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***Not for them or on them:  
Exploring advocacy outcomes with  
people, with learning difficulties***

E Gratsias

***PhD***

***2021***

***Not for them or on them:  
Exploring advocacy outcomes with  
people, with learning difficulties***

Emmanouil Gratsias

A thesis submitted in partial fulfilment  
of the requirements of the  
University of Northumbria at  
Newcastle  
for the degree of  
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Research undertaken in the  
Faculty of Health and Life Sciences,  
Department of Social Work,  
Education and  
Community Well-being.

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## **Abstract**

The PhD study looked at the outcomes and impact of advocacy from the point of view of the people that use the service. According to Atkinson (1999) advocacy in its simplest form is “speaking up” for oneself or others nonetheless it is very rarely that simple. Gray and Jackson (2002) suggested that advocacy is based on the fundamental principle that all people are citizens with the same rights and responsibilities and that there is a need to combat the exclusion and marginalisation experienced by members of our society by promoting access to human as well as legal rights. Macadam et al. (2013) argued that few research studies systematically examined advocacy’s outcomes and impact. The lack of systematic evidence has been suggested to be even bigger in terms of advocacy impact and outcomes from the perspective of the people that use the service (Ridley et al., 2018).

The study used principles of participatory research, an approach that encourages participants to actively take part and contribute to the research (Northway, et al., 2014). The researcher worked closely with a steering group of self-advocates with learning difficulties that were actively involved and contributed to all the stages of the research process. The study used focus groups and narrative interviews with 13 participants to explore the advocacy outcomes and impact of advocacy. The study was underpinned by the social constructivist research theoretical framework, a framework compatible with the principles of the participatory research approach and advocacy (Holstein and Gubrium, 2008).

The analysis of the findings suggested that advocacy is producing mainly two types of outcomes. End-point outcomes which involve reaching (fully, partly or not at all) a practical target, such as a house move, agreed in the start of the partnership. And process outcomes, such as learning and or positive feelings, which are associated with the advocacy partnership’s journey. The participants reported that both types of outcomes were valued however, process outcomes were highlighted to be important and valued even when the desired end-point outcome was not reached.

The study concluded with developing the Advocacy Partnership model which describes the advocacy partnership process or journey and also looks at the utility of advocacy work. It is argued that although advocacy strives to empower people to speak up and self-advocate the best outcomes from advocacy will be realised when people with learning difficulties self-advocate for themselves and their views and wishes are listened to and acted upon. It is nonetheless asserted that, during our often hostile for people with disabilities times, advocacy has an important role of an ally to play by continuing the struggle for a more equal, fair, just, inclusive and equitable society alongside advocacy partners and self-advocates.

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## **Declaration**

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work. I also confirm that this work fully acknowledges opinions, ideas and contributions from the work of others.

Any ethical clearance for the research presented in this thesis has been approved. Approval has been sought and granted by the Northumbria University Ethics Committee on 21/08/2012.

**I declare that the Word Count of this Thesis is 88162 words**

Name: **Emmanouil Gratsias**

Signature:

Date: **24/12/2021**

# **1. Introduction**

## **1.1. Overview**

The first chapter introduces the main areas of the thesis. It defines some key terms in the research study such as advocacy, learning difficulties, co-production, empowerment and advocacy outcomes. The introduction chapter continues by succinctly exploring the theoretical and philosophical framework underpinning the doctoral research project, the methodology and the approaches to data collection and analysis. It also explains the motivation behind carrying out this research study. The chapter continues by introducing the research questions as well as having a first look at the findings, the discussion and the conclusion chapters to follow.

## **1.2. Defining Advocacy**

Advocacy can be seen as a somewhat confusing term for people not familiar with the health and social care sectors in England and Wales and in general. According to the Oxford Dictionary of English (2010) advocacy is a noun with a dual meaning. “Public support for or recommendation of a particular cause or policy” and “the profession or work of a legal advocate”. It originates from the medieval Latin *advocatia* meaning “summon, call to one’s aid”. The term has been widely used from the legal professions in the UK and the rest of the English-speaking world but also in several other languages with Latin origin such as French, Spanish, Italian and Portuguese and in the countries speaking those languages. The legal professions have claimed ownership of the term and as Donnison (2009) suggested they were not particularly keen to have the word used by a different sector and initially objected to the use of the term by advocacy projects and advocates.

However, apart from struggling to be accepted, by the legal professions, advocacy also often came into conflict with other long established professionals such as medical doctors. Donnison (2009) reported that a number of psychiatrists have, particularly in the beginnings of mental health advocacy, objected to the presence of advocates as they were claiming that advocacy can disrupt the therapeutic process of the patient. I can testify, as

a practising advocate, that although advocacy is much more recognised nowadays and widely accepted in different settings, there are still occasionally some professionals that not always welcome the share of their power with the advocacy partners and particularly being challenged about decisions they have made.

Atkinson (1999), in one of the most influential definitions, proposed that advocacy in its simplest form is “speaking up” however she also noted that is very rarely if ever that simple. From a historical point of view advocacy behaviours such as speaking up for yourself and or others have been part of the repertoire of human behaviours for millennia (Donnison, 2009). Gray and Jackson (2002) however noted basic distinctions between the human disposition towards advocacy behaviours and more formal advocacy which is part of a more structured and regulated system. Gray and Jackson (2002) suggested that advocacy schemes are based on the fundamental principle that all people are citizens with the same rights and responsibilities and that there is a need to combat the exclusion and marginalisation experienced by members of our society by promoting access to human as well as legal rights. Atkinson (1999) sees the main principles of advocacy, shared in slightly different forms by all advocacy schemes.

### **1.2.1. *Why research Advocacy and its Outcomes?***

Advocacy has seen an increase in its popularity and size in the UK since its beginnings in the 1970s onwards. Advocacy grew following the successes of the service-user, disability and other social movements but mostly with the development of self-advocacy groups such as People First in London (Macadam et al., 2013). Furthermore, it grew bigger with the introduction of certain government initiatives such as Valuing People (2001) and the shift towards the personalisation agenda. Different schemes provided different types of advocacy services for a wide range of groups of people. The provision, in numbers, grew even further with the introduction of different types of statutory services such as the Independent Mental Health Advocacy (IMHA) service in 2009, which is looked at in more detail in the following chapter.

Advocacy research did not follow the same high growth rate as advocacy practice. A few research projects have looked at advocacy however they were mostly concerned with looking at the different principles of advocacy. The same can be said for research looking at the outcomes of advocacy but also at its monitoring and evaluation (Ridley et al., 2018). Although only a limited number of research projects were carried out, empirical evidence suggested that advocacy can bring a positive change (Townesley et al., 2009). What is striking though is that the research, that was carried out in order to explore advocacy outcomes, was involving a number of different stakeholders however not the people that were using the service. Research was carried out with social workers and other social services professionals, professional advocates, advocacy managers, advocacy commissioners, parents, doctors, nurses and other health professionals, but very rarely with the people that were using the service themselves (Ridley et al., 2018). It is hard to believe that the research, exploring advocacy the service that was developed to support people to be empowered and included, was excluding the people that the research was about!

### **1.2.2.     *How the idea for the research study was formed***

I have now been actively involved with advocacy for over thirteen years. I have been involved as an independent advocate working one to one with advocacy partners in different roles and settings such as with people with learning difficulties and with people experiencing mental health difficulties. Moreover, I have worked as a co-facilitator of self-advocacy groups mainly with people with learning difficulties. I have experienced first-hand that advocacy can bring a positive change in peoples' lives and can have different positive qualities. Furthermore, I have been involved in monitoring the outcomes of the advocacy project in order to demonstrate good value and anecdotally I have witnessed the positive feedback provided by the people that use the different services. However, when it was needed to demonstrate that added value with the existing tools it was demonstrated that there was no concrete method identified to capture advocacy outcomes.



I was and still am a strong believer that the principles and philosophy of working within an advocacy partnership can be a transformational force for change by sharing the power between advocacy partners thus making it a more equal working relationship. This way of working comes into contrast with more traditional ways within the health and social care settings. Where it is often the case that the expert professionals hold all the power within the working relationship and simply tell people, that use their service, what to do or how to do things in order to achieve the right outcome for them. It was thus highlighted that demonstrating the impact and the outcomes of the advocacy partnership would be very important in order to show that the advocacy way of working was different but also an effective way with great potential.

It was, however, the work with the self-advocacy group that really contributed to the formulation of the idea that led to the development and implementation of the advocacy outcomes research study. The creative, thoughtful and inspirational work within the self-advocacy group together with the members' willingness, motivation and self-determination to be involved and to share their views, thoughts, opinions and experiences around advocacy and its outcomes and to create knowledge was unparalleled. The self-advocacy group was well established and had already achieved a number of successes before I became a co-facilitator. At the collective level, they have managed to argue their point, campaign and succeed in obliging their local authority to create a more user-friendly transport network that was enjoyed by many. At the individual level again by arguing their point of view, speaking up and self-advocating they have managed to succeed in many desirable placement moves for individuals from multi-occupancy houses to independent dwellings. The desired placement moves were enjoyed by a number of the group's members. Additionally, they have together successfully managed to remove many barriers placed by society and organisational structures and to overcome difficulties for the group's members and others to enjoy more fulfilling lives.

Working together with the self-advocacy group led to the realisation that although research on advocacy outcomes, and in general, was not listening, there were advocacy partners out there willing, able and determined to speak up and be listened to as well as look for answers, carry out research and create knowledge. The decision was made with the self-advocacy group to be involved in the development of a research project that explores advocacy outcomes from the point of view of the people that use the service, the most important people, with lived experience, first-hand knowledge and expertise of the topic. The research aimed to not only look at advocacy outcomes and its impact but also to explore advocacy in an inclusive way that can be replicated by future advocacy research but also by smaller projects such as in evaluations of advocacy services.

### **1.3. Defining Key Terms**

The previous sections introduced advocacy, how the idea for the research project was formulated and why it is worthy and important to explore advocacy outcomes with the people that use the service. The chapter continues by defining some important terms and thus set the ground for the main part of the thesis to follow.

#### **1.3.1. Advocacy Outcomes**

It is important to define advocacy outcomes and clarify the differences between outcomes and other key terms such as outputs aims and objectives. It is particularly important to define and clarify them since it has been highlighted in the literature that outcomes can sometimes be confused with aims, objectives or outputs of advocacy (Miller, 2011). Outcomes describe the result of the actions taken while trying to achieve the goals and targets that have been identified and agreed at the beginning of the advocacy partnership. The advocacy organisations and commissioners also set aims and objectives as targets and try to meet them however outcomes describe what actually happened. For instance, an aim or objective of a service could be to support people with learning difficulties to express their views and

wishes. The outcome could be that the person managed to have their views and wishes listened to and respected (fully, to some extent or not at all).

Furthermore, the main difference between outcomes and outputs is that outcomes are the direct result of the output. For instance, working with an individual in an advocacy partnership, on a complaint issue, is an output whereas making a successful complaint or one with some success or no success for the person is an outcome. The outputs are usually absolute numbers of, for instance, how many people the advocacy service worked with. In contrast, the outcomes are more complex and can be divided into many different types according to the literature (Thomas et al., 2016). Thomas et al. (2017) categorised the different advocacy consequences into outputs, outcomes and impact. Thomas et al. (2017) described outputs as measures of demographic information, cases taken and recording systems which are relevant to how the advocacy services work however they are beyond the scope of our study. Thomas et al. (2017) described impact, as the general effects of the advocacy provision, which again is not directly relevant to the advocacy outcomes study. Finally, outcomes were described as the actual consequences of the advocacy work and they are going to be examined in detail as they are the main focus of this research study.

### ***1.3.2. Learning Difficulties***

The term, learning difficulties, is used in the thesis because it is the preferred term of the self-advocacy movement (Goodley, 2011) but most importantly because it is the preferred term of the group of self-advocates that acted as co-researchers and the steering group for this research study. Other terms that are used in the UK, or the rest of the world following the medical model or the personal-tragedy model of disability, often with negative connotations for people with learning difficulties, are not be used in this thesis. The study consciously adopted the view that people with learning difficulties are able and willing to express their views, thoughts, wishes, opinions and attitudes as well as create their own terms and knowledge which should be listened to and be respected.

The term learning difficulties symbolises that people are able to learn as opposed to the, commonly used in the UK, term learning disabilities which potentially implies that people are not able to learn. Goodley and Armstrong (2001) reported that some members of the self-advocacy group, they were working with, were objecting even to the term learning difficulties because it singles them out and also because of the negative connotations that are attached even to that term. The famous slogan of the People First self-advocacy movement said it also very concisely and powerfully “label jars not people”. Ryan (2017) also made a great point when she proposed that ideally, we should not talk about people with learning difficulties because there shouldn’t be a need for that division as everybody would have a right to make their own choices and those choices would be listened to and be respected. Therefore, there would be no need for a distinction between people with and without learning difficulties as that distinction would be irrelevant. Ryan (2017) however also pointed out that we are very far from this to come true yet, nonetheless, it is an ideal that we should all aspire to.

### ***1.3.3. Co-production***

Co-production and collaborations between academic researchers and social actors is not a new idea in different academic disciplines. As discussed earlier in the chapter it was the aim of the study to work together, myself the PhD student and practising advocate, with a group of self-advocates and advocacy partners in order to explore the meaning, the impact and the outcomes of advocacy. Moreover, it was one of the main aims to do that in a way that is meaningful for all but also a collaboration that produces good quality research and knowledge. Philips et al. (2013) suggested that collaborative research projects with the aim of co-production have a long tradition particularly in the areas of action research. Liddiard et al. (2019) defined co-production as the partnership between academics carrying out research with different partners to produce research that would have not been possible working in isolation. Moreover, Liddiard et al. (2019) proposed that co-production seeks to put principles of empowerment into practice by sharing the power of producing knowledge with partners who would not otherwise have access to these opportunities. Co-production was also

described as contesting the dis/ableist and elitist ways of carrying out research.

Our project aimed to go beyond the traditional researcher-participants relationship. The self-advocacy group's members demonstrated their willingness and motivation to not just take part or be consulted in this research but to be an essential part of it as co-researchers and co-producers of the knowledge. The group's motivation and determination to share their experiences, views and expertise and to work together as co-researchers and co-producers of knowledge was so strong that tirelessly worked for this project for no external incentive since there was no funding stream attached to this project and therefore no external incentives could have been offered. However, intrinsic motivation was present throughout the group's meetings along with a sense of satisfaction that we were achieving something beyond the realms of everyday group work. We were carrying out research together and producing knowledge via, what can be described as, our research project. The self-advocacy group demonstrated that they were not only keen learners, critical thinkers and able co-researchers but also willing, motivated and determined to take up such roles in order to share their knowledge but also to demonstrate their skills and qualities.

