

# The Valued Social Role of Parenthood for People with English Learning Difficulties in Britain

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## I. Introduction

Broadly speaking, the topic of the paper is people with English learning difficulties. Parents with English learning difficulties generally have one thing in common. They face a high risk of losing their children. This seems to hold true in all countries with an infrastructure of child protection services (Booth 2000). Recent statistics for England and Wales show that 48.0 per cent of the parents with learning difficulties are not looking after their own children (Emerson *et al.* 2005). Llewellyn and McConnell report that parent will learn difficulties are 15 to 50 times more likely than other

parents in the community to have their children removed and placed in care (Llewellyn and McConnell 2005). There is a widely-held belief that people with English learning difficulties lack the competence to provide 'good-enough' parenting (Booth and Booth 1998).

Concerns about the welfare of children of parents with English learning difficulties are not new. In the UK as early as 1926, the Board of Control was appealing to the welfare of the offspring of marriages between 'mental defectives' to support its opposition to any relaxation of policy (regarding the right to marry) (May and Simpson 2003). Throughout history people with English learning difficulties have been stigmatised. Society did not allow them to have any identity, other than that of having English learning difficulties. Marriage and parenthood are issues that for many people with English learning difficulties carry the promise of an escape from their identity of being learning 'disabled' (May and Simpson 2003). Identities, or 'labels' being placed on a person can have a major impact on how the individual copes or is accepted within society. According to the concept of Social Role Valorisation, developed by *Wolfensberger*, labels, such as having a 'learning disability' can lead to oppression and discrimination (Thomas and Woods 2003). Social Role Valorisation stresses that people with English learning difficulties should be able to occupy socially valued roles within their communities. Parenthood and marriage for people with English learning difficulties can be such valued social roles, and can help a person with English learning difficulties to be assigned and adopt a new identity, a new label. This paper aims to look at developments in society from the perspective of parenthood for people with English learning difficulties as a valued social role. It is based on the belief that the concepts of human rights, valued social roles, and the social model of disability are closely interlinked, perhaps intertwined. They should be the underpinnings of any social education practice with people with English

learning disabilities. In recent times they have become, at least officially, widely acknowledged and enshrined in policies and legal provisions.

## II. Literature Review: Historical Perspective

### 1. Eugenics

Throughout history sexuality and parenthood of people with English learning difficulties have always been notions which society has been struggling to come to terms with. At the best of times they have only been causing discomfort, at the worst of times they have been met with open rejection and even blunt hostility (Oakes 2003). There were times when all the ills of society were blamed on the class of the so-called ‘mental defectives’ (i.e. all persons described as either ‘idiots’, ‘imbeciles’, ‘feeble-minded’, or ‘moral imbeciles’) (Oakes 2003). People with English learning difficulties were described as ‘feeble-minded’ in those times, mainly the early part of the 1900s. This class formed the bottom of society. It was feared that the national heritage of intelligence and ability was being eroded by the ‘feeble-minded’. Genetic decline became something that pre-occupied many, in, what has been called the ‘genetic scare’ or ‘alarmist’ period (Circa 1890-1925), theorists and politicians alike (Wolfensberger 1972). Underlying idea to the considerations of the time was, what has become known as ‘Social Darwinism’, ‘Social Darwinism’ claimed that the human race depended on a healthy pool of genes, which could be contaminated by English learning difficulties and any form of deviant behaviour. The genetic threat to society was reportedly inherited. It was compounded by alleged sexual hyper-activity of people with learning difficulties (Oakes 2003). Particularly women with learning difficulties

were thought to be promiscuous, immoral, and likely to produce large numbers of children similar to themselves (McCarthy 1999). The perceived necessity to stop the 'feeble-minded' from reproducing led to the formation of an 'Eugenics Movement'. It was to introduce and promote measures and legal provisions to stop the procreation of the 'feeble-minded'. Eugenics basically refers to ways of achieving a population, which ideally consists of a 'healthy' and 'genetically desirable' stock only. In a nutshell eugenics is about deciding who should be born, who should die, and who should reproduce. The term 'Eugenics' stems from the Greek word 'eugenes' for 'well born'. Interestingly the idea of eugenics was developed by Charles Darwin's cousin Francis Galton (Oakes 2003). Eugenics can take two different shapes: 'Positive' eugenics and 'negative' eugenics (Priestley 2003). 'Positive' eugenics promotes the procreation of what is considered to be the most desirable in society. The methods it uses are for instance selective breeding or artificial insemination. 'Negative' eugenics seeks to reduce the procreation of what is considered to be the least desirable in society (e.g. through forms of birth control including sterilisation, through abortion, or through segregation of the sexes). Both 'positive' and 'negative' eugenics use a systematic approach, take systematic measures, whether decisional or programmatic, to achieve the intended outcome (Atherton 2004). People with English learning difficulties have been subject to 'negative' eugenic measures in any way possible. In the past, depending on where they were living, they have been subjected to mass sterilisation programmes, strict segregation of the sexes, or indeed mass killings as well. In today's society there is an ever-present threat to their very existence due to the possibility of detecting genetic defects even in the unborn child by genetic screening during pregnancy. In the UK unborn children with a 'serious disability' can even be aborted until the pregnancy is at full term (Oakes 2003). It has been

argued that eugenics today, though remaining potent, operates more by stealth (Richardson 2005). Abortion laws, which allow the abortion of disabled foetuses until the pregnancy is at full term, are clearly a very obvious form of eugenics. As already mentioned, in the past the eugenic measures which people with English learning difficulties were subjected to, depended to a large extent on where they were living. However regardless of their residence for people with English learning difficulties there was no way of escaping at least some form of eugenic measures. Segregation of the sexes and institutionalisation were experiences shared by people with English learning difficulties in many places around the world. A number of countries had, on top of segregation and institutionalisation, programmes for the involuntary and compulsory mass sterilisation of people with English learning difficulties.

