An investigation into the meaning and purpose of the advocacy and self-advocacy in the lives of people with learning difficulties in England

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Dedication

It is with deep gratitude and in humbleness that I confess this research would not have been possible without the almighty God's great compassion and grace. So I dedicate this piece of work to God, for his unfailing love, protection and guidance over my life especially during staying in the UK, it was indeed His blessing, wisdom and knowledge that enabled me to write this dissertation. I also dedicate this research to my three sisters whom despite their physical disabilities were a great source of love and inspiration, Anita Verma, Sangeeta Verma and Rita Verma. Special thanks to late Anita Verma and Rita Verma, who left us and ascended to their destination in the heaven. I also dedicate this research to my family as evidence of why I was away for a period of two years and also for their tolerance of my misunderstandings. This research is also dedicated to the all people with disabilities and their families.

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Abstract

The focus of this research is in the area of advocacy and self-advocacy in the lives of people with learning difficulties in England. In order to explore the concept of advocacy and self-advocacy I identified and discussed some definitions of disability, learning difficulties. In addition, I focused on general issues around advocacy and self-advocacy as well as rights and the current economic crisis in the lives of people with learning difficulties.

A survey approach was adopted in this qualitative research. Interview and documentary methods were used for collecting the data. The qualitative research consisted of six interviews and one focus group interview. The respondents were from two advocacy and self-advocacy groups in England.

The findings from this research reveal that there are some challenges faced by people with learning difficulties, such as their identity in disabled world, fighting for their rights, challenges in attaining independent self-advocacy for themselves. The results of the research illustrated that in spite of these challenges people with learning difficulties are capable of speaking up on their own with the help of advocacy and self-advocacy groups. The study suggests that though there have been some developments into advocacy and self-advocacy in the lives of people with learning difficulties, there is still much work that has to be done to ensure that people with learning difficulties get their voice heard.

Keywords: advocacy, self-advocacy, learning difficulty, learning difficulties.

Chapter One - Introduction

My dissertation topic is entitled: *An investigation into the meaning and purpose of the advocacy and self-advocacy in the lives of people with learning difficulties in England.*

This chapter gives a brief description of the aims and contents enumerated in this research which includes background of the advocacy and self-advocacy in the lives of people with learning difficulties. It also contains a brief discussion of the aim, objective of the research, research question, and significance reasons of the study.

1.1 Background

Advocacy is the representation of the views, feelings and interests of one person or group of the people with learning difficulties, whereas self-advocacy is the action or expression of an individual on their own without the behalf of the intervention of another. Garner and Sandow (1995) stated that the historically changes from advocacy to self-advocacy is an ordinary extension of the process of experience of other groups in society, who have wanted to speak up and demonstrate their feelings through their own actions. Self-advocacy can be understood as a *counter-movement* where people with the label of learning difficulties apparently support each other to speak out against the discrimination in the culture of England in the United Kingdom (UK) (Goodley, 2000).

Since the declaration of the *White Paper Valuing People* (Department of Health (DoH), 2001), advocacy and self-advocacy have been on the government's agenda for people having learning difficulties in England. In addition, a new strategy for people with learning difficulties was created, *Valuing People Now*: *a new three years strategy for* *people with learning disabilities* (DoH, 2009) set an overall policy objective for advocacy. However, Rapaport et al (2005) argued that advocacy is not a new agenda in the disability sector, for the government of the UK, it began in the late 1970s. The *Valuing People Now* policy provides resources and funds for additional improvements in the lives of people with learning difficulties. This is that, altogether people with learning difficulties can speak up and be heard about what they want in their lives. Concerning this, they can take big decisions. Within this document, self-advocacy is defined as "people coming together to speak up for themselves" (DoH, 2009, p. 100).

Over the past thirty years the services for people with learning difficulties have come a long way, when people were institutionalised under perplexing situations (Chappell, 1997). Due to some advocacy and self-advocacy groups took initiatives to change and improvement of their quality of lives. As a result, many people with learning difficulties have left the institutions and began to live their own lives. These people with learning difficulties associated with self-advocacy groups may speak up on their own difficulties (Mitchell et al, 2006). However, accessing the independent self-advocacy is difficult for this population (Goodley, 2000). The support for the self-advocacy from government and professionals is an uncertain, even inconsistent issue as self-advocacy is leading the activities of people with learning difficulties. As Goodley (1998, p. 377) argued:

> "Self-advocacy is not a separate issue. It is intrinsically a part of a movement that threatens to break-down the dominant oppressive understandings of disability. As a source for political change self-advocates stand in direct opposition to prejudiced discourse and thus should be supported".

The promotion of advocacy and self-advocacy may sound simple and straightforward, but looked at more closely, it has different meaning and purposes when looked closely. Goodley (2000, p. 14) claimed that “The self-advocacy movement is complicated, a container for a variety of struggles and a context not so easily understood as relating directly to the self-empowerment of its main players- self advocates with learning difficulties”.

Consequently, although self-advocacy related to the actions of people with learning difficulties themselves, it is based on a diversity of background and brings discourses together. Mcnally (2003) pointed out that advocacy and self-advocacy in the lives of people with learning difficulties are related to concepts, for instance, their rights, choices and independence. However, the dominant focus on learning difficulties as pathology or disaster way in which people *so-labelled* are struggling for their human rights in a disabling environment (Goodley, 2000).

1.2 Structure of the Research

The research consists of five main chapters: chapter one is an introduction part gives a brief description of the information contained in this dissertation which includes background of the advocacy and self-advocacy in the lives of people with learning difficulties. It also contains a brief discussion of the objective, research questions, and significance of the study. Chapter two provides an in-depth literature review, which involved definitions of the disability and learning difficulty, identifying the concepts of the advocacy and self-advocacy by discussing the self-advocacy movement and disability rights. Chapter three will consider the methodology and methods of the research, which outlines multi-methods that took the form of desk based research and qualitative research. The Interviews and documentary research are the main tools of this research. Chapter four will consider the main findings of this research and discuss the themes that come up as a consequence of these results from the qualitative research. Following limitations of the research have also been discussed. Finally, chapter five will outline the conclusion with a summary of learning and implications of these findings in my future practice.

1.3 Aim

A few researches have been done work on both concepts of the advocacy and self-advocacy in the lives of people with learning difficulties, also less attention paid on the groups, who work with people with learning difficulties. The aim of the undertaken this research to have a better understanding of these groups and to investigate the concept of advocacy and self-advocacy in the lives of people with learning difficulties within England context.

1.4 Objective

The objectives of this research are: To explore the development of advocacy and self-advocacy provision at national level by looking at the legislations, policy and practice in England. To understand or assess the work done by two advocacy and self-advocacy groups Group A (G-A) and Group B (G-B). In addition, to identify the common challenges and the necessary actions to enhance advocacy and self-advocacy with people with learning difficulties.

1.5 Two Groups Chosen for this Research

G-A is a self-advocacy organisation operated by and with people with learning disabilities to raise awareness of and campaign for the rights of people with learning difficulties. The *G-A* is supported by an organisation based in the middle of England in a large city. *G-B* is located in middle of England and works for and with people with learning disabilities to be valued equally, participate fully in their communities and be treated with dignity and respect in. In addition, both groups work in partnership with people who are facing such difficulties and groups who work with them and other support groups. Although the permission is granted from these two groups to use information and documents collected from them. The confidentially of the name of the groups, pictures and name of the respondents will be kept.

1.6 Research Question/s

Working as a social worker in Indian rural area, and carrying out the research, frequent contact were made with schools, parents, and children and people with learning difficulties. The idea for the research arose from the situations which I had observed whilst carrying out my role in my organisation. Further, taking concern on this subject and proper advices from my supervisor helped me in exploring the literature and some groups on internet in relation to advocacy and self-advocacy in the lives of people with learning difficulties in England.

In order to find out the role of advocacy and self-advocacy groups for the research, two research questions are posed. First, how do advocacy and self-advocacy groups' impact upon the lives of people with learning difficulties? To attain meaningful results, it is necessary to ensure second question, how self-advocacy groups work for and with people with learning difficulties. However, in addressing with the above enumerated questions, few more need to be answered like what is advocacy and self-advocacy?

1.7 Reasons for Undertaking the Study

This topic was chosen for a number of reasons. The main purpose of this research is to investigate the concept of the advocacy and self-advocacy in context of people with learning difficulties in England. Furthermore, an understanding of the impact of advocacy and self-advocacy is required in the lives of the people with learning difficulties.

Another reason, behind choosing this research my experiences, based on both personal circumstances and professional experiences. In my case, I am a sibling of three sisters with disabilities. Therefore, I have a first-hand experience regarding the discrimination against people with disabilities and learning difficulties in India is known. Advocacy and self-advocacy are necessary for people with learning difficulties in India, owing to the reason that several people believe in myths and this attitude leads to people with disabilities and learning difficulties being isolated. According to the Indian cultural perspective disability is regarded as a family indignity. It is much more difficult for a family if a child, especially female child, experiences from any form of disability, because they are discriminated on two levels, such as their gender and then their disability. Therefore, Advocacy and self-advocacy are important for many people who have capacity to make decisions about care but who feel ignored or unvalued by care providers. In addition, the concern expressed by people with learning difficulties and their families is to speak up on their own. The result of it is being found advocacy and self-advocacy become a way understand the rights and equality of people with learning difficulties.

Lastly, reason for selecting this research topic is, the research in England would assist me to know importance of advocacy and self-advocacy groups, some challenges to their formations and how people with learning difficulties overcome these challenges. Through this research I would learn from advocacy and self-advocacy provisions and practices in England context.

Next chapter of the research will be review of the relevant literature.

