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From disability to capability: sex and relationship learning for children and young people with a learning disability

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Abstract

This study focuses on sex and relationships learning and is concerned with the securing of sexual rights for people with learning disabilities. The intent is to identify the characteristics of effective sex and relationship learning as well as address the broader role that adults can play to enable safe, happy and fulfilling personal relationships for children and young people with learning disabilities. What will result is an understanding of what social justice means in the lives of people with a learning disability and how this might be applied to personal and sexual relationships. What will be claimed is the right to (and the experience of) relationships lived as an integral part of a life lived with human dignity.

Preface

> "Justice is about justice, and justice is one thing that human beings love and pursue".
> Nussbaum M.[1]

As a young gay man growing up in the 70s and 80s my politics were influenced by the failure of my own educational experience to recognise and validate my sexuality and sexual orientation. Further, they were informed by the women around me, by ideas and ways of living life prompted by feminist thought and the new sexual and identity politics which informed the culture and political struggles that engaged me. The emergence of HIV/AIDS and the impact this has had and continues to have on friends means that there has never been a time for me when the personal has not been political, and when sexuality and health have not been at the heart of political ideas and actions. Also in this period my professional choices as an educator in formal and informal settings brought me to a place where I began to see learning as a necessity, a tool for good health and wellbeing and a human right for all, equally, regardless of any characteristic of birth or trait acquired in the course of life.

In terms of this doctoral work I decided I wanted to explore what sex and relationship learning for children and young people with a learning disability *could* look like - where it can happen, when, facilitated by whom and how. The professional influences on this choice of subject will be reflected on in the main body of the work but in the course of doing so a personal story other than my own increasingly preoccupied me. My aunt Linda was only 5 years older than me and the same age as my older sister. She was born with Down's Syndrome, the last child of a large poor working class family and, as I learned when I was growing up, lived the first 5 years of her life hidden away at home. At the age of 5, in the early 60s, she was institutionalised and remained so until she died at the age of 39. My memories of her are few but as a child I can remember a number of visits to a large hospital where she was resident. Mostly I remember the smell and the noise, it was frightening to me, I remember that she was kept in a large cot like bed, with the side bars raised, and she seemed only to wear a nightdress. Sometimes she was allowed to come and sit with us outside. As I grew older the visits weren't mentioned to me but I assume they continued.

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[1] Nussbaum M. (2006: 89) Frontiers of Justice: Disability, Nationality, Species Membership

In recent times I had to get a copy of my mother's death certificate and curious about what had happened to Linda, who I knew had died, I asked for information and discovered that she had only died in the mid 1990s. For me, and perhaps for many other family members she had been forgotten. This experience was brought home to me when I read the following:

> Individuals with disabilities were not asked what they wanted; they were typically sent away and often forgotten… in some cases parents were told to forget that they ever had the child[2].

It seems that Linda's story is not uncommon, it's shameful, and it's not very old. This enquiry is about what sex and relationship learning should be like, but to reach that set of conclusions I have found it necessary to tell a longer story about society's response to learning disability and to sexuality and to identify how the two stories connect.

Now that this work is completed, and it has allowed me to engage with new ideas (none more interesting to me than Nussbaum's work on human capabilities which I did not previously know) I have a much clearer understanding as an educator, whose interests lie in sex and relationship learning and broader issues of sexual health, what learning in this area should be like. I am also more conscious that there is some way to go before we get there.

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[2] Gerowitz A. (2007) 'Social Support Systems for Quality Service Delivery: A Historical View' in The Facts of Life and More Ed. Leslie Walker-Hirsch Paul H. Brookes Publishing pp 97 – 123 (quoted in Chapter 4)

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Chapter 1

1.1 Introduction

The Doctor of Education (Ed.D.) programme has offered me the opportunity to connect study with my own professional activity and interests. In terms of my practice this includes my interest in young people's targeted sexual health services, learning about sex and relationships and my commitment to promoting awareness and learning about children's human rights. The first two strands of work have formed a part of my work programme in the social research company where I am a partner (The TASC Agency[3]) and the latter is central to my work as Co-Director of the voluntary sector agency The Children's Parliament[4]. The preface to this work has also outlined personal influences.

In terms of my professional interests several factors came together to make the focus of this enquiry compelling to me. In 2005, I was commissioned to undertake research as part of an NHS Health Scotland Evidence Review concerned with bringing together evidence on effective and promising practice regarding the provision of sexual health information, learning and services for young people with a learning disability (TASC Agency 2005a). I was commissioned specifically to gather the views of young people about access to and use of sexual health services. This work reflected previous work for the Scottish Executive's health demonstration project Healthy Respect (TASC Agency 2003b) and parallel work for a further evidence review process examining similar questions in relation to young people from Black/Minority Ethnic communities in Scotland (TASC Agency 2005b).

In the course of this work I learned that there were children and young people with a learning disability in Scotland who were receiving no formal sex and relationship learning at school. While I had formed a view from other work in this area that much sex and relationship learning in mainstream school settings is inadequate in terms of content and methodology - being poor at pupil engagement and focusing largely on physical changes at puberty and avoidance of sexually transmitted infections with a failure to address the

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[3] The TASC Agency at http://www.tascagency.co.uk
[4] The Children's Parliament at http://www.childrensparliament.org.uk

emotional aspects of relationships – my concern was that this situation was discriminatory and most likely rooted in ignorance and fear.

To explore the possibility of undertaking my study on the theme of sex and relationship learning for children and young people with learning disabilities I initiated some informal conversations with teachers and voluntary sector workers working with children and young people with learning disabilities, reviewed the curriculum material which was available and sought to ascertain whether issues had been explored in current literature.

In terms of what is currently delivered in Scotland’s schools I looked at some of the emerging curricula, delivered in a minority of non-denominational schools, but which claim to take more informed and theory based approaches but found that other than containing a series of lesson plans, most reflecting traditional information-led workshops, there was little that would suggest (or at least nothing explicit) that the experience in the classroom for learners with or without a learning disability was likely to be particularly supportive of children and young person facing important physical and emotional changes and choices which might affect them for the rest of their lives. In the course of my work a new framework for teaching and learning in Scotland’s schools emerged as Curriculum for Excellence, but even as this has developed and is being implemented, with the intent that ‘health and wellbeing’ is a cross curricular theme, there remains no evidence that what has emerged from the initiative (in the course of my writing) will change, never mind transform, sex and relationship learning in Scotland’s schools.
I then wondered if there was any better understanding in Scotland of how parents and carers of children and young people with a learning disability understood their role as co-educators in sex and relationship learning, but found nothing which explored what parents think, feel or do in relation to such learning. My starting point then was to assume it was likely to be reactive, unplanned and unsupported.

From early reading it also became evident that the sexuality and sexual health of people with learning disabilities are not well addressed in the literature and where they are this is in relation to adults and not to children and young people; Cambridge (2006: 2) identifies that these are “themes which have in common a history of neglect and invisibility in the learning disability literature" and even where the issues are addressed the views and experiences of people with learning disabilities themselves are barely present. To help explain this lack of information, Grant et al (2005: xvii) argue that in terms of social policy, service provision and in the community "the voice of people with learning disabilities is still conspicuously lacking" and that this is "one of the lasting manifestations of a society that has too easily categorised and segregated people with learning disabilities". Indeed Rembis (2009: online) goes further, proposing that it is a consequence of oppression and control that sex and disability remain "incompatible".

As a result of this early consideration what developed was an understanding that some sex and relationship learning is done with pupils with learning disabilities, but that where there is this is at best ad hoc or as Tripp and Mellanby (1995: 272) describe it "more patchwork than pattern"; however what I did not understand was *why* provision was so poor and *how* educators might effectively identify and meet learning needs if sexuality and disability are viewed as such conflicting parts of the same person. The recognition of this inadequate understanding and approach was later confirmed by the findings of the aforementioned evidence review (NHS Health Scotland 2008: 4) which concluded that:

> Exploring the sexual health needs of young people is always challenging. This is particularly so for this research as sexual health and wellbeing has not historically been a topic for open discussion with young people with learning disabilities.

Further the Review reported that:

> Although this is generally true for Scotland's young people as a whole, there are additional issues to be overcome for young people with learning disabilities, including a legacy of the past failure to accept their rights to have sex and relationships education and subsequent fulfilling sexual relationships if this is what they wish to pursue.

My initial considerations led me to reach not a conclusion but a starting point; that if a child or young person with a learning disability can grow up without opportunities for learning that addresses sex and relationships (and their sexual rights) this feels like an affront to their human rights and an injustice; my principle would be that ignorance and denial is simply unacceptable.

1.2 Purpose and approach

Arising from these concerns the questions which this work addresses are: **what are the characteristics of effective sex and relationship learning for children and young people with a learning disability** and **what role might professionals and parents have in supporting this learning?**

The enquiry is committed to exploring whether there is a way, through a better understanding of what people need to learn, how they learn, and who can support their learning in their childhood, that people with a learning disability might be better served, better protected, and able to have, manage and sustain personal and (as adults) sexual relationships. The work will seek to build an understanding of what can be done to ensure children and young people, as they move into adulthood, can live their lives with dignity. The study will also make a distinction between learning about sex and relationships in school and in the family; identifying the challenges in both and making a case for the imperative for adults to consider how they might achieve a closer integration of approaches and the possible roles which adults from both can play. In terms of the nature of this work, while the intention is to describe the characteristics of effective sex and relationship learning in a way which might be described as pragmatic, the scope of the work is broad and will challenge the assumptions, many historical, which inform policy and practice to date.

It is also important to make some initial comment about the approach this work takes because drawing from my own practice on occasion would suggest that this work might have engaged more directly in the generation of empirical data. When originally conceptualising how this work might be done I had been keen to engage directly with children, young people and their parents. Such an approach is typical of the work I do as an independent researcher where my company The TASC Agency is commissioned to speak to individuals or groups which a service provider or policy maker has identified as 'harder-to-reach', often about issues which the commissioning agency views as complex or problematic. However in development, guidance was given which has led me to undertake this study which, rather than focus on qualitative research presenting the 'voice' of people at the heart of 'a problem', (which had I done so would have ascertained what young people, parents and teachers felt were the effective aspects of sex and relationships learning) I have been able to look elsewhere, across a more substantial arena, for the information and knowledge located within the philosophical and sociological literature that I have explored. As a philosophical enquiry I have engaged in an exploration of what sexuality and learning disability mean, particularly at the interface of sex and relationship learning for children and young people with a learning disability. Other key ideas are also examined critically along the way; this includes discussion and questioning of concepts which often define the discourse about sexuality and people with learning disabilities; vulnerability, protection and consent. Wilson (1963: 10 - 14) highlights there is need to explore such meaning and that "the whole point of asking such questions is that the definition of these words is unclear" and that it is important "to become self conscious about words which hitherto we had used without thinking – not necessarily used wrongly but used unselfconsciously".

Framed as philosophical enquiry it is possible to support Robinson's view (on line: section 38.3-38.4) that as educators and researchers there is a moral nature to our work because "we intervene in the lives of people" and this means that in itself "education is a moral undertaking, and therefore our practice within education must be open to reflective inquiry". Further, she argues that to engage in such reflection, in philosophy, is to "theorize, to analyze, to critique, to raise questions about, and/or to pose as problematic". It is intended that as philosophical enquiry the study creates a space within which I am able to undertake a rigorous analysis and examination of the political, moral and ethical beliefs and values that underpin current provision and practice in this area of learning. Further, as a philosophical enquiry the study has allowed me to identify and reflect on what Bridges (2003: 64 – 65) describes as evidence which might "challenge our ideas about what is in fact happening" in order to question "the ends of purposes which are guiding our practice and the values and principles which are governing their pursuit"; and in doing so provide "alternatives to the ideas which frame our understanding of and interpretation of what is going on in our classrooms, schools or educational systems".

To reach the point at which it is possible to propose a framework for sex and relationship learning I have found it necessary to tell a longer story about society's response to learning disability and to sexuality and to identify how the two stories connect; recognising "the context of educational problems to be social and cultural life" (Giarelli and Chambliss 1984: 40). Indeed, when it comes to the final outline of what might constitute good sex and relationship learning the aspects of the teaching and learning described can only be understood if they are located in the real lives of people and the complicated histories that both sexuality and learning disability have in our culture. To assist this process I have also drawn occasionally on my own professional practice, using examples of observations of sex and relationship learning, conversations with children, young people, parents, carers and professionals to focus on the complexities and challenges which individuals face; this reflection reminds me that children and young people with learning disabilities and their parents and carers are not a homogeneous group, but individuals and families each with their own set of circumstances.

As philosophical enquiry it has also been possible to draw on empirical research and the professional practice and insight of others; this has supported me to conclude that more needs to be done to unpack, articulate and explore some of the assumptions that lie behind the current drive for better sexual health in order to better serve a population of people often described the most vulnerable and socially excluded in society. My professional interests have been identified above (and personal interests outlined in the preface) but in terms of the body of this work the premise is that a clear and shared discourse about learning disability and sexuality is missing from current discussion, policy and practice and that, when it comes to learning programmes which focus on sex and relationships, according to Wight and Abraham (2000: 26) “little guidance is available on how to translate theoretical ideas into acceptable, sustainable and replicable classroom programmes”.

Ideas from human capability theory have been particularly helpful in this task, and are discussed in more detail shortly, but principally human capability is concerned with emancipation and the practical application of the human rights of all people; such a theory, critical of how things are supports the framing of this study as a philosophical enquiry because both are what Cohen et al (2000: 26) describe as “deliberately political” so that the model of philosophical enquiry is not just an attempt to describe or understand how things are but to change them, in this sense the “intention is transformative: to transform society and individuals to social democracy... to bring about a more just, egalitarian society”.

I am now grateful for the opportunity to undertake this study framed as such; it has required me to understand and reflect more profoundly on the sexuality of people with a learning disability and on describing sex and relationship learning which might better meet needs. Unlike emerging school-based sex and relationship curricula, some which specifically seeks to address the learning needs of pupils with disabilities, I now have an understanding of why this is a complex and poorly served area and while I recognise that the provision of no sex and relationship education is unacceptable, further attempts at formulaic and poorly considered curricula delivered by adults who feel ill equipped and do not have an understanding of the reality of children and young people's lives merely perpetuates our failure to respect the complexity of these aspects of life and so meet needs.

As stated at the outset the Ed.D. programme connects study with professional practice. Perhaps the strongest messages for me which I want to take into practice and my engagement with others is the need to put significant value and effort into sex and relationship learning in the context of family life, to reconsider and be realistic about what can be achieved in school alone, and to see learning about sex and relationships for children, young people and adults with a learning disability as a more integrated and life-long responsibility. Framed as an *entitlement* of the individual with learning disabilities and as an *obligation* for those who give support and love, the framework or description of the approach to sex and relationship learning for children and young people with a learning disability which is outlined in the final chapter is I believe an addition to thinking and work in this area.

This work takes me to a place as an educator/researcher where I have an interest in doing more to complete the picture this enquiry has started. As this enquiry concludes I/we still do not know enough about the experiences and needs of children and young people with learning disabilities and their parents and carers in relation to sex and relationship learning from *their* perspectives. Further, although this work seeks to frame how sex and relationship learning might be constructed and delivered it is just a framework. Parents and professionals need to be prompted to consider what I intend to be a set of supportive and positive conclusions and I would welcome opportunities to be part of further learning and debate.

1.3 The meanings of *sexuality* and *sexual identity*

This study has an interest in moving beyond the sex/gender of the individual to the ways in which *sexuality* matters, and in turn through an exploration of human sexuality how we come to understand and construct it today, to a better understanding of what learning opportunities young people with a learning disability might benefit fromas a basis for good sexual health and wellbeing.

There are however important issues about the meanings of sexuality. Hawkes (1996:9) expresses a concern that sexuality can be simply understood as ‘having sex’; giving importance to “a given outcome – reproduction and (a modicum of) ordered pleasure”. Such a narrow view, Hirst (2004: 126) proposes, denies us “individual sensual experience, with a greater or lesser degree of affective involvement” which she views as the most interesting aspects of human sexuality. Building on our understanding of sexuality as more than having sex the World Health Organisation (on-line) offers the following understanding of the meaning of sexuality:

> Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors.

Jackson (1998: 131) also describes some of the problems with terminology from the perspective of feminist theorists, with a claim that the “linguistic confusion” when we talk about sex or sexuality “is not a mere accident, but tells us something about the male dominated and heterosexist culture in which we live”. Bristow (1997: 1) then points to the interpretation of sexuality as something that is defined by physiology and anatomy whilst *also* being about pleasure and fantasy, so something to do with “both the realm of the psyche and the material world”. He points to the recognition of human diversity which such an understanding allows.

Hawkes (1996: 8) also argues that sexuality is not a given, but socially constructed, that as sex and sexuality have meanings beyond ‘having sex’, there is a need to resist an understanding of sexuality as “something that you had, something almost tangible, which had a form and a clear cut boundary”. Sexuality as a social construct is one of the most influential ideas of Michel Foucault whose work will be considered in later chapters. Weeks (1986: 25) identifies that from Foucault comes this key idea that sexuality “is a product of negotiation, struggle and human agency”.

With the perspective of sexuality as a social construct Hawkes (1996: 135-136) also highlights that any notion of *sexual identity* is also very much a contemporary one in which late modernity “has released sexuality from the confines of a single hegemony and replaces it with ‘sexual pluralism’” so that what was once fixed has become sexual identity “defined and structured by individual choice, where sexual choice becomes one of many elements in lifestyle choice”. Graber and Archibald (2001: 3) also suggest that it is useful to think about *sexual identity*, which they describe as follows:

> Development of a sexual identity, or formation of an identity that includes seeing oneself as a sexual being, is the process of engaging in sexual behaviours, forming attitudes about sexual experiences and sexuality, and navigating the social, emotional and physical challenges of sexual behaviour.

We will return to the value of this perspective in later chapters in thinking further about the development of sexual identity in childhood and adolescence and broader issues of how children and young people, including those with a learning disability, might be supported in their navigation of such matters.

1.4 The meanings of *sexual health* and consideration of Scotland’s sexual health

We come to the growing knowledge base about the sexual health of the population at a time when sexual health is increasingly located in a political and social policy context with an interest in tackling inequality and social exclusion. Health is being seen in a more holistic way; good health is viewed as both an aspiration and importantly as a right, and contributing positively towards one's own sexual health is promoted as a social responsibility. In this study the definition of *sexual health* provided by the World Health Organisation (on-line) will be used:

> Sexual health is a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled.

Scotland's sexual health is perhaps accurately described as sexual *ill*-health. Scotland's national sexual health and wellbeing strategy *Respect and Responsibility* (Scottish Executive 2006: on-line) states that "sexual health in Scotland is poor" and that "sexual health and wellbeing tend to be worse among more deprived communities". There is an increasing body of statistical data which points to the problems which Scotland faces, and while this study will evidence a lack of specific data about the sexual lives and sexual health of people with learning disabilities discussion of the *general* picture of sexual health in Scotland today will help locate later discussion about the sex and relationship learning needs of children and young people with learning disabilities.

In terms of *sexually transmitted infections* Health Protection Scotland (2008) report upward trends, identifying that young people up to the age of 24 account for the majority (58%) of STI diagnosis in Scotland. In terms of the numbers of men and women in the population who have *ever* diagnosed with a STI the NHS Health Scotland (2002) Analysis of NATSAL data for Scotland (section 5.3) reports that 14.5% of young women and 4.9% of young men interviewed (aged between 16 and 29) have had a positive diagnosis. Health Protection Scotland (2008) also report that the rate of *teenage pregnancy* in Scotland is now steady at 57.9 per 1000 women aged 16 to 19 and 8.1 per 1000 for girls under 16 years old. Figures are also available regarding the outcomes of these pregnancies in terms of delivery or abortion/miscarriage (for which figures are combined); 40% of 16 – 19 year olds pregnancies and 51% of 13 – 15 year olds pregnancies end in abortion or miscarriage, with teenagers in the least deprived communities more likely to have a pregnancy terminated. Information is also available as to *why* teenage pregnancy matters. NHS National Services Scotland (1998) report that mothers under 20 are more likely to give birth to their baby pre-term and more likely to give birth to babies of lower weight, that is less than 2.5 kilos. In other work the DFES (2006) also highlights the characteristics of younger mothers, this data points to the link between poverty, poor education, low or limited aspirations and a set of social realities of teenage pregnancy which include poorer outcomes for children born to younger mothers.

Information is now also available about *first sexual intercourse* and young people's competence regarding this event. The National Survey of Sexual Attitudes and Lifestyles (NATSAL 2000) reports that the median age for *first sexual intercourse* for young men and women in Scotland is 16 years of age however 23% of young women and 30% of young men report first sex before their 16th birthday. Survey respondents were asked to report on a range of factors about timing and the conditions of first sexual experience and by considering a range of variables the NATSAL study team have constructed a measure of sexual competence at first sex. Young people responded to questions pertaining to *self reported regret*, *willingness, autonomy of the decision* and *use of contraception*. The findings indicate that a lack of sexual competence is by far more likely the younger the person is. The data tells us that in terms of young men 66.6% of young men who had first sex at age 13 or 14 were not sexually competent, 46.4% of those who had first sex at age 15 were not sexually competent and 43.2% of young men who had first sex at age 16 were not sexually competent. For young women the figures are more striking; with 91.1% of young women who had first sex at age 13 or 14 not being sexually competent, 62.4% of 15 year old girls are not competent and 49.7% of 16 years olds are not sexually competent. Reflecting the emerging data reported earlier about links between poor educational experiences and socio-economic factors, those who report early intercourse were more likely to have left school at 16, live with one parent and if parent(s) work that they do so in manual work. These young people also reflect what can be viewed of as an emerging disconnect with positive adult role models and educators in that these young people report that the main sources of information about sex are *neither* school nor parent.

The evidence indicates that in Scotland sexually transmitted infections (STIs) and high rates of unplanned teenage pregnancies and terminations are deeply rooted, even endemic in our society. But how have we come to this place? Weeks (1986:96) has expressed a view that in British society, when it comes to sexuality, there is "a crisis of values and meanings, a climate of uncertainty and (for some) confusion”. The picture painted of Scotland’s sexual ill health in this introductory chapter lends credibility to such a claim.

1.5 The meanings of *learning disability*

Mackenzie (2005: 51) reminds us that (like sexuality) “learning disabilities are socially constructed” and that “an individual comes to meet diagnostic criteria for learning disabilities and to be identified as learning disabled as the end point in a complex interplay of biological, psychological and social processes. As a result who comes into the category varies over time and between societies”.

In the UK the International Classification of Mental and Behavioural Disorders (ICD-10) is used in terms of diagnosis of learning disability. The need to use a broad range of sources and information in diagnosis is emphasised; diagnosis should be influenced by local cultural norms and there is recognition of the limitations of IQ testing. Within the broad definition of learning disability there are sub classifications for *mental retardation* used: *mild*, *moderate*, *severe* or *profound*. People with severe or profound learning disability are more likely to be recognised as they will have a clearer need for support and services. In addition to ‘mental retardation’ the classification scheme also recognises that developmental disorders, such as Autism or Asperger’s Syndrome, come within the broad understanding of learning disability.

Classification should however be treated with some caution; Mackenzie (2005: 53) identifies that “decisions made every day in service settings to categorise service users as having a learning disability are not generally based on the rigorous application of the operational diagnostic criteria” as described here. More fundamentally, Baylies (2002: 729) reminds us that within such classifications while “a social context to disability has been conceded” the use of such systems requires “expert practitioners to establish ‘anchor points’ (i.e. of ‘normality’)” which “remain somewhat spurious”, particularly because they retain an emphasis on what the individual is perceived to be incapable of doing rather than the how the society within which they live disables them. Davidson and Baker (2010: 44) agree that “arbitrary definitions and thresholds...are at least partly responsible for the fixed and stigmatised social positions” people with learning disabilities hold in society and so “working collaboratively with people with learning disabilities to formulate their own difficulties” is therefore essential to “challenge some of the assumptions about the social and intellectual incompetence of the people to whom these classifications and sub-classifications are applied”.

There will be further exploration of perceptions and labelling of people with learning disabilities as incapable or lacking in capacity in later chapters but, in general, for the purposes of this work a definition of learning disability is borrowed from the most important contemporary work by Government on learning disability in Scotland in recent years, ‘Same as You? A Review of Services for People with Learning Disabilities’. The review focused on people’s lifestyles and takes the view that people with learning disabilities should be able to lead normal lives. The Review (2000:103) defines learning disability as:

> A significant lifelong condition that has three facets: a reduced ability to understand new or complex information or to learn new skills**;** a reduced ability to cope independently**;** a condition which started before adulthood (before the age of 18) with a lasting effect on the individuals development.

This definition recognises the difficulties an individual may have in coping with their every day environment and recognises that to be categorised as learning disability impairment has to be present in the key developmental period of childhood. When it comes to the *causes* of the impairments which lead to learning disability these are described by the British Institute of Learning Disabilities (on-line) as follows:

> Impairments which cause or contribute to learning disability can happen before, during or after birth. Before birth or pre-natal these are known as 'congenital' causes and include Down Syndrome or Fragile X syndrome. During birth or peri-natal causes: for example oxygen deprivation resulting in cerebral palsy. After birth, or post natal causes such as illnesses, injury or environmental conditions, for example, meningitis, brain injury or children being deprived attention to their basic needs - undernourished, neglected or physically abused.

In terms of prevalence, figures for Scotland reported by the Scottish Executive in 2002 in 'Promoting Health, Supporting Inclusion' suggest that there are some 120,000 people in Scotland with some degree of learning disability, of which approximately 15% will be a severe or profound disability. Whatever the causes of definitions, categorisation or prevalence we are reminded by BILD (on-line) that classification schemes are always open to differing interpretations and that "learning disability is a label which is convenient for certain purposes, but people with learning disabilities are always people first".

In the context of the focus of this dissertation, learning about sex and relationships, it is important to remember that in the definition or consideration of causes of learning disability there is no link between learning disability and biological maturity including age of puberty which is linked to chronological age. However, for the young person with a learning disability, while there are the same processes of physical maturity there are perhaps fewer of the life experiences and milestones of other adolescents alongside which puberty can be explored and understood. For Walker-Hirsch (2007: 36) "This dissonance between biological maturity and social/emotional maturity often requires additional attention" including guidance and protection and learning opportunities, issues we will return to in later chapters.

The historical view of learning disability in chapter 3 explores in more detail the social construction or the *experience* of learning disability. The chapter looks at early labelling of people with learning disabilities as *innocents*, *imbeciles* and *moral defectives*, through the influence of urbanisation, institutionalisation, segregation and eugenics, to more contemporary positions of care in the community and concerns for issues of protection and more personalised service responses with a stronger understanding of individual human rights. Throughout the enquiry the work of Martha Nussbaum on human capabilities (introduced and discussed further below) will remind us that meeting the needs of people with learning disabilities "in a way that protects the dignity of the recipients would seem to be one of the important jobs of a just society" (Nussbaum 2006: 102).

1.6 The meanings of *rights* and considerations of *dignity* and *social justice*

Nussbaum (2000: 97) states that “the language of rights is well established” but also that “the idea of rights is by no means a crystal clear idea”. In beginning this work my own approach was located in what I would refer to as a human rights perspective; the language of this perspective would have been about equality and respect and notions of participation, protection and dignity. My human rights perspective would be evidenced and reflected in the struggle of women, oppressed peoples and minority groups for justice and freedom and so the idea of rights is linked to a world which is fair and in which there is the experience of social justice. Whether *rights* offer a *good enough* basis for the enquiry which will unfold in this study is a key question. Sen (2005: 151) highlights that “despite the tremendous appeal of the idea of human rights, it is also seen by many as being intellectually frail – lacking in foundation and perhaps even in coherence and cogency”. To explore this further it is useful to look at what is meant by rights and then consider whether there is anything additional, specifically from the work of philosopher Martha Nussbaum which might extend our understanding of the meaning of human rights and which might support the enquiry undertaken.

When it comes to more publicly recognised or understood contemporary understandings of what human rights mean these are most likely rooted in the establishment of the United Nations in the shadow of the human rights abuses of World War 2. The UN promotes its purposes in terms of human rights and freedoms through various instruments, primarily the 1948 Universal Declaration of Human Rights which affirmed that every human is born free and equal in dignity and in rights. The rights enshrined in the Declaration are often described as inalienable, and reflect all aspects of life; civil, political, economic, social and cultural. In turn each of these rights is argued to be indivisible and interdependent. However over the last 60 years there has been an increasing awareness that for the most part such a universal declaration may not have been enough to protect and promote the rights of specific populations. These populations, which include people with disabilities, may well be born free and equal but life experience is somewhat different.

As a result of the recognised need to both protect and support individuals and groups who may be vulnerable to denial of their rights further UN declarations have followed. In relation to the areas of interest to this study in 1971 the importance of the human rights of people with learning disabilities was reflected in the Declaration on the Rights of Mentally

Retarded Persons. The declaration affirms that: “The mentally retarded person has, to the maximum degree of feasibility, the same rights as other human beings”. This was followed in 1975 by the Declaration on the Rights of Disabled Persons which also called for recognition of the rights of all disabled people. In terms of children and young people the UN Convention on the Rights of the Child of 1989 also reaffirmed commitments, this time for those under 18, to live a life with “inherent dignity” and continued to focus on a belief that “the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world”. The UNCRC makes specific reference to the rights of children with disabilities by highlighting in Article 23 the requirement that State signatories recognise “that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance, and facilitate the child's active participation in the community”. In more recent developments The Convention on the Rights of Persons with Disabilities which opened for ratification by states in March 2007 asserts that the rights of people with disabilities must be given an equal basis as the rights of others, and as with other Conventions there are mechanisms outlined which aim to ensure that State parties who ratify the Convention can be held to account for implementation. Each of these formal declarations as statements of rights has contributed toward a move to see disability itself as a human rights issue. Degener (2003: 153) sees this arising out of “the paradigm shift from the medical to the social model” in terms of understanding disability. The social model is explored further in chapter 3.

In addition to rights for specific groups the framework and language of rights has also been used in relation to areas of human life; of interest to this study is the notion of *sexual rights* which the World Health Organisation (on-line) claims should define the environment necessary for positive sexual health. This idea of *sexual rights* asserts that every person should be “free of coercion, discrimination and violence” in relation to sexual relations, marriage and reproduction. *Sexual rights* also recognise importance of access to sexual and reproductive health care and of sexuality education for all. Efforts to articulate *sexual rights* points to and clarifies where and how the human dignity of an individual can be adversely affected by the actions of others and recognises that *every* human being has a sexual identity. Specifically, where individuals and populations have experienced violations of basic human rights which are related to their sexual identity or sexual lives, whether that be thorough violence, denial, or acts such as enforced sterilisation, defining sexual rights provides a benchmark against which those actions can be judged to be unacceptable. Whether the sexual rights of people with a learning disability are protected and promoted in Scotland today will be discussed in this enquiry.

While this enquiry does not offer a detailed history of human rights, in order to locate contemporary debates and dilemmas the importance of human rights can be traced to earlier notions from philosophy that there is a natural or moral order which is in fact independent of human laws or traditions; such an order demands that laws and so the rights of the individual should be concerned with goodness, happiness, sociability, respect, doing to others as you would have done to yourself and ultimately with justice. However, challenging the perspective of such natural law comes the view that human rights are formed in a set of rules to which the individual agrees because in turn the society to which they belong offers security and the means by which life can be lived; such a perspective sees human rights formed as a *social contract* between individuals. It is important to touch on this perspective, and to identify why this philosophy, developed by John Rawls (1971) in his work on social justice, remains influential but is open to criticism in contemporary understandings of equality and inclusion.

Human rights, imagined as some form of social contract, are based on some significant assumptions. Firstly, it is argued that parties to such a social contract must have some necessity for co-operation, that they are roughly similar in terms of physical and mental powers, that the contract can protect any one from the aggression of others and that co-operating together is necessary because resources are limited in some way. In addition, entering into agreement brings with it some benefit or advantage to both parties. Furthermore, parties to such a social contract are free, equal and independent; in other words the social contract cannot be reached in the context of tyrannical states, people should be free to pursue their own interests as long as they do not harm others, they should have roughly equal powers and resources. With all these assumptions in place social contract theories argue that the basic political principles of social justice can be agreed.

Social contact theories have of course been hugely influential in contemporary politics and social policy and in our understanding of what social justice means and how it can be achieved in contemporary Scotland. In the language of current educational policy in

Scotland two of the four main purposes of Scottish education for young people, as described in *Curriculum for Excellence*, are to see pupils become ‘effective contributors’ and ‘responsible citizens’. Notions of a social contract between the state, via the school, and the young person are implied. In the language of *Curriculum for Excellence* there is a basic requirement of the individual to *contribute* before they are seen as capable or deserving of equal participation in society; that to be a citizen, with rights, you need first to be (or learn to be) *responsible* and *effective* in your contribution. This implies the *ir*responsible and the *in*effective are excluded, to be dealt with at a later time or by special means. Social contract theory is problematic for this very reason, because it sets up a distinction between those who might be considered *active* or *passive* citizens – with the active citizen being the individual who brings something (which would be considered positive or constructive) to the contract, with the passive citizen being imagined as the other; perhaps a child or a person dependent on others for care or survival. For the passive citizens it seems that the best that can be hoped for is to benefit from the goodwill of others.

Nussbaum (2006: 3) recognises that while a theory “may be truly great” it might also “have serious limitations in some area or areas”. When it comes to social contract theories, and notions of political or social justice which are based upon them, a failure to reflect and respect the lives and realities of many people, and this might include people with disabilities, means that they cannot ensure human dignity or social justice; they do not take enough account of the realities of people’s social context and experience; they set up social justice and human dignity to be earned, negotiated or bartered for; they value the *contributor* over those who require care or support. As Nussbaum (2006: 31-32) states: “In particular justice for people with severe mental impairments and justice for nonhuman animals cannot plausibly be handled within a contract situation so structured”. With this in mind, while human rights provide a framework which will be drawn on in this study - Nussbaum (2000: 100 - 101) recognises that there is a need to retain some commitment to the language of rights as a “terrain of agreement” because this “reminds us that people have justified and urgent claims to certain types of treatment” - in a search for understanding about human dignity in lives of people with a learning disability this work will also draw on a further perspective – that of *human capabilities*.

1.7 Ideas of *entitlement, social justice* and *human dignity*

This introductory chapter has mapped out some of the key concepts and areas which will be considered throughout this enquiry; *human rights*, *learning disability* and *sexual health* and in particular *learning about sex and relationships* are the overarching themes of interest. However while they provide what we might imagine to be staging posts in the story which will emerge, they perhaps fall short of constructing the framework necessary to consider how concepts of social justice, fairness and a life lived with dignity apply in the day to day life of people with learning disabilities. To help, the work of Martha Nussbaum on *human capabilities* will be a recurring theme in this enquiry for as Nussbaum (2011:16) identifies this approach “supplies insight”.

Nussbaum (2006: 155) describes a human capabilities approach as “a political doctrine about basic entitlements”. As such, the idea of human capabilities addresses the challenges faced by questions of social justice and fairness, and how such notions might apply to populations which have often been peripheral or excluded. In her work Nussbaum (2000: 5) explicitly addresses the lives of people with learning disabilities and is concerned with providing “the philosophical underpinning for an account of basic constitutional principles that should be respected and implemented by the governments of all nations, as a bare minimum of what respect for human dignity requires”. For Nussbaum, (2006: 155) and others developing this notion of human capabilities, human dignity is understood to be “an intuitive idea” but one which can be enshrined in constitutional rights or guarantees and can be implemented in law. For Nussbaum (2011: 30) the idea of dignity is important because “it does make a difference” in that it goes beyond more simple notions of satisfaction with life because it demands that in many areas, including education, “a focus on dignity will dictate policy choices that protect and support agency, rather than choices that infantilize people and treat them as passive recipients of benefit”. To understand what is required to live a life with dignity Nussbaum’s (2000:5) describes human capabilities as “what people are actually able to do and to be”.

Nussbaum (2006: 155) “specifies some necessary conditions for a decently just society, in the form of a set of fundamental entitlements of all citizens” and questions the need “for a social contract based on the idea of mutual advantage” (2006: 45). Indeed Nussbaum (2006: 157) thinks optimistically about humanity, and envisages human beings as "cooperating out of a wide range of motives, including the love of justice itself, and prominently including a moralised compassion for those who have less than they need to lead decent and dignified lives". Khader (2008: 20) agrees that justice for people with learning disabilities "begins with attention to their flourishing".

It is suggested by Nussbaum that human capabilities can be understood and accepted by any person, regardless of politics, culture or any conception of what is good. She presents human capabilities as *entitlements* which every person should have, regardless of gender or ability or any other characteristic, whether innate or socially constructed. For Nussbaum (2000: 5) these entitlements can only be meaningful when every person is treated "as an end and not as a mere tool of the ends of others". In particular, when it comes to women in society, Nussbaum rejects any notion that such human capabilities can be pursued if an individual is viewed as subordinate or secondary. Nussbaum states that in terms of the entitlements due to each human being there is a threshold which implies that life beneath this threshold, in terms of any of the human capabilities (see below), all of which are equally important, is a life lived without human dignity.

For other authors developing human capability ideas the attempt Nussbaum (2006: 80-81) has made to identify a list of *central* human capabilities (10 in all, discussed shortly) potentially applicable to *all* contexts, which are based on "ideas of mutual respect, reciprocity, and the social basis of self respect" is questioned. Amartya Sen (who has developed human capabilities approaches in the area of economics) resists identifying a *central list* because of his interest in assuring that a capabilities approach is embedded in complex but real social contexts, always flexible, and developed through a shared understanding and negotiation. With this in mind Sen (2005: 157) has "difficulty in seeing how the exact lists and weights would be chosen without appropriate specification of the context of their use (which could vary) but also from a disinclination to accept any substantive diminution of the domain of public reasoning". Nussbaum challenges the suggestion that her central human capabilities are at all fixed, even in light of challenges from Sen, Nussbaum's work, by describing how each capability can be understood in day to day life and by emphasising the thresholds which must be met, allows us to apply these capabilities explicitly to what we might see as aspects of the sexual health of the individual whilst also providing a way of thinking about learning disability and the lives and opportunities which people with learning disabilities have every day. Human capabilities will be explored in more detail throughout this work but in broad terms it is possible to identify initially why the approach is helpful in this enquiry.

Nussbaum's identification of the individual's entitlement to ***life*** is interpreted by her to mean that every person should be able to live life to the full and not have their life cut short by poverty or a lack of access to adequate health care or resources for living. For Nussbaum an integral part of any life lived to the full is also the necessity for ***play***, for laughter and for recreational activity. As this enquiry will show, people with a learning disability, through institutionalisation, separation and social isolation, have often been denied such a quality of life *but* that better understanding of life experience, personalised services and learning opportunities can foster skills for independent living and improve physical and emotional health and wellbeing.

The human capability perspective also identifies the necessity for ***bodily health*** and ***bodily integrity***; essential parts of which must be good reproductive health, freedom of movement and choice in the realm of sexual lives and reproduction. This enquiry will report on worrying findings about the sexual experiences and sexual health of young people and adults with a learning disability, highlighting how far there is to go in achieving personal safety and satisfaction. It will also be possible to clarify the role of family members and professionals in the provision of sex and relationships learning which can positively impact on bodily health and the capacity to make choices about sexual lives.

By exploring the lives and aspirations of people with learning disabilities this enquiry will identify that there is much to be done in facilitating lives which reflect other of Nussbaum's human capabilities including ***control over one's environment***, ***practical reason***, including the right to reflect and plan one's life and ***affiliation***, which implies the possibility of living and interacting with others whilst being valued and equal. There have been significant shifts in public policy and service provision in recent years and it is now more likely that a person with a learning disability will not live in an institution; but in the realm of personal and sexual relationships this enquiry will explore the extent to which individuals with disabilities control their own environment, plan their own life and have rewarding relationships with others and whether opportunities for learning about sex and relationships can support efforts towards making these entitlements a reality.

