities. There seems to be an infantile image or label put on people with intellectual disabilities by society which is very difficult to escape, which adds to the problems of under educating (Kelly, 2013). Another issue that arose from the research was the idea that people with intellectual disabilities do not have the capacity to deal with or understand a situation such as sexual education (Kelly, 2013). This view is a reoccurring theme which staff and family have that people with intellectual disabilities are infantile or perceived as dependent (Shakespeare, 1996).

It seems to be preferred by staff and family to not acknowledge the sexual urges of people with intellectual disabilities (Kelly, 2013). Instead it is preferred to assume that people with intellectual disabilities do not understanding what they are doing and so remain to be perceived as "not sexually interested" (Kelly, 2013, pp. 396). Restricting knowledge in the area of sexual education for people with intellectual disabilities results in staff and parents remaining in anxiety of the unknown, in turn the service users become secretive and deceptive when wanting to sexually express themselves.

McConkey & Leavey (2013) conducted a longitudinal study of over 1000 people to find what the Irish public's attitude is towards people with intellectual disability having sexual relationships. It came to light that the public felt it to be more acceptable for someone with a

physical or sensory disability to have a sexual relationship rather than a person with an intellectual disability. These results reiterate the difficulty in shifting the social perspectives/ attitudes towards people with intellectual disability and sexuality. In Western society it is a force of habit to treat a person with an intellectual disability as infantile.

As mentioned earlier McConkey and Leavey (2013) were researching what the Irish public's attitude is towards people with intellectual disability having sexual relationships. In McConkey & Leavey's (2013) research it was found that "agreements were highest in all years for persons with physical disabilities" (pp.183) to have relationships whereas it was also lower for persons with mental health issue and people with intellectual disabilities. Is this entirely due to paternalism? Does society perceive people with intellectual disabilities as infantile? It is very much the case that people with intellectual disabilities are considered to not "have the same right to fulfilment through sexual relationships as everyone else" (McConkey & Leavey, 2013, pp. 183).

Participants of the McConkey and Leavey's (2013) survey that disagreed with people with intellectual disabilities having the same rights to sexual fulfilment had reasons such as the service users not having the capacity to make appropriate decisions (McConkey & Leavey, 2013). This fear of 'lack of capacity' could be remedied in many cases through sexual education as it teaches a person to have appropriate sexual knowledge and help in protecting a person from abuse or exploitation. Apart from these benefits there is still paternalism, there is a fear of people with intellectual disabilities falling pregnant and not being having the capacity to raise the child. An additional issue for people with intellectual disabilities that was mentioned previously is that people with intellectual disabilities are viewed as asexual and thought to not have any interest in having a relationship, less still a sexual one.

2.2.2 Empowerment

Healy, E. et al (2009, pp. 906) set out to "gather information from people with an intellectual disability about their knowledge, experiences and attitudes towards sexuality" in Ireland. The method they used to gather the information were focus groups, 32 service users with intellectual disabilities participated in these focus groups. The participants were selected randomly from the "service-user database in a community-based service for people with intellectual disabilities, located in the west of Ireland" (Healy et al. 2009, pp. 907). Although it was not specifically stated what level of disability the participants had mentioned that the focus groups consisted of a "range of different disability levels" (Healy et al. 2009, pp. 907) Through their research they discovered that the participants had received sexual education when under the age of 18, but it was evident from their answers that the information they were given was not appropriate to their needs. A question presented to the participants was, how do girls fall pregnant, which received a number of responses but one boy in particular replied; "by eating too much" (Healy et al. 2009, pp. 909). This corroborates what was stated in the previous section, that there is a major need for there to be tailored sex education for persons with an intellectual disability. Through this research, the need for individually tailored sexual education was evident as there may be possible gaps in their learning. Although the research was empowering as the researcher spoke directly to the service users there is an element of paternalism as there was a lack of knowledge of relationships and sexuality. This shows that it is not a black or white situation; paternalism and empowerment are intertwined especially in a case of supported empowerment which I will discuss later in this section.

There had been an absence of the voices of people with intellectual disabilities in research on this topic (Kelly et al. 2009). Provisions cannot be developed without the critical perspectives of the service users. Restrictions to having relationships and lack of information

on the topic can have negative results on the service users. Healy et al. (2009, pp. 910) discovered from the service users that "secrecy and deception were sometimes necessary to exercise their sexual rights". This secrecy and deception is due to the paternalistic attitudes society has for people with intellectual disabilities. Society wishes to protect people with intellectual disabilities and keep such groups unaware of the dangers such a sexual abuse and the harsh realities of a sexual relationship such as sexually transmitted diseases and unplanned pregnancies.

Supported Empowerment

Carrying on with the topic of tailored methods of sexual education for people with intellectual disabilities and supported empowerment, Duke & McGuire (2009, pp.728) set out to investigate whether sexual "education improves capacity to make sexuality-related decisions". The participants were chosen from a group home in Ireland, there were four participants 2 male and 2 female aged 22 and 23, and participants all had moderate levels of intellectual disabilities and had not received any formal sexual education before this. If people with intellectual disabilities received education on sexuality and had more knowledge in the area maybe societies perspectives would gradually change. Duke & McGuire (2009) through their research created individually tailored sex education for four adults with moderate intellectual disabilities. The results were positive, "all four participants improved their decision making capacity" (Duke& McGuire, 2009, pp.727), the National Disability Authorities' (2010) supports this theory that a tailored method of sexual education for people with intellectual disabilities would improve a person's capacity to make sexuality related decisions. This proved with supporting service users in receiving this information can improve their capacity to make informed and correct decision. Duke & McGuire (2009) had discussed that there was a difficulty in providing sexual education that both facilitates sexual expression and guards

"against exploitation and abuse" (Duke & McGuire, 2009, pp. 727). As mentioned in earlier sections there are people with intellectual disabilities capable of having relationships but there is also a minority group who unfortunately do not have the capacity to deal with a sexual relationship and so must be protected from exploitation and abuse. To equally balance these liberal and protective perspectives with education methods is a difficult task.

Advocacy

The *Inclusive Research Network* is a network in which people with disabilities are assisted in carrying out research. Bane et al (2012), a group of researchers with learning disabilities, investigated relationships of people with intellectual disabilities, it was not stated what level of intellectual disability the researchers or participants had; they held 16 focus groups across different parts of Ireland. Many of the interviewees of the research felt "treated like children regarding relationships" (Bane et al, 2012, pp.119). This issue of being treated like children will be discussed further under the paternalistic perspective. Bane et al's (2012) research is placed under the empowerment perspective as people with intellectual disabilities are researching and speaking for themselves, and are providing their perspective on provisions. As stated previously, to equally balance a liberal and protective perspective is a difficult task but with the input of the service users it may help in the balancing of perspectives. From Bane et al.'s (2012) research two very beneficial suggestions from service users were gathered. The first suggestion was that "training and guidance should include viewing adults with learning disabilities as adults with rights" (Bane et al, 2012, pp.119). The second suggestion was that people with learning disabilities should be "involved in the training of staff and families on the right … to have relationships" (Bane et al, pp.121). These improvements to provisions could make a large difference to the perspectives staff and family members have of people with intellectual disabilities.

Recently RTE 1 showed a documentary called '*Somebody to Love'* (17th February 2014) which allowed people with disabilities discuss their sexuality and their right to express it. The documentary aimed to give the general public an insight into the lives of a person with a disability and hopefully change people's perspectives on people with disabilities having relationships and to advocate for them being allowed have 'somebody to love'.

2.3 Conclusion

This review has covered Irish perspectives on the issue of sexual education for people with intellectual disabilities. The literature reviewed suggests that there is support from a range of stakeholders in relation to implementing appropriate sexual education for people with intellectual disabilities so as to support them in making sexuality-related decisions. This is seen as beneficial to their learning and it is suggested that with the right supports can improve a person's capacity to make sexuality related decisions. Furthermore the literature promotes the view that it would be most beneficial for the development of sexuality education to have the service users involved in determining what type of education might be most useful to and appropriate for them.

The bulk of the research in Ireland suggested that people with intellectual disabilities have an interest in having relationships and expressing their sexuality but often there aren't appropriate provisions or support from staff and parents. The staff, parents and public in this review came across as having a paternalist perspective of people with intellectual disabilities and my primary research with service providers and parents which is detailed in subsequent chapters examines this further.

A key question that arises when reviewing this literature is whether or not views on the sexuality of people with intellectual disabilities have changed over time? I believe that the answer is yes they have, we saw at the beginning of the chapter the first piece of research we analyses was by Allan & Seery (2007) who discussed the lack of appropriate sexual education which then moved on to the general publics, staffs and parents attitudes towards people with intellectual disabilities sexuality by Evans (2009), Foly & Kelly (2009) and McConkey & Leavey (2013). Although these pieces the participants did not condone people with intellectual disabilities expressing their sexuality, the fact they spoke about it and noted their concerns about providing information on how to have relationships showed they acknowledged the person with an intellectual disability as a sexual being but did not wish for them to act on it. We then saw the literature move toward a more empowering perspective in which it discussed such topics as supported and advocacy, throughout the different pieces we also so the introduction of participatory research in which people with intellectual disabilities assisted in carrying out the research. It even developed to the point that in Bane et al. (2012) had people with intellectual disabilities conduct the research themselves. The views on people with intellectual disabilities have developed so far that even a documentary programme (*Somebody to Love*) was produced to acknowledge the fact that just because you have an intellectual disability or any form of disability does not make you any less of a human and you should still be allowed full access to provisions and support in expressing sexuality.

This review has brought up issues such as parental and service provider attitudes on the sexuality of people with intellectual disabilities which has influenced my primary research to delve deeper into this issue and ask parents and service providers first-hand what their attitudes

are towards this issue. I had intended doing focus groups with people with intellectual disabilities on this topic but due to time restraints this was not possible. However the research in this review which interviewed people with intellectual disabilities advocates for greater rights for people with intellectual disability as it supports the ideas of people with intellectual disabilities being consulted in research. It is now time to begin "viewing adults with learning disabilities as adults with rights" (Bane et al. 2012, pp.119)

3. Policy Review

3.1 Introduction

In this chapter the policies and legislation that provide the socio-legal context for people with intellectual disabilities in Ireland in terms of sexuality will be explored. The policies and legislation will be discussed as they developed throughout history, the themes to be discussed are; protectionism, equality and rights. Under these headings the keys policies and legislation will be discussed and analysed in terms of the effects on people with intellectual disabilities expressing their sexuality. The advocacy that has gone into amending out-dated legislation will also be discussed. The chapter will conclude with consideration of how these policies and legislation have influenced the sexuality education provided to people with intellectual disabilities.