Chapter Two Literature Review

In this chapter, firstly the definition of disability with the supporting of a social model of disability viewpoint will be addressed. Secondly, the term learning difficulty will be discussed and critically examined. Thirdly, the concept of advocacy and self-advocacy will be undertaken. Fourthly, the understanding the self-advocacy groups will be addressed. Fifthly, the rights and movement will be highlighted. Finally, the impact of the current economic crisis on the lives of the people with learning difficulties will be briefly discussed.

2.1 Definition

This section of the chapter will be discussed on the definitions of the disability and learning difficulties.

2.1.1 Disability

Over the years, self-help as well as self-advocacy are conflicting an individual understanding of disability (Oliver, 1996), a social model viewpoint is functional in the context of this work. The term 'social model' was invented by Michael Oliver in 1981 (Oliver, 1981 cited in Barnes, 2007). According to Barnes & Mercer (2003) this approach, subsequent of a disabled people's movement, it defined by the Union of the Physical Impaired Against Segregation (UPIAS), distinguishes between impairment and disability:

> "Impairment is lacking part or all of a limb, or having a defective limb, organism or mechanism of the body.

> Disability is the disadvantage or restriction caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities" (UPIAS, 1976, quoted in Oliver 1990, p.11).

Barnes & Mercer (2003) argued that the transfer of the origin of disablement from the individual to society has made the social model, which is one of the most significant tools in the struggle for disability equality. On the other hand, it fails to clarify the causes of disablement or offer a social theory of disability (Finkelstein, 2004).

The matters mentioned above are considered within different theoretical accounts. While the idealistic accounts stressed the character of the culture in the creation of disability, the materialistic approaches emphasis upon structural and economic forces. According to a materialist perspective, disability can be defined as domination which society imposes on people with impairments (Finkelstein, 1980; Oliver, 1990). Oliver (1990) provided a comprehensive investigation on how the conceptual approach of thought has created an individual understanding of disability. In addition to this, the scientific prescription has played a major role in the formation of the oppression of people with impairments. The medicalization has had main impact on the lives of people with disability as it has determined the welfare policy, being provided to individual technical and teaching supports (Oliver, 1990).

Although, the focus on physical issues and social divisions, for instance gender, ethnicity and race, the reluctance to address experiences of impairment and the lack of interest in the social construction of the impaired body have led to a variety of criticism towards the social model of disability (Barnes, Mercer & Shakespeare, 1999). The circumstance of learning difficulties has constantly been addressed within such debates and will be elaborated upon further below. It is interesting to note, that the application of considering impairment issues has been rejected by some activists of the social model due to its original aim to be " a pragmatic attempt to identify and address issues that can be changed through collective action, rather than medical or other professional treatment" (Oliver, 1996, p. 48).

2.1.2 Learning Difficulties

In this study the term 'learning difficulties' is used in the place of terms like 'learning disabilities' since it is a term preferred by many British people those in self-advocacy movement. Amongst of them as one self-advocate pointed out, "If you put 'people with learning difficulties,' then they know that people want to learn and to be taught how to do things" (Sutcliffe & Simon, 1993, p. 23).

Walmsley (2001) argued that the linguistic shift from 'mental handicap' to 'learning difficulty' which took place during the late 1980s and 1990s. A study by Hasting & Remington (1993) evaluated the impact of different labels of this population. Under this study, seventy seven undergraduates were assessed with seven different labels. Almost all terms were discovered to be rated negatively mainly the term 'mental retardation'. However, 'learning difficulty' and 'learning disability' were rated least negatively.

The term 'learning difficulties' in the UK is alike to the use of 'intellectual disabilities' and 'developmental disabilities' in other nations (Mitchell et al, 2006).

The UK government's *White Paper, Valuing People* (Department of Health (DoH), 2001) defines the learning difficulties in the following way: People with learning difficulties are people first. We focus throughout on what people can do, with support where necessary, rather than on what they cannot do. A learning difficulty includes the presence of:

- "a significant reduced ability to understand new or complex information or use new skills (impaired intelligence), with;
- a reduced ability to cope independently; a condition that started before adulthood (impaired social functioning);
- which started before adulthood, with a lasting effect on the individual's development" (DoH, 2001, p. 14).

Kerr (2007) agreed with the term learning difficulties defined by the *White Paper Valuing People* mentioned above. However, this author claimed that no two people will experience their difficulty/disability in the same way (Kerr, 2007). In contrast, Firth and Firth (1982) argued that psychologist assumed that people with learning difficulties have the equal emotional values as any other person.

The *White Paper Valuing People* (DoH, 2001) stressed that low intelligence is not the only factor for determining whether somebody has learning difficulties, however, "social functioning and communication skills" (DoH, 2001, p.15) also need to be taken into consideration. Therefore, this definition has traditionally been used for diagnosing learning difficulties from a medical perspective. Nunkoosing (2011) identified that low intelligence and adaptive functioning has shown uncharacteristic. However, these can eventually be deconstructed and factors located in the socialisation and institutionalisation of people with learning difficulties these influences that need also to be considered. Therefore, the basis for the diagnosis of learning difficulties is historically and socio-culturally prejudiced (Goodley, 2000).

In order to the social model outlined above, the term ‘learning difficulties’ labelled a category of impairment. However, seeing learning difficulties solely as biological impairment category is not appropriate. Abberley (1987) pointed out that the concepts of impairment need to be questioned as the location of difference in genetic appearance of identifies the humanity of certain people and neglects the importance of social environments. Harris (1995) argued that there are a large number of literatures discussing the social construction of learning difficulties and it shows that it is an inadequate notion.

Whatever the term or description used, the features listed above in *White Paper Valuing People,* are usually associated with low status and a devalued role in society (Wolfensberger, 1983). Walmsley (2002) stressed that the problematic notion of constituting individual subjectivity as pre-social and argued that the individual and his/her impairments are never separable from the social world and the knowledge it is constituted of. The creation of learning difficulties is hence inevitably linked to the medical and psychological discourses it was created by. As Goodley and Rapley (2006, p. 135) argued, learning difficulties “must be understood rationally, historically, practically”. The authors advocated to examine both impairment and disability as political as well as social aspects of disablement and undertake a breakdown of the category of learning difficulties by presenting some specific criteria associated with it, for instance, consent and syndrome-specific behaviour disturb the personhood of so-labelled people (Goodley and Rapley, 2006). They argued for a social theory of impairment, which conveys “impairment and disability together as co-existing social and political facts of disablement” (Goodley and Rapley, 2006, p.138). However, it is uncertain why this social theory is essential as according to authors “part of the political struggle against disablement” (Goodley and Rapley, 2006, p.138). In addition, Goodley and Rapely (2006) pursuit the social theory approach of impairment, whereas Olive (1996) recommends developing a social model of impairment instead of the criticizing the social model of disability.

Nunkoosing (2011) pointed out that attitude towards learning difficulties have changed over the last few decades. It being deliberated first a moral, then a psychiatric, subsequently a legal and finally a medical condition. The author stresses on the impact of science in creating categorisation of individuals which led to a medical, individualised understanding of learning difficulties and disability in general (Nunkoosing, 2011). Observing at the history of the people with learning difficulties, it has been worth noting that their personhood has been even more challenged then that of people with physical impairment (Parmenter, 2001).

The right to a voice from the history has been provided changing perceptions of an individual’s ability to stand up for their rights (Gray and Jackson, 2002). The authors argued that “The essential personhood of people with learning difficulties has been more widely acknowledged, and with an entitlement to support” (Gray and Jackson, 2002, p. 7). The literature indicates that in the past people with learning difficulties experienced dominated in a disabling society, they are fighting for their human rights and dignity (Rix, 2006; Mitchell et al, 2006; Goodley, 2000; Dybwad, 1996).

After exploring the literature on disability and learning difficulties, I strongly believe that advocacy and self-advocacy are the best ways to raise the voice of people with learning difficulties for their rights. It is worth noting, that there have been socio-political, legal and educational reasons for the improvement of advocacy and self-advocacy in the lives of people with learning difficulties (Garner and Sandow, 1995). This argument leads more discussion in to advocacy and self-advocacy, which is discussed in next section.

2.2 Advocacy and Self-advocacy

In this section, I will review the literature in relation to advocacy and self-advocacy in the lives of people with learning difficulties.

2.2.1 Advocacy

The term advocacy comes from the Latin word ‘ad voce’ means ‘towards a voice’. The key interpretation of advocacy is empowering a person to have a voice. Mitchell et al (2006) stated that advocacy means speaking up for others and yourself. Advocacy involves an advocate speaking up on behalf of a person or a group whereas self-advocacy occurs when a group or an individual are capable of speaking up for themselves on their own (a detailed reflection on the self-advocacy will explain in the next section of this chapter). Advocacy is reaffirmed in the following definitions:

> “Advocacy is actively supported a cause or issue; speaking in favour of; recommending; supporting or defending; arguing on behalf of oneself or on behalf of another” (Birmingham, 2001, p. 9).

In relation to disabled people:

> “Advocacy involves a person(s), either an individual or group with disabilities or their representative, pressing their case with influential others, about situations which either affect them directly or and more usually, trying to prevent proposed changes which will leave them worse off” (Brandon, 1995, p.1).

The *White Paper Valuing People* (DoH, 2001) stated that advocacy is an important way for people with a learning difficulty to have more choice and control in their lives.

The importance of advocacy in terms of having a voice and creating the opportunity to speak up whether people are self-advocates or representative advocates are emphasised in the above definitions. However, the intention why advocacy is of specific importance in relation to disability (Jackson, 2004) lies in the perception and oppression (Finlkelstien, 1980; Oliver, 1990) disabled people face.