Through human capabilities Nussbaum also describes the importance of ***emotions*** and of ***senses, imagination and thought***. For Nussbaum every person has the need to make attachments and to love. They should also live a life in which they avoid fear and anxiety. To build capacity to imagine, think and reason about their life and circumstances they must have an education. As this enquiry will show through fear and stereotypes associated with the sexuality and sexual lives of people with learning disabilities these entitlements have often been denied and there is a need to refresh our approaches to learning for sex and relationships to ensure these entitlements are recognised as key to a life lived to the full and with dignity.

Nussbaum’s central human capabilities also have some other important characteristics. For Nussbaum they can be revised and added to. Nussbaum (2006: 78) also perceives of the capabilities as “somewhat abstract” so that they can be located and agreed in more detail (although not compromised) by those who seek to use them in their own context; this also means that each can be meaningful and applied in all cultural circumstances. Further, Nussbaum also specifically concerns herself with key liberties, perhaps more traditionally found in rights frameworks, specifying the entitlement to freedom of speech, association and conscience. Nussbaum (2006: 78) is also clear that while the list of central human capabilities is “a good basis for political principles all around the world” she does not seek to “license intervention with the affairs of a state that does not recognise them”. Although not undermining the usefulness of Nussbaum’s work on capabilities for *this* study it is important to identify that these claims to the flexibility of the central capabilities identified and the universality of the central list are challenged by some. Clark (2005: 7) for example points to the fact that while “some descriptive content has been added and some parts of the list have been reorganised” that throughout its development in Nussbaum’s work “no categories... have been added or deleted”. In addition, in terms of the global application of the central list it is suggested by Clark (2005:7) that their application to diverse communities might benefit from being considered a “starting point” and that more participatory approaches might bring more local relevance and usefulness to the concept. Certainly, the conclusions drawn by this study and discussed in chapter 7 suggest that learning for sex and relationships, based on ideas of social justice and human dignity, require that the partners in the process of learning - children and young people with learning disabilities, their parents and carers, and associated professionals – each have individual experiences, needs and aspirations and these should inform the learning and the application of the intuitive idea of human dignity central to those entitlements described in Nussbaum's human capabilities 'list'. Dean (2009: 11) would agree, suggesting specifically about young people that "...ways must be found for their authentic voices to be heard; for their understanding of capabilities to be articulated".

1.8 Human capability and disability: a decent and dignified life for all

Across the entitlements articulated with human capability approaches is a focus on how the individual experiences life, with an implicit understanding that it is society's imposition of limitations on people with impairments that is disabling. Writing about how human capability approaches influence how we think about disability Mitra (2006: 241) states that "an individual is disabled if he or she cannot do or be the things he or she values doing or being" while Terzi (2005: 452) identifies that human capabilities helps us to view disability "as one aspect of human heterogeneity" which avoids seeing "diversity as abnormality". Burchardt (2004:742) goes further, suggesting that human capability ideas are about freedom and that: "Liberation from disability is about having choices, not about living life in conformity to some pre-defined notion of normality." Some further exploration of the usefulness of human capabilities is undertaken here, alongside recognition of the challenges to the approach which should also be considered.

Of central importance within human capabilities approaches is a concern with *outcomes*, so that while Nussbaum (2000: 101) recognises that the language of human rights places some emphasis "on people's choice and autonomy" Nussbaum also proposes that *rights* themselves are meaningless unless the individual has the capability/capabilities to make them real. The concern is that rights can deliver different things to different people; for example every individual or group in society may have the *right* to health care, the *right* to privacy, the *right* to freedom of association, the *right* to be free from sexual exploitation and abuse, but having that right does not mean that there is *equity* in terms of access or experience, however “...thinking in terms of capability gives us a benchmark as we think about what it is to secure a right to someone” (Nussbaum 2000: 98).

Human capabilities take this issue of securing rights and propose an important distinction between *capability* and *functioning*;this will be of some importance across this enquiry. For Nussbaum (2006: 179) the human capabilities approach is a matter of making a commitment to provide a “decently dignified life” for all human beings. Nussbaum (2006: 181) accepts that in some circumstances, she cites the person in a persistent vegetative state, it might be argued that “the life is not a human life at all, any more” because this person is cut off from “the entirety of a group of major human capabilities” such as “possibilities of thought, perception, attachment”. In this regard, for some critics, the application of human capabilities to the lives of people with learning disabilities has its limitations. The starting point for these concerns is Nussbaum’s interest, described above, with the issue of functioning and the idea that there may be occasion where the life is not a human life any more. While Stein (2007: 97-98) for example recognises that “Martha Nussbaum’s capabilities approach deals with the concerns about practical content and moral priority of human rights, and provides a productive space for understanding their implementation” he (2007: 94) also argues that human capabilities is problematic in that “it is fundamentally under-inclusive of some people with intellectual disabilities” because (2007: 77) “ it requires that individuals be capable of attaining each of ten functional abilities as a prerequisite to being “truly human” and thus wholly entitled to resource distribution”. Bernardini (2007: 5) agrees that even though Nussbaum “sets the extreme threshold after which a life is not human anymore, close to the medical definition of death” this is unacceptable in that it provides “a specific notion of who a person really is” rather than protecting all human beings. A more inclusive approach for Stein (2007: 77) would “acknowledge the value of all persons based on inherent human worth, rather than basing value on an individual’s measured functional ability to contribute to society... This approach is necessary if human rights are to apply to all humans”.

While it is the case that Nussbaum’s work on human capabilities in relation to people with learning disabilities may not *explicitly* state the right of the disabled person to simply be in the world, and while her account of disability recognises that there are people for whom some degree of guardianship is required or for whom most functioning is compromised, Nussbaum recognises (in relation to an individual who cannot use one or more of the capabilities because of cognitive impairment or who chooses not to use one or more of the capabilities because of religious or cultural practices) that the primary focus must be on ensuring the capability is present in life, and the functioning of the individual is based on their engagement with their life and the availability of support or care necessary to make the functioning above the threshold of a dignified human life possible. In this sense the importance for Nussbaum (2006: 186) is that while the capabilities list is a single list “the conceptions of flourishing are plural”. In this sense then the challenge of understanding this distinction between capability and functioning in the lives of people with learning disabilities is recognised by Nussbaum; particularly that for some people limits to cognitive capacity will mean that an individual may never, despite support, be able to utilise one or more of the capabilities listed; for example political participation or critical reflection in planning one’s life. However, Nussbaum (2006: 188) warns against “tinkering with the list” because as a consequence the possibilities which exist to bring people with particular impairments to the level at which human dignity can be achieved may be undermined by discriminatory attitudes or a lack of willingness or ability to commit resources required; Nussbaum (2006: 188-189) reflects on the history of society’s responses to disability (considered further in chapter 3) which are characterised by low expectation and a view of the disabled as “permanently and inevitably dependent on others” resulting in “constructed failure” where the potential of the individual is not met. Crucially then, Nussbaum’s (2006:285) list of capabilities are not based on the actual functioning of the individual, “but on the basic capacities characteristic of the human species”.

This concern with *dependency* as a *problem* can also be taken further in terms of considering the value of human capabilities ideas to this enquiry. It is noticeable that throughout much of the case for capabilities approaches outlined above there is a focus on the *individual* and as such it is important to recognise that one objection to the capabilities approach might be, according to Dean (2009: 5), that it frames “the individual as an independent entity” and so might then “problematise dependency” where the individual cannot function adequately without the support of others. Dean sees this as a particular challenge for western societies because we are “so imbued with the individualistic ethic” that we “become strangely blind to human interdependency”. However Dean also acknowledges that feminists who have supported the usefulness of human capabilities ideas, including Nussbaum herself, have recognised our interdependency, and give particular value and recognition to the role of women in particular as care-givers. Further, in terms of Nussbaum's central list of capabilities there is of course recognition of the entitlement to *affiliation*, which is concerned with living and interacting with others, and as stated earlier an underpinning of the human capabilities approach by Nussbaum's (2006: 157) with "a moralised compassion" for others.

One further challenge to human capability ideas is about a practical aspect of their application; specifically in relation to resources. The question of promoting rights where they are thought to have resource implications which require the prioritisation of actions is not a new problem. This enquiry is also interested in children's human rights, and as long ago as 1923 Eglantyne Jebb, the founder of Save the Children and author of the first Declaration of the Rights of the Child for the International Save the Children Union (Save the Children Fund: on-line) identified that while each child "must be given the means requisite for its normal development, both materially and spiritually" it is also necessary that in a just and humane society "the child must be the first to receive relief in times of distress". To return to human capabilities and this question of resource allocation Nussbaum recognises that not every person with disabilities will reach the threshold level of every capability the obligation is to try to bring the person to as close to the threshold as possible. Stein (2009: 499) highlights however that while: "The impossibility of raising every person to the threshold of all capabilities is not, in itself, a problem for Nussbaum's theory" still "the problem is that even when it is impossible to raise people to the threshold, it is often possible to spend an unlimited amount of resources raising them *toward* the threshold". He clarifies the problem further as: "This is the problem of insatiable entitlements, also known as the problem of voracious needs or the bottomless-pit problem". For Stein the challenge to the thresholds presented by human capability ideas continues when decisions need to be made about whom best to help if resources are indeed limited. While Jebb's original Declaration of the Rights of the Child argues for the prioritisation of children's needs and rights Stein (2009: 500) proposes that human capability ideas do not address such problems, that indeed Nussbaum "appears not to be aware of it". Having identified such criticisms Stein does recognise that Nussbaum (2006 : 402) herself states that the thresholds should not be set up "in a utopian or unrealistic way" and that "we must ask what combination we can hope to deliver to people under reasonably good conditions" but he also notes that Nussbaum (2006: 175 *supra* note 1) responds to the need to tackle conflicts about who to help where there are conflicting claims as “a purely practical question what to do next, not a question of justice” and this he rejects this as an inadequate response.

Following such criticism Nussbaum (2011: 45) has begun to address the issue of resource allocation more specifically. Responding to the work of other theorists on human capabilities approaches this has recently included defending the notion that “each capability has importance on its own, and all citizens should be raised above the threshold on all ten capabilities” whilst recognising that in some contexts some capabilities “may justly take priority, and one reason to assign priority would be the fertility of the item in question, or its tendency to remove a corrosive disadvantage”. Nussbaum concludes that improved access to education, freeing women from domestic violence or providing credit for the self employed in disadvantaged communities would each be examples where it would be advantageous to devote “scarce resources” to enhancing specific capabilities more than others. To some extent Nussbaum has begun to address the question of resources, and while this would perhaps benefit from further consideration, in the context of *this* enquiry, with its focus on sex and relationship learning, the framework which is described in the concluding chapter whilst influenced by Nussbaum’s work does not, I would suggest, propose a set of solutions which make significant resource demands, although there are implications for current teacher education and support for parents, as they focus on changing the attitudes, values, expectations and skills of adults who support the child’s learning and social experience. Nonetheless were this study about another contemporary issue, for example access to new cancer treatments, this criticism may well require further consideration.

Finally, Alexander (2003: 18) recognises that an important challenge for human capability ideas “...lies in looking for effective ways to translate its philosophical and ethical insights into effective public policies”. In this enquiry it is my intention to use human capabilities ideas and apply them to the challenges of sex and relationship learning for children and young people with learning disabilities. In terms of the usefulness or application of the capabilities approach (referred to as CA in the following quote) Clark (2005: 11-12) recognises that these are in fact ideas which are offering new insights to *many* problems faced by society:

> Attempts to apply the CA have mushroomed in recent years. Among other things the CA has been used to investigate poverty, inequality, well-being, social justice, gender, social exclusion, health, disability, child poverty and identity. It has also been related to human needs, human rights and human security as well as development more broadly. The sheer number, quality and diversity of practical applications that have emerged in recent years arguably lays to rest any remaining concerns about the possibility of making the capabilities approach operational.

In terms of this enquiry the capabilities approach is but one of the theoretical frameworks which will support the analysis offered and in turn inform the conclusions drawn about the nature of sex and relationship learning which we might deliver for children and young people with learning disabilities. For Nussbaum (2006: 190 - 191) human capabilities are essentially a set of social entitlements which require society to “work tirelessly” to bring all people with disabilities “up to the same threshold of capability that we set for other citizens”. Nussbaum (2011: 187) also reminds us that the capabilities approach “is not a dogma that must be swallowed whole” but rather “a contribution” to debate on a broad range of social and economic issues; that it should be “pondered, digested, compared with other approaches”. With this in mind human capabilities ideas are helpful to this project because they offer a radical perspective from which to view the lives of people with learning disabilities, including in terms of personal and sexual relationships. From the useful perspective of human capabilities this enquiry will support Nussbaum’s assertion that individuals with disabilities “are just as much individuals as anyone else is, not types, not a lower kind that we set off from human kind”. Such an approach recognises that particular impairments might impact on functioning but all possible effort, including in the realm of sex and relationship learning, must be put into making a life as fully functioning as possible.

1.9 An outline of this study

This study focuses on sex and relationships learning and is concerned with the securing of sexual rights for people with learning disabilities. The intent is to identify the characteristics of effective sex and relationship learning for children and young people as well as address the broader role that adults can play to enable safe, happy and fulfilling personal relationships for children and young people with learning disabilities. What will result is an understanding of what social justice means in the lives of people with a learning disability and how this might be applied to personal and sexual relationships.

What will be claimed is the right to (and the experience of) relationships lived as an integral part of a life lived with human dignity. The remainder of this work will be structured in the following way:

Chapter 2 provides historical context by uncovering the story behind contemporary debates and developments about sex, sexuality and sexual health and wellbeing. Nussbaum (2010: 17) recognises the challenges which sex presents with the view that “sex is a site of anxiety for anyone who is ambivalent about having an animal and mortal nature, and that includes many if not most people”. With this in mind the chapter explores how the problematisation of diverse human sexualities and behaviours has come about; consideration is given to the influence of feminism, Freud, postmodernism and Foucault. Using the analysis brought by Weeks (1986: 89-90) it is recognised that there is “a growing crisis over the meaning of sexuality in our culture, about the place we give to sex in our lives and relationships, about identity and pleasure, obligation and power, choice and consent”.

Chapter 3 again takes a historical view, and describes views on learning disability over the past 200 years. It maps the legislative, social policy and service responses to learning disability in this period and explores society’s views of and responses to the sexuality of people with a learning disability. The story explores the influence of urbanisation, institutionalisation, segregation and eugenics, and more contemporary positions of care in the community and concerns for issues of protection and more personalised service responses with a stronger understanding of individual human rights. The chapter highlights the choice that we (professional, parent or carer) make in relation to our perceptions and opinions towards the person with a learning disability; framed by Nussbaum (2010: xvii) as such: “Seeing the shape of a human being before us, we always have choices to make: will we impute full equal humanity to that shape, or something less?”

Chapter 4 considers what it is about sexuality in childhood that matters and identifies what it is we know about children and young people’s experiences and needs when it comes to relationships and sexual health. The chapter pays particular attention to the perspectives and experiences of people with learning disabilities including the importance of friendships and relationships, the limited opportunities that are available to develop these and how experiences and anxieties about violence and abuse have framed policy and service responses to the sexual lives of people with learning disabilities. In discussing vulnerability and consent the chapter explores the value of abandoning a deficit approach to considerations of the individual's capacity, promoting a human capabilities approach which looks toward what the individual can achieve (as a result of assessment, support and learning) in relation to personal and (where appropriate) sexual relationships. The chapter concludes that there is some way to go in providing an appropriate balance of support and protection for the person with a learning disability so that they can experience personal relationships which are safe and nurturing

Chapter 5 builds on the premise that sexuality is a cultural phenomenon and that important learning takes place in childhood. It examines *where* and *with whom* children and young people learn about sex and relationships; looking at learning in the context of school and family. In the course of discussion the limitations, challenges, strengths and potential of different settings are examined; the family emerges as an important setting for sex and relationship learning. The chapter considers learning for all children and young people but also focuses on particular issues for those with learning disabilities, discussing which learning environments, and who within them, might best serve an intention to use sex and relationship learning to promote sexual rights and the experience of a life lived with dignity.

Chapter 6 looks further at *what* children and young people need to learn and *how* sex and relationship learning can be best facilitated. An overview is given of current developments in school-based sex and relationship learning in Scotland's schools and a note of caution is struck about an overemphasis on school as the most important location for sex and relationship learning. The chapter examines whether *what* and *how* children and young people with learning disabilities need to learn might be different from their non-disabled peers; exploring current developments in theory and evidence and investigating the usefulness of ideas such as empowerment, self-esteem, self efficacy and self-determination to sex and relationship learning.

Chapter 7 draws conclusions from the enquiry. It asserts the value of human rights and human capabilities approaches to understanding the lives of children and young people with a learning disability where there is an imperative to both protect and to enable them to live life to the full. In conclusion the chapter identifies the characteristics of effective learning about sex and relationships for children and young people with a learning disability and addresses the broader role that adults (both parents/carers and professionals) can play to ensure that children and young people with learning disabilities experience personal relationships lived as an integral part of a life lived with dignity.

Chapter 2

Sex and sexuality: Historical context and influences on contemporary considerations about sex and relationship learning

2.1 Introduction

> So there is sex and sex; on the one hand, a source of fear and embarrassment; on the other, a source of infinite happiness and fulfilment. (Hawkes 1996: 6)

Hawkes (1996: 5) proposes that discussion of sex produces both anxiety and fascination in people, and that as such sex "has a significance which is profoundly social, whether this manifests itself positively or negatively". This chapter reflects on whether this has always been so and helps locate the current state of our sexual health as well as contemporary views about sexuality and learning about sex and relationships. Whilst recognising from Bridges (2003: 190) that "there is always a problem with philosophical writing... with how far back you go in the argument" the chapter considers what has become known as the science of sexology prevalent in the 19th and early 20th centuries and continues with an exploration of the impact of Freud and psychoanalysis, feminist perspectives and the contribution of Foucault.

2.2 Understanding sexuality: the science of sex

The word sexuality was first used in the 1830s in botanical writings but became a term used about men and women with the increase in scientific studies of sex in the nineteenth century; a time when scientists had a fascination for classifying and determining all things. When it came to human sexuality this interest had a concern for *labelling* sexual behaviour with a focus on the problematic, disease and dysfunction. Porter and Hall (1995: 177) view the period and the work of the so-called sexologists who drove it by applying "the rigours of scientific rationality to a highly emotive area" as resulting in "a radically new way to make, unmake and remake sexual knowledge". Weeks (1986:113) proposes that those engaged in this new study "offered an alternative world outlook to the religious cosmology much of its initial energy was directed against. It claimed to be uncovering the truth of Nature in opposition to the truths of mere prejudice or tradition".

Since this time Bristow highlights that social scientists continue to report on the problematic and foster a view of sexuality as being about *having sex*. This is of course still true in Scotland today; consequently we know more about when people first have sex or how many have a sexually transmitted infection *rather than* the meanings of sex or what human capability theory might articulate as each person's experience of their *entitlements* to emotional attachment, pleasure and sexual satisfaction. Such an approach, Bristow (1997: 16) argues, means that:

> Hardly ever do they question the biases that have for more than a century been inscribed in their methods for organising this material. So it remains difficult for their readers to gain insights into the cultural conditions and ideological pressures that gave rise to the idea of sexuality in the first place.

Of importance to this study is Bristow's (1997: 17) view that associations between sexuality and a number of other factors including women's sexuality and homosexuality are all the result of "the interpretive lens through which it is observed", he describes *a science of sex* which amounts to "an exhaustive effort being made to derive natural truths from cultural phenomena".

Further examples of this legacy of the early science of sex may also be useful in exploring current assumptions about sexuality. Perhaps some of the most important and useful to sketch out briefly are the views which were developed on areas such as masturbation, homosexuality, prostitution and a broader perspective of sexuality itself as something dangerous, in need of control. This latter idea is challenged by notions of entitlements to sexual satisfaction and choices in terms of reproduction located within a human capability approach but these issues also matter in the context of this dissertations specific interest in learning disability and sexuality because it is within these emerging perspectives that we find the basis of discriminatory and fearful responses to the emerging sexual identities of people with disabilities and some explanation as to why sex and relationship learning for children and young people is seen as contentious.

2.3 Problematising sexuality: masturbation, homosexuality and prostitution

In these three realms we can track some important legacies for our consideration of contemporary debates and responses to sexual health and wellbeing and to learning about sex and relationships, particularly for people with learning disabilities. A useful starting point is to consider, when it comes to the sexuality of young people with a learning disability, there is a particular preoccupation, particularly in relation to young men, with the issue of masturbation. In particular there are concerns about young people understanding the difference between private and public acts and that where a young person with a disability gets this wrong then masturbation in inappropriate places leads to them being labelled as dangerous to others. It is also the case that young people with learning disabilities need to learn how to protect themselves from abusers who may give contradictory messages about behaviours such as masturbation.

In terms of some of the historical legacy, masturbation or ‘autoeroticism’ often preoccupies those seeking to understand human sexual behaviour. In 1760 the first and key text which problematised masturbation was published with the title ‘On Onania’ which articulated what would become the view of masturbation as debilitating. Moore and Rosenthal (1993: 3) report that in the early 20th century the Surgeon General of the United States warned that masturbation caused heart disease, hysteria, impotence and insanity and that in a 1906 New Zealand Borstal institution review a Dr. Symes argues that masturbators who remained uncured should be “put on an island and flogged with the cat o’ nine tails”. Medical views of masturbation led some Victorian doctors to perform female genital mutilation to remove the clitoris of girls and women accused of the practice. Laqueur (1990:227) writes that “the underlying pathogenesis of masturbatory disease in both sexes was thought to be the same: excessive and socially perverted nervous stimulation”. While Laqueur (1990: 228) supports Foucault’s analysis that much of the writing on the subject can be viewed as scientific pornography, designed to generate “erotic desire in order to control it” it is in this period that fears about masturbation are linked to social stereotypes of the feeble-minded; with both the masturbator and feeble-minded identified as dangerous, social control can be legitimised.

In terms of homosexuality, whilst the term itself emerged around 1870, and our views are now influenced by contemporary political perspectives and liberation struggles, there is evidence of same sex desire and relationships across cultures and throughout human history. In terms of homosexuality as *identity* however Gilbert Herdt (2001: 269) observes that before the later 19th century:

> …in the absence of marked categories of sexual identity, the classification of persons was by individual design, less than by cultural difference; by their sexual and gendered acts, not by sexual identities, for these identities awaited invention. Likewise, the distinctions between homosexual and heterosexual had to wait the time of new social distinctions, with rewards (heterosexuality) and punishments (homosexuality) meted out along the way.

These distinctions did emerge; Garton (2004: 97) quotes Trumbach as identifying the emergence of an identifiable "adult effeminate sodomite" at the end of the 17th century, men who increasingly became visible through dress and association in special clubs. Throughout the next 200 years increasing numbers of men were arrested for sodomy and persecution flourished. Networks of women who loved women also emerged, although less publicly. By the end of the nineteenth century the new science of sex had begun a process of developing a view of homosexuality as something perverse, and like those born 'idiots' or 'imbeciles' the homosexual was inflicted with a congenital condition.

In 1903 the work of philosopher Otto Weininger captured much of the mood of the time. In his work 'Sex and Character' he proposed that masculinity and femininity are derived from one sex, however Weininger's position was to argue that homosexuality and bisexuality is a sign that the individual has too much of 'the other' in their make-up, and that it is necessary to resist such conditions and to construct 'ideal' types of men and women, essentially heterosexual. Garton (2004:99) highlights that "increasingly men, out of fear, began to constitute themselves around the identity of being sexually interested only in women" and so embedded the much safer and acceptable "emergence of the idea of a heterosexual identity" which meant "sex ceased to be seen as something between an active and a passive partner, regardless of gender, but ideally as an act between men and women" with those who questioned this ideal experiencing "legal and social retribution".

In time this science of sex also addressed same sex relationships amongst women, so that they too became seen as deviant. There are different views amongst feminist historians about the impact of this attention on women, with one argument that such labelling and categorising of female sexuality from a predominantly male perspective is damaging, to another view that while the period saw women's sexuality being problematised at least it gave name to an identity allowing women who loved women to see themselves.

A further focus, indeed fascination of the times was prostitution. While not a focus of interest in this dissertation as such, it tells us about views of women and female sexuality. In urban environments in the mid 19th century female prostitution was often very visible. Myths about women working as prostitutes dehumanised and demonised them and laws emerged which criminalised the acts of the women rather than men who paid for sex. But the hypocrisy of 19th and early 20th century society is particularly stark when it comes to child prostitutes in which we find attitudes and behaviours which are deeply abusive. Hawkes (1996: 47) reports that:

> A Royal Commission in 1871 found that in three London hospitals there were 2700 cases of venereal disease among girls of 11 and 16 years. The sexual use of young girls was indirectly sanctioned, as 12 was the age of consent. Girls of this age could be purchased for the (substantial) price of £20, a valuation which gave some clue to the social class of the purchasers… That virginity was highly prized erotically was reflected in the still popularly held notion, despite medical advice to the contrary, that sex with a virgin was a cure for syphilis.

This chapter will come to the importance of later 20th century feminist discourse on these matters shortly, but reflecting back on what has been considered so far, and pulling together a number of themes above Hawkes (1996: 46) identifies that by the mid 19th century certain groups of people, committing certain acts, had become seen as acting in opposition to what could be deemed natural, they had become *sexual deviants*. By establishing a concept of deviant the new "central pillar of the bourgeois sexual orthodoxy: the pre-eminence of a masculinist sexuality" had been put in place and so we can begin to trace social attitudes and policy and legislative responses to human sexuality which make the struggle for human capability ideas about bodily health, freedom from violence, the need for emotional attachment and self worth increasingly important.

2.4 Men, women and early feminism

The science of sex brought a particular focus on the sexuality of both women and men, and so the relationships between them. Laqueur (1990: 193) proposes that the 19th century saw "endless micro-confrontations over power in the public and private spheres" while Garton (2004: 97) sees gender put centre stage in the 19th century "by the struggle for political and social rights based on claims of liberty and equality". In the realm of the family, the private, which Nussbaum (2006: 1) identifies was considered "immune from justice" we see men win out with the Enlightenment position that while marriage is a voluntary association someone still has to be in charge; Laqueur comments (1990: 194) "that someone is the male, because of his greater force of mind and body".

The science of sex engaged in investigation and debate throughout the period in relation to women's sexuality, for example on whether and how women could have an orgasm, on the relationship between ovulation, menstruation, sexual desire and on the responsibility of women to be chaste. Laqueur identifies (1990: 217) that "whatever one thought about women and their rightful place in the world could, it seemed, be understood in terms of bodies endlessly open to the interpretive demands of culture". Bland sees the period between 1885 and 1914 as one in which early feminists had an interest in both *sexual danger* and *sexual pleasure*. Concerns for freedom from violence, and an entitlement to pleasure and the avoidance of pain, are also central to human capability theory. In chapter 4 the experiences of sexual violence and abuse of men, women and children with learning disabilities will be discussed in more detail, highlighting the continued relevance of these issues and a clear indication of the challenges which remain and the distance still to travel to achieve social justice and dignity for people with disabilities.

In this era fertility also became a key area of interest and struggle for women. Malthus's 'Essay on the Principle of Population', although published as early as 1798, articulated concerns about a growing population. Malthus argued for birth control whilst Garton (2004: 106) observes that in response others saw abstinence and "moral restraint was one answer". In terms of birth control natural methods such as withdrawal had long been practiced but the 19th century also saw the availability of sponges, spermicidal jelly and diaphragms. The invention of vulcanized rubber allowed for the manufacture of condoms but these were too expensive for the working class. Abortion was another option. Bland (1995: 190) writes that despite being illegal since 1803 abortion "was the main form of female birth restriction, widely resorted to by women of all classes, although especially working class women in urban areas" and that its use was largely a matter of economics as abortions "were much cheaper and easier to obtain than contraceptives". Of course abortion in unhygienic and illegal circumstances posed real physical dangers for all women.

Contraception was established as a matter of controversy in 19th century Britain; and many of these arguments are reflected in contemporary discussion of the teaching about contraception in schools. For some objectors contraception permitted immorality or sexual activity without consequence. Further objections came from those with concerns about women refusing to fulfill their natural place as mothers. For others, including early feminists, there were fears that the middle classes would have far fewer children, whilst the poor and degenerate would not. Bland (1995: 306) identifies an uncomfortable fit between the early feminist stance on the moral superiority of women over men and the view that "motherhood gained new dignity as a 'duty for the race'". The legacy of eugenics remains with us when it comes to the reproductive rights of women with learning disabilities and will be returned to later.

In terms of heterosexual men the concern of the time was largely about sexuality and control, about men's drives and needs, but also about class and gender. In the late 18th century Malthus argued that central to the future of humanity was control of human sexuality and urges, and that only then could population growth be addressed. Bristow reports on the work of Richard von Krafft-Ebing who asserted one hundred years later in the late nineteenth century that the sexual appetite of men was like that of animals and that it was civilised or moral society's responsibility to control it. Krafft-Ebing claimed that there were three civilising factors required; clothing, respect for women and the meeting of their needs for love and protection, and heterosexual monogamy. Continuing this theme Porter and Hall (1995: 125) recognise in this science of sex that:

> …a national desirability of populousness, the new cult of motherhood, ameliorating economic prospects, and an emphasis on the family as the linchpin of the community

> all encouraged the institution of matrimony and promoted the notion that happy, fruitful sex within marriage was a personal blessing and a social cement.

Hawkes identifies that the Enlightenment view of sexuality was essentially *refined* sexuality. By this she means that dependent on gender and on class, sexuality could be enjoyed, having sex could be encouraged, and men's desire to have sex was seen as natural. Hawkes quotes Porter (1982:21) as recognising that "above all, sex with sensibility seemed to solve that constant problem of the English Enlightenment: how individuals could indulge their own selfish passions without danger to the social order". Thus, the legacy of the 19th and early 20th century interest in human sexuality is the emphasis on the role of reproduction and heterosexuality as the purpose and norm which should be practiced and promoted; pleasure is rejected as an acceptable part of the picture. Once again, such socially conservative views influence the content and purpose of sex and relationship learning in the contemporary context. From the 19th century we are left with the legacy that those who do not fit, the deviant and the incapable, are deemed to live in "a hinterland of practitioners of non-procreative sex" (Hawkes 1996: 49) and sexuality is thus interwoven with morality, a morality to be enforced by church or state and a fear of anything perceived to be different or perverse. Hawkes continues:

> A focus on practices, ordered positively and negatively, promoted an economy of sex where expression of sexual desire deemed superfluous to the project of reproduction and mastery of desire, were considered wasteful both in the moral and physiological sense. Directly or indirectly sexuality became more amenable to systematic analysis, in a period in which scientific approaches to the investigation of human behaviour were increasingly being deployed.

There is a strong legacy of what we can now see as social conservatism in this science of sex. It raises questions about the extent to which people with disabilities also inhabit the 'hinterland' Hawkes identifies. However, the sexologists were to be challenged more by the ideas of psychoanalysis, by 20th century feminism and by the work of Foucault, and these are now considered in the search for key influences on contemporary views of sexuality and learning about sex and relationships.

2.5 Sexuality and the unconscious mind – Freud and psychoanalysis

Garton (2004: 189) observes that whereas sexology had focused primarily on the problematic and the perverse, and in doing so informed a morality based on religion and fear, the work of Sigmund Freud and later psychotherapists such as Jacques Lacan, “sought to examine ‘normal sexuality’”. With a wider view of sexuality, psychoanalysis provided a theoretical base which was then more able, according to Bristow (1997: 36) “to account for how far culture could and did depart from nature”.

Vice (1998: 162) recognises that “psychoanalysis is closely concerned with gender, sexuality, familial relations, and… the fact that their expression and construction are not always available to the conscious mind”. In essence the work of Freud challenged the assumption that sexuality emerges in adolescence and has its natural conclusion in reproduction within heterosexual relationships. Freud grounds his challenge to this view in what Bristow (1997: 62) identifies as three phenomena which “…show that eroticism extends well beyond the scope of the reproductive capacities of sexually mature adults”. Bristow identifies these phenomena as identified by Freud as follows:

> First there is the widespread existence of homosexuality. Second, there are people classified as ‘perverts’ whose desires ‘behave exactly like sexual ones but who at the same time entirely disregard the sexual organs or their normal use’. And third there is the question of why young children frequently take an interest in their genitals and experience excitation in them.

Freud’s theory was, Garton (2004:187) writes, that “all sexual life, not just perversions and nervous illness, was the product of unconscious conflicts between instincts and society”. Freud presented an alternative view to that of the time, arguing that repression of sexuality, of unconscious desires, was damaging. Freud proposed that to reach normal gender and sexual identity the child had to resolve both oedipal and castration complexes, and that the location for this process was the family; while Freud’s work is problematised below this identification of the family as a context for consideration of the individual’s sexuality, sexual life or indeed sex and relationship learning is of value to this enquiry.

As alluded to above, Freud’s work is seen as problematic, it lacks historical context and presents analysis as if it is timeless and fundamentally its focus is on something that cannot be understood because it is unconscious. McLaren (1999: 111) describes Freud as original but far from revolutionary, that the “real interest of psychoanalysis resided in the fact that it drew on contemporary sexological investigations and many of the common sexual preoccupations of the early twentieth century”. Indeed McLaren argues that by explaining that “all neurosis had a sexual origin” Freud and other psychoanalysts could be perceived as merely “supplying an anxious population of consumers with a variety of services to construct maintain and repair their identity”. This notion of an anxious population would seem to have continued resonance in terms of current social policy focus on the sexual health and wellbeing of young people as well as apprehension or fearfulness about the sexual lives of people with learning disabilities.

Across his work Freud focused on the sexual life of men, he continued to theorise of women as passive, they were less ethical and rational than men. In particular psychoanalytic phallicism is seen as problematic, with female sexuality only viewed in relation to how women come to terms with ‘penis envy’. With its focus on the sexual problems of the individual any cultural or societal changes, such as those argued for by feminism, lose their place. Vice (1998: 165) refers to Irigaray’s interpretation that Freud’s view on the nature of women is that their “nature is strikingly similar to that of melancholia, or depression. Like the melancholic a woman prefers affection to passion; has little interest in the outside world; and has suffered a primordial disappointment – castration, in the woman’s case. In other words female sexuality is necessarily pathological, as melancholia in men”.

Perhaps the key legacy of psychoanalysis, coming as it did out of the time of biological sexology described earlier, is that sexuality became perceived more as a process than something pre-determined, that as a process there is a need to consider sexuality in childhood (and so the main realm in which children live, the family), and that much of our understanding of human sexuality must take cognisance of what we find in the unconscious. The relationship between sexuality and childhood remains problematic, and in chapter 4 a specific focus on this will allow us to explore further ideas and debates about acquiring and assessing sexual knowledge, children and young people’s own perspectives and the importance of improved understandings of notions of vulnerability and consent. Further, in terms of legacy McLaren (1999: 123) observes that psychoanalysis has played some part in helping “to chip away at the solidity of the idea that reproductive heterosexuality was a natural given” and while Bristow (1997: 83) recognises problems with psychoanalysis he also identifies that Freud’s work remains “an immensely fruitful resource for comprehending the intricate, if at times baffling, psychic processes that create masculine and feminine, heterosexual and homosexual, desires and identifications”. Finally, it is worth recognising that psychoanalysis continues to be practiced as a branch of psychological medicine.

2.6 Feminist perspectives after Freud

In the earlier reflection on the period from the mid 19th to early 20th century, much of the legacy of the time can be seen as negative, many socially conservative views of gender and sexuality were embedded and what was labeled different became perverse. However it was also a time where new knowledge did emerge, for example about the physiology of human bodies, and where ideas about the rights of women to be safe and healthy in relationships, or ideas about education in terms of sex and sexual health, all began. These ideas are central in considerations of social justice and human dignity through a human capability approach. Mid to late twentieth century feminism also sought to draw attention to a number of key areas which will aid this consideration of what young people, including those with disabilities may need from sex and relationship learning, with discussion and debate around key areas such as sexual violence, consent, prostitution, pornography and sexual rights. The shared focus in this new feminist theorising is on what Jackson and Scott (1998:2) describe as “the social and cultural shaping of human sexuality” with sexuality clearly contextualised as a political issue.

To turn briefly to the importance of terminology the very language of ‘sex’, ‘gender’, and ‘sexuality’ is complex and there are continuing debates about what each means, and the interrelationship between them. For clarity this dissertation is adopting the World Health Organisation definitions of sex and of sexuality (see chapter 1). Importantly however, Jackson and Scott (1998:2) re-emphasise a key issue of interest to this work that “sexuality is not limited to sex acts but involves our sexual feeling and relationships, the ways in which we are or are not defined as sexual by others, as well as the ways in which we define ourselves”. When it comes to sex/gender feminism of course recognises at the core of its ideas and debates that it is the aforementioned social and cultural distinctions which in turn impact on the sexual lives of women.

Earlier sections have described the development of perspectives around women’s sexuality and men’s efforts to control it. From the mid twentieth century however social changes in the lives of both women and men, including opportunities to work, to learn, to control fertility all had significant impacts on women’s lives; albeit to different degrees in Scotland depending on issues of class, geography or religion. Legislative changes also occurred, and while not wanting to overstate the impact these would have had on people’s day to day lives divorce, abortion and male homosexuality were the focus of more liberal legislation. In this new context women also began to question aspects of their personal relationships and to challenge entrenched social attitudes and behaviours which they encountered in the private and public realm. Sexual relationships and sexuality became issues which were increasingly debated. In very real ways women influenced by feminist principles and ideals created new ways to live life as a family; with same sex parenting, shared parenting and communal living. Jackson and Scott (1998:6) observe that this questioning and these alternative representations soon became “a fundamental critique of heterosexual practice and ultimately of the institution of heterosexuality itself”.

Feminism made public the challenge to oppression based on socially constructed difference. Feminists refused to accept the stereotypes, the violence, the denial of pleasure, the refusal of rights due to women, and in doing so politicised what had been seen as, and devalued as, personal or individual experience. The legacy for people with learning disabilities, and for human capability approaches, has been to legitimise demands for equality, dignity and social justice not just in terms of jobs or education but also in relation to personal relationships and sexuality; the specific experiences and needs of children and young people in this regard are the key focus of chapter 4.

Feminism has also not only influenced, but become essential to human capability theory and ideas about sexual rights where the importance of sexuality, sexual health and interpersonal relationships are weaved across the entitlements of all people. In particular human capabilities approaches reject the “distinction between the public and the private spheres, regarding the family as a social and political institution that forms part of the basic structure of society” (Nussbaum 2006: 212). Further, in terms of learning about sex and relationships, feminist theory and ideas of freedom, choice and consent have also influenced school-based programmes here in Scotland such as SHARE (discussed in more detail in chapter 7) and will inform the framework for sex and relationship learning for children and young people with learning disabilities outlined in chapter 7.

2.7 Postmodernism, sex and human rights

Contemporary feminism and post war ideas about human rights and human capabilities approaches have emerged in the era of postmodernism. Beginning in the 1950s Waugh (1998:178) proposes that postmodernism “is best thought of as a ‘mood’ arising out of a sense of the collapse of all those foundations of modern thought which seemed to guarantee a reasonably stable sense of Truth, Knowledge, Self and value”. Postmodernism calls into question what we claim to know; seeing much knowledge as constructed and situated and not objective or rational.