3.2 Protectionism

3.2.1 Institutionalisation

The historical background of these pieces of legislation evolved from legislation associated with institutions which accommodated people who were considered to be 'lunatics'. Society at the time was not so accommodating towards people with intellectual impairments and so it was considered safer to have people with intellectual disabilities in institutions where they would not have the opportunity to 'procreate' or be a danger to themselves or society.

As just mentioned society felt institutionalisation was the best choice for people with intellectual disabilities. It was to become a method of removing anyone "who refused to

conform" (Oliver, 1990, pp.32) to society's idea of normal. Unfortunately people with intellectual disabilities were deemed to fall under that definition. Richmond Asylum in Dublin was the first psychiatric institution built in Ireland; it was opened in 1815 with 250 beds (Porter & Wright, 2003). It was also to be one of the first places in Ireland to institutionalise people with intellectual disabilities.

Historically people with intellectual disabilities were regarded as being 'uncontrollable' and "sexually threatening" (Kelly, 2013, pp. 349). It was also believed that intellectual disabilities were "genetically inherited" (Kelly, 2013, pp 350). If a woman with an intellectual disability fell pregnant it was assumed her child would have this disability too. This concern is reflected in *The Criminal Law Amendment Act 1935*, which states under section 4 (1) that;

> *Any person who, in circumstances which do not amount to rape, unlawfully and carnally knows or attempts to have unlawful carnal knowledge of any woman or girl who is an idiot, or an imbecile, or is feeble-minded shall, if the circumstances prove that such person knew at the time of such knowledge or attempt that such woman or girl was then an idiot or an imbecile or feeble-minded (as the case may be), be guilty of a misdemeanour and shall be liable on conviction thereof to imprisonment for any term not exceeding two years*
>
> (*Criminal Law Amendment Act,* 1935, Section 4.1)

It is of great importance to acknowledge that at the time this was a protective piece of legislation. It was established to protect those with intellectual disabilities from sexual abuse and exploitation. But it was also making a 'protective' move for society, resulting in people with intellectual disabilities who became "sexually threatening" (Kelly, 2013, pp.349) restricted from having relationships or families.

In the 1930s "the Irish Free State was found to have the highest rate of institutionalisation for the insane or the mentally defective" in Europe (O'Sullivan &

O'Donnell, 2012, pp.10). In Ireland institutionalisation was due to the fact that "inspectors consistently advised the government from the 1860s through into the 1910s that institutionalisation was the only answer" (Porter & Wright, 2003, pp.322). The institutionalisation of people with intellectual disabilities carried on into the 1960s.

In the 1960s there began to be a move away from institutionalisation and an introduction of those with intellectual disabilities back into society. This move toward deinstitutionalisation and normalisation was flagged in section 45 of the *Commission of Inquiry on Mentally Handicapped* (1965) which stated "the accommodation in district mental hospitals of mentally handicapped children should be discontinued" (pp. 18). It was also agreed that the treatment of adults should be discontinued unless they were elderly clients, in which case it would be too disruptive for them to go through deinstitutionalisation (*Commission of Inquiry on Mentally Handicapped*, 1965)

3.3 Equality

As mentioned previously, from the mid to late 1960s there began to be a disability rights movements, resulting a move away from enrolling people with disabilities into institutions, this move away from institutionalisation was called deinstitutionalisation (Considine & Dukelow, 2009). The disabilities rights movement which had been influenced by the Civil Rights movement in the 1960s helped people with disabilities recognise their right to be active participants in society.

3.3.1 Deinstitutionalisation

Ireland was beginning to move away from institutionalisation and to bring about a more equal society. There was also a move towards providing adequate and tailored education to people with intellectual disabilities. The *Commission of Inquiry on Mentally Handicapped* (1965) suggested under Section 37 "voluntary bodies should provide adult training designed to fit mildly handicapped adults for employment and for life in the community" (pp. 17). The perception of people with intellectual disabilities being "sexually threatening" (Kelly, 2013, pp. 349) was now beginning to diminish. The *Commission of Inquiry on Mentally Handicapped* (1965) aimed to integrate people with intellectual disabilities into the community and teach them, "through development of social adequacy, to obtain security, and happiness in adult life as a self-reliant member of the community" (Section 65, pp. 67). This 1965 document represented a key turning point for the way in which those with intellectual disabilities were responded to. Significantly it promoted the view that those with ID should be accorded the opportunities available to the non-disabled population, including education and employment opportunities.

3.3.2 Normalization

During the 1970s there began to be a stronger move away from institutionalization and emphasis on 'normalization'. The idea of normalization was the "utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviours and characteristics which are as culturally normative as possible" (Wolfensberger, 1972, pp.28). Although the principle originated from Scandinavia, it was developed most by

Wolfensberger in Canada. The aim was for there to be a social acceptance of difference (Wolfensberger, 1972). An example of Ireland's compliance to the normalization principle was the development of the *Training and Employment Report* (1974), it aimed to teach life skills to those with intellectual disabilities. These life skills would help in the process of becoming an active participant in employment and in the community. Normalization and deinstitutionalisation were to go hand in hand in the reintroduction of people who were in institutions coming back into the community. People who were in these institutions were in need of training and special education to integrate back into the community.

3.3.3 Social Model

The 1980s in the U.K. saw the term 'Social Model' develop, it was to suggest that "rather than disability being inescapable, it becomes a product of social arrangement, and can thus be reduced, or possibly even eliminated" (Oliver (1990) cited by Shakespeare, 2006, pp.29). This section discusses the policy and legislation in place that promotes the social model in Ireland, beginning with *Toward a Full Life* (1984)

Toward a Full Life (1984) was a Green Paper issued by the Government, it was developed to highlight what services are in need of development for people with disabilities. Up until this, many of the developments and supports for people with disabilities were lobbied for by advocacy groups and charities. This report was also looking at the suggestions made by the *Commission of Inquiry on Mentally Handicapped* (1965) to see where Ireland was in terms of provisions for people with intellectual disabilities. The Green Paper was to advocate for the inclusion of people with intellectual disabilities into the community. Although it does not

discuss people's sexualities it is speaking of social inclusion and provisions to promote independent living. Some of the changes the Green Paper made was it recognised the need for equal employment by "creating greater awareness among employers of the skills and abilities of disabled people" and promoted employment opportunities (*Toward a Full Life*, 1984, pp. 58. It also made a movement towards social integration as it promoted "interaction between disabled people and non-disabled people from the earliest possible age" and in most aspects of life (*Toward a Full Life*, 1984, pp. 116). It wished to "improve community understanding and contact with disabled people" which are important for full integration into a community (*Toward a Full Life,* 1984, pp.116)

In 1990 the *Needs and Abilities* report was established, the aim of this document was to provide people with intellectual disabilities with appropriate education. It was argued that providing appropriate education would result in the child developing life skills with which they can get jobs and be active members of the community. It recommended that the term 'mentally handicapped' be abolished and instead be replaced by "general learning difficulties" and "moderate, severe or profound degree of intellectual disability" (*Needs and Abilities*, 1990, Section 3.4, pp. 14). This change was a great development as it acknowledged inappropriate terms such as 'handicapped'. One major development on the topic of intellectual disabilities and sexualities was stated under section 5.8, where "the need to have sex education and family planning advice made available for people with general learning and intellectual disabilities" was identified (*Needs and Abilities*, 1990, Section 5.8, pp.19), it was a statement made when discussing the development of provisions on integrated community based services who would then be responsible for providing people with intellectual disabilities these services. *Needs and Abilities* addresses the issue in the report when it questions, what people with intellectual disabilities who are integrated into the community, will need in terms of support is around

sexuality. This shift to a capacity and right based approach is significant, but questions have to be raised as to the extent to which it prompted legislative or practical changes around sexuality for those with intellectual disabilities.

3.4 Rights

This section aims to give a brief review of key policies and legislation that provide the current policy and socio-legal context for people with intellectual disabilities in Ireland in terms of sexuality. In particular this section will be looking at the *Criminal Law (Sexual Offences) Act* 1993, *The Disability Act* 2005 and *Sexual Offences and Capacity to Consent* 2013, under the headings of the right to information and paternalism.

3.4.1 Paternalism

Criminal Law (Sexual Offences) Act 1993 has become a major barrier for people with intellectual disabilities to sexually express themselves. It has also had major impacts on the perspectives of service providers and parents in terms of sexual education for people with intellectual disabilities. Due to this act, in Ireland it is illegal for a person to have or attempt to have a sexual relationship outside of marriage with someone who is considered to have an intellectual disability. This piece of legislation was influenced by *Criminal Law Amendment Act* 1935 which had been established as a piece of protective legislation for those with intellectual disability. Though this is a protective piece of legislation it has been critiqued for also being "over-paternalistic and creating uncertainty regarding whether two people with intellectual disabilities can legally have sexual intercourse with each other" (Law Reform 2005;

2011 in Kelly 2013 pp.350). This legislation is not complying with the U.N. Standard Rule which will be discussed later in the chapter. The *Criminal Law (Sexual Offences) Act* 1993 is over paternalistic and discriminatory. No one group should be categorised as unable to have fulfilling relationships or families unless married, it is against a person's human right. The issue with the *Criminal Law Sexual Offences Act* 1993 is it is putting everyone with an intellectual disability into the one category, the Act is protecting those who have a profound disability that may not be able to have such relationships, but is unfortunately restricting and confusing to those who have the capacity.

Another piece of protective legislation is *The Disability Act* (2005). It is Ireland's main piece of legislation for people with all forms of disabilities. While originally intended to be protective and empowering, it defines a person with a disability as having "substantial restriction in the capacity … to participate in social or cultural life" (*Disability Act*, 2005). It is oppressive in itself to be defined as lacking the ability to participate in society. It categorises people with disabilities as a minority group or 'the other'. This definition can participate in the development of a person's perception of disability especially in terms of sexuality and sex education. This leads on to another issue with the *Disability Act* (2005), it states that it is "an Act to enable provision to be made for the assessment of Health and Education Needs occasioned to persons with disabilities by their disabilities" (2005. Pp.5), yet in no part of the act does it consider sexual education to be a component of a person's educational needs. This failure of the Disability Act (2005) to exclude sexuality and relationships as a component of a wider health, education and rights agenda, reflects traditional concerns and fears around sexuality and intellectual disability. Furthermore this act highlights the fact that sexuality has not been recognised as an issue of rights in Irish disability legislation.