According to Henderson and Pochin (2001) advocacy is a method of representation of a person’s affair. They stated that the purpose of advocacy is enhancement of rights and conducted by someone who does have little or no conflict of interest. Although, advocacy is no longer a new concept, there continues to be considerable confusion as to its meaning and purpose (Jackson, 2004). Mitchell (2006) pointed out that the purpose of the advocacy is to secure rights for an individual with disabilities, which may involve giving emotional and practical support.

From the disability movement's perspective, it can be questioned that which types of advocacy are applicable in signifying disabled people's case without continuing their dependency (Henderson and Pochin, 2001). The literature acknowledged the types of advocacy, such as citizen advocacy, self-advocacy, peer advocacy, family advocacy (Walmsley, 2002; Gray and Jackson, 2002; Henderson and Pochin, 2001).

The citizen advocacy has been known as a root of today's fashionable advocacy, however, it has been prohibited by people with disabilities (Henderson and Pochin, 2001). The other person volunteers to listen to and speak up on behalf of the advocacy partner (Wolfensberger, 1989). The citizen volunteer is supposed to advocate in the interests of the vulnerable people and their needs against the service system. The citizen advocacy is when a non-disabled person is assisting to a person with a disability (Atkinson, 1999). However, a peer advocacy is when a person with disability supports another person with a disability (Henderson and Pochin, 2001)

It sometimes means that people who have same experienced and they support each other in a similar situation. A peer advocate is, often a person who is also a self-advocate. However, Grant et al (2005) argued that the peer advocate does not always go through the same experiences, if the other person has a different disability. Gray and Jackson (2002) believe that peer advocacy plays an essential role in an individual's life.

Self-advocacy is a form of speak up, which can be characterised as umbrella term that is functional to discuss to rather different aspects of the activities of people with learning difficulties in a political context (Brandon, 1995).The investigation on self-advocacy now moves into next part for further discussion on it.

2.2.2 Self-Advocacy

Some people are capable to communicate or speak up for themselves on issues which affect their lives, but need varying levels of help to do so. Gray and Jackson (2002) emphasised the importance of developing self-advocacy as they consider it to be the most important form of advocacy for people with learning difficulties. The literature on self-advocacy describes that self-advocacy is the action or words of a person with learning difficulties on their own behalf without the intervention of others. A self-advocate with learning difficulties and a former president of People First London described that: “Self-advocacy enables us to make choices and make our decisions and control the way that our lives should be made” (Goodley, 2000, p. 6). Similarly, DfES (2001, p. 28) described that “Self-advocacy is about speaking up for yourself. People need to understand what it is like to do be a person with learning difficulties”.

Test et al (2005) pointed out that self-advocacy is a goal for education, an action or a skill and alike of self-determination. However, Goodley (2001) claimed that there is suspicion about the significant definition of self-advocacy in the lives of people with learning difficulties, because there is not one way to self-advocate this population in general. Similarly, Sutcliffe and Simons (1993) stated that self-advocacy is difficult to define.

A popular definition, which was adopted during the Second National Annual North American People First Conference in Nashville, Dybwad, stated:

> “Self-advocacy is about independent groups of people with disabilities working together for justice by helping each other take charge of their lives and fight discrimination. It teaches us how to make decisions and choices that affect our lives

> so we can be more independent. It teaches us about our rights, but along with learning about our rights, we learn about our responsibilities. The way we learn about advocating for ourselves is supporting each other and helping each other gain confidence in themselves to speak out for what they believe" (Dybwad, 1996, p. 2).

The self-advocacy, therefore, means working against discrimination, increasing choice and independence, creating an awareness of rights, accountabilities mutual support amongst disabled people. Definitions of self-advocacy generally refer to action on an individual as well as group level (Goodley, 2000). For instance, self-advocacy is a way of life that encourages people with learning disabilities to become as an independent as possible in their thoughts and actions (Longhurst, 1994).

An individual level, self-advocacy is defines as an expression of individual's feelings, understanding of rights and the ability to make choices (Sutcliffe and Simon, 1993). On the other hand the literature focused on combining action, which is usually based on some form of groups support (Goodley, 2000; Dybwad, 1996). In addition, Goodley (2000) indicated that the self-advocacy groups are a good way to encourage each other. These groups are run by people with learning difficulties who sometimes have supporters so that people feel able to speak up for themselves.

2.3 Understanding the Self-advocacy Groups

The needs of people with learning difficulties are most effectively addressed when people with learning disabilities advocate themselves. For this very reason, self-advocacy groups are formed so that people with learning difficulties can unite their voice to represent themselves in society. When several people discuss or heard of self-advocacy, they think in terms of self-advocacy groups and the activities done by these groups (Goodley, 2000).

Many studies drawn upon a group typology, which identified the independent group model as most helpful and criticises the service systems (Crawley, 1988; Simon, 1992). However, Goodley (2000) emphasised problematic issues around typologies. According to his study, the data on self-advocacy in the UK indicates that such a typology seems to simply issues surrounding the work of various self-advocacy groups. His qualitative study on the life stories of self-advocates and the observation of the work done by self-advocacy groups stresses on the complexity of self-advocacy in the lives of people with learning difficulties. He stressed that though social model of has been changed in the lives of people with disability, people with learning difficulties still live in the institutes.

Disability organisations or organisation for disabled people (Oliver and Barnes, 1998) are practices and old fashion, they are typically controlled by non-disabled people or dominated by professionals and emphasis largely on the service provision for a particular groups of disabled people, often identifying them by their impairment. Whereas, disabled people have merely limited control over those organisations. The professional organisations, for instance BILD and British Psychology Society Interest Group may claim to advocate for people with learning difficulties (Gray and Jackson, 2002).

Other professional organisation in England with a more explicit advocacy role is Mencap (Gray and Jackson, 2002). It works in partnership with people with a learning difficulty, their families and carers through providing the training and services to help people with learning difficulties to develop the skills, confidence and knowledge they need (Rix, 2006). Mencap has produced a video called ‘My Life- what’s important to you?’ (MencapDirector, 2012). This video shows that people with learning difficulties have started telling, what is important to them. However, parents spoken more than people with learning difficulties in this video. As Mack (2001) argued, some self-advocacy groups are competent between self-advocates and parents, such as Mencap. On the other hand it is not surprising that Mencap has found the increase of self-advocacy within its group such a challenge (Mack, 2001).

Gary and Jackson (2002) argued that People First is the group in the UK which has advocacy as their chief goal and it promotes self-advocacy. The People First originated in the United States in the 1960s and in the UK in the 1970s, although, there are many organisations called ‘People First’ all over the country they are not one organisation and are not all linked to each other, they all work together (Mack, 2001).

The National Forum of People with Learning Disabilities conducted a survey of 80 self-advocacy groups in 9 regions across the country (DoH, n. d.). The report of this survey says that self-advocacy groups are led by and for people with learning difficulties. These groups provide the trainings to people with learning difficulties and their support groups. Furthermore, these groups create the jobs for people with learning with difficulties, where they work together and help each other to become more confident. Some groups work in their local areas to make sure that people with learning difficulties are treated equally. In contrast, some groups work nationally to make sure the government hears their voice (DoH, n. d.).

2.3.1 Personal Account of Self-advocacy

A number of life-histories/stories were presented in the literature, which revealed not only self-advocacy has occurred from outside the groups, but that many of personal experiences which led people to speak up their own (Mitchell et al, 2006; Rix, 2006; Goodley, 2000). Stories from different part of England focussed much attention on the lives in the families and in the institutions, and practice as a self-advocate. For instance, Spencer and Walmsley (2006) stated that due to Spencer's learning difficulty, she had a difficult relationship with her family, therefore, she was placed in an institute. But she left that place when she and involved in People First in Northampton. Later she became Chair of Central England People First and played an important role in English self-advocacy movement.

One other example, Jeremy et al (2006) who has a learning difficulty said, "self-advocacy is becoming stronger and making decisions on your own…..I get paid for job I do with the group, which is important to me. It really means I have got work" (Jermey et al, 2006, p. 112).

2.4 Disability Rights Movement

In this section I will discuss about the rights and self-advocacy movement of the people with learning difficulties.

2.4.1 Rights of People with Learning Difficulties

The United Nations Convention on the Rights of the People with Disabilities (UNCRPD) is an international treaty that identifies the rights of persons with disabilities (United

Nations, 2007). The Article 24 of the Convection indicates that UN General Assembly officially adopted the UNCRPD on 13 December, 2006 at the UN Headquarter in New York and was opened for signature on the 30 March 2007 (United Nations, 2007). Harpur (2011) indicates that the ratification of the convention will provide a prevalent incentive for people with learning difficulties to fight their rights and entitlements with the support of an advocate and self-advocate. However, people with learning difficulties were discriminated in the disability movement have been imposed to fight for equality and their rights (Armstrong, 2002). Furthermore, this movement has influenced positively to people with disability, people with learning difficulties do not recognise their rights and privilege in this movement Goodley (2000). In addition, people with learning difficulties were advised that the provision of an advocacy and self-advocacy is needed to enable these people to take control of their own lives and be more active (Goodley, 2000). Stone (1999) argued that for year people with learning difficulties have been labelled as people without power, rights and value. Therefore, Gray and Jackson (2002) addressed the self-advocacy movement throughout England, which will be discussed in the next section.

2.4.2 The Self-advocacy Movement

The actions of people with learning difficulties in the disability rights movement and disabling setting gave *rise to the birth* of self-advocacy movement (Goodley, 2000). Self-advocacy movement is considered a civil rights movement for people with learning difficulties, because it impact on individuals and changing national policies to ensure the rights of citizens with learning difficulties are protected (Armstrong, 2002). On the other hand Goodley (1998) argued that self-advocates depend on advisers, therefore, decisions are potentially not taken by people with learning difficulties themselves. Test et al (2005) pointed out that self-advocacy movement known as a People First movement. However, Goodley (2000) argued that the foundations of the self-advocacy movement are not merely is People First.