Arslan (1999) identifies that postmodernism is problematic in terms of the idea and struggle for human rights which is central to this enquiry and as such postmodernism requires some examination. Arslan (1999: 196) describes human rights as “a plural and tolerant framework in which individuals live” but highlights that the postmodern idea is essentially hostile “to the concept of the autonomous subject and to the idea of universality” which undermine a rights perspective. In her work on human capabilities Nussbaum addresses both these challenges from postmodernism, affirming the usefulness of human capability approaches to this enquiry. Firstly, in terms of a view of the person as an *autonomous subject* human capabilities, as “one species of a human rights approach” (Nussbaum 2006: 78), recognises “ideas of human dignity and the inviolability of the person” as “core intuitive ideas” (Nussbaum 2006: 80). This challenges a homogenisation of human beings who share a characteristic, including learning disability, and ensures, for Nussbaum (2006: 80), that society does not “neglect the separateness of each life” and so “subordinate certain groups or individuals”. For human capabilities approaches a necessary focus must therefore be on the recognition of each individual's entitlements and the provision of care and support to the individual where they encounter an impairment or barrier to their functioning. Secondly, in terms of postmodern criticisms of the idea of *universality*, where human rights apply to all human beings at all times, Nussbaum (2006: 163) argues for the possibility of an "overlapping consensus among citizens who otherwise have different comprehensive views"; rejecting postmodern criticisms that human rights are solely "drawn from the traditions of Western democracies". In terms of human capabilities Nussbaum also identifies that the universality of the approach (which would include entitlements to health, bodily integrity and affiliation with others) is abstract enough to be applicable in any cultural or national context; with the understanding that, in support of pluralism, it is the entitlement (the capability) that is supported and not the function that is required.

With these challenges and responses in mind, postmodernism, along with feminism, questions Enlightenment views on gender and normalcy regarding sexual identity and behaviour. Specifically, Waugh (1998) highlights that postmodernism supports feminisms (and so human capabilities) challenge to the Enlightenment position of splitting what we see as private and public; a split used to define and limit the role of women. The problem however, again using Waugh's useful analysis, is that the Enlightenment also brought with it understanding of and commitment to reason and justice; it legitimised the struggle for freedom, emancipation and rights. Waugh suggests that to reject the gains of the Enlightenment and adopt wholeheartedly the perspective of postmodernism may well undo progress made. Waugh (1998:188) goes so far as to argue that the position of those committed fully to the notion of postmodernism "bears no relation to the constraints imposed on our actual being in the world" and that while postmodernism "may seem to offer an escape route from biological, social and cosmic determinism" strong postmodernism contradicts the ability to establish "any kind of politics, ethics or epistemology which assumes the necessity for personal and collective agency and responsibility". Postmodernism then can be seen to undermine any identification of the need for action on social injustices, including the denial of sexual rights, articulated within human capability ideas.

Whatever the position taken, Waugh (1998: 181) quotes Hekman as arguing that "feminism and postmodernism are the only contemporary theories that present a truly radical critique of the Enlightenment legacy of modernism" Waugh (1998:192) also proposes that feminists, and by implication proponents of human capability ideas, can and should pick and choose what postmodernism offers:

> If feminism, like some versions of the post-modern self, is an ever revisable narrative project, then, like a good author, it needs a sense of the appropriate moment to stand back from its creations, to decide what is worth retaining and what has had its moment, what is of lasting value and what is simply pandering to fashion.

2.8 The contribution of Foucault

Deveaux (1994: 223) argues that "few thinkers have influenced contemporary feminist scholarship on the themes of power, sexuality, and the subject to the extent that Michel Foucault has". Weeks (2005: 187) also recognises that Foucault provides us with "a box of tools" which offer us "ways of thinking" about sexuality which in turn can help to "try to understand our present uncertainties." Berard (1999: 203) quotes Foucault himself as saying that his work tries "to locate three major types of problems; the problem of truth, the problem of power, and the problem of individual conduct".

Foucault's work which is of most interest to this study was produced over three volumes titled 'The History of Sexuality'. Volumes two and three, produced shortly before his death, sought to explore the period between the 5th century BC and early Christian times. In exploring the ancient Greeks Foucault covered an area of interest for Martha Nussbaum, whose development of human capabilities is central to this enquiry; however while Nussbaum (1985: on-line) recognises the value of the first volume of Foucault's work on sexuality, later volumes, written in the years before his death and during illness, she describes as vague, incomplete and mediocre; "a departure from views about the inseparability of ideas from social institutions that have been his most valuable legacy to modern philosophy". However, it is the first volume of Foucault's work which is of most relevance and interest here; in it Foucault challenges the common notion that sexuality has been systematically repressed in western society since the 19th century, in fact arguing that as a result of the interest of science, medicine, state and Church, there has been ever increasing discourse on the matter. He explores the role of the Church and psychoanalysis, and the demand that people *confess* not only sexual indiscretions but even their thoughts about sex in the search for sin or the unresolved conflicts of the subconscious mind. Foucault (1976:17-18) discusses the complexity of such processes within which on the one hand there are “instances of muteness which, by dint of saying nothing, imposed silence. Censorship” yet on the other “institutional incitement to speak about it, and to do so more and more; a determination on the part of the agencies of power to hear it spoken about, and to cause *it* to speak through explicit articulation and endlessly accumulated detail”. Foucault (1976: 35) identifies that:

> What is peculiar to modern societies, in fact, is not that they consigned sex to a shadow existence, but that they dedicated themselves to speaking of it *ad infinitum*, while exploiting it as *the* secret.

For Foucault these discourses on sexuality saw increased observation of and control over women’s bodies, the problematisation of women’s sexual health, the need to ‘protect’ children from anything deemed sexualising such as masturbation (this is explored in more detail in chapter 4) and the “psychiatrizing of perverse pleasure” (Foucault 1976: 105) that is any sexual acts committed by adults out with the norm of heterosexual relationships for reproduction. Akin to Hawkes (1996: 48) description, quoted earlier, of the focus on the “hinterland of practitioners of non-procreative sex” Foucault (1976: 39) identifies that:

> …what came under scrutiny was the sexuality of children, mad men and women, and criminals; the sexuality of those who did not like the opposite sex; reveries, obsessions, petty manias, or great transports of rage. It was time for all these figures, scarcely noticed in the past, to step forward and speak, to make the difficult confession of what they were. No doubt they were condemned all the same; but they were listened to; and if regular sexuality happened to be questioned once again, it was through a reflux movement, originating in these peripheral sexualities.

One of the most important things about Foucault’s analysis is that he sees sexuality as *socially constructed* rather than a natural category. Weeks (1986: 25) recognises that Foucault views sexuality as “something which society produces in complex ways. It is a result of diverse social practice that give meaning to human activities, of social definitions and self-definitions, of struggles between those who have power to define and regulate, and those who resist”. Building on this, Weeks identifies some broad areas that are the foundations of this social organisation of sexuality. Each of these are of interest when we come to explore in more detail the sexuality and sexual identity of children and young people (in particular in chapter 4) and people with a learning disability throughout remaining chapters (but particularly in chapter 3 which explores the connections between responses to learning disability and sexuality).

For Weeks, the first building blocks for the social construction of sexuality are kinship and family systems. This, it is argued, is the arena in which, at least in Western culture, sexual and gender roles and relationships are modelled for us, where we learn what is thought to be acceptable and what is not. In chapter 6 we begin a more detailed exploration of the family as a setting for sexual health learning and identify that much of this learning might be seen as implicit, opportunistic and spontaneous rather than explicit, considered and planned. Then there are also broader economic and social organisational influences on the construction of our sexuality; for example changes and shifts in populations or gender roles influence understandings and practices relating to sexuality. Weeks then identifies the role of social regulation, laws, political interventions and less formal social and community mores or standards as key to understanding and constructing sexuality. Certainly, for people with learning disabilities legislation and other means of social control have played a significant part in the control of personal and sexual relationships and undermined entitlements to freedom and dignity in these areas. Finally Weeks identifies the role of resistance and “alternative knowledge” evidenced by, for example, feminism and homosexual identities. For Weeks (1986: 30), in support of Foucault’s analysis, sexuality is “a product of many influences and social interventions. It does not exist outside history but is a historical product. This is what we mean by the social construction of sexuality”.

Foucault’s work is also valuable in terms of his observations about *power* in social relationships and its relationship with *pleasure*. Notions of men’s sexuality and sexual needs as overwhelming them , as being over*powering,* were part of both the basis of the science of sex and a part of the interpretation of psychoanalysis, as discussed earlier. Foucault’s analysis is more complex. He challenges the interpretation of the Victorian period as one of sexual denial and repression, the reigning in of sexuality, but sees it in fact as a period of censorship *and* obsession about everything sexual. For Foucault, part of this obsession sees the state as active in trying to control the body and sexuality; in terms of health, reproduction, population control, birth, mortality and morality. Foucault calls this the biopolitics of the population or ‘biopower’. In practice this can mean the forced sterilisation of women with learning disabilities or increased prenatal surveillance and screening, for example in contemporary times HIV testing for all pregnant women. For Foucault (1976: 140-141) this biopower was “without question an indispensable element in the development of capitalism; the latter would not have been possible without the controlled insertion of bodies into the machinery of production and the adjustment of the phenomena of population to economic processes”. This idea matters to the lives and experiences of those with disabilities, who with urbanisation and industrialisation became less able to fulfil a ‘productive’ role and who increasingly became perceived of as a burden and incapable.

Foucault’s (1976: 93) views on power are also important because it is not necessarily understood as a negative force, nor always top-down; however it is always present. Power then “is produced from one moment to the next, at every point, or rather in every relation from one point to another. Power is everywhere; not because it embraces everything, but because it comes from everywhere”. Foucault challenges any understanding of power between men and women as *necessarily* being about domination or victimization but sees power as something which, according to Deveaux (1999: 231) reflects “the interweaving nature of our social, political and personal relationships”. For Foucault power can only be present when those involved are free subjects and have the possibility of reacting to the other’s power, so for example if violence or subjection is involved power is not present because the victim has none. And it is in the realm of social relationships that Foucault sees the possibility of establishing values, rejecting any attempt by Church or state to impose values, arguing that morality can only be worked out individually and collectively through social relationships. Such a view informs human capability theory where morality conceived of as a desire for human dignity must be achieved in the social relations between individuals, communities or nations. Ideas about power, values and moral behaviours are also considered as significant elements of the framework for sex and relationship learning which is proposed in chapter 7.

Returning to the idea of sexuality as a social construct, the proposition that sexual *identity* is necessarily then *also* a construct has great importance in the way we consider the conditions, experiences and rights, including sexual health rights, of groups within contemporary society, particularly when sexual identity or identity politics are a cornerstone of liberation struggles. Deveaux (1999: 240) recognises the dilemma that Foucault's analysis presents, that if identity is also a social construct "...how does a group or an individual simultaneously *resist* an identity *and* mobilize around it for the purposes of empowerment and political action?" (My emphasis) There are also related criticisms of Foucault's work in relation to power. Weeks (2005: 196) proposes that Foucault "was relatively indifferent to gender" and so there is criticism about whether Foucault takes enough account of women's individual and collective experience, that *their* freedom is not the same as men's freedom, that the starting points are not the same because of structural inequalities. Such a criticism might also be put in relation to other groups such as people with learning disabilities. When it comes to the ideas of the social construction of identity and of biopower feminists have also criticised Foucault's work, agreeing with Weeks assertion that he fails to identify how women, or indeed any other group, can resist such monitoring and surveillance; that while Foucault does talk of resistance as integral to power relationships, there is little room for what might be described as struggle and empowerment in his analysis from the *subject's* perspective. As Deveaux (1994: 230) states: "Foucault's biopower analysis helps to reveal the implications of the mechanisms for the control and regulation of our bodies… however, taken unamended, the paradigm obscures both individual women's and collective struggles against coercive medical and social practices". Again, this clearly relates to the individual and collective experience of people with learning disabilities in terms of medicalisation, institutionalisation and social control which will be explored in more detail in the next chapter.

Tobias (2005: 65) recognises the concern and criticism that Foucault's analysis appears to be "incompatible with social activism and political advocacy" and as such leaves "no room for agency within the nexus of institutional, disciplinary and discursive constraints...from which to resist the status quo" however he argues that Foucault himself wanted to describe how constraint works, to encourage the individual to be vigilant of social control, but leave reactions or responses to such repression – including resistance and transgression - to the individual's self-determination. Tobias (2005: 66) puts forward a view that, within Foucault's understanding of power in relationships, power (when used legitimately) can result in freedom and in terms of the individual "can orientate political action". There remains a concern however that a focus solely on individual agency sits in opposition to a view brought by human capabilities approaches that there should agreement about the entitlements of all members of society, and then collective efforts to ensure that each person functions and flourishes to the greatest extent possible regardless of factors – poverty, ill-health or disability – which can as Tobias (2005: 79) recognises “erode the capacity of the subject to function as an active agent within the networks of power”. However Tobias (2005: 82-83) points to Foucault’s occasional interest in practical political issues, such as the status of refugees and issues of asylum, where he argues Foucault, in public statements and interventions, did recognise “an obligation to certain people may at times consist in working for their psychological, material of physical rehabilitation as a condition for the exercise of their freedom” and that while “persons capable of forging their own ethical-political project should be left to do so... not all persons, at all points in their life, may be so capable”.

While there is debate about the disparity between ideas of intrinsic human rights (which this enquiry suggests are fundamental to understanding a life lived with dignity) and Foucault’s work which Larmour et al (1998: 18) argues “shows little confidence in the success of ‘liberation’ politics since power is ubiquitous and inescapable” Foucault does offer a complex and comprehensive analysis of the views and practices we have inherited from Victorian society. Weeks (2005: 191) argues that Foucault’s analysis can suffer the over subscribing of meanings to his work, but he argues that real value comes from it when it is seen as:

> …a challenge to linearity, to easy progressivism, to wanting sexuality to be a force against power; and instead, a recognition of the significance of the social, a heterogeneous assemblage of practice where sexuality, as human institution, has become increasingly the heart. In this complex field of force it wasn’t sexuality that was subversive. It was the practices of friendship and relationships as much as of the body and its pleasures... In the process of this developing analysis sexuality was problematised and opened to serious study.

2.9 Conclusion

This chapter opened with a quote from Hawkes which presented polarised views of sex; seeing it as a source of fear and embarrassment or a source of happiness and fulfilment. Nussbaum (2010: 17) also recognises the challenges which sex presents with the view that “sex is a site of anxiety for anyone who is ambivalent about having an animal and mortal nature, and that includes many if not most people”. More than this, Weeks (1986: 89-90) proposes that “to an unexpected and unusual degree, sexuality has become a battleground for contending political forces, a new frontline”. He identifies a crisis, at the centre of which is the relationship between men and women; a “struggle over the present and future of sexual difference and sexual division” and that “this in turn feeds a growing crisis over the meaning of sexuality in our culture, about the place we give to sex in our lives and relationships, about identity and pleasure, obligation and power, choice and consent”.

If indeed there is a crisis in contemporary understandings of sexuality, and continuing discriminatory responses to the sexuality of those deemed to be “peripheral” (Foucault 1976: 39) then Week’s perspective is that this is influenced by three major shifts over the past two hundred years: a disconnection between sexual values and religious values matched by the growth in the influence and power of the medical profession; a liberalisation of attitudes which sees shifts in terms of matters such as sex out with marriage, birth control, homosexuality; and fundamental changes to the notion of family with a shift from traditional heterosexual marriage with children to alternative, more diverse representations. With such shifts in mind Weeks has formulated three options in relation to how we continue or best frame our relationship with sexuality. The first option he sees as moral absolutism which represents a view of sex/sexuality as disruptive and threatening and in need of control by social institutions such as marriage. Meanwhile, the libertarian tradition sees sex as good, an opportunity to break away from tyranny. Thirdly, the liberal tradition allows us to talk about sexuality within the framework of rights and a respect for the privacy of the individual who can be supported to define him/her self and determine what he/she wants.

This enquiry, framed by ideas from human capability approaches and sexual rights, builds on this third tradition and its relevance to the lives of people with a learning disability, particularly children and young people. The historical perspective taken has affirmed the usefulness of an approach which disassociates our understanding of sexuality and the need for positive sexual health from a morality based on fear and ignorance to one based on dignity and social justice.

Chapter 3

Learning disability: Historical context and influences on contemporary considerations about the personal and sexual lives of people with a learning disability

3.1 Introduction

The focus of this enquiry is on the nature of the learning experiences offered to children and young people with a learning disability in the realm of sex and relationships; with a view of learning as both a fundamental entitlement and a resource for living. However to decide what learning might address, where this learning might happen and how we can support learning about sex and relationships (addressed in subsequent chapters) in the context of a commitment to human dignity and sexual rights it is necessary for parents, carers and professionals to understand the injustice that frames our response to the sexuality of people with a learning disability. As Jackson (2000: xii) reminds us:

> Only if we pay attention to these facets of the past can we begin to recognise precisely why certain people were institutionalised, sterilised, stigmatised and excluded. And it is only through a comprehensive, and historically informed, analysis of the past that we can begin to create a future free from such prejudice and stigma.

This chapter describes views on learning disability over the past 200 years or so. The chapter maps the legislative, social policy and service responses to learning disability in this period. As this history unfolds it will become clear that over time there has been a strong association between perspectives and responses to the individual's learning disability and to their sexuality, and that while it is possible to make claims that "human beings have a dignity that deserves respect from laws and social institutions" (Nussbaum 1999: 5) much of the prejudice and discrimination which will be described points to a conclusion that, to date, we have failed to address "the problem of doing justice to people with physical and mental impairments" (Nussbaum's 2006: 1).

This overview starts with how learning disability was constructed and experienced in the 19th then 20th centuries. Following this, the eugenics movement is identified as bringing together the worst of enlightenment views of human sexuality, with its focus on the role of reproduction and heterosexuality within an ordered society, with the fear and loathing of disability and mental ill health. However, later in the 20th century changing attitudes and deinstitutionalisation are described as important steps forward and it is recognised that concepts of normalisation, community care and advocacy are shifting perceptions of the lives and rights of people with disabilities. From 19th century experiences to present day questions and challenges this historical perspective brings us up to date to consider where we are now when it comes to the realisation of a life lived with dignity for people with learning disabilities.

3.2 From rural to urban lives and institutionalisation

In pre-industrial rural economies, when people with disabilities survived into adulthood, they may have been more likely to have been perceived of as part of family or community life if they were able to contribute something to the work to be done. This is not to suggest that living with a disability was at all unproblematic, in fact as Gabbay and Webster (1983: 169) state:

> There is of course little evidence that pre-industrial society was a golden age for the handicapped. Modern studies demonstrate that deviants of all kinds were likely to be pushed to the fringes of society and even to become exposed to punishment for sorcery or witchcraft.

However with the growth of urban Britain the new industrialised environment was considerably more hostile to the idea that the disabled could contribute. Nussbaum (2006: 160) identifies that when society is predominantly founded on the productivity of its members, when we abandon or fail to identify that “society is held together by a wide range of attachments and concerns, only some of which concern productivity” then those perceived of as vulnerable and in need of care become marginalised and opportunities to realise a life lived with dignity contract. From a human capabilities perspective these changes define a new period where “the idea of the citizen as a productive augmenter of social well-being is strained” (Nussbaum 2006: 128) by the inclusion of those with a disability. Brigham (2000: 31), in an account of the experiences of people with disabilities in the 19th century, observes that families became less able to support the ‘non productive’, and with a shift from contributor to burden this meant “for ‘idiots’ who were not supported by families, the workhouse, prison or asylums for the insane were their most likely destinations".

With few specialist institutions as such to be found until later in the 19th century Brigham reports that by 1881 there were 29,452 individuals recorded as 'idiots' to be found in England's workhouses, prisons or asylums. In this age of scientific rationality interest grew in observing and analysing disability. Chapter 2 explored the application of reason and rationality on understandings of and responses to sexuality, and there was no less an influence on the fate of people labelled 'mad' or 'idiot'. There were also specific developments in Scotland in the mid to late 19th century. Thomson (1983: 233) writes about the activities of philanthropists such as Sir John and Lady Ogilvie of Baldovan, Dundee, who in 1852 established "a community geared to the institutional care and education of 'imbeciles'". Other institutions for 'defectives' were also established and in 1861 The Society for the Education of Imbecile Children in Scotland was formed.

For people with a learning disability living in this period McClimens (1995: 31) sees the beginning of "a slow and cumulative process" which was to see a "gradual inclusion within the orbit of social care". Initially the intention of the institutions which emerged was to create environments where care could be given and those deemed incapable of caring for themselves could, to some degree, be educated, with a recognition that the individual's actual functioning in their world (which was to be the institution) could be improved. These institutions were further legitimised and populated as a result of emerging legislation based on perceptions of mental ill health or learning disability as a social problem. In Scotland the Lunacy (Scotland) Act 1862 licensed institutions who gave care to 'imbecile' children. In this process of institutionalisation it was thought that people would be better cared for separated from their family and community. In this period Gerowitz (2007: 98-99) sees the origins of a view of people with learning disabilities as 'special', forever childlike and lacking in capacity to understand or make choices for themselves:

> Individuals with disabilities were not asked what they wanted; they were typically sent away and often forgotten… in some cases parents were told to forget that they ever had the child.

However in time McCarthy (1999: 43) observes that the institutions changed and paternalistic intentions to bring care, learning and understanding, even cure, became lost and replaced by moral management "with its emphasis on will-power, obedience and conformity" which became "in itself a rigid discipline which destroyed people's individuality". At this point the person with a learning disability was removed from any consideration that they were "part of the public realm" (Nussbaum 2006: 15). The isolation and control of people with disabilities had begun on a considerable scale and in ways that would for the next 150 years impact on their freedom, rights and dignity. Human capabilities offers a perspective which challenges society to "begin with a conception of the dignity of the human being" (Nussbaum 2006: 74) but in the 19th century we find such dignity stripped away from the individual labelled mad or idiot. For McClimens (2995: 31) "disability seen as deviance was a peculiarly nineteenth century creation" and we find the roots of new, emerging fears and a dehumanisation of those with learning disabilities linked with the medicalisation of them as problematic.

From the perspective of human capability approaches institutionalisation erases opportunities to live life to the full, to love freely, to seek out and experience relationships and to control one's environment. Specifically institutionalisation separates and isolates the targeted group from the rest of society; identifying some characteristic of the individual or group as the problem. Such institutions created environments which were the antithesis of what Nussbaum (2006: 80) declares as the centrality of "human dignity and the inviolability of the person" which human capabilities or human rights frameworks require.

3.3 Sexuality, coercion and control

With disability established as deviance, and the medicalisation of responses to disability gaining ground, sexuality was to become a key area in which people with learning disabilities were to see their rights undermined and denied. In 1869 Frances Galton published *Hereditary Genius* and articulated the views of what was to become the eugenics movement, with a call to intervene to prevent the continuation of 'inefficient human stock'; the sexual behaviour of the 'feebleminded' had become a threat to society. Kerr and Shakespeare (2002: 4) agree that the emergence of eugenics was about the "coercion and elimination of the so-called genetically defective". Brigham (2000: 34-35) quotes Samuel Howe as an example of the emerging culture of the time.

> Idiots form one rank of that fearful host which is ever pressing upon society with its suffering, its miseries and its crimes and which society is ever trying to hold off at arm's length – to keep in quarantine, to shut up in jails and almshouses, or, at least to treat as a pariah cast; but all in vain.

Eugenics grew as a movement and, with its close ties to Psychology, Universities in the UK and elsewhere legitimised its claims by offering academic study. In 1930's Germany Universities offered courses in 'race hygiene'. A further consequence of eugenics is the popular support which its ideas received amongst what Kerr and Shakespeare (2002: 13) refer to as the "gentlemanly amateurs" and those who have with time been seen as liberal or radical thinkers. Such people include Marie Stopes whose interest in contraception was driven by her support for the moral superiority of women over men and the need to control reproduction amongst the poor. As Bland (1995: 306) remarks, already highlighted in chapter 3, motherhood amongst women of the middle and upper classes "gained new dignity as a 'duty for the race'".

In this context Stainton (2000: 89) describes the early 20th century as "one of the darkest periods in the history of people considered to have some form of learning disability". With the ideology of eugenics finding its place groups such as the National Association for Promoting the Welfare of the Feebleminded demanded action on what they saw as dangers to the welfare of society. As a result The Royal Commission on the Care and Control of the Feebleminded, meeting from 1904 to 1908, and the subsequent 1913 Mental Deficiency Act (1913) and equivalent Scottish legislation the Mental Deficiency and Lunacy (Scotland) Act (1913) were strongly influenced by eugenics. Stainton (2000: 89) describes the Royal Commission's report as capturing the "transition from a period of relatively humane paternalism to active suppression and control". The 1913 Acts formed the main legislative framework around mental ill health and learning disability until the 1950's, establishing that care and protection (in other words institutionalisation) for so called idiots, imbeciles, feeble minded and moral defectiveness was more important than liberty. As Welshman (2006: 19) observes the legislation framed the belief that "Permanent care was both scientific and moral". Segregation and control became the focus of responses to learning disability. For Stainton (2000: 92) the 1913 Acts meant that “to all intents and purposes, it became a crime to have a learning disability”.

One of the main areas of coercion and control in the 20th century became the reproductive rights of the disabled. Kerr and Shakespeare (2002: 11) highlight many of the consequences of the Royal Commission and subsequent legislation, including the call from the National Union of Teachers in 1929 that “the time is now right for a scientific enquiry into the whole question of reproduction among the mentally defective” and the lead given by medical professionals for sterilisation. While enforced sterilisation was more common in the United States, along with institutionalisation came practices of so called voluntary sterilisation in the UK. McCarthy (1999:54) writes that this was seen as a dual approach which meant that the institutionalised “could be ‘trained and socialised’, then ‘voluntarily’ sterilising them with a view to re-establishing them back in their own communities”.

As a key legacy of eugenics, sterilisation remained a common practice throughout the 20th century. Kerr and Shakespeare (2002: 73) highlight that: “In Scotland sterilisation was particularly common, often for genetic reasons”. In one year from April 1968 to April 1969 10,545 women in the UK were sterilised during abortions; many if not most of whom, it is assumed, will have been women who were poor or who had learning disabilities or experienced mental ill health. Enforced sterilisation remains a controversial issue in many parts of the world. Lansdown (2009: 98), exploring the interface between the rights of the child and the rights of people with disabilities reports that in Australia, between 1992 and 1997, 1,045 sterilisations of girls with learning disabilities, some as young as 9 years old, took place.

For Gabbay and Webster (1983: 170) the legacy of eugenics is that those individuals and groups who promoted the ideology from the mid 19th century have “left a permanent mark on public attitudes, modern pressure groups and public policy”. Certainly, in terms of programmes of learning about sex and relationship for young people with a learning disability there is nothing intrinsically empowering or rights-based about the idea of sex and relationship education, it is possible to envisage programmes which could focus on control rather than being grounded in ideas about sexual expression, safety, freedom and choice. This will be discussed in later chapters, but this historical perspective brings us to a place where in addition to what Foucault (1976: 39) recognises as “peripheral sexualities” and what Hawkes (1996: 48) describes as the “hinterland of practitioners of non-procreative sex” comes what Kerr and Shakespeare (2002: 20) see as the emergence of the “genetic outsiders”.

3.4 The emergence of changing attitudes

The establishment of the National Health Service (NHS) in 1948 was a radical step which raised expectations of an entitlement to health services amongst those previously poorly served. However in terms of those people with learning disabilities most affected by the care and control approach of the institutions to which they were sent Welshman (2006: 20) sees the 1940s and 50s as still very much reflecting the attitudes and practices of the previous century with “no discernable intellectual change to the assumptions underpinning institutionalisation as the optimum treatment, or to segregation of the sexes intended to prevent ‘breeding’ by defectives”. Welshman (2006: 20) argues that in post-war Britain so called “mental defectives” remained “as a threat to society”.

Change was to emerge with the influence of families affected by disability and mental ill-health. In post-war Britain families began to meet (as an example The National Society for Parents of Backward Children was established) and organise and demand more for their children. In the context of the atrocities of the war, notions of human rights emerged more strongly and the National Council for Civil Liberties (1951) exposed the conditions of patients in institutions in the report *50,000 Outside the Law: an examination of the treatment of those certified as mental defectives.* The report highlighted the plight of many people placed in institutions and identified exploitation of individuals, a lack of legal rights and poor personal care. Their work led to the release of many people from institutional care, case by case, and to the establishment of the Royal Commission on the Law Relating to Mental Illness and Mental Deficiency in 1954, which reported in 1957. The Commission took evidence from parent’s organisations as well as professionals. Welshman (2006: 23) observes that the Commission “implicitly rejected eugenics” and supported the development of services in the community and access to generic services for all.

In 1971 an emerging focus on the rights of people with disabilities was articulated in the Declaration on the Rights of Mentally Retarded Persons proclaimed by the General Assembly of the United Nations which stated in article 1: “The mentally retarded person has, to the maximum degree of feasibility, the same rights as other human beings”. Whilst this human rights instrument provides an important framework, the UK also saw some developments in attitudes towards learning disability and to service provision including move towards deinstitutionalisation. Indeed, Emerson and Hatton (2005: 36) state that “deinstitutionalisation has dominated the development of social policy for people with learning disabilities in most of the world’s richer countries”. Following the Royal Commission, The 1959 Mental Health Act (England and Wales) and the Mental Health Scotland Act (1960) the Jay Committee on Mental Handicap and Nursing in 1979 supported development toward life in the community, with an emphasis on the right of people with disabilities to be treated as individuals and a recognition of the need for support for families providing care. In 1981 the Department of Health’s ‘Care in the Community’ strengthened the move in this direction. However this has not been without its problems in terms of implementation and the reality of ensuring benefits for the person with learning disabilities, Welshman (2006: 24) argues, has been limited because the concept of care in the community “was not systematically defined, it’s very meaning ambiguous” and so Governments have interpreted the term in relation to the administration of services, rather than the experience of individuals.

To understand current social policy commitments to equality, a shift in views of learning disability and the nature of education and other services which people with disabilities receive it is important to recognise that the years preceding the move towards community care were influenced by a number of key concepts: *normalisation*, *social role valorisation* and the *social model of disability*.

The 1960s and 1970s saw the emergence of the concept of normalisation; emphasising that opportunities should be provided so that “people with intellectual disabilities would learn to display behaviours that were considered normative” (Owen et al 2009: 29). Normalisation is concerned with supporting actions to ensure that the disabled person mixes with non disabled people at work, in the community and in social environments. However, Owen et al (2009: 29) argue that normalisation is “not necessarily about integration or inclusion" because there is an overt focus on ensuring the individual with disabilities functions in certain ways rather than develop their own capabilities (this will be returned to shortly). When it comes to normalisation McCarthy (1999: 45) writes that "the fact that practically every service for people with learning disabilities has adopted at least some of the principles and practices of normalisation… is a testament to the strength of the ideology" however she also emphasises the need to see normalisation as a principle, not a dogma; she identifies the need to give people with disabilities the right to choose how they live their lives rather than have lives in which they only meet and socialise with non disabled people thrust upon them.

Identifying the limits of normalisation Wolensberger developed the concept of social role valorisation (SRV) in the 1980's. While SRV also encouraged the development of behaviours and characteristics in people with learning disabilities which mirrored their non-disabled and non-stigmatised peers, SRV required that people with disabilities access generic services, take up valued employment and avoid behaviours that could be perceived as childlike or inappropriate for an adult. An important component of SRV was an explicit recognition of the rights of the individual, and a call on professionals to support the disabled person to articulate and claim those rights. Furthermore SRV required changes in societal and community perceptions and behaviours in order that the social stigma associated with learning disability is challenged; communities and individuals were expected to be welcoming of all, regardless of ability.

A third key idea emerging in this time is based on questioning a view of the individual with a disability as intrinsically limited or disabled. Building on earlier rights frameworks, in 1976, the Union of Physically Impaired Against Segregation (UPIAS) produced the 'Fundamental Principles of Disability' which outlined a view that later became known as the *social model of disability*. UPIAS argued that it was not impairment that disabled people but society's response to impairment which was disabling. The social model shifted the focus from individual deficits to social barriers that have to be tackled. Although primarily concerned with physical disabilities the social model has been used to understand all forms of disability including learning disability.

The application of these radical concepts has not been without complexity, and it is possible to identify challenges in terms of the personal and sexual lives of people with learning disabilities. Wheeler (2007: 17) writes that in his practice as a learning disability nurse in 2001, thirty years on from the Declaration on the Rights of Mentally Retarded Persons and the acceptance of normalisation principles, “one ‘right’ that was not being strongly argued for was the right of people with a learning disability to express their sexuality and to experience personal and intimate relationships”. As a further example, a key area for parents and children with a learning disability has been the debate about the place of children in mainstream or special school settings; with on the one hand those in favour of ‘mainstreaming’ (emerging as an educational practice as a result of ideas of normalisation and SRV) suggesting that children with disabilities should be with their non-disabled peers while some parents remain concerned about the quality of the disabled child’s learning and social experience in mainstream education. Specifically in terms of the interest of this enquiry, when it comes to sex and relationships learning there may well be complexities in meeting the learning needs of pupils with disabilities in the mainstream setting where key concepts might need to be re-visited, language may need to be specific and unambiguous rather than guarded or euphemistic, or where particular vulnerabilities may need some focus.

Whilst the social model of disability explores societal views of disability and provides a perspective which indicates a significant shift in how people with disabilities are viewed, normalisation and social role valorisation can be criticised for retaining an overt focus on the individual, with a concern for setting targets in relation to functioning which make the person with disabilities acceptable in social or work environments; in doing so they can fail to contextualise the broader social factors which explain how the lives of people with learning disabilities are restricted. A capabilities approach however recognises that there are important questions in terms of functioning but the starting point is the person’s entitlement to live their life to the full and with dignity (their full entitlement to capabilities) and so the job of a just society is not to make them fit into given social activities or behaviours but to ensure the opportunity is there, for example, to live independently or have rewarding personal relationships. The entitlements of all citizens envisaged by human capabilities do not call for approaches which “dragoon all citizens into functioning” in certain ways (Nussbaum 2006: 171) or judge certain behaviours as inappropriate or inadequate; rather it is recognised that the individual, as far as is possible "should be given ample opportunities... but the choice should be left up to them" (Nussbaum 2006: 80).

Within her work on human capabilities Nussbaum recognises that for some people with learning disabilities a concern for functioning may be relevant when the capacity of the person to make choices is limited by their disability; in such circumstances Nussbaum (2006:178) recognises "the importance of care as a primary social entitlement" and that carers or professionals may have to protect the individual from harm. However, where protection is necessary, and where a person with disabilities is considered to have "dependencies" they remain fully-fledged citizens and must be treated as "distinct and individual" (Nussbaum 2006: 219). In the area of consent to sexual relationships the complexities of assessing individual capacity and the balance required to ensure the individual lives their life to the full, enjoying bodily and reproductive health, brings questions of functioning and capability to the fore; this is discussed in chapter 4 where it is recognised that while consent and vulnerability are complex issues people with learning disabilities are individuals and a capabilities approach seeks to build on the entitlements of the individual, support learning and build capacity rather than focus on personal deficits.

In the last 50 years there have been significant changes in the language and key concepts which inform attitudes towards people with learning disabilities and so the services they receive. Within each of these key developments it is possible to find emerging ideas of freedom of expression and movement, access to services and resources for living, opportunity to live and interact with others and to participate in society; all entitlements intrinsic to human capability theory. However, while normalisation, social role valorisation and the social model of disability provide a more optimistic framework within which we can view society's responses to learning disability there is also a need for caution about what has actually been achieved in the day to day lives of individuals. It can be argued that the change which normalisation, social role valorisation and policies of care in the community have brought to date remain more reflective of paternalism and charity rather than the realisation of human dignity and social justice which a human capabilities and rights-based approach is more able to provide.

3.5 Personal relationships and sexual lives: progress and challenges

The move away from large institutions to smaller community homes or more support for care within families and independent living has required carers and professionals to recognise and respond to the personal relationships and sexual lives of people with disabilities. In tracking the changing attitudes of services toward sexuality and sexual behaviour McCarthy (1999: 57) reminds us to make links back to the historical perspective taken of sexuality and sexual behaviour reported in Chapter 2 where from the 1960s there was a *general* liberalisation of attitudes towards sex, the availability of contraception and the development of school based sex education for young people which in itself is likely to have had some positive impact on the experiences of people with learning disabilities. She identifies for example that in the literature in the 1970s there was an increased recognition of "the right for people with learning disabilities to date the opposite sex and marry" but that this *right* was far from inalienable and still firmly contextualised within a package that must also include sex education and the promotion of the use of contraception, echoing fears of the reproductive capacity of adults with disabilities.

Since the 1980s advocacy and self advocacy is also now a feature of service provision and has impacted upon issues of personal relationships. While McCarthy (1999: 46-47) recognises that "self advocacy has a number of meanings and operates on a personal and political level" it is essentially about "people speaking up for themselves and on behalf of others". Writing in Tizard Learning Disability Review the agency People First (Scotland) (2003: 25) identify that up to 50 groups of people with learning disabilities meet to influence and change policy and services. Walmsley (2006: 54) identifies that self advocacy, at its most powerful, tells the individual and collective story and contributes "greatly to a broader understanding of how people with learning disabilities see and experience the world, not always as passive victims but also people with agency, feelings and relationships". Self advocacy brings voice to disenfranchised or marginalised individuals and groups and will have a useful role to play in any development of sex and relationship learning programmes which are designed to be inclusive or target people with learning disabilities. As an example 'Them Wifies' is a community arts group based in Newcastle which works with girls and women with learning disabilities. Its Josephine Project, which sees professionals work alongside women as peer educators, uses a largerthan-life cloth woman, drama and storytelling as a tool to work with learning disabled women on health issues with a focus on sexual health and wellbeing.

But McCarthy (1999:48) has concerns about claims which might be made regarding the impact of advocacy, highlighting that it has failed to impact significantly because although most service providers would now say they ‘listen’ to the voices of service users, to really take on board the views of people with learning disabilities would require “those in power to relinquish it” and this remains unlikely when the voice of people with learning disabilities may still be seen as a threat to professional skills and training. Ideas about voice and participation in decision making are of course central to various United Nations instruments, including the Convention on the Rights of the Child (1989) and the Convention on the Rights of Persons with Disabilities (2007) as well as human capability ideas about reflecting and planning one’s life which is describes as *practical reason* as well as the importance of *control over one’s environment*. These are discussed in more detail in Chapter 4.

Advocacy and self-advocacy are also component parts of a further key development in more individualised support to people with learning disabilities, often arising from person-centred planning. This model is not concerned with framing the individual disabled person as a customer whose needs are addressed in isolation and in competition for resources, but instead works to bring smaller numbers of professional people alongside the individual in order to get to know them and to work alongside them to plan what they want and how to get it. Building on ideas of normalisation and the social model of disability Gerowitz (2007: 109) describes person centred planning as focusing on “people’s strengths and preferences, not what is wrong with them, and what they actually want to do” and while honouring “a person’s choice, it still also requires that professionals help the person to develop a life that is both healthy and safe”. For Nussbaum (2006: 168-170) good care for the individual with learning disabilities in a “decently just society” is about the appropriate level of care, carefully considered and balanced where any assessment of what the person requires is based on being “knowledgeable about and attentive to the particular nature of the person’s impairment” and “in short... is individualised care”. In many ways person-centred planning is the opposite of previous decades of organised mass institutionalisation, the rejection of individuality and the denial of many of the ideas of human capability theory – not least notions of attachments, freedom and choice.

The key components of person-centred planning are to ensure that the individual with a learning disability has choices and a real and active presence in their local community, that their life and contributions have dignity and that they are supported adequately to achieve their goals. A part of the individualised nature of the approach which person centred planning can bring can be a commitment to working positively in the realm of personal relationships, including sexual relationships. Gerowitz (2007: 110), reflecting some of the themes about the importance of interpersonal relationships which are expanded in the next chapter, argues that:

> Loneliness and the craving for friends and relationships is something that must be addressed through person centred planning and system change if people are to experience fully involved, satisfying lives.

There is some evidence however that person-centred planning delivers more if the individual has fewer needs so those with higher support needs or with more complex communication support needs get less from the approach. There may also be tensions between what the person with disabilities wants and what their carers think they need and this may well be played out in relation to choices and behaviours regarding personal and sexual relationships. Person-centred planning and more personalised approaches to support and service provision are therefore not without their challenges.

3.6 Conclusion

Nussbaum (2006: 222) recognises that “the lives of citizens with mental impairments, and of those who care for them, will continue to be unusually difficult lives” and much of this chapter has explored aspects of the difficulties faced, including how people with learning disabilities are viewed and treated both collectively and individually. As Nussbaum (2010: xvii) recognises every one of us makes choices in our perceptions and opinions towards another human being, so that:

> Seeing the shape of a human being before us, we always have choices to make: will we impute full equal humanity to that shape, or something less?