#### ***1.3.4. Inclusion***

Part of the motivation of the self-advocates to share their, views, stories and experiences could be argued that came from the lack of opportunities, from society, to do just that. It was discussed earlier in the chapter that although advocacy was talking about inclusion, equal rights and citizenship, advocacy research mostly excluded people with learning difficulties from the research process. People with learning difficulties were not even, in most projects, asked about their opinions on a topic that is directly relevant to them and they should be seen as experts by experience in this field.

The truth, however, is that the advocacy researchers were not doing anything different compared to the vast majority of mainstream academic research projects, from different fields of enquiry, that have also excluded

people with learning difficulties for a long time. Goodley and Rapley (2002) argued that modernist viewpoints have discredited people with learning difficulties describing them as incompetent to even report their own views, beliefs, feelings or tell their stories. However, with the rise of the self-advocacy movement and a shift to a more post-modern way of thinking, by a section of the academic community, people with learning difficulties were no longer excluded and were increasingly provided with opportunities to express their views, knowledge and stories which were valued. Goodley (2000) suggested that self-advocates were speaking out against discrimination and were speaking up to achieve their goals. And although this research was published in 2000 and it may seem as if we have moved very far since then, publications such as Ridley et al. (2018) still point out a lack of research on advocacy from the viewpoint of the people who use the service. Thus reminding us that we have not travelled nearly far enough yet.

#### **1.3.5. Power**

According to Foucault (1982) power is created through knowledge and we are all disciplined through the power of knowledge. Foucault argued that powerful discourses and ideologies show us how to behave by creating norms and truths and by prescribing what is normal/abnormal and right/wrong. Powerful ideologies and systems instruct that whoever falls outside of those norms and truths is seen as a deviant by society and should be excluded. Foucault (1975) demonstrated that people are treated according to the discourse of the dominant ideology. For instance people with learning difficulties when thought of as needing protection they were locked up in institutions and when thought of as ill they were medicated and so on (Inglis and Swain, 2012).

However, with the important work of the service user movement, disability activists and self-advocates new alternative constructs were created capable of challenging the truths of modernist ideologies (Mineur et al., 2017). The work of the different social movements, including self-advocates with learning difficulties, demonstrated that new powerful discourses and knowledge can be constructed and can counterbalance the detrimental

effects of dominant modernist ideologies. Self-advocates have demonstrated their resilience and self-determination to provide resistance and challenges to powerful systems' truths. Docherty et al. (2005) argued that research with people with learning difficulties is important in order to create new knowledge that can bring the truth of people with learning difficulties at the forefront and demonstrate that being different can be positive and accepted.

### **1.3.6. Empowerment**

Empowerment is a commonly used term within the disability movement. Empowerment is defined as power to the disabled people to make their own decisions and choices and to express their views and be listened to (Cook et al., 2019). This power is often taken away by non-disabled experts who held the power, oppressed the disabled people and have been making the decisions for them. The term has been seen as controversial because very often the choice of the empowerment of the disabled people rested with the oppressors who chose when to give the empowerment to the oppressed. Cook et al. (2019) argued that this transfer of power has not always been democratic and pointed out that true empowerment involves disrupting current ways of thinking rather than merely replicating them.

Moreover, Goodley (2005) claimed that professionals seeking to empower disabled people can be seen as the powerful passing over the power to the weak thus reinforcing a victim status for disabled people. Goodley (2005) highlighted that true empowerment comes from self-advocacy giving the directions and leading the political agenda. Non-disabled people should be acting as allies rather than as experts and decision makers.

Despite many years of social injustice systemic disempowerment, suppression of their rights and their voice people with learning difficulties upped their resistance, their fight and voices and managed to start gaining power back. Following the disabled peoples' social movements, including the People First self-advocacy movement campaigning, something has started to change (Goodley and Ramcharan, 2010). Although this fight for resistance, speaking up and empowerment had many achievements, following social

movements campaigning, it was not as straightforward from the beginning. People with learning difficulties were not seen as equal partners and did not play a big part in the initial disabled peoples' social movement. Gray and Jackson (2002) argued that people with learning difficulties have been partly excluded and even according to some were not treated as equals by fellow disabled people who did not see their cause and interests as the same. Anastasiou and Kaufman (2011) suggested that the Union of the Physically Impaired Against Segregation (UPIAS), one of the first disabled peoples' movements, did not include the causes of people with learning difficulties in their original manifesto. People with learning difficulties instead created their own movement Self-Advocacy with groups such as People First.

Some theorists widely shared their disagreement with the view that saw the causes and interests of people with learning difficulties as different from the causes and interests of physically disabled people. Authors such as Goodley (1997) argued that impairments of the body or the mind create disability and therefore impairments and disability are synonymous and inseparable. Thus, the dichotomy between physical and mind impairments was challenged as disability could be better understood as a continuum rather than a dichotomy. Goodley (1997) proposed that the self-advocacy movement, that campaigned to promote the inclusion and the empowerment of people with learning difficulties, provided more critical views of disability and impairment compared to the mainstream social model of disability (proposed by Oliver, 1990) which was primarily designed with physically disabled people in mind. The self-advocacy movement had the potential and challenged the dominant discourses and processes that have excluded and marginalised people with learning difficulties. Self-advocacy challenged the very processes of the dominant systems such as diagnosis, treatment and rehabilitation (Goodley and Ramcharan, 2010). With the rise of the self-advocacy movement and People First, at the forefront, people with learning difficulties started to gain increasingly ground and become more empowered. People with learning difficulties started increasingly to share and publish their own versions of stories, views, and opinions and collectively and individually fight back



against ruling systems' ideologies and discourses (Atkinson and Cooper, 2000).

Furthermore an increase in the use of participatory research approaches and co-production led to the implementation of more democratic research projects that do not exclude certain voices such as those of people with learning difficulties (Cook et al., 2019). According to Reason and Bradbury (2008) the knowledge produced by the empowered people, with learning difficulties, challenged the practices and the exclusionary elitism afforded to mainstream research.

People with learning difficulties increasingly carried out research and produced knowledge and their own powerful discourses which contrasted those imposed by dominant ideologies (Grant and Ramcharan, 2009). As Foucault (1981), argued creating knowledge is power and by creating knowledge people with learning difficulties produced a number of challenges to the modernist ideologies and empowered themselves as well as other people with learning difficulties in general. Goodley and Ramcharan (2010) suggested that the self-advocacy movement and more personalised forms of advocacy in the last 30 years made substantial gains to have the voices of people with learning difficulties heard in different fora. The advocacy movement via collective campaigning alongside individual forms of everyday resistance and protest have managed to challenge the dominant modernist views and gain ground towards empowerment and inclusion. Advocacy has supported people with learning difficulties to make their views, wishes and ambitions known and be listened to and to counteract the effects of control and disempowerment imposed by ruling systems.

The advocacy outcomes study carried out research with self-advocates and advocacy partners with learning difficulties and promoted their empowerment. The study co-produced new discourses and knowledge and challenged the modernist views of people with learning difficulties. Self-advocates and advocacy partners demonstrated a number of positive

qualities and contributed to a positive identity for people with learning difficulties.

#### **1.4. Research Aims and Questions**

The main aim of the study was to explore the advocacy outcomes and impact from the point of view of the people that have used advocacy services. The study also envisaged to alter the traditional participant-researcher relationship and by using a participatory research approach share the power of knowledge creation. The research questions were identified following a preliminary literature review and discussions with the steering group. The advocacy outcomes study aimed to not only explore advocacy outcomes but also to discuss recommendations for the development of advocacy theory and practice. As it is a strong belief of the study that knowledge creation can be used to bring positive change. Finally, the study sought to explore the notion that advocacy can aid the empowerment of people with learning difficulties. The following questions, agreed with the steering group, were investigated by the study.

- What is the relationship between advocacy theory and practice and the empowerment of disabled people?
- What recommendations can the study produce which can be used for the development of advocacy practice impact?
- Does current advocacy practice contribute towards positive or negative outcomes for the people using the service?

#### **1.5. The structure of the Thesis**

The study was divided into 7 chapters with sections and sub-sections further discussing the different chapters. Following the introduction chapter, the thesis continued by reviewing the literature surrounding advocacy research, theory and practice. The third chapter outlined the methodological approaches used in the advocacy outcomes research study. The fourth and fifth chapters explored the findings of the study. Chapter six discussed and

critically appraised the main findings along with evidence from the literature. The seventh chapter drew the conclusions from the study, answered the research questions and reflected back on the study. Finally, the conclusion chapter also introduced and discussed the Advocacy Partnership Model. The chapter continues with a short introduction of the chapters to follow.

### ***1.5.1. Literature Review***

The literature review put advocacy into context by looking into its historical background but also by reviewing key relevant legislation and social policies that impacted upon the development of advocacy in its current form. Advocacy's main principles as well as main types, aims and objectives were reviewed and discussed. The second chapter reviewed and discussed current issues in advocacy practice, monitoring, training, research and outcomes. The literature review examined the theories linked to advocacy. The chapter also discussed and critically appraised advocacy's relationships with normalisation theories, the social model of disability, the disempowerment of people with learning difficulties, the self-advocacy movement and critical disability studies. Finally, the literature review, which focused mainly on advocacy within England and Wales, looked at advocacy in other parts of the world, mainly Scotland, USA, Australia and Sweden.

### ***1.5.2. Methodology***

Qualitative methods were employed in the study to explore a relatively under-researched topic. Nind (2008) proposed that qualitative research methods are useful for exploring rich data such as human experiences and viewpoints. Principles of the participatory research method were used in the study to promote the co-production element of the study and actively try to co-research. Northway et al. (2014) argued that the participatory approach encourages participants to actively take part in the research process rather than just be asked about their views. Elements of the narrative method were used in the collection as well as the analysis of the data. The narrative method encouraged the exploration of the research questions in more depth and did not set pre-requisites for participation. Most importantly, the narrative

method facilitated the participants' contributions and valued them as did not accept that there is only one truth.

The social constructivism theoretical framework underpinned the study. The social constructivism methodological paradigm's main principles were compatible with the rest of the research methods employed and were shared by the study's philosophy. The advocacy outcomes study shared the view that people with learning difficulties, that have used advocacy services, had the expert knowledge to inform research about advocacy. We worked together as a team with the steering group of self-advocates to research together the topic and co-produced the knowledge.

The methodology chapter also looked at the ontology and the epistemology of the study. The study's ontological approach focused on the importance of the experience and expertise of the participants and co-researchers. The study sought to transform traditional researcher-participant power relations and shared the power of knowledge creation with the people that have lived experience of using advocacy.

### **1.5.3. Findings**

The participants that contributed to the study shared their stories, views, attitudes, perceptions, thoughts and feelings about advocacy and produced a wealth of information. Together with the steering group of self-advocates, we managed to analyse the data and came up with nine main themes and a number of associated sub-themes related to advocacy outcomes. The main themes were divided into two main categories of outcomes. The first main category was end-point outcomes which were the result of the advocacy partnership's process or journey towards an agreed goal, set at the beginning of the partnership. End-point outcomes can either be met fully, partly or not at all. Participants reported that end-point outcomes were important and they were valued particularly when the goal set in the beginning was met. The second main category was process outcomes such as learning or satisfaction which were associated with the advocacy partnership's process or journey. Participants reported that process

outcomes were important and valued even when the goal set at the beginning of the partnership was not achieved.

The findings were presented and analysed in two chapters, advocacy outcomes and further exploration. In the first one, a top-down approach was adopted by identifying and exploring the main themes from the participants' data. The second one further explored and analysed the data by adopting a bottom-up approach. The second findings chapter looked at the smaller entities of the data such as quotes and sub-themes and from those identified the top findings.

#### **1.5.4. Discussion**

The discussion chapter compared and contrasted our findings with evidence from other studies involving people with learning difficulties but also other groups of people that have used advocacy. A number of similarities but also differences were identified between our findings and advocacy research with different groups of people. One of the main differences was with the claim that advocacy has been reported not to aid the empowerment of people in settings of extreme disempowerment such as secure mental health hospitals (Newbigging et al., 2015 and Barnes and Tate, 2000)

The study explored apart from advocacy outcomes and its impact also the theoretical basis of advocacy. As discussed earlier in the introduction chapter one of the main principles of advocacy is to aid the empowerment of advocacy partners to speak up and self-advocate. This notion was further investigated and critically appraised. The chapter suggested that although self-advocates and advocacy partners have demonstrated that they are more than able and willing to speak up and self-advocate in some situations and contexts advocacy can be an ally to the causes of people with learning difficulties.

#### **1.5.5. Conclusion**

The conclusion chapter answered the research questions set at the beginning of the study. The theoretical implications of the study were

discussed and critical reflexivity was used to look back at the study and identify its limitations. The thesis concluded with developing the Advocacy Partnership model which describes the advocacy partnership's process or journey components. Additionally, the conclusion chapter looked at the utility of advocacy work and of the advocacy outcomes study in general. The utility of the study was examined with regard to its relevance to the lives of disabled people, its relevance to policies about disability and its connection to the activism and politics of disability. It was argued that the study and the model produced are relevant to the lives of disabled people, are connected with the politics and activism of people with learning difficulties and can inform relevant policies.

## **1.6. Summary**

The first chapter introduced the main areas of focus for the thesis, the structure to be followed and defined some key concepts surrounding advocacy and people with learning difficulties. It then outlined the research questions and offered an explanation as to how they were formed. It also provided the main reasons why a research study exploring advocacy outcomes "with" people with learning difficulties rather than "for" them is significant. The chapter also asserted how working together with a group of people with learning difficulties can support inclusion, sharing of the power of knowledge and ultimately empowerment. Finally the introduction chapter gave an overview of all the chapters to follow in the thesis.

## **2. Literature Review**

### **2.1. Overview**

The second chapter looks more closely on what is advocacy. Advocacy and its context is looked at together with the complexities and competing priorities between different types. The attempts to unify advocacy and see it as a whole rather than individual types are also examined. The historical background of advocacy is explored together with relevant health and social care policies and legislation historic and current. Following that the advocacy principles, aims and types are discussed. The chapter continues by looking into the issues surrounding advocacy practice, monitoring and research. Then current issues surrounding advocacy outcomes are explored followed by issues around advocacy theory and the lack of a unified theory. Subsequently, the chapter looks at developments in advocacy in the rest of the world with a focus on Scotland, USA, Australia and Sweden. The chapter draws to closure by looking at the future prospects of advocacy research and practice.