As Shakespeare (2000) indicates, self-advocacy movement is a new and outside from the traditional politics. Oliver (1996) stated that several people would not believe that this movement is a new movement, however, he argued that it is a new social movement because it provides a voice to people with disabilities ‘where they previously did not have one’ (p.159).

Although stating that self-advocacy is about leadership of people with learning difficulties, the people of “human services standing up, organising and saying that they want control over their lives is a departure from former social roles” (Bersani, 1996, p.265). The rise of self-advocacy is not only reflected as a political movement or part of the disabled people’s movement: “The continued growth of self-advocacy in Britain is due to some extent from the mid-1980s….It required the views of people with learning difficulties to be taken into account and so self-advocacy became an integral part of the service delivery process” (Dowse, 2001, p. 130). Therefore, especially self-advocacy in service perspectives associates to the notions of empowerment and community care to some extent with discourses around service provision (Goodley, 2000).

2.5 Impact of the Current Economic Crisis on People with Learning Difficulties

The BBC (2012) reported that the current economic recession has a significant impact on the development of advocacy and self-advocacy in the lives of people with learning difficulties to a great extent. Similarly, People first (2011) stresses on anxieties of people with learning difficulties about cutting the Disability Living Allowance. Disabled people and their families are being hit hard by the cuts to the disability benefits (BBC, 2012), because it will effect on advocacy and self-advocacy groups and services they need to live their lives.

People First (2011) reports that disability living allowance will be replace in personal independent payment benefit. It means some extreme cuts in terms of disability funding in the areas of health, social welfare and others. People First (2011) urges the government to make fair and equitable decisions regarding this funding, as cutting benefit money will lead to people with learning difficulties having less independence.

In conclusion, the interrelation between the discussed on the terms disability, learning difficulty, advocacy and self-advocacy are highlighted. Disability is considered as the oppression and segregation that people with impairment in social structure rather than individual bodily asset. The term learning difficulties is problematic, but it is preferred by most people labelled, therefore, this term used in this study. Advocacy and self-advocacy give a voice to people with learning difficulties and they can speak up on their own behalf, but they supported by the groups. Then the argument was moved on rights of people with learning difficulties and self-advocacy movements.

Having discussed all these issues from the literature, it is apparent that I need to understand the topic and research questions of the study in the England context. Therefore, with these knowledge at hand, I have set up a bearing in relation to what my research seeks to address using the research questions mentioned in chapter one. This cannot be successful without taking the appropriate approach and methods as discussed in the next chapter.

Chapter Three - The Research Design and Methods

3.1 Methodology

The choice of an appropriate methodology can be described as a process or design lying behind the choice of particular methods (Crotty, 1998). For this small scale qualitative study as it allowed for a wealth of information to be generated in respect of thoughts, feelings and opinions of respondents. The research wanted to understand the concept of advocacy and self-advocacy in the lives of people with learning difficulties in relation to two groups. The most proficient way of attaining this was through the collection of qualitative data as opposed to quantitative data. The research did not incorporate any statistical data as it was not felt to be advantageous to the aims and objectives of the research. Densombe (2007) advocated that qualitative data enables the focus to be firmly placed on the context and detail which is general rather than correlations. The data was obtained from interviewing the respondents gave in depth information that answered those questions. Qualitative research is recommended, as it is multi-method in focus involving an interpretive approach to its subject matter. Consequently, qualitative data was the most appropriate method to this study because of this small scale research, my interest of social science world and need for flexibility in the research design (Robson, 2011).

The aim of this research was an investigation on the concept of the advocacy and self-advocacy in the lives of people with learning difficulties. Prior to the commencement the research I approached two advocacy and self-advocacy groups (G-A and G-B) in a large city of England. The selection of these groups was based on prior survey which aimed for me to learn and understand the groups, who work with people with learning difficulties in England as well. In my research proposal only one group G-A was selected, but because of insufficient data and due to less accessibility of the literature, my understanding on the topic was not clear. In addition, related to my research, the answers of some certain questions were not found. However, when I associated with G-B and had opportunity to collect the data from them, I discussed with my supervisor and was permitted to involve this group into my research.

3.2 Procedure

Following, the procedure of the collecting data from relevant groups is explained.

G-A

For this research I explored the online search engine to reach out the G-A. The phone number was obtained and I called up several times, but could not reach out to them. Approximately after two months the conversation was held with them. However, I was not able to communicate about my concern of the research to them. May be the language was an obstacle for us in properly communication on the telephone, as English is my second language. Email addresses were exchanged and I could write my interest of study to them. Finally, they communicated with my supervisor and I was permitted to visit them. Dates were then arranged to being group discussion in their office.

Once I entered in the office of G-A, with the aim of discussion and conversation on my research topic and to get some public documents from them, I could not stop myself noticing the information spread all around. The walls of the office were fully decorated with the information. The office rules were displayed on the wall, which were not collected as I was informed that those were only for the office people. The two paid staff and six learning disabled (word they used) volunteer (self-advocates) were presented in the G-A’s office. We introduced each other and research aim was shared. Moreover, the research proposal and summary was presented. I was asked several questions from them about my experience in the disability field. They were satisfied after know about my family background and work experiences with people with disabilities in India. Following, their agreement to participate in the research, a focus group interview was conducted on the same time in their office. As mentioned before some questions were prepared, but because of the time limitation, only two questions were asked. In the focus group interview six self-advocates who have learning difficulties and two paid staff participated. These two paid staff helped in asking the questions from people with learning difficulties. In fact they lead the conversation and eancrouged to people with learning difficulties for their responses. The amount of the time of the interview and conversation was around two hours. After an informal discussion and introduction, some questions were asked, which led the conversation ahead. The full set of summarized data can be found in the appendix 1 (please see Appendix 1).

The permission was granted for taking the notes and recording the focus group interview, however, some part of the conversation was not recorded as those were too personal. I was not permitted for second visit, the reason behind this was one respondent with a learning difficulty was not agree. Therefore, further, I corresponded via email with one paid staff to clarify the answers of some questions, which discussed in the focus group interview. In addition, I was able to obtain some documents needed for the research.

G-B

I had an academic opportunity to attend G-B's three days annual international conference, which held in a big city of Wales. The sessions and activities held at the conference were observed. During the conference I encountered with group members who support to the people with learning difficulties and the staff members of G-B. The concern of my study was expressed to the five support service people from five different groups, who were associated with G-B and the staff members of G-B. Further, during the conversation the aim of the study was exhibited and the proposal of my study was shared. They were from the non-governmental organisation (NGO) and work with people with disabilities and learning difficulties. As per my background from NGO as a social worker in similar field, they were agreeing to become a part of the study. In addition, a trustee of G-B who has a sibling with learning difficulties felt familiar with my research concern and wanted to discuss in detail. Similarly, one trainer, and a communication officer took an interest in my research topic as it was relevant of their work. These three people from G-B and five support service people were invited to become a part of my study. But because of the busy schedule of three staff members, in the conference, they invited me in their office for further conversation. We developed a good relationship, therefore, could correspondence via email and telephone, and then we arranged the dates for meetings according to their convenient time.

After agreement of respondents from G-B interviews were held with them in different places. As I mentioned some certain questions were prepared related to my study.

These questions were used during the interview with G-B. The interviews were conducted with support service people in the hotel, where conference was held in their appropriate time. It was the second day of the conference and we all had time after finish the sessions. The amount of the interviews with support service people were around 30 minutes each. Around twenty days later the interview was conducted with the trustee in a hotel in England, we discussed on the learning difficulty issue around two hours. As we had some similar experiences due to both of us have siblings with disabilities. First we discussed on personal issues then he answered my questions. His answers were quite lengthy, but I tried to keep those answers in short in my notes.

The interviews with the trainer and the communication officer took place in G-B's library in different days, which was around 30 minutes each. They were asked some certain questions and their answers were very structured and clear. Meanwhile, they provided some extra information about their group, which was not related with my research. I was allowed to use their resources from their library. In the library, I was introduced with a self-advocate, who has a learning difficulty, who works in that library. During my visits to the G-B's library, this self-advocate was interested in my research topic, later she was agreeing to discuss on some certain aspects, which took place of the unstructured interview. The questions can be found in appendix 2 (please see Appendix 2).

Among of the five support service people from G-B, the two people's interviews were used in this study. Because I focused on a group, the selection of a few respondents from the group was inevitable. Therefore, a manageable number of respondents were selected. By selecting the six different experienced respondents from G-B, it does not allow room for generalising the findings, but for the purpose of this study, the sample was sufficient and has provided enough data for the study.

The sample chosen was small, one focus group and six individuals with specific opinions on my topic of the research. The approach chosen to achieve this is a small scale qualitative study was a survey approach. Bell (2010) stated that surveys can extract information that can then be analysed so as to identify outlines and comparisons. Interviews were selected as the key data collection instrument with the additional use of observation and documents to cross validate the information gained from interviews.