## **2. Eugenics in the Britain**

In the UK, despite being the birthplace of eugenic ideas, and despite the UK being a significant contributor to their advancement, segregation and institutionalisation were not superseded by more extreme eugenic measures, such as sterilisation. There were people with English learning difficulties who were sterilised, but the concentration was clearly on institutionalisation (McCarthy 1999). That sterilisation as a eugenic measure was ultimately rejected does not mean that its introduction had not been attempted by its proponents. In fact the possibility of introducing eugenic sterilisation was discussed on two separate occasions.

The first occasion was the debate about the Mental Deficiency Bill (1912). The sterilisation (in this case voluntary sterilisation) of 'mental defectives' had been among the proposals in the bill. The notion of curtailing people's human liberties through the backdoor of voluntary

sterilisation was something that many backbenchers could not get accustomed to (Atherton 2004). For that reason the bill was to be met with their strong opposition. The government was forced to remove the sterilisation clause. The bill laws then eventually passed in 1913, as the Mental Deficiency Act (1913). The Mental Deficiency Act (1913) was the first comprehensive legislation to control the 'feeble-minded' in the world (Walmsley 2000). It was to determine the fate of people with English learning difficulties in the UK for nearly 50 years, until it was eventually superseded by the 1959 Mental Health Act. Eugenic sterilisation as an object for political consideration re-appeared on the agenda in the 1930s. Since the 1920s, the eugenicists had started to campaign for compulsory sterilisation of what they termed the 'unfit to breed' (Richardson 2005). Following the Mental Deficiency Act (1913) the Board of Control had been set up. The purpose of this new government department was to administer all mental health care. In June 1932 its chairman, Lord Brock, had been commanded by the government to set up and steer a Departmental Committee to look into ways of how best to manage the control of birth by people who were considered 'mentally deficient'. In 1934 the committee presented its findings in the Brock Report. The Brock Report clearly endorsed sterilisation, though not as a compulsory measure, to manage the control of birth by the 'mentally deficient' (Thomas and Woods 2003). That was certainly less than what the eugenicists had hoped for. Since compulsory sterilisation was rejected by the Brock Committee, they were forced to change their tactics and were henceforth campaigning for voluntary sterilisation. By that time the Nazis in Germany had already started with their mass compulsory sterilisation programmes (and the mass killings of people with learning difficulties), and the mass involuntary sterilisations in the United States were also well under way. Witnessing that happening made support for sterilisation dwindle in the UK. Support

was further weakened by emerging doubts as to whether 'mental defect' was actually hereditary or not (Digby 1996).

Though, as we have seen, there has never been any legal endorsement of mass sterilisations in the UK, unlike in other countries, sterilisations were certainly carried out. The extent to which these were carried out is difficult to identify, and whether they were voluntary or compulsory even harder to establish (Thomas and Woods 2003). Sterilisation, though not in a eugenic sense, returned to the agenda in the 1950s and 1960s. This time the discussion was based upon women's right to a life free from the burden of childbearing. Sterilisation as a means of birth control would basically have to be voluntary, but in the case of the woman concerned being deemed to be incapable of caring for offspring due to English learning difficulties, sterilisation could be enforced (Richardson 2005). Concerns about the care for the offspring of people with English learning difficulties, rather than the previous concerns about the 'genetic decline' of society, began to dominate the discussion.

In the UK sterilisation has never been accepted as a viable means of stopping the procreation of people with English learning difficulties. Instead the preferred eugenic method was segregation. Segregation through institutionalisation had been the key recommendation of the 'Royal Commission on the Care and Control of the Feeble-Minded' in its final report, published in 1908 (Atherton 2004). The commission had been established in 1904 to investigate the problem of the 'feeble-minded'. The Mental Deficiency Act (1913) formed the legal basis for the segregation of the sexes by institutionalising men and women with English learning difficulties. The Act placed a duty upon all local authorities to certify 'mental defectives' and set up certified institutions (Thomas and Woods 2003). Under the Act 'mental defectives' could either be placed in an institution for an indefinite period, placed with a suitable guardian, or

placed under statutory supervision, subject to quarterly visits from an agent of the local authority (Walmsley 2000). There was no legal right to petition against continued detention, and inmates often stayed in the institutions for life. The institutions were usually found in isolated locations, away from the rest of society. Within the institutions the sexes were strictly segregated from each other. Segregation of the sexes took place in all aspects of life. There were separate wards, during the day there was separation at work, and after work the sexes were strictly segregated when socialising (Thomas and Woods 2003). Institutionalisation in the UK took place in large numbers. Exact numbers appear not to be known, but it is estimated that in the first half of the twentieth century there were at least, 60,000 people with learning difficulties in the UK, who were institutionalised (Richardson 2005).