3.4.2 Right to Information

In this section we look at the issue of accessible information for people with intellectual disabilities on their sexuality. Currently in Ireland there is no regulated or consistent way of teaching sexual education to people with intellectual disabilities (Kelly, 2014, pp. 350), leaving people with intellectual disabilities confused on what they can and cannot do and often misinformed, due to staff and parents being unsure of what they can or cannot say.

Assisted Decision-Making (Capacity) Bill 2013

Under the U.N. Standard Rules (1993) when speaking about the rights of people with disabilities it states under Rule 9.2;

> *"Persons with disabilities must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood. Taking into account that persons with disabilities may experience difficulties in getting married and setting up a family, States should encourage the availability of appropriate counselling. Persons with disabilities must have the same access as others to family-planning methods, as well as to information in accessible form on the sexual functioning of their bodies"*
>
> (U.N. Standard Rules, 1993, Rule 9.2)

This stands for all people with disabilities including those with intellectual disabilities. it is important that there should be the appropriate provisions and accessible information for those with the capacity to have fulfilling relationships.

A report by the Law Reform Commission published in 2013, entitled *Sexual Offences and Capacity to Consent* (Law Reform Commission, 2013) suggests that there should be a "multi agency approach" that would go on to develop a high quality sexual education course for people with intellectual disabilities. It also recommended that there should be an "emphasis on supporting the positive exercise of a person's legal right to sexual expression" (Law Reform Commission, 2013). The Law Reform Commission suggested these recommendations as it

believed the current legislation did not cooperate with the U.N. Standard Rule (1993) and so should be considered deficit (McCárthaigh, 2013). The National Disability Authority (2010) argued in their National Disability Authority Strategic Plan that what would be most beneficial is a tailored form of sexual education to suit each person's need. Having a good knowledge of sexuality would help those with intellectual disability to develop healthy sexual relationships and would also be a form of protection from exploitation (Law Reform Commission, 2011). People should be made aware that there is no issue with a person expressing their sexuality, especially if a person's mental capacity is not an issue (Law Reform Commission, 2013).

The *Criminal Law (Sexual Offences) Act* 1993 causes major barriers for people with intellectual disabilities practicing their decision-making skills in terms of sexual expression. The act has criminalised people with intellectual disabilities having sexual relationships with someone if they are not married (*Criminal Law (Sexual Offences) Act*, 1993, Section 5). This shows we are still not compliant with rule 9 of the U.N. Standard Rules. Section 5 of the *Criminal Law (Sexual Offences) Act* 1993 has oppressive effects on people with intellectual disabilities.

The most recent development in terms of intellectual disabilities and sexuality is the *Assisted Decision-Making (Capacity) Bill* 2013. This Bill was designed as a means to develop and amend pieces of legislation associated with people whose decision making capacity is often brought into question. But one year on and it has still not been enacted, on the 14th of July the advocacy group *Inclusion Ireland* addressed the issue in a meeting with the UN Human Rights Committee (*Inclusion Ireland*, 14th July 2014). The *Assisted Decision-Making (Capacity) Bill* 2013 gave hope that Section 5 the *Criminal Law (Sexual Offences) Act* (1993) would be

amended or be considered deficit but if implemented it will make no changes to current legislation. Under Section 106 of the *Assisted Decision-Making (Capacity) Bill* (2013) it states;

> *Unless otherwise expressly provided, nothing in this Act shall be construed as altering or amending the law in force on the coming into operation of this section relating to the capacity or consent required as respects a person in relation to any of the following:*
>
> *(a) marriage;*
> *(b) civil partnership;*
> *(c) judicial separation, divorce or a non-judicial separation agreement;*
> *(d) the dissolution of a civil partnership;*
> *(e) the placing of a child for adoption;*
> *(f) the making of an adoption order;*
> *(g) guardianship;*
> *(h) sexual relations;*
> *(i) voting at an election or at a referendum;*
> *(j) serving as a member of a jury.*
>
> (*Assisted Decision-Making (Capacity) Bill*, 2013, Section 106, pp.86)

Although the *Assisted Decision-Making (Capacity) Bill* (2013) states it will make no changes to legislation related to sexual relations. Though changes have not yet been implemented, it is important to note that the issue has been acknowledged to be in need of immediate change, it will take time before a draft amending the current legislation will be published (*Inclusion Ireland*, 14th July 2014).

3.5 Conclusion

Throughout this chapter I have explored the policies and legislation most influential for people with intellectual disabilities in terms of capacity and independence. The historical perspective

taken here highlights the development of a rights perspective for people with intellectual disabilities. Education was a key theme throughout, it was the theme that is most important to this topic of intellectual disabilities and sexuality as education in sexuality is something that is underdeveloped. Although there have been many barriers crossed and many developments made for people with intellectual disabilities, it is unfortunate that the sexuality of people with intellectual disabilities is not a norm. It is still being kept out of reach and still people with intellectual disabilities are being kept in the dark about the realities of having a sexual relationship. But there is hope that in the near future with enough self-advocacy this barrier too will be passed.

4. Methodology Chapter

4.1 Research Design

In this section there will be a discussion on how the research was done, the research approach, methods, ethics and data management techniques will be outlined. A lot of thought has gone into the research design as an Ethics Approval Form was submitted to the UCC Social Research Ethics Committee. The research took a qualitative approach to gather primary date which will be discussed throughout this chapter. The research project is a CARL Project, The CARL (Community-Academic Research Link) initiative provides a link between researchers and community and voluntary groups. Another part of the initiative I undertook is I got to work in collaboration with the group Down Syndrome Cork throughout my research (CARL, 2013). This research is important as there is no definite answer to what type of sexual education people with intellectual disabilities want or need. There is also the issue that adequate sexual education is not being provided to people with intellectual disabilities due to the issues of capacity and legislation (Irish Family Planning Association, 2012). Through this research I investigated the opinions of parents from Down Syndrome Cork on the sexuality of their children and the opinions of service providers on sexual education and the sexuality of their service users.

4.2 Research Approach

This research adopted a qualitative approach to explore the views of service providers and parents on the issue of sexual education for people with intellectual disabilities in the Cork area. Qualitative research allows people to express their view on an issue in a way they understand, rather than through numbers which would be considered quantitative (Kalof, 2008). In the words of Holloway (1997, pp.2);

Qualitative research is a form of social inquiry that focuses on the way people interpret and make sense of their experiences and the world in which they live. A number of different approaches exist within the wider framework of this type of research, but most of these have

the same aim: to understand the social reality of individuals, groups and cultures. Researchers use qualitative approaches to explore the behaviour, perspectives and experiences of the people they study.

This topic is under researched and sensitive and people may have very mixed views and emotions on the issue. This approach allows for conflicts and views to be drawn out. An interpretive approach will be taken as this allows participants to describe their lived experiences from their point of view with the researcher making sense of these experiences (Kalof, 2008; Bryman, 2008). This approach is useful to my research topic as it allows me to have more in-depth conversation with the participants and to gain broader view of the issue.

4.3 Data Collection & Research Methods

The primary research consists of information that I gathered through my focus group with parents of people with intellectual disabilities and my one to one interviews with service providers. My secondary research consists of books and journals which I accessed through UCC's Boole Library and online resources. The two methods I used for gathering primary data for my dissertation were focus groups and semi-structured face to face interviews which I will discuss later in this chapter. Data is separated into primary data that was gathered through the focus groups, interviews and the secondary data that I gathered for my policy and literature review. Primary data is information that is received first hand; in this research the researcher gathers such data through focus groups and semi-structured face to face interviews (Kalof, 2008).

4.3.1 Method 1: Focus Groups

A focus group is a group interview, focused on a topic set by the researcher. The group interact and together construct answers or meanings in response to the questions or topics identified by

the researcher (Bryman, 2008). This method is useful as it may prompt conversation and make other participants feel more comfortable to have a conversation on the topic. The disadvantage of this type of interviewing is that it results in some participants being out spoken. I held a focus group held with parents from Down Syndrome Cork. This was an ideal method to use to gather broad views on the issue of sexual education. The information gathered from the focus group had an influence on the topics discussed with the service providers. I did not have to recruit these participants, as this research is a CARL project the person I liaison with from Down Syndrome Cork was able to recruit the parents for the research. The person I liaised with for this research was Karen O'Sullivan who was fundraising co-ordinator for the organisation. Below is a table of details on the parents that participated:

Parent:	Child Gender:	Childs Age:
Parent 1	Son	11
Parent 2	Daughter	14
Parent 3	Daughter	20
Parent 4	Daughter	15
Parent 5	Son	13
Parent 6	Son	14
Parent 7	Son	43
Parent 8	Son	25

4.3.2 Method 2: Semi Structured Face to Face Interviews

Semi-structured interviews consist of conversations with interviewees on a pre-defined topic. (Fylan, 2005) This method was useful to my topic as I was able to have in-depth discussion

with the interviewee and delve deeper into issues that arose. A disadvantage of this method was the difficulty to not prompt or be judgemental of the replies. The semi structured interviews were carried out with Service Providers and a sexual education teacher for people with intellectual disabilities from the Sexual Health Centre.

The secondary data collection was carried out when doing the literature review and policy review for this research. Secondary data is information that is already available in the public domain (Kalof, 2008). How I went about gathering my secondary research data was through resources such as UCC Boole Library website, Google, The Irish Statute Book, LENUS and the Law Reform Commission. For my policy chapter when searching for Acts I went to the Irish Statute Book's website I clicked on 'Acts of the Oireachtas' which led me to a selection of different years to search, I went through each to find Acts that related to my topic. When finding publications in LENUS I went to the search bar and inserted 'People with Disabilities' which then brought up various reports relating to the topic but specifically *Toward a Full Life*. I also went to the Law Reform Commissions website, there I clicked on publications, Reports and Consultation Papers and went through the different options to find reports and consultation papers relevant to this topic. What had also been influential on my policy review were the articles and books I used for my literature review. I found Grace Kelly's 2009 article and her chapter on "Constructing the Sexualities of People with Intellectual Disabilities" in the book *Sexuality and Irish Society: A Reader* by Máire Leane and Liz Kiely to be key pieces for this research when finding articles and books significant to this research.