3.3 Approach

For my small scale qualitative research survey approach was chosen. The aim of the research was investigate the concept of the advocacy and self-advocacy in the lives of people with learning difficulties. I wanted to understand the topic of my research from my respondents at the essence of the study and obtaining as much detail as possible through the survey. Bell (2010) indicated that the primary emphasis of a survey is fact findings and could be a quick way of acquiring information. As this research was a time limited a survey approach was ideal for this research. It might be worth noting, that survey approach is a quick way of gathering information but it was essential that the information contained as much detail as possible and that it truly reflected the perceptions of the respondents. Robson (2011) suggested that surveys are appropriate to empirical studies from specific sector of the population. As a small sample from a specific sector was chosen, a small scale survey was considered the most appropriate approach rather than a case study which focuses on individual, on a service, or a single location or situation. Though, the majority of the surveys use large samples that represent the public in general, the study undertaken was on a small scale and cannot be generalised in a statistical way. The findings, however, do provide an understanding and insight into the concept of the advocacy and self-advocacy in the lives of people with learning difficulties that may use full for others, who are concern in this arena.

The choice of approach was determined by strength in relation to the size of research, availability of the resources and timescale of considering the research. In the issue of the design concern and the various things (Robson, 2011) I was cautious when undertaking this research. In addition, British Education Research Association (BERA, 2011) stresses that we should use approaches that directly address the problems and issues of practice which may lead to the development of strategies and produce usable knowledge. Therefore, I feel that the survey was the best approach to understand the advocacy and self-advocacy in the lives of people with learning difficulties.

3.4 The Methods or Instruments

Research methods are described as the techniques for data collection. The reason for choice of my methods I used in this study was, as based on what kind of information is being sought, from what kind of circumstances (Robson, 2011). The primary method used to gather the qualitative data was interviews, observation and documentation were used in combination with findings. The use of multiple methods is considered (Cohen, 2007) a good practice and leads to effective research studies. In my case, I mainly used interviews and public documents of two groups (G-A and G-B) in conjunction with observation and secondary data from literature reviews. Denscombe (2007) mentioned that through many types of interviews data can be collected, however the unstructured interviews was used , which had loads of freedom and gave room to a lot of lengthy answers.

As mentioned previously, that the six unstructured interviews and one focus group interview were chosen, because of its adaptability and flexibility. This method was selected because through interviews it was possible to discover the ideas, exploration responses and investigate motives and feelings, which the questionnaire can never do (Bell, 2010). The interviews conducted, which were guided by conversations and discussions rather than structured or semi-structured interviews. Even though, I was pursuing the concept of advocacy and self-advocacy in terms of learning difficulties, my questions were flexible and fluid rather than inflexible (Yin, 2009). Conversations were not constituted and it took a form of unstructured interview (Hitchcock and Hughes, 1995). In addition, a group interview was used in complementary roles in order to collect the data. “The strength of the group interviews lies in the insights that they can provide into the dynamic effects of interaction between people […] how views are formed and changed” (Hitchcock and Hughes, 1995, p. 161).

The interviews were conducted in different situations with G-A and G-B, which explained earlier. The answers to the questions came out in the real project. In addition, the questions were used to an appropriate level and they were neither too easy and nor too difficult. Words like advocacy and self-advocacy were not frequently used during the interviews, instead easier then advocacy such as confidence, independent were used.

There were many reasons for my choice of the interview method. The qualitative research interviews are necessary in a certain circumstances (Robson, 2011). For example questionnaire responses that are taken at face value, interview responses can be developed and clarified through encourages. Hitchcock and Hughes (1995) argued that the unstructured interview depends for its attainment on the association that is developing between interviewer and respondents. In particular, Denscombe (2007) stated that interview technique can produce words in the form of comments and statements. Its aim is to find out people’s feelings and experiences from their own perspectives rather than from the researcher. In this study the interviews allowed to respondents to express their views, feelings and opinions which may help to fill any gap in practice (Winter, 2000a) in the area of advocacy and self-advocacy in the lives of people with learning difficulties. For the interviews, I did not want to use a prescriptive schedule but opted for one that allowed for more flexibility and that encouraged to respondents to express their feelings and opinions openly. Consequently, the interviewing process, for this study, the appointments were done to avoid inconveniencing the busy schedule of my respondents.

Throughout the interviews, the notes were prepared on both verbal and nonverbal communication. This was an important factor as the subject in the G-A group has learning difficulties, even though they were verbal, they did not always have an appropriate vocabulary to describe feelings and opinions. However, the body language gave a good indication as to what was felt in response to a question.

The advantages of using this method for the collection of the data, that it does not only allowed me listen to the verbal responses from the respondents, but also allowed for the observation of their body language. On the other hand interviews are time consuming, very subjective technique (Bell 2010) and sometimes respondents answered very long.

During the three days conference, I attended with G-B, the observation helped me to understand about support services' work with people with learning difficulties. The observation was an additional instrument in providing the extra information (May, 2001) about the groups being studied directly (Robson, 2011). Likewise, it provided me a better understanding of what is happening in the culture (Bell, 2010) or to find the answers of my research questions.

The documentary research method is another method used for data collection. This is because two groups involved in this study have documents that trace the information about them. The documentary resources were divided into two categories, primary sources and secondary sources data (Bell, 2010; Cohen et al, 2007). The term primary sources are those found into existence in the research time for instance, visiting of the groups, focus group interviews, interviewing through conversation or discussing (Hitchcock and Hughes, 1995). Secondary sources are those the people with learning difficulties described, but descriptions were obtained from other sources, for example, quoted materials, annual reports, news published in newsletters (Bell, 2010), and videos were used in this research. One of the main advantages of the documentary research method, that it was less expensive, (Robson, 2011) than the structured interview. I adapted a flexible research design to accommodate information and analysis the data throughout the research (Robson, 2011) process. It helped me in to break the documentary research into steps to answer the research questions (Hitchcock and Hughes, 1995). The documents appertaining to the G-A (please see Appendix 3) has had the name of the groups removed so as to maintain anonymity.

3.5 Ethical Consideration

Cohen et al (2007) recommended that the ethical dilemma facing researchers is balancing the demand to find the truth and observing to the rights and values of the subject. Further, he indicated that the principle of informed consent should be apparent at the initial stage of the research study. In other words the informed consent has been obtained, which allowed me to visit the groups and had gave me the access to respondents. To obtain consent for the study, the permission was granted by telephonic and face to face verbally during the collection of the data. A summary of the study was presented that provided full details and its primary focus. After obtaining all respondents' consent, to assure the people from groups of anonymity and confidentially, it was agreed that neither their name nor age would be used in the final research draft. After sampling, the people in both groups were asked if they were willing to be interviewed. Having given their consent, the initiated was taken for the study. Robson (2011) stated that in research it refers to general principles of what one ought to do especially when dealing with vulnerable people, for instance, children or the disabled people. The ethical issues that arose from my study were informed consent, access, matters of privacy and confidentiality. During the interview and discussion with respondents it was explained to them that they do not have disclose anything that makes them feel uncomfortable, only what they feel happy with. As they spoke openly and freely in a relaxed atmosphere, there was a sense of confidence. I assured them that this is also a learning process for myself and my endeavour is to understand each individual and group, then implement this knowledge in future practice. I also expressed how it was their choice to end the conversation at any point should they wish to do so. It is worth noting, that not one of them stopped the discussion or conversation at any point.

A information letter (please see Appendix 4) was written for my research, but when I shared my personal experiences as an employee in the disability field in India, some of my respondents did not required that. Instead I obtained a verbal permission from both groups and respondents. My presence as a researcher was an important factor that allowed all to be open about their feelings and personal experiences. Myself being a female and a family member of the sisters with disabilities from India, and studying in Inclusive and Special Educational Needs in the UK, I have been highly praised by the majority of the respondents. Once the data had been collected it was stored correctly due to its confidential nature (BERA, 2011).

3.6 Validity

Validity and triangulation are essential elements to an effective research study. The concept of validity is defined by a range of terms in qualitative studies. For Winter (2000, quoted in Golafshani, 2003) this concept is not a single or universal concept, but “rather a contingent construct, inescapably grounded in the processes and intentions of particular research methodologies and projects” (p. 602). Cohen et al (2007) advocated that in order to ensure validity there are many ways in which verification on the validity of the findings can be undertaken. In similar notion, Denscombe (2007) proposed that researcher to avoid overs implications and make sure that they offer consistency. He further suggested that the research findings to be backed by information so that they may give their opinions on the explanations given in the research. In the case of my study, it is obvious that all these issues were observed. This includes making sure that the research was honestly conducted based on principles that allow triangulation (Kirk and Miller, 1986), and my experience as a social worker, who is coming from a similar background has not affected the research study in any manner that would falsify the data. My experience was used, as I used to visit in fields and conducting the interviews with people with the disabilities and social supporters. I was persisted the objective all the time. The respondents were interviewed from two groups and had corresponds via email with them for further information. To achieve reliability and validity one focus group interview (G-A) and six respondents (G-B) were chosen for the study. A further method selected to crosscheck the findings was triangulation. Robson (2011) believes that triangulation is essential to assure an in depth understanding of the issues. Moreover, he stressed that it is important in the analysis of the qualitative data in relation to its trustworthiness. I tried to compare the collected data from different methods such as focus group interview, face to face interviews and documentations for its validity. In addition, I realised that respondents answered the questions openly and decently, therefore adding to the validity of the study and measuring its reliability if someone else were to do similar research.

3.7 Practical Issues

There were some practical limitations occurred during the collection of the data. Firstly, the main limitation of the research is the limited time to collect and understand the data. The study was conducted in West Midland in England, which is a relatively large area to cover. I travelled to G-A twice but to G-B was visited several times to use their resources and to meet with the people were interviewed. Secondly, these two groups involved in this study, the information flow from workers was strictly controlled by the authority. Hence, some past documents and displayed information were not obtainable. Thirdly, the sense of novelty from the groups was quite challenging. The challenges were accepted and I tried to work as a mission on it. However, during the research occasionally I lost confidence in collecting and analysing the specific data, because collected data was unstructured. Likewise, there was a problem in accessing the secondary data from textbooks, journal articles and on-line research in the university library, because may be less attention has been given in this arena. Fourthly, the attitude towards being an international student was another cause of hindrance. For instance, obtaining the permission to conduct the research with groups from the relevant authority was a constraint. Finally, the constraint I felt, as interviewees lacked focus on the topic because interviews were conducted in an informal conversation and discussion way.