The historical perspective taken in this chapter has shown that people with learning disabilities have indeed often been seen as *something less*. As has been explored it is in the area of sexuality that much control has been exerted on the lives of people with disabilities and there has been a failure to deliver the experience of sexual rights. Rembis (2009: online) argues that oppression and control means that sex and disability remain “incompatible” and that as a result people with disabilities are viewed as “broken or damaged, but also incompetent, impotent, undesirable, or asexual” and so the individual with a disability lives with “an intrinsic limitation, an unfortunate but unavoidable consequence of inhabiting a disabled body”.

Correcting the injustices done continues but this process is far from complete. The past decade has seen some important legislative changes which bring this historical view up to date and there is increased recognition that characteristics such as learning disability are “not a legitimate basis for the systematic legal subordination of a group” (Nussbaum 2010: xvi). Most recently the Human Rights Act (2000) supports the rights of people with a learning disability to explore and express sexuality and have relationships and the Mental Health (Care and Treatment) (Scotland) Act 2003 and (Modification of Enactments) Order 2005 have introduced changes to mental health legislation to improve and address issues of consent. Furthermore, service responses have been informed in Scotland by ‘Same As You? (2000:94), discussed in earlier chapters, which has also made attempts to balance protection and rights to sexual relationships and stated that “professionals and services need to recognise that adolescents and adults with learning disabilities have sexual rights and needs, while at the same time making sure those who may be vulnerable to abuse are protected”.

Seen alongside each other notions of community care, normalisation, the social model, advocacy, more personalised approaches to meeting the needs of the individual and rights written into legislation all signify important changes in social attitudes towards learning disability and in turn public services (including education) which are provided. Indeed Degener (2003: 153) argues that the introduction of laws which now recognise discriminatory experiences and practices, and new approaches in welfare/social provision now commonly based on “equality, dignity, autonomy and solidarity” underlie “the transformation process of viewing disability as a human rights value”. However, as several authors have identified - Welshman on the issue of community care, McCarthy on normalisation and Wheeler on the rights of individuals to express their sexuality and to experience personal and intimate relationships – the experience of these human rights can be interpreted or curtailed by the professional or family carer. Nussbaum, in addressing matters of social justice and impairment, proposes that it is in our very *idea* of disability as something which is not normal, of the disabled person as unproductive, which means that simple notions of human rights alone cannot deliver the experiences (the outcomes) that those living with disabilities require from a just society. Nussbaum (2006: 122) frames the challenge as follows:

> The benevolence that full inclusion of people with impairments requires is extensive and deep, requiring the willingness to sacrifice not only one’s own advantage, but also the advantage of the group. It means cooperating with people with whom it is both possible and advantageous not to cooperate at all.

With this test in mind we might still be hopeful that the lives of young people with learning disabilities, including their personal lives and relationships, will not be blighted by the ideology of eugenics and the experience of institutionalisation, each with their pernicious focus on controlling the personal and sexual lives of people with learning disabilities. Progress made *might* suggest that there is a *possibility* that a young person with learning disability might live a life more like their non disabled peers; more akin to a life lived with dignity that we would hope for all our children. Nussbaum (2006: 102) reflecting on responses to learning disability recognises that there is a requirement to both protect and enable and that:

> There are a lot of people whose health, participation, and self-respect are at stake in the choices we make in this area. Meeting these needs in a way that protects the dignity of the recipients would seem to be one of the important jobs of a just society.

In the chapters which follow we explore this further, specifically in the realm of personal and sexual relationships and the description of what support and learning opportunities children and young people with learning disabilities require.

Chapter 4
Sexuality: children, young people and learning disability

4.1 Introduction

From discussion in earlier chapters human sexuality has emerged as a complex fusion of relationships, biology, sexual acts, identity, fantasy and pleasure. From human capability approaches it has also been possible to recognise the value of human dignity and social justice in relation to human sexuality. Of interest to this enquiry is Nussbaum's assertion (1999: 5) that "human dignity is frequently violated on grounds of sex or sexuality".

Further chapters have mapped out how our contemporary views on sexuality have developed. The historical perspective identified that sexuality is a social construct and its expression by certain groups, including those with learning disabilities, has often been pathologised and controlled. A persistent problem in this exploration of sexuality is that its complexity is often misrepresented or ignored; this work has already identified that discussion and understanding of human sexuality is restricted when it simply means 'having sex'. Certainly when discussing sexuality and childhood Jackson (1992: 2-3) reminds us that childhood and sexuality are both established as "special" areas of life and so "any meeting between the two is likely to be explosive". In order to protect those we view as vulnerable, where sexuality is indeed just having sex, Jackson recognises the argument would be "children and sex should be kept apart". In chapter 3 it was possible to track similar emerging attitudes in terms of people with learning disabilities; indeed Rembis (2009: online) proposes that it is a consequence of oppression and control that sex and disability remain "incompatible".

Earlier chapters have also identified contemporary worries about childhood and adolescent sexuality for those with and without learning disabilities; these worries often made real in the statistics about unintended teenage pregnancy, sexually transmitted infections, regret and low expectations. It would seem that keeping childhood and sexuality apart has done little to help us explore what children and young people need to ensure a healthy and happy adult sexuality because such a position fails to explore what sexuality means, and why it matters, in childhood. Equally, as this chapter will show, adults with a learning disability living in Scotland today experience social isolation, loneliness and disproportionate levels of sexual violence and abuse which points to questions about whether a denial of their entitlements to attachment to others, love, pleasure and good reproductive health means they are any better served by a lack of understanding of what sexuality means to them.

This chapter explores what it is about sexuality in childhood that matters and identifies what it is we know, whether they have a disability or not, about children and young people's experiences and needs. The chapter considers the importance of friendships and social relationships, of assessment of sexual knowledge, concerns about violence and the key areas of vulnerability and consent which inform responses to the personal lives of children and young people with learning disabilities and to the learning programmes provided for them.

4.2 Childhood and sexuality

In considering childhood and sexuality Stevi Jackson would have us return to the analysis in earlier chapters where historical positions and understandings of sexuality saw debates about what might be considered natural and 'unnatural'. Jackson (1992: 9) argues that whilst biology is a factor in all human sexuality, like all behaviour, the expression of sexuality is "modified by social factors" or the cultural norms, rules or boundaries of society. For Jackson (1992: 18), all the acts or aspects of biology we may be tempted to view as natural are "socially constructed definitions" of what is sexual and so it can be argued that "given that culture, not nature, shapes the form of our sexuality it is clear that most of our sexual behaviour is learnt".

However, as alluded to earlier, there remains a problem when discussing sexuality (and so sex and relationship learning) and childhood because it requires us to understand the interface between the two in the context of a culture where the recognition of human sexuality in day to day life has become more and more disassociated from childhood. Like the characterisation of people with learning disabilities as innocents, what has become embedded in our traditions is a view of the child as ignorant of all matters relating to sexuality. Childhood is understood – *constructed* – to be something separate from the realm of adulthood and it is only in adulthood that sexuality can be understood and expressed. In the construction of childhood we have problematised sexuality per se.

What has been created it would seem is an association, even obsession, between adult life and sexuality; and a growing gulf between childhood (as something special and different) and sexuality. As an example, the need to separate childhood and sexuality has been played out in debates about the ‘sexualisation of childhood’ by the media with concerns about the marketing of certain products to children which reflect sexual imagery or messages. The Scottish Parliament (2009) has explored these issues through the commissioning of research about the prevalence of “products, such as toys and clothing, which appear to be aimed at children under the age of 16 and which employ age-inappropriate sexual imagery or have other sexual connotations through, for example, association with certain adult brands, elements of the product design or in the way the products are marketed”. However, while the report acknowledges concerns that children are exposed to images and goods which the adult perceives of as sexual, and that children “construct and develop their identities in part through what they consume” it would be simplistic to conclude that children are “in any sense simply the dupes of marketers”.

In a world where we see children as vulnerable and in need of protection Jackson (1992: 49) argues that sexuality is *in itself* viewed as a “threat to their wellbeing”. Hawkes (1996: 46) agrees, identifying that “arguably, it is the attitudes to children and sexuality where tensions and anxieties, as well as the contradictions of modernist sexuality, are most evident”. She confirms that the “construction of children as being both asexual and sexually corruptible, both innocent and dangerously impure” means that “superficially the response to these doubts and fears was the separation of sexuality from childhood, accomplished through what Foucault has called the pedagogisation of children’s sex” and that finally “the monitoring and controlling of the distressing presence of sexual nature was to be accomplished through the attentions of medical experts, and more indirectly through legal frameworks which distinguished children as a separate social category”.

This idea of children as separate creates challenges, particularly if human capability theory influences the way in which we construct learning opportunities. Human capability approaches, and indeed notions of sexual rights, encourage us to see learning about entitlements to good reproductive health, to freedom from sexual violence, to love, to sexual satisfaction as appropriate elements of a curriculum for all learners, particularly where learning can be viewed as enhancing outcomes for children and young people in later life. These issues will be returned to in subsequent sections.

4.3 Being heard: understanding children's perspectives

If we are to tackle Scotland's poor sexual health record, and consider what, how and where children and young people with a learning disability need to learn it can only help to know more about children and young people's own perspectives and experiences in relation to the interface between childhood and sexuality. The value of listening to children and young people, and enabling their participation in all areas of decision making in their lives, is enshrined in various UN human rights instruments. A right to express views is central to the Convention on the Rights of the Child (1989) which in Article 12 states that "the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child" and similarly the Convention on the Rights of Persons with Disabilities (2007) in Article 3 makes the full and effective participation of people with disabilities a general principle while Article 7 mirrors the UNCRC Article 12 with a reminder that disability must not be allowed to be a barrier to full participation.

Human capabilities, whilst not specifically addressing participation rights as such deals with this notion of entitlement to being heard as the entitlement of all individuals to be able to reflect and to plan one's life, to have experiences of being valued and be equal to others as well as choice in terms of reproduction. In this way human capability theory enhances our understanding of what notions of 'having your say' might be like as real experiences in day to day life by demanding, for example, that we consider how to support the child with disabilities to make friends or how we help them decide what they want from personal relationships. Whether using UN human rights instruments, or drawing on understandings of the entitlement to participation and being heard from human capability theory, subsequent sections of this chapter will show that there is some way to go in understanding, valuing and using children and young people's perspectives in the design and delivery of learning about sex and relationships.

In discussing school based sex and relationship programmes Hirst (2004: 124) identifies a problem; that despite the right to be heard, as adults our “silence or an unwillingness to elicit young people’s insights and opinions” means that we fail to understand need. In the context of adults who are embarrassed, unable or resistant to facilitate children and young people’s learning about sex and relationships then myth, stereotype and ignorance step in. Before considering some of my own work directly with children it is also worth contextualising the complexity of delivering sex and relationship learning in the Primary School. In work for NHS Forth Valley (TASC Agency: 2003a) which reported on Primary School teacher’s views of sexual health training which was intended to support the development of knowledge and skills for delivery of classroom programmes, participants identified that the context for facilitation of learning is challenging, particularly that they can feel isolated and exposed to criticism from parents or colleagues and that senior staff in a school can block the introduction of new sex and relationship programmes. To quote one participant (TASC Agency 2003a: 7):

> “Management can set a restraining conservative ethos. You have to be a very confident and/or experienced teacher to take this on, sometimes we need to challenge where they are coming from”.

To turn now to the direct voice of the learner whilst it is easier to identify material from research with teenagers (in the next section of this chapter) it is more difficult to find evidence from the literature about children discussing sex and relationships. However, working again in NHS Forth Valley, I have conducted some work on children’s perspectives (TASC Agency 2006a) and will now make use of that work to illuminate several points about the value and importance of understanding children’s perspectives. NHS Forth Valley have been engaged with Falkirk Council in development of their school based sex and relationship education programme. Within the context of training for teachers and other professionals, and with parents in relation to consultation about the curriculum, Health Promotion staff identified ongoing questions about whether what was being provided matched what children needed and wanted to know. For some professionals, also reporting back from parent’s views, some questions from children were seen as surprising or embarrassing. There was also a view reported from some teachers and parents that, in their view, the school curriculum was in danger of raising issues, particularly in terms of contraception and homosexuality, that primary age children should not or did not need to discuss.

In response Health Promotion staff asked me to work with them to design a workshop for children which would allow them to tell us what they know (confidently or otherwise) and ask questions in relation to a number of key themes in the school curriculum: physical and emotional changes in growing up, relationships, conception, pregnancy and birth. The workshops were designed so that children (208 in total from 4 primary schools) could ask any question they wanted to, this would be recorded, but no answer would be given. Although on the one hand this allayed fears expressed by some parents about external facilitators giving children information the actual purpose of the approach was to create a different space where children did not expect the adult to act as expert and so where they had freedom to discuss issues amongst themselves and declare questions about anything that was on their mind.

As facilitators of this process myself and my colleagues were struck by several issues which now inform this enquiry. Children were generally aware of the physical changes that occur with puberty but were less informed and articulate about emotions and feelings; leaving a sense that what they had been told or had learned disassociated what was happening to their bodies with what was happening to them emotionally and socially. Children were very aware of the difficulties which adults had in some relationships; sadness, loneliness, the impact of alcohol and violence in relationships were all raised. In discussion children in P6 and P7, particularly boys, described violent and pornographic images viewed in video games and began to use offensive terminology about women and about lesbians and gay men. But children also discussed happiness which was related to intimacy, expressions of love and romance and the joy in new babies and feeling safe in your family. They identified that sex is important to grown-ups and they had many questions not just about sexual acts but about why sex is important and what it means to people.

Throughout the process discussion flowed easily and there were many questions. The children, with minimal adult facilitation, talked about many human capability ideas about bodily integrity, senses, imagination and thought and emotions. Where there was confusion or discomfort this arose when children perceived what they were saying might be considered secret or dirty. In relation to some comments it was clear that children were repeating adult prejudices and identifying negative adult behaviours (fighting, drinking, leaving) which were upsetting and confusing because the children were not able to understand or frame these ideas or behaviours within a clear sense of how personal and intimate adult relationships *should be*.

These discussions with primary age children emphasised for me that childhood is *the* stage of human life where there is an imperative to facilitate learning about sexuality which will give accurate knowledge, encourage the development of personal values and build behaviours which are protective of sexual health. In time, it can be concluded, this is then more likely to enable children and young people to understand notions of human rights and sexual rights, as well as live their lives in ways which ensure both dignity for themselves and others. Clearly however this is more complex and challenging than it appears, for the reality of working openly and positively with children of primary school age means understanding their behaviour in ways which are different from the way we understand adult behaviour. In discussing childhood/pre-teen sexuality Stevi Jackson has a concern that adults are prone to either overestimate or attribute meaning which is not deserved, or underestimate (that is deny the presence of) sexuality in childhood. This problem can be explored by looking briefly at one aspect of behaviour.

In chapter 2 the issue of masturbation was discussed, perhaps more than any other behaviour it has been problematised. Masturbation can be a particularly challenging issue for parents as their sons and daughters with learning disabilities grow older. In the course of this enquiry I have taken opportunities to attend a number of events or conferences where the sexuality of people with learning disabilities has been discussed, hoping to hear about new work and gain a better understanding of the issues at the core of this enquiry. These events are frequently attended by parents and while researchers or policy makers talk about important but nonetheless for families often intangible policy or service design issues parents wait for their space to tell of their concrete and day to day struggles with understanding and managing aspects of sexuality such as masturbation. In particular where their child has complex needs, communication difficulties or physical disabilities and they require personal care parents can struggle with language, finding it difficult to find *any* word which they can use to describe masturbation, they tell stories of their embarrassment at their child masturbating when being changed or bathed by them or others carers, they seem simply overwhelmed and want it to go away. Hearing these stories is a reminder that no-one has adequately supported these parents to view their child as having a sexuality, or helped them understand that masturbatory behaviour simply feels pleasurable to the young man or woman, and there seems to be nowhere to go to ask for support about how to react to the behaviour or manage it confidently. A further concern I have also heard expressed by both parents and professional staff in terms of people with a learning disability, who may struggle with understandings of *public* and *private*, are concerns about individuals being labelled as sexual threat because of inappropriate masturbation in public places (where this can mean shared toilet facilities or shared rooms or places where someone can walk in unexpectedly). Jackson raises masturbation as a key example of how as adults we must understand and reframe childhood sexuality; so that masturbation needs to be accepted as something that can and does happen in childhood, that it is important that children learn rules about such behaviour, but that engaging in such a pleasurable activity does not mean that it has the sexual meaning that would be associated with it by adults. The imposition of adult understandings of sexuality, and so behaviours such as masturbation, Jackson lays at the door of Freudian interpretations of so much of childhood behaviour as sexual. Jackson (1992: 77) argues that

> ...the basic faults in the psychoanalytic approach lie in overestimating children’s sexual capacities and attaching too much sexual significance to their desires and activities. These traps are easy to fall into if we interpret children’s actions through the filter of adult sexual knowledge and experience. To avoid it we need to question how far children’s behaviour can be seen as sexual (that is, as sexually motivated and meaningful) and this means that we should look closely at the desires and interests we attribute to them.

Feminist responses to the legacy of psychoanalysis have been to challenge aspects of Freud’s work; in Chapter 3 these were described. Again from feminist thought and analysis there is also the need to recognise and understand the importance of gender and how learning about gender in childhood then influences sexuality and personal relationships in adulthood. Further, in terms of the complexity of learning in this area it is important to recognise that in affirming the link between childhood and sexuality the key worry or fear for many parents, carers and professionals is that of exposure to sexual violence or abuse; that by educating children in the early and primary school years about sexuality we somehow inappropriately sexualise them. This is often a fear expressed by parents of children and young people of all ages who have a learning disability. Jackson (1992: 64) recognises the dilemma and poses this question:

> Here is a predicament: how can we teach children to see sex positively, while at the same time warning them that it can be used to hurt and humiliate them?

Jackson (1992: 64) recognises that children must understand issues of personal safety and have an awareness of adults who may seek to harm them; that they need to learn that “the world is not all sweetness and light; they must learn that sexuality is no exception”. However, she suggests that there is a need to view sexuality as akin to other aspects of what makes us human, and to be aware that children themselves are capable of understanding the conventions and behaviours that are expected of them across every part of their lives. This means that if children grow up in families where adults are comfortable with their bodies and with their own sexuality and sexual relationships, where adults have and use positive language about sexuality and relationships, and where children’s questions are answered honestly, there will be less of a distinction between sexual and non sexual aspects of life. We will return in more detail to the role of the family in the child’s learning about sex and relationships in subsequent chapters.

4.4 Understanding young people’s perspectives

My own work with children, described above, evidences that children want to converse with adults about sex and relationships and have questions as a result of their engagement with the world around them where there is an abundance of messages (often confusing, often undermining of attempts to promote sexual rights and human dignity) about gender, sex and relationships. It would appear children are looking to make sense of it all, they want understanding, guidance, clear boundaries and to feel safe.

Moving into their teenage years young people also have perspectives and experiences which adults who see or seek a role as educators must consider. In Chapter 1 findings from national surveys were reported which provided some information about early sexual experiences and gave some indication of notions of sexual competence. Reading this research leaves a sense that young people in Scotland today are far from experiencing their sexual rights, an integral part of human rights, which include the rights of all persons to be free from coercion, discrimination and violence. In a climate of worry and fear for our teenage children it is also important to listen carefully to the kinds of experiences, questions and needs which are emerging from research which engages young people in more than describing sexual activity, but encourages and captures reflection on the meaning of sex and relationships.

Despite concerns about sexual competence reported in Chapter 1 other research challenges simplistic notions of vulnerability where young women are seen to lack agency in sexual encounters. Maxwell (2007: 540) highlights that young women are “reworking the givens of heterosexual practice such as initiating sex, stating conditional terms for relationships with men, participating in casual sex, making efforts to ensure their own sexual pleasure and so forth”. Young men also increasingly challenge assumptions that what they want from a relationship is *just* sex; Allen (2003: 228) reports that young men state their interest in trust, honesty, respect and commitment. *However* what might be perceived of as optimistic or positive indicators of teenage sexual activity are outweighed by the experience of many young people and in particular the sexual lives of young people are set in context by issues of social class and gender. Thomson (2000: 424) reports that in her work with young people from an affluent community “there was little to be gained from sex and potentially much to lose” whereas for young people from a less affluent community “sex was less easy to avoid” with young men seeking to build sexual reputations and young women gaining authority from motherhood. For Arai (2003: 212) it is clear that while young mothers in the study she conducted “did not specifically refer to poverty, lack of opportunity and low expectations” as factors in their subsequent early parenthood it could fairly be assumed that “their stories suggest that these are prominent themes in their lives”.

Maxwell (2007: 555) also recognises that young women experience “sexual pleasure and sexual pressure *within the same relationship*” (my emphasis). Meanwhile Hirst (2004) reminds us that working class young women report that for the most part sex was not in private, often outdoors, in bad weather and was rushed. The young people also had poor awareness of sexual anatomy and limited or inaccurate vocabulary to describe and negotiate their sexual experiences. Mitchell and Wellings (2002: 393) also report concerns about the role of ambiguity and poor communication and that work needs to be done to build young people’s language, skills and confidence; identifying that “lack of clear communication on a date may put young people at risk of having sex that is unwanted, unanticipated or regretted”. Issues of ambiguity, improved communication and planning for risky situations are all returned to in Chapters 6 and 7 in further exploration of essential elements of sex and relationships learning. What stands out from this reporting of young people’s experience is, in human capability terms, a lack of experience of being valued and an inability to imagine the situation of another person or to conceive of what might be good in personal and intimate relationships.

The purpose of this brief overview of findings from research is to ensure that what follows, further consideration of the experiences of young people and adults with a learning disability and exploring learning about sex and relationships, is located in the real experience of children and young people. While it must be noted that it is a gap in the research identified above that there is no indication of whether participating young people have a learning disability or not, it would seem that the lack of language, knowledge, control and pleasure reported by young women certainly matches the experience of adult women with disabilities described in subsequent sections of this chapter. Whatever the characteristics of the young people whose experiences are described above, being aware of what they tell us helps with the analysis offered by this work because the notion of understanding and respecting their ‘standpoint’ reaps benefits for sex and relationship education and learning; Hirst (2004: 124-125) suggests that:

> Demonstrating a genuine commitment to privileging young people’s perspectives appears to lead to greater trust. This encourages young people to speak more frankly and henceforth opens up the language for sex... These strategies bring us a step closer to a meaningful understanding of young people’s authentic experience. In turn this permits a closer matching of provision with need and more routinised and effective communication between adults and young people.

4.5 Understanding the perspectives and experiences of people with learning disabilities

The chapter now considers what we know about the experience of sex and relationships for people with learning disabilities, and explores what we know about their knowledge, perceptions and hopes in this area; helping us to consider the extent to which they experience personal and sexual relationships which are part of a life lived with dignity. This task is not as straightforward as the exploration of these issues for the general population because although young people with disabilities will have been present but unidentified in many of the studies considered above Wheeler (2007: 17) reminds us that there is a "lack of literature on how men and women with learning disabilities experience their sexuality and sexual identity, both in the UK and in Western society more widely". Cambridge (2006: 2) agrees, identifying that sexuality and sexual health are "themes which have in common a history of neglect and invisibility in the learning disability literature". In addition, almost all of what has been published about the sexual lives and relationships of people with learning disabilities does not address the views and experiences of young people; this means that much of what little we do know comes from work with and about adults. To help explain this lack of information, Grant et al (2005: xvii) argue that in terms of social policy, service provision and in the community "the voice of people with learning disabilities is still conspicuously lacking" and that this is "one of the lasting manifestations of a society that has too easily categorised and segregated people with learning disabilities".

In addressing what we *can* learn from the experiences and needs of adults with learning disabilities it is important to think about what we could be doing in childhood and the teenage years to address the risk or build the protective factors which this work points to as crucial in building health and happy adult sexualities. The remainder of this chapter turns to two further sources to help identify what we know. First, there is a growing body of work from those researchers undertaking qualitative research and practitioners who are building a picture of the experiences of people with a learning disability from practice, or who are delivering creative community based service responses which support people to build personal relationships. It is because of this emerging qualitative research and person centred work that we know, that despite the wishes of young people with learning disabilities to live their lives like non disabled peers, the reality is somewhat different.

Second, there is work which looks at the formal assessment of sexual knowledge and experiences. While this is often undertaken on an individual basis there may be general lessons which can be taken which point to how learning for sex and relationships is considered. However, before addressing sexual relationships the importance of friendships and non-sexual relationships in children and young people's lives is explored; understood in human capabilities terms as the person's entitlement to *affiliation* and to be able to live and interact with others.

4.6 The importance of friendships and relationships

Sociability and the entitlement to affiliation with others, with associated benefits of being valued and being considered equal to peers are central to a life lived with dignity. In my own work with the Children's Parliament the importance of friendships is frequently expressed. In discussing play in a recent consultation (Children's Parliament 2011:4) children describe playing as a social activity, that their friends are those they are most likely to play with and that play is seen as a way to build and sustain friendships. As one 4 year old child stated: "My favourite person to play with is my friend Cindy – we play hide and seek. It would make me cry if I had to play on my own". Considering friendship and its importance to young people, Shucksmith et al (1993: on-line) remind us that while relationships with parents are of fundamental importance in determining "longer-term preferences, attitudes and values" it is friendships which are often of more immediate or explicit concern to young people.

> Friendships are based on a completely different set of structural relationships to those with parents. They are more symmetrical and involve sharing and exchange. Friendships are important to young children but there is a change at the beginning of adolescence - a move to intimacy that includes the development of a more exclusive focus, a willingness to talk about oneself and to share problems and advice. Friends tell one another just about everything that is going on in each other's lives. Friends literally reason together in order to organise experience and to define themselves as persons.

In terms of the lives of people with learning disabilities Nussbaum (2006: 219) places value on "the chance to form friendships and other political relationships that are chosen and not merely given" and it is clear that friendships are of equal value and importance to people with a learning disability as they are to others. From their work with adults Knox and Hickson (2001: 276) conclude that “close friendships enrich a person’s life... the experience of friendship has long been recognised as an important element in a satisfying lifestyle for people with intellectual disabilities. In short the presence of meaningful friendships is an essential element of their well-being”. Murray and Greenberg (2006: 220) also recognise the importance of social relationships and experiences for young people with learning disabilities who they argue are otherwise “a vulnerable population whose members are more likely to experience peer rejection, depression, anxiety, behavioural and conduct problems, delinquency, poor academic adjustment, school drop-out and poorer long term outcomes than are children, youth and adults without disabilities”. They conclude that peer relationships are linked directly to emotional wellbeing and call specifically for “strategies for intervening in the lives of children and youth with high-incidence disabilities in ways that enhance the quality of their relationships with adults and peers”.

Exploring the experience of loneliness amongst adults with learning disabilities McVilly et al (2006: 191) claim that “stable and rewarding interpersonal relationships are arguably the most important factor influencing a person’s quality of life”. In their work they have found that adults with a learning disability were less likely to be lonely if they had attended mainstream education and if they were in employment. However, for many participants in their study those relationships they describe as friendships were not necessarily mutual or rewarding, and a lack of connection to a social network meant greater risk and experience of loneliness. McVilly et al (2006: 201) conclude that “personal relationships are one of the key areas requiring attention if people with a disability are to experience a quality of life as valued members of the community”, however there is much to be done and efforts to connect people to friends and social networks would be more successful if “family members and support professionals had a greater understanding of the experiences and aspirations of people with intellectual disability”.

As alluded to above the human capabilities approach sets out a number of entitlements which have been discussed throughout this work and the case has been made that these are universal entitlements, and include ideas about *affiliation,* thought of as the entitlement of the individual to be able to live and interact with others. When it comes to friendship young people with a learning disability want the same things as their non disabled peers, with Williams and Heslop (2006: 32) arguing that this means aspiring to “some form of independent living as a life ambition” and a life in which through social relationships “they can be key players in helping to fill emotional gaps for each other, and may only need the right support to take a greater level of control over their own lives”. Yet despite the evidence that social and personal relationships are important to young people with disabilities there is a strong sense from the limited body of qualitative research that meaningful relationships are difficult to achieve. In spite of this it is also difficult to find evidence in the literature about services or initiatives which are *systematic* in their attempts to do something to support friendships and social relationships by addressing fundamental gaps and barriers in the lives of individuals with a learning disability. Again, it is only by looking to service based responses that it is possible to find some small-scale attempts which can usefully be drawn on to think about how friendships and personal relationships might be made possible.

In a creative example of the kind of support that can work the pilot *Relationship Support Service* facilitated by the agency Consent and local authority partners in and around Hertfordshire provided one approach for adults with a learning disability where it was decided to do something about the social isolation and lack of opportunity to make friends and meet possible new partners. Adults were introduced to others through a matching process, much like other dating agencies but only available to people with a learning disability and who had basic social skills, sexual knowledge and who could engage in a healthy and respectful friendship or relationship. The service was evaluated, and participants and carers identified the work as successful. However funding was not guaranteed beyond the pilot year which Jenner and Gale (2006: 44) conclude is a consequence of the importance of relationships for adults with learning disabilities not being “recognised enough, and more specifically, sexual relationships are still considered by many as a taboo subject”. It would appear that friendships and relationships make real (for the non-disabled professionals and carers around the disabled person) anxieties about the potential for sexual lives to develop.

As a further example of the issues raised by the *Support Service* the *Living Safer Sexual Lives* was a three year action research project in Victoria, Australia which explored how people (adults aged 25 to 60) with learning disabilities view personal and sexual relationships. Through qualitative research, which engaged the voice and experience of adults with a learning disability, the study identified four key themes from the life stories shared: that attitudes of both service providers and families put blocks in the way of adults developing personal relationships, that there was a lack of accurate information about sexuality and lack of clear guidance for professionals about the issues, and finally that feelings of loneliness and isolation were common. Johnson et al (2002: 6) report that "the silence about sexuality and relationships and various prohibitions encountered led many of the story tellers to have secret sexual lives". While the initiative moved into an action phase in which there was training and information provision, efforts to tackle social isolation proved difficult; Johnson et al (2002: 8) conclude that a key factor in this remains "prevailing negative attitudes in the community about the sexuality and relationships of people with learning disabilities".

When it comes to the experience of marriage McCarthy (1999: 60) points to two studies in the 1970s (she highlights the issues have not been returned to since) on the experience of people with learning disabilities. Marriage is presented in these studies as a largely positive experience, where the couples support each other to live independently. But McCarthy (1999: 63) poses an important question in relation to personal and sexual relationships: can people with learning disabilities "simply be educated into having the same kinds of sexual lives as other people" with the assumption that they "are just the same as other people"? In response issues of personal safety come to the fore; for example it is worth considering that of the 25 participants in the *Living Safer Sexual Lives* project described above 11 women and 8 men reported experiences of sexual abuse. In discussing the research about marriage McCarthy highlights that the work fails to address a pattern which sees the men in these relationships as more intellectually able than their partners. From her experience McCarthy (1999: 60) suggests that less able women are vulnerable to men who "can dominate their partners and shape the relationship to meet their own needs".

It is this reality which means that the lives and experiences of people with learning disabilities are often not the same as non-disabled peers; while one reason for this may be the experience of sexual violence and abuse there are other factors which also require identification and exploration in order to ensure that our reaction to negative experience does not disproportionately impact on the entitlements and needs of people with learning disabilities to attachments, love and pleasure. For this reason subsequent sections consider what is known about sexual knowledge, why enhancing sexual knowledge through learning matters, and what consequences there are if we only frame our view of the sexual lives of people with a learning disability by notions of vulnerability and concerns about capacity to consent.

4.7 Assessing and building knowledge

To consider how we might support children and young people learn about sex and relationships, and build their capability to engage in healthy and happy relationships, it is essential to know more about what they know, what they feel and what they hope for. To some extent the research already identified in this chapter begins to describe the experience and aspirations of young people, although we know little specifically about young people with learning disabilities. Some work concerning adults with a learning disability has been highlighted, but this work has been small-scale and McCabe et al (1999: 242) argue it does not go far enough in identifying what sexual knowledge people have and need because "there has been a general reluctance to approve sexual expression among people with disabilities". Further they highlight that such difficulties "are exemplified by the lack of assessment instruments to evaluate the sexual knowledge, experience, attitudes, or needs of these people". With such a reluctance framing responses to sexuality and learning disability it is useful to identify and examine emerging work and to consider why assessing sexual knowledge matters and whether, once assessment is undertaken, this helps to identify what sex and relationship education for young people with learning disabilities might address.

In considering the centrality of sexuality to every person Galea et al (2004: 350-351) remind us that sexuality must be considered as part of any consideration of the quality of life of an individual and that "socialisation and the formation of meaningful relationships with people of both sexes can be affected by both their sexual knowledge and their attitudes towards sexuality". However despite this they are concerned that "many people experience feelings of discomfort, confusion and ambivalence when the topic of sexuality and intellectual disability is raised". Galea and colleagues share the view that that a lack of sexual knowledge leads to increased vulnerability to abuse, unplanned pregnancy and to sexually transmitted infections. They conclude that “the nature and extent of support required by people with an intellectual disability can be determined only through assessment of their sexual knowledge and examination of their attitudes”.

McCabe et al (1999) have developed a measure which can be used with people with learning disabilities, as well as with people physical disabilities and with the non-disabled population. The assessment tool, SexKen, explores the broad range of aspects of sexual health and relationships which might be addressed by a school or community based programme for young people; friendship, dating and intimacy, body part identification, sex and sex education, menstruation, sexual interaction, contraception, pregnancy, abortion, childbirth, sexually transmitted infections, masturbation and homosexuality. McCabe et al (1999: 243) report consistency in findings from work in this area, stating that “people with mild intellectual disabilities were found to demonstrate low levels of knowledge” and that “sexual experience of people with intellectual disabilities was also found to be low compared with people in the general population”. The team conclude:

> Given that people with intellectual disabilities are at risk of sexual exploitation, there is a strong need to further develop this measure so that we will obtain a clearer understanding of the level of sexual experience and the place of this experience in the lives of disabled people.

In addition to the SexKen tool other sexual knowledge and attitudes assessment tools have also been identified by Galea at al; these tools include the Socio-Sexual Knowledge and Attitudes test (SSKAT), the Human Relations and Sexuality Knowledge and Awareness Assessment and the Assessment of Sexual Knowledge (ASK) package. Whilst the main purpose of the work by Galea and colleagues was concerned with evaluating the component parts of these tools they also report findings about participants, where a common feature of adults with learning disabilities is identified as limitations in their sexual knowledge, with both men and women scoring poorly in relation to knowledge in key areas including puberty, safer sex practices, sexually transmitted infections and contraception.

Exploring the sexuality of people with Asperger’s Syndrome, Henault and Attwood (2006) also conducted a small study of 28 adults to ascertain whether the sexual profile they reported was different from that of the general population. Using a tool called the Derogatis Sexual Function Inventory which covers 11 aspects of sexuality including sexual experiences and sexual values they report that compared to the general population participants had: poorer body image; fewer sexual experiences; greater experience of psychological or physiological distress and more negative emotions such as loneliness, anxiety, guilt, sadness; a lack of information on physiology, behaviour and sexual health; and similar levels of desire but fewer opportunities for sexual relationships. Henault and Attwood (2006: 189) conclude that: “The results of this study confirm the importance of teaching social and sexual skills to individuals living with high functioning autism and AS”.

One of the few studies conducted into the sexual experiences of *young people* with learning disabilities has been undertaken by Cheng and Udry (2005); and findings also support the emerging picture of low levels of awareness and knowledge. The study uses data from the 1994-95 first wave of the National Longitudinal Study of Adolescent Health which engaged with all 7th to 12th graders in the United States. With such a wide and representative sample Cheng and Udry were then able to extract information from young people who had ‘low cognitive ability’, a total of 422; 2% of the total sample, with a mean age of 16.7 years, with an equal number of young men and young women making up the sample. This data could then be compared to responses from those who were ‘mentally average’ in relation to a number of areas: romantic attraction, coital sex, use of contraception, sexually transmitted infection and pregnancy.

In their analysis Cheng and Udry report that young people in the low cognitive group are more likely to come from disadvantaged communities and one parent families. As reported in chapter 1, UK evidence (see DFES 2006) also shows that young people from disadvantaged communities are also more likely to engage in earlier onset of sexual activity, with associated feelings of regret, and be at increased risk of unintended pregnancy; all of which are key features of sexual ill-health described in earlier chapters. Further, Cheng and Udry identify that young people with a learning disability report less experience of romantic attraction to either sex or are more likely to report that they do not know their sexual preferences. The young people with disabilities also have less experience of sex than young people with no learning disability. The young men in the group studied report a lower likelihood and experience of forcing sex on another person and girls report lower experience of having sex forced on them. From this Cheng and Udry (2005: 169) suggest that “for the stage of adolescence at least” this is “at odds with the claim that the mentally retarded are sexually aggressive or promiscuous”.

However, when these young people *are* sexually active a more worrying picture emerges. The study shows that while both boys and girls with low cognitive ability are less likely to use birth control it is girls most at risk of unplanned pregnancy, only 38% girls in the low cognitive group had used birth control compared to 63% of girls with ‘average intelligence’. In addition the risk for girls of STIs is also considerably higher than for their non-disabled peers: 26% of the girls with a low cognitive ability had had an STI, compared with only 10% of the other girls in the study. In considering why young people with learning disabilities are less likely to use contraception and have increased risk to STIs they conclude that these young people are less likely to understand and have control over scenarios as they develop, that as a consequence they might be driven by sexual impulses rather than any conceptualisation of the consequences of the behaviour, that they have poor understanding of how to protect themselves, and that they are more likely to be generally confused about their sexual feelings and identity. As a result, Cheng and Udry (2005: 170) conclude that learning programmes and counselling services should be available “to guide and protect these adolescents in their sexual understanding and development”.

4.8 Experiences of violence and abuse; the role of gender and power

In human capability terms *bodily integrity* requires the individual to be free from all forms of violence and coercion .While the purpose of this study is to focus on the sexual health and wellbeing of children and young people with a learning disability attitudes towards and the experience of sexual and relationship based violence for the general population paint a general picture which helps contextualise issues for the population of most concern to this work.

In relation to reporting of sexual violence, statistics regarding crimes of indecency were recorded in Scotland in 2006/2007 to have increased from 6558 the previous year to 6726.

Within this figure 1,123 rapes were recorded. An issue however is what happens to such reports in terms of convictions, and whether these statistics reflect the actual experience of such violence in the community. As an example, of the 794 alleged rapes in 2003 only 31 resulted in successful prosecutions and while the British Crime Survey estimates that there are 190,000 incidents of serious sexual assault in the UK every year, with 47,000 of these being the rape or attempted rape of a woman, fewer that one in seven are reported to the Police. The concern is that reported cases are merely the tip of an iceberg.

Considering the experiences and views of young people in relation to sexual violence in 1998 Burton and Kitzinger undertook research for the Zero Tolerance Trust on young people's attitudes. Over 2000 young people aged between 14 and 21, living in Edinburgh, Glasgow and Manchester took part in surveys and discussion groups in which they explored issues. A key finding was that 1 in 2 young men and 1 in 3 young women found it acceptable that a man might hit a female partner in certain circumstances while more than half of the young people thought that women provoked such violence, for example by the way they dress or by flirting. Over half the young people knew a woman who had been hit by their male partner and half knew someone who had been sexually assaulted. In 2006 Health Scotland published further research. In 'Young People's Attitudes Toward Gendered Violence', via a questionnaire based survey completed by 1,395 young people, and in discussion groups involving young people aged between 14 and 18 years. The key findings included that 1 in 10 girls reported being hit, kicked or bit by their boyfriends while the same number reported their partner had tried to force them to have sex. One in twenty of the young men in the survey considered that regularly slapping or punching a partner was 'just something that happens' while one in fourteen considered that forcing a partner to have sex was also 'just something that happens'. Such research points to the need to consider violence in sex and relationship learning for *all* young people and in broader social policy responses to sexual health and wellbeing.