For my Literature Review I searched the UCC Boole Library website for books under the search terms 'Disability and Sexuality', 'Intellectual Disability and Sexuality', 'Sexual Education for People with Intellectual Disabilities' and 'Sexuality, Intellectual Disabilities,

Ireland'. These search terms were also used when searching the journal databases JSTOR and SocIndex – EBSCO. Another resource I used for finding articles for my dissertation was Google Scholar, I inserted the above search terms in Google Scholar and if articles of relevance to my topic arose I went back to the UCC Boole Library website, selected 'Searcher' and inserted the title of the article to gain access to it.

4.4 Description of Sampling Methods

4.4.1 Purposive Sampling

I used purposive sampling for my dissertation when recruiting the participants for my semi structured face to face interviews, "the goal of purposive sampling is to sample cases/ participants in a strategic way so that those sampled are relevant to the research questions that are being posed" (Bryman, 2012, pp. 418).

4.4.2 Interview Sampling

A purposive sampling technique was employed whereby I identified the key managerial staff in each organisation (COPE, Co-Action, St Joseph's Foundation) willing to speak on this topic and who would have had the information on the policy and practice of sex education in their organisation. I made direct contact with the organisations and the sexual education teacher in the Sexual Health Centre myself with an email with letter of introduction attached and a letter from Down Syndrome Cork explaining the research that was being carried out (See Appendices 8.1, 8.2 & 8.3). The only inclusion criteria as mentioned previously, is that the service providers would be familiar with the sex education policy and practice in the organisation.

4.4. 3 Details of Interviewees

St Joseph's Foundation is located in Charleville, there are 800 service users availing of the centres services. Conor Counihan was speaking for the adult members of the service; there are 300 adult service users in total. The sexual education programme they have in place is Raising Understanding and Awareness Programme also called RUA.

COPE Foundation is located in Montenotte, there are 2,500 service users availing of its services. There is no formal form of sexual education within this centre nor is there any policy on relationships or sexuality.

Co-Action located in Castletownbere, there are 25 people availing of their services here. They had a programme called TOPS which was a basic form of the Stay Safe Programme. In 2003 they developed their own programme called the Social, Personal and Health Education Programme.

4.4.4 Convenience Sampling

Convenience sampling was used for recruiting the parents for the focus group, "a convenience sample is one that is simply available to the researcher by virtue of its accessibility (Bryman, 2012, pp. 201). The reason for the focus group being convenience sampling was due to the dissertation being a CARL project and the person I liaised with was able to recruit parents for my focus group.

4.4.5 Focus Group Sample

As stated earlier this is a CARL Project with Down Syndrome Cork, Down Syndrome Cork organised the focus groups. The aim was to interview at most 8 people in the group as it would be too difficult to moderate and transcribe if the group were to be any larger. The parent focus group criteria for the focus group were that participants have a child with an intellectual disability and ideally would be stratified on the basis of the age of their children. An effort was made to recruit parents of children in the following age categories: 10 – 13; 14 – 17 and 18 years plus. An effort was also made to recruit both male and female parents but only female parents turned up on the night.

All parents from the focus group for anonymity have been given the pseudonyms Parent 1 to Parent 8 to represent them. Any identifiable characteristics have been taken out. All other participants have consented to their name and organisation to be referred to. Listed below again are the parent's numbers, gender of child and age:

Parent:	Child Gender:	Childs Age:
Parent 1	Son	11
Parent 2	Daughter	14
Parent 3	Daughter	20
Parent 4	Daughter	15
Parent 5	Son	13
Parent 6	Son	14
Parent 7	Son	43

Parent 8	Son	25

4.5 Ethical Research Practice

4.5.1 Informing Participants of the Research

I sent letters of information on the research to Down Syndrome Cork to hand out to those interested in participating in the research. In the letter to the parents of children with intellectual disabilities, I informed them of the research topic and of the themes of the questions. (See appendix 8.3 for the Letter).

The letter to the service providers informed them of the research I am carrying out and also the topics I wish to discuss with them, namely the policies their organisation has on sexual education for their clients and also how they put these policies into practice. I also attached a letter from Down Syndrome Cork supporting this research. (See appendix 8.7) for copies of the Letter.

4.5.2 Consent

I obtained written informed consent from the interview and focus group participants, they were asked to fill out consent forms with me present so I could then answer any questions they wish to ask about the research and before the interview began. (See Appendix 8.4, 8.5 & 8.6 for Consent Forms)

4.5.3 Debriefing

The parents and the service providers that participated in the research also receive the details for the Sexual Health Centre and a reading list with key documents and articles on the topic of

sexual education for people with intellectual disabilities. (See Appendix 8.8 for Debriefing Material)

4.5.4 Data Management

All interviews were taped with a Dictaphone and transcribed for the research. The participants were guaranteed confidentiality and anonymity by using pseudonyms when transcribing and writing up the final report. All identifiable characteristics were changed, the recordings were kept in a secure location and destroyed within days of the report being finalised.

4.5.5 Ethics

In total the main ethical issue in this research was in relation to the involvement of parents of people with intellectual disabilities in the focus group as the information they were providing was very personal to their child. I was the researcher who conducted the focus groups but Down Syndrome Cork selected the participants due to the CARL agreement. I was relying on them to identify parents with a variety of aged children with intellectual disabilities who would be comfortable with the process of research and are interested in participating. During the interviews with the parents there was a staff member of Down Syndrome Cork present to support participants with anything that is of concern to them and who was also a parent of a child with Down Syndrome. All the participants were voluntary participates in the research and consent forms were signed before interview are carried out. The steps I took to secure all ethical research steps were practiced I presented all participating parents with an information letter which informed them of the research and what topics were to be discussed, these letters were sent out a week previous to the focus group. Due to this private information being discussed in the focus group I reassured the parents that their names will be replaced with pseudonyms and that any identifiable characteristics were to be removed from the transcript. On the night of the

focus group I handed out the letter again with the consent form attached for those who might have wanted to ask questions before hand or had not received the letter previous to the focus group. Once all parents agreed they were happy to participate in the focus group and provide such personal information on their child they signed the consent forms attached to their letters and handed them up to me. I and all participants agreed to full disclosure of all personal and confidential information I then held the focus group, once completed I handed each parent debriefing information which included the contact details of the Sexual Health Centre in Cork, books and journals all on the area of sexuality of people with intellectual disabilities. I recorded the interviews through a Dictaphone, once all the interviews were complete a began transcribing them. When all interviews were transcribed I sent the transcripts back to all participants for approval, as there were so many participants in the focus group instead of sending the entire transcript I made an executive summary of the information.

4.6 Reflection

Initially this research intended to have a focus group with people with intellectual disabilities, due to time restraints this was not possible. If there was more time a focus group with adults with intellectual disabilities on the issue of sexual education would have been beneficial towards the research. In correlation with that statement better time management on my part would have been more beneficial in regards to gathering my primary information. I would not have left the interviews as let in the summer as transcription of these interviews is time consuming.

Each one to one interview took 45 to 60 minutes in total, I recorded these interviews with a Dictaphone. Before the interview commenced I had the participant sign the consent form and ask any questions they needed answering about the research. In the interview with St.

Josephs a member of staff that was trained in RUA (their sexual education programme), sat into the interview to answer any questions about the programme. It was very informative to have the sexual education teacher in the interview.

The focus group I held with the parents of people with intellectual disabilities took up to an hour and a half, this interview was also recorded with the Dictaphone. It was beneficial to interview the parents as it helped in building an image of the different perspectives on the sexuality of people with intellectual disabilities. If there were more time it would have been worthwhile to hold focus group with another group of parents covering topics not discussed in the previous focus group.

5. Findings Chapter

5.1 Introduction

In this chapter the findings from my primary research will be discussed. Four one to one interviews and a focus group were held to gather this information, all interviews were audio recorded and transcribed. The people interviewed for the one to one interviews were: sexual education teacher Phil Corcoran, CEO of St Joseph's Foundation Conor Counihan, director of development and innovation in COPE Foundation Sean Abbott and area manager of Co-Action Castletownbere Conor McAtasney. The focus group consisted of 8 parents from Down Syndrome Cork. Details on the interviewees were provided in the methodology chapter.

The data gathered in these interviews was analysed thematically and is presented and discussed in the remainder of this chapter.

5.2 Relationships and Sexuality: Policies by Service Providers

To begin with in this part of my dissertation I wish to discuss the policies in place in the organisations St Joseph's Foundation and Co-Action. COPE is not included here as they currently do not have a policy in place in relation to relationships and sexuality which will be discussed in my analysis chapter under the practice of sexual education heading. This chapter will be broken into the topics Relationships and Sexuality, Consent and Privacy; I chose these topics as they were the common themes throughout the services policies.

5.2.1 Relationships and Sexuality

St Joseph's Foundation has a very comprehensive policy on relationships and sexuality; they cover all areas from friendship to contraception. St Joseph's Foundation state that "people with

intellectual disabilities have the same rights as other human beings and no-one should be prevented from making choices about his or her own life simply on the grounds that he or she has an intellectual disability" (St Joseph's Foundation, 2013, pp 2). In the introduction to their policy they state the importance of relationships and sexual education;

> *Relationships and Sexuality Education is a lifelong process of acquiring and understanding and of developing attitudes, beliefs and values about sexual identity, relationships and intimacy. This education is delivered consciously and unconsciously by parents, teachers, peers, adults and the media*
>
> (St Joseph's Foundation, 2013, pp.1)

Co-Action's policy is named Policy on Relationships and Sexual Health of Service Users. The policy covers Staff Training and Education all the way to Response to Sexual Misconduct. Co-Actions Policy states that;

> *People with intellectual disabilities have the right to:*
>
> - *Be provided with information and education on sexuality*
> - *Express their sexuality.*
> - *Marry or live together*
> - *Have children.*
> - *Make choices in all areas of sexuality.*
> - *To be supported to access sexual and reproductive health care.*
> - *Be free from abuse and exploitation of any kind.*
>
> (St Joseph's Foundation, 2013, pp. 2)

Like St Joseph's Foundation Co-Action believe that having an intellectual disability should not affect you having a relationship or expressing your sexuality.

Emphasising what I had been stated in previous chapters when discussing the importance of providing sexual education to people with intellectual disabilities. In Co-Action Due to the Capacity to Consent legislation not having gone through the Oireachtas yet the centre are not yet able to "fully commit" (Conor McAtasney) to their clients having full relationships within the centre homes and so "there is still a bar on people having sexual relationships within Co-Action group home" (Conor McAtasney) but that does not mean they are "barred from having a sexual relationship in their own homes" as mentioned by Conor McAtasney.