In conclusion, in this chapter I have endeavoured to outline the methodology and methods. For this small scale qualitative research the survey approach was used. I have used interview as a key methods in this research for collecting the data with the documentary methods. In addition, ethical consideration and validity of the qualitative data were discussed. Finally, practical issues in gathering the data were highlighted. In the next chapter I will analysis the collected data and then following, the discussion of the findings will be discussed.

Chapter Four- Data Analysis and Discussion of the Findings

Perhaps the most challenging task in this research study was the analysis of the qualitative data. In this chapter, firstly, the process of the analysing the data will be addressed, which categorised by linking up ideas depending on the relevant themes. Secondly, analysis and discussion of the findings come under the themes are discussed in relation to the literature review and the research questions. Following, I very carefully attempt to cautiously generalise my findings and reflect on its recommendations. Finally, I will discuss the strengths and limitations of the research.

To assure the respondents' anonymity and confidentiality, it was agreed that neither respondents' name, age nor the name of the groups would be used in the final draft of this study. Considering ethical compliances, I used fictitious names in codes, in the findings and discussions of my research. The sample of the coded name of my respondents from G-A and G-B is given in appendix 1 and 2 (please see Appendix 1 and 2).

At the first stage, the data collected from the G-A and G-B through interviews was recorded in the form of note and later written out in full. During this process of analysis, I had started to identify the themes and ideas from interviews and documents. Further, made the tentative points next to certain details and related them to the relevant questions and the literature review. In the second stage of data analysis, I initiated the formal coding (mentioned above) and categorising as I attempted to search for patterns, relationships and uniqueness. I then colour coded the information according to themes heading. Alongside this I began to cross reference points with the relevant documentation and made short notes and indication as to where the significant sections were to be found. Thus, the final analysis of the information was initiated. I was quite surprised to discover that some of the data, collected from the two groups, was not relevant to the presentation and analysis of the research. However, I realised that it was relevant to the discussion. Therefore, I used that data according to my themes and colour coded them too.

This research investigated the concept of advocacy and self-advocacy in the lives of people with learning difficulties. The findings are interwoven and discussed in three questions, coming under the themes included one of the research questions. Now I am being with the analysis of the following questions:

1 What is the meaning and purpose of advocacy and self-advocacy? 2 How advocacy and self-advocacy groups impact on the lives of people with learning difficulties? What are the challenges faced by individuals and the service providers of the people with learning difficulties?

4.1 What is the Meaning and Purpose of Advocacy and Self-advocacy?

This is a simple question but yet it was an important to ask this in order to understand the concept of advocacy and self-advocacy. It is apparent from the literature and the respondents' responses that the terms advocacy and self-advocacy tends to be a broad spectrum. However, findings of my research highlight that the meaning of advocacy and self-advocacy is 'speak up' for themselves and everyone should be listened to on an equal basis. In addition, the main purpose of advocacy and self-advocacy seems to be the importance of enhancing the quality of life for the people with learning difficulties and to be treated as equal citizens in the community.

The respondent TT says that advocacy and self-advocacy skills can give to people with learning difficulties certain advantages in the most difficult situations to speak up themselves. For instance, he expressed that,

> "*Advocacy for people living with a disability or learning difficulties involves speaking up with, or on behalf of, a person or a group, in order to safeguard their rights and improve the quality of life*".

Further, he expressed his thoughts, that the advocates for the people who raising the voice for people who are in need. However, he felt that advocacy and self-advocacy cannot be defined as he said:

> "*It is very difficult to explain what is advocacy and self-advocacy in the words. I just contribute my experiences with G-B and help the people in their lives. I encouraged the people to join us because it is important for people with learning difficulties and without society's contribution it is not possible to help who are in need."*

On the other hand, the findings of this research show that advocacy is to stand up or speaking up for others to make changes in their lives, such as:

> "*Advocacy means to speak up for someone. Most of us at sometimes in our lives speak up for others or hope that someone will speak up for us when we need*

> *support. Moreover, advocacy is about making things change because people's voices are heard and listened to*".
>
> (*G-B, webpage*)

According to above illustrative quotes advocacy is to speaking up for others. However, self-advocacy is the speaking up by people with learning difficulties on their own. According to annual report of G-B (2009-2010), there is a person with a learning difficulty who was a member of the self-advocacy group became trustee in the G-B. He found his role exciting,

> "*I have had my point of view listened to and it has helped me to understand other people's problems and that everyone has rights*"

He felt that he has a big responsibility in this experience he said that:

> "Although I am a self-advocate *it is an achievement to do work as a trustee and it gives me responsibility to say what I want and what I think, it is a responsible job"*
>
> (*G-B Annual Report, 2009-2010*)

Similarly, during the conversation, SA who has been working for seven years with G-B, expressed her responsibility and joy to be associated with this group. During the conversation about her experiences, she was observed and found her confidence and the joy on her face. About her responsibility she said:

> *"I look after the library and update the database here, I feel as an independent and responsible individual*".

However, she mentioned that she faces some challenges in her life. As every day SA commutes some distance from her house, which may be challenging for SA. She puts it this way:

> "*I travel everyday by bus which is pretty much an exhausting task and quite exhausted challenging for me. I must be during very vigilant whilst the travelling and sometimes I feel tired from the journeying*".

The above quotations exemplify of the contrast opinions, because in the office SA is confident and responsible person. However, at the time during the travelling SA might not feel secure and autonomous, even she may not self-advocate her own.

Throughout the focus group interview with G-A, I found people with learning difficulties' satisfaction to be associated with the group. In addition, the majority of the respondents expressed their feelings and confidence to speaking up for themselves and other people in the community. According to them self-advocacy is about empowering to the people to speaking up for on their own. However, every member of this group indicated that they need support from groups to speak up themselves. Moreover, the literature illustrates (Goodley, 2000; DfES, 2001) that advocacy is representation of the views and interests of one person or speaking up on behalf of someone while self-advocacy is expression of an individual on their own. Through this discussion on self-advocacy, still it is not clear that self-advocacy is advocacy by self or with the help of others.

It is clearly signifying that interviewee from G-A not only work together, but for their encouragement they need support from the group. This transpires in their newsletter as one person said:

> "*I think that it's important to be able to get together as a group and talk about the things that we want to change*."
>
> (*G-A Newsletter, Spring 2010*)

The above quotes also indicate that they need to work collectively to raise their voice. Moreover, literature shows that self-advocacy is a collective action, it does not an individual action (Goodley, 2000; Dybwad, 1996).

The results of my study show that advocacy and self-advocacy is taking a self-decision by people with learning difficulties altogether. As in the group interview with G-A, PS2 indicated that:

> "*All of the work carried out by and with learning disabled people through G-A is a person centred. In addition, that G-A run by a management committee of 12 learning disabled people. At the meetings we discuss the work […] we take decision altogether".*

Furthermore, during the focus group interview most of the interviewees expressed that with the help of the G-A, they could find out their own flat and left the parents' house. However, the findings from G-A's newsletter illustrates that they also work with parents to build their confidence, because:

> "L*earning disabled people have a right to a family life but that the children of learning disabled parents are often taken away by services*".
>
> (*G-A Newsletter, Autumn 2010*)

This statement shadowing that G-A favour to the family life, in contrast, adults left their parents' house. Hence, it is not clear that G-A supports to the adults with learning difficulties to become independent, but the question arise, how do they provide the support to family life? It can be noted from the literature, that groups support the people with learning difficulties, so they can speak their own as an individual and/or as a group. In this case, people with learning difficulties may often depend on others for their decisions.

4.2 How Advocacy and Self-advocacy Groups Impact on the Lives of People with Learning Difficulties?

The findings of the research show that G-A and G-B work in partnership with people with learning difficulties and with other groups to provide the trainings for their learning and development. However, the literature review of the research illustrate that the training is the focused goal of the groups to enhance the understanding of the rights of the people with learning difficulties , which does not put the emphasis on independent self-advocacy. The findings of the research disclose that independent self-advocacy services are the most difficult challenge for people with learning difficulties. The G-B provides the trainings to groups, however, CO from G-B said:

> *"We work in partnership with a wide range of organisations in development for workers in the learning disability sector. We provide trainings to the groups to enhance independent living of people with learning difficulties".*

However, G-A works in a different way for independent self-advocacy services, according to its newsletter:

> “*G-A have been working to supports organisations to work well with learning disabled volunteers, because we believe that learning disabled volunteer should get the same chance to advocate as everybody else*”.
>
> (G-A Newsletter, Autumn 2010)

The above both quotes show that the procedure of the groups is different, such as one group provides support to the groups, but anther group provides an independent self-advocacy service. The findings of my research reveal that accessing independent self-advocacy service is the most difficult challenge for people with learning difficulties, as TR expressed:

> *“Training for the independent self-advocacy is the most difficult challenge for us, because historically people with learning disabilities used to live in the institutes and advocacy was provided by service providers”.*

The findings of the study and the literature show that (Rix, 2006; Mack, 2001) groups work in partnership with independent self-advocacy groups in an easy way. For instance, G-B uses a specific packs that produced by DfES (2001) entitled Self-Advocacy Action Pack that focuses specifically on teaching adults with learning difficulties how to speak up for themselves. This pack has pictures with text, which is easy to understand for people who are not able to read. Similarly, in the interview LDV4 said:

> *“I cannot read words, but I can read pictures. Good pictures help me to understand the information. […] easy words and pictures are important to help learning disabled people understand the information”.*

In spite of advocacy and self-advocacy trainings people with learning difficulties are dependent on the groups or supporters. Findings of my research reveal that people with learning difficulties associate with the self-advocacy groups and stand up for their rights. But they do not make their own decisions. They are helped by groups for their everyday needs. For instance, in the conference (G-B) during the session, one person with learning difficulties exhibited his experiences. He said:

> “*I was in an institute, my family rarely visited me. I associated with the Mera Ghar support group (change the name of support group), they helped me to come out from the institute. Now I live in my own flat and I am an employee in a small company. The people from Mera Ghar support group helped me with all my needs”.*

This statement shows that he lives independently, however, as per my observation this person was not speaking up on his own. The supporter was standing behind him and constantly asked the questions and guided him for answers. I felt that the support service person may have put the person under pressure in the conversation. I noticed a similar experience during the group interview with G-A, most of the time PS1 and PS2 were leading the conversation and according to their indication people with learning difficulties replied. However, some respondents were very confident to answer the questions and expressed their feelings.