### **2.2. Advocacy in Context**

The chapter explores a number of different types of advocacy with different groups of people. However, the main focus is placed upon advocacy with and by people with learning difficulties. As described in the previous chapter, defining advocacy is a rather difficult task as several studies have indicated (Atkinson, 1999, Townsley et al., 2009 and Macadam et al., 2013). Forbat and Atkinson (2002) highlighted the lack of consensus around the meaning of advocacy and the lack of a unified identity with different types of advocacy focusing on different principles. Furthermore, it has been suggested that there are different views in the advocacy movement around which approach works best and which principles are more important than others. Despite the different approaches and views expressed a consensus has been reached regarding a number of principles at the Advocacy Manifesto for England and Wales agreed by Action for Advocacy and UK Advocacy Consortium in 2010 (Action for Advocacy, 2010). Although the different types of advocacy have

differences in philosophy as well as priorities and focus it is widely accepted that the core principles are shared between all types of advocacy.

Stewart and Macintyre (2013) argued that advocacy can support individuals to access the information they need, get to know their rights, voice their views, opinions and make their own choices. They also noted that although advocacy contains some elements of, is not about giving advice, counselling, mediation and or befriending. The manifesto of independent Advocacy services, as defined by Action for Advocacy (A4A, 2010) described independent advocacy work as striving to create a fairer society by supporting people to have a voice in all aspects of their lives. According to the manifesto, Independent advocacy tries to ensure that people are listened to in key decisions in their lives by enabling them to access the right services and support and by challenging discriminatory and poor practices. Independent advocacy organisations locally support vulnerable and disempowered people to live fulfilled lives. Advocacy's main principle is to empower people to speak up, to have a voice and have control in decisions about their lives. Nationally independent advocacy creates a powerful safeguard against poor practices and human rights abuses (Action for Advocacy, 2010).

### **2.3. Historical background**

Informal advocacy has a very long history within human society however the first recognised movement concerning people with learning difficulties began in the late 1960s in Sweden and the USA (Gray and Jackson, 2002). Wallcraft et al. (2013) proposed that advocacy originated from the service user movement and it has been developed as a response to the negative experiences of people using health and social care services. The negative experiences were demonstrated to negatively affect the capacity and confidence of people, using those services, to speak up for themselves. Self-advocates, disability activists and critical theorists, in particular, have argued that the voice of people has not been listened to and been ignored on unfounded grounds (Goodley, 2005). Advocacy, therefore, it can be



suggested that was developed to aid the empowerment of people to speak up in situations and contexts where they have been disempowered and not allowed to express their views, wishes, needs, to speak-up, self-advocate and be listened to.

According to Gray and Jackson (2002), the work of Nirje, Wolfensberger and O'Brien on normalisation has also been influential in the development of the advocacy movement. The normalisation principles hold that marginalised members of society, such as people with a learning difficulty, have devalued roles in society and should be supported towards achieving more valued roles. Mineur et al. (2017) criticised the normalisation theories by arguing that the application of their principles for decades did not prevent the social injustice and social exclusion of people with learning difficulties from society. Mineur et al. (2017) proposed that the emancipation of the people with learning difficulties happened when they no longer accepted the subordinate roles assigned to them by society. Moreover, Tideman and Svensson (2015) suggested that the organisation of people with learning difficulties in self-advocacy groups contributed to societal change, the development of a positive identity, to more independence and a collective voice.

### ***2.3.1. UK Developments***

The chapter continues by outlining key significant UK developments in the formulation of what we now know as advocacy. Significant developments in the United Kingdom include the birth of Scope (original name "National Spastics Society") in 1952 requiring equal rights for disabled people such as equal rights for disabled children in education and adults in employment (Scope, 2015). Mencap was formed in 1946 with the original name of "National Association of Parents of Backward Children" which was changed in 1955 to "The National Society for Mentally Handicapped Children". Mencap advocated for the move of disabled children from hospitals to small home environments, a move that was shown to be positive for the emotional and health well-being of the children as well as for their social skills (Mencap, 2015). Mencap also advocated for equal rights for disabled people in education and employment. Scope and Mencap suggest that they continue

to campaign for disabled people to access equal opportunities and improved living conditions as well as for the change of the negative attitudes in society.

However, Scope and Mencap, as well as other large charities, provide a wide range of services to disabled people including information, advice, residential and care services. Although the contribution of organisations such as Mencap is seen as important they are not without their critics such as Mack (2001) who looked at self-advocacy and identified potential conflicts of interest between competent self-advocates and parent dominated organisations such as Mencap. Sewell (2015) highlighted criticisms towards Mencap for concentrating on representing the rights of carers which sometimes conflict with the rights of people with learning difficulties. Furthermore, since the charities have also been offering different services (including residential ones) they have been criticised for the conflict of interest which has led them to potentially not speak up in the same way for people that have been in their care.

In 1994 the UK Advocacy Network (UKAN) published the first comprehensive Advocacy Code of Practice which drew together existing principles and guidelines for good practice. The UKAN code of practice formed the basis for Action for Advocacy's (2002) Advocacy Charter which was produced in consultation with several advocacy schemes. In 2006 Action for Advocacy published the Quality Standards for Advocacy Schemes and the Code of Practice for Advocates again in consultation with a wide range of different advocacy projects across the country. In 2009 the National Advocacy Qualification was launched and since a lot of advocates, as well as people who would like to be involved in practising advocacy, have enrolled and achieved this qualification.

#### **2.4. Relevant Legislation and Policies**

Significant Law changes include the introduction of the Welfare State after the end of World War II with Acts of the Parliament such as the National Health Service Act in 1946 and the Abolition of Poor Law in 1948 the year

when NHS was born (NHS, 2015). Other significant law changes include the Education Act in 1944 which provided universal free education and of the Children Act in 1948 which provided a number of measures to ensure the protection of the welfare of children (Spicker, 2014). The National Assistance Act 1948 stated that every local authority had the duty to provide residential accommodation for people that were in need of care and attention which was not otherwise available to them. The Chronically Sick and Disabled Persons Act 1970 introduced the duty of the local authorities to assess the individual needs of people that qualified under the National Assistance Act 1948. The first disability rights legislation is believed to be the Chronically Sick and Disabled Persons Act 1970 which placed a duty on local authorities to provide allowances for disabled people to more fully participate in the community and adaptations to meet peoples' needs (The College of Social Work, 2015). Oliver and Barnes (2012) argued that it was the growing disability activism that led to the introduction of legislative measures concerned with disability such as those included in the Chronically Sick and Disabled Persons Act 1970.

#### ***2.4.1. Mental Health Act 1983 (Amended 2007)***

The Mental Health Act 1983 was enacted and together with the associated code of practice emphasised the rights of the mental health patients including the rights of information and representation (Dalrymple and Boylan, 2013). It was the amendments of the Mental Health Act 1983 in 2007 that introduced the role of the Independent Mental Health Advocate (IMHA), a statutory advocacy role, in 2009.

In 1984 People First was founded which is seen as the first formal Self-Advocacy group in the UK which contributed to the further development of advocacy groups around the country (Atkinson, 1999). Walmsley (2002) noted that self-advocacy sat in many ways uneasily with the mainstream disabled peoples' movement. Walmsley argued that disabled activists were putting the emphasis on bodily impairments which effectively meant that the interests of people with learning difficulties were marginalised. The

relationship between the disabled peoples' movement and people with learning difficulties is discussed in greater detail later in section 2.14.

#### ***2.4.2. Disabled Persons Act 1986***

The Disabled Persons Act 1986 is seen as the first piece of legislation which identified the right for disabled people to have access to an independent advocate (Dalrymple and Boylan, 2013). The individual had the right to have access to a representative such as an independent advocate and also the right to be represented or accompanied by that person in meetings and reviews. The Disabled Persons Act placed on local authorities a duty to undertake a written assessment of people with disabilities for services when asked to do that by the individual, their carer or representative.

Children Act 1989 emphasised the participation of children and young people in decision-making. Independent advocacy had a role in ascertaining their wishes and feelings and promoting their meaningful involvement (Brady, 2011). The NHS and Community Care Act 1990 placed a requirement on local authorities to consult with voluntary organisations representing the interests of service users and carers with objectives which included the need to promote choice and self-determination (Social Care Institute for Excellence, 2015). Furthermore, the NHS and Community Care Act 1990 formally introduced the role of Complaints Advocacy.

#### ***2.4.3. Disability Discrimination Act 1995***

The Disability Discrimination Act 1995 brought new powers to challenge social exclusion and discrimination and remained a core piece of legislation, for many years, despite being significantly extended and amended since then (The College of Social Work, 2015). The Disability Discrimination Act made it illegal to discriminate against people with disabilities in education, employment, goods and service provision. A duty was imposed on employers to make reasonable adjustments to working environments and practice so that a disabled person is not disadvantaged. Gray and Jackson (2002) argued that people with learning difficulties continued to face discrimination as there were get-out clauses from the act. For instance, often

employers did not see it as a reasonable adjustment to provide a support worker for an individual until they learn the job. Unjustified actions like that made the legislation at large ineffective for people with learning difficulties.

#### **2.4.4. *Direct Payments Act 1996***

Community Care (Direct Payments Act) 1996 provided local authorities with the power to make direct payments to working age adults and it was the first act of parliament relating to the personalisation agenda. The introduction of direct payments for people with learning difficulties and mental health issues has been seen as a victory of campaigning from self-advocacy organisations as direct payments were originally seen as support for people with physical impairments to meet their social needs. Brandon et al. (2000) claimed that few service users as well as carers and staff had knowledge of direct payments and also those that did felt anxious about the practicalities which were seen as unclear. Brandon et al. (2000) argued that more training and information needed to accompany the implementation of such changes in policy to make them more relevant.

#### **2.4.5. *Human Rights Act 1998***

The introduction of the Human Rights Act 1998 was rather important to advocacy. One of the main principles of advocacy is seeking to safeguard partners' human rights and if needed challenge any decisions considered breaching the person's human rights (sometimes with the support of a legal representative). Independent advocacy is largely informed by the Human Rights Act 1998 particularly articles 3, 8, 10 and 14. For example, The Human Rights Act 1998, c.42 article 3 states that "No one shall be subjected to torture or to inhuman or degrading treatment or punishment". A right that might seem obvious has, however, been shown to be repeatedly breached in today's society, as exposed in the Winterbourne View abuse scandal by the BBC TV programme *Panorama* (*Panorama*, 2011). The programme showed that a number of residents, with learning difficulties, have been subjected to serious physical and emotional abuse over a considerable length of time by different members of staff. The programme moreover highlighted failings of the system overlooking the private hospital where abuse took place. Since

then several academic articles have looked at the scandal and the lessons that need to be learned (e.g. Northway and Jenkins, 2012).

Furthermore, authors have suggested a number of strategies to be used to prevent similar scandals from happening again. The Department of Health responded by producing the “DH Review – Transforming care: A National Response to Winterbourne View Hospital” (Department of Health, 2012). In this report, the Department of Health identified, as one of the priorities to prevent further such incidents, that individuals are provided with the advocacy support they need to understand and have the opportunity to express their views (Department of Health, 2012). Thus recognising the important role that advocacy can play to safeguard people from abuse. The support that was identified included independent advocacy as well as self-advocacy for the person and their family. The stance of the central government to the need for the provision of advocacy support is discussed in greater detail later in the chapter.

#### ***2.4.6. Valuing People 2001***

In 2001 The Valuing People White Paper formally introduced the right of people with learning difficulties to advocacy. Valuing People (Department of Health, 2001) suggested that an emphasis is put in ensuring that people with learning difficulties are not left out and that their needs are being met. Valuing people recognises that advocacy can play an important role in making sure that peoples’ views and wishes are being expressed and listened to. Valuing people highlighted the importance of people with learning difficulties being involved in the community and that this is something that advocacy can support them with. The White Paper also recognised that advocacy has an important role to play in supporting people with very complex high needs in more actively participating in community matters and expressing their views and wishes as well as promoting their rights. Moreover Valuing People suggested that there were lower levels of uptake of direct payments amongst people with high support needs and that advocates could support these people to increase their uptake of direct payment hours. Furthermore, it mentioned that advocacy can be an effective method of

supporting people with learning difficulties. Valuing People 2009 strengthened even more advocacy by highlighting the importance of advocacy work with people with learning difficulties.

#### ***2.4.7. Mental Capacity Act 2005***

In 2005 the Mental Capacity Act introduced the first statutory advocacy provision. Independent Mental Capacity Advocates (IMCAs) are working with people who have been assessed as lacking the mental capacity to make certain important informed decisions. Important decisions as described by the Mental Capacity Act 2005 include change of long term accommodation, serious medical treatment, care reviews and safeguarding procedures. The IMCAs promote the person's involvement in the decision-making process and make sure that their views, wishes and choices are listened to by decision-makers.

According to the Social Care Institute for Excellence (2015), the Mental Capacity Act (MCA) 2005 has been designed to empower and protect people who may lack the mental capacity to make decisions in their lives. The decision about who lacks the mental capacity to make an informed decision lies with the identified decision-maker who has to make sure that a two-stage capacity assessment is satisfied. For instance when the decision is about a medical issue then the treating medical Doctor is the decision-maker. The MCA has certain principles that guide decision-makers. One important principle is that capacity should be assumed unless it is proved otherwise. Moreover, all practical steps should be taken to support the person to make this decision. Another important principle is that all decisions made for a person should be in their best interests and the least restrictive option. The Court of Protection oversees the operation of MCA and also tries to resolve any disputes regarding objections to decisions made under the MCA.

Munro (2014) argued that the Court of Protection (CoP) and the MCA state that the wishes and feelings of the person should be considered in the decision-making process. Munro (2014) however proposed that evidence suggests that the Court of Protection often ignores the person's current

views and wishes something that Munro describes as legally and ethically problematic. Munro (2014) concluded that the Court of Protection must make active efforts to consider the person's wishes and feelings in accordance with the Mental Capacity Act (2005). Lonbay and Brandon (2017) reported that IMCAs support can improve the engagement levels of older people in safeguarding processes.