### **3. The Age of Normalisation**

With the end of the era of fascism came the end of Social Darwinism as a notion (Oakes 2003). Eugenic ideas started to be in decline. The eugenic fear that people with English learning difficulties would reproduce a large number of genetically inferior offspring was eventually discredited (Llewellyn and McConnell 2005; Rifai 2010). Instead of eugenic ideas notions of human and civil rights began to become an important factor. The human and civil rights of their citizens were an emerging concern in many different societies. Eventually these concerns started to have an import on the situation of people with English learning difficulties as well. From the 1950s onwards policies based on institutional segregation and the marginalisation of people with English learning difficulties were increasingly questioned (May and Simpson 2003). Institutions were more and more seen as places of incarceration, which are denying people with



English learning difficulties their individuality and basic human rights (Atkinson and Walmsley 1995; Rifai 2010). Interestingly Denmark, which had been at the forefront of eugenic sterilisation policies in Europe, became the first country to take steps to overcome this seemingly abnormal situation. The concept of what was to become known as 'normalisation' was first introduced in the Danish Mental Retardation Act 1959. It emphasises access to lifestyles that are valued by society as a whole for people with English learning difficulties. Normalisation has been defined as: "A concept that focuses on people with learning disabilities being able to live and function within the same structural norms as the rest of society" (Thomas and Woods 2003: 65). Clearly, according to normalisation people with English learning difficulties are entitled to, and are supposed to have, a full life, just like people with no English learning difficulties, a life considered 'normal' by society's standards. Services for people with English learning difficulties are supposed to be there to give them the support they need in order to achieve the life they want.

The initial concept of normalisation, as it was developed in Denmark, focuses on the aspects of housing, education, work and leisure conditions in the lives of people with language learning difficulties (Atherton 2007). Other aspects of life, such as sexuality and parenthood, were later added to the concept. The UK took the first step towards ending the abnormality of life in the institutions in 1959 with the passing of the Mental Health Act, the successor of the Mental Deficiency Act 1913. The Act ended compulsory certification, and hence provided the means by which individuals with English learning difficulties who were detained in institutions for no legitimate reason could be discharged and return to the community (Atherton 2007).

By the mid-to late 1960s attitudes toward sexual relationships of people with learning disabilities started to change (Oakes 2007). The 1970s saw

the emergence of an increasing research activity covering the topic of personal relationships and sexuality of people with English learning difficulties. According to Oakes (2007), In the UK two landmark studies on marriages of people with English learning difficulties in 1993 were published. Both findings were predominantly positive about marriage as a choice and lifestyle for people with English learning difficulties (McCarthy 1999). A form of companionate marriage was clearly favoured by the advocates of people with English learning difficulties at that time. The importance of close personal relationships for people with English learning difficulties became more and more accepted in the 1970s and 1980s. Parenthood of people with English learning difficulties, on the other hand, was still something that even staunch advocates of people with English learning difficulties seemed to find difficult to make the case for. Wolfensberger was certainly one such staunch advocate for people with English learning difficulties. In the 1970s he developed the concept of normalisation further and came up with the following definition: "The utilisation of means which are as culturally normative as possible, in order to maintain personal behaviours and characteristics which are as culturally normative as possible" (Wolfensberger 1972: 28).

His considerations regarding the sexuality of people with English learning difficulties were based on the belief that sex is a biological necessity and that sexual relief is a paramount importance. He saw sexual expression as a right, and argued that it was simply not fair to expect certain groups in society to remain celibate. Interestingly for him the right of sexual expression was only applicable to heterosexual relationships, not homosexual relationships (Wolfensberger 1972). Parenthood of people with English learning difficulties was seen as fraught with too many risks and demands, and hence refraining from having children was seen as a necessary condition for people with English learning difficulties to have a

successful heterosexual relationship. Perhaps because it has been denied or at least severely restricted to people with English learning difficulties for such a long time, sexuality subsequently became a key concept in the process of normalisation (Aunos and Feldman 2002).

The right of people with English learning difficulties to lead a 'normal' life was at the same time also acknowledging on a very different level. The 1970s saw the adoption of two landmark declarations by the United Nations. The first one was to 'Declaration on the Rights of Mentally Retarded Persons 1971'. S.1 of the Declaration states: "The mentally retarded person has, to the maximum degree of feasibility, the same rights as other human beings" (<http://www2.ohchr.org/english/law/res2856.htm>). Also the 'Declaration on the Rights of Disabled Persons 1975' appears to be guided by normalisation principle, stating in S.3: "Disabled persons have the inherent right to respect for their human dignity. Disabled persons, whatever the origin, nature and seriousness of their handicaps and disabilities, have the same fundamental rights as their fellow-citizens of the same age, which implies first and foremost the right to enjoy a decent life, as normal and full as possible" (Degener and Koster-Dreese 1995: 374).

The 1980s saw a broader and more developed discussion about the sexuality of people with English learning disabilities (McCarthy 1999). Parenthood as a right for people with English learning difficulties finally emerged on the agenda. Parenthood of people with English learning difficulties had more and more become a fact, and was more and more recognised as such. Deinstitutionalisation and community care had created a climate that made it possible for the first time to give serious consideration to parenting of people with English learning difficulties (May and Simpson 2003). Wolfensberger (1972) re-thought the concept of normalisation, and came up with a successor for it, which he called 'social role valorisation'. Social role valorisation refers to the creation, support

and defence of valued social roles for people at risk of devaluation.