4.3 What are the Challenges Face by Individual and the Service Providers of People with Learning Difficulties?

The findings reveal that advocacy and self-advocacy enhanced the quality of lives for some people with learning difficulties. However, people with learning difficulties still face some challenges to live independent lives. This section of this chapter will discuss the challenges, which are discovered from the collected data of this study as well as from the literature.

4.3.1 Perceptions Shift from the Medical Model to Social Model of Disability

The perceptions shift from medical model to social model of the disability, this has proven to be a significant challenges in terms of accessing advocacy and self-advocacy services in the lives of people with learning difficulties. Historically people with learning difficulties have been perceived as people with a medical condition up until the last few years. In the light of the literature discussed in chapter two it can be seen that the formation of disability movement and self-advocacy movement has enhanced the shift to the social model of disability. However, people with learning difficulties were not included in the disability movement in comparison to people with physical disability. Moreover, it is clear from the definitions of disability and impairment, that people with learning difficulties are still tend to be perceived as people with a medical disorder. In this case, people with learning difficulties placed into institutions, which is unfair. For instance, TT expressed his feelings that people with learning difficulties should not put in to institutions. He said:

> "*I do not know why people put their family members, who have a learning difficulty, into institutions. The family must take responsibility for their children or*

> *adult with learning difficulties. My brother lives with us and we are happy with him*".

Several people have been moved from institutionalised care to community. SP2, who support the people with learning difficulties by moving them from institutes to community, said:

> "*These people who have lived in institutions all their life are now frightened of staff and other people in the community making them incapable to access their basic needs and choices*".

He expressed that sometimes even the family members do not accept them, so these people live on their own with the support of services. SP2 argued that staff or service providers, who have been working with people with learning difficulties, perceive them as with a medical condition. The majority of the respondents indicated that despite there have been changes in attitudes, still there remains a considerable number of people living in institutes. This affects their prospects of receiving advocacy and self-advocacy services. For example, PS2 expressed:

> "*G-A operates the social model of disability and recognises that meeting the access requirements of learning disabled people facilitates true involvement, however, we face challenges when society do not give them any respect"*.

It is worth noting, that in G-A's documents and in the focus group interview they use term 'learning disabled'. However, two respondents from G-B, SP1 and SP2 used the term carefully and during the interview they supported to the social model. They stressed that how a shift from the medical model to the social model is crucial to enable the in order for people with learning difficulties to get access the advocacy and self-advocacy services in the community.

4.3.2 Attitude towards People with Learning Difficulties

The findings of the research indicate that people with learning difficulties are speaking up for their dignity and rights. According to the respondents, some people in the community do not treat to people with learning difficulties with equal respect or dignity. It might be due to a lack of awareness and a negative attitude towards the people with learning difficulties. As mentioned in the chapter one that advocacy and self-advocacy in the lives of people with learning difficulties are related to concepts, for instance, their rights, choices and independence. However, SP1 stated that this population still institutionalised and staff members, service providers and volunteers, find difficulty to change their attitude from medical way. In the interview TT expressed his anger and said:

> "*My brother was confronted with many problems in the school due to his poor writing and reading. Even now he faces several challenges, but he has developed considerably in his study. I felt anger when people labelled him as 'mentally handicapped' to him. Now it is labelled 'learning disabilities', although it is remain a label but not quite as hurtful as before. However, I feel that people have not changed their attitudes towards these people*".

However, in the G-B's office SA was observed with respect and dignity. The people around her were behaving with her in an equal bases their attitude was positive.

4.3.3 Relationship and Networks

Another leading theme arising from the findings of this research, that the respective roles of people without the label of learning difficulty within and outside the self-advocacy movement. Issues that were deliberated included: What is the nature of the relationship between the self-advocate and the supporter? To what extent have self-advocacy groups associated with parents and professionals? It is worth noting, there are still a certain number of people living institutionalised lives even though social model of disability has been changed dramatically (Goodley, 2000).

The paper presented by Bush (2012) at the conference, (I attended at the G-B) addressed the key issues of advocacy and self-advocacy in the contemporary services, that pertinent to current policy and practice in learning difficulties support services. Interesting the supporter is employed by the advocacy and self-advocacy groups in England. The employee's role may have a wide remit, including general administrative support, as well as a specific advisory function in research and office. Many supporters are family members such as parents and siblings, it appears that they remain closely tied to the self-advocacy groups in their roles as advisors. As mentioned in the literature (Mack,2001) that some groups are competent between self-advocates and parents. In the Mencap's video parents were speaking up for people with learning difficulties. Similarly, in the video from G-B namely 'Deprivation of Liberty safeguards' (Group B, 2009) there is more voice of parents than people with learning difficulties.

TT supported this idea and expressed dissatisfaction from the provision and policies, he said: "*Family members know about needs of their disabled family member. Therefore, in* *advocacy system they must be involved".* Even he highlighted the role of siblings in advocacy, due to the close nature of the sibling relationship.

However, some respondents expressed their disappointment of the services. For instance, SP1 resisted poor services, damaging attitudes and oppressive practice for people with learning difficulties. He said:

> "*There are conflicts in the relationship between disabled and non-disabled people. In addition, there are sometimes complex negotiation between people with learning difficulties and staff paid to work with them, their families".*

This shadowing has made their dependency on the groups. As literature also indicated that disabled people are controlled by non-disabled people, disabled people have only limited control over their groups (Oliver and Barnes, 1998). Likewise, in the focus group interview some respondents showed dissatisfaction about difficulty to live independently in the community and speaking up on their own. They expressed their sincere disappointment concerning to the dearth of support from professionals and family members. LDV4 who used to live with parents but after her mothers' death she was taken in a social care home with the agreement of her father, where she faced some challenges:

> "*I was living with other people in that social care home, but I had a problem there, which I cannot explain and I was not happy there".*

This statement shows that she was not satisfied with the services they were providing to her.

4.3.4 Funding and People with Learning Difficulties

The majority of the respondents in this study show their disappointment on current financial crisis. During the focus group interview some of the respondents expressed:

> "*Learning disabled people are become more isolated due to cuts in taking place both the support and day services".*

To oppose the government's provision the members of G-A and their families, attended a peaceful rally against the cuts in October 2011, according to their newsletter:

> "*We campaign to bring together disabled people and disabled people's organisations to tell the government to stop the cuts*".
>
> (G-A Newsletter, Autumn 2011)

Even during the conference almost every present supporter had an anxiety that cutting the funds will increase the pressure in the lives of people with learning difficulties. According to the SP2:

> "*The government must urgently reform the system and invest more money to end the care crisis or many people with a learning difficulties, their families and carers will struggle*".

As findings reveal that in the time of the cuts, people with learning difficulties' human rights are more important than anything else. The literature also show (BBC, 2012; People First, 2011) that the current economic crisis has significant impact on the development in the lives of people with learning difficulties in England.

4.3.5 Challenges in Human Rights

One criticism discovered in the literature review was the people with learning difficulties were discriminated in the disability movement (Armstrong, 2002). Therefore, it is clear from the literature that advocacy is taking actions to help people with learning difficulties to say what they want, secure their rights, represent their interests and obtain the services they need. DfES (2001) declares that self-advocacy is about the speaking up of people with learning difficulties for their rights. In relation to this issue, the TR expressed that G-B has challenges in providing the services for the rights of people with learning difficulties. He said:

> "*We provide trainings to people about the rights of people with learning difficulties, but it is difficult to achieve the goal"*.

Furthermore, according to G-B's annual report (2009-2010) the aim of the G-B is achieving the rights, which are for people with learning difficulties about being treated respectfully and as an equally to everyone else. My respondents believe that people with learning difficulties have exactly the same human rights and in all aspects of their lives the right to be treated. For instance, they have the right to speak up, to live independently.

Despite the declaration of UNCRPD (2006) and the *White Paper Valuing People* (DoH, 2001) many efforts have been made in England by support services in achieving the rights. However, annual report of G-B reports that from black, Asian, minority and ethnic communities, several people with learning difficulties feel more discrimination in achieving their rights. The annual report illustrates that:

> *“They talked about the cultural barriers to getting the right information, about what the right support would be and how to make health and social care organisations better understanding what they need”.*
>
> *(G-B Annual report, 2009-2010)*

In general, people with learning difficulties need to be treated with dignity and respect. Recently the Minister of State for Care Services pointed out that people with learning difficulties have a right to lead their lives, as fearless being and he persists in his efforts on the government to take actions on this matter (UKPA, 2012).