All services agreed on the need to provide all service users with "advice and information appropriate to their needs" (St Joseph's Foundation, 2013, pp 2) and "support on matters in a person centres and meaningful way" (Co-Action, 2013, pp. 1).

5.2.2 Capacity

In this section I wish to discuss the policies take on capacity and the capacity to consent. As stated by St Joseph's Foundation "no one should be prevented from making choices about his or her own life simply on the grounds that her or she has an intellectual disability" (2013, pp. 2). Co-Action in their policy makes reference to the U.N. Convention on the Rights of Persons with Disabilities about providing their service users with the appropriate measures to exercise their legal capacity. Co-Action aims to provide support in increasing their service users "knowledge, skills and ability to give and withhold their consent for sexual activities" (Co-Action, 2014, pp. 4). The centre goes about ensuring this with couple by putting them through a functional assessment, the functional assessment team consist of a senior clinical psychiatrist, support circle and other specialists (Co-Action, 2013).

This brings me onto to the issue of consent and the procedures taken by the services for their service users to give informed consent. As previously discussed Co-Action does a functional assessment on a couple to assess their capacity to have a full relationship, the key elements of this assessment are that "both partners in the relationship have been provided individual counselling to determine their capacity to understand decisions that they make in terms of relationships, abuse and sexuality", that capacity would be reaffirmed regularly to avoid abuse and that "both partners have received training in the area of relationships, sexuality and decision making and understand the implications of the choices they make" (Co-Action, 2013, pp. 6).

5.2.3 Privacy

Many of the services provide group homes to their services users in which privacy can be a difficult thing to achieve in group homes but is an important aspect of someone's life, as Co-Action states in their policy "privacy of space and time is presumed to be a need for all people, allowing for independent thought, relaxation, pursuit of personal relationships or disengagement from social pressures" (2013, pp. 3). St Joseph's Foundation aspires to providing the people in their service privacy, in the residential services "staff must knock before entering a bedroom or bathroom" (St Joseph's Foundation, 2013, pp. 4).

5.3 Sexual Education: Characteristics of Provision by Service Providers

This section of the chapter will present my research findings in relation to the many different types of sexual education that interviewees identified as being provided to adults with intellectual disabilities in the Cork area. It will also discuss the different ways this education

was delivered and the reasons why it was introduced in the various services. In the previous chapters the policy of relationships and sexuality education in these centres were discussed.

The *Stay Safe Programme* was designed by the HSE in 1998 to be delivered in all primary schools across the country and taught by primary school teachers. The aim of the stay safe programme is to "reduce vulnerability to child abuse and bullying through the provision of a personal safety education programme for children" (Stay Safe, 18th September). The majority of the participants in my interviews mentioned that their service users or adult child had done the *Stay Safe Programme* in their primary schools. In St Joseph's Foundation service users receive the programme from the age of 5 to 18, before moving into the adult centre where they begin the *Raising Understanding and Awareness (RUA) Program* which will be discussed later. Conor Counihan stated that when the service users come to the adult centre "their minds are broadening and they're asking more questions and trying to get an understanding of things" to do with their sexuality and so a programme like Stay Safe is just not adequate to their needs any longer. Conor McAtasney, from Co-Action also felt that there were limitations to Stay Safe:

"staying safe is one thing but if you look at a person to be sexually healthy then they should have the same rights as other people … we have moved away from just staying safe, life is for living and people want to have a full life and to be able to have sex is part of that"

(Conor McAtasney)

Co-Action in Castletownbere designed their own sexuality education programme; entitled the *Social, Personal and Health Education Programme*. The programme was designed to teach the adult people in their service about personal hygiene all the way up to contraception

and relationships. It is delivered to all adult service users in the Castletownbere branch of Co-Action. It was designed by a staff member within the organisation along with the centre's psychologist and has been in place within the centre since 2003. The programme is split into 6 modules and taught to single sex groups by a male and female staff member. *The Social, Personal and Health Education Programme* in Co-Action Castletownbere is taught by Conor McAtasney and a female member of staff, "only the staff that went on the training (HSE Sexual Health Team) would then deliver the training to the individuals" (Conor McAtasney). The training that the staff received was a "10 day foundation course in sexual health which is run by the sexual health team in the HSE", and the course was held in Killarney 2 nights a month for 6 months. The name of the course was Sexual Health Foundation Course in Sexual Health Promotion, it was targeted for anyone "working in the health, education, youth and community sectors whose work currently or potentially involves aspects of sexual health promotion" (HSE). It was not designed specifically for people working with people with intellectual disabilities. But this training influences the basis of the programme that is being offered in Co-Action today even though the programme itself is custom made to suit the needs of the client group, this tailored form of sexual education had also been discussed in my literature review where researchers recognised the benefits of tailoring it to the needs of the service users.

The programme in Co-Action is taught weekly, it had been developed previously to Conor receiving the training and was called Relationships and Sexuality after the training the programme was renamed Relationships and Sexual Health. Conor McAtasney stated "it is important to reiterate points and go back over things". The programme ranges from "personal hygiene and looking after your clothes" and then moves along until you have all the basic things covered, it then "moves up to the area of the physical body and talking about how babies are made" (Conor McAtasney). Conor also mentioned the importance of visual exposure or interaction when educating people with intellectual disabilities. He explained that; "we have a

model [of the human body] that we bring out every so often and you can interchange the parts … anything that is visual like that really encourages debate and discussion" (Conor McAtasney).

The *Raising Understanding and Awareness Programme* (RUA) is used in the adult centre in St Joseph's Foundation. RUA was established in 2003 within The Callan Institute as part of St John of Gods Community services. The mission of RUA was "to support individuals with intellectual disability to enjoy friendships and close relationships, and where appropriate, to support their family and staff teams to be comfortable and skilled in talking about issues relating to friendships, relationships, sexuality and intimacy" (RUAJOG, 18 September). St Joseph's Foundation has this programme in place for seven years, the staff trains in the programme which consists of 12 modules ranging from sexual development through the life cycle all the way to values, attitudes and comfort level. Once the training is complete the staff do a needs assessment with the service users to establish a programme which responds to the groups common interests and abilities. When asked why it was decided to bring a programme like this to his centre Conor Counihan replied that "we saw a gap", and noted that previous to the programme being introduced they had been "dealing with things in an ad hoc way with no structure to it. Situations were arising" and staff "weren't as well equipped to deal with them" (Conor Counihan). Once aware of the gap the organisation began looking at various programmes to see which might be best for the organisation. Following recommendations they came to RUA and since its introduction to the centre as Conor Counihan noted; "everyone is much clearer in terms of what their roles and responsibilities are and the benefit of that is it being beneficial from our service user view point". The RUA Programme is taught to some specific staff members "who would then train other staff members" and they then get involved in "educating the service users" (Conor Counihan). When speaking about RUA Conor

Counihan said it "has been good for our staff and our services users have benefitted from it", showing positive results. RUA is taught in a classroom setting with a mixed sex group of people with intellectual disabilities but "for some of the more sensitive parts of it we would break up into groups" (Mary Hughes, St Joseph's Foundation Social Worker). The programme ran once a week for 10 weeks and covered different areas each session.

Two out of the three services I interviewed had policies on relationships and sexuality, namely St Joseph's Foundation and Co-Action, COPE Foundation however there was no formal sexuality education within their services and do not have an organisational policy on relationships and sexuality. Sean Abbott, Director of Innovation and Development in COPE, stated that relationships and sexuality "was something the organisation avoided" but have been trying to change this in the last few years. He stated that sexuality and sexual education is something that is beginning to be discussed more within the service and noted that a change of attitude needs to happen. Sean observed that people with disabilities have been seen as "needing to be protected from all this kind of discussion" but commented this idea is now changing. He stated that "if they are young adults and we feel they have the capacity to make a decision, then I will support them" in having a relationship if they family does not. He felt that parents of people with intellectual disabilities can't understand the concept of their child as sexual beings and stated that maybe the education may need "to go on the parental side" (Sean Abbott). Sean noted that education about their bodies was not provided to the service users, commenting that "nobody goes down that road at the moment. It's kind of taboo". He did however express the view that this was changing and that lack of sexuality and relationships education was a "source of criticism" amongst the staff in COPE but believed that a key factor in introducing this was the attitude of parents: "it's all down to the parents and the strength of the parents" (Sean Abbott).

5.4 Sexuality Education: Alternative Sources of Education

As mentioned earlier I conducted an interview with a sexuality education teacher for people with intellectual disabilities from the Sexual Health Centre in Cork, called Phil Corcoran. Phil described his sexual education programme which was influenced by his work in the Brothers of Charity who he was employed by for four years. Phil as a sexual education teacher goes out to various settings to give training When Phil was an employee within the Brothers of Charity centre he identified issues around "relationships and inappropriate behaviour" but it was more teaching about relationships and boundaries rather than sexuality (Phil). In the centre Phil worked in conjunction with a psychologist on the topic of sexual health which brought about his interest on the issue, he then went on to do some "training in Sheffield and then started collecting resources". He began his own training programming, Phil programme varies from centre to centre "some centres may just need some work around relationships and boundaries. Other centres will request a fuller programme, with information on contraception, S.T.I.'s, and screening" (Phil) especially centres with more mild to moderate intellectual disabilities. In discussing the benefits of sexual education Phil Corcoran observed "When we are looking at direct sexual issues, its information that everybody needs" (Phil Corcoran). He also understood information as a source of protection for adults with ID noting "I think it allows people to get the information they need to protect themselves". In Phil's sexual education programme he covers such things as "the importance of friendships" all the way up to "why do people have sex?" (Phil Corcoran). Phil Corcoran also contributes to a module on Health and Wellbeing which includes sexuality and relationships inputs on the Certificate in Contemporary Living (CCL) in UCC. This is a two year part-time programme for young adults with intellectual disability, his sexuality education classes are always taught in mixed gender groups if his client group are male and female.

Phil draws on *The Busy Bodies* programme which is run by the HSE and taught in Primary and Post Primary schools to all children aged 10 to 14. It was introduced in 2008 and later reviewed in 2010. The mission of the Busy Bodies programme is to provide "information on the physical and emotional changes that children may experience during puberty, to reassure them that puberty is a normal part of growing up" (Busy Bodies, 18 September). Phil uses an edited version of this programme from time to time for participants in his sexual education class who may have never had "education about their bodies or education around the difference between men and woman" (Phil Corcoran). It is used to educate them more about puberty and the male and female sex organs in an easy format as the programme is on DVD.