#### **2.4.8. Care Act 2014**

The Care Act 2014 has been described as one of the most significant pieces of legislation in the health and social care sector since the establishment of the welfare state. The Act defines the primary areas of responsibility for the local authorities for the promotion of individual well-being. It has been noted that there is an important change from the duty of local authorities to provide services to meeting the needs of the relevant people. This change requires local authorities to put the person in the centre of the focus rather than providing one size fits all services (Social Care Institute for Excellence, 2015). Furthermore, a key part of the Act is that preventative work and supporting existing resources, such as carers (family members or friends) who are given new entitlements under the Act, are prioritised. Carers as well as individuals who have substantial difficulty being involved in social care assessments and reviews, and don't have someone willing and appropriate to support them, are entitled access to advocacy to support them to exercise their new rights and entitlements and be involved in the social care processes including assessment, planning, appeals or safeguarding (VoiceAbility, 2015). This is a change in advocacy provision as advocacy was very rarely available during the assessment and planning processes. Furthermore, a key difference in the Care Act is that a National minimum threshold for the entitlement for support is set instead of local authorities assessing their own levels of need locally.

### **2.5. Advocacy Principles**

Different organisations, as well as academic work, have produced different sets of principles, standards and recommendations in their own publications



about advocacy. According to the Advocacy Charter published in 2002, there were 10 key advocacy principles that all advocacy organisations should promote (Action for Advocacy, 2002). The ten key advocacy principles in the Advocacy charter were putting people first, independence, empowerment, clarity of purpose, equal opportunity, accountability, supporting advocates, accessibility, confidentiality and clear complaints policy (Action for Advocacy, 2002). Brandon and Brandon (2001) highlighted that the views, wishes and aims of the client should be at the core of advocacy practice and its main focus. Gateshead Independent Advocacy Code of Practice put forward 4 main principles which included putting people first, accountability, independence and accessibility (GAIN, 2010).

Barnes, Brandon and Webb (2002) proposed standards and recommendations for the creation of the role of the specialist independent advocate. Barnes et al. (2002) recommended that the specialist advocacy service should be independent, empowering, inclusive, impartial, confidential and free. In the revised Advocacy Code of Practice (NDTI, 2014) an additional key principle, "safeguarding", has been added to the 10 described at the Advocacy Charter in 2002. NDTI (2018) further updated the advocacy charter for advocacy providers and continues to be the organisation that manages and implements the Advocacy Quality Performance Mark.

It could be argued that different types of advocacy put more weight on different principles. For instance, an advocacy organisation that provides only a citizen advocacy service and receives only funding from different non-statutory organisations potentially puts more weight on the independence principle compared to an advocacy organisation that provides only the statutory service of IMCA and thus receives funding only from Local Authorities. Furthermore, a self-advocacy project being run by a group of people with learning difficulties could be argued that puts more weight on the principle of putting people first and of empowerment compared to an advocacy project that employs non-disabled advocates to work with people with learning difficulties. Likewise, a purist citizen advocacy project can potentially put less weight in following the accountability principle by not

actively monitoring the partnership between the citizen advocates with their partners as the relationship is seen to be only between the two with little involvement from the project.

## **2.6. Aims of Advocacy**

Advocacy, as is further examined in the following section, provides a variety of types of service to a wide range of groups of people. Advocacy schemes, following the principles discussed in the previous section, strive to meet certain aims and objectives. Advocacy services strive to work with their partners to express their views, wishes and choices as well as support finding trustworthy information to be better informed and exercise their rights. Advocates work with individuals to promote access to equal opportunities, inclusion and respect. Advocacy partners work together to tackle unfairness, injustice and discrimination, to challenge those appropriately and try to put things right, by for instance raising complaints, if something goes wrong. Furthermore, advocacy practice involves striving to work with individuals to be involved in important decisions about their lives and having a voice in the decision-making processes. Advocacy partners working together to be empowered and self-advocate is a main aim of any advocacy service. Brandon, Brandon and Brandon (1995) suggested that even from the early days of advocacy in the United Kingdom it was highlighted that the empowerment of the advocacy partner was the ultimate goal.

Moreover, mostly in collective advocacy, a main aim is to campaign for changes in policies and legislation as well as in peoples' attitudes. Advocacy is about standing alongside, taking the side and standing up with people who have been or are in danger of being marginalised from society. Advocacy projects aim to actively encourage advocacy partners to be involved in the running of the schemes and make sure they express their views about the service they receive and act on the feedback. Advocacy projects aim to make sure that advocates have received appropriate training about health and social care policies and procedures as well as relevant legislation. The advocacy projects aim to evaluate their services regularly and keep up to

date with relevant legislation as well as change policies and procedures accordingly. People that use advocacy ought to be involved in the evaluation and monitoring of the service as they can best describe what works best for them. Furthermore, advocacy aims to access funding from different sources and take relevant measures to remain independent as well as free from conflicts of interest. NDTi (2018) has revised the Advocacy Charter to provide an up to date comprehensive code of practice where is entailed what advocacy projects, as well as advocates, should do to provide a good quality service that is transparent, clear and meets the four main principles included in the code of practice. The code of practice has been developed in order to apply to all advocacy services irrespective of type or the group of people that use the service.

## **2.7. Advocacy Types**

There are many different types of advocacy already established which work differently however at the essence of all of them there is the notion of “speaking up” (Atkinson, 1999). A big distinction in advocacy is between self-advocacy and advocacy with another person such as an advocacy partner, often referred to as independent advocacy. According to Atkinson (1999) advocacy can be divided into three main types which can be seen as group or collective advocacy (e.g. peer advocacy), self-advocacy where someone speaks up for himself/herself often in a group setting and advocacy with others e.g. citizen advocacy or case/crisis/community (paid) advocacy. Those different forms of advocacy co-exist together for quite some time now and they can all be seen as rather important but not without their advantages and disadvantages (Stewart and MacIntyre, 2013). All forms of advocacy face different challenges and as social policy focus changes different forms become more or less popular or face difficulties even of extinction.

### **2.7.1. Self-Advocacy**

Self-advocacy, compared to other types of advocacy, can be seen as being about the people advocating for their own needs rather than relying on others representing them (Walmsley, 2002). Self-advocates speak up for

themselves and others often in group settings compared to one to one. The self-advocacy movement in the UK, at least officially, started in the early 1980s with People First in London credited to be the first established self-advocacy organisation (Gray and Jackson, 2002). Self-advocacy is seen as beneficial for the people involved by enabling people to have a voice and be heard, enhance identity, support self-determination and raise self-esteem (Atkinson, 2002). Self-advocacy often involves people with learning difficulties mutually supporting each other and gaining power to speak up for their rights rather than rely on other people to do it for them.

Self-advocacy can also be seen as a process of development which gradually gives someone the confidence and determination to speak out for themselves and express their thoughts and feelings more openly (Townesley et al., 2009). According to Gray and Jackson (2002), self-advocacy services for people with physical disabilities have a longer history, compared to services for people with learning difficulties, and have been more successful in promoting better access to education, employment and other societal activities that are even legally recognised for this group (e.g. Disability Discrimination Act 1995). Goodley and Armstrong (2001) suggested that self-advocacy provided opportunities for people with learning difficulties to individually and collectively speak out for human rights and challenge a disabling society. A main disadvantage of self-advocacy is that self-advocates do not always have specialist knowledge or access to such required resources. Moreover, self-advocates may require support for organisational and administrative purposes from non-disabled individuals.

### **2.7.2. Peer or collective Advocacy**

Peer or collective advocacy involves people with similar experiences getting together and forming groups where they can support each other and make their voices be heard even louder. Peer advocates can often also speak up for each other on a one to one basis. Peer advocates have a lot of times in the past pressed, quite successfully, for better services and for involvement in their design and implementation (Brandon et al., 1995). The provision of direct payments for people with learning difficulties and mental health

problems has been seen as a victory for peer and self-advocacy organisations that campaigned for that as direct payments were originally proposed to provide support only for people with physical impairments (Brandon et al., 2000).

Furthermore, peer advocacy, which is seen as part of collective advocacy, has been noted to be preferred by self-advocates with learning difficulties when self-representation is not possible. Self-advocates have claimed that another person with similar experiences can often be better able to represent them compared to a non-disabled advocate (Atkinson, 2002). There are many similarities between collective or peer advocacy and self-advocacy as they share many common values such as believing that people who face the same experiences and problems are better able to represent themselves rather than rely on non-disabled advocates to represent them. Furthermore, both approaches believe that the partnership between a disabled person and a citizen or paid advocate is on a different basis compared to between two or more disabled people working together to support each other. One of the main disadvantages of peer advocacy is that the levels of experience between the peer advocates can vary thus potentially creating a power imbalance between the different peer advocates.

### ***2.7.3. Citizen Advocacy***

Citizen advocacy was one of the earliest forms of formal advocacy and was based upon the normalisation and social role valorisation theories. The main principle of normalisation was that people with learning difficulties should have access to quality of life and living conditions similar to the ways of life of the rest of society (Nirje, 1980). Social Role Valorisation theory emphasizes reversing the consequences of social devaluation to establish, enable and or maintain valued roles in society for people with disabilities (Wolfensberger, 1983). Walmsley (2002) noted that both theories represent advocacy that is for people without disabilities arguing for improvements in the lives of people with learning difficulties something that comes in contrast with other contemporary social movements. Furthermore, Tideman and Svensson (2015) were critical of the theories and argued that following the principles of

normalisation and social role valorisation, for a lengthy period in Sweden, did not prevent oppressive structures and the discrimination of people with learning difficulties as it legitimised their subordinate roles in society.

Citizen advocacy typically involves a one-to-one relationship between a volunteer “respected citizen” advocate and the partner. Citizen Advocates are usually unpaid members of the local community who get involved in a long-term one-to-one relationship with an advocacy partner (Wertheimer, 1998). Citizen advocates are often seen as the ordinary friend for some people who have sometimes no contact other than with paid staff who provide care (Atkinson, 2002). The advocate supports their partner and whenever required they represent them as if they were representing themselves. The main differences between citizen and case (paid) advocacy are that the case advocate is getting paid for the service provided and the relationship is usually shorter in length of time. Citizen advocates are often treated as employees and receive supervision and sign confidentiality agreements as paid employees do however in its purist form citizen advocates are independent of the advocacy service (Atkinson, 2002). According to the purist form of citizen advocacy, the scheme matches the two advocacy partners and then the advocate is accountable to their partner rather than the service.

One of the main criticisms that citizen advocacy draws is the obvious great power imbalance between the “respected” citizen advocate who has the power and knowledge of how to navigate health and social care systems in contrast with the advocacy partner who is seen as disempowered and in need of help. The citizen advocacy way of working is also seen as reinforcing stereotypes that it aspires to combat such as between expert professional providers of service and disempowered “victim” service users. Another main criticism is that citizen advocacy, due to its long term scope, has the potential to influence dependency and not to promote self-advocacy.

#### **2.7.4. Professional Advocacy**

Professional or case advocacy is a shorter to medium term type of advocacy which aims to support an individual (advocacy partner) with a specific issue (or a number of issues) for as long as the involvement is needed (Henderson and Pochin, 2001). Professional advocacy is often also referred to as community, case, crisis, independent or paid advocacy because in contrast to citizen advocates who are unpaid volunteers case advocates are mostly paid for their involvement. Professional advocacy involves actively supporting someone who has difficulties representing their views and wishes. Professional advocates work with a wide range of groups of people who are seen as being, or in danger of being, disempowered or marginalised.

Typically the professional advocacy partnerships involve working on a one to one basis rather than within a group setting. The advocacy partners work together to promote the expression of voices, views, wishes and choices as well as access to relevant information, rights and services. The professional advocate can provide also representation however only when the partner asks them to do so and with the aim of empowering the partner to self-advocate. Often different advocacy projects have professional advocates specialising in different areas such as in work with parents with learning difficulties or people with dementia (Townesley et al., 2009).

Before the creation of the role in the health and social care sectors different views had been expressed over who should have undertaken the role of the specialist advocate and whether social workers were in the best position to fulfil that role (Stewart and McIntyre, 2013). Policymakers decided however to introduce a new role of the independent advocate. The rationale behind this decision has been argued to be that if professionals played that role then a conflict of interest could potentially arise in instances where they from one side represent their partner to access the relevant support and from the other side they try to manage scarce resources (Beresford and Croft, 2004).

Case advocacy has been reported as particularly valuable when there is a fall out between the advocacy partner and the social worker when an

independent advocate can act as a diplomat between the two parties and can help to try and repair the damaged and non-functioning relationships. One criticism of the term professional advocacy has come from other types of advocacy which suggest that the term professional can imply that the rest of advocacy types may be seen as unprofessional something that is not true (Donnison, 2009).

The different types of advocacy and their main advantages and disadvantages are summarised in table 1. An individual can be involved in different advocacy partnerships as it is often the case particularly for members of self-advocacy or peer-advocacy groups and citizen advocacy where the partnership can be a longer-term one.

A main criticism against professional advocacy is that, due to its often strict funding criteria and priorities, the scope of the advocacy provided can be very restricted to only working with people falling under certain categories. Moreover, the professional advocacy service may fail to fully encompass the partner's agenda. Advocacy involvement may be restricted to the part of the person's agenda that also meets the funders' and the service's criteria. Furthermore, similarly to citizen advocacy, professional advocacy can be seen as reaffirming professional expertise and creating a power imbalance between the specialist advocate and the disempowered advocacy partner.

Table 1. Advocacy types and their main characteristics.

<b>Type of Advocacy</b>	<b>Length of relationship</b>	<b>Type of partnership</b>	<b>Advantages</b>	<b>Disadvantages</b>
<b>Self-Advocacy</b>  (Goodley, 2000)	Self-advocacy partnerships can vary in time. There is no set length of time.	Self-advocacy can be implemented at the individual or collective level. Collectively self-advocacy involves a number of people advocating for self and others but also for the greater benefit of the group and the community.	Self-advocacy is reported to support self-determination, enhance identity, develop the self-advocacy movement, be listened to, mutual support, enhance levels of empowerment, and capacity to advocate for self.	Self-advocates do not always have specialist knowledge or access to such resources. May require support for organisational and administrative purposes.



<b>Type of Advocacy</b>	<b>Length of relationship</b>	<b>Type of partnership</b>	<b>Advantages</b>	<b>Disadvantages</b>
<b>Peer or Collective Advocacy</b> (Brandon et al., 1995)	Peer or collective advocacy partnerships do not have a set length of time.	Two or more peer advocates (one usually more experienced) advocating for each other as well as for the benefit of their collective goals and their community.	Peer advocacy offers mutual support and understanding by one or more peers with similar experiences. It has demonstrated to be effective in achieving goals.	Levels of experience between peer advocates may be different thus having the potential for power imbalance.
<b>Citizen Advocacy</b> (Wolfensberger, 1983)	Citizen advocacy partnership tends to be long term.	The partnership is between an unpaid member of the local community (volunteer advocate) and the advocacy partner.	Citizen advocacy can develop to a positive long-term relationship.	It can influence dependency and may not promote self-advocacy.
<b>Professional Advocacy</b> (Atkinson, 1999)	Professional, case or community advocacy partnerships tend to be short-term.	The partnership is between the professional specialist advocate and the advocacy partner.	Professional advocates have specialist knowledge over the issue and access to specialist resources. One to one partnership can work well and can be effective. It can provide practical and process outcomes.	Professional advocates can be tied to the criteria and priorities of the service and cannot always work according to the partner's wishes (i.e. out of the scope of the service). It reaffirms professional expertise.