Returning to sexual abuse, research has also explored prevalence and incidence of sexual violence and abuse for people with learning disabilities – *prevalence* recording the experience of abuse across a lifetime, *incidence* the number of reported instances of abuse. McCarthy (1999: 70) quotes several prevalence studies including her own in the UK which in 1991 showed a prevalence rate of 61% for women and 25% for men. In terms of incidence the largest UK based studies took place in 1992 and 1995 in the South East Thames region which produced an incidence rate of 0.5 per cent per thousand per annum which would mean 940 cases of abuse in the UK. In fact more recent figures quoted by Howlett and Danby (2007: 4) show that there will be approximately 1,400 new cases of sexual abuse of people with learning disabilities actually reported in the UK each year. In terms of the earlier lower rate McCarthy (1999; 71 - 72) recognises that there is evidence that services "forgot" cases over the period of the two parts of the study, and that professionals might not be the most reliable source of accurate data on experience of sexual abuse. Indeed, McCarthy (1999; 71 - 72) argues strongly that "incidence figures are readily acknowledged to be the tip of the iceberg" and that "reported incidences of sexual abuse decrease the further away from the individuals the focus of the study is. Therefore, the highest rates of sexual abuse are reported when the individuals themselves are questioned".

Whilst studies point to higher prevalence and incidence of abuse experienced by women it is also important to reflect on how men with learning disabilities experience and talk about their sexual experiences. Wheeler (2007) reports on work undertaken between 2001 and 2003 in which he interviewed men aged between 16 and 42 and explored their views and experiences of their social lives and their sense of self including their sexuality. Across the work Wheeler identified two recurring common threads which included issues of agency and autonomy – reflecting McCarthy's concern for women's sexual agency above. He also confirms earlier claims in this chapter that in terms of aspirations and dreams about relationships the men wanted what many other (non-disabled) men might want; a long term loving relationship and perhaps marriage and children. The men spoken to by Wheeler also talked about the differences between themselves and other men in terms of social and more personal or intimate relationships; they report being perceived of and treated as children and that, even though they lived away from family, family members controlled and restricted relationships, including sexual relationships. These limitations were often reinforced by a lack of employment and financial independence. Wheeler (2007: 26) highlights the challenge for carers, service and the general public is to "recognise these facts and to act in a way that enables men with learning disabilities to develop their sexual identities and express their sexuality in a lawful manner".

Thompson (2001: 5) also reports on his practice with men, referring to 10 years work with around 140 men with learning disabilities about their sexual lives. He agrees with McCarthy's analysis that gender and power are central issues:

> When men with learning disabilities are having sex with women, the sex is initiated and controlled by the man, with the singular agenda of meeting his sexual desires, with the possibility of pleasure on the part of the woman undermined by the man's general lack of knowledge about women's bodies.

Thompson (2001: 5) also reports that the men's female sexual partners were: "Invariably women with learning disabilities. By contrast many of the male partners of both women and men with learning disabilities do not have learning disabilities". Thompson's view is that the non-disabled man, or more able man, tends to hold and exercise the power in a sexual encounter. Thompson reports that for men with a learning disability, men having sex with men is as likely in community settings as it was when adults with a learning disability were segregated and institutionalised. As with experiences in institutions, same sex encounters were often reported to be abusive and perpetrated by fathers or workers. A particular concern for Thompson relates to men's use of public sex environments and the risks associate with unprotected anal intercourse. Thompson (2001: 8-9) argues that "the men have essentially only one script for sexual contacts" and that "the dominant model of sex with men, for men with learning disabilities, is of the exploitation of power". Finally, Thompson (2001:9) suggests that sexual experiences for men with learning disabilities are primarily about the physical aspects of sex rather than any emotional connection and he argues that "men's inability or unwillingness to consider their partner's feelings is explained more by their gender than by their learning disability", leaving some hope that despite this sad and abusive picture than men can *learn* how to behave with respect to partners, and in turn to expect more for themselves.

To re-emphasise the vulnerability of both men and women with a learning disability to sexual violence and abuse McCormack et al (2005) report on work investigating sexual abuse over a 15 year longitudinal study in Ireland. Allegations of sexual abuse involving 250 service users in a community based service were examined. The study examined the responses to reports of abuse and at assessment and outcomes. The work recognises that there are some key aspects of the lives of the abused person with learning disabilities which undermine disclosure and investigation – these include dependence of the person on the abuser or service provider, fears of retaliation and feelings of shame as well as powerlessness and inability to challenge authority. In addition the study recognises the difficulties the individual may have in understanding both what is happening to them in terms of the abuse or investigation. The team identify that “a key issue in weighing evidence is credibility”; in other words those who have experienced abuse and violence become even more disempowered by views of them as unreliable or lacking competence and so already low levels of prosecution and conviction amongst the general population become significantly worse for those with disabilities.

McCormack et al (2005: 217) observe that “the incidence of confirmed episodes of sexual abuse of adults with intellectual disabilities may be higher than previously estimated” and conclude (2005: 227) as a result of examination of problems with disclosure and investigation that “training in sexuality and relationships, in self protection and personal rights are important”. While this conclusion is important in terms of this enquiry into what might characterise good sex and relationship learning provision for children and young people with learning disabilities there is, in addition, an important conclusion about the failure of adults (professionals and carers) to fulfil their duty of care to people with a learning disability of all ages who should, by right, be free from violence and exploitation.

Having highlighted this notion of ‘duty’ however, it is important to consider what this means to the life of the person with learning disabilities and to the use of the human capabilities approach which informs this enquiry. The concern with a focus on ‘duty’ is that there is a risk that it detracts from the entitlements of the individual (which are the starting point of human capabilities) and suggests that we merely owe something (in this case protection from harm) to the person with disabilities. A sense of duty therefore implies passivity on the part of the recipient whose functioning in the world is limited and controlled by those who police it. For Nussbaum (2006: 276) duties “are never generated in a vacuum” and before we can identify and allocate responsibility for a particular duty, such as protection from abuse, we must first articulate entitlements which in turn will then “inform us why the duty is a duty, and why it matters”. From the perspective of human capabilities then, and in consideration of the experience of violence or abuse, Nussbaum (2006: 277) argues “we need to have some sense of what it is to respect human dignity, of what treatment human dignity requires from the world, if we are to be clear about what treatment violates it". Finally, in terms of identifying who has the 'duty' to protect a child or adult from violence or abuse so that their life is lived with dignity, Nussbaum (2006: 280) responds "we all do".

4.9 Notions of vulnerability and consent

In chapter 1 the idea of *sexual competence* at first sex was discussed. In terms of the general population of young people findings from the NATSAL survey showed that if sexual competence were to be defined by *no degree of regret, willingness to have sex, autonomy of the decision made* and *use of contraception* then in terms of young men 66.6% of young men who had first sex at age 13 or 14 were not sexually competent, of those who had first sex at age 15 as many as 46.4% were not sexually competent. For young women the figures are even starker with 91.1% of young women who had first sex at age 13 or 14 not being sexually competent while for 15 year olds as many as 62.4% are not competent. In my own work I have been made aware of the importance of vulnerability when considering young people's sexual health. In 2009 on behalf of Scottish Government I undertook an external review of a national provider of young people's sexual health services; this included direct observation of young people's engagement in clinical consultations and interviews with young people following consultations. A common theme evidenced from observations of clinical practice was the complexity and risk which were evident in discussions of sexual behaviour. This included experiences of unplanned sexual activity often influenced by alcohol use. Although the importance of condom use was understood by young people attending the clinics young women reported that young men resisted suggestions to use them. Pregnancy testing for young women aged 14 to 16 years old was common and young men who attended clinics were often repeatedly diagnosed as positive for the STI Chlamydia. Professional interviewees confirmed the vulnerability of clients, with one staff member stating (TASC Agency 2009: section 9.4)

> In general, over time, pressure in the clinics has increased in terms of under 16s, complexity of decisions we need to make and time pressures. It is difficult to handle the emotional stuff; you can get a string of distressed clients, under 16s. It's real pressure. (section 9:4)

It seems then that with regard to sexual experiences a majority of young people are in some way vulnerable, that their first sexual experiences can be defined by pressure, doubt and the risk of pregnancy and sexually transmitted infection. It becomes clearer then that concerns about willingness and autonomy can be considered in a broader idea of consent. When it comes to young people with a learning disability the issue of vulnerability is much more to the fore; implicit in worries about harm and abuse are questions about whether young people or adults with learning disabilities *can* be willing, autonomous individuals who can consent to sexual relationships. While human capability approaches are grounded in the belief of the autonomy, human dignity and inviolability of the individual, for some, the question may be can the individual with a learning disability make a choice *at all* when it comes to personal and sexual relationships? While vulnerability and consent are linked and require discussion Lyden (2007: 17) recognises a dilemma in trying to do so when dual "responsibilities to empower and protect persons with intellectual disabilities" are presented as in conflict with each other. This complexity is also evident in reflecting on sexual rights and the entitlements articulated by human capability theory where avoidance or protection from coercion and sexual violence sit alongside entitlements to experience attachment, love and pleasure.

Considering vulnerability first, Delor and Hubert (2000) propose the term is often not clearly defined. In their work on vulnerability in the context of HIV/AIDS prevention Delor and Hubert (2000: 1558) recognise that while vulnerability is commonly associated with concerns about victimisation, insecurity and risk it's meaning is becoming less clear; that it is in danger of "losing its heuristic capacity and political and practical relevancy through increasingly frequent but ambiguous use". To help clarify the usefulness of the concept Maxwell (2006: 143) suggests that vulnerability can be explained in two ways; one "by social context" and the other "in terms of the individual propensity to risk".

These ideas will be returned to shortly but firstly in relation to the day-to-day impact of concerns about vulnerability Burke and Cigno (2000) recognise that for the parents of children with learning disabilities vulnerability is a wider concern, and so in addition to concerns about sexual abuse parents are also concerned about the risks and hurt associated with negative experiences in relationships with peers. The concern however is that such broad-based fears can lead to over-protection and parents or professionals can focus on weaknesses rather than strengths, and over-dependency on close relationships with adults in the family or caring professionals develops as the norm, increasing social isolation and withdrawing children and young people from the learning possible through the social interactions which their non-disabled peers have; in such scenarios a low level of expectation of the capabilities of children and young people leads to helplessness and poor functioning.

It seems then there needs to be a clearer approach to concerns for the safety and wellbeing of young people with a learning disabilities and, as with earlier sections of this chapter, it is possible to learn more about key vulnerability by understanding the experiences and needs of *all* young people. In her work exploring the meaning of vulnerability in the sexual lives of young women Maxwell (2006) highlights a number of factors which define vulnerability. Maxwell asserts that vulnerable young women have few if any gaps between sexual relationships; relationships become sexual more quickly; they are unclear about what they want from their relationships, particularly at a young age; they prioritise relationships over other areas of their lives such as education or employment; they are more assertive in terms of sexual pleasure; they are more likely to use alcohol or drugs; and they are more likely to experience sexual violence in relationships (although the majority of young women in Maxwell’s work whether perceived of as vulnerable or not had to some degree experienced sexual coercion or violence). In addition those seen as vulnerable start their sexual relationships at a younger age and have more sexual partners. Maxwell’s work, although it is not clear the extent to which young women with learning disabilities may have been involved, points to the need to recognise vulnerability as an issue in *all* young people’s lives, particularly young women.

To return again to Delor and Hubert (2000) and their search for understanding and the useful *application* of the concept of vulnerability, it is suggested that identifying *whole* groups who might be at risk of violence or abuse is unhelpful because it runs the risk of stigmatisation of that group and implies no risk for others. The importance of consideration of the individual rather than labelling and generalising about whole groups is consistent with human capability ideas where there is a focus on individual experience and outcomes. Equally unhelpful Delor and Hubert argue, is to associate risk with specific behaviours, for example unprotected sex, as this implies that through interventions targeting a specific *behaviour* rather than the *individual*, risk might be eradicated.

Instead Delor and Hubert (2000: 1558) argue vulnerability is best approached through understanding the "characteristics of the relationships and interactions in which risk takes place" with a focus on "enablement and empowerment" and to apply the concept of vulnerability "to actual situations". This emerging focus on the individual learner and their specific circumstances is a key consideration in what will emerge in this enquiry about the characteristics of effective sex and relationships learning. To do this Delor and Hubert suggest that in relation to each individual there is a need to understand their *social trajectory* or life course; and specifically to take account of the sexual behaviours and choices they are making at that time. Secondly this understanding of individual vulnerability is concerned with the *social interactions* the person has. In relation to the sexual behaviour of a person with a learning disability this will be influenced by their status or position and we have seen earlier in this chapter that power and gender have important roles to play. Thirdly, vulnerability can be considered in relation to the *social context* or social norms for sexual encounters; in relation to people with learning disabilities it has already been established that there are significant cultural barriers to freedom in the realm of personal and sexual relationships and so to avoid the secret sexual lives which emerge, acceptance and engagement with the sexual lives of people with learning disabilities will be protective.

Finally in terms of vulnerability, Delor and Hubert (2000: 1560) highlight the importance of identity to understanding vulnerability and building protective factors; identity construction is thought of as "a process aimed at maintaining, expanding, or protecting the living space in which the subject is socially recognised". Identity, and from it recognition of oneself as a sexual being, is seen as the key protective factor in coping with risk and making healthy choices in sexual situations. These ways of thinking about and approaching vulnerability - identifying the importance of context, locating consideration of the idea in real situations, understanding and making choices, developing a strong sense of personal identity and belief in oneself - will be explored in subsequent chapters, further identifying what children and young people need to learn when it comes to sex and relationships.

To turn to consent, the common understanding of the importance of consent is in relation to the ‘age of consent’ or the legal age at which sexual intercourse is deemed lawful. This is complex because while in Scots law the age of 16 is understood to be the age at which sexual intercourse is generally within the law young people also have rights which mean that they can consent to sex at the age of 13. This leaves young people aged 13, 14 and 15 in a position where consent is possible but the act of sex illegal. There are of course well understood consequences for those people over 16 who have intercourse with someone aged 13 to 15; but in addition boys who may be aged 13 to 15 and who have sex with a 13 to 15 year old partner, even if that is consensual, may also be open to prosecution. Despite what might be described as a confused picture regarding ‘age of consent’ it is generally assumed that the ‘age of consent’ is in some ways a marker and it is assumed that at 16 that a young person has the capacity to consent to engage in sexual intercourse. For young people with learning disabilities however there is often no automatic assumption of capacity to consent at 16. As Lyden (2007: 4) recognises there may be “consent capacity questions” and these need to considered alongside the emergence of the rights of the individual to personal and sexual relationships. To problematise this discussion however Murphy and O’Callaghan (2004: 1348) also observe that the emergence and commitment to the rights of people with disabilities came just as “evidence emerged of high rates of sexual abuse” so leaving some difficult questions about the interface between “an imperative to empower people to make their own sexual choices” and protecting people from assault. Kaeser (1992: 35) recognises that there is a danger that “the laws which are designed to protect this special group of people from harm are the same laws which work to exclude them from ever engaging in mutual sex behaviours”.

In considering these issues Lyden (2007: 5) reminds us that in terms of consent “capacity is a state and not a trait. It can vary over time” so that, for example, while an individual may be deemed to lack the knowledge to enable them to consent to sex, it is possible that such knowledge can be learnt, through education or by being supported through experiences of social situations. In practice assessing the sexual consent capacity of a person with learning disabilities (and so their learning needs) may entail reviewing their health records, discussing the person with carers and other professionals as well as engaging directly with the person her/himself to judge levels of knowledge and understanding of the choices to be made. Such an approach, like human capabilities, has a concern for how the person functions in their world and increasing their ability to function well, rather than making limiting assumptions about capacity to consent based on a diagnosis of ‘learning disability’. Earlier in this chapter various knowledge assessment tools were discussed, each of which has helped to define the areas and domains that sexual knowledge entails.

As well as knowledge, and reflecting ideas of sexual competence and its identification of willingness and autonomy of decisions, Lyden also identifies the need for assessments of capacity to consent to include assessment of rationality and voluntariness as key components. For Lyden (2007: 12-13) rationality is “the ability to critically evaluate, to weigh the pros and cons, and to make a knowledgeable decision”. Lyden observes that when a person has an IQ measured above 69 (the level at which a learning disability might be diagnosed) then it is generally assumed that “the individual probably has capacity”. However, with an IQ of below 69, and particularly for individuals with an IQ of below 40, Lyden (2007: 13) argues for a careful assessment of rationality to ensure they have:

> ...awareness of person, time, place, and event; ability to accurately report events and to differentiate truth from fantasy or lies; ability to describe the process for deciding to engage in sexual activity; ability to discriminate when self and another are mutually agreeing to a sexual activity; and ability to perceive the verbal and non verbal signs of another’s feeling.

Alongside knowledge and rationality, Lyden (2007: 14) describes the importance of voluntariness, which requires that the individual is aware that “he/she has a choice to perform, or avoid, prospective sexual conduct” and can “take self protective measures against unwanted intrusions, abuse and exploitation”. These characteristics of capacity reflect aspects of sexual rights and human capability approaches in that they seek to ensure the individuals good health and wellbeing, whilst also recognising that no harm should be done to the rights and entitlements of others.

In their work Murphy and O’Callaghan (2004) agree on many of Lyden’s characteristics of capacity to consent. They looked at two groups of people; one a group of 16 year olds from the general population and the other a group of adults with learning disabilities (with a mean age of 37.6 years). They identified six criteria for a positive assessment of capacity to consent to sexual relationships which included: basic sexual knowledge; knowledge of the consequences of sexual relations such as STIs or pregnancy; an understanding of appropriate sexual behaviour; understanding of choice; the ability to recognise potentially abusive situations; and ability to be assertive and reject unwanted advances. Murphy and O'Callaghan (2004: 1355) found that levels of knowledge in areas such as STIs, pregnancy, contraception or understanding of social situations where there were issues of consent or abuse were significantly lower in the population of adults with learning disabilities. Amongst the group of adults with disabilities the study also found that "previous sex education did make a difference to the scores... on a number of measures" including knowledge and understanding consent and abuse. This leads them to argue that it is this lack of knowledge and awareness which has implications for capacity to consent to sexual relationships. They also agree with the earlier assertion from Lyden that capacity is not fixed and that in fact understanding and assessing capacity to consent is often about "the question of when a person 'knows enough' to be safe, so that they can be protected from abuse whilst at the same time maintain a right to freedom of sexual expression".

In describing the need for knowledge, rationality and voluntariness Lyden argues that sexual consent capacity need not be a simple case of yes or no; that there may be circumstances in which a person may have *limited* capacity. Limited capacity is described as a person being able to consent to sexual relationships with say one specified person, or to be able to consent to some sexual behaviours but not others. Lyden (2007: 14) recognises that this idea of limited capacity means that parents or professionals are charged with a complex "challenge of needing to provide adequate supervision and monitoring to ensure that the individual's sexual behaviour remains within the recognised level of capability".

Assessing a person's capacity to consent to sexual relationships is complex. What also comes to mind is whether we are in danger of applying criteria and intervening in the lives of young people with learning disabilities in ways which we do not do for other young people, despite the fact that we know that many, as this chapter has described earlier, do not meet criteria for *sexual competence*. From the perspective of human capabilities this suggests the danger of adopting a different set of entitlements for the person with disabilities, a lowering of the expectations we can have for them in how they are and interact in the world. With this in mind Murphy and O'Callaghan (2004: 1355) recognise the need to strike a careful balance “between requiring people to know enough without requiring them to know everything”.

The conclusion must be that while consent and vulnerability are complex issues it is important that each is considered at the level of the individual person and that, in human capability terms, people with learning disabilities are supported to function to their maximum capability and as “freely choosing adults, each in his or her own way” (Nussbaum 2006: 220). To view people with learning disabilities as a homogenous group, all and always vulnerable, all and always with limited capacity to consent, is a deficit approach which contradicts the progress made by new approaches underpinned by the social model of disability, by notions of human rights and human capabilities. What is also clear is that to build identity and address concerns about vulnerability and consent, learning about sex and relationships must build sexual knowledge but also address equally complex ideas about promoting self efficacy and self determination; this is considered in forthcoming chapters. Murphy and O’Callaghan (2004: 1356) highlight the importance of learning when it comes to addressing vulnerability and building capacity to consent with the finding that, in their work:

> ...sex education was associated with higher levels of knowledge and lower levels of vulnerability amongst people with intellectual disabilities. There needs to be a better provision of sex education, particularly on-going sex education, as opposed to the ‘single inoculation’ model in order to allow people with intellectual disabilities to exercise their sexual rights, while at the same time protecting themselves from abuse.

4.10 Conclusion

Chapter 3 sought to explore the legacy of the past 200 years or so on current understanding of, and policy responses to, learning disability. When it came to personal and sexual relationships there was some hope expressed that we might expect, even find, that young people and adults with a learning disability are now able in the 21st century to enter into positive personal and sexual relationships. However what this chapter has shown is that for young people, disabled or not, sexual relationships can be safe and pleasurable but they can also be risky and abusive. Where young people are at risk it is clear that this is linked strongly to a lack of knowledge and poor vocabulary. For some young people the *experience* of personal and sexual relationships does not meet the threshold required to live life with dignity and as Nussbaum (2006: 281) reminds us, until entitlements are a shared and common experience “our world is not a decent and minimally just world”.

This chapter has also explored knowledge, attitudes and experiences of children, young people and adults with a learning disability and has shown there are significant gaps in our knowledge of many aspects of life from *their* perspective. What we do know is that they often lack opportunities to make and sustain friendships and experience social isolation. Once sexually active they have been shown to be at increased risk of poor sexual health; a lack of language, a poor sense of rights and systems which fail to protect, support and believe disclosure leave children, young people and adults exposed to sexual violence.

Considering the experiences of adults Thompson (2001: 10-11) argues that people with learning disabilities have often failed to conceptualise what they do or what is done to them as abuse because they were “immersed in a world where their compliance was required and in which they had second-class status”. Thompson fears that control rather than learning and a commitment to sexual health rights will emerge as the dominant response. To combat these negative experiences and enhance knowledge McCarthy (2001: 19) suggests the need for opportunities to learn about choices and mutual pleasure and how to identify and challenge coercion. In addition, for women with learning disabilities Paparestis (2001: 22) highlights the need for opportunities to address “the shame that is so strongly felt about expressing their sexual feelings” and the “very negative feelings about their body”. This chapter has already established that learning in these areas must begin in childhood and continue through teenage years.

In discussing vulnerability and consent it has been possible to identify links to considerations of human dignity and social justice. Human capability approaches suggest that rather than see the individual with a learning disability as incompetent, lacking in capacity to consent and so helpless, it is also possible to value the individual and assess what that person needs to be able to experience the basic entitlements which a life lived with dignity requires. In consideration of vulnerability and consent this suggests abandoning a deficit approach to the individual’s capacity and capability and instead looking toward what they can achieve in terms of independence, freedom from violence, pleasure, sexual satisfaction, attachments and love.

Earlier chapters have shown a history of discrimination toward people with a learning disability, including in the realm of sexual and reproductive health. In contemporary society an improved but still unsatisfactory picture emerges. It would be fair to conclude that there is some way to go in supporting and protecting children, young people and adults with a learning disability to have personal and (in adulthood) sexual relationships which are safe and nurturing and experienced in the context of a life lived with dignity. Stainton (2000: 88) highlights that the language and experience of rights, equality, human dignity and social justice has, as yet, failed to deliver:

> In recent years the language of rights, liberty and citizenship has become common in the discourse around learning disabilities. This is a discourse which has been at the heart of modern western society since the enlightenment, a discourse from which people with learning disabilities have been consciously and explicitly excluded. The boundary which separates the equal citizen from the *other* has proved to be one of the most intractable which people with learning difficulties must cross, but cross they must if they are ever to achieve the rights, liberty and equality which the vast majority of citizens take for granted.

Chapter 5

Sex and relationships learning: *where* children and young people learn and *who with*

5.1 Introduction

In work I conducted (TASC Agency 2005a: 5) in which young people with learning disabilities talked about aspects of sex and relationship learning contributors made the following comments.

> "I've never really had anybody I could talk to about these things".
>
> "When you first have sex you don't know what's happening. I was 13. I didn't know what I was doing. He just said 'do you want to have sex' and I said yes and that was it. People should tell you stuff at 12 or 13 so you're prepared, then you know".

The question which arises from these comments is: if someone "should tell you stuff" who should this person be and where should they be located? The NHS Health Scotland (2002) *Analysis of NATSAL data for Scotland* reports on young people's views on sources of learning about sex and relationships for the general population of young people. For young men the main sources of information reported are friends (32.3%), school (26.8%), media (14%) first sexual partner (13.8%) and finally parents (with only 11.2%). For young women their friends (25.2%) and school (22.3%) are also identified as main sources of information and while more young women identify parents this is still only 1 in 5 young women (22%). However, when asked which source they would *prefer or have preferred* for information on sexual matters, the 16 to 29 year olds reported that parents and school would be the key sources of choice; with 1 in 3 young men (32%) and nearly half of young women (46%) identifying parents as a preferred source and 2 in 5 young men (41%) and 1 in 3 young women (33%) identifying their school as a preferred source of information. Whilst there is a gap between actual experience and what young people would prefer there is a clear wish expressed by young people to see school and family as the main settings for sex and relationship learning. The importance of parental and other key adult involvement is supported by further work of my own for the Scottish Government initiative Healthy Respect (TASC Agency: 2003*b*) where, when asked about the nature of the targeted young people's sexual health services they would like to see young people identified that a part of what they wanted was for parents and teachers to be better informed about their sexual health needs and for them to be more supportive of young people finding out about and accessing sexual health information and services.

Further evidencing the importance of where young people learn about sex and relationships the NATSAL findings also compare the responses from 16 to 29 year olds who identified parents or school as main sources of information to those who did not in relation to questions about pre-16 sexual activity and condom use. In conclusion the report finds that school and family based sex and relationship education is positive in its impact in terms of delay of first sexual intercourse and condom use, reporting that:

> …respondents whose main source of information about sexual matters was school lessons (or their parents) were significantly less likely to report first intercourse before the age of 16 and significantly more likely to report condom use when the event did occur …. It could be argued that the question should not now be whether to provide sex education, but rather how best to deliver it.

This chapter explores settings for sex and relationship learning and in doing so identifies key adults in these settings who have a role in learning. In the course of this discussion the limitations, challenges, strengths and potential of school (and school-based professionals), family (and parents/carers) and peer group will be examined. The chapter will consider learning for all children and young people but look in particular at the issues for children and young people with learning disabilities, discussing which learning environments, and who within them, might best serve an intention to promote sexual rights and the experience of a life lived with dignity.

5.2 Sex and relationship learning in Scotland’s schools

In 2000 a Working Group on Sex Education in Scottish Schools was established by the Scottish Executive to review the range of curricular advice and support available to teachers on sex education. The subsequent report became known as the McCabe Report. Following the publication of the McCabe Report the Executive released Education Department Circular 2/2001 which placed the values of respect and responsibility at the heart of sex and relationships education. Within the McCabe report the specific context of sex education for ‘Young People with Special Educational Needs’ was addressed. The report recognised that programmes should take account of levels of understanding, that there should be recognition of the disadvantage young people with disabilities face in making social relationships and that teachers must engage in discussion with pupils about how their disability impacts on relationships. The McCabe report also recognised that young people with disabilities may struggle to understand conventions and rules about sexual behaviour and they may find it difficult to express themselves.

Alongside the curricular advice and support from McCabe the Executive revised the National Guidelines for Health Education 5-14 with Health Education established as a free standing element within the 5-14 curriculum guidelines, strengthening existing links between sex education, Personal and Social Education and Religious and Moral Education. As a result, sex education in Scotland’s schools was expected to be embedded in a curricular package which emphasises good health, personal responsibility and positive relationships. In recent times the purpose, scope and context for school based learning has once again changed and Curriculum for Excellence describes the purposes of learning from 3 to 18 and entitlements for all learners. This will be discussed further in Chapter 6.

Traditionally school-based sex and relationship learning has been provided by primary school class teachers and in secondary school by teachers with remits for Guidance or Personal and Social Education (PSE), sometimes supported by a School Nurse. Increasingly external agencies, with staff from local NHS Boards, or voluntary sector agencies such as Caledonia Youth or the Family Planning Association are also supporting learning in school. Reflecting the results from the NATSAL survey reported above Burtney (2000: 7:1) recognises that in Scotland: “There is a widespread expectation from young people and parents that schools will be the main route through which young people receive information about sexuality”.

Whatever the experience or preference of children and young people, school based sex and relationship education is not an uncontested area, with different views on whether learning in this area is appropriate for the school environment and questions about what impact school based learning might have. There is also variance in the experience children and young people have regarding school based sex and relationship education. In my own work

(TASC Agency 2005a) for NHS Health Scotland (quoted at the start of the chapter) I discovered in a consultation focusing on what young people with a learning disability wanted from specialist sexual health services that some pupils in special schools in Scotland, at that time aged 16 and 17, had received no formal school based sex and relationship education at school. In other work I have conducted, including a review of a national voluntary sector sexual health service (TASC Agency 2009) I have also become aware via classroom observations that there are other senior pupils with learning disabilities, aged 16 and 17, for whom sex and relationship learning is only now addressing names for parts of the body and has not begun to address feelings, hopes, desires, sexual experiences, keeping safe or contraception. It appears that for these young people opportunities had been missed throughout their school lives and in partnership with parents to build knowledge, consider behaviour and understand sexual rights. In mainstream schools Burtney (2000: 7:2) also reports that sex education might only account for “anything from between four and ten periods in the school year” and might vary in content and approach. Indeed, despite curricular guidance there has been no national overview of how sex and relationship learning is actually delivered in practice until the NHS Health Scotland (2008) ‘Review of Sex and Relationship Education in Scottish Secondary Schools’ and in 2010 results from a similar exercise conducted in the primary school sector.

The review of secondary school provision was commissioned to identify the characteristics of effective Sex and Relationship Education Programmes (SREPs) by accessing available literature published over the past 10 years in English (worldwide but predominantly from the United States), to map and appraise current SREP activity in Scotland’s secondary schools, and to make recommendations for policy and practice and research as a result. In relation to the first purpose of the Review a number of characteristics of effective school programmes or interventions were identified from the literature, including that programmes should start young, be age specific, should include some single-sex work and should address both physical and biological development. While there may be concerns amongst some parents or professionals that sex and relationship education in some way advocates or encourages sexual activity the review identified that effective school programmes were seen to promote delay for those not already sexually active and, for those who had already been sexually active, they found effective encouragement to use contraception and efforts to reduce the number of sexual partners. In terms of the scope of interventions it was found that effectiveness is increased by targeting one specific behaviour at a time (reflecting the view of Delor and Hubert in Chapter 4 who proposed targeting specific behaviours rather than general fears as a way to address vulnerability) for example condom use, especially if learning interventions provide communication and negotiation skills and promote specific values and norms. The review of literature reports that those delivering SREPs need to be trained to do so and that, finally, theory based interventions, particularly using social learning theory, that take into account social and environmental factors as well as individual behaviour, are most likely to be effective.

Aspects of these characteristics of effective interventions which relate to content and methodology will be explored in more detail in the next chapter, but in terms of an overview of sex and relationship education in Scotland’s secondary schools the Review concludes that while the policy context is positive, delivery in Scotland’s schools is not good enough; concluding that while schools agreed that pupils need to learn about sex and sexual health in the context of broader learning about relationships there is no consistency about how this is done in practice. As an example 33% of schools responding to the Review survey report they develop their programme solely in house, 10% use an external programme and 50% develop their programme with the support of external professionals from statutory or voluntary sectors. The Review doubts that multi-agency collaboration is being used effectively, with external contributors to a school programme often not being included in the process of design or follow up, resulting in poor links to external sexual health services.

Other key findings of interest to this enquiry include that amongst professionals charged with delivering sex and relationship learning there is a range of confidence and competence and training for staff is inadequate. Where schools report problems with their programme they identify this is largely in terms of staff feeling uncomfortable about teaching the programme, often because of a lack of training and poor resources. In my own work I have been aware of such issues. In the work reported as ‘People Should Tell You Stuff’ (TASC Agency 2005a) I visited several special school settings with the intention of speaking with pupils. Preparation for the work included pre-discussion group visits to each of the groups of young people to meet and ascertain what their preferred leaning styles and levels of sexual health knowledge were. This visit also included meeting with school staff who would also be present at the workshop, to ensure they understood purpose and content. Part of this preparation was to clarify the language/terminology that would be used; this included the word masturbation. On returning to one school for the main workshop with pupils when this word was used there was no recognition by the young people and so before we could progress an early coffee break was organised and I had the opportunity to discuss with the teacher present why this word was not known when it had been part of the preparatory materials. It transpired that the teacher, responsible in the school for sex and relationship learning, did not feel comfortable using the word and feared parental responses if the pupils used it at home. The workshop continued with me as facilitator explaining what the word masturbation meant. Pupils understood this, and had other words which they normally used, and we could progress, but what was clear was that these pupils, about to leave their secondary school education, did not have a relationship with an educator which enabled them to discuss all aspects of their sexual health and wellbeing.

The example above also highlights inadequate discussion between school and parents, and this lack of communication is also reported in the Review of Secondary education provision. Around 1 in 3 schools (37%) report that parents were involved in some way in their programme; however this was mostly described as ‘consultation’ via written information or discussion at School Boards. Just over half of schools (55%) reported ‘pupil involvement’ through course evaluation following delivery rather than commitments to the right to express views meaningfully as is central to the UN Convention on the Rights of the Child (1989); indeed the Review highlights that it is unclear whether this pupil involvement impacts in any way on course content or delivery.

There are further differences in the experience of school-based learning in Scotland which are explained by a child attending a denominational or a non-denominational school. This can mean that in Scotland today a child will experience sex and relationship learning differently dependent on what school they attend, rather than any assessment of their learning needs. This difference between the child’s experience of sex and relationship learning is particularly evident in the city of Glasgow where a new curriculum for sex and relationship learning has been developed, piloted and is now being rolled out across the city (this is discussed further in chapter 6) but only in non-denominational schools. I have been commissioned to support this new curriculum by developing booklets for children and young people (from P6 to S6) and currently (2011) in exploring parental views of the curriculum. When it comes to such differences in the leaner's experience the NHS Scotland secondary school Review describes provision in denominational schools as being underpinned by (NHS Scotland 2008*b*: 2) "strong beliefs around appropriate sexual behaviour" and "the dominant moral code offered by the Roman Catholic Church". The term 'appropriate' is not explored in the report - for example it is not clear whether appropriate means behaviour in accordance with sexual rights or a commitment to human dignity; nor is the position of the Roman Catholic Church explained or explored in any critical way.

Continuing with a critical reading of the Review, when it comes to inclusion and the needs, experiences and sexual rights of young people with learning disabilities in relation to learning in the secondary school sector this is dealt with poorly; despite 76 of the 392 school questionnaires returned coming from 'special schools'. In terms of inclusive practice the Review identifies that for many teachers diversity was viewed only in terms of maturational age and "a readiness of pupils to deal with sexuality" (NHS Health Scotland 2008*b*: 7) but again this language is not explored or explained. The Review concludes that "few schools had the capacity/skills to deal with issues of inclusion competently" (NHS Health Scotland 2008*b*: 2). This stark statement indicates a serious failure in the role of Scotland's secondary schools to ensure learning which promotes basic entitlements characterised in human rights and human capability theory around issues such as bodily health, including reproductive health, for people with disabilities.

Compounding the poor quality of sex and relationship learning for pupils with learning disabilities a case study from one special school's work on sex and relationship education is described in the Review as being focused on keeping safe, managing social settings and recognising risky situations. There is a tone of protection and control about the descriptions of practice given (NHS Health Scotland 2008*a*: 61) as opposed to descriptions of practice which might be committed to and understand the need for young people to learn about and have opportunities for emotional attachments described in human capability theory. In one example of a failure to address the needs and rights of pupils with disabilities there is no explanation of why a key area in a sex and relationship programme – contraception – is viewed as ‘problematic’ in the following description:

> Clear and specific messages were produced about behaviour, and efforts to support young people to recognise and deal with risky situations made this approach much clearer than that offered in mainstream schools. However dealing with contraception often remained more problematic.

From contributions reflecting on the experience of pupils with learning disabilities in the mainstream, the Review (NHS Health Scotland 2008*a*: 60) identifies that secondary schools are responding to what is described as “a mix of experience and naiveté amongst pupils” with one contributor stating that there is “a fine line between wanting our children to be included in mainstream as much as possible but making sure that the quality of the education we give them is at their level and they understand it”. The approach is then recognised as follows: “It looks a bit ad hoc you know”.

In terms of the Review of primary school activity on sex and relationships learning the NHS Health Scotland report (2010) indicates similar problems: with a story of poor understanding amongst schools of local policy and variation across the country of the support available from Local Authorities. In terms of teacher’s role and competence to deliver sex and relationships learning the Review reports low levels of teacher confidence and training. Again, partnerships with parents is described as poor and while parental complaints about sex and relationship learning are rare schools report they are often anxious about parental views. The Review (NHS Health Scotland 2010: 6) also reports that decisions about what to teach and when are “bound by what is deemed ‘stage appropriate’ and that much teaching is designed to protect pupils from too much knowledge at too early an age”. The Review (NHS Health Scotland 2010: 7) reports that while schools acknowledge “that young people should enter adolescence with sufficient information to be able to keep them safe while, at the same time, enabling them to make informed choices” it also reports that topics such as contraception, STIs, gender stereotypes and discrimination “elicited a wide variation in opinions from school staff as to whether they should or should not be included”; this was particularly so in denominational schools where, for example, 76% of schools reported that contraception would *not* be discussed with pupils even if they ask a question.

The picture painted by the Reviews of both secondary and primary school based sex and relationship learning in Scotland shows that what is being delivered is far from adequate. There is a failure to assess and address learning needs from the child's perspective; the influence of teachers and parents - and in denominational schools management of the curriculum by the Catholic Church - means that pupils experience of sex and relationship learning is defined by a lack of adult confidence, incompetence and social conservatism; all of which sit in opposition to a commitment to education which promotes the human rights and human dignity of the learner.

There are however new packages or programmes emerging, particularly in NHS Greater Glasgow and Clyde (highlighted earlier and discussed in more detail in Chapter 6) and via the SHARE (Sexual Health and Relationships: Safe, Happy and Responsible) programme developed in Scotland discussed below; although delivered in a minority of Scotland's schools it is worth considering whether elements of these programmes address widespread shortfalls identified in the Reviews as described above and offer some indication of what might characterise the sex and relationship learning that children and young people with a learning disability require as a basis for a life lived with dignity.

5.3 Developments in school based learning: the SHARE programme

As an example of emerging provision in Scotland's schools The SHARE (Sexual Health and Relationships: Safe, Happy and Responsible) programme was developed between 1993 and 1996 by staff at the Medical Research Council Social and Public Health Sciences Unit at Glasgow University, working with an experienced sex and relationship education trainer. The programme is described as theory based, research based, values based and teacher led. The programme initially provided 5 day training for facilitators who would deliver back in school, but this is now provided over 3 days due to difficulties in releasing teaching staff. Those delivering SHARE are mostly teachers but can also be allied professionals involved in schools. The SHARE package contains 22 lessons delivered over two school years to 13 to 15 year olds; more recent guidance suggests that some work on the programme can begin in S2. Training emphasises that providers should see the package as flexible and provide opportunities for supplementary work where there is such a possibility. While the SHARE materials (NHS Health Scotland 2006: 4) recognise that “sex and relationship education is a lifelong process” the programme is targeted at S3/4; Wight and Abraham (2000: 27) explain this is so because it was thought that younger pupils would not “consider the programme personally relevant in the immediate future, and it would have seriously limited what content was deemed acceptable to education authorities and parents”. This latter comment might suggest that in Scotland today programmes of sex and relationship education continue to be informed significantly by what gatekeepers will allow rather than by notions of sexual rights or entitlements articulated in human rights instruments or human capability theory. However, having expressed this concern, the SHARE package does explicitly address sexual rights. The value statements which are provided include articulating young people’s rights to respect, to their own feelings and thoughts, to good information, to safety and to be able to say ‘no’. The materials (NHS Health Scotland 2006: 4) recognise that young people do not just need knowledge “but also the opportunity to explore attitudes and emotions and to practice skills”.