### III. Sexuality and Parenthood of People with English Learning Difficulties as Valued Social Roles

#### 1. Society's Attitude

In the past society always had a negative and stigmatising attitude towards the sexuality of people with English learning disabilities. Perceptions were centred around two completely contradictory myths or stereotypes (Drury *et al.* 2000). According to the first myth, people with English learning difficulties were 'sexless', had no sexual feelings whatsoever. According to the second myth, they were 'sex mad' and sexually promiscuous, had an uncontrolled sexuality. It, as an either way, was thought that their sexuality needed to be controlled. Society needed to be protected from the sex mad people with English learning difficulties, the sexless people with English learning difficulties needed to be protected from all the sex going on in society. To protect society from the sex mad, they were institutionalised and segregated. To protect them in their sexless, they were deliberately kept ignorant about sex.

According to Priestley society's attitude today is still influenced by those two myths (Priestley 2003). People who are not familiar with the lives of people with English learning difficulties, despite community care still the majority in society, still often believe that people with English learning difficulties do not have sexual feelings. However sexual feelings of people with English learning difficulties are certainly undeniable for

those who have significant contact with them, like their carers for instance (McCarthy 1999). They were considered to forever have the mind of a child. They were associated with child like interests and pursuits and often treated as if they were children. As sexuality was, and is, linked to adulthood, they were assumed being sexless. Much of that belief still prevails in society. Individuals with English learning difficulties are still regarded as non-adult in any intellectual, psychological or social sense. People with English learning difficulties are for instance often allocated 'mental ages' by professionals, which have then accepted by judges and other lay persons in their judgments and decisions about people with English learning difficulties (Jenkins 1989). The allocation of 'mental ages' affects the sexuality of people with English learning difficulties in ambiguous ways. On the one hand it certainly protects them from the risks of sexual abuse. On the other hand it can make it impossible for people with English learning difficulties to have sexual relationships at all. In order to be able to enter into a lawful sexual relationship people with English learning difficulties need to have the capacity to consent. As people with English learning difficulties are generally deemed 'vulnerable', with limited or no capacity to consent to any act of a sexual nature, the law, in the UK the Mental Capacity Act 2005, is ever present to oversee and regulate their sexuality. It has been argued that the law, instead to protect the 'vulnerable', as it is set out to do, often protects society from the vision of people with English learning difficulties having a sexual person (Evans and Rodgers 2000).

Sexuality and parenthood are culturally significant markers of adult social status (Priestley 2003). Adulthood is a complex and multi-faceted social identity (Jenkins 1989). Adulthood is also a social construct. In modern Western societies it is often linked to notions of independence, competence and autonomy (Priestley 2003). People with English learning

difficulties are typically dependent on support in their daily living, they have to prove their capacity all the time, and their autonomy is limited in many ways. In other words, adulthood constructed in such a way is hard to achieve for them. Rights are in many ways linked to adulthood. In order to enjoy all the rights in a society one has to be a citizen of that society. Citizenship again has been closely linked to the same notions of independence, competence and autonomy already mentioned, and claims to rights by people with English learning difficulties have been widely contested on the grounds that they lack the independence, competence and autonomy required to be accorded adult status (Priestley 2003).

Wolfensberger (1972) argues that the sexuality of people with English learning difficulties makes other people uncomfortable. He identifies five prominent reasons for it: (a) sex, which might result in impaired offspring; (b) people with more severe impairments would be inadequate parents; (c) severely disabled people are not seen as fully human, and can therefore not marry; (d) people reject socio-sexual or marriage relationships other than one they can imagine for themselves; (e) people with severe English learning difficulties are arguably not capable to meet certain standards required for marriage, i.e. they are not capable to give an intelligent, meaningful consent to a marriage-type contract. Regarding the possibility of parenthood of people with English learning difficulties and its acceptance, Wolfensberger (1972: 84) is very sceptical: "The North American public will not now approve, and probably never will, childbearing by those unlikely to be capable of child rearing. The same stipulation would probably apply to most other societies". His scepticism obviously has to be seen in the North American context, but with regard to the UK still widespread reservations have been identified as well. Drury *et al.* (2000: 129-130) write: "The idea that people with learning disabilities might reproduce themselves, that is, become parents (possibly having a

child who also has learning disabilities), still raises concern (despite some progress has been made in valuing people with learning disabilities as precious individuals in their own right)".

Both comments show that society, both in North America, and in the UK, still appears to be way off any acceptance of parenthood of people with English learning difficulties. Interesting is the difference in the underlying reasons, lack of ability of child rearing on the one hand, and people with English learning difficulties reproducing themselves on the other hand. The myth that people with English learning difficulties will always produce off-spring with English learning difficulties is clearly disproved these days (Sellars 2002).

## **2. Attitudes of People with English Learning Difficulties Themselves, Their Parents and Their Carers**

Faced with those afore mentioned myths and stereotypes, one would imagine that people with English learning difficulties find it hard to feel good about their sexuality (Mirandola *et al.* 2011). The picture yield by research is not clear. Some studies such as McCarthy (1999) and Priestley (2003) show that people with English learning difficulties have the same sexual needs and desires as persons without English learning difficulties. Aunos and Feldman (2002), based on research on the attitudes of people with mild English learning difficulties towards marriage and parenthood, came to the following, rather mixed findings: "A majority of people with mild leaning disabilities (60% to 90%) want to marry and raise a child".