All parents recalled their adult child receiving some type sexuality education, four parents spoke of their child receiving it from a woman named May Gannon from Dublin who was a counsellor and drama therapist for Down Syndrome Ireland. The parents perceived that she had taught their children a bit about sexuality and it appears that she had put a lot of emphasis on the need for privacy about parts of the body and the need for private spaces "if you wanted to do something in private" (Parent 2 from the focus group). Apart from May Gannon the only other form of sexuality education the parents discussed was the *Busy Bodies Programme* and the parents of younger children noted that they would have received this in Primary School as it was introduced in 2008. In general the parents in the focus group did not have much to report on sexuality education their children as many of them weren't aware of the extent to which they had received it.

The exposure which young adults with intellectual disabilities have to sexualisation in their everyday worlds was raised by some parents in the focus group and was also commented

on by one of the service providers. In the parent focus group, parent 8, stated that it must be remembered "that they watch television". She made this statement as they were discussing the amount of knowledge their children may have about sexuality and about which the parents might not be aware. Sean Abbott also acknowledged that "what you often see is that television is becoming the biggest educator", a statement that was also supported by Conor Counihan who felt "a lot of the education our service users get rightly or wrongly is television based". The negative aspects television being an educator for people with intellectual disabilities was highlighted by Sean Abbott who stated that the "relationships you see on T.V. are not real. It doesn't happen like that". His concern however is that that people with intellectual disabilities may not realise this and may have unrealistic expectations of what a real relationship might involve: "when reality strikes it is just about meeting up for coffee, going for a walk, having a fight on the phone or what it might be" (Sean Abbott).

5.5 Empowerment vs Paternalism

My earlier review of the literature highlighted two key attitudes to the sexuality of people with intellectual disabilities, that which focused on empowerment and that which focused on protection. Analysing the approach taken by the service providers from this perspective was very useful and their positions in this regard are discussed below.

The first centre I interviewed was St. Josephs Foundation, as discussed previously it has up to 800 service users with 300 of them being adults. The centre follows the RUA programme when teaching sexual education to adult clients and the nature of this programme and the orientation of the management indicates that St. Joseph's Foundation adopts an empowering approach. The programme of education in St. Joseph's Foundation provides much more than basic education and gives service users information on an extensive range of topics

including contraception and sexual relationships. This suggests that the organisation supports the view that some young adults with intellectual disabilities are capable of and entitled to have a sexual relationship.

Co-Action in Castletownbere, like St Joseph's Foundation, provides formal sexuality education in their centre which they designed in house for the people that avail of their services. As such t Co-Action Castletownbere adopts a very client focused approach which is certainly empowering in orientation. They are enabling the people within their services to have the knowledge required to engage in a fulfilling relationship. Although there is no sexual activity allowed in the group homes due to the lack of capacity legislation, they are supportive of the people having relationships in their own homes if they wish to do so.

Sean Abbott noted that while he himself was an advocate for people with intellectual disabilities having relationships, COPE Foundation as an organisation was not quite there yet. Given that no formal sexuality education programme is delivered to service users the approach adopted by COPE would have to be identified as protectionist and paternalist. Sean Abbott pointed out however that that is beginning to change as the service now has " people with disabilities starting to speak up for themselves" He also emphasised that staff are slow to fight for sexuality education it as it is such a taboo. Sean flagged that as an organisation COPE Foundation was trying to re-orient its service focus to "being driven and directed by the person we serve rather than the families" and in that context he reported that the organisation was discussing the introduction of sexual education . As discussed in chapter 2 of this thesis, the Disability Act 2005 sets out "to enable provision to be made for the assessment of Health and Educational Needs" (pp.5) but like COPE it too excludes sexuality and relationships as a

component of a wider health, education and rights agenda. This reflects the traditional fear that parents, centres and legislation have of people with intellectual disabilities expressing their sexuality.

Thus my data suggests that two of the three services are empowering and supportive of their clients having relationships and being educated in having a fulfilling relationship. COPE Foundation although not quite there yet are trying to make changes in their ethos and develop sexuality education services for their clients. However at present as an organisation they appear to be more focused on the parent's demands over their clients and as such are support a paternalistic attitude.

5.6 Key Issues of Parental Concern around Sexuality

In terms of intellectual disability and sexuality, capacity is a key issue as the capacity to consent legislation has not yet been passed In this section I will discuss appropriate behaviour and privacy which can aid a person to have the capacity to have a fulfilling relationship.

The importance of teaching about appropriate sexual behaviour was a common theme throughout the interviews and focus group. Appropriate behaviour was most discussed in the focus group; Parent 6 referring to her son, noted how she "just wants him to know what the right way to behave is". The need for education to counter what young people with intellectual disabilities see being portrayed as normal behaviour on television was as a big challenge. When talking with Sean Abbott about the influence television has on a person with disabilities learning about sexuality, he explained that for people with intellectual disabilities "that's what

they see and that's what they expect" (Sean Abbott). Conor Counihan also brought up the issue of being influenced by television and observed that an adult with intellectual disability might be acting "not very appropriate" but believe it is appropriate because it's what they have seen on television. Sean Abbott makes the point that what non-disabled people automatically understand often needs to be consciously taught to people with intellectual disabilities. When speaking about teaching personal development he explained; "its life skills we learn automatically but they need to be taught about".

Parent 5 had concerns about her 13 year old son's sexuality, although she stated that she has "no problem with his sexuality" it was a major issue "trying to get a handle on where he is physically and put brakes on him to teach him how to behave appropriately". She described him as being very interested in girls and acknowledged that she wants him to have girlfriends but before that she wants him to have knowledge on how to act appropriately and take things slow. When discussing his interest in girls she stated she can be "nervous of girls" in case something was to happen and even if both parties were willing he may come out of it in a negative light. Such fear is understandable and P.8 expressed similar concerns observing "our kids could be naively pursuing what nature makes them want to do" but noted that as a parent she felt that she had to ensure he had " frequent reinforcement of appropriate rules and just how to behave and all that" (Parent 8). While such fears are held by most parents of adolescents, the more limited capacity of young people with intellectual disabilities created even greater challenges in this difficult aspect of parenting.

Another common theme discussed in the parent focus group was 'Privacy'. Many of the parents at the focus group had sons and so the conversation often turned to concealing

erections and how to act appropriately in public. Parent 8 said "we have taught them that it's inappropriate to touch when you're in public or when there are people in the room", Parent 7 supported this statement by discussing how she taught her son that there are private things and private places for such things. Parent 7 felt that masturbation was a normal part of life "if he is not going to have a real relationship he'll need a bit of an outlet sometimes", and she said she talked to him about not "rubbing it in front of people … if you have to do something like that do it in your bedroom" (Parent 7). Parent 8 emphasised that "understanding privacy cannot be stressed enough. Once they have that they know right and wrong".

Parent 1 in the focus group raised the issue of sexual assault of young women with intellectual disabilities and noted that "if a child or a girl or a woman is raped they won't take her testimony as being factual in court which is completely underestimated and undermines our children". While Parent 8 argued that this was now changing she acknowledged that it is still an issue and observed that without capacity legislation people with intellectual disabilities are being left vulnerable. Conor McAtasney also was of the opinion that "they are very vulnerable" and observed that at times during his sexual education programme someone in the group will disclose information about a situation not realising there may have been abuse involved. One aspect of the training which Conor delivers includes teaching his group how to write a letter of complaint if they are or have been abused.

There was however some disagreement among parents about the amount of education or information students should get. Parent 8 stated "I think sometimes we want to give too much information", a view also shared by Parent 7 who stated that the information "all comes naturally in the end, the amount they need to know and want to know". That statement was not

just made in the parent focus group, Sean Abbott also believed that "sometimes too much information can be dangerous as well because then people want to explore it a bit further". Although Sean Abbott is an advocate for sexual education for people with intellectual disabilities he worried that some parents have the attitude "they need to know but they don't need to do" and then it becomes cruel to say to a person "you can go down this far but you can't go the rest of the way" (Sean Abbott).

The question of whether it was desirable or not for people with Id to have relationships emerged in the data. The control which parents have over educational and relationship opportunities for their children was commented on by Parent 8 who acknowledged "we have the gift of relationships to them" and she felt that this was very unfair. Parent 8 who has a son with down syndrome as well as a daughter with a physical disability discussed how her daughter always tells her "look all we want is a relationship or all we want is somebody to love or all we want is somebody to love us" (Parent 8). Although a few parents within the focus group hated the thought of their child not having somebody to love them or for them to love (Parent 1), Parent 4 stated "I would be very much against my child having boyfriends; I would be very worried about her being broken hearted". When Parent 4 made this statement there were not much support from the other parents. Parent 5 asked was "it not better to have loved and lost then never have been loved at all", Parent 1 described fearing "the thought of [her son] having nobody to love him and for him to love". This section relates back to the earlier section on empowerment vs. paternalism, as we see here that some of the parents such as Parent 1 and Parent 5, have a more positive or empowering view on their child having a relationship whereas Parent 4 has a fear of her child having a relationship . This fear of her child being hurt would be very much a paternalistic perspective on her child. The diversity of opinion which exists among parents as a group was commented on by Sean Abbott who felt that COPE as an

organisation was often "fighting the demands of the parents versus the demands of the individuals" and he described the challenge for an organisation when "you've got individuals wanting to have relationships with people and parents against it" (Sean Abbott). But Sean observed that he had explained to a couple of parents who have a child that has the capacity to have a fulfilling relationship "if your son or daughter says to me they want to have a relationship and you say no, I am going to go with them" (Sean Abbott). He explained that an organisation voicing such an opinion can be very challenging for a parent and he described how parents can feel that they are being over-ruled. As such organisations can be in an uncomfortable place if they seek to uphold what they believe to be the rights of a person with intellectual disabilities when their parent holds a different view about what is appropriate in terms of sexuality or relationships. Sean commented on the process of change COPE were going through noting that in previous years parents have been the guiders and have had control of what their child does and doesn't do but noted from the perspective of the organisations "that's what we are trying to change now" (Sean Abbott). Sean was very cognisant that this is a challenging area for parents and a difficult area to bring about change in "It's difficult for parents to accept that their sons and daughters with disabilities are also sexual beings and have those feelings" (Sean Abbott). Conor Counihan made the point however that "if people have the capacity then you certainly can't stand in their way", suggesting again an empowering rather than a paternalistic attitude towards people with intellectual disabilities having relationships.