From the initial piloting of SHARE, and then from learning as part of a roll out of the programme in a small number of Local Authorities there was recognition that the programme may not meet the needs of pupils with learning disabilities in the mainstream setting. With this in mind work was undertaken in 2006 to put in place additional materials and altered approaches, called *Enhanced SHARE*, which could be used to ensure engagement. The use of SHARE as a programme for pupils with learning disabilities has now progressed and trainer and co-author Hilary Dixon, has now published a new programme called *SHARE Special: An SRE Curriculum for Young People with Special Needs*. This new programme provides materials for use in schools for young people with moderate or severe learning difficulties and autism spectrum disorder and is intended for use alongside *Enhanced SHARE* in mainstream settings or in special schools or units. As a new programme there is as yet no information on the use or evaluation of *SHARE Special*.

The SHARE programme is perceived of as innovative in its scope and expectations have been high of a programme which has utilised current evidence to build a theoretically based approach for the school context. However, evaluation through an initial cluster randomised trial with follow up six months after the initial intervention, and then 4.5 years after intervention, has shown that while the SHARE programme was rated positively by pupils, their knowledge of sexual health improved and they reported improved quality of sexual relationships, in terms of other areas including less regret of sexual activity, impact on sexual behaviour, use of contraception and rate of conception or terminations, there has been no impact. In terms of the interest of this enquiry - to understand and describe the best possible model of sex and relationships learning for children and young people, particularly those with a learning disability - this points to the limitations of what can be expected from school-only based programmes and to programmes delivered at an age when young people may have formed views or had experiences for which they were poorly prepared. It seems clear that if we want sex and relationship learning to impact on the experiences young people have when they do become sexually active, and if we want learning to promote an understanding of and commitment to sexual lives lived within frameworks of human and sexual rights, then even the most progressive current school based programmes in Scotland today are failing to deliver.

5.4 Young people’s view of sex and relationship education in school

Building on ideas about the value and importance of young people’s perspectives and right to be heard - explored in Chapter 4 and enshrined in UN instruments including the Convention on the Rights of the Child (1989) and the Convention on the Rights of Persons with Disabilities (2007) – it is important to understand what children and young people themselves say they want school based learning to be like. Two key points are highlighted in the literature and are explored further below; the role of external professionals in school and the timing of programme delivery.

Firstly, Tripp and Mellanby (1995: 274) identify that teenagers want outside professionals to be involved in school programmes. They report that young people find it difficult to engage with teaching staff, ask questions or raise worries for fear that they will breach confidentiality and share knowledge of sexual activity with others. In addition young people identify that teachers get embarrassed while external professionals are more comfortable talking about sex and relationships. This has also been a theme in my own work (TASC Agency 2003b; 2005a; 2005b) where young people from different groups all confirm this interest in drawing in external expertise to their school based learning. However, while Douglas et al (2001: 160) recognise the positive impact external professionals can have, they also identify that they must demonstrate purposefulness and effectiveness with clarity about “how the work will benefit young people and compliment the schools’ existing activities”. Overall though Douglas et al recognise that in the input from an external professional young people often find characteristics which include “fun; openness; light-heartedness; and a participatory, non-didactic, non-judgemental teaching style where young people were invited to determine and discuss their own views and values”.

Secondly, secondary school pupils also identify that sex and relationship education programmes should be taught earlier and learning should be revisited as they mature. Hirst (2004: 120) identifies that young people in her study “bewailed the fact that sex and relationship education took place too late. For optimum impact, guidance best occurs before teenagers enter into sexual liaisons and is then followed up so as to reinforce the endorsement of abstinence or safer behaviours”. This would certainly reflect the view of the young person which opened this chapter where there was a plea that young people should be *prepared* so then they *know what they need to know*; this further highlights the limitations of programmes such as SHARE delivered to young people who may already be sexually active.

In Chapter 3 the lack of information coming directly from young people and adults with learning disabilities about their experiences of sex and relationships was flagged up however there is some evidence about school based sex and relationship learning in the study I conducted for NHS Health Scotland (TASC Agency 2005a). Young people with learning disabilities discussed who they talk to about sex and relationships and where they would get, or would like to get support, advice or information. While the main thrust of the work was about sexual health services young people did talk about what they could talk to teachers about; messages included that some young people would never talk to a teacher about anything to do with sex or relationships because of concerns about confidentiality and particularly that information might be shared with a parent. On the other hand some young people said that while there were some classes where they learned about sex and relationships any questions or worries they had would be best dealt with in a private discussion with a teacher, out of the group. For some young people conversations with a teacher are based very much on choosing the adult with certain characteristics; those considered as caring, good listeners and respectful of the young person's right to confidentiality would be chosen.

5.5 Learning in the family

In the document 'Teenage Sexuality in Scotland' Burtney (2000: 8:1) states: "Whether or not they want it, parents have a role in educating their children about sex and relationships". Mellanby et al (1992: 455) also address parental willingness to support learning and identify that some "may be content to devolve the process to others". Tripp and Mellanby (1995: 273) also comment on parental responsibility, and while they assert the importance of the role their criticism of how that role is fulfilled is evident:

> Traditionally sex education is the responsibility of the family but it appears that in the current context this is not enabling young people to develop safe sexual relationships.

These views capture the tone of much of the writing about the context of family and the role of parents in terms of sex and relationships learning, that without wishing to undermine the challenges faced, essentially parents can be viewed as resistant, ignorant, embarrassed or just failing to do their job properly; presenting parents as part of the problem rather than the solution. This enquiry will outline a more constructive way to consider sex and relationship learning in the family and so this chapter seeks to learn from recent research which explores the perceptions and experiences of parents as co-educators in this area. It has also been possible for me to reflect on the practical application of this notion in my professional life. In a project undertaken for NHS Health Scotland (TASC Agency 2010) I managed a team which produced a resource for parents and professionals which collated materials – books, leaflets, DVDs, descriptions of training programmes – which support the parent's role or recommend publications which older children and teenagers might be given to support sex and relationship learning. Published as 'Learning Together' the resource is available from NHS Health Scotland.

To return to the role of the family, and reflecting Weeks' (1986) assertion that the family is one of the key building blocks for the social construction of sexuality Kakavoulis (2001:

164) also asserts that "the family has been recognised as the most influential context in which the child develops and it shapes sexual identity and behaviour from the beginning of life". In their exploration of the parental role in sex education Turnbull et al (2008: 183-184) recognise that parents are central to *all* aspects of development, growth and health so that "sex education is no exception to general education, where parents provide their children with information that helps them to form attitudes, beliefs and values about identity, relationships and intimacy". From this perspective parents are engaged in a process which they might not necessarily conceptualise as learning for sexual health or relationships, but may see as a focus on establishing and maintaining "the culture and ethos present within the family".

Considering a more explicit role as sex educators in her qualitative research with parents Walker (2001) reports that while sex and relationships learning provided by parents for their children varied in terms of whether parents were comfortable with the role, a common factor was that it was unplanned. She reports that where parents reported some degree of active engagement in learning this generally began with discussion of factual knowledge with young children, moving on to dialogue more concerned with social and emotional aspects of relationships with older children. Across her research Walker also reports that parents are making decisions as their child grows about what issues they feel their child is ready to have more information about; this means that discussion is often reactive and led by the child's questions. However, waiting for questions that might not come, or recognising that they gave subtle signals that they are nervous about discussion, Walker (2001: 136) identifies that some parents are grateful for a lack of discussion, feeling that they have been "let off the hook". For others however there was a sense of missed opportunities for dialogue and learning. Walker identifies that distancing, procrastination, abdication and inapproachability all undermine positive dialogue.

The adopting of such avoidance strategies, or alternative approaches based on a willingness for dialogue and learning, is to some extent influenced by what topics or areas parents choose to address with children in relation to sex and relationships. Rosenthal and Feldman (1999), working with high school students in Australia and gathering data from their experience of communication with parents, have developed a model which identifies four domains, covering 20 areas, within which parents may have a role in learning:

development and societal concerns (which would include issues such as menstruation, puberty, pregnancy, abortion, homosexuality and sex before marriage) *sexual safety* (issues such as safe sex, contraception) *experiencing sex* (issues such as dating, dealing with pressure, desire, talking about sexual needs) and *solitary sexual activity* (masturbation and wet dreams). Rosenthal and Feldman conclude that parents do not deal with each of the domains equally; focusing mostly on risk and safety, while girls get more information from mothers on issues such as menstruation, pregnancy and dealing with pressure. The most striking finding however is that young people report that their parents did not communicate with them *at all* about 75% of the topics listed across the domains. Rosenthal and Feldman (1999: 848) report that this lack of communication is for the most part welcomed by the teenagers who “attach very little importance to parent communication about private areas of sexuality” while they are accepting of parental interest in risk and safety as these are “external to the immediate experience of youths and do not threaten their fragile sense of privacy and self-identity”. Of course such a conclusion presents real difficulty if the purpose of sex and relationship learning requires communication across the areas identified by Rosenthal and Feldman if on the one hand there is a parent who is ill equipped to talk about many of these areas, and on the other an adolescent who is resistant to that discussion taking place anyway. This would seem to point to the need to establish sex and relationship discussion and learning well before the teenage years.

As with much of the information sourced as part of this study it is unclear from research identified the extent to which young people with learning disabilities or the parents of young people with learning disabilities have informed findings. However, on the matter of the parental attitudes of parents of a child *with* learning disabilities towards learning about sex and relationships at home Cheng and Udry (2003) provide one insight from the United States which extracts information about young people who had ‘low cognitive ability’ (a total of 422 with a mean age of 16.7 years) from a national survey. They report that parents of children with a learning disability feel less knowledgeable about how to talk to their child about sex and birth control and that they are less likely to have talked about these issues with their children compared to parents of young people with no learning disability. It seems then that from an early age and throughout childhood, in the context of the family, for children and young people with learning disabilities there are particular disadvantages and their rights to positive sexual health and wellbeing may be undermined by poor opportunities to learn in the context of family.

5.6 Parents as sex *communicators*

Much of what has been sourced in this section of the chapter is about what young people or parents report separately. An interesting issue is whether young people actually recognise when their parents are trying to have, or are successful in having, what King and Lorusso (1997: 52) have called “meaningful discussions” with them about aspects of sex. From King and Lorusso’s US based work, with 530 university students and their parents, there was disagreement about whether discussions had taken place; with most students saying they had never had a meaningful discussion with a parent, while parents report that they have. King and Lorusso conclude that parents underestimate what their child wants to know, they assume their child is more conservative in their views than they actually are and parents miss opportunities to offer clear messages by choosing to “convey their attitudes and values about sex indirectly”. Turnbull et al (2008) also argue that when the child becomes an adolescent a subtle approach to dialogue on sex and sexual health might not be so effective when more explicit or open discussion is required to clarify expectations or norms around sexuality and sexual behaviour. This issue will be returned to in framing sex and relationship learning in Chapter 7.

Whether young people remember or recognise parental efforts to communicate about sex and relationships there is consistency across the literature in the view that children, especially girls, are more likely to communicate with their mother than father and that mothers are more likely to assume the role of educator. Walker (2001: 138) reports from her work that “there were few fathers who shared positive experiences of providing sex education to their sons”. Turnbull et al (2008) speculate that possible explanations might be that fathers themselves have received poor education, another may be that that fathers never had the opportunity to talk to a parent in their own childhood, and finally fathers may conceptualise ‘sex education’ as being something that women need to deal with because it is mostly about menstruation and pregnancy. This would indicate that if children and young people are to learn about their sexual rights – for example to understand their entitlements to choose their partner, to decide to be sexually active or not, to pursue a safe and pleasurable sexual life as adults – then parents (and especially fathers) require support and learning themselves to expand their current view of what might be part of sex and relationship education in the home. From Walker’s research there is also the interesting notion that for some parents sex education at home is to be done in a formal sex talk to their children. She reports this is seen by parents as a significant barrier to ongoing less formal and less stressful continuing engagement. Walker argues (2001: 140) that “sex education would therefore be made easier by removing this barrier and exposing the myth that it is necessary to provide children with a comprehensive sex talk”.

What emerges from this exploration of the parental role in sex and relationship learning is the importance a parent being “open and receptive” to communicating on sexual matters (Turnbull et al 2008: 185). However, Walker (2001: 141) recognises a number of blocks to parental communication in the realm of sex education which includes a lack of awareness of the child’s need for learning, a lack of awareness about the role a parent can play and an uncertainty about what to talk about and when. With such blocks in mind it is useful to consider the language used, and to address whether the language of parents as *sex educators* is in itself problematic. Rosenthal and Feldman (1999: 836) adopt the work of Warren who makes a distinction between sex *education* and sex *communication*, identifying that “education is unidirectional, involving the provision of information in a top down manner, from expert to novice, whereas communication is bidirectional, involving two partners in mutual dialogue with the viewpoint of both being valued”. For Rosenthal and Feldman (1999: 849) the effectiveness or impact of this communication role is enhanced by establishing dialogue early, by respecting the privacy of the adolescent and by avoiding imposition of parental views.

> We argue that parents cannot and should not impose their views about the need for communication on their teenage sons and daughters and that they need to consider whether their teenagers are willing recipients of parental communications, especially about matters which are regarded as personal and private. If parents start the communication process early in their child’s life and include sex as only one of many matters worthy of discussion, they can establish a pattern of reciprocal sharing of information, values and beliefs before adolescents confront the twin tasks of integrating sexuality and dealing with issues of autonomy and independence.

In discussion of parenting the child with learning disabilities Schwier and Hingsburger (2000: 125) agree that “it is better to conceive the process as relationship training rather than sex education” and this idea about communication between parent and child would seem to usefully inform a parent’s role in promoting human capability entitlements, not only to bodily health (arising from improved sexual health), but also to commitments to build attachments to others and, in Nussbaum’s (2006: 77) discussion of human capabilities to be “able to form a conception of the good and to engage in critical reflection about the planning of one’s life”; in this case one’s sexual life.

5.7 Learning in the context of friendships and relationships

This enquiry is concerned largely with the role adults play in sex and relationship learning, but an interest in peer learning also matters because of the role which adults can play in terms of support and influence. Relationships with other young people, including first sexual partners, are recognised by young people as a context for learning about sex and relationships and learning from others can be informal, or formalised through provision of peer education programmes. In her work Powell (2008: 292) recognises the importance of friends and peers in discussing sex and relationships; with young people confirming that friends are “the first people you go to”. Friends are seen as having common experiences and shared values. Further, if friends have specific experiences, for example they are going through puberty or they have already had sex, their legitimacy as a source of learning increases. Powell reports that young people’s dependence on partners and friends grows as young people get older, while more formal sources or contexts such as school diminish.

Informal learning from peers however does raise questions about whether information or advice might be consistent, accurate, helpful or unbiased; particularly if friends have also had poor learning opportunities, negative experiences which they have normalised or may themselves have disabilities which might mean understanding and retention of information is limited. Of course in this context it may also be the case that children and young people may not be exposed to specific messages and understandings about sexual rights if these are not part of the experience or lexicon of peers. In my own work with young people with learning disabilities participants reported that while friends are an important source of information, advice and support there are limits in terms of what can be discussed; with masturbation, periods and being gay viewed as more embarrassing or likely to lead to a negative response. Furthermore the young people expressed concerns about confidentiality, commenting (TASC Agency 2005a: 22) that friends “...might tell people things you don’t want them to, this can cause you trouble”.

The challenge in terms of learning about sex and relationships would appear to be to support friendships (particularly for young people with learning disabilities where social isolation and loneliness has been identified as a concern) but also to ensure that young people get the information, support and advice they need from sources which are informed, accurate and respectful of confidentiality whilst promoting understanding and acceptance of sexual rights and notions of human dignity in personal relationships. In order to foster such learning, which is more likely to be accurate and helpful, learning from other young people can be formalised through models of peer education where a young person, usually following training and with ongoing support, becomes a role model or teacher for others. The extent to which this process is formal (with a set programme of training and support for the peer volunteers) or informal (perhaps a role built from informal conversations) may vary across programmes. At its heart though peer education taps into the peer volunteer's own interests in a particular subject and their desire to support others in areas of learning or behaviour which they recognise can be problematic – be that bullying, offending, drug or alcohol use or sex and relationships. Turner et al (1999) make three main claims in support of peer education approaches. Firstly it is claimed that peers are a credible and acceptable source of information; secondly that being a peer is in itself empowering in the area of interest; and thirdly that peers are better at reaching and reinforcing messages targeted at young people considered 'harder-to-reach' by adults or service providers.

However the efficacy of peer education for sexual health and wellbeing is questioned. On the one hand peer education has its supporters; the A PAUSE programme (Added Power And Understanding in Sex Education) is one programme used in the UK. The programme is delivered by doctors, teachers and young people who are trained as peer educators. The intention of the programme is to debunk myths and encourage discussion between young men and women so that young people learn negotiation skills for relationships. Such a programme is based on claims that social learning, that is learning which is done alongside peers (and in this case facilitated by professionals and trained peers) is more likely to mean that skills and values will be impacted upon and transferred into subsequent choices and behaviours; often with a focus on helping young people resist the choices or behaviours that have been identified as having a negative impact on health and wellbeing. Tripp and Mellanby (1995: 276) explain the success of the A PAUSE programme as follows:

> Factual information is used as a vehicle to promote discussion, and it is the active discussion of sensitive matters within safe ground-rules that is one essential

> component of social learning. In simple terms if a teenager in class, surrounded by classmates of both sexes, states that teasing and exploitation are unreasonable methods of getting sex then they will find it harder to do those things outside the classroom.

But while participation in peer education, as a peer educator or as a recipient of a peer-led input, can support efforts to increase knowledge or help promote human capability entitlements for social interaction and affiliation with others, Milburn (1995) in a review of the approach for the Health Education Board for Scotland concluded that peer education work has not been adequately evaluated, nor does it report clearly about outcomes. In terms of the theoretical basis for the work both Milburn (1995) and Turner et al (1999) recognise that peer education makes claim to be informed predominantly by social learning theory, this will be explored further in the next chapter, but with questions around formalising and utilising peer learning in the form of peer education programmes Milburn (1995:418) concludes that “the premise that young people will be more effectively informed and their behaviours altered by sexual health education from their peers should, at present, still be treated with caution”. In a review of both peer led and adult led school sex education Mellanby et al (2001) argue for the importance of adults, and that what is likely to be most effective is a mix of adult-led *and* peer-led approaches to providing information and addressing perceptions and attitudes towards sex and relationships.

5.8 Conclusion

That sexuality is a cultural phenomenon and that learning takes place in childhood has been established in earlier chapters. In literature explored in this chapter young people confirm the need for learning about sex and relationships across childhood. The conclusion would be that if we want children and young people to have healthy and happy sexual and personal relationships in their adult life then adults can help to shape those healthy, happy sexualities in childhood in a range of settings where learning is possible. However, in considering where learning takes place – school, family and peer group - a number of limitations, challenges, strengths and potential can be highlighted.

Reflections on learning in the school setting dominate the literature about sex and relationships learning. Young people identify school as one of the main sources and preferred settings for learning, while parents it would seem assume that schools are meeting need. In terms of social policy, the pressure on schools to deliver improved sex and relationships learning is growing. As a consequence, in Scotland’s schools today new curricula are emerging and in mainstream settings there are efforts to recognise the needs of young people with learning disabilities. In special school settings, where it has been the case that pupils may have had no formal sex and relationship education in their time at school, it is to be hoped that Curriculum for Excellence and new programmes such as *SHARE Special* will impact positively. Reflecting the growing understanding that sex and relationship learning needs to be more than its traditional focus on puberty or sexually transmitted infections , in other words more than just about ‘having sex’, new curricula reflect an intention to shift school based learning to also address the emotional wellbeing and safety of children and young people.

However developments linked to Curriculum for Excellence are not yet implemented and knowledge of current sex and relationship, informed by NHS Health Scotland’s commissioned Reviews of secondary and primary education provision, shows that despite a positive national policy context delivery is poor because teachers and other facilitators lack confidence and competence, engagement with pupils and parents in terms of reflecting on their learning for sex and relationships is inadequate, and links to external sexual health services and expertise need to be improved. Practice in Scotland’s schools still appears to be traditional in approach, with worries about socially conservative views from parents or faith groups overtly influencing content rather than a clear commitment from school-based professionals to meeting obligations explicit in sexual rights or more broadly children’s human rights. In particular the NHS Health Scotland Review (2008) of provision in secondary schools has shown that the needs of young people with learning disabilities are still not well understood or met.

While Scotland has been seen to be at the forefront of developments of a theory, research and values based programme for older secondary education pupils via the SHARE programme, evaluation of the programme has shown that school based learning has its limits; while an impact on knowledge and better experiences of sexual relationships have been found, and these must be recognised as extremely important, the programme has had no impact on sexual behaviour, use of contraception and rate of conception or terminations. Such findings lead to the conclusion that more could be done, that school-based programmes alone are not adequate to meet learning needs, and that as Bandura (1998: 644) reminds us “comprehensive approaches that integrate school-based health programmes with familial and community efforts are more successful in promoting health than if schools try to do it alone”.

In relation to these other settings for learning this chapter has also looked at the family and the peer group. The NHS Health Scotland (2002) *Analysis of NATSAL data for Scotland* reminds us that it is the family setting which young women want as the main source of sex and relationship learning (46%) with a significant minority of young men in agreement (32%). However, when it comes to families it has been shown that some researchers and educationalists view parents as part of the problem rather than part of the solution; with parents seen as resistant or ignorant rather than fulfilling a role as co-educators. To some extent research supports the rather negative view of parental input in this area. Walker (2001) reports that while sex education provided by parents for their children varies, a common factor is that it is usually unplanned and often avoided. Meanwhile, Powell (2008: 300) in her work with young people finds that information from parents is frequently based on their “unbalanced opinions” which lack “an advisory element” necessary for good decision making. It has also been shown that where there is parental input it tends to be focused on puberty and body changes and issues of risk and safety rather than recognising emotional aspects of relationships and matters of desire or pleasure.

Yet, with limits on the role and impact of school-based learning established the family emerges as an important setting for sex and relationship learning. Framing parents as sex communicators who can have meaningful discussions with their children about all aspects of sex and relationships will allow children and young people to learn about their sexual rights and seek support when faced with the challenges of personal and, in time, sexual relationships. However, in their work Cheng and Udry (2003), discussed earlier, have shown that parents of children with a learning disability are less knowledgeable and less confident about fulfilling this role and so efforts to develop holistic rights-based programmes would be enhanced by taking account of their learning needs as parents.

In terms of where children and young people learn about sex and relationships this chapter has shown that learning is enhanced when it takes place across settings and is not left to formal school-based programmes alone. Powell (2008: 301) recognises that “young people’s information and advice seeking behaviour is haphazard and sporadic… coming across information on an incidental or accidental basis”. For Powell, this tells us that sex and relationship information and advice givers “are best advised to adopt multi-faceted approaches that supplant information in the many and varied contexts that young people inhabit.” In particular Powell highlights that young people’s information and advice seeking reminds us of the importance of “informal areas” and that as well as school a further salient contexts for young people’s learning for sex and relationships is in the family. While the next chapter examines *what* children and young people need to learn and *how* learning for sexual health and relationships can be best facilitated the importance of both formal and informal areas will continue to be explored.

Chapter 6

Sex and relationships learning: *what* children and young people need to learn and *how* to do it

6.1 Introduction

The previous chapter explored *where* learning about sexual health and wellbeing takes place and *who* with; exploring learning in the setting of school and family. This chapter looks further at *what* children and young people need to learn and *how* learning about sex and relationships can be facilitated to ensure that learning enhances sexual health and wellbeing in the context of sexual rights and a life lived with dignity. The chapter will look at examples of new practice in sex and relationships learning in Scotland's schools and it will be highlighted that while new programmes appear to be located in an improved rights or entitlement based framework a note of caution will be struck about an overemphasis on school as the most important location for sex and relationship learning. The chapter is also an opportunity to explore whether *what* and *how* children and young people with learning disabilities need to learn might be different from their non-disabled peers; exploring current developments in theory and evidence and how they might inform a view of the usefulness of ideas such as empowerment, self-esteem, self efficacy and self determination to sex and relationship learning.

Whilst much of what will be explored here can apply to all children and young people the chapter will pay particular attention to the needs of children and young people with learning disabilities. This is particularly important because the needs of children and young people with learning disabilities *are* different. This was made clear to me in the course of my early thinking about undertaking this enquiry and this reflection on an account of a teacher's experience is a useful pointer towards the complexity of the challenges faced and addressed in this chapter.

I was speaking with a teacher in a special school setting where I was able to spend some time with a class of senior students. This teacher gave me a very strong sense of her care and commitment to her students; she had taken a specific interest in their sex and relationship learning. In their final months at school she had developed an in-house sex and relationship programme which the class would follow. The learning was designed to reflect their interests and social experiences. It was evident that the students respected their teacher; they were relaxed in her presence, and open in their conversations about their friendships and relationships. After spending time with the class the teacher took some time to try to explain to me some of the challenges in her work and chose to tell this particular story about the previous year's student group. For a particular group of girls there were increasing opportunities to socialise in clubs and pubs on a Friday and Saturday night where there were disabled and non-disabled peers; these were times when young people had space to meet, flirt and if they chose encounters might lead to sexual activity. Part of discussing this social space and the choices which the young women needed to make included encouraging them to be prepared for sex by carrying and using condoms. Skills to use condoms properly were learned. Several months after leaving school one of the young women returned and informed the teacher she was pregnant having met and had sex with a young man one night at a club. The teacher, admitting that she was disappointed that the information given and behaviours practiced had not been carried through, asked the young woman *why didn't you use a condom, didn't we learn about it*? The young woman replied that yes, she did take her condoms with her on a Friday and Saturday night; but that this had happened on a Tuesday. The young woman had taken on board information, had learned skills, but had only applied them specifically to behaviour on a Friday and Saturday night because the learning had focused on behaviour on those nights. For the teacher, open and honest in her reflection, this experience pressed home the need to think about her practices and ask whether what is currently provided and how it is facilitated is good enough to meet needs.

6.2 Sex and relationships: *what* do children and young people need to learn?

For the most part adults make choices about what children and young people learn in sex and relationships learning programmes and this can result in limitations regarding the content or focus of much school-based learning. When it comes to secondary school programmes Hirst (2004) argues there is an overemphasis on risks of pregnancy and STIs; in essence a framing of sex and relationship learning as being predominantly about having sex, and in turn having sex conceptualised as penetrative sex. This then denies many important areas of learning, including about the emotional aspects of relationships, of other sexual activity, the connections between sex and other influences such as alcohol, having the necessary vocabulary, communication between partners, knowledge of anatomy, expectations around sexual pleasure, knowledge of rights to safety and choice. A young woman contributing to Hirst's (2004: 120) research comments:

> It's like in sex education, you either have sex, as in, with a willy inside ya, or you don't. Well it's not true, there's all sorts going on between that.

Recognising this, Hirst (2004: 126) calls for sex and relationship learning which provides "opportunities for fun, consciousness raising and learning about strategies to bolster self-esteem and achieve aspirations", if this is not provided Hirst fears that young people "leave school poorly resourced to negotiate their journey through to sexual adulthood and with a propensity to take individual (rather than collective and societal) responsibility for any perceived failings". Hirst sets out a broader context for the location of sex and relationship education in the school setting where learning, facilitated by skilled and confident adults, provides:

> ...more time for connecting sexuality to the politics of the body and the variety of ways in which individuals of different genders, sexual orientations, ethnicities and abilities experience identity and practice, and the mechanisms by which they are regulated.

In my own work (TASC Agency 2003b; 2005a; 2005b) I have also heard from young people about their interest in locating sex and relationship learning and the provision of sexual health information, support and services in a more holistic context where 'having sex' is or may be only part of their relationships and sexual health is only an aspect of their health and wellbeing. There is also some professional agreement that sexual health and professional responses to knowledge about sexual activity might be better understood and more coherent if young people's sexuality and sexual behaviour was seen in broader terms. In work I have conducted for NHS Health Scotland (TASC Agency: 2006b: 20) on the theme of confidentiality and its interface with child protection in relation to under 16's sexual activity professionals articulated their concerns about a narrow view of young people's sexuality and sexual behaviour with too much focus on 'having sex' and a concern that all sexual activity is viewed as a negative experience for the young person. In this context one professional contributor proposed that rather than the default position for a service provider to respond with child protection protocols: “We need to focus on getting sex education right, build the confidence and competencies of young people”.

In Scotland’s schools the content of curriculum is changing, with increasing attention being paid to the concerns expressed by Hirst above. In Chapter 5 the SHARE programme was discussed and in the next section other developments are explored and discussed in terms of the role sex and relationship learning has in the promotion of sexual rights and the expectation that personal and sexual relationships should be experienced with dignity.

6.3 Developments in school-based learning

Learning about sex and relationships in Scotland’s schools is now framed by Curriculum for Excellence which promotes the idea that across learning, including learning for health and wellbeing, every child should be supported to become a successful learner, a confident individual, a responsible citizen and an effective contributor; reflecting notions of engagement, participation and social responsibility which can also be found at the heart of human rights instruments and ideas about sexual rights. Curriculum for Excellence also describes the purposes of learning from 3 to 18 and entitlements for all learners, with the language of *entitlement* flagging up the possibility that Curriculum for Excellence might sit well alongside the perspective of human capabilities.

Curriculum for Excellence gives guidance on how and what children and young people learn from the early years to the end of S3, presented through experiences and outcomes piloted in schools in 2008 – 2009 and which have now been published in their final form for implementation in 2010 - 2011. The curriculum is understood to include the ethos and life of the school, curriculum areas and subjects, interdisciplinary learning and opportunities for personal achievement. Curriculum for Excellence structures learning based on 8 areas, including 3 which are seen as the responsibility of all staff; those being Literacy, Numeracy and Health and Wellbeing. The experiences and outcomes associated with each area are written at five levels, many written to span two or more levels with the intention that they should be revisited to ensure that pupils progress individually in their development and learning. The framework is intended to be flexible in order to facilitate planning for those with additional support needs. Levels and stages are described in the table which follows:

Table 1 **Curriculum for Excellence: Levels and Stages**

Level	**Stage**
Early	The pre-school years and P1, or later for some.
First	To the end of P4, but earlier or later for some.
Second	To the end of P7, but earlier or later for some.
Third and Fourth	S1 to S3, but earlier for some.
Senior Phase	S4 to S6, and college or other means of study.

Within Health and Wellbeing six overarching sets of experiences have been identified; one of which is a focus on ‘Relationships, Sexual Health and Parenthood’ which states that children and young people should be able to develop knowledge, skills and understanding of relationships, sexual health and parenthood whilst also exploring and debating values, attitudes and behaviours. Within this learning there is an expectation that pupils should recognise their own identity and develop a sense of self worth with the context of healthy relationships. In order to develop and sustain such relationships it is expected that children and young people will understand the impact of risk taking behaviour on life choices, respect uniqueness and acknowledge diversity. Finally, sex and relationship learning is located in the need to understand the importance of family relationships. Within these overarching intentions there are also a number of more specific outcomes which state that learning must address issues such as commitment and trust, power within relationships, pressure, empathy, choice, personal responsibility and finding help and support.

When it comes to ‘Relationships, Sexual Health and Parenthood’ 33 outcomes are stated, although looking across levels these are often linked and indicate progress and a deepening of understanding and ability to put learning into practice. It is worth taking some time here to explore some examples of these outcomes in order to understand whether this new framework might contribute to an understanding of what social justice means in the lives of young people, particularly those with a learning disability, and how this might be applied to the personal, social and sexual relationships they experience; in other words to clarify whether Curriculum for Excellence can make a contribution to framing an approach to learning which is committed to social justice and a life lived with human dignity. For the purposes of this discussion the following 3 outcomes facilitate some discussion from across learning in early years through to secondary school.

Table 2 **Curriculum for Excellence: Relationships, Sexual Health and Parenthood**

Level	**Example outcome**	**What might this outcome contribute to social justice and human dignity?**
Early/First: From pre-school to the end of P4 but later for some	I recognise that we have similarities and differences but are all unique.	In work on human capabilities Nussbaum (2006: 80-81) identifies the importance of mutual and self-respect. This outcome uses language which promotes an understanding of difference but implicitly challenges any notion that difference means *less than*; it can be argued that difference defined as *uniqueness* is more likely to contribute to feelings of self respect and equality in interpersonal relationships. Further, recognition of similarity and difference lends itself to opportunities for *affiliation*, understood as an entitlement to live and interact with others and to do so free from humiliation and discrimination. In this chapter the role of self determination in the lives of people with learning disabilities will also be explored with an understanding that people should understand their disability – their uniqueness - and its impact on learning, behaviour and their interface with the world.
Second: To the end of P7, but earlier or later for some.	I know that all forms of abuse are wrong and I am developing the skills to keep myself safe and get help if I need it.	Human capability theory argues that every person must be free from violence; that *bodily integrity* is an entitlement for all. Vulnerability to sexual violence and abuse is a particular concern for people with a learning disability and while it is the responsibility of adults and agencies to adequately protect individuals it is also important that people with learning disabilities understand that abuse is wrong, that skills development is addressed to the extent which self protection is realistically possible, and that people know how to get help.
Third and Fourth: S1 to S3, but earlier for some.	I understand and can explain the importance of, and need for, commitment, trust and respect in loving and sexual relationships. I understand the different contexts of such relationships including marriage.	A central human capability is that of *emotions*, understood as the entitlement of the individual to have attachments and to love. Alongside *bodily integrity* with its understanding of the importance of sexual satisfaction this particular outcome also sits alongside aspects of sexual rights language with a right for all persons to choose their partner and to consensual sexual relations. For people with a learning disability this outcome may have particular importance in light of the social isolation and abusive sexual experiences. Delivering this outcome also challenges professionals, parents and carers who seek to deny the experience of personal and sexual relationships.

This has not been a comprehensive exploration of Curriculum for Excellence but has allowed some reflection on whether this flagship policy and guidance sits comfortably with the main interest of this work in locating sex and relationship learning within the context of intuitive ideas about social justice and human dignity. From the exploration above it would seem that this new curricular framework provides a better rights-based or entitlement-based framework for school-based learning than has previously been in place, that this is a framework which reflects the intent and meaning of the language of sexual rights and indeed aspects of human capability theory. The problem is however that this has required some deeper analysis, that the language of Curriculum for Excellence is in itself not explicit enough, and teachers are still required to develop curriculum content, acquire the skills and build the confidence to deliver. As Curriculum for Excellence is implemented across Scotland's schools it is perhaps best thought of at the moment as providing an improved context, with some considerable distance to go regarding delivery.

6.4 Developments in school-based learning: an example from NHS Greater Glasgow and Clyde

In City of Glasgow schools a new sexual health and relationship education curriculum is being rolled out in 2010-11. The development and delivery of the curriculum has been led by health professionals, supported by teacher colleagues. I have good knowledge about this new work because I was commissioned to write booklets which have been produced for every child in P6 through to S6 which capture and summarise key themes and learning and which children can take home both for their own reference and as a means to inform and engage parents. It is helpful to explore the overarching themes of this programme in some detail to understand what a specific school-based programme, developed in the broader context of Curriculum for Excellence, might look like, particularly in relation to the contribution a school based programme might make to pupils' learning about sexual rights and those entitlements articulated in human capability theory. In the primary school there are 4 overarching themes, a further 2 themes are introduced in secondary school; these are discussed in the following tables.

Table 3 **NHS Greater Glasgow and Clyde sexual health and relationships school's curriculum Primary and Secondary school theme:** *Me, Myself and I*

Me, Myself and I	**What might this aspect of the curriculum contribute to sexual rights and human capability entitlements?**
Starts in P1 (approximately age 4 or 5) with the use of proper names for body parts and a focus on the uniqueness of the individual and on feelings and emotions; this continues throughout the primary school years. By P4 (approximately age 8 or 9) children are exploring the life cycle of the baby in the womb and in P5 learn about pre-puberty body changes. Sexually transmitted infections and HIV are also introduced. In P6 and P7 (approximately age 10 to 12) children continue to explore puberty, including periods, wet dreams and personal hygiene. They focus on emotional changes connected with puberty and developing sexuality including attraction to others. In S1and S2 (approximately age 12 to 14) classes are concerned with understanding and building self esteem, confidence and their impact on decisions in relationships. Pupils consider their own values and by S3 and S4 (approximately age 14 to 16) they explore feelings, risks and behaviours associated with sexual relationships and how to manage conflict and pressures. In S5 (approximately age 16 to 17) pupils again focus on self esteem.	Human rights instruments and human capability approaches place an importance on personal and social responsibility. Specifically, human capability approaches identify the value to be placed on good health, particularly good reproductive health, and commitments to understand the feelings and experiences of others. Freedom from violence in personal relationships is articulated as a basic requirement of a life lived with dignity. Throughout this theme – from the commitment to understand the uniqueness of individuals, knowledge about the human body and a focus on understanding feelings and emotions - this work implicitly and explicitly promotes respect for self and others and in doing so promotes good health as a resource for living a life with dignity.

Table 4 **NHS Greater Glasgow and Clyde sexual health and relationships school's curriculum Primary and Secondary school theme:** *Rights and Responsibilities*

Rights and Responsibilities	**What might this aspect of the curriculum contribute to sexual rights and human capability entitlements?**
Starts in P1 and P2 with a focus on keeping safe, this includes that someone close to the child may harm them and encourages children to identify who they can talk to about worries. In P3 and P4 children address bullying and have more discussion about making choices. Work through P5, P6 and P7 continues on the themes of keeping safe in the context of rights to privacy and not being harmed. Strategies to stay safe are explored. In secondary school years S1 and S2 the focus remains on child protection within a rights focus. This includes how their actions can affect others and respect for the right to say 'no' and change your mind. The law and sources of information and support are discussed. In S3 and S4 the emphasis is more explicitly on the law including marriage, civil partnership, consent and discussion of rape.	This theme addresses fundamental human rights to freedom from violence, abuse and fear. The theme contextualises intuitive ideas about respect and dignity through an understanding of legislation and human rights instruments which address these issues.

Table 5 **NHS Greater Glasgow and Clyde sexual health and relationships school's curriculum Primary and Secondary school theme:** *Relationships*

Relationships	**What might this aspect of the curriculum contribute to sexual rights and human capability entitlements?**
Starts in P1 and P2 with identification of who is important in the child's life, including family relationships. In P3 friendships are the focus, as are changes in family situations which can be difficult; loss, separation, domestic violence. By P4 children explore problem solving and seeking help. In P5, P6 and P7 children focus on seeing parents as a source of help and on managing and understanding friendships; with an emphasis for boys on the importance of talking about feelings. The S1, S2 and S3 curriculum explores different types of relationships and the importance of friendship. Assertiveness, communication, negotiation, boundaries, the differences between emotional and physical attraction and delay of sexual relationships are emphasised. S3 includes some single sex class work. In S4 and S5 intimacy, commitment, equality and respect in relationships is explored and sources of support are identified.	This theme recognises the centrality of social relationships; in human capability terms the importance of affiliation. The theme also recognises the need to understand notions of power and boundaries in social relationships; focusing on personal relationships as the site for potential abuses of power. Gender emerges as an important area, with opportunities to work in single sex settings. This theme allows for discussion and learning on what human capability theory refers to as *bodily integrity* with ideas about freedom and opportunities for satisfaction within relationships and *emotions* with ideas about experiencing attachment and love whilst avoiding fear and anxiety.