In some cases, on the other hand, adults with English learning difficulties still hold negative attitudes towards sexuality and sexual relationships. In the cases of older adults, that might come from having been deliberately 'kept in the dark' in the institutions. Sex education for

people with English learning difficulties has never been on the agenda until the 1970s (McCarthy 1999). However young adults with English learning difficulties, particularly when at the transition to adulthood, can also sometimes not imagine, or do not want, to get married and have children of their own (Barnes 1997). Their parents' attitudes, who often avoid talking about sex with their disabled children, may have something to do with that (Aunos and Feldman 2002). Community care has certainly opened up more possibilities for young people with English learning difficulties to form relationships and have sex (Atkinson and Walmsley 1995). In comparison to their non-disabled peers, though, these possibilities are still limited (McCarthy and Thompson 1995). Young people with English learning difficulties are taking up the possibilities, which are there, and they indeed do form sexual relationships (Priestley 2003).

That appears to be the case even within the confines of repressive institutions, not only today but also in the past. There have always been people who found ways to overcome the deliberate institutional policy of separation, and meet. Even restrictive and punitive practices in the institutions failed to deter the more determined inmates. Rarely, nonetheless, did they manage to beat the system to the extent of being able to establish anything like normal adult relationships (May and Simpson 2003). Parents of children with English learning difficulties generally feel uneasy towards and attempt to restrict their child's sexual expression (Aunos and Feldman 2002). They avoid talking about sex with their children, which often leads to their child not receiving adequate information on sexuality. Many parents try to exert maximum control over their child's sexuality. However with growing age the child's sexuality becomes less and less controllable. Some parents see the uncontrollability of their child's sex as frightening. In the past their lead many parents to notification of their child to the authorities under the Mental Deficiency Act 1913,



particularly often in the case of girls (Thomson 1996). The development of their child's sexual interests was a shock for many parents, and their felt that the institutions were better equipped to deal with it.

Parents' attitudes towards their child's sexuality are very ambivalent or restrictive, particularly in comparison to those of the child's professional carers. That has been linked two factors: The much greater emotional bond and their tendency to take a much more longer-term view (McCarthy 1999). Many parents see only problems when they think about their child's sexuality (Drury *et al.* 2000). Their children need and desire play if a role at all, then only a minor one. Parents can imagine and would support their son or daughter having a close loving relationship (Barnes 1997). However as soon as the relationship become of a sexual nature, their support wanes. Parents' concerns are greatest, when it comes to their son or daughter becoming parent. Most parents cannot imagine their son or daughter having children of their own, and some are very opposed to the idea (Barnes 1997). Aunos and Feldman even quote a figure of 75 per cent of the parents of children with English learning difficulties being against their child having children of their own. Children are usually seen as creating pressures that their sons or daughters would not be able to cope with. They fear that eventually they would have to care for their son's or daughter's baby because of his or her inability to do so (Drury *et al.* 2000).

The picture when it comes to the attitudes of professional carers towards sexuality and possible parenthood of their service users is a mixed one. Services have come from an approach of utter denial and repression of their users' sexuality to an approach, which is more focused on the management of service users' sexuality. There is certainly an element of control left in service provision. Services remain reluctant to enable people to take their own decisions and act upon them in respect of sexual and

personal relationships (Oakes 2003). Heshuisu (1987) reports a “continued authoritativeness” in the group homes and normalised settings with regard to residents’ sexual expression. Service users’ sexuality is limited to what can be supervised and therefore observed in public. Privacy, which is so vital for a meaningful sexual expression, is rarely granted. The risk of relationships between service users becoming abusive, and possible legal repercussions for staff and management, who have a duty to care, are perhaps, at least to some degree, responsible for this cautious approach. A certain caution can also be observed in the approach to sex education for people with English learning difficulties. It increasingly takes place, but emphasis still is on teaching service users how to ‘cope responsibly’ with their sexuality, rather than on introducing them to a part of human life, which is vital and essentially positive.

Attitudes of staff of residential institutions and group homes have certainly become more progressive towards an acceptance of a social-sexual life for the persons in their care. Most of the staff working in services for people with English learning difficulties accepts the sexual needs of their clients. However there are still remnants of negative attitudes left. Two separate, but connected, movements have been identified as responsible for the change (McCarthy 1999). The first one is the development of a more liberal and open attitude towards sexuality in society generally since the 1960s. The gradual adoption of the principles of normalisation in English learning difficulty services, which includes opportunities for sexual expression, has also played its part. Certainly not to be underestimated is the widespread availability of effective contraception in recent times. Parenthood of people with English learning difficulties appears still to be something difficult to come to terms with, despite all the progress, which has been made in English learning difficulty services. McGaw (1997) state: “The concept of people with English

learning disabilities becoming parents and being responsible for children tests the ideologies and philosophies of the most progressive services within our communities". The widespread availability of effective contraception means that people with English learning difficulties, like anyone else, can have sex without inevitably having children.

## IV. Social Role Valorisation for Parents with English Learning Difficulties

### 1. Social and Individual Model of Disability

Besides the paradigms of normalisation and social role valorisation, human and citizenship rights, there is another paradigm, which is highly relevant in order to explain and understand the processes around sexuality and parenthood of people with English learning difficulties. In fact, the social model of disability, which I am referring to, is closely linked to the other concepts. For actual social education practice and involvement with parents, who have got learning difficulties, it matters a great deal, whether the educator follows a social model of disability approach, or whether he pursues an approach based on the antagonistic individual model of disability.