Based on the findings of my research it is clear that advocacy and self-advocacy are in controversy. For instance, people with learning difficulties are allowed to be self-advocates or can they be advocate for others. In order to analyse advocacy and self-advocacy, our society has generally relied upon advocates. In the past, we required these advocates because traditionally, ordinary people could not read or speak and they depended on the politicians, charities and health professionals. However, much of the unusual criticism was targeted against those institutionalised forms of political and welfare provision.

As it has been mentioned in the literature review, since the self-advocacy movement started in England much progress has been made in changing the attitudes of both people with learning difficulties as well as those people providing services to them. It is worth noting, that the self-advocacy movement has been developing the lives of people with learning difficulties. The literature also show some examples (in 2.3.1) of life stories about self-advocates, which reveal that not only self-advocacy has occurred from groups, but that personally people with learning difficulties are capable to speak up on their own. Therefore, society has become much more aware of the needs and rights of the people with learning difficulties. Furthermore, the legislation, such as the *White Paper Valuing People* (DoH, 2001) given the legal underpinning and support to obtain equality and accessibility in all areas of their lives.

However, there is still much work that has to be done to ensure people with leaning difficulties get their rights. By providing the insight into and dilemmas surrounding advocacy and self-advocacy, it can be argued that if self-advocacy is understood as a political process, which enables individuals to empowerment. Therefore, it is significant to pay attention to its link to the wider self-advocacy movement. It is clear from the literature that people with learning difficulties are fighting for their identity and self-advocacy, which is far from being an outspoken issue (Goodley, 2000; Harris, 1995; Simon, 1992). In addition, within the field of the self-advocacy movement, various questions remained unanswered. For instance, who decides if someone has a disability or has a substantial impairment? Are people with learning difficulties really making the decisions on their own or are support service people making the decisions for them? Are people with learning difficulties only allowed to be self-advocates or can they be advocate for another person? How many self-advocates sit in a leadership position of the groups?

Although it was not possible to find out the exact answers of these questions, however, advocates must be extremely careful to make sure, that what is advocated for and what self-advocates want. It is crucial to have independent advocates supporting to the people with learning difficulties in order to decrease the level of conflict between service providers and the people with learning difficulties. This is evident from the literature and responses from the respondents that this is a common issue for them with the staff being more concerned for their safety as if it is a medical disorder.

Moreover, self-advocacy by self-advocates seems to be the effective action, as LDV4 has been self-advocate since 1996 and it has enhanced her quality of life enormously. Furthermore, TR highlights the importance of self-advocacy and needs to promote the service providers to encourage the people to join a self-advocacy group in the community. Some members in the focus group interview, respondents expressed the related thoughts, LDV1 stated:

> "*I think we have to give priority to enhance the capability of the people with learning disabled people to become self-advocates. Then the resources should be introduced to the community".*

It appears that self-advocacy is a significant factor to enable people with learning difficulties to speak up for themselves.

Findings of this research show that the advocacy and self-advocacy groups develop equality and to enhance the advocacy services in the community. As for the question posed in this research, it is difficult to answer it precisely.

The anticipated funding for independent self-advocacy schemes, promoted in the White Paper Valuing People (DoH, 2001) may lead to the action of self-advocacy. However, during the conference conducted by G-B, support groups and speakers indicated that this will not happen at this time due to the cuts being made to the disability allowance in England. It was discussed that this will have a significant impact on the provision of services for people with learning difficulties. So, it is really important for the government to have face-to-face meetings with self-advocacy groups if they want people with learning difficulties to know about changes to their benefits. The new benefits should be for all disabled people including those on the lower and higher support needs. Unfortunately, it is often the case that those with learning difficulties do not even qualify for the lower level of support, which often results in a higher level of support being required when matters deteriorate.

The focus group of this study, opposed the governments' new cutting funding scheme. They expressed that there should not be any cut at all made to the disability living allowance if it leads to more people with learning difficulties having less choice in their lives. Making these benefits cuts may lead to people with learning difficulties having less independence. However, TR expressed that advocacy is not all about the money alone, but people with learning difficulties need support from support service people (advocates) to speak up for them on their issues and rights.

From the results of my study, another component I would like to mention that I was not able to find any gender issue in the lives of people with a learning difficulty. However, a female with a learning difficulty, who tried to raise this issue, argued with her colleagues she was told that "People with a learning disability are just that people with a learning disability" (Rix, 2006, p. 168). Even my respondent PS1 from G-A, who has physical disability, expressed that she is discriminated by society on an increased level. Firstly due to her gender, being female and secondly due to her disability. When I discussed the issue of discrimination of girls/women with disabilities in India, she expressed that even in this developed country (England) several times she faced discrimination by society. But women with learning difficulties face more discrimination because disability society is dominated by physical disabled people itself. Apart from this none of the respondents, mentioned gender discrimination in this area. However, LDV4 articulated her anger against a male social carer in the institute, but it was not clearly explained. It may be due to it being so uncomfortable for a woman to share certain feelings and issues with others.

A future recommendation would be to involve more respondents from learning difficulty groups in order to give a more comprehensive insight to the concept of advocacy and self-advocacy. People with learning difficulties must be involved in the research as it is a powerful resource of providing accessible information and to empowering those with learning difficulties.

4.4 Limitations of the Research

This study has several limitations. A limitation of this study was it used a small number of respondents from two groups in one region in England, which means that this limits the possibilities for generalisation. The research papers, books and reports that discuss on advocacy and self-advocacy component in the perspective of the people with learning difficulties were not easily accessed in the library. Therefore, the main difficulty I had to overcome during this study was that to travelling from my destination to G-B several times in order to use their resources to collect the data, which required expenditures, time and the physical ability efforts. One more limitation which I would like to mention was the limited resources available on the Indian provision and practice on the advocacy and self-advocacy in the lives of the people with learning difficulties for comparison with the England’s provision, which was quite a challenge for me. In this case, the England context was selected for the research project due to the limited I had to collect the data for in-depth research. Another major challenge was the short period of the time available to explore the first-hand experience in this country. In addition, the culture, education system and environment of the England, are different from my country (India). Hence, I could not easily familiarise with the lives of people with learning difficulties in this nation. As an international student and a non-native speaker, to collecting the information from both groups was also a challenging task for me. Besides those limitations I feel that the voice of people with learning difficulties is not sufficiently represented in this study. Although, two forms of instruments were used to collect the data, I feel this was not sufficient for triangulation purpose in some parts of the research, for instance when respondents from G-B were interviewed.

Regardless of these, focusing on literature and fewer respondents, the data obtained in this research was unique and relevant to the research, which gave me a deeper understanding of the topic of my research. It has been a process of value which was pretty much inspirational in the experiences that I encountered while interacting with two groups in England. Moreover, I became quite a friend and as a member of G-B, am able to access more information on these issues. Having the opportunity to network with international researchers who work with people with learning difficulties, I am hoping to share my research results with them.

In conclusion, the results are illustrated in this chapter of the challenges which people with learning difficulties are facing. Amongst which are, their identity in leading their lives as disabled, their fight for dignity, acquiring and accessing what is rightfully theirs, fighting against government cuts and the attitude of the service providers. Despite all these challenges people with learning difficulties are beginning to speak up for themselves, on their own and with the help of advocacy and self-advocacy groups. Furthermore, the limitations of the research are discussed. The next chapter is concerned with the conclusion and implications of my learning.

Chapter Five -Conclusion and Implications

In conclusion, a brief background of the advocacy and self-advocacy in the lives of people with learning difficulties in England is considered. From the review of the literature, I have learned that the disability is considered as the oppression and segregation that people having impairment in social structure rather than individual bodily asset. Furthermore, the term learning difficulties can be seen as individual impairment. I also learned that advocacy and self-advocacy give a voice to people with learning difficulties and they can speak up on their own for their rights with the help of groups. A qualitative research was designed and I have used multi-methods, such as interviews and documentary methods to collect my data. The specific findings highlighted, that the challenges faced by people with learning difficulties, such as their identity living life as a disabled person, fighting for their rights, and the attitude of the service providers are the challenges in attaining independent self-advocacy by people with learning difficulties. An overall conclusion from this research is that people with learning difficulties need to be given the opportunity to speak up regarding their basic rights. Although there have been several improvements in the lives of people with learning difficulties through advocacy and self-advocacy movement, there is still much work that has to be done.

This study has not enabled me to gain appropriate answers of the questions, which outlined in the introduction. However, I obtained a deeper understanding of advocacy and self-advocacy in the lives of people with learning difficulties in England. The whole Inclusion and Special Educational Needs programme (ISEN) and this research provided me insight and much in-depth knowledge on these issues. During the research I have learned that people with learning difficulties face endless challenges leading their lives in their disabled world.

However, I am not satisfied with the methods I used in this research. Therefore, I will further investigate the life-history or story approach and continue with interviews amongst people with learning difficulties as part of the research. In the future, I hope to carry out similar type of research with people with learning difficulties and their families in India, attempting what kind of the challenges they face in the Indian context. In addition, I intend to undertake interviews so as to ascertain the day to day trials and triumphs they experience. With the participation of the families and relevant charities this in turn will hopefully lead to some changes in policy and practice.

As a result of this research, I have planned to include a component on advocacy and self-advocacy with people with learning difficulties in the training provided by my organisation back in India. My practice is related to disability with my colleagues, who also work with communities in rural areas of Rajasthan state in India, I hope to organise training sessions on interventions for disability rights in two cities (see appendix 5). I will also consider the possibility of involving their families. I will develop these initiatives through discussions with my colleagues. I will further consider whether this is something that can be transferred to community awareness programmes as well, so as to initiate a beginning for social awareness and societal responsibility, with the hope that this will lead to changes that are in line with the social model of disability.

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