## 2.8. Statutory Advocacy Provision

Independent Advocacy organisations currently provide four statutory services Independent Mental Capacity Advocacy (IMCA), Independent Mental Health Advocacy, Independent NHS Complaints Advocacy and from April 2015 Care Act Advocacy.

### 2.8.1. Independent Mental Capacity Advocacy (IMCA)

The IMCA service has been introduced, in 2007, as a result of changes brought with the Mental Capacity act 2005. IMCA work aims to promote the involvement and representation of people who are seen to lack the capacity

to make important decisions in their lives. The Mental Capacity Act 2005 has introduced a legal duty to Health (local NHS trusts) and local authorities to refer people, who meet the eligibility criteria, to the IMCA service and consider their views and wishes before decisions are made. The role of IMCA advocates (IMCAs) is to represent and support people in important decisions being made about their health and social care. IMCAs are involved when the person facing the decision is assessed to lack the mental capacity to make it and is not supported by any family or friends to make the decision. The capacity to make a decision can be diminished for a number of reasons such as dementia, acquired brain injury, a mental health condition or profound learning disabilities, however, having one of these conditions does not automatically mean a person lacks capacity (Townesley et al., 2009).

The main important decisions that IMCAs are involved to support an individual with include changes of long-term accommodation, care reviews, safeguarding processes and serious medical treatment decisions. After the implementation of the Deprivation of Liberty Safeguards (DoLS) on 1<sup>st</sup> of April 2009 IMCA advocates also have the important role of supporting people who may be subject to these safeguards (Department of Health, 2009c). IMCAs audit the decision-making processes to make sure the principles of the Act have been followed. Furthermore, IMCAs have certain powers to challenge decisions such as asking for a new mental capacity assessment, a second medical opinion or even referring the case to the Court of Protection.

Lonbay and Brandon (2017) suggested that IMCAs can be useful as an extra safety net for older people involved in safeguarding processes. Lonbay and Brandon (2017) however also argued that the understanding of the IMCA role by professionals involved in safeguarding processes was limited. Gorczynska and Thompson (2007) proposed that the IMCA role is different compared to other types of advocacy as it mostly involves non-instructed advocacy work as a lot of the time the work is not directed by the person themselves but professionals. Thus, IMCA work poses some questions as to whether it meets all of the advocacy principles, discussed earlier in section 2.5, particularly the principle of putting people first and of independence.

### ***2.8.2. Independent Mental Health Advocacy (IMHA)***

The IMHA service was introduced in 2009 as part of the amendments to the Mental Health Act 1983 in Mental Health Act 2007. IMHA advocates (IMHAs) support individuals who are detained under the powers of the Mental Health Act in a mental health setting. Furthermore, other eligible individuals include those on supervised Community Treatment Orders, provisionally discharged from hospital and informal patients who consider serious medical treatment in response to a Mental Health condition. IMHAs support individuals to represent their views, access information and know their rights under the Act and the parts that apply to them. Moreover, IMHAs support the individuals to exercise their rights, such as ask for a Mental Health Tribunal or a Hospital Managers hearing to review their case, if they wish to do so. Furthermore, IMHAs support individuals to obtain information about and an understanding of the medical treatment they receive or might receive and the reasons around that (Department of Health, 2008).

### ***2.8.3. NHS Complaints Advocacy***

NHS Complaints Advocacy is a statutory advocacy service set up in April 2013 to replace the Independent Complaints Advocacy Service (ICAS). ICAS provided advocacy support to individuals who wished to make a complaint about NHS. According to the Local Government Association (2012), ICAS was commissioned centrally by the Department of Health whereas the NHS Complaints Advocacy service is commissioned by the local authorities. The new NHS Complaints Advocacy Service support may range according to the needs of the individual who wishes to make a complaint about the NHS. NHS Complaints Advocacy can be seen as one of the few areas of advocacy that works with the general population rather than with specific groups of people.

### ***2.8.4. Independent Care Act Advocacy (ICAA)***

The Care Act 2014 introduced a new form of advocacy, from April 2015, Independent Care Act Advocacy. According to the Care Act 2014 local authorities ought to involve people in decisions made about their care and support. The Care Act 2014 mentions that regardless of how complex the needs of a person are the local authorities have a requirement to help people

express their views, wishes and feelings and support them in considering their options and making their own decisions. According to the Department of Health (2014), Care Act advocacy is introduced to provide advocacy support to eligible people to be fully involved in key decisions that shape their lives such as care assessments, care or support planning meetings and reviews as well as safeguarding enquiries and reviews. The eligibility of a person is similar to that of a person eligible for IMCA support, although broader. A person is eligible when they have been assessed to have a “substantial difficulty”, in understanding, retaining and weighing relevant information and or in communicating their views, wishes and feelings. Furthermore, the eligible person has no other “appropriate person” such as family or friends however an independent advocate can work alongside them if required. The main difference with the IMCA service is that Care Act Advocacy covers a wider range of decisions that entitles the person to use the service and also that Care Act advocacy provides also support to carers that face certain difficulties. The Care Act also makes provision for ICAAs of carers supporting people going through an assessment or review. Moreover, the person can choose not to have a friend or relative involved but rather to opt for support from an independent advocate.

## **2.9. Advocacy Practice**

Advocacy organisations can vary in size from small local organisations with only a few volunteers and paid advocates to larger ones that run multiple services nationally. Some advocacy projects offer only one type of advocacy and work with one particular group whereas other projects provide multiple services including statutory ones to different groups of people. According to Donnison (2009), there is a tendency for bureaucrats to prefer to work with projects that provide a number of services rather than having to deal with several smaller projects which is something that probably puts smaller projects in a disadvantaged position.

Advocacy projects most often involve people that use their service in the running of the organisation such as being executive committee members or

even chairs of the organisation. A number of advocacy organisations have been created as well as run by and for disabled people including people with learning difficulties such as the self-advocacy project People First that has projects around the country. Furthermore, most advocacy schemes are charities that only offer advocacy services with the exception of some projects that are part of bigger organisations that offer a wide range of services such as Age UK. It is important however that in such instances all the necessary measures were taken for the advocacy project to maintain its operational independence from the rest of the organisation and services provided to avoid any potential conflicts of interest. Most advocacy organisations receive funding from their respective local authorities usually in order to provide the statutory services such as IMCA, ICAA and IMHA. However, advocacy projects seek and often succeed securing funding from alternative sources including from foundations, grants, other charities, the Health authorities, and the Big Lottery Fund as well as from their own fundraising activities.

Although most advocates at the beginning of the advocacy movement were volunteers, particularly citizen, peer and self-advocates, since the introduction of case and statutory advocacy the number of paid advocates has increased. Citizen advocates are recruited by the project and are offered training and support however after they have been matched with a partner often do little formal reporting to the project. Peer and self-advocates that are also mostly volunteers, however not always, usually have peer support and supervision sessions in order to share and learn from each other's experiences. Peer and self-advocates are often part of collective advocacy organisations and the sharing of experience informs their campaigns for change in areas identified by a number of advocates.

Paid advocates, particularly in smaller projects, work with different groups of individuals and provide different services including statutory IMHA or IMCA. Most of the paid advocates, particularly in smaller projects, are employed with short term contracts and often work on a sessional basis according to the needs of the service. This reflects the nature of the funding mostly

available, to advocacy organisations, which is often short term and not secure. However, there are also a number of contracts which go out in tender from the local authorities, to cover mostly statutory advocacy services, and are considerably longer-term (2-3 years) and bigger in size. Advocates are recruited via advertising mostly in local and regional voluntary networks but also internally with volunteers often taking up paid advocacy roles.

Common issues that advocates tend to be involved include problems with other service providers such as care or housing providers. The advocates using the relevant principles support individuals or groups to liaise with other professionals, attend meetings, find the relevant information to help making a decision, know their rights, access services and entitlements as well as making a complaint among other issues. Although different types of advocacy services are provided to different groups of people the vast majority of services are available to people who are seen as vulnerable or in danger of being marginalised from society. Groups of people accessing advocacy services are often people with learning difficulties, physical disabilities, mental health issues, older people, looked after children and young people as well as people from ethnic minorities, particularly refugees and asylum seekers. Most advocacy projects accept self-referrals as well as referrals from professionals and family members or friends except for some statutory services that have specific processes for receiving referrals.

In a typical advocacy partnership in the initial meeting, the advocate explains their role as well as the relevant procedures such as confidentiality and complaints procedures. Furthermore, the advocate and the partner agree together an action plan which includes the expected goals using the partner's preferred method of communication. Depending on the type of advocacy the relationship can last from a few days to a number of years as is often the case in citizen advocacy partnerships. Advocates strive to develop a positive and trusting relationship with their partner however using the underpinning principle of empowerment that entails that advocacy should promote self-advocacy. In case advocacy typically the partnership comes to an end when the issue identified has been dealt with, following the agreed action plan, and

there are no further issues. Advocates actively seek feedback from their partners in order to inform practice, support the evaluation of the service as well as provide evidence to funders of how the service is doing. Apart from the expected outcomes of the advocacy involvement that can be relatively easily measured, it is thought that advocacy work can contribute towards other outcomes such as improved skills or confidence for the person. This suggestion is looked at closely in different sections of this study and is discussed in different chapters throughout the thesis.

## **2.10. Advocacy Monitoring**

Following government initiatives (e.g. Valuing People, 2001 and Valuing People Now, 2009) recommending the use of independent advocacy several organisations offer advocacy services throughout the country. However, although there are currently frameworks that monitor the quality of the service provided by advocacy organisations they are not universally accepted and to date they are not used as a legal requirement. For example, the Quality Performance Mark which was originally introduced by Action for Advocacy in 2008 (QPM, 2008) and is currently being implemented by the National Development Team for Inclusion (NDTi, 2018). The work of NDTi to review QPM was commissioned by the Department of Health and Action for Advocacy (A4A) in order to build and update the existing work after A4A ceased operations in 2013. The QPM, in its 4<sup>th</sup> edition from May 2018, is used by independent advocacy providers to show their ability and commitment to providing high-quality advocacy services which are seen as essential to support people to have their voice heard and to exercise control and choices. Furthermore, the Scottish Independent Advocacy Alliance (SIAA) is providing a quality assurance project specific to independent advocacy providers in Scotland (SIAA, 2010). The SIAA evaluation framework provides some tools for measuring the effectiveness of the service against their standards and principles.

Early attempts to measure the quality and performance of advocacy provision include Citizen Advocacy Performance Evaluation (CAPE), Citizen

Advocacy Information and Training (CAIT) and Advocacy Network Newcastle Evaluation Tool (ANNETTE) (Action for Advocacy, 2009). CAPE has been seen as rather useful in providing evidence for Citizen Advocacy specific standards such as the rejection of a service approach however its design is specific for demonstrating the value of Citizen Advocacy schemes rather than advocacy projects in general. CAIT similarly to CAPE was developed to provide evidence of good value for Citizen Advocacy schemes however it was less purist in its approach. CAIT although less purist it was still mostly relevant to Citizen Advocacy projects. ANNETTE was originally devised in 1995 however has undergone considerable update and revision in 2004 something that made it more relevant for demonstrating the outcomes of advocacy work other than citizen advocacy. However, ANNETTE is not without its disadvantages, for example, the outcomes being measured are assessed by the advocates and not by the partners (Macadam et al., 2013). Other independent advocacy organisations have developed their own evaluation and monitoring tools for the purpose of monitoring and evaluating their own work however those tend to be used only internally.

Action for Advocacy has also developed its own evaluation tool (Lost in Translation published in 2009), apart from the monitoring tool described earlier (QPM, 2008). The Lost in Translation evaluation toolkit focused more on the outcomes of advocacy work. Action for Advocacy (2009) developed the toolkit to make it available to different advocacy organisations that can utilise it and review it according to their needs alongside the Quality Performance Mark thus better demonstrating the value of advocacy work. However, although these attempts have included some evaluation of the effectiveness of advocacy they have not put much focus upon the outcomes from the service users' perspective. Beresford and Croft (2004) suggested that involving the users of a service in the process of evaluation is an important element of any credible evaluation tool. Service user involvement can include scoping the area, discussing and interpreting the results as well as making sure that the summary material is accessible. Ridley et al. (2018) argued that the perspective and the experiences of people using advocacy can bring valuable insight into the real advocacy impact and outcomes for



the people who use the service. Ridley et al. (2018) however also highlighted the lack of research studies exploring advocacy from the point of view of the people who use the service and called for more research with this method in order to fill this gap in the existing knowledge.

### **2.11. Advocacy Training**

The need for formal independent advocacy became apparent following the release of governmental White Paper, Reforming the Mental Health Act 2000, which proposed a statutory right to specialist advocates for people detained under the Mental Health Act in England and Wales. Barnes, Brandon and Webb (2002) were commissioned to study and identify the essential characteristics of the new specialist mental health advocacy service. The study reported a number of recommendations for the suggested role and those were utilised to produce an agreed set of standards and an agreed code of practice. The standards and code of practice from the recommendations were an essential part of the construction of the specialist independent advocacy training.

The independent advocacy qualifications have been developed in a partnership between the Department of Health, City and Guilds and the Welsh Assembly Government (Department of Health, 2009b). The qualifications aimed at helping the practising/prospective advocates to learn more about how to represent an individual's interests and to interact with individuals as well as with other organisations and agencies. A main aim also, according to the Department of Health was to achieve quality and consistency in advocacy training. The qualifications were introduced in 2009 in anticipation of the addition of the Independent Mental Health Advocacy (IMHA) statutory service and of Deprivation of Liberty Safeguards (DoLS) to the existing Independent Mental Capacity Advocacy statutory service. A Level 3 certificate in Independent Advocacy was introduced along with a Diploma in IMCA-DoLS practice with a specialist module about the IMHA practice. Regional centres registered with City and Guilds are providing the advocacy qualifications. A Care Act advocacy practice module started being

delivered in 2015 alongside the implementation of the Care Act 2014 from 1<sup>st</sup> of April 2015.