Table 6 **NHS Greater Glasgow and Clyde sexual health and relationships school's curriculum Primary and Secondary school theme:** *Gender, diversity and equality*

Gender, diversity and equality	**What might this aspect of the curriculum contribute to sexual rights and human capability entitlements?**
Introduced as a theme in P2 where abilities and similarities of boys and girls are considered. In P3 perceptions about gender roles are discussed and in P4 respect and care for others is introduced. Difference is identified including race and disability. By P5 this theme is linked to rights and responsibilities. In P6 children look at media influences and attitudes toward gender. Discrimination and domestic violence are addressed. P7 includes learning about sexual orientation; recognition is given to the fact that some people grow up gay, lesbian and/or have gay/lesbian family members. S1 explore gender stereotypes. S2 and S3 discuss domestic violence, support for those who have experienced sexual harm, and discrimination against lesbian and gay people. S4 learn about the unacceptability of domestic violence and about sex as a commodity: pornography and prostitution. In S5 media images of sexuality and gender stereotypes are addressed.	Again this theme explores gender as a central area in learning for sexual health and wellbeing and so a life lived with dignity. Understandings of gender are linked to broader learning about diversity – including race and disability. Specifically and across the theme learning addresses violence, humiliation and abuse; including sex as a commodity – issues addressed across human rights instruments and captured in human capability ideas about entitlements to freedom from violence and to be valued equally to others.

Table 7 **NHS Greater Glasgow and Clyde sexual health and relationships school's curriculum additional Secondary school themes**

Additional themes	**What might this aspect of the curriculum contribute to sexual rights and human capability entitlements?**
Safer sexual practices In S3 pupils learn about sexual activity and related risks. This includes preventing pregnancy and STI/HIV infection; emphasis is given to male behaviour and responsibilities. In S4 self examination (breast and testicular) and sexual health screening is raised in single sex classes. In S5 pupils visit a sexual health service.	This theme addresses knowledge, attitudes and behaviour which either supports or undermines entitlements to bodily health, personal safety and satisfaction in personal and sexual relationships. Linking learning with external support means pupils are more likely to access adequate health care or resources; intrinsic to human capabilities ideas about life which is lived to the full and not cut short by a failure to access such services.
Becoming a parent In S3 and S4 the role of stable parental relationships as enhancing children's health and development is emphasised as is the role and legal responsibilities of parenthood for men and women. In S4 the impacts of parenthood and good health in pregnancy are discussed.	Whilst other themes focus on an understanding of contraception and safer sex this theme promotes ideas about both the consequences of choices (*not* to use contraception, *not* to consider the impact of a child on one's life) and the need to understand parental responsibility toward a dependent child (protecting their rights). In human capability terms the importance of *practical reason* is emphasised: which entails an entitlement to reflect on and plan one's life. The work undertaken in this theme encourages pupils to consider that becoming a parent needs to be a positive choice.

6.5 Current developments: Overview

It would seem that the SHARE package (discussed in Chapter 5), Curriculum for Excellence and the new NHS Greater Glasgow and Clyde package provide an improved context for learning. The content of these different curricula are wide in scope and attempt to reflect on many of the issues or concerns that children and young people may have, as well as those areas which adults would want to locate in children and young people's understanding, including values and attitudes towards sex and relationships. Whilst these programmes are only in initial stages of implementation they have the potential to be more reflective of Hirst's earlier concern for learning more connected to "the politics of the body" and young people's real experience.

However a note of caution must be struck in relation to any emphasis on school as *the* context for learning around these areas, specifically in relation to the time allocated to the work, the need for evaluation and the importance of expectations which are realistic. As one example, in the SHARE programme 22 classes (of approximately 35 minutes) are to be devoted over 2 school years; schools may chose to deliver over 3 years. The programme targets pupils in S3 and S4, the programme is not located in what may have come before or indeed after. Evaluation of the SHARE materials identifies limits on what can be expected (discussed in Chapter 5). Furthermore, when it comes to enhancements to SHARE which target pupils with learning disabilities there has been no evaluation of the *Enhanced SHARE* materials or of the new *SHARE Special* programme and so while it is certainly possible to be hopeful about their positive impact claims cannot yet be made that they are protective, promoting improved bodily health, enhancing personal and sexual relationships or effectively promoting pupil's with learning disabilities understanding of their sexual rights.

Further, despite the innovative and more long-term approach of the NHS Greater Glasgow and Clyde school programme there are still only 6 lesson plans provided for each of the school years P1 through to S5. Whilst teachers can build on this material and follow up in other parts of the curriculum (as the philosophy and intended practice of Curriculum for Excellence would encourage) it is not clear as whether this will happen. From the analysis undertaken earlier it is clear these materials have the potential to promote children and young people's understanding of their sexual rights and entitlements to bodily health and safe and nurturing personal and sexual relationships; but as yet no evaluation of Curriculum for Excellence or its impact has been undertaken and it is not known if any future evaluation will focus on measuring such issues.

Finally, and perhaps a key concern for any future evaluation of new curricula is the importance of the facilitation of the learning described across these packages. Essentially the packages are a set of lesson plans with supporting material. While each has training associated with it it is not clear what criteria are used for assessing or reviewing the competence of staff to deliver. While pack authors might seek to contextualise their work in an ethos of participation and effective engagement there is no way to drill down to the experience the children and young people have as recipients and we do not know if these packages are or will impact on sexual health outcomes.

6.6 Sex and relationships learning: is *what* children and young people with learning disabilities need to learn different?

Emerging curricula indicate a move toward learning about both physical and emotional aspects of sex and relationships and it is possible to argue, although often not explicit, that the programmes discussed earlier also reflect understandings of sexual rights and intuitive ideas about human dignity in the context of personal and sexual relationships. Young people themselves confirm this interest in physical and emotional wellbeing is necessary; both male and female respondents to the NATSAL survey (discussed in the previous chapter) shows that young adults report that when they were younger they would have liked to have learned more about sexual feelings and relationships as well as STIs and contraception.

It would seem that in Scotland there is an emerging understanding of what the parameters are in terms of *what* children and young people need to learn. Drawing from human capability approaches that support the view that every individual has the same entitlements – based on what is considered all human beings should have rather than judgements about actual, individual capability - this enquiry supports the notion that children and young people with a learning disability need to engage in learning which provides them with the opportunity to achieve the same outcomes as every other child; in this context safe, healthy and happy personal (and when appropriate sexual) relationships. However, this also requires us to explore whether the child/young person with a learning disability requires their programme to be different in any way from non-disabled peers; in other words whether there is anything *additional* which they need to learn, or anything which should be given particular *emphasis.* Whilst on first examination this might seem to imply different or separate programmes which undermine equity of provision or perhaps focus on deficits, on the contrary Terzi (2005: 244-245) warns against “accentuating ‘sameness’ and offering common provision”, that instead it is useful to identify “children’s differences in order to provide for them differently” and in doing so to determine “a just educational entitlement”; in this case to sex and relationship learning. This also matters given that, as established in earlier chapters, young people with a learning disability have been found to have poorer levels of knowledge, that they are often socially isolated, have difficulty in applying knowledge of safe sex or contraceptive use, are at greater risk of abuse, have fewer sexual experiences and that sexual experiences when they do occur are less likely to be pleasurable; indeed that they are less likely to have knowledge and experience of their sexual rights and so to live a life with dignity.

To explore these questions we can be guided by what is addressed in sexual knowledge assessment tools used with people with learning disabilities with the intention of identifying what *knowledge*, *skills* or *attitudes* adults should have, and so we can fairly assume they should be provided opportunities to learn about in childhood and the teenage years. In Chapter 4 the SexKen Intellectual Disability (SexKen-ID) and ASK (Assessment of Sexual Knowledge) assessment tools were described. What we can see from these assessment tools is an interest in building knowledge and skills *and* exploring attitudes, experiences, feelings and needs. To some extent this broad approach is emerging as a feature of some of the current developments in sex and relationship learning but the assessment tools for adults discussed above would suggest that for young people with learning disabilities there is a need to be more explicit in the way sex and relationships learning is envisaged if we want young people to have the awareness of rights and safe, healthy and happy personal relationships in adulthood.

Having established some initial parameters for *what* should be addressed in sex and relationship learning some consideration must be given to *how* best to do it. In the exploration of both evidence and theoretical frameworks which follows ideas about what should be contained within sex and relationship learning, particularly for children and young people with learning disabilities, will be revisited.

6.7 *How* should we facilitate learning about sex and relationships?

In their analysis Wight and Abraham (2000: 26) remind us that young people in Scotland, whose sexual experiences can so often involve coercion and feelings of regret, require "interventions to better prepare young people for sexual relationships" and that to ensure effectiveness these interventions should be "sophisticated, theory driven, research based". However they also identify that currently "little guidance is available on how to translate theoretical ideas into acceptable, sustainable and replicable classroom programmes". While it is implicit in Wight and Abraham's reflection that there is an emphasis on school as *the* place for learning this chapter now looks at what we can learn from the emerging evidence about what supports effective learning for sex, relationships and sexual health in school and in more informal settings, particularly in the family.

A characteristic of much of the debate about professional practice in health education and health promotion has become the drive to ground interventions or programmes in evidence of effectiveness. In recent years NHS Health Scotland have commissioned *Evidence Based Reviews* in relation to the sexual health needs of young people from Black and Minority Ethnic Communities and young people with learning disabilities, both of which I have contributed work to by speaking to young people about what they want from targeted young people's sexual health services (TASC Agency 2005a; 2005b). Learning from evidence about effectiveness is seen as important because, as Mellanby et al (1992: 455) have identified, when it comes to the impact of health education in Britain "there have been few attempts to determine outcomes other than to measure a programmes acceptability". Oakley et al (1995: 160) also observe that sexual health education programmes and interventions have often lacked sound evidence of effectiveness; they conclude that it is imperative to "base social interventions in health care, including health education and health promotion, on sound evidence about which strategies are effective and which are not".

Since this observation extensive work has been undertaken by Douglas Kirby and team from independent body The National Campaign to Prevent Teen and Unplanned Pregnancy in the United States. They have sought to identify the characteristics of effective programmes which promote positive sexual health. This work has been taken up in recent times by NHS Health Scotland[5] to inform developments in Scotland. It is also beginning to inform how sexual health services for young people are evaluated; in 2009 I completed a review of the young people focused sexual health agency Caledonia Youth for Scottish Government (TASC Agency 2009) which used the work of Kirby and colleagues to help frame the approach.

In their work Kirby and colleagues review research findings on the effectiveness of 450 programmes in the United States which seek to reduce teenage pregnancy and/or sexually transmitted diseases (they use the term STD rather than the more commonly accepted term in Scotland, STI). The programmes reviewed may focus explicitly on some aspect of sexuality (such as knowledge, beliefs or attitudes about sex or condom or contraceptive use) or on nonsexual factors such as connections to school or family, or improving educational or career opportunities; some of the programmes explored do both.

In exploring effectiveness Kirby and colleagues have developed responses to two questions: *Which factors influence adolescents' decisions about sex? Which of these factors can be altered?* The intention of the work is to look at whether programmes successfully identify those factors that affect adolescents decisions about sex, and which factors can then be targeted and changed by such programmes. In this process there are useful findings and conclusions which can influence our understanding of what learning about sex and relationships for children and young people with learning disabilities might look like. To return to Kirby's two key questions; in understanding factors that influence decisions about sex Kirby et al (2007) have identified more than 500 risk or protective factors, these are defined as follows:

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[5] 'Promoting a Healthy Respect: What Does the Evidence Support?' S.M. Fraser (2008)

> Risk factors are those that encourage behaviour that could result in a pregnancy or sexually transmitted disease (STD) or, conversely, that discourage behaviour that could prevent them. Protective factors are those that discourage behaviour that could lead to a pregnancy or STD or that encourage behaviour that can help prevent them.

Kirby and colleagues state that an effective programme is successful in efforts to decrease risk factors and/or promote protective factors. Risk and protective factors are categorised by Kirby and colleagues into four themes: *individual biological factors* such as age or gender; *disadvantage, disorganisation and dysfunction* in the lives of the young people or their environments which would include substance abuse, violence or low levels of education; *sexual values, attitudes, and modeled behaviour* including young people’s own values and those of other people in their lives; and *connection to adults and organisations* that discourage sex, unprotected sex or having children. Kirby (2007: 13) identifies that “programmes should focus on those risk and protective factors that they can markedly improve and that causally affect sexual risk behaviour”.

Kirby and Lepore (2007: 2) then go on to consider whether those factors identified can be influenced; and so factors are categorised in three groups as either factors that, for an organisation or programme, are impossible or difficult to change, factors that are difficult unless an agency adopts a special programme or has special capabilities and finally factors “that most directly involve sexuality and reproductive health and are therefore more amenable to change by organisations accustomed to addressing reproductive health”. Kirby and Lepore (2007: 2-3) recognise that “myriad dynamics are at play when it comes to teens’ decisions about sex” and that this “breadth of factors is both good news and bad news: good in the sense that there are multiple avenues that organisations can pursue” and “bad in that the sheer number of factors involved can seem overwhelming”. They conclude that it therefore makes sense that organisations focus on those factors on which it can impact “given its mission and resources”.

Kirby’s extensive review is clear in its recommendations about what should characterise an effective agency-led intervention. In terms of developing the curriculum professionals should draw on their own experience as well as other research and theory, they should assess the needs of the target group, pilot work where necessary, and in specifying the behaviours that their intended programme seeks to impact upon be clear about which risk and protective factors are to be addressed. They identify that topics addressed should be covered in a logical sequence and the planned programme, which must be delivered by trained competent facilitators, should be completed. In terms of goals, objectives or messages to be imparted these should be clear and focus as narrowly as possible on specific behaviours, for example condom use or delaying sex. Situations in which choices will need to be made, and what risk and protective factors affect sexual behaviour, should be discussed. In relation to methodology it is proposed that a range of participatory approaches should be used to engage learners, as much as possible learners should be encouraged to relate directly and personally to the key messages being delivered. Finally, it is also suggested that an effective intervention requires the consent of the learner to participation and that, while engaging, they feel safe.

A problem in terms of conclusions which can be drawn for *this* enquiry is that the focus of Kirby and colleagues is on the impact which *formal, agency led interventions* can make. This is of course helpful when considering programmes such as those delivered in school, or by a specialist sexual health service, but their characterisation of factors which can be influenced as amenable, difficult or impossible can easily be read as being a shopping list from which *only* those factors amenable to change by agencies or formal interventions become *everyone's* policy or practice priorities. Kirby (2007: 14) recognises that "of all the known risk and protective factors, teens' own sexual beliefs, values, attitudes and intentions are the most strongly related to sexual behaviour" but the work lacks consideration of the role of family and community (including informal learning providers) in building those protective factors and addressing those risk factors which formal or professional interventions might find too difficult; or which might be more successful if non-professionals in the child's life were also part of a shared effort. With this in mind it is worth highlighting a few examples from Kirby's work on risk and protective factors to find a role for adults, including family members, who are not part of formal programmes. .

In terms of environmental factors such as *community disorganisation* (which would include violence or substance misuse) or *family disruption* (including divorce or parental separation) these are identified as risk factors for early pregnancy or exposure to STD. Kirby identifies that such factors are extremely difficult for most pregnancy or STD prevention programmes to change; the concern is then that these factors become less important because they are not amenable to change by service interventions, including learning programmes. Regardless of complexity I would argue that these issues need to be *society's* priorities. Families affected by such factors also need to understand the impact they have on their child's sexual health and wellbeing and be encouraged to take responsibility for minimising such risks and building other protective factors; where possible agencies including schools could support such efforts.

Considering individual factors such as *being behind in school* or *having problems at school* or *being part of a gang* or *alcohol use,* again these are all identified as risk factors for early pregnancy or STDs. From the evidence in Kirby's review these are identified as difficult for pregnancy or STD prevention programmes to change but, once again, I would contend they are issues which must concern both families and schools and should form part of work with individual children and young people and with peer groups. As an example, issues of alcohol use are particularly important in terms of work here in Scotland. In my own work evaluating the sexual health service provider Caledonia Youth (TASC Agency 2009) professionals and young people raised the connection between alcohol use and unsafe sexual practices; in broader terms Scotland's relationship with alcohol is very much a current political issue with national debates about minimum pricing and young people's access to outlets which sell alcohol. The complexity and politicised nature of these debates must not result in their importance being ignored or action avoided.

These short examples are intended to recognise that the evidence base on which we can plan, design and deliver formal programmes or interventions has been developed by Kirby's US based team; but the extent to which the role or potential of non-professional adults (either separately or in more integrated efforts) including family members have to play in addressing risk, promoting protection and supporting young people to understand and commit to sexual rights and relationships which are influenced by respect and dignity, are not adequately considered.

6.8 The usefulness of theory and its application to learning about sex and relationships

The work of Kirby and colleagues has established the importance of evidenced based practice when it comes to the development of formal programmes addressing sex, relationships and sexual health. Kirby and colleagues also propose that education should be located within a theoretical framework. Tripp and Mellanby (1995: 276) also identify the importance of drawing on theory in the realm of sexual health and wellbeing so that we might be in a better place to question established practices which have been "dependent on adult thinking, believing that teenagers will base rational behaviour on knowledge".

Wight and Abraham (2000: 26) support the proposal that when it comes to sex and relationship learning there is an important role for theory and they recognise that there has been "a shift away from atheoretical information provision to theory-based approaches". In their early work to develop the SHARE programme, already discussed in this and the previous chapter, Wight et al (1998: 318) sought to formulate a theoretical basis which was "intentionally eclectic" and in doing so they have drawn on the importance of social influences on sexual behaviour, they consider how these impact on the individual's perceptions or beliefs (individual cognitions) and finally, they have used social and psychological research to understand the importance of the social contexts of sexual behaviour. While earlier comment reflected on the SHARE programme Wight and colleagues' work goes beyond that particular programme and offers a theoretical framework for an improved programme of learning which might be considered for children and young people with learning disabilities.

6.9 Challenging the focus on empowerment and self esteem

Before considering the work of Wight and colleagues on how social or psychological theory might help us construct learning for sex and relationships it is necessary to address those concepts which have underpinned the 'atheoretical information provision' which typifies sex and relationship learning to date, what Wight and Abraham (2000: 28) have referred to as the "health education orthodoxy" with a focus on *empowerment* and *self esteem*.

The World Health Organisation Ottawa Charter for Health Promotion (1986) is concerned for "the process of enabling people to increase control over and to improve their health". This commitment to individual and community empowerment has been a powerful influence on sex and relationship education programmes. There are two key principles which underpin empowerment; one that the individual or community defines what is important to them and secondly the individual or group participate in solving that problem. When it comes to applying these principles to learning for sex and relationships Spencer et al (2008: 347) argue that there is much talk of empowerment but much less "analysis of what empowerment might actually mean". Hagquist and Starrin (1997: 225) recognise that empowerment in the school setting is perhaps only aspirational rather than practical with their view that "to some extent empowerment models can be seen as an expression of a search for more successful methods of health education in schools". Spencer et al (2008) agree that the *principles* of empowerment are highly relevant, but as yet have never adequately been applied to *practice* in schools. Rissel meanwhile identifies that although empowerment may be a positive objective its meanings are not well articulated and it is difficult to find evidence that empowerment has a positive effect on health. Rissel (1994: 40) quotes Rappaport's work which states that "empowerment could not be measured, but could only be considered case by case in its own unique context".

In addition Wight identifies three significant problems with empowerment in the context of learning about sex and relationships; while his work does not specifically address the needs and experiences of the pupil with a learning disability it is possible to extrapolate how this focus on empowerment is disabling to these pupils. Firstly empowerment principles require that programme participants state or disclose their needs; Wight argues that this may not always be possible for children and young people if their interests do not fit with what might be acceptable to declare in the context of a classroom (or for that matter family or peer group). Wight (1999: 237) reminds us that "since sexuality involves some of our most private emotions and experiences it requires exceptionally trusting and accepting relationships between people to allow them to disclose publicly what their perceived needs are in sex education". The assumption is that school-based professionals cannot be assumed to have established such relationships with the child. Secondly, Wight recognises that much sex and relationship education is about equipping the child or young person for future situations or choices, and argues that it is difficult for a young person to state what their learning needs *may* be in the future. Thirdly, empowerment implies that the individual or group whose health related concerns have been identified will engage actively in exercises to address concerns, in the case of children and young people learning about sex and relationships this means participation in the classroom. Wight recognises that while some pupils may engage actively, many will not, partly because once again they do not want to disclose experience *or* inexperience. Fundamentally, whilst seeking to ensure that learning for sex and relationships must be grounded in real needs and active participatory approaches, and that learning must make explicit to young people what key messages are, Wight and Abraham (2000: 28) question the efficacy of children and young people identifying the purpose or content of their sex and relationship education programmes.

> The principle that teachers should support students to set their own agendas is frequently alluded to in health education literature. This conflicts with the research based recommendation for standardised behaviour-specific advice.

Empowerment is also a challenging concept for human capability approaches. It would seem that while the idea of empowerment is appealing in that it suggests that the individual or community will have more control over aspects of their lives it is unclear about how this state of empowerment will come about. Further, in terms of empowerment and health it suggests that component parts of a person's life can benefit from the individual 'being empowered' without taking account of other aspects of life. Human capabilities on the other hand is concerned with the totality of the life experience and with specific outcomes for all human beings, bringing a focus on what support or resource is required to ensure that each person is functioning to their maximum capability. To this extent an intuitive idea about human dignity and its application across life is more helpful than an ambiguous concept such as empowerment.

The second key orthodoxy in health education, and impacting significantly on sex and relationship education, has been a focus on raising self esteem. Wight and Abraham (2000: 29) propose that self esteem or a child/young person's "general psychological disposition" is not predictive of health related behaviours such as choices about having sex. While supporting human capability ideas about entitlement, the notion that "a reasonable level of self esteem should be something a child is entitled to" McGee and Williams (2000: 580) also recognise that raising self esteem has become "a psychological immunisation against a variety of societal ills" and "health compromising behaviours" (2000: 569). By examining the literature which looks at self esteem and what might be seen as unhealthy adolescent behaviour, including drinking alcohol, smoking cannabis, problem eating or early sexual intercourse, they find that while a young person may well be involved in a cluster of these behaviours at any time, unsafe sexual activity or early onset of sexual activity in itself is not related to low self esteem. Indeed they highlight that in some studies “those with higher levels of self esteem showed slightly higher levels or alcohol and drug use, and sexual activity, although perhaps this might be expected if these behaviours raised self-esteem”. In human capability terms Nussbaum (2006: 73) also highlights that while it is of value to know “how individuals feel about what is happening to them, whether they are dissatisfied or satisfied” it is also necessary to know and to consider “what they are actually able to do and to be”; pointing us to considerations of how children and young people actually experience life and more useful theoretical foundations for learning which supports a life lived with dignity such as support for self-efficacy and self determination which are now considered.

6.10 More useful theoretical foundations

Having shown the need to move on from a traditional emphasis on empowerment and self esteem Wight and colleagues emphasise the need to look at what psychological and sociological theory can tell us which is helpful in consideration of *what* should be learned and *how* that learning can be supported; specifically considering the influence of social influences on sexuality and sexual behaviour, the importance of individual cognitions and the significance of social context.

Considering the *social influences* on sexuality and sexual behaviour these have been discussed to some extent in the historical perspectives adopted in earlier chapters; Chapter 2 set out some historical context and its relationship to contemporary debates and developments about sex, sexuality and sexual health and wellbeing. Again in earlier chapters the social construction of childhood and sexuality were established and young people’s experience of sexual relationships were described. From Wight et al (1998: 323 - 324) there is confirmation that central to an understanding of sexual relationships are issues of gender and power and they conclude that to promote equality and better understanding, and resist abuses of power, fundamental to human rights perspectives and to sexual rights, we must work with young people to help them to engage explicitly with these issues through discussion about sex and relationships with the intention of engendering a greater empathy and concern for a partner's perspectives.

In discussion of the development of the SHARE programme Henderson et al (2007: BMJ on line) argue that it is the intention to support the development of "negotiation skills for sexual encounters" which sets the SHARE programme apart from more traditional school based approaches. Wight et al (1998: 320) confirm that "extending the world of speech into sexual encounters" makes "communication on such practical issues as contraception and sexual pleasure more likely and more effective". Indeed they argue that communication will require young men to "integrate feminine and masculine perspectives of sexual relationships". Wight et al (1998: 323-324) go on to propose that social level influences of gender and power are not just abstract concerns but that they directly impact on individual understandings and behaviour; that they are "translated into sets of socially shared understandings or cognitions" which inform whether individuals are "more or less likely to engage in particular health-related behaviours".

Moving on from social influences Wight and colleagues also suggest there are a number of specific *individual cognitions* which have a relevant focus for learning. First, they suggest that to behave in certain ways, for example to use contraception or condoms or avoid sex when using alcohol, the young person must have some understanding and belief in their personal susceptibility to risk. While young women would appear to be more aware of risk, for example about reputation or pregnancy, Wight and colleagues are concerned that many young people have a poor sense of risk which undermines how they might develop behaviours to manage or avoid potentially risky situations. Whether young people with learning disabilities face particular challenges in understanding risk will be returned to shortly.

Second, in addition to improved awareness of risk, the individual young person must also perceive the benefits of a particular behaviour and be aware of any barriers to making the better health related choice; for example the young person must believe that condoms will protect them from STIs and any difficulties in accessing condoms need to be considered before sex. Wight et al (1998: 324) highlight that “actions which are thought to be effective, rewarding and having few costs are more likely to be initiated”. Again, the capacity to make such an analysis of benefits and costs may well be challenging concepts for some young people with a learning disability.

Third, Wight and colleagues point to the importance of understanding social approval and disapproval; for example this could point to the value of promoting a positive attitude toward condom use and an expectation that both partners in any encounter are likely to approve of the other stating condom use is expected. In terms of young people with a learning disability this will of course require educators, whether they are a professional person or parent, to be explicit and consistent with the young person about what is approved of or not, and this in turn will require, for example in the context of condom use, that the adult recognises that sex is indeed an option for the young person.

Finally, Wight et al (1998: 325) recognise the role of self efficacy; that “those who believe they have the ability successfully to undertake an action are more likely to intend to take that action and are likely actually to succeed”. Work to foster self efficacy is described as requiring good explanation, the opportunity to see actions modeled by others, encouragement and practice. Wight et al recognise however that in terms of many young people’s sexual encounters it can be difficult for a young person to retain intentions and behave as planned if situations arise which are riskier than intended. A further complexity can be what is termed as ambiguity about intentions. This can mean that, for example, negotiating condom use is left to very late in the encounter because of a lack of stated intention that sex is possibility. For Wight and Abraham (2000: 26 and 29) “control over sexual behaviour depends upon anticipating and managing social interactions in which sexual activity is negotiated” and that “action planning are essential prerequisites of action”. This means that young people need to plan for situations in which sex is or might be an option, and learn to be able to make judgements as situations unfold; particularly as situations unfold quickly. Fundamental then to sex and relationship learning for the young person with a learning disability is to understand and be able to stop, take stock and consider what they might later regret if a particular action or intent is not followed.

In addition to recognising these behaviour specific individual cognitions the new and developing sex and relationship curricula highlight the importance of *social context* and draw on social learning theory. Social learning theory is a key informant of the development of self efficacy, and claims that modelling, discussing and practicing a desired behaviour or attitude supports learning and so attitudinal or behavioural change. However social learning theory is not straightforward. Indeed in relation to learning in peer education its impact is questioned. A peer education programme establishes peers as people with credibility and locates them in an ongoing process where it is claimed other young people feel empowered by what they see, hear and can practice. Through peer education, it is claimed, young people can be supported to develop skills and to resist social pressure to behave in unhealthy ways. However while Turner at al (1999: 235) recognise that "credible peers can influence health behaviour change and can reinforce such changes afterwards" they also state that "with regard to more fundamental claims, evidence for effects of modelling on behaviour is weak". It is perhaps the case that social learning theory is more helpful in the school, family or peer setting where programmes involve both peers *and* adults to support shared learning.

Social learning theory and the work of Wight and colleagues to state the importance of individual cognitions, social level influences and the social context for sexual behaviour challenges educators to develop learning programmes which are different from traditional approaches based on simply giving of facts and focusing on biology and reproduction; and these new approaches can be located successfully in approaches brought to sex and relationship learning by human capability ideas and notions of sexual rights which recognise that gender and abuse of power commonly interface with sexual experience. Bandura (1998: 623) the main author on social learning theory also recognises that approaches to health promotion and disease prevention have changed "from trying to scare people into health, to rewarding them into health, to equipping them with self-regulatory skills to manage their health habits, to shoring up their habit changes with dependable social supports". In other words, sex and relationship learning needs to move from being purely informative or instructive to more evidently relevant and participative with a focus on enhancing and building capabilities to impact on how young people experience their personal (and sexual) relationships.

However, the problem with many current approaches to learning for sex and relationships for young people, Wight and colleagues argue, is that traditional school based approaches have not kept up with this shift and at best they maintain their focus on themes of empowerment and raising self-esteem despite knowing that these are *not* prerequisites of behaviour change. In comparison, interventions which focus on the behaviour specific cognitions outlined above, and create opportunities for facilitated social learning, with a clear articulation of the sexual rights of the individual, would improve likelihood of impact on what the young person is able to choose and then do in the context of relationships.

6.11 Children and young people with learning disabilities: from self efficacy to self determination

In considering both content and approach toward facilitating sex and relationship learning it is necessary to question whether the importance which has emerged and is being placed on developing self efficacy is either straightforward or indeed sufficient for children and young people with learning disabilities; as with questions about whether the child/young person with a learning disability requires anything *additional* which they need to learn, or anything which should be given particular *emphasis*, it is important to consider whether self-efficacy is a sufficient enough an outcome for the child/young person with a learning disability.

Earlier, the goal of empowering children or young people through sex and relationship learning was identified as a traditional aim of health (and so sex and relationship) education but this was questioned because in its use to date it is ambiguous and unproven in its effectiveness on health behaviours. There are, however, other ways of thinking about empowerment; Hagquist and Starrin (1997: 229) propose that if by empowerment we mean “enablement” then “empowerment can be seen as a motivational concept” and as such then adults in school, family or community settings “can contribute by shaping and structuring experience in such a way as to assist young people in empowering themselves”. This might suggest that as educators we need to return to something more fundamental that will put in place the foundations for safer, happier and rights based personal and sexual relationships. In human capability terms this might mean a useful focus on supporting the child/young person to develop and enhance their functioning in key areas, thus enabling the experience of their basic entitlements. However, for children and young people with a learning disability self efficacy, or even this concept of enablement in the realm of personal or sexual relationships, may be unattainable unless we consider a much broader aspiration for learning; this could be thought of as the provision of opportunity to learn personal control or *self-determination*. This will now be examined and using the work of a number of theorists who explore self-determination these ideas will be applied by this enquiry to considerations of sex and relationship learning for children and young people with learning disabilities.

Self determination is about the individual deciding what is best for them rather than being told what to do and so has real value in terms of consideration of sex and relationship learning for children and young people with learning disabilities. For Wehmeyer (2002: online) "self-determined people are actors in their own lives instead of being acted upon by others". A general definition of self-determination is given by Wehmeyer (2002: online) as:

> A combination of skills, knowledge, and beliefs that enable a person to engage in goal-directed, self-regulated, autonomous behaviour. An understanding of one's strengths and limitations, together with a belief of oneself as capable and effective are essential to self-determination. When acting on the basis of these skills and attitudes, individuals have greater ability to take control of their lives and assume the role of successful adults in our society.

Before exploring how this concept of self-determination might look in the context of sex and relationships, Ryan and Deci (2000: 76) have developed a model of self-determination theory which assumes that "humans have an inclination toward activity and integration, but also have a vulnerability to passivity". Their focus then has been to "specify the conditions that tend to support people's natural activity versus elicit or exploit their vulnerability". In relation to this enquiry self determination theory is already helpful in the context of commitments to human rights and human dignity because it is intrinsically positive and does not take a deficit view when applied to people with disabilities.

Ryan and Deci propose that at the heart of self-determination is *motivation*, recognising that people can be moved to act because they intrinsically value or have an interest to do so, or because there is external pressure to do so. Motivation is commonly understood to be an essential part of any learning; writing about teaching for effective learning Learning and Teaching Scotland (2007: 46 - 47) propose that “motivation and achievement are closely linked” and that “the best form of motivation is self-motivation”. In their work Ryan and Deci (2000: 70) state that social-determination theory proposes that *intrinsic motivation* is indeed what we should be interested in when it comes to health and wellbeing, with this being defined as “the inherent tendency to seek out novelty and challenges, to extend and exercise one’s capacities, to explore, and to learn”; this is seen as “essential to cognitive and social development” and “represents a principal source of enjoyment and vitality throughout life”.

In social-determination theory Ryan and Deci are concerned with finding *what* encourages intrinsic motivation to flourish. They identify that there are three innate psychological needs which must be met to ensure self-determination: *autonomy*, *competence* and *relatedness*, these are now discussed. It is suggested that autonomy, or feelings of control, are enhanced by experiencing choice, opportunities for self direction and by having feelings acknowledged. In terms of competence they propose that this is built by positive feedback, but may be undermined if behaviour is purely motivated by external rewards rather than understanding and belief in the benefit for a given behaviour. The third aspect of relatedness is also concerned with a sense of security and positive emotional connections to those around you. With this in mind Ryan and Deci (2000: 71) also propose that “people will be intrinsically motivated only for activities that hold intrinsic interest for them” and that we should not assume that the individual will always have “active personal commitment”. The challenge then, for example in terms of building young people’s motivation to make personal commitments to something like delay of sexual activity or condom use, means adults need to avoid overtly stated external regulation but rather build relationships and strong personal connections which create opportunities for the young person to consider and practice the desired behaviour, and in doing so bring the behaviour into congruence with their other values and needs. Much of what underpins ideas about social-determination mirror the useful theoretical ideas about social and individual cognitions identified by Wight et al and discussed above.

Although their work does not address the specific application of self-determination theory to people with learning disabilities there are elements of Ryan and Deci's work which present challenges for this population. Ryan and Deci (2000: 73) argue that in terms of children and young people's motivation to act in a particular way they must be "developmentally ready" to master or understand what is expected and be able to "grasp its meaning and synthesise that meaning with respect to their other goals and values". Clearly for many young people with a learning disability it will be such understanding and application which poses challenges and which will call for specific learning and teaching strategies to be applied in sex and relationship learning.

The challenge of applying ideas about self-determination to learning for those with a learning disability has been taken up by Hoffman (2003: online) who recognises that "students with learning disabilities face some unique barriers to becoming self-determined". To start, Hoffman recognises that learning disabilities can be 'hidden' in the sense that the individual may not acknowledge their disability either personally or publically, sometimes for fear of stigma. This lack of acceptance or awareness of the strengths and the weaknesses that might result from a disability may mean that the disabled person is inhibited from "self awareness and belief in themselves". In addition a failure to recognise strengths and weaknesses may well leave the individual open to exploitation or abuse. Hoffman then points to "learned helplessness and self-deprecating attributions" and a "lack of a positive, realistic self-concept" as undermining effective and self-determined choices and decisions. Further, Hoffman identifies that for many children and young people with learning disabilities there may have been limited opportunities to build and practice social skills. Finally, children and young people may not have or have had the opportunity to learn executive functioning skills – organising, planning, considering options and initiating a task - to help make decisions and choices.

These challenges point to the need for approaches to sex and relationship leaning which work with the individual with learning disabilities in personalised ways and in programmes which must start before the teenage years when parental or professional anxiety about sexual behaviour might come to the fore. Wehmeyer (2002: online), considering all learning agrees that learning to become self-determined must start in the early years and should be supported throughout childhood and adolescence; this would include providing opportunities for making choices in day to day life, planning, independent learning, considering benefits and disadvantages to decisions, encouraging problem solving, reflection and linking decisions to goals. Field and Hoffman (2002: 115) have also developed guidelines in the form of nine quality indicators which promote self-determination in educational settings and across school communities, which for the authors means not just learning *in* school but (linking to earlier ideas about social learning) recognising that there is a need for a "collegial community for learning" which includes family and community life. In their model self-determination should not just be a goal for the child or young person with a learning disability but for peers and for all the adults in their lives too so that "students' role models demonstrate positive learning experiences about self-determination"; this means that there are opportunities for experiential learning and choice, there is an emphasis on listening to the child, that children understand the consequences of actions and behaviour and that self determination skills are taught explicitly across the curriculum "just as direct instruction is provided for academic skills such as maths, reading and writing". In addition Field and Hoffman (2002: 114) argue that the knowledge, skills and beliefs that inform self-determination can be understood and applied through five steps: "know yourself, value yourself, plan, act and experience outcomes, and learn". It is clear that these steps can be applied to the picture of evidence and theory based learning for sex and relationships which is emerging in this chapter; and would sit comfortably within perspectives drawn from human rights and human capability ideas.

This idea of self-determination adds to notions of self efficacy and can be presented as a key element for learning throughout life, to be established long before young people are making choices and decisions about sexual relationships. Ryan and Deci (2000: 75) propose that social contexts, including contexts for learning, which are committed to development of the basic psychological needs which underpin self-determination – competency, autonomy and relatedness - will "provide the appropriate developmental lattice upon which an active, assimilative, and integrated nature can ascend" but that "excessive control, nonoptimal challenges, and lack of connectedness, on the other hand, disrupt the inherent actualizing and organisational tendencies endowed by nature, and thus such factors result not only in the lack of initiative and responsibility but also in distress and psychopathology".

This chapter has presented self-determination as an outcome for *all* children and young people with learning disabilities. As an outcome it is not something ‘done’ to the individual but a state of being in the world. Wehmeyer (1998: 8) stresses the importance of this conceptualisation of self-determination as an outcome, and not a process, as follows: “Gaining control over one’s life is a process, being in control of one’s life is not but instead a state, status, or outcome”. With self-determination constructed as an outcome the adult concerned with sex and relationship learning (or the provision of broader support for the individual to be an agent in their own personal relationships) can imagine what they are trying to achieve with the individual in mind. But questions may remain as to whether this key concept can and should apply to all regardless of the degree of impairment. It is with this question in mind that self-determination needs to be understood, like human capability ideas, as having a concern for the autonomy of the individual alongside an interest in establishing the conditions which create opportunities which maximise personal control over all aspects of life – education, personal relationships, personal finance, housing, care - and in doing so, promotes human dignity.

To link self-determination to some notion of a fixed idea of individual capacity would be to misunderstand it and suggest that self-determination is simply a set of skills, rather than a right. Like human capability ideas, self-determination, is concerned with human functioning and requires the provision of support or resources which each individual needs to achieve, the best they can, the “general goals” (Nussbaum 2006: 75) which human dignity requires. For some, the support required to maximise their capability for self-determination will be significant. As was discussed in chapter 5 self-determination in the realm of personal and sexual relationships will require those who provide care and support to consider how they can build capacity to consent to sexual relationships; challenging ideas that in adulthood the person with learning disabilities has fixed and limited capacity to understand and make choices about what they want.

Wehmeyer (1998: 11) proposes that “the terms self-sufficient and self-reliant are not typically associated with people with the most significant disabilities, who may need numerous and complex support systems to function as independently as possible”. This enquiry has shown however that education is every child’s right and specifically that education must have a concern for self-determination in the realm of personal and sexual relationships, informed by the idea of human dignity.

6.12 Conclusion

In this and earlier chapters exploring the experience of learning about sex and relationships it has been suggested that when it comes to children and young people with learning disabilities their experience of sex and relationship learning is “more patchwork than pattern” (Tripp and Mellanby 1995: 273). It has however been possible to highlight the range of areas and issues which learning might address; from what might be seen as the traditional interest or focus for sex and relationship learning – puberty and body changes, STIs, contraception – to those which Rosenthal and Feldman (1999: 839) describe as “the more psychological and interpersonal aspects of sexuality” such as dealing with pressure or talking about sexual needs. It has also been possible to recognise that while adults may find it difficult to talk about some of these issues, children and young people themselves want to be able to explore and learn about both sexual feelings and relationships alongside physical development and safety. From an exploration of the tools for assessing sexual knowledge which have been developed in use with adults with learning disabilities it has also been possible to acknowledge that people with learning disabilities need *their* programmes of learning to deal with experiences, feelings and needs too.