The social model of disability rejects the idea that disability is a characteristic of an individual person. A person may have an impairment of bodily or mental function, but that only becomes a disability to the extent that society is not structured to cater well for people with that restriction, and other people's interactions exacerbate rather than overcome any difficulties (Williams 2006). The individual model of disability on the other

hand locates the problem within the individual and fails to take into account the way that the physical and social environments are disabling (Oliver and Sapey 2006). The social model of disability involves a switch away from focusing on the intellectual limitations of particular individuals with English learning difficulties to the way the social environment imposes limitations upon them as part of a particular group or category of people. Adjustment is a problem for society, not for the disabled individual. English learning difficulties can also be seen as less the problem of the intellectual impairment of certain individuals, but more related to general expectations about levels of social competence, for instance as a child-rearer. The social model of disability demands a 'citizenship approach' to service provision (Oliver and Sapey 2006). As we have seen, the concept of citizenship is in modern Western societies closely linked to that of adulthood, and adulthood and having an English learning difficulty have often been viewed as mutually exclusive. Social model of disability and citizenship approach demand that people with English learning difficulties are to be seen as full citizens, with all the rights and responsibilities that are implied, including that of parenthood. It has been argued that supporting people in valued social roles is one way, in which the social model of disability seeks to reverse the processes of vulnerability, the vulnerability of not being seen as adult and citizen for instance (Williams 2006). According to the social model of disability, disabilities are imposed upon impairments. The task for the educators is to identify the ways, in which this is done. He then has to find the remedy. Remedial of the disabling factors is to be achieved by helping the service users to locate the personal, social, economic and community resources to enable them to live the life they want. An approach to service provision, which is based on the individual model of disability, on the contrary, would narrowly be geared to the problems of individual limitations, rather than to alleviating the restricting effects of

the social environment. Educators following such an approach would be focused on personal resources only, and would not look at wider, social and community resources.

## 2. Educators and Their Value Base

Education is a distinctive profession because of the emphasis it has placed on values. Education values determine how educators ought to behave with their clients. They exert considerable influence on actual social education practice. The educator's value base may influence his/her thinking in promoting a person's rights to a particular educational service. Values represent the profound aspirations of professional commitment. They may be resistant to change and immune to evidence concerning practice outcomes (Mirandola *et al.* 2011). Biestek, a Catholic Priest, developed the first set of social service values as social education. His list included individualisation, the purposeful expression of feelings, controlled emotional involvement, acceptance, a non-judgmental attitude, client self-determination and confidentiality (Mirandola *et al.* 2011). The central council for education, the body previously responsible for developing guidelines for the training of social workers in the UK, suggested a value base, which contained, amongst others, the following values: (a) respect and value uniqueness and diversity, and recognise and build on strengths; (b) assist people to increase control of and improve the quality of their lives, while recognising that control of behaviour will be required at times in order to protect children and adults from harm; (c) practise in a manner that does not stigmatise or disadvantage either individuals, groups or communities (Thomas and Woods 2003). Undeniably all of us have our own beliefs, views and values. The values of the society we live in influence our thinking and our actions. That is why it is important to have

universal guidelines to adhere to. A educator, who adheres to the aforementioned values and ethical principles, has to first and foremost keep in mind: whatever a person's ability, each individual has the right to self-determination, and it is part of the role of the educator to endeavour to find ways to best support the person in achieving this.

## V. Support for Parents with Learning Difficulties in their Parenting Role

The levels of support needed by parents with English learning difficulties differ. Some parents require intensive support and guidance to assist them in their parenting, while others do not (McGaw 1997). However in any case: Support given has to be the right support. Inappropriate support can even be detrimental to successful parenting of parents with English learning difficulties. All services can contribute to the support of people in positively valued social educational roles or (however unconsciously or unintentionally) hinder it. Support also has to be given in the right fashion. The attitude of those delivering support is a crucial factor determining its effectiveness (Booth and Booth 1995). Negative, or stereotypical, attitudes about parents with English learning difficulties on the part of staff in some services are one of the barriers to support (Tarleton *et al.* 2006). Some parents have been so "bruised" by agency intervention in the past that they will not (or cannot) accept such help when it is available (McGaw 1997). Booth and Booth (1995) have identified "consistent, non-intrusive and non-threatening support" as most effective. It helps when support staff develops positive relations with the parents and provides them with ongoing emotional support (Ward and Tarleton 2007). Parents with English learning difficulties themselves

clearly have certain preferences of how they want their supporters to operate. They want them: (a) to take feedback; (b) to listen; (c) to pay attention; (d) to do what being asked; (e) to be non-judgemental; (f) to have confidence in them; (g) to trust they can do it (Ward and Tarleton 2007). Besides having the right attitude, there are other factors, which are crucial for the effectiveness of support. Early intervention and sustainability are perhaps the most prominent ones. The Framework for the Assessment of Children in Need and their Families clearly acknowledges the importance of early intervention: “Where professionals fail to provide adequate support in the early stages of intervention there is an increased likelihood of the child becoming looked after” (DOH 2001). Ward and Tarleton (2007) view early support as possibly beneficial for a number of reasons. It can: (a) lessen concerns about child protection; (b) reduce the stress on parents; (c) boost parents’ self-confidence; (d) enhance their ability to parent successfully.