5.7 Conclusion

There is a diversity of attitudes among service providers, a diversity of types of training being delivered and a diversity of policies within these centres. This ranges from empowering attitudes in some services with full sexuality education and policies for their service users to

have the information to fully consent to a full relationship such as St. Joseph's Foundation and Co-Action who recognised there was a need to provide sexuality education to their clients as there was a gap in the education for their adult clients. The education they provided was like programmes such as RUA who aim to provide information on relationships, sexuality and intimacy to people with intellectual disabilities. Then there is paternalistic and underdeveloped service providers that have not yet made the movement to advocate for their service user's needs over the parents desires. Although COPE are trying to flip this around it is still not there yet by not having a formal form of sexuality education or a policy within the service on relationships and sexuality.

Parents were concerned with sexuality, and in particular worry about appropriate behaviour and strive to teach their children about what is appropriate. The parents desired education strategies that would help modify their children's behaviour to ensure that they deal appropriately with their sexual urges as it was a fear that they may act inappropriately with others and not know boundaries. If a person with intellectual disabilities understands privacy, they will know what's right and wrong behaviour as stated by parent 8.

This desire for education on sexuality suggests the parents acknowledge the natural sexual urges of their children and accept that they are sexual beings to an extent. Many of the people with intellectual disabilities were said to have received the Stay Safe Programme when in Primary School but that is only helpful to an extent it does not provide information on having a fulfilling relationship or sexual expression.

There is however more diversity in relation to whether or not parents believe that their child should engage in a relationship, particularly a sexual one. Some parents want this for their children and others are afraid of what it might bring. This diversity of opinion provides challenges for organisations, as identified by Sean Abbot as he described the efforts he is making to reorient the approach to sexuality and relationships in COPE but the strength of parents against sexuality and relationships still have more strength then those who advocate for it. The clash between an empowering and a paternalistic approach is a difficult one for an organisation to negotiate but some organisations such as Co-Action are uncompromising in their support of an empowering approach informed by the right of the person with intellectual disabilities, on enrolment to the centre it is stated sexuality education is provided and from there it is the parents decision.

Finally the data suggests that the lack of capacity legislation makes parents and staff more fearful of encouraging relationships and it is imperative that this be addressed. Parents fear that due to the lack of capacity legislation their children are deemed to lack the capacity to make a complaint if abused.

6. Conclusion & Recommendations

6.1 Introduction

In this conclusions chapter I wish to draw upon my findings from my previous chapters and relate them to my research topic, intellectual disabilities and sexuality. This piece of research has been discussing the policy and practice of sexual education for people with intellectual disabilities I have investigated relevant pieces of legislation, key works of literature and primary data collected by holding a focus group with parents of people with intellectual disabilities and semi-structured one to one interviews with service providers for people with intellectual disabilities. It has been most beneficial to do this dissertation as it was in correlation for Down Syndrome Ireland a non-profit organisation who would have found it difficult to have conducted this research themselves. It has also been beneficial to have done research on an under researched topic. I hope this piece of research highlights the importance of providing provisions and supports on sexuality relationships as through this research I have highlighted the benefits of doing so.

In this final chapter of my dissertation I will be answering the key research questions which I set out in my introductory chapter. The two research topics I intended to investigate when I started this dissertation were; Exploration of parental attitudes and knowledge of people with intellectual disabilities on the topics of sexuality and sexuality education and an investigation into the policy and practice of sexuality education of services in Cork County with an emphasis on the attitudes of service providers on the sexuality of people with intellectual disabilities. I use both my primary and secondary data to address these issues I will begin with the data I received from my literature review and how that information carried on into my primary research.

6.2 Exploration of Parental Attitudes and Knowledge of People with Intellectual Disabilities on the topics of Sexuality and Sexuality Education

In my literature review some discussion on parental attitudes towards people with intellectual disabilities was discussed. These parental attitudes were promoting a paternalistic or protective attitude rather than a liberal one as discussed by Kelly et al. (2009) and Kelly (2013).

When we speak about the attitudes on an issue such as sexuality of people with intellectual disabilities there is often an uncomfortableness and this idea that people with intellectual disabilities are "incapable of understanding or acting on these feelings" (Allan & Seery, 2007, pp.9) but that is where sexual education can make the difference in their capacity to understand and appropriately act. This attitude in Foley & Kelly (2009) and Kelly (2013) research is contradicting to my own primary research where I found the majority of the parents that participated in my focus group to be empowering of their child's sexuality. This refers back to my empowerment and paternalism section in my literature review, some of the parents are positive of their child acting on the sexual education they receive but Parent 4 was very hesitant of this and did not wish for her daughter to have a boyfriend showing a paternalistic perspective of her child. It was highlighted that there is a need for sexual education for people with intellectual disabilities as to counter what they perceive on television as normal relationships, which I discussed in my Findings Chapter. In my Literature Review Kelly (2013) discusses the issue of parents not wanting to consider their child as having sexual urges which in my data was then reiterated by Parent 8 who expressed concerns that their children were just "naively pursuing what nature makes them want to do", insinuating that they are not understanding these sexual urges.

This leads me on to discuss the issue of appropriate behaviour that was a main theme within the focus group and an element important to sexual education. In my one to one interviews with service providers and parents they brought into discussion the influence television has on people with intellectual disabilities learning about relationships and appropriate ways to behave. Although in my literature review researchers were discussing the influence a tailored form of sexual education can have on a person's capacity television was not a factor brought to attention. From my interviews it came across to be one of the most influential, particularly in services such as COPE Foundation who have no formal form of sexual education so television is the most accessible form of education for their service users.

The final issue that I will discuss before coming to a conclusion to this research question is the importance of capacity legislation for people with intellectual disabilities. The service providers and parents I interviewed all highlighted the fact that people with intellectual disabilities are very vulnerable and without the appropriate capacity legislation they are left even more so. Parent 1 in the focus group raised the issue of sexual assault on a person with intellectual disabilities and feared that if it were to happen that her child may be considered to lack capacity to report it.

To conclude my answer to this research question was the parental attitudes and knowledge of sexual education and sexuality of people with intellectual disabilities explored? To an extent it was, I felt the research findings were more focused on the attitudes of parents on sexuality more so than sexual education, also from my primary research data it was evident that the parent focus group did not have an in-depth knowledge of what sexual education their child had received apart from the appropriate way to behave which they would have taught their child. So from this I conclude that from my own primary research the majority of my

parent focus group participants were empowering rather than paternalistic of their child's sexuality.

6.3 An Investigation into the Policy and Practice of Sexuality Education of Services in Cork County with an Emphasis on the Attitudes of service Providers on the Sexuality of People with Intellectual Disabilities

This section discusses my findings on service providers and their policy and practice of sexual education. In my literature review there was a number of research pieces in which service providers were interviewed on their perspective of people with intellectual disabilities sexuality, which led me on to want to do my own primary research on four of the main service providers in Cork County. Like my previous section I will begin with discussing my secondary research findings and lead on then to discuss the relation to my primary research findings, from there I hope to come to a concluding answer on the question of attitudes and provisions on sexuality of people with intellectual disabilities from service providers.

In my Literature Review a lot of discussion of service provider attitudes on the sexuality of people with intellectual disabilities is under the paternalistic heading. It was felt by researchers that many service providers were in preference of people with intellectual disabilities having platonic relationships rather than sexual ones (Evans et al. 2009), which was not the case in my primary data. I found from my primary research data that the service providers I interviewed were empowering of their service users expressing their sexuality and provided such programmes as *Raising Understanding and Awareness* and *Social, Personal and Health Education.* COPE Foundation are still very much influence by the desires of the parents rather than the needs of their service users and as found in my literature review parents of

people with intellectual disabilities can be resistant to accepting their child as a sexual being a needing education in that area, this can then have effects on staff who are positive regarding the sexuality of people with intellectual disabilities as they can feel they cannot advocate this positivism due to the parent's paternal attitudes. We witnessed this in terms of Sean Abbott a staff member in COPE Foundation although an advocate for people with intellectual disabilities expressing their sexuality he is not protected as a staff member to provide support to service users doing so. This was mentioned previously in my literature review when Foley (2009) stated that service providers can be "afraid that in supporting people with intellectual disabilities in this area, they may be endorsing or promoting illegal conduct" (pp. 9). This can be a difficult situation to be in for an organisation which wants to change but the staffs are not protected to do so.

I wish now to discuss the variety of provisions of sexual education for people with intellectual disabilities, as I have done so already in my finding chapter this will just be a short discussion with cross reference to my literature review on the topic. The main piece of research from my literature review that discussed the influence of sexual education on people with intellectual disabilities was Duke & McGuire (2009) this piece of research was done with a group of people with intellectual disabilities who they then provided tailored sexual education to their needs, in this piece of research it was found very beneficial and even proved that a person's capacity is not static and with the right support and provisions can be altered for someone to be deemed to have the capacity to have a full relationship. As I mentioned earlier and in my previous chapter St Joseph's had the RUA programme for their service users and Co-Action had personally developed their own form of sexual education for their clients called *Social, Personal and Health Education.* In both interviews the service providers felt that these programmes were beneficial to their clients and "seemed to be working" (Conor Counihan).

Also in my findings I discussed the foundation sexual education courses such as Stay Safe and Busy Bodies which are provided to all children in primary and early in post primary school. I also got to interview a sexual education teacher for people with intellectual disabilities named Phil Corcoran, this was most beneficial to find someone specifically trained and interested in teaching people with intellectual disabilities on their bodies, relationships, contraception and so on. From this I have found that although in some services they are still paternalistic and there is a lack of sexual education being provided to people with intellectual disabilities across the country it was fascinating to find the numerous different provisions of sexual education within such a small area such as Cork.

This brings me on to discuss the policies within the services before concluding this section of my thesis. As I have already spoke about these policies in my previous chapter I will not spend long discussing them here, I just wish to give a synopsis of what has already been discussed as to answer my research question. The three services policies I looked at were St Joseph's Foundation, Co-Action and Brothers of Charity as COPE Foundation currently have not published a Relationship and Sexuality Policy as of yet but do have one in draft. The attitude held in St Joseph's Foundation, Co-Action and Brothers of Charity was that people with intellectual disabilities have the same right as everyone else. As stated by St. Joseph's Foundation's policy "no one should be prevented from making choices about his or her own life simply on the grounds that he or she has an intellectual disability" (2013, pp.2). In Co-Actions Policy they state the fact that due to the lack of capacity legislation not having been passed they do not allow their service users have sexual relationships within the group homes.