Other routes of training for advocacy practice include in house training delivered by the advocacy organisations. Furthermore, advocacy training can be offered by regional as well as national organisations such as by Kate Mercer Training and Cloverleaf Advocacy and in the past by Action for Advocacy before ceasing its operations. Apart from the formal qualification and training advocates inform their practice from their own experiences and life skills as well as often from skills from previous work or volunteer experience in relevant fields such as health and social care. Personal qualities for advocates include active listening, empathy, communication skills, assertiveness as well as being passionate about what they are doing and believe that can make a difference. All advocates ought to keep up to date with the relevant legislation as well as local policies and procedures in their area of work. Furthermore, it is recognised that practising advocates, particularly in a statutory role, need to access continuing professional development training apart from completing the relevant qualification such as training on their specialist areas and participating in regular forums in their fields.

## **2.12. Advocacy Research**

There is a lot of anecdotal evidence and stories suggesting that advocacy works and supports partners to develop certain skills however a lack of robust evidence to support this notion has also been highlighted (Macadam et al., 2013). Reasons behind this include the fact that there has been little research interest given to advocacy in general, due to various reasons, and also due to the difficulty of measuring the outcomes of any advocacy work. Another reason cited for the lack of systematic evidence is the number of different types of advocacy services provided with differing aims and objectives (Stewart and MacIntyre, 2013). Fazil et al. (2004) attributed the limited evidence base to conflicting definitions as well as a general lack of understanding around the role of advocacy.

The need for further research into advocacy work and subsequent evidence has intensified since many more advocacy schemes are operating throughout the country and they need to demonstrate good 'value for money' in order to receive the necessary funding to continue to operate (Macadam et al., 2013). Moreover, since the introduction and expansion of statutory advocacy services, it is even more important for the services to demonstrate the outcomes and potential value of their work.

### ***2.12.1. Methodologies used in Advocacy Research***

Although the research interest on advocacy has been limited a number of studies have been conducted using different research methods and approaches both qualitative and quantitative to explore advocacy, its outcomes and impact. Rapaport et al. (2005) reviewed the literature in regard to the different models of evaluation used by funders of advocacy projects for people with learning difficulties in the UK. The six main models used by funders to evaluate advocacy work and its benefits and drawbacks were discussed. Hussein et al. (2006) conducted survey research with funders, from local authorities, in order to examine how they evaluated advocacy work. The research attempted to investigate the types of support provided by funders to advocacy projects and their requirement for reports from them. Rapaport et al. (2006) conducted a series of 27 semi-structured interviews with a variety of different stakeholders of advocacy schemes for people with learning difficulties in the UK in an attempt to investigate their perceptions of the effectiveness of advocacy work. Fazil et al. (2004) conducted a 20-month action research project with ethnic minority families with children who were seen as having severe disabilities and received support from an advocacy project. Fazil et al. (2004) carried out the interviews with the families at different stages of the advocacy involvement including before during and after working with advocacy. Palmer et al. (2012) used the outcomes tool developed by Action for Advocacy (2009) to explore advocacy outcomes. Forbat and Atkinson (2005) tried to involve advocacy service users in their evaluation of advocacy mostly via questionnaires. Forbat and Atkinson (2005) commented that they received several questionnaire responses with

“not sure” and or “don’t know” however they did not elaborate further as to whether these responses were the pitfall of the method of data collection or due to other reasons.

### ***2.12.2. Research exploring Advocacy’s monitoring and evaluation***

Rapaport et al. (2006) reported that the views of stakeholders around advocacy services highlights the need for further, evaluations and recommendations for change. It was highlighted that although the demonstration of outcomes is increasingly needed it is not universally in place and the development of adequate tools to do this is paramount. Rapaport et al. (2005) highlighted that although there is a potential for the evaluation from the funders to infringe advocacy schemes’ autonomy there is a need for an effective evaluation process to be in place for reasons of public accountability. The authors concluded that advocacy projects should work towards adopting a model of evaluation that works best for them as well as being seen as useful by their funders.

Hussein et al. (2006) concluded that external monitoring and evaluation is not extensively used and well understood. They also suggested that user involvement is seen as appropriate from funders however they expressed that it is not as developed as it could be. The authors argued that advocacy services have shown accountability and an interest to develop methods that enable them to more effectively measure and demonstrate the outcomes of advocacy work, however, the tools to be used for this purpose are not there. Fazil et al. (2004) reported that advocacy improved access to resources, services and information and provided support in a non-stigmatising way. Forbat and Atkinson (2005) reported that advocacy makes a positive difference however they also highlighted that advocacy evaluation has concentrated on the positive aspects of the practice whereas the whole range of advocacy partners’ views need to be explored and not only the positives. Palmer et al. (2012) study reported a significant increase in self-reported self-efficacy, wellbeing and empowerment for the participants. Palmer et al. (2012) suggested that given that increasing empowerment is one of the main objectives of advocacy the outcomes reported could be

viewed as rather positive. Furthermore, Palmer et al. (2012) acknowledged that the responses from the participants could have been influenced by a number of different factors such as the mood of participants and the tendency to provide perceived desired responses. They also acknowledged that the sample size could be seen as a limitation for the study in terms of the generalisability of the findings.

### ***2.12.3. Advocacy Research without the people that use the service***

As discussed in the previous sections there has been limited research exploring advocacy, particularly around monitoring and evaluation. However even less research has focused on involving the people with disabilities that actually use the service being studied. For instance Fazil et al. (2004) carried out their research by interviewing the parents of children with disabilities. Rapaport et al. (2005) reviewed the literature of the different models of evaluation used by funders of advocacy projects for people with learning difficulties in the UK. Hussein et al. (2006) conducted survey research with funders, from local authorities, to examine how they evaluate advocacy work. Rapaport et al. (2006) conducted a series of 27 semi-structured interviews with a variety of different stakeholders of advocacy schemes for people with learning difficulties in the UK. Forbat and Atkinson (2005) tried to involve advocacy service users in their evaluation of advocacy mostly via questionnaires however they imply that they were not very successful in doing so.

A criticism for Forbat and Atkinson (2005) as well as the other studies is that they could have employed a design that better captured the responses and the views of the advocacy partners. A further criticism for all these research projects discussed above is that they failed to provide insights into the experiences of people with learning difficulties themselves. This is an important point because to better understand and improve a service you have to first understand how the people that use it perceive it.

Ridley et al. (2018) also highlighted that there is a lack of involvement of people that use advocacy services in research. Ridley et al. (2018) suggested that further research involving people that use advocacy should be carried out as this is a core component of credible service evaluation. The lack of research from the point of view of the people that use advocacy deprives research of experts' points of view that can inform advocacy theory as well as practice. Furthermore, Newbigging et al. (2015a) highlighted that further research is required to explore the process outcomes of advocacy as the majority of research concentrated on outputs and end-point outcomes.

### **2.13. Advocacy Outcomes**

Advocacy can be seen as providing two main types of outcomes often described as hard or end-point and soft or process outcomes. End-point outcomes usually involve reaching a practical target agreed with the service user and are relatively easy to measure. Process outcomes such as increased confidence, learning, better communication skills or reduced anxiety are associated with the process of advocacy work and are more difficult to demonstrate but also of equal, if not greater, importance.

Townsley et al. (2009) highlighted that research is needed in advocacy to show the potential benefits for service users not only from the actual outcomes of advocacy work but also from the process of the advocacy partnership. As the latter is sometimes overlooked and not always perceived as an added benefit. Townsley et al. (2009) listed several benefits coming out of advocacy work across a number of different areas. Stewart and McIntyre (2013) suggested that the difficulty to effectively examine the impact of advocacy outcomes for people who use the service can be partly attributed to the wide range of projects with sometimes conflicting aims and objectives.

Advocacy work is rather complex and can vary depending on the two individuals involved in the advocacy partnership. Therefore inherent difficulties exist in evaluating the effectiveness of advocacy particularly in

relation to outcomes. Outcomes such as communication, assertiveness and social skills are considered to play an important part in peoples' lives. Stewart and McIntyre (2013) suggested that despite the lack of empirical evidence it has been demonstrated that people who use the advocacy service can benefit to a large extent not only from the actual outcome of the involvement but also from the process of having and working with an advocate. Featherstone et al. (2012) proposed that when considering the outcomes of advocacy involvement it is important to separate them. They elaborated that although an actual end-point outcome of the advocacy involvement can be negative such as not being able to access the desired services the work with the advocate can be a positive experience, for example, aiding the empowerment of the person to speak up for themselves.

### ***2.13.1. Advocacy Outcomes Types***

Different authors suggested a different number of main categories for advocacy outcomes. Thomas et al. (2016) and Thomas et al. (2017) came up with three main categories of advocacy outcomes "improving participation and giving young people a voice", "personal growth and development" and "getting a result and other practical changes or achieving practical change and resolving issues". The first two types of advocacy outcomes, identified by Thomas et al., are best described as process outcomes as they are both coming out of the work within the advocacy partnership to achieve the practical goal set at the beginning of the relationship. Improving participation and giving young people a voice outcome was identified as important by all the different types of participants in their study. Personal growth and development outcome demonstrated the personal change following advocacy work for example increase in self-esteem, learning and confidence to self-advocate. Thomas et al. third main category is clearly related to the end-point advocacy outcomes type, as it is measured against the actual target set at the beginning of the advocacy partnership. Getting a result and other practical changes or achieving practical change and resolving issues outcomes are also very important outcomes as they appear to provide a big motivation for the young people to work with advocacy in order to try and

bring some resolutions to their issues. Practical changes can include removing restrictions, changes in contact and changes in living arrangements. However, it has also been demonstrated that advocacy outcomes were by far not restricted to practical changes.

Miller (2011) suggested that there are three main types of outcomes quality of life outcomes, change outcomes and process outcomes. Quality of life outcomes are closely related to end-point outcomes in contrast to process outcomes which are closely related to the advocacy journey. Finally, the change outcomes term is rather generic and can include both end-point and process outcomes. Hoggarth et al. (2004) used the term process outcomes, however, also used the term destination outcomes to describe the end-point outcomes in the work with the young people. Macadam et al. (2013) preferred using the terms process outcomes and advocacy outcomes. Newbigging et al. (2015b) chose the terms process outcomes and change outcomes to best describe the main types of advocacy outcomes identified in their study. Townsley et al. (2009) used the term process outcomes and the term benefit outcomes. Townsley et al. (2009) however also highlighted that people who have used the advocacy service did not always see the benefit outcomes as positive. Stewart and McIntyre (2013) used the terms soft or process outcomes and improvement outcomes.

All the different studies' approaches to name the different types of advocacy outcomes, discussed above, included and highlighted two main types of advocacy outcomes. The outcomes which are the end result of the advocacy partnership and the outcomes that are coming out of the advocacy process. However because the words improvement, change and benefit used to describe outcomes, in many studies discussed above, are inherently positive the more neutral description of end-point outcomes was preferred in our study. The main reason for this decision is that it has been argued that the outcomes of advocacy work are not necessarily perceived by individuals who use the service as always positive but can also be perceived as neutral or negative. Moreover, our research study approached the topic of advocacy



outcomes with an open mind aiming to explore the views of people who have used advocacy rather than carry out the research with pre-conceived ideas.

Advocacy outcomes are best described by two main categories end-point outcomes and process outcomes. Those two categories can capture the entire variety of outcomes that can then be divided into sub-categories. End-point outcomes are the measurable result of the advocacy partnership, or a specific intervention whereas process outcomes are coming out of the advocacy process or journey. Process outcomes can be produced in parallel with trying to succeed in achieving the end-point outcomes (targets or goals) agreed at the beginning of the partnership. It has been well documented in the literature that process advocacy outcomes can be present even if the agreed goal or target has not been reached (Macadam et al., 2013).

### ***2.13.2. Advocacy Outcomes Research***

There are a limited number of studies and papers exploring advocacy and its outcomes. The vast majority of the studies are looking into advocacy and advocacy outcomes from the point of view of different other stakeholders and not from the point of view of the people who actually use the service. As discussed in the previous section there have been studies looking into advocacy outcomes from the point of view of social services professionals (Rapaport et al., 2006), from the point of view of professional advocates (Forbat and Atkinson, 2005, Carver and Morrison, 2005) from the point of view of parents (Fazil et al., 2004), from the point of view of mental health professionals (Jugessur and Iles, 2009) and commissioners of advocacy (Hussein et al., 2006 and Rapaport et al., 2005). However, there are very few research studies exploring the views, experiences, thoughts and feelings of people, who use advocacy services, around its outcomes (Ridley et al., 2018).

Advocacy research and practice demonstrate that it cannot be assumed that the views, of the people that use the service, on outcomes are necessarily the same as those of organisations and practitioners (Felton, 2005). It has been highlighted that involving people who use the service, in determining

the outcomes that they see as important and they wish to achieve, can be empowering and lead in increased relevance to the support provided (Beresford et al., 2011). Miller (2011) proposed that a focus on personal outcomes, in a service, offers the potential of placing the attention on what really matters most to people who use that service, with potential advantages for the individuals involved, practitioners and organisations. It has also been highlighted however that although outcomes have been considered as important in social policy for a long time, a number of challenges are still present regarding their measurement.

From the few studies that have involved people who have used advocacy services, and explored their views and experiences, a limited number has concentrated on the views experiences and feelings of people with learning difficulties. Thomas et al. (2017), Thomas et al. (2016) and Oliver et al. (2006) looked at the impact and outcomes of advocacy involving children and young people. Thomas et al. (2017) and Thomas et al. (2016) used interviews and focus groups to explore how children and young people understand and value advocacy and what difference does it make in their lives. Thomas et al. (2016) concluded that advocacy can be significant, for the lives of children and young people, as it does not only impact on them directly but also indirectly via the impact on wider services they use. Oliver et al. (2006) carried out in-depth semi-structured qualitative interviews with 48 children and young people of varying ages, disabilities and ethnic origin. Oliver et al. (2006) participants expressed that a number of advocacy outcomes are relevant to them. Oliver et al. (2006) findings identified several process advocacy outcomes but also some end-point outcomes that were highlighted by the participants.

Bocioaga (2014), Bright (2008), Wright (2006) and Murphy (2001) explored the impact of advocacy on the lives of older advocacy partners. Bocioaga (2014) looked at the challenges faced by older advocacy partners, but also at the advocacy process and advocacy outcomes. Bocioaga (2014) described the advocacy process as the actions taken to achieve a specific goal chosen by the advocacy partner at the beginning of the partnership. The study used

qualitative methodology involving 13 individuals, with experience of working with advocacy, recruited from different advocacy organisations across Scotland. Bocioaga (2014) reported that the older advocacy partners suggested that hard or end-point outcomes such as advocacy supporting them to maintain their independence or regain control of their circumstances, completing forms, making complaints and navigate the complex systems were important. However, apart from the hard outcomes, they also found soft or process outcomes to be very important. Bright (2008) carried out interviews with older people who have worked with advocacy. Participants from the Bright (2008) study highlighted a number of process outcomes but also some end-point outcomes. Townsley et al. (2009) criticised Bright (2008) study by suggesting that the robustness of the study was limited due to the small sample size, with only three participants taking part in the interviews.