Parents with English learning difficulties in most cases need support over the long term (Llewellyn and McConnell 2005). Sustainability of support is very important. Once provided, support has to be sustained as long as it is needed (Booth and Booth 1995; Van Kraayenoord *et al.* 2009). Another aspect of support often cited as crucial for its success, is that of close collaboration and coordination between all the parties involved. Parents with English learning difficulties are typically in contact with a multitude of professionals from different agencies. Different professionals often have different concepts of parenting against which parents are assessed. That can lead to conflicting advice. Parents with English learning difficulties need consistency in their support. Mixed, conflicting messages can leave parents disempowered and without choice or control (McBrien and Power 2002). Parents’ ability to cope can be further impaired.

According to Booth (2000: 178), “professional practice and service

organisation often undermine parents in their parenting and heighten their vulnerability.” The support, which is provided, is rather competence-inhibiting than competence-promoting. Competence-inhibiting support is based on the assumption that the parents are incapable of managing on their own. It tends to be de-motivating, crisis-orientated, and unresponsive to the parents’ view of their needs. Competence-promoting support, on the contrary, tends to: (a) allow parents to feel in control; (b) encourage them to handle their problems on their own; (c) reinforce and develop their skills and sense of self-worth (Booth and Booth 1994).

Whether the support provided is competence-promoting or competence-inhibiting clearly has a bearing on the parents’ actual level of competence, which itself then loops back to affect how they are perceived by the support system. Booth (2000: 178-179) also speaks of the existence of a “support gap”. There is an underinvestment in the kind of services and supports than might enable parents with English learning difficulties to bring up their children. Llewellyn and McConnell (2005) argued that there is a lack of support services that are able and/or willing to support parents in their parenting role. Referrals are often made too late. Parents with English learning difficulties often get referred to adult and specialist support services “only at crisis point” (Ward and Tarleton 2007). By that time it is often too late for them to receive the social education support needed for adequate parenting.

The findings of the Social Education Services Inspectorate, in its report *A Jigsaw of Services*, on services to support disabled adults in their parenting role, also show a pretty gloomy picture (Gooding 2000). Parents with English learning difficulties report that accessing appropriate services to support them in meeting the day-to-day demands of being a parent is difficult. Services to meet parents’ needs and services to meet children’s needs can hardly be brought together to educational support



parents with English learning difficulties in undertaking their parenting role. Educators seldom focus on the whole family and how to support and help the parents in the discharge of their parental duties in their social setting. Key Educators from children's services teams often lack awareness of parents' disability. Key educators from adult services often lack awareness of children's needs (Van Kraayenoord *et al.* 2009). Many staffs are unclear, and far from positive, about parenting needs being part of community care. Eligibility criteria and priority matrices hinder access to services because those for adult's services did not recognise the potential import of being a parent and for children's services parental disability was not an important factor. Staff not having the necessary skills undertakes assessments of parenting skills and parenting courses. Critical decisions about the children of parents with English learning difficulties (e.g. child removal) can be made on inappropriate or inadequate information. Based on these and other findings the Social Services Inspectorate comes to the following conclusion: "A philosophical and practical shift in the approach to working with disabled parents is required. It needs to be underpinned by recognition of the right of disabled people, within the bounds of current legislation, to be supported in fulfilling their roles and responsibilities as parents" (Gooding 2000: 2).

There have been important policy and legal initiatives, like Valuing People and Fair Access to Care Services since. However a relatively recent briefing of the Social Care Institute for Excellence (SEIE) still reports: (a) limited funding; (b) a lack of skills among professionals for assessing and supporting parents with learning disabilities; (c) negative attitudes about parents with learning disabilities; (d) tendencies to pass responsibility between children's and adults services (SCARE 2005). It seems as if more needs to be done in order to provide effective support for parents with English learning difficulties in their parenting role. What is

going on in the support system for parents with English learning difficulties has been described as “system abuse” (Booth 2000). Policies and practices that rather harm than benefit the families they are supposed to support or protect. With regard to policies there certainly have been changes in the right direction recently. However they will remain little more than rhetoric of practices does not change. Booth and Booth (1995) view independent advocacy as one way to overcome ‘system abuse’. Independent advocacy could certainly be a viable way, however negative attitudes toward parents with English learning difficulties on many sides appear to be hard to break.

## VI. Conclusion

The history of intimate relationships and parenthood for people with English learning difficulties is a history of gradual progress (Van Kraayenoord *et al.* 2009). Progress has been slow, and there are still major obstacles to overcome before we can speak of them as being ‘normality’. Not so long ago there has been utter rejection of the notion that people with English learning difficulties could have sexual relationships, or could indeed become parents. Society resorted to all sorts of measures to ‘make it not happen’. In the UK the measures used were not quite as drastic as in other countries, but measures were used nonetheless. Despite all the measures used to stop people with English learning difficulties to have sexual relationships and become parent: There have always been cases of people with English learning difficulties becoming parents. This clearly indicates that the myth of the person with English learning difficulties being an ‘eternal child’ is nothing but a myth. The fact that people with English learning difficulties are sexual beings

too, became slowly, but gradually accepted. In recent decades, which saw a general increase in emphasis on human rights, their human right to parenthood and marriage became enshrined in a number of Acts and conventions, both in the UK and internationally. In the UK there are only occasionally still measures taken to make parenthood 'not happen'. Parents in their majority would still like to see their child sterilised. However, courts have in recent years become very reluctant to grant their approval, in cases where the person with English learning difficulties is deemed 'not to have the capacity' to give their informed consent. Sterilisation in any case has to be voluntary. Parents today base their requests for sterilisation typically on concerns about the welfare of their son's or daughter's offspring. From concerns about possibly 'genetically-inferior' off-spring of parents with English learning difficulties, society has moved on to concerns about the welfare of the off-spring.