A theme running through this chapter has been recognition of the need to draw on evidence and the exploration of theoretical frameworks for sex and relationship education. From work emerging from the United States, from Kirby and team, and in Scotland from Whyte and colleagues, it is now possible to clarify what characteristics learning for sex and relationships might have. This requires us to question established orthodoxy in sex and relationship learning; including a focus to date on notions of empowerment and raising self esteem; instead considering how programmes address risk factors, build protective factors, foster self efficacy and across the life of the young person teach and nurture self determination. It has also been possible to recognise that even in this useful emerging work there is still an overemphasis on formal, agency-led interventions and a lack of consideration of the role and value of learning at home and in the community.

Earlier chapters have reported that people with learning disabilities have commonly been viewed and treated as incompetent, incapable and dependent and as a result sexuality and its expression through personal and sexual relationships has been ignored, denied or controlled. A commitment to enabling lives to be lived with dignity suggests the need to reverse this historical approach and the cultural practices which have shaped the personal and sexual lives of people with learning disabilities. When it comes to the sex and relationship learning it is necessary for integrated and life-long programmes to see all people, whatever their (dis)ability, as individuals for whom the achievement of a maximum degree of personal control is the intention. Pearson (2006: 615) emphasises how this commitment to self-determination applies to sexual choices:

> A sense of personal control may be an important means of empowerment for young people in making sexual choices. Personal control is the sense that outcomes are the results of one's actions rather than the consequences of luck or chance. People who have a high sense of personal control believe they can master and shape their own lives.

The concluding chapter reviews what has been learned across this enquiry and identifies how we might create effective learning opportunities for children and young people with learning disabilities which support them to expect and experience personal and sexual relationships which reflect their sexual rights and entitlement to a life lived with dignity.

Chapter 7

Creating new possibilities: the importance of sex and relationships learning

7.1 Introduction

In earlier chapters stereotypical views on the sexuality of people with learning disabilities were discussed. The consequence of the view of people with learning disabilities as forever children, assumed to be asexual, has been an overemphasis on protection and a denial and repression of sexuality or sexual behaviour. The view of the sexuality of people with learning disabilities as dangerous, informed by eugenics, involved control through institutionalisation, segregation and sterilisation. These stereotypes have provided what McCarthy (1999: 53) calls contradictory but powerful “distorted frameworks” through which the sexuality of people with learning disabilities can be viewed.

However new ideas have had a significant impact; the social model of disability and a commitment to person-centred and individualised services within the community, as well as human rights which encompass sexual rights, means there is now a recognition that people with learning disabilities have both a need and a right to form personal and, if they wish as adults, sexual relationships. Human capability approaches have helped frame the view of this enquiry that living and interacting with others, the experience of love and pleasure, and good reproductive health are fundamental entitlements and their denial is a “violation of basic justice”. (Nussbaum 2006: 155) Addressing the wrongs of the past, in both policy and practice, there is now a more visible commitment to better understand and enable people with disabilities to experience their rights and needs for friendships and relationships. Additionally, rejecting institutionalisation, children and young people with learning disabilities are more likely to grow up in their families and in their communities and be seen as distinct individuals, resulting in what Lofgren-Martenson (2004: 197) sees as an opportunity to create and witness new “social and emotional possibilities for this new generation”.

It is with this ‘possibility’ in mind alongside recognition of the remaining challenges that this enquiry will close. This concluding chapter will establish sexual health as a human rights issue and clarify the view that through human rights, but particularly through the perspective offered by human capability theory, that the provision of sex and relationships learning is a necessary basis for a life lived with dignity. The chapter will emphasise the value in exploring and redefining what we mean by sexual health and wellbeing and the importance we place on it; suggesting that we have placed too much emphasis on deficits and ill-health and have failed in both social policy and service provision (including via opportunities for learning) to see sexuality as a positive aspect of our humanity. This final chapter will also identify that there is an imperative to learn more about the sexual lives and sexual health and wellbeing of people with learning disabilities in Scotland, including from their perspectives.

The central interest of this work is what is provided in terms of sex and relationships learning. While this final chapter will recognise the value of school-based sex and relationship education programmes and will acknowledge that there are some signs of progress in terms of what is provided in Scotland's schools the limits to school-based learning will also be identified and some emphasis will be placed on the role of the family as a setting for learning. Further, this final chapter will stress the imperative to protect *and* to enable people with learning disabilities to live their life to the full, refuting any notion that adequate protection requires a life to be lived without personal and sexual relationships.

The final sections of this concluding chapter draw on learning from across the enquiry and in doing so identify *the characteristics of effective learning about sex and relationships* as well as addressing *the broader role that adults can play* in their role as enablers of safe, happy and fulfilling personal relationships for people with learning disabilities. While these final sections are informed by the evidence and analysis offered throughout this enquiry, they are also underpinned by a commitment to human rights, including sexual rights, and influenced by the perspective of human capability theory which challenges each and every one of us, professional and parent/carer, to consider our role in bringing dignity and social justice to the lives of children, young people and adults with learning disabilities.

7.2 Human rights, social justice and learning as foundations for a life lived with dignity

Goodland and Riddell (2005: 53) state that "social justice provides a basis for identifying that certain people are not getting what is due to them". Nussbaum (1999: 5) goes further and sees social *in*justice as an affront to human dignity; with dignity based on the notion of accepting all men and women as of equal worth "just in virtue of being human". It has been shown across this enquiry that people with learning disabilities have suffered discrimination, abuse and the denial of human (and sexual) rights over time and unfortunately this denial of rights and human dignity continues. In 2007 a report by Mencap, a national learning disability charity, entitled *Death by Indifference*, used a case study approach to describe the experiences of six people with a learning disability who died because of unsatisfactory NHS treatment. Further, in 2008 The House of Lords House of Commons Joint Committee on Human Rights published a report on the human rights of adults with disabilities. Amongst many examples of lives lived short of any notion of human dignity they report examples of service provision in the UK where physical, emotional, environmental and financial abuse continues and where adults with learning disabilities in day and residential services are controlled by over-medication and prolonged use of restraint.

The idea of human rights matters because it locates this enquiry, and any discussion of learning disability and learning about sex and relationships, in an idea that equality and social justice should be guiding principles for the way we live our lives. This perspective helps us shed a problematic view of both learning disability and sexuality; particularly where the sexuality of people with learning disabilities is labelled dangerous, deviant or peripheral. Instead, this work has sought to establish the view that sexuality is a fundamental part of who we are as human beings; it can then be argued that human rights can only be meaningful if they address that aspect of our humanity as much as they do other domains. Further, if we consider human rights as universal and indivisible, then human rights (and so sexual rights) apply *equally* to *everyone*. In 2008 the International Planned Parenthood Federation (IPPF) made the connection between human rights and sexual rights explicit with the publication of *Sexual Rights: an IPPF Declaration*. The declaration recognised that sexuality goes beyond reproduction and includes aspects of human sexuality which it describes (IPPF: 2008: iii) as "fragile, ignored or considered ambiguous by many". The sexual rights which are identified relate to a set of entitlements that "emanate from the rights to freedom, equality, privacy, autonomy, integrity and dignity of all people" (IPPF: 2008: iv); with notions of *entitlement* and *dignity* mirroring the perspective which human capabilities has given to this work. For the IPPF there are specific rights in this area which include freedom from discrimination, the right to bodily integrity, to privacy and to personal autonomy, the right to health, education and information and to be able to marry and to have children.

However an important challenge to the idea of applying human rights equally to everyone, including sexual rights, is when ideas about equality and citizenship (with the citizen understood to be a bearer of rights) are perceived to be for the deserving, for those who have capacity, or those who can prove they posses some notion of 'reason'. As Nussbaum (2006: 16) identifies when it comes to society's basic principles people with learning disabilities are often "not included in the group of choosers" nor are they "included (except derivatively or at a later stage) in the group of those for whom principles are chosen". This ideology goes back a long way and has implications for people with learning disabilities to this day. Stainton (2000: 88) quotes Locke from 1690 who writes:

> But if through defects that may happen, any one comes not to such a degree of reason wherein he might be supposed capable of knowing the law… he is never capable of being a free man… So lunatics and idiots are never set free from the government of their parents.

With this in mind Nussbaum (2000: 97-98) recognises that "the idea of rights is by no means a crystal clear idea" and as such peripheral or marginalised individuals and communities may be excluded from benefits associated with the allocation of rights. In response the concept of *human capabilities* has been helpful to this enquiry because for Nussbaum (2006: 75) human capabilities "give shape and content to the abstract idea of dignity" as well as giving "us a benchmark as we think about what it is to secure a right to someone" (Nussbaum 2000: 98) .

Considering further what we mean by securing rights Lansdown (2009: 19) reports that during the drafting of the UN Convention on the Rights of Person with Disabilities the Chairperson contemplated such issues and "stressed that what was needed was a paradigm shift in the attitudes and treatment of people with disabilities – from seeing them as objects of charity to seeing them as individuals with human rights". Nussbaum (2006: 91) also reflects on this shift and argues that in the application of social justice for people with learning disabilities we must "tap into what is fine in actual human beings", recognise it is our moral duty to make social justice real, and bring to an end a societal response to disability which is based on "duties of charity or compassion" (Nussbaum 2006: 22).

This study has argued that human capability approaches brings a paradigm shift because it provides a way of seeing the lives of people with learning disabilities which is complete, enlightened and focused on outcomes. The theory asks us to consider how every individual human being (indeed in Nussbaum's work every living creature) is enabled to live their life with dignity in a society where justice and an aversion to inequality prevail. Terzi (2005*a*: 448) agrees that human capabilities provides a new framework for our understanding of disability where: "Differences and diversity, therefore, instead of constituting a 'dilemma', have to be promoted and celebrated". In her work on human capabilities Nussbaum (2006: 218) recognises that "human beings are inevitably dependent and interdependent" and that some individuals will require care and support but nonetheless the intention is to "always put the person in the position of full capability".

Specifically, applying ideas of human dignity and social justice to the sexual rights of people with learning disabilities, their rights are equal to the rights of others; in terms of the capabilities described Nussbaum (2006: 188) warns against "tinkering with the list" in any way because through the lens of human capabilities we will know there is fairness and dignity when people with disabilities are able to live their lives to the full, interact with others, have good reproductive health, live free from violence, pain and humiliation, have opportunities for sexual satisfaction and can experience pleasure and love. These entitlements impact on the role, purpose and responsibilities of social institutions in society; be that government, schools, health services, residential institutions or care homes, religious groups and the family. Both human rights frameworks and explicitly human capabilities ideas require that individuals – and for Nussbaum (2006: 216) capabilities should be delivered "to each and every person" - vulnerable to poorer health outcomes, loneliness and isolation, violence or abuse are provided with the support and opportunities they need to experience their life with dignity. It is possible to view human capabilities described by Nussbaum as making a direct demand on policy makers, service providers and parents/carers to see all the capabilities as “important human and political goals” (Nussbaum 2006: 216).

This study has focused on the key area of *sex and relationships learning* and has understood it to be a fundamental right of all children and young people; framing the delivery of this learning as the responsibility of government, family and other social institutions because without learning it is impossible to provide a person with the knowledge, awareness, skills, confidence, expectation and aspiration that is essential to experience the happy and healthy personal and sexual relationships which are central to a life lived with dignity. Drawing on the work undertaken in this enquiry characteristics of effective learning about sex and relationships are explored later in this chapter.

7.3 The meaning and importance of sexual health and wellbeing to the capable citizen

Sexual rights and human capabilities ideas articulate a set of entitlements for every citizen that they should experience happy and healthy personal relationships; for adults this can include sexual relationships. However, the current reality is that sexual health in Scotland today is characterised by problematic rates of unplanned pregnancy, terminations, sexually transmitted infections and feelings of regret associated with first sexual experience. It is easy to understand why Government, service providers and parents might feel overwhelmed. In Scotland it seems that sexual health policy and service responses including sex and relationship learning are primarily a response to the deficits in our sexual health. Subsequently, such a focus reinforces the view that sexuality is merely the problematic act of sex with associated negative outcomes of STI transmission and unintended pregnancy.

With the support of entitlements articulated by human capabilities and ideas of sexual health rights it is time to reflect again on what sexual health means to us and to re-frame what we know and what we want for children and young people; to see sexuality as a positive aspect of our humanity which is with us throughout our life, and to plan accordingly. This enquiry has sought to emphasise that this is especially important for children and young people with a learning disability. This work has identified that young people with learning disabilities have the same hopes, dreams and aspirations as others - for friendship, companionship, love and family - but their experiences are different. Social isolation is common and the knowledge, awareness, language and self-assurance needed to form friendships and personal relationships can be lacking. It seems that parents and professionals can act as a block to experiences which every child and young person should have in their teenage years; having independent friendships, having romantic interests, flirting, dating, falling in love, becoming intimate and, when the time is right, having sex. As a result of our failure to recognise the sexuality of young people with learning disabilities there are consequences into adulthood where Johnson et al (2002) identify, as reported in chapter 4, that "the silence about sexuality and relationships and various prohibitions encountered" can lead many adults with learning disabilities "to have secret sexual lives" which may expose them unnecessarily to unsatisfying relationships, ill-health, exploitation or abuse.

A focus of much of this study has been on learning about sex and relationships - at home or in school - and it has been identified that programmes of learning would benefit from a broader understanding of what sexuality and sexual health means. In early chapters an exploration of the meaning of sexuality and sexual health reminded us that sexuality involves how we think about gender, sexual attraction, pleasure, desire, relationships and (possibly) reproduction. If we accept a broad an inclusive view of sexuality then sexual health implies not just an absence of disease or dysfunction but a sexual life which is safe and pleasurable. With a wider perspective on the meaning of sexuality, and by taking a historical perspective, it has been possible to identify from the work of Foucault and others that our sexuality is socially constructed. As Weeks (1986: 60) states:

> Our sexual identities – as men or women, normal or abnormal, heterosexual or homosexual – are constructed from the diverse materials we negotiate in our life courses, limited by our biological inheritance, altered by contingency, social regulation and control, and subject to constant disruptions from unconscious wishes and desires.

This construction of sexuality takes place in the context of family, where roles and behaviours are modelled for us, and in society where dominant views and norms about aspects of our identity, such as gender and disability, are imposed, questioned and altered. This study has argued that every adult in a child's life can assist in the navigation the child must make in the process of forming attitudes, understanding and managing physical and emotional changes and interacting with others in social and personal relationships. But people with learning disabilities have not yet benefited enough from an exploration and expansion of our understandings about sexuality and sexual health. In my own work, discussed in chapter 5, I found that there were still young people with learning disabilities in Scotland today who had received no formal sex and relationships education at school.

It seems that a legacy of subjugation, and the picture of sexual ill-health amongst many young people in Scotland today, suggests that there is a long way to go before we can support children and young people with learning disabilities to construct positive sexual identities which will see them through life; identities which include a recognition that we are all sexual beings and that we all require the knowledge, skills and attitudes which enable us to engage in relationships (sometimes sexual) which are happy and healthy. For Nussbaum (2010: xv) our failure to see the centrality of human sexuality means that we fail to connect its value and importance to a life lived with dignity, that unless we recognise that sexuality is "intimately connected with a search for a meaningful life" we also fail to see that its "abridgement or legal restriction inflicts profound psychic damage". Connecting the individuals sexuality to their role as the capable citizen Nussbaum (2010: xvi) argues that:

> Equal respect for citizens, many believe, precludes the infliction of such damage on those who simply seek to act on their desires without violating the rights of others.

7.4 The need to know more about the sexual lives and sexual health of people with learning disabilities

This study has evidenced (see chapter 4) that levels of knowledge and skills for relationships amongst adults with learning disabilities fall short of those in the general population (see McCabe et al 1999; Galea et al 2004; Henault and Attwood 2006) and that adults with learning disabilities are more likely to have experienced sexual violence and abuse (see Thompson 2001; McCarthy 1999; and Howlett and Danby 2007). There is also some evidence from the United States (see Cheng and Udry 2005) that the experiences of young people with disabilities, when they become involved in sexual relationships, are likely to be characterised as riskier and less satisfying compared to non-disabled peers.

In recognition of the need for improved knowledge at a national level Scotland's strategy to promote positive sexual health and wellbeing *Respect and Responsibility* (2005) recommended better awareness of the needs of people with learning disabilities and the recognised the need for evidence-informed practice which supports them attain good sexual health. The problem however is that the depth and quality of information about the sexual health and wellbeing of people with learning disabilities in Scotland is sparse; when it comes to young people with learning disabilities even more so. Despite this gap, six years after the publication of *Respect and Responsibility*, services in Scotland still do not collect, analyse or report information about learning disability when recording unplanned pregnancy or STIs. This means we do not know whether young people and adults with learning disabilities are accessing GP or targeted sexual health services with concerns or questions about their sexual health and we do not know, for example, whether with regard to Scotland's increasing number of HIV diagnoses if people with learning disabilities are represented, disproportionately or otherwise.

Beyond the policy focus on unplanned pregnancy and STIs there is some work with young people and adults with learning disabilities being done in the realm of personal relationships and broader aspects of sexual health and wellbeing. This study has drawn on both professional practice and qualitative research; this has helped build an emerging picture of children and young people's experiences, however little of this is from Scotland. Nussbaum (2010: 47) suggests that "equality and equal respect cannot come into being, or long survive, without the ability to imagine the situation of a person in a different social group and to assess it from that person's point of view" and so until more work is undertaken and published about the experiences of people with learning disabilities it is difficult to assert any true claim to equality and respect for people, either individually or collectively.

It has been necessary then, in this enquiry, to draw on what we know about the general population to try to unpack what children and young people know, need and experience. What these elements of this enquiry have shown is that a lack of competence, poor levels of knowledge, a lack of autonomy, gender stereotypes and violence mean that *many* young people often find themselves at risk. In her work, discussed in chapter 4, Maxwell (2007) recognised that young people's sexual relationships may often involve sexual *pressure* as well as sexual *pleasure* and that ambiguity in sexual encounters makes planning and choices complex. If these challenges are present for the general population it is fair to assume that a sense of urgency is required to better understand and tackle the situation for young people with disabilities. While more research on the sexual lives of people with learning disabilities is needed, in the context of an overall picture of poor national sexual health described in earlier chapters and recognised in national policy, this enquiry has viewed this current set of circumstances as an opportune time to consider carefully what children and young people with a learning disability need in order to better equip them for happy and healthy personal and adult sexual relationships; and in particular what sex and relationships learning might look like.

7.5 Learning about sex and relationships: The limits of school, the importance of family

In earlier chapters new sex and relationship education programmes found in some of Scotland's schools have been explored; and it is suggested that progress is being made, with emerging programmes increasingly bringing current evidence and theory to inform the work. But it has also be shown that success of school-based programmes is limited if we are to measure gains in terms of delay of sexual activity, more positive experiences of sex and fewer conceptions or terminations. Part of the problem may well be that that in reviewing the delivery of sex and relationship education in school it has been found that teachers often lack confidence or skills and fail to grasp the importance of active, participative approaches and the value of locating learning in the real, complex and often ambiguous experiences of young people.

Perhaps most obvious is the fact that the time allocated for learning about sex and relationships in school is limited and introduced only after many young people have faced choices and had sexual experiences for which they were poorly informed and prepared. Some developments, such as those developed by NHS Greater Glasgow and Clyde and described in chapter 6, are taking a view which seeks to plan a sex and relationship curriculum across the school life of the child; but there are still only a handful of hours allocated in the course of the school year. When it comes to Curriculum for Excellence there is an identification that learning for health and wellbeing is everyone's business, from early years through to secondary school. In chapter 6 it was possible to show that this provides an improved context for learning, and sits comfortably alongside understandings brought to this enquiry by human capability theory: for example in relation to recognising diversity and uniqueness as strengths, in stressing the importance of knowledge and understanding about bodily health, in identifying all forms of abuse as wrong and promoting the development of skills and empathy for others in the making of choices about relationships and sexual behaviour. However, whilst the new context is positive there is a considerable way to go with development and delivery in the classroom.

The complexities and specifics of sex and relationships learning show that if gains are to be made and sustained it is in the family that much learning can take place, particularly when that learning focuses on building self-efficacy and self-determination. Human capability approaches, informed by feminist theory, help us understand that the distinction between private (the family) and public (school and other institutions) have undermined progress in terms of human rights and the entitlements to attachments, love and pleasure which should inform the experience of social justice in the realm of personal relationships. In reviewing the points which follow shortly, characterising what effective learning about sex and relationships might look like, it is vital that these are understood to be as relevant to the role of a parent as they are to a professional educator. In earlier chapters results from the NATSAL survey showed that nearly half of young women and one third of young men aged 16 to 29 identified that their parents would have been their *preferred* main source of learning about sex and relationships as children; findings also confirm that where young people have had opportunities to learn from school or parents they are more likely to delay first sexual intercourse and use condoms when they do have sex. This can only affirm the importance of the family alongside school.

In undertaking their role as educators about sex and relationships parents and carers themselves would benefit from understanding the importance of their role. This study has proposed that by recognising and valuing their child's developing sexuality and bybuilding their own knowledge, confidence and skills parents and carers will be more equipped to facilitate the communication which will support their child's learning and healthy social and sexual development. For some parents this role may be easy to fulfil; others may require opportunities where they too can learn and be supported. It is essential that professionals with an interest in the sexual health and wellbeing of children and young people with learning disabilities create opportunities to build partnerships and shift the perception that parents are part of the problem rather than part of the solution.

7.6 The imperative to protect *and* to enable

The human capability approach which has informed and shaped this enquiry has been described as having a primary focus on outcomes; in this sense it is a theory of social justice which is concerned with the *experience* of dignity and fairness. This has never been more necessary than when consideration is given to the evidence explored in chapter 4 where the work of Thompson (2001) McCarthy (1999) and Howlett and Danby (2007) confirmed that compared to the general population people with a learning disability are disproportionately affected by sexual abuse. In thinking about creating environments for improved outcomes, the question is where responsibility for this lies and what can be done about it; it would appear that over time, rather than recognising abuse as resulting from the behaviour of the abuser, operating in context of inadequate agency policy or professional practice, people with disabilities themselves have been viewed as passive, weak and lacking in agency. In such circumstances learning disability has come to mean the individual is incapable of understanding and experiencing intimacy and subsequently there has been a failure to take responsibility for protecting people whilst also supporting them to build protective factors associated with knowledge, autonomy and self-efficacy. A view of people with learning disabilities as victims is extended into a view of them as essentially vulnerable and an assumption that they will be unlikely to be unable to consent *at all* to personal and sexual relationships. While progress has been made as a result of de-institutionalisation, community care and personalised services it has been recognised in this enquiry that of all the aspects of quality of life which new professional and societal values and approaches have addressed, sexuality has often been the one area with which families and professionals continue to struggle.

This enquiry has sought to explore the assumptions and practices which have underpinned considerations of the sexuality of people with learning disabilities. Firstly, as Witcher (2005: 57) reminds us “people have multiple aspects to their identity” and “a disabled person is not just a disabled person. In common with others, each also has a gender, a sexual orientation, an age, an ethnic origin and a place of residence”. It is necessary then to avoid seeing people with disabilities as homogeneous, and throughout this study there has been a consistent message about personalising support and opportunities for learning. It has also been recognised however that there is a dearth of research in the realm of the sexual lives of people with learning disabilities, particularly in relation to young people. Whilst on the one hand this is a problem, it has also meant that it has been necessary to look at what we know about the sexual health and wellbeing and the sexual lives of the general population of young people. As highlighted earlier, what this has shown is that vulnerability, consent and sexual competence are issues for *all* young people. Exploring vulnerability and consent (see chapter 4) has shown that competence, agency and personal safety, as well as expectations and understandings of rights, can be addressed and built though programmes of learning at home and in school. It is important then to refute any notion that adequate protection requires a life to be lived *without* personal and sexual relationships.

7.7 The characteristics of effective learning about sex and relationships

In the preface to this enquiry I described myself as an educator, stating a belief that ignorance is unacceptable and that education is a fundamental right. Terzi (2005*b*: 218) agrees that “education is good in itself” and proposes that “being educated, other things being equal, enhances the prospects of engaging in a wide range of activities and fully participating in social life” and so “being educated contributes to a more fulfilling life”. To ensure education provision in the area of sex and relationship learning is as good as it should be, and fulfils the expectations expressed by Terzi, we must also accept the premise, established in earlier chapters, that sexuality is both learnt and socially constructed, and as such “it is therefore theoretically open to change” (Wight et al 1998:

327). To foster the understanding, values and behaviours which underpin positive and respectful personal and sexual relationships it is essential to identify what we can learn from the emerging evidence and from theory explored throughout this work and articulate specific strategies for teaching and learning whilst clarifying the content or focus in learning that such programmes for children and young people with learning disabilities might have.

When it comes to *what children and young people need to learn* the emerging evidence (from young people themselves, discussed in chapters 5 and 6, as well as work emerging in terms of assessment of sexual knowledge described in chapter 4) tells us that *all* children and young people need opportunities for learning about sex and relationships which provide knowledge *and* opportunities to explore experiences, feelings and needs. As identified in chapter 6, this dual focus addresses concerns that sex and relationship learning to date has all too often simply focused on the act of sex. In terms of *knowledge* this suggests providing opportunities to learn the language children and young people need and ensure comprehension about menstruation, puberty, pregnancy, birth, contraception, condoms, abortion, abuse, diversity, gender, masturbation, wet dreams, STIs, ideas about what is private and public, and the law. Considering the *emotional aspects* of what might be learned, programmes would provide opportunities for learning about friendships, romantic relationships, dealing with pressure, desire, pleasure, sexual practices, the influence of friends, safety and making choices and decisions.

With an intention to provide a balance between the physical and emotional aspects of sex and relationships other learning from earlier chapters indicates that adults with a role in supporting the learning of children and young people with learning disabilities can also ensure that learning about sex and relationships considers a number of other key areas now discussed; whilst non-disabled peers might also benefit from what is discussed the focus is firmly on those with learning disabilities.

Firstly, it is important to make some broad observations about *the learning environment*. From their review of the effectiveness of programmes in the United States (discussed in chapter 6) which have sought to reduce teenage pregnancy and/or sexually transmitted diseases Kirby and colleagues concluded that sex and relationship learning is enhanced when it is provided in settings where both young people and adults are comfortable and free from stress; this is more than just about the physical environment, although that matters, but also connected to the quality of relationships between learner and teacher or parent. In research (Douglas et al 2001 see chapter 5) young people have expressed a desire to learn about sex and relationships with adults who are respectful of confidentiality, open to young people's views and non-judgemental.

Wight et al (1998) confirm, discussed in chapter 6, that central to an understanding of sexual relationships are issues of gender and power. It can be argued then, that to promote equality and better understanding, and resist abuses of power (fundamental to human capabilities perspectives and to sexual rights) *young people will benefit from consideration of issues of gender, power, empathy and feelings* with the intention of engendering a greater empathy and concern for a partner's perspectives. Similar issues have also been raised, discussed in chapter 4, by Thompson (2001) and McCarthy (1999) where issues of power imbalance in the sexual relationships and experiences of men and women with learning disabilities points to a need for opportunities for young people with learning disabilities, especially young men, to learn about the exercise of power in sexual encounters. Cheng and Udry (2005) agree that young people with learning disabilities, as a consequence of difficulties with cognitive reasoning and building empathy, need to develop improved awareness of their feelings, the feelings of others and learn about what is and is not acceptable behaviour towards partners.

The extensive work by Kirby and colleagues at The National Campaign to Prevent Teen and Unplanned Pregnancy in the United States (explored in chapter 6) also points to the conclusion that learning and other interventions about sexual health and wellbeing should be *informed by the risk and protective factors which influence young people's decisions about sex*. Kirby and Lepore (2007: 2-3) recognise that "myriad dynamics are at play when it comes to teens' decisions about sex" but nonetheless this complexity must be addressed. Key to this task is effective communication between the adults in a child's life so that they can identify which factors can be altered by whom. In chapter 4 Stevi Jackson (1992: 64) identified an important dilemma in education in this area when she discussed how to "teach children to see sex positively" while "at the same time warning them that it can be used to hurt and humiliate". The work of Hoffman (2003) (also explored in chapter 6) also extends our understanding of the importance of risk and protective factors for the young person who has a disability and so*sex and relationship learning for them would usefully include support to understand their disability, their strengths and where their disability might relate to their personal susceptibility to risk.*

From a reading of the work of Wehmeyer (2002), Ryan and Deci (2000) and Hoffman (2003) it has been possible to point to *the centrality of autonomy, self-efficacy and self-determination in effective sex and relationship learning*. Whilst recognising the challenges faced by learners with cognitive impairments (who may have also learned helplessness) programmes for learning have a role in developing awareness in the child/young person about how their behaviour affects their health and can encourage a belief they can have the health outcomes they desire. Learners need to progress their mastery of skills and see progress is being made by them; fostering pride in their achievements and skills in self management so that they are not always dependent on others. This requires a belief in personal efficacy. It has been learned from an exploration of ideas about self-determination and motivation in chapter 6 that across their lives and from the early years, in all contexts for learning, and in relation to the context of personal and sexual relationships, children and young people with a learning disability would benefit from building a sense and an experience of autonomy and feelings of control, this means having opportunities to be and feel competent, and to have secure and positive emotional connections to others; much of which is reflected in ideas from human capability theory. In further support of these notions Bandura (1998: 635) writes:

> The more capable people judge themselves to be, the higher the goals they set for themselves and the more firmly they remain committed to them. Those who harbour self doubts about their capabilities are easily dissuaded by obstacles or failures. Those who are assured of their capabilities intensify their efforts when they fail to achieve what they seek and they persist until they succeed.

Already alluded to above, but important enough to clarify explicitly, *the young person with a learning disability must see that sex and relationship learning is about them so that through this learning they can connect with their feelings and experiences.* In chapter 6 the work of Field and Hoffman (2002: 114) helped identify that the knowledge, skills and beliefs that inform self-determination can be understood and applied through five steps:

"know yourself, value yourself, plan, act and experience outcomes, and learn". Further, learning about sex and relationships means helping the young person to identify and understand what might stress them in particular social or relationship contexts and understand how this affects their decisions and personal efficacy. Bandura (1998: 627) identifies that: "Most human stress is activated while learning how to exercise control over environmental demands and developing and expanding competencies".

Alongside the characteristics already identified, Henderson et al (2007) and Wight et al (1998) remind us that *young people need the skills and language to negotiate sexual encounters and we need to encourage them to make a commitment to communicate on issues like contraception or sexual pleasure.* Further, Wight and Abraham (2000) also discussed in chapter 6, remind us that *effective learning is set in the complex reality of young people's sexual encounters* where setting or ambiguity can mean that plans and beliefs can be undermined. Young people need to be able to plan for different situations, to be more aware of the dangers of ambiguity, and to be able to see the value of taking time to stop and reflect on what might be unfolding; considering as they do what they might regret if they do not follow through on what they had intended (for example not having sex or condom use). In order to do this successfully educators must take the time and the care to individualise and personalise guidance and feedback; providing opportunities to review and embed learning as often as the individual requires. It is easy to see how this approach might be perceived of as particularly challenging for some professionals or parents because it requires adults to recognise explicitly that young people can find themselves in situations where there are choices to be made about sex.

In relation to the complexity of choice Wight and colleagues (1998) - discussing the development of theory based learning interventions in the school setting explored in chapter 6 – warn against vagueness in terms of the expectations and norms promoted in sex and relationship learning. In other words, *learning is enhanced when the learner is encouraged to understand and consider outcomes and social norms explicitly*. In discussing parent and child communication about sex and relationships in chapter 5 Turnbull et al (2008) also identified that for the adolescent a subtle approach to dialogue on sex and sexual health might not be effective when more explicit or open discussion is required to clarify expectations or norms around sexuality and sexual behaviour. Whether in school or in the family establishing expectations and norms requires reflection and self-evaluation, so that the young person gets to know what leaves them feeling better about themselves, and what does not, leading to the conclusion that *children and young people need to learn what important people in their lives will and will not value or approve of; in other words what boundaries there are.* In understanding these boundaries the child/young person can also then see the reward for them and the social approval which will result in relation to positive health related behaviours (for example condom use or delaying sex). Establishing expectations and norms provides children and young people with the chance to be part of a group that shares values and intentions to behave in certain ways. Within this group opportunities for the young person to see other people like them succeed, and then hear those people tell them 'you can do it too', will support learning.

Finally, in considering sex and relationship learning all *children and young people with learning disabilities require goals* that are not be too easy to achieve, nor set so high that the learner fails every time and so does not develop any sense of personal efficacy. Some setbacks are okay and reflection will lead to learning. Bandura (1998: 634) identifies that: "Goal setting enlists evaluative self-reactions that mobilize efforts toward goal attainment".

7.8 Helping to create healthy and happy personal and sexual lives: what professionals and parents can do

In considering what justice means to all human beings Nussbaum (1999: 8) identifies that while it is "incumbent upon us to develop an account of what is due to people and to their dignity" she also proposes that "the solutions that are proper vary from region to region and group to group" so that "any good solution to a problem must be responsive to the concrete circumstances for which it is designed". This enquiry has used ideas from human capability theory and from human rights to frame the perspective offered. The previous section began with identifying content or focus in sex and relationship learning and went on to identify strategies for teaching and learning; it is also the intention of the enquiry to identify what adults can actually do to support the sex and relationships learning described above.

Firstly it is necessary to acknowledge a gap. While the last thing people with learning disabilities need is further intrusion and judgemental responses to their sexual lives it is impossible to meet the needs of a population of people without understanding what their needs are. We know little about a number of things, *for example*: how young people with learning disabilities first experience sex and whether they are more or less likely to be competent to do so compared to non-disabled peers; the extent to which young people or adults with learning disabilities are accessing sexual health information or services; the degree to which young people and adults with learning disabilities are affected by the year on year rise in sexually transmitted infections; whether the decrease and relative stability in unplanned teenage pregnancy has been the same for young women with learning disabilities and those with no learning disability; whether sexual violence or abuse is or continues (as we have assumed from previous research) to disproportionately affect people, particularly women, with learning disabilities, and if it does what support is accessed by people. *This enquiry concludes that professionals who make decisions about services and research should consider making a commitment to find out more, here in Scotland, about the sexual lives and the sexual health needs of young people and adults with learning disabilities. Once a clearer picture emerges this new knowledge can be used to engage in discussion with people with learning disabilities and with parents and carers, as well as other professionals, about how policy and services (including sex and relationship learning) are designed and delivered.*

This enquiry has recognised that parents, carers and professional people are active participants in the shaping of children and young people's sexuality. As such it can be argued that they have a responsibility to have a clear, rounded picture of what sexuality is; seeing sexuality as an integral part of human life (not just an act) and something that is shaped by those around the child. In exploring the theoretical basis for emerging sex and relationship learning programmes Wight (1999), quoted in chapter 6, has recognised that sexuality is often considered a private aspect of who we are and so to expect the child or young person to be open to discussion or learning about it requires a mutually trusting and accepting relationship to exist. *This enquiry concludes that parents, carers and professional people who are connected to a child with a learning disability will more ably support the learning of the child when they recognise the importance of, and take responsibility for, the quality of their relationships because it is through those caring and loving relationships that they will shape the child's sexuality.*

If we conceptualise parents, carers and professional people as co-educators it is possible to imagine them as co-designers and facilitators of learning programmes where learning at home and at school is integrated. The work of Wehmeyer (2002) on self-determination, explored in chapter 6, identifies that the challenge faced in fostering self-determination for people with learning disabilities means that joint and integrated efforts would bring more benefit if they were started in the early years and supported throughout life. This enquiry has taken these messages and applied them equally to promote an idea that sex and relationship learning can be everyone's responsibility, start early and of course reflect the characteristics of effective programmes identified earlier. Discussion of the parental role in chapter 5, using the work of Rosenthal and Feldman (1999), helped to recognise that the role of 'educator' may seem off-putting and instead it might be more useful to emphasise the importance of parents as *communicators* when it comes to sex and relationships. *This enquiry concludes that children and young people with a learning disability would benefit from every adult in their life understanding what might characterise effective sex and relationship learning. With this in mind adults could usefully review what they have done, make changes, and increasingly put the child at the centre so that there is a plan and consistency across the learner's life course;rather than seeking to deliver fixed time-limited packages or one-off 'sex talks' the role of communicator takes a lifetime.*

The importance of friendships and social connections have also been highlighted in this enquiry. Williams and Heslop (2006: 35) remind us that at the heart of good mental health, and essential for resilience, children and young people need friendships and peer relationships which "can make people stronger and more able to resist the emotional turmoil of moving into adulthood". In this enquiry human capability approaches have also been helpful because they recognise human beings as social, who find "fulfilment in relations with others" (Nussbaum 2006: 85). Yet a striking aspect of what has been reported in this enquiry has been the social isolation and loneliness experienced by people with learning disabilities. In chapter 3 Gerowitz (2007) reminded us that addressing loneliness and building opportunities for personal relationships should be core activities when services consider what people with learning disabilities need. It would seem that it is assumed that the child without disabilities will have opportunities to build friendships that enrich their lives, that these will become increasingly independent, that as the child grows into their teenage years this might begin to involve having romantic interests. However it would appear children and young people with learning disabilities can be denied opportunities to do likewise, meaning they cannot learn the language or skills they need and gain from the experience of social interaction as others do. *This enquiry concludes that in response adults have a central role in supporting children and young people with learning disabilities to have social opportunities which help them prepare for adult life and adult relationships. Tackling social isolation from the early years through to adult life will be most effective when it is a focus of everyone's effort.*

Moving beyond social isolation there is a need to see every child and young person with learning disabilities as capable, as having potential to be an active agent in their lives; to have control. This means providing school, family and community settings within which children and young people do not learn helplessness but instead build awareness and a belief in themselves; essential components of self-determination. Perhaps more challenging is the idea that being a capable person means having and making choices about personal and sexual relationships so that one can experience attachment, love and pleasure. In chapter 4 it was recognised that parents can have general fears about hurt caused to their child when they are rejected by peers or experience cruel language or behaviours but it is perhaps in the realm of choices in adulthood about sexual activity that as a group people with learning disabilities have been perceived of as vulnerable, with capacity to consent considered a fixed trait rather than something which can vary over time and be addressed by personalised support and learning. *This enquiry concludes that to become self-determined the child/young person with learning disabilities will benefit most when adults listen to their views and aspirations, when adults help create appropriate social opportunities, and when they provide support for skills development in areas such as planning, problem solving, weighing up risks and benefits, making decisions and reflecting on outcomes. These skills and the personal belief which will result are a tool for healthy and happy personal and sexual relationships. Furthermore, although a complex and challenging task, where there are concerns about an individual's capacity to consent to sexual relationships it will benefit the young person and adult with disabilities when the focus of those who care is on the context rather than the diagnostic label acquired. Finally, what is clear from the evidence reviewed in this enquiry is that learning in the realm of sex and relationships builds capacity to consent.*

Finally, this enquiry would suggest to the important adults in every child's life that each and every child has much to gain when those adults have an active commitment to the human rights of that child. If human rights are somewhat abstract then Nussbaum and others have described the human capabilities approach as a kind of human rights language but in doing so have articulated a set of entitlements which are explicitly about how a person lives their life. At the heart of the human capabilities approach is the intuitive idea of human dignity and the belief that no area of life is immune from social justice. While Nussbaum (2006: 222) recognises that "the lives of citizens with mental impairments and of those who care for them will continue to be unusually difficult lives" she also recognises that people with disabilities also have "capacities for love and achievement" (2006: 414) and that whatever the degree of individual support and care a person might need, there is no place in a just society for "confinement and mockery" (2006: 220).

This enquiry concludes that the final commitment of the adult is to ask the question: *Is the child or adult I love, care for or provide a service to living their life with dignity?* This question asks parents, carers and professionals to go to the heart of their commitment to the person with learning disabilities, to recognise the person's sexuality and to provide support through their life course in ways which enable them to experience healthy and happy personal and (when they choose) sexual relationships. Nussbaum (2006: 290) argues that "to say that people have a right to something is to say that they have an urgent entitlement to it"; having established the urgency of the claim for the human and sexual rights of people with learning disabilities, which includes opportunities for sex and relationship learning, creating the means and environments which enable the experience of dignity and justice is now, as Wehmeyer (1998: 14) recognises "a matter of will and willingness".

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