Wright (2006) carried out interviews and focus groups with 35 older people with experiences from using different types of advocacy services. Wright (2006) study involved participants that were seen as a representative group in terms of age, gender, ethnicity, disability and geographical area. Wright (2006) study reported that process outcomes, as well as end-point outcomes, were important for them. Wright (2006) reported also a number of process outcomes including increased self-confidence, self-worth and emotional well-being. Participants also reported that they felt encouraged and supported by the advocate to find solutions. End-point outcomes reported by the participants included increased income via improved access to financial entitlements and more independence via being supported to obtain appropriate equipment and physical adaptations. Wright (2006) participants reported that they valued the advocacy service even if the agreed end-point outcome was not reached.

Murphy (2001) interviewed older people who have used an advocacy service and explored its effectiveness. Murphy (2001) highlighted a lack of understanding by both people who have used the service and professionals who expressed expectations that were in contrast with fundamental

principles of advocacy. Advocacy is not about giving advice but rather about working together to find accurate information and fight for rights and involvement in decisions. Two of the most consistent goals cited by advocacy users and organisations are empowerment and self-advocacy.

Newbigging et al. (2015b), Palmer et al. (2012) and Eades (2018) explored advocacy and its outcomes using focus groups and interviews with people who have been detained under the powers of the Mental Health Act (2007) and with people who have experienced using mental health services. Newbigging et al. (2015b) participants highlighted several advocacy outcomes mostly process but also some end-point ones. Newbigging et al. (2015b) study highlighted problems with accessing advocacy (IMHA) particularly for people with specific needs relating to ethnicity, age and disability. A key strong point of the Newbigging et al. (2015b) study was that mental health advocacy service users were members of the research team sharing their skills and experiential knowledge.

Palmer et al. (2012) explored advocacy outcomes using qualitative interviews with 10 participants (long term in-patient residents) who had experience using a specialist independent mental health advocacy (IMHA) service. Palmer et al. (2012) similarly to Newbigging et al. (2015b) argued that a proactive opt-out rather than opt-in approach will increase the accessibility of the specialist advocacy service. Eades (2018) explored an IMHA service and its outcomes in a secure hospital. Eades (2018), unlike the previous studies, suggested that one of the study's main purposes was to provide quantitative evidence to gain a better understanding of the impact of IMHA services.

Darwin and Pickering (2007), OPAAL (2009) and Barnes and Tate (2000) carried out qualitative research studies that looked into the experience of advocacy by vulnerable adults who had been alleged perpetrators or victims of anti-social behaviour. Darwin and Pickering (2007) carried out the research with vulnerable adults who have been victims of anti-social behaviour. Darwin and Pickering (2007) participants highlighted many

advocacy outcomes. OPAAL (2009) worked with victims of elder abuse and explored their views and experiences working with advocacy services. Barnes and Tate (2000) carried out research with patients at the Ashworth secure hospital and explored their experiences of the advocacy service based in the hospital. The participants at the Barnes and Tate (2000) study came up with a number of different advocacy outcomes including process and end-point outcomes.

A limited number of studies carried out research with parents with learning difficulties and looked at their views and experiences of advocacy. These studies appear to be some of the very few that worked specifically with people with learning difficulties, who have experience of advocacy work, exploring advocacy outcomes. Tarleton et al. (2006) carried out research with a group of parents with learning difficulties and explored their expressed issues as well as positive practices in supporting them and their children. The parents with learning difficulties talked in interviews about their views and experiences when working with an advocate and about the support they received. Tarleton (2007) conducted a study looking at the experiences and views of people with learning difficulties on advocacy and its associated outcomes. Tarleton (2007) research involved 14 parents with learning difficulties and explored how they viewed and experienced working with two advocacy services.

### ***2.13.3. Research with Self-Advocates***

Moreover, research has been carried out with self-advocacy group members, with learning difficulties, exploring the self-advocacy membership outcomes. This type of research is not directly looking at independent advocacy or different types of advocacy and their outcomes but rather focuses only on self-advocacy work. It is however of interest to compare and contrast outcomes from self-advocacy group members with learning difficulties and outcomes from people with learning difficulties who have experiences of different types of advocacy. Llewelyn and Northway (2008) worked with people with learning difficulties who have experiences of advocacy exploring advocacy's meaning and definition from their perspective. The research

concluded that advocacy had different meanings for different groups of people with learning difficulties in different situations.

Gilmartin and Slevin (2010) carried out an inclusive study with participants with learning difficulties using a phenomenological approach to explore the experiences and feelings associated with being a member of a self-advocacy group in Ireland. The findings suggested that belonging to a self-advocacy group enhanced the quality of life of its members. The self-advocacy groups were described as having the potential to empower people with learning difficulties who have experienced feeling disempowered and the potential to bring positive change and make a real difference to the members' lives. Clarke et al. (2015) explored the experiences of six members of a well-established self-advocacy group with learning difficulties. Clarke et al. worked with the self-advocates collaboratively carrying out individual and group interviews and identified benefits and difficulties of being a member using thematic analysis.

Caldwell (2011) carried out in-depth interviews, adopting a life story approach, with 13 leaders (10 with learning difficulties) in the self-advocacy movement in the United States. Caldwell (2011) used grounded theory as the adopted method of analysis. Caldwell (2011) findings suggested that five main themes were identified including reclaiming disability and personal transformation, resistance/claiming personhood and voice, interconnection with the broader disability rights movement, bond with social justice and interdependency and connection with the disability community.

Goodley and Armstrong (2001) adopted the participatory research philosophy to explore the significance and meaning of self-advocacy in the lives of people with learning difficulties using two qualitative methods ethnography and narrative inquiry. Goodley and Armstrong (2001) carried out the research with four different types of self-advocacy groups a service-sponsored, an advocacy-supported, an organisational and an independent group. Goodley and Armstrong (2001) findings identified seven main themes. *Living and experiencing self-advocacy* which is a theme directly linked with

the lack of opportunities and chances created by disabling environments and faced by the self-advocacy group members. Members of a self-advocacy group had the opportunity to do something they really want and choose to do rather than take part in something that others have organised for them such as at a day centre.

Goodley and Armstrong (2001) reported that other themes identified in their research with self-advocates were *Deconstructing learning difficulties* by providing peer support to each other and creating alternative meanings. *Informing the social model of disability and disability politics* by challenging demeaning notions and by showing that people with learning difficulties are capable of working with themselves without the need to be dependent on more capable others. *Supporting self-advocacy and conceptualising rights* for people with learning difficulties that have been often denied the most basic rights and are in danger of losing them again due to policy and funding changes. *Supporting and understanding self-advocacy in policy-making contexts* and realising the dynamic shifting nature of power within self-advocacy. *Self-advocacy, narrative methods and ethnography* emphasise the self-advocates' perspectives on self-advocacy work as well as its achievements. The final theme was *recommendations for doing disability research and supporting disabled researchers*.

Goodley and Armstrong (2001) emphasized the lack of space left for people with learning difficulties in the mainstream disability studies movement. Goodley and Armstrong (2001) claimed that the social model of disability failed to consider the role of impairment in disability and thus leaving to the medical model the main account of impairment. Goodley and Armstrong (2001) suggested that self-advocacy provides opportunities for people with learning difficulties to individually and collectively speak out for human rights and challenge a disabling society.

## **2.14. Advocacy Theory**

Although informal advocacy is thought to have been a human trait since the earliest times of human history, with possibly the keenest of advocates being parents, the formal advocacy movement has been relatively recent (Gray and Jackson, 2002). Many marginalised groups, such as people with learning difficulties and mental health problems, who have suffered from a society, which even questioned their essential humanity, and been excluded were encouraged by advocacy to have a voice. There is a wide variety of advocacy schemes speaking up for marginalised groups of people. Schemes established, particularly in the second half of the twentieth century, included survivors from long-term mental health institutes as well as people with physical disabilities however for the purpose of this section the main focus is on advocacy by and for people with learning difficulties. The following sections are going to introduce and discuss four theoretical approaches that influenced or continue to influence advocacy theory and practice. The following sections explored the influences in advocacy by the normalisation theories, the social model of disability, the self-advocacy movement and the critical disability studies model.

### **2.14.1. Normalisation Theories**

The first theories that talked about advocacy and speaking up for people with learning difficulties were the Normalisation and Social Role Valorisation theories. Normalisation emerged in the early 1960s as a movement to redress the inequalities and injustices suffered by people with learning difficulties. The main concept was that normal patterns and conditions of everyday living become available to people with learning difficulties, then called “mentally retarded”, in order to enable them to live a life as “normal” as possible (Nirje, 1980). In around the same time Wolfensberger used the Normalisation principles (later renamed Social Role Valorisation) in an effort to speak up for people with learning difficulties to reverse the consequences of social devaluation by enabling people to establish and maintain “valued” social roles in society (Wolfensberger, 1983). Similarly, O’Brien’s 5 Accomplishments theory suggested that people with learning difficulties



should be included and be enabled to have a Community Presence, Relationships, Choice, Competence and Respect (O'Brien, 1987). Citizen Advocacy was a direct result of the development of the Normalisation, Social Role Valorisation and 5 Accomplishments theories. Citizen advocates were seen as the valued members of society that give up some of their time to support and speak up for their partners to have increased access to normal patterns and conditions of everyday life and take up valued roles in society (Wertheimer, 1998).

Williams and Schoultz (1982) criticised the normalisation theories by suggesting that Wolfensberger went as far as to argue that citizen advocacy partnerships were a prerequisite for people with severe learning difficulties to grow towards independence and self-advocacy. Foucault (1975) argued that dominant discourses used the apparatus of normalisation to examine and categorise people in order to exclude those falling outside of the norms. Moreover Swain and French (2000) put forward the affirmation model which proposed that the experiences of people with learning difficulties should be re-evaluated as positive without being categorised and normalised. Additionally, Walmsley (2002) suggested that normalisation theories as well as the citizen advocacy movement were in the hands of non-disabled people arguing for improvements in the lives of people with learning difficulties. Mack (2001) argued that this came in contrast with the development of movements around the same time where the people who were the targets of ill-treatment and discrimination were those who were leading the fight against their oppressors in nearly every group apart from people with learning difficulties. However, that was to change with the development of the Self-Advocacy movement explored later in the section.

#### ***2.14.2. Social Model of Disability***

Oliver and Barnes (2012) summarised a number of criticisms of normalisation theories. They argued that they ignored individual differences such as gender, age, class and race within and across marginalised groups as well as failed to question prevailing notions of society for normality. Moreover, they argued that normalisation does little to diminish the impact of

professional authority over the lives of disabled people and it puts the focus on shared values and consensus rather than power relations between professionals and service users. Oliver and Barnes (2012) concluded that normalisation requires individuals to try and adapt to the norms of the society of the able-bodied and able-minded and accepting those as normal without questioning them.

Oliver and Barnes (1983) were amongst a number of theorists that proposed an alternative to Normalisation, as well as the Medical and Personal Tragedy models of disability. The Social Model of Disability, which was mostly developed in the UK, proposed that the explanations provided by the other models viewed disability as pathology or a personal tragedy and disabled people as patients or victims requiring treatment and help (Oliver and Barnes, 2012). The Social Model of Disability questioned the prevalent notions of normality in the society of the able-bodied and minded and highlighted that it was the barriers put up by society that excluded disabled people from participating in mainstream society as equal citizens rather than their impairments (Barnes and Oliver, 1995). Apart from only developing a theory, the Social Model of Disability called for the society to take action in order to change the negative attitudes and practices and to remove the barriers to empower disabled people to participate as fully as possible in the society (Barnes and Mercer, 2010). Furthermore, The Social Model of Disability advocated for service user involvement at all levels and also put forward the emancipatory research paradigm which seeks to advance the interests of oppressed groups and change society as well as emancipate the oppressed people by promoting their central role in the planning and implementation of research (Oliver and Barnes, 2012).

The Social Model of disability was a reaction and a critique of the dominant Medical Model of Disability, Personal Tragedy theory and Normalisation theories (Oliver and Barnes, 2012). The Medical model of disability viewed disabled people as needed to be fixed in order to conform to normative values. Personal tragedy and or charity model of disability saw disabled people as victims of their circumstances who deserve pity and was used by

non-disabled people to define disability (Oliver and Barnes, 2012). In contrast, the Social model of disability (Oliver, 1981) highlighted the barriers, exclusion and negative attitudes towards disabled people that prevented individuals from participating in mainstream society as equal citizens. Oliver and Barnes (2012) criticised Normalisation theory because it requires individuals to adapt to the norms of society in order to become more like “normal” people and does little to question the mainstream notions of normality. Similar criticisms are being held against the Medical and the Personal tragedy models of disability which are seen as promoting a range of disabling practices from medical and rehabilitation professions which are analogous to the normal/disabled dichotomy. The Social Model of Disability called for the society to change those attitudes, practices and remove the barriers in order to empower disabled people to participate as fully as possible in the society (Barnes and Mercer, 2010).

Advocacy has been linked with the Social Model of Disability viewpoint as it shares a number of principles with those expressed by social model theorists. Advocacy has been playing an important part in continuing to work together with individuals to change attitudes and practices and to remove barriers that prevent people with learning difficulties to be fully involved. Furthermore, it is important for advocacy to continue to promote the agenda of the advocacy partners and to continue to be an ally of people with learning difficulties. Because if advocacy was not to promote the peoples’ agenda but rather its funders’ or commissioners’ then advocacy will be heading towards becoming another professional service that potentially adds to the disempowerment of disabled people rather than aiding their empowerment. This notion is discussed further in the discussion and conclusion chapters to follow in the thesis.

### **2.14.3. Disempowerment**

Foucault (1981) proposed that powerful institutions produce dominant discourses and subsequently, those discourses influence ideas, thoughts and actions. Foucault (1981) highlighted that creating and controlling knowledge is power and thus the power and the creation of knowledge and

dominant discourses are interlinked and complement each other. Foucault (1981) argued that dominant ideologies have been built from powerful systems to legitimise their ruling and exert of power. Foucault (1975) described how ruling systems exerted power by labelling, using surveillance and other forms of control to impose their discourses onto people with learning difficulties and in the process took their identity away. Goffman (1961) similarly explained how total institutions exerted power and control over people with learning difficulties, as well as other marginalised groups, in order to remove their identity, crush any forms of resistance and as a result disempower them.