Parenthood for people with English learning difficulties could be seen as a 'valued social role'. The intention for it to become a valued social role is that it could serve as a 'counter-balance' to 'devalued social roles' otherwise often attributed to people with English learning difficulties (e.g. being 'un-productive', receiver of benefits etc). However society needs to be willing to accept such a role for people with English learning difficulties. All of educators including institution teachers could potentially be the agent of change in that regard. They could play an enabling role, and they should play an enabling role, according to their profession's values. Values such as supporting self-determination and building on clients' strengths are clearly intended to enable rather than disable. The working of Educators with parents with English learning difficulties is divided. There are the educators for children on the one hand. And on the other hand there are the educators working in adult teams supporting people with English learning difficulties. Quite often a 'conflict of interest' between the

two can be observed, a conflict of interest, which not necessarily need to be a conflict of interest. Educators for children clearly put children's needs first. Educators in adult teams usually take sides for the adult parent and his or her right to parenthood. Educators for children and adult team educators tend to have a narrow focus on the 'individual incapacity' of the parent, typically measured in terms of their cognitive ability. The 'individual model of disability' appears to be the base for their approach. Adult team educators on the other hand tend to apply a more holistic focus. Parents with English learning difficulties usually suffer much from social exclusion, affecting all aspects of their lives, including their parenting. A more holistic approach appears to be fully justified and appropriate in that regard. Current law clearly requires educators to pursue a holistic approach in their work with families headed by a parent with English learning difficulties, but clearly not limited to the work with those families only. The law also requires inter-agency cooperation between children and families teams and adult teams. The underlying philosophy appears to be: What helps the family as a whole helps the children. According to the children act 1989 children are first and foremost supposed to grow up in their own family. Child removal is supposed to be 'the last resort', after all other options to support the family have been exhausted and unsuccessful. Nonetheless in practice child removal appears to be an easy and readily available option.

All the evidence shows that children of parents with English learning difficulties in most cases can do equally well as children of non-disabled parents. Children of parents with English learning difficulties do not necessarily need parents of 'normal' intellectual functioning in order to flourish. Parenting usually takes place as a 'joint effort'. Parenting competence is distributed across a wider social network. As long as there are other adults available for them, children will have the chance of

developing 'normally'. The problem in the case of families headed by parents with English learning difficulties often is, that they do not have such social networks, since they are socially excluded. In the cases of parents with English learning difficulties, who need support in their parenting (many parents with learning difficulties actually do not need support), this clearly has to be taken into account when providing support. Support has to include the tackling of social exclusion. Generally support has to be 'the right support'. It has to be given in a timely fashion, and it has to be given with 'the right attitude'. The parents need to have the feeling that they are 'in control of their own affairs'. If they do not have that feeling they tend to withdraw, which is detrimental to the course and makes matters worse. Negative attitudes towards parents with English learning difficulties appear still to be a problem. However what can change attitudes? Independent advocacy has been suggested and it could certainly be one way. Knowledge and understanding can usually change attitudes. Educators for children in particular need to know about the lives of people with English learning difficulties. Many of them have no or only little knowledge of the lives of people with English learning difficulties. To sum things up: children's education welfare and parents rights certainly do not have to be mutually exclusive, as it so often seems to be the case for families headed by parents with English learning difficulties.

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Abstract

## The Valued Social Role of Parenthood for People with English Learning Difficulties in Britain

Hyeon-Ju Choi

There have always been concerns about parenthood for people with English learning difficulties. The emphasis of these concerns has shifted from concerns about people with English learning difficulties producing ‘genetically-inferior’ off-spring on a massive scale, to concerns about the welfare of their off-spring. Not so long ago society actively tried to stop people with English learning difficulties from procreating. The measures taken in the UK were certainly less drastic than in other countries, but measures were taken nonetheless. Today people with English learning difficulties have a right to have intimate relationships and become parents. In the UK the Human Rights Act 1998 clearly acknowledges this right. However in many cases parents with English learning difficulties find their parenting rights curtailed. Their children often get removed from them. They are said to be not capable of caring for their children, to lack the necessary ‘parental competence’. When assessing the ‘parental competence’ of parents with English learning difficulties, educators for children often narrowly focus parents’ cognitive ability along. Wider factors, such as social exclusion, are not taken into consideration, despite the legal requirement to do so. Other legal requirements, such as inter-agency cooperation, take place only in an insufficient manner. The vital input an expertise, which adult team educators could provide, gets limited hence. Educators for children and adult team educators are usually coming from a

different approach in their work with parents with English learning difficulties. The approach used by educators for children appears to be more orientated on the 'individual model of disability', whilst the approach used by adult team educators appears to be more orientated on the 'social model of disability'. This can in practice lead to conflicts and clashes between the two. Some parents with English learning difficulties do not, but most parents with English learning difficulties do need support in their parenting. Support, which is given, has to be 'the right support', 'competence-promoting', and not 'competence-inhibiting'. The attitude, with which it is given, matters a great deal in that regard. If support is not given with a positive attitude towards the parenting of parents with English learning difficulties, they tend to withdraw, which in turn is detrimental for their parenting, and makes matters worse. Negative attitudes, particularly amongst educators for children, still appear to be wide-spread and need to be overcome.

**Key words:** Education, Social Role, Parenthood, English Learning Difficulties, Britain

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