To conclude my answer to the research question on policy and practice of sexual education for people with intellectual disabilities of four service providers in Cork County, I covered all areas as well as the service provider's attitudes on the sexuality of people with intellectual disabilities. I found that two of the services St Joseph's Foundation and Co-Action services had policies on the topic of relationships and sexuality of people with intellectual disabilities and these two services were also empowering of their clients to express their sexuality and not be limited due to the fact they have an intellectual disability. I also found from my primary research the numerous practices of sexual education in Cork County for people with intellectual disabilities. So I have come to the conclusion that currently in Cork County three of the four main service providers are empowering, have published policies on sexuality and relationships of people with intellectual disabilities and practice sexual education within their services.

6.4 Recommendations

This section discusses the recommendations for future research and legislative amendments in this area of sexuality and intellectual disabilities.

In future research it would be most beneficial to have same sex focus groups with people with intellectual disabilities to give them the opportunity to voice their opinion on this subject as much of this research was second hand information from service providers and parents.

From my secondary and primary research it came to light the lack of capacity legislation creates difficulties for parents and services and leaves people with intellectual disabilities in a very vulnerable situation. There is a need for the Criminal Law (Sexual Offences) Act to be amended to address this. .

All services for people with intellectual disabilities should have some form of sexuality, relationships and personal health programme for their service users to avail of and act upon if they wish to do so.

Services should make their policies on sexuality and relationships more accessible for their service users and parents by having them on their website, as many did not have them available unless requested.

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8. Appendix

I. Phil Corcoran Information Letter

Dear Phil Corcoran,

My name is Louise O'Sullivan, I am currently doing my masters in University College Cork and in conjunction with Down Syndrome Cork. In my research I am looking at the issue of sexual education for people with intellectual disabilities. I wish to interview you on the policy and practice of sexual education for people with intellectual disabilities. I am conscious of how busy you must be and I would be very grateful if you could spare the time to talk to me. I envisage that the interview would take between 30 and 45 minutes. In the interview I would be interested in discussing such issues as;

- What is your opinion on sexual education for people with intellectual disabilities?
- What makes you qualified to teach sexual education to people with intellectual disabilities?
- How does current Irish legislation regarding sexual relationships for people with Intellectual Disability influence your teaching approach to sexual education to people with intellectual disabilities?

Your participation will benefit recommendations and improvements that need to be made on the issue of sexual education for people with intellectual disabilities.

The interview will be taped and transcribed for the research; your own name will be published in the research project unless you decide that you would prefer them not to be used. The recording will be stored in a secure location and destroyed once the report is finalised. Before the interview you will be asked to sign a consent form indicating that you are participating in the interview on a voluntary basis and that you agree with the plans for the use and storage of any data collected.

I would like to hold the interview in the next couple of weeks, if there is a specific date and time that would be convenient to you please let me know. Attached to this letter is a consent form for you if you wish to participate. Also attached is a letter from Down Syndrome Cork indicating their support for the research.

If you require any further information please feel free to contact me by email: louiseos15791@gmail.com or 110338143@umail.ucc.ie

Kind Regards,
Louise O'Sullivan

II. Service Provider Information Letter

(Date),

Dear _____,

My name is Louise O'Sullivan, I am currently doing my masters in University College Cork and in conjunction with Down Syndrome Cork. In my research I am looking at the issue of sexual education for people with intellectual disabilities. I wish to interview a member of the managerial staff about the organisations policy and practice of sexual education for your clients and if possible a member of staff who provides the sexual education. I am conscious of how busy you and your management team must be and I would be very grateful if you could spare the time to talk to me. I envisage that the interview would take between 30 and 45 minutes. In the interview I would be interested in discussing such issues as;

- What is your opinion on sexual education for people with intellectual disabilities?
- Does your organisation try to provide sexual education for your clients?
- Is there a qualified staff member in your organisation who teaches sexual education?
- How does current Irish legislation regarding sexual relationships for people with Intellectual Disability influence your organisation's approach to t providing sexual education to your clients?

Your participation will benefit recommendations and improvements that need to be made on the issue of sexual education for people with intellectual disabilities.

The interview will be taped and transcribed for the research; the organisation's name and your own name will be published in the research project unless you decide that you would prefer them not to be used. The recording will be stored in a secure location and destroyed once the report is finalised. Before the interview you will be asked to sign a consent form indicating that you are participating in the interview on a voluntary basis and that you agree with the plans for the use and storage of any data collected.

Attached to this letter is a consent form for you if you wish to participate. Also attached is a letter from Down Syndrome Cork indicating their support for the research.

If you require any further information please feel free to contact me by email: louiseos15791@gmail.com or 110338143@umail.ucc.ie

Or by telephone: 0860766962

Yours Sincerely,
Louise O'Sullivan

III. Parent Information Letter

To whom it concerns,

My name is Louise O'Sullivan, I am currently doing my masters in University College Cork and I am carrying out research with Down Syndrome Cork. In my research I wish to look at the issue of sexual education for people with intellectual disabilities, I am currently looking for parents of people with intellectual disabilities to participate in a focus group for the research. In the focus group I will be asking the following questions;

- Has your child received sexual education?
- What is your opinion on providing sexual education to people with intellectual disabilities?
- What age do you feel your child should receive sexual?
- Should it be an ongoing class throughout their lives?
- What changes would you like to see made to sexual education for people with intellectual disabilities?

The data gathered from the focus group will influence the interview questions asked to the managerial staff of the organisations Cope, Brothers of Charity, Co-Action and St Joseph's Foundation. The interviews with these service providers will discuss sexual education policy and practice in their organisation. Your participation will be a major contribution to the research.

The focus group will be taped and transcribed for the research, but I guarantee there will be confidentiality and anonymity by using pseudonyms when transcribing and writing the final report. I will also be changing all identifiable characteristics of the participants and the recording will be stored in a secure location and destroyed once the report is finalised.

After the focus group I will be providing you with contact details for the Sexual Health Centre in Cork and a reading list to help you with any questions and to give you further information on the issue of sexual education for people with intellectual disabilities.

Attached to this letter is a form to indicate your consent to participate in the research. Please return it to Down Syndrome Cork by Friday 27th of June if you wish to participate in the focus group.

If you require any further information please feel free to contact me by email: louiseos15791@gmail.com or 110338143@umail.ucc.ie

Kind Regards,

Louise O'Sullivan

IV. Phil Corcoran Consent Form

Research on Sexual Education for People with Intellectual Disabilities

Thank you for agreeing to partake in this research, which is being carried out by Louise O'Sullivan and Down Syndrome Cork. The research is exploring the issue of sexual education for people with intellectual disabilities. Your participation will contribute to the understandings of policy and practice around sexual education for people with intellectual disabilities and will influence recommendations that need to be made in this area.

The interview will be carried out by Louise O'Sullivan. The interview will be taped and transcribed. Your name will be published in the research unless you decide that you would prefer it not to be used.

The tape will be held in a secure place and will be destroyed on completion of the thesis. The thesis is expected to be finished by the end of September 2014.

Participant's Name: _____

Having read the above, I agree to take part in the research

_____

V. Service Provider Consent Form

Consent Form

Research on Sexual Education for People with Intellectual Disabilities

Thank you for agreeing to partake in this research, which is being carried out by Louise O'Sullivan and Down Syndrome Cork. The research is exploring the issue of sexual education for people with intellectual disabilities. Your participation will contribute to the understandings of policy and practice around sexual education for people with intellectual disabilities and will influence recommendations that need to be made in this area.

The interview will be carried out by Louise O'Sullivan. The interview will be taped and transcribed. The organisation's name and your name will be published in the research unless you decide that you would prefer them not to be used

The tape will be held in a secure place and will be destroyed on completion of the thesis. The thesis is expected to be finished by the end of September 2014.

Participant's Name: _____

Having read the above, I agree to take part in the research

_____

VI. Parent Consent Form

Consent Form

Research on Sexual Education for People with Intellectual Disabilities

Thank you for agreeing to partake in this research, which is being carried out by Louise O'Sullivan and Down Syndrome Cork. The research is attempting to discuss the issue of sexual education for people with intellectual disabilities. Your contribution will benefit the research as it will highlight the difficulties that arise for parents of children with intellectual disabilities in terms of sexual education and influence recommendations and improvements that need to be made in this area.

The focus group will be carried out by Louise O'Sullivan. The interview will be taped and then transcribed. Your confidentiality and anonymity are guaranteed.

- Pseudonyms will be used in transcribing from the tape
- Pseudonyms will be used in all documentation, including the final report
- All identifiable characteristics (occupation, name, names of places) will be changed
- The tape will be held in a secure place and will be destroyed on completion of the final report. The report is expected to be finished by the end of September.

After the focus group you will be provided with the details of the Sexual Health Centre in Cork and a reading list to help with any questions or further information you may wish to receive on the issue.

You may withdraw from the research at any stage.

Participant

Having read the above, I agree to take part in the research

_____

VII. Letter from Down Syndrome Cork



Down Syndrome Cork

Unit 7, Kilnap Business Park

Old Mallow Road

Cork

January 21st 2014

Dear Ms. O' Sullivan,

I am happy to inform you that your request for the co-operation of Down Syndrome Cork in relation to your pursuit of your CARL Masters programme was unanimously approved at the last board meeting of the organisation held on January 13th 2014.

We believe that the dearth of information in the area of sexual education for our teenagers and young adults warrants further research and are hopeful that your research will fill in a lot of the blanks in an area that is of growing importance to our members.

We will facilitate you in any way possible, both indirectly i.e. by sharing information or directly i.e. organising focus groups or hosting discussions on the subject among members.

We look forward to co-operating with you in the future and wish you the best of luck in your research.

Yours sincerely,

Paul Ahern

Co-ordinator of Services

VIII. Debriefing Letter for Parents

Debriefing Letter

Sexual Health Centre, Cork

Telephone Number: 021 427 6676

Email Address: info@sexualhealthcentre.com

Address: 16 Peters Street, Cork.

Website: http://www.sexualhealthcentre.com/

Reading List:

- **A Strategy for Equality** (1996) Summary of the Report of the Commission on the Status of People with Disabilities. Ireland <http://www.fedvol.ie/_fileupload/Next%20Steps/strategy_for_equality.pdf>
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