Furthermore, dominant modernist views of people with learning difficulties have proposed, without much opposition for the biggest part of the 20<sup>th</sup> century, that people with learning difficulties are story-less and therefore powerless (Corker and Shakespeare, 2002). The dominant ideologies, by dismissing the point of view of people with learning difficulties, managed to take away their collective identity and impose a modernist identity with negative connotations onto them. The medical model of disability pathologised people with learning difficulties by deciding that they require intervention, treatment and rehabilitation without considering the barriers placed onto them from society and without considering the point of view of disabled people (Oliver and Barnes, 2012). Furthermore often when people, labelled with learning difficulties, showed some form of resistance or disagreed with the ruling system's discourses and viewpoints were described as displaying challenging behaviour and thus requiring treatment to be compliant, disempowered and to behave according to the expected norms (Nunkoosing and Haydon-Laurelut, 2012). Labelled people with learning difficulties were not allowed to display individual differences such as liking certain things and disliking others. Labelled people with learning difficulties were not afforded to be different and express themselves as they were seen as going against the dominant discourses, which dictated how they can and cannot behave (Gray and Jackson, 2002). People with learning difficulties often had even their basic human rights denied and ignored. Gray and Jackson (2002) cited the Gold (1975) deviance competence hypothesis to

demonstrate that people with learning difficulties could not afford even to narrowly deviate from their “expected” behaviour which was determined by the dominant ideologies’ discourses. If people with learning difficulties showed some resistance to what was dictated to them they were seen as troublesome and in need of behaviour therapy to bring them back into their expected position (Nunkoosing and Haydon-Laurelut, 2012).

Even following the de-institutionalisation movement and the closure of long-term stay hospitals, where over 100.000 people were living, when labelled people with learning difficulties started to live in the community, the disempowerment, to some extent, continued. People with learning difficulties living in group homes in the community were referred to the Community Learning Disability Teams (CLDTs) to receive treatment and for their care plans to change accordingly in order to alter their behaviours and stop them from displaying “challenging behaviour” or any resistance (Nunkoosing and Haydon-Laurelut, 2012). Even worse for some people labelled with learning difficulties or autism they were taken away from their homes and their communities, where they were living, and taken to so-called short term stay hospitals such as Assessment and Treatment Units (Glover and Olson, 2012). It has been reported that people with learning difficulties or autism have ended up staying in the Assessment and Treatment Units (ATUs) for much longer than expected even longer than ten years for 15% of the detained people (James, Neary and Hatton, 2016). James et al. (2016) cited several reasons for the unnecessary delays in the discharge of people such as lack of suitable housing to meet their needs.

Furthermore, James et al. (2016) argued that the principles of the Mental Health Act have not been followed in many occasions regarding the detention of people with learning difficulties and therefore the relevant legislation protecting them has been disregarded and violated. For example, people with learning difficulties and autism have been detained without a specific treatment plan although the MHA (2007) clearly states that this is a legal requirement. Nunkoosing and Haydon-Laurelut (2010) proposed that it appears that not much has changed from the total institutions described by

Goffman (1961) when comparing them with the present day disciplinary regimes of the 21<sup>st</sup> century. The authors suggested that the institutions now and then were and still are using discourses from dominant ideologies, surveillance and disciplinary powers to stigmatise, dehumanise and change the identity of people with learning difficulties and other excluded groups of people.

Reports have also brought to light stories of widespread abuse taking place in so-called short-stay hospitals, such as Winterbourne View private hospital, where people with learning difficulties and autism have suffered at the hands of people and systems that were there to support them to live better and more fulfilled lives (Panorama, 2011). Furthermore, 8 years after the Winterbourne View scandal Panorama (2019) published similar footage of abuse from a different short-stay hospital (Whorlton Hall) thus highlighting that not much has changed in the last 8 years despite the big plans and promises.

Glover and Olson (2012) reported that people with learning difficulties and autism have experienced a catalogue of negative effects from their stay in short-stay hospitals including enduring prolonged periods of seclusion, increased number of accidents, restraints, self-harm and assaults. Ryan (2017) gave a personal account of the events that led to the preventable death of the Laughing Boy (LB) Connor Sparrowhawk. LB, within days of his admission, was restrained, taken away from his family and everything he loved and for 107 days until his early and preventable death at the age of 18 suffered from a system that was developed to support him to live a more fulfilling life (Ryan, 2017). LB's early and preventable death, under those circumstances, led to a wave of resistance from self-advocates, disability activists and artists campaigning for anti-discriminatory practices and human rights protections in short-stay hospitals.

Furthermore, it has become apparent that the scale of such scandals have been far more widespread than it was initially thought. Mencap (2012) reported 74 suspicious deaths and counting of people with learning

difficulties and autism that have been identified in NHS and private hospitals however few of those deaths have been properly investigated by the health authorities. Ryan (2017) suggested that for example, the Southern Health NHS Trust investigated less than 1 per cent of deaths of people with learning difficulties and 0.3 per cent of older people in mental health services between 2011 and 2015. Moreover, Ryan (2017) noted that the Trust has failed to investigate over 1000 unexpected deaths something which led Ryan to conclude that “some people do not count, in life or in death”. Those very few deaths that have been investigated and reviewed properly showed a catalogue of catastrophic systematic failings that contributed to the death of people with learning difficulties and autism.

Northway and Jenkins (2012) reported that people with learning difficulties have been abused and have even died because of indifference, ignorance and poor care practices where people should have been looked after and receive appropriate care and treatment. The Centre for Disability Studies (2017) published the Learning Disabilities Mortality Review (LeDeR) report. The report suggested that people with learning difficulties die on average 15-20 years sooner compared to the general population with a number of deaths being identified as preventable and at least partly attributed to the poor quality of care delivered to the people. The Centre for Disability Studies (2017) LeDeR programme report provided several recommendations for better practice and delivered training for expert reviews as well as training to improve service provision for meeting the health and care needs of people with learning difficulties.

In the above section, it was discussed how people with learning difficulties have been historically disempowered by being described as story-less and having their rights and voices taken away by dominant ideologies and ruling systems. The section also discussed recent reports which demonstrated that the systematic disempowerment of people with learning difficulties did not end with the closures of the long term stay hospitals. People with learning difficulties and autism continued to be disempowered by dominant systems that were developed to support them to live a better fuller life. The next

section discusses how people with learning difficulties fight back and gain back power. Moreover, the next section explores how advocacy aids the empowerment of people with learning difficulties and challenges the inequalities, bad practices and their disempowerment.

#### **2.14.4. Self-Advocacy Movement**

According to Gray and Jackson (2002), the self-advocacy movement for people with learning difficulties was initially developed by parent dominated organisations such as Mencap as well as other professional organisations including the British Institute for Learning Disabilities. The first independent Self Advocacy only schemes in the UK were developed in the early 1980s, for instance, People First. The first People First project was established in London however the projects soon spread around the country. Atkinson (2002) argued that self-advocacy is about celebrating the identity of people with learning difficulties rather than denying any differences. Self-Advocacy achieved the linguistic shift from mental handicap to learning disabilities in the 1990s which was seen as important by people with learning difficulties (Goodley and Ramcharan, 2010). People First self-advocacy movement despised all labelling and captured that in their famous slogan proposing to “label jars not people” thus challenging the purpose of the medical diagnoses (Goodley, 2000).

Self-advocacy, unlike citizen advocacy, does not have clear theoretical origins (Walmsley, 2002). Walmsley (2002) argued that although Self-Advocacy can be seen as a social movement with a set of principles, commitment and solidarity it relied mostly on non-disabled theorists for making the argument something that would be inconceivable for other similar movements. Walmsley gave the analogy of the black people’s movement account being written by a white person. Gray and Jackson (2002) suggested that the disability movement for people with physical disabilities has a longer history and is seen as having achieved more in terms of policy as well as legislation changes, compared to the movement for people with learning difficulties. Buchanan and Walmsley (2006) argued that positioning the Self Advocacy movement of people with learning difficulties within the



broader disability movement and the Social Model of disability can be helpful. However, they noted that this has not been straightforward as initially, the disability movement was theorising only for people with physical disabilities and also because there were some fundamental differences.

Goodley (1997) argued that impairments of the body or the mind create disability and therefore impairments and disability are synonymous and cannot be separated. Goodley (2000) suggested that the preference of self-advocates for the use of terms such as learning difficulties which imply the potential for learning comes in contrast with the preference of disabled activists to use even negative words used to describe them as an act of embracing their identity. Moreover, Walmsley (2002) argued that disability movement theorists put the emphasis of their writings on bodily impairments which effectively marginalised the interests of people with learning difficulties. Goodley (2014) suggested that dichotomies such as between physical and mind impairments should be rejected in favour of a view of disability as a continuum.

Furthermore, Walmsley (2002) argued that another big difference was that people with learning difficulties often needed the support of non-disabled academics to represent their theories something that came in contrast with the Social Model of Disability calls for disabled researchers being in the core of disability research. However, with the rise of the self-advocacy movement, this started to change when self-advocates with learning difficulties increasingly shared and published their stories, views, experiences and created knowledge. They were, collectively and individually, fighting back against powerful systems and ideologies (Atkinson and Cooper, 2000). People with learning difficulties were actively involved, carrying out research, producing knowledge and sharing their own powerful discourses and stories in contrast to the discourses imposed to them by dominant ideologies (Grant and Ramcharan, 2009). As Foucault (1981), suggested knowledge is power and by creating knowledge self-advocates with learning difficulties challenged the modernist ideologies and empowered themselves as well as people with learning difficulties in general.

#### **2.14.5. Critical Disability Studies**

Critical Disability Studies were described by Goodley (2011) as a second wave disability theory that has evolved from the Social Model of Disability. Critical Disability Studies share a lot of the causes of the Social Model of Disability however they place more weight in theorising about disability compared to the Social Model that puts more weight on activism. Unlike the Social Model that relied theoretically on the Marxist and Gramscian Materialist traditions Critical Disability studies, draw on the work of a variety of humanities, arts and social science disciplines and influences from post-structuralists, feminists and cultural analysts as well as Marxists (Hughes et al., 2012). Critical Disability Studies (CDS) proponents such as Goodley and Garland-Thompson reject the dichotomous views put forward by the materialist Social Model of disability. CDS scholars also reject simplistic binaries such as disability/impairment, woman/man, medical/social and normal/abnormal in favour of a more fluid viewpoint. Goodley (2011) has drawn parallels between disabled people and other oppressed and marginalised groups of people making parallels between disablism, racism and sanism. Goodley et al. (2014) argued that in a postmodern world, what it is to be human needs to be looked at more critically. Goodley et al. (2014) proposed that by understanding disability better we can further enhance our understanding of what it means to be human in a postmodern post-human world.

Shakespeare (2013) suggested that the Critical Disability Studies approach is focusing more on discourses, cultural and artistic representations, emotions and affect rather than political commitments and activism, which were the main foci of the social model of disability. However, the CDS model similar to the materialist approach highlights the importance of the social context and the experiences of people rather than focus on individuals. Shakespeare (2013) criticised the CDS approach for being overly theoretical and not offering much on the way of understanding or providing evidence that can advance policy and practice that can improve the life of disabled people.

Critical Disability Studies theorists such as Sherry (2010) also proposed that impairment, disability experiences and identities were better conceptualised as a continuum rather than a dichotomy contrary to what has been proposed by the materialist approach. Swain et al. (2013) in disabling barriers and enabling environments highlighted the importance of impairment in the lives of disabled people as opposed to the notion supported by the materialist model which claims that disability can be explained only in terms of social oppression, social barriers and capitalism. Shakespeare (2013) suggested that the social constructivist theoretical framework has been adopted by Critical Disability Studies.

Roets (2009) and Goodley (2011) suggested that they were drawing from the works of the post-structuralist feminist author Rosi Braidotti in order to challenge existing ontological assumptions around learning difficulties. Roets (2009) proposed that impairment (of the body or the mind) and disability should be interpreted within a critical socio-political field. Goodley (2011) from a social constructivist perspective challenged the label of learning disabilities, which was identified using a culture-biased test. Goodley (2011) argued that someone with a learning difficulty in the past would have not been seen as someone problematic as intellectual knowledge was not prioritised as much as it is today. For example not being able to read or write or follow complicated instructions was not seen as a problem. However, in a modernist world, people with learning difficulties are seen as vulnerable and in need of supervision and surveillance. Goodley (2011) expanded that the competences of people with learning difficulties have been dismissed as they have been systematically scrutinised, devalued and ignored.

Nunkoosing and Haydon-Laurelut (2012) also emphasised the role of cultural biases by the modernist viewpoint which sees the person with learning difficulties as vulnerable and in need of supervision and surveillance in order to follow what society sees as culturally “normal”. Goodley et al. (2019) proposed that disability is above all a discourse which has been associated with the oppression and marginalisation of disabled people as demonstrated by the exclusion of impaired children from mainstream schools, exclusion of

disabled people from employment and the denial of their basic human rights. Goodley et al. (2019) concluded that disability studies research and theory have never been more needed.

### **2.15. The need for advocacy**

The following sections discuss the importance and the need for advocacy in relation to the current socio-political climate. The socio-political climate, in the UK and the rest of Europe, for the past ten years has been underpinned by prolonged austerity driven by neoliberal politics (Malli et al., 2018). Malli et al. (2018) argued that following over ten years of prolonged austerity and neoliberal politics in the UK and worldwide (2008 until 2018), disabled people in general and people with learning difficulties, in particular, faced unprecedented cuts to their income and services. During those difficult and even hostile times advocacy was demonstrated to have an ever more important of a role to play. Karanikolos et al. (2013) suggested that most governments in Europe, including the UK, adopted the neoliberal political ideology leading to big cuts in public services, which resulted in the health and social sectors going into crisis. Runswick-Cole and Goodley (2015) argued that the UK government has promised a lot to people with learning difficulties such as citizenship, empowerment, community, social action and a route out of poverty, however, offered little in return. Runswick-Cole and Goodley (2015) proposed that contrary to their promises the UK government delivered cuts to personal budgets as well as important health and social care services including advocacy services. Runswick-Cole and Goodley (2015) reported though, that despite the negative effects from these policies, self-advocates continued to fight and speak up for their rights, advocate for better services for all and resist the processes of neo-liberalisation.

Cheetham et al. (2018) explored, the effects of Universal Credit rollout in the North East of England, and suggested that disabled people, and particularly people with learning difficulties, were amongst those hit the hardest from this reform. Cheetham et al. (2018) reported that disabled people did not only lose on average over 10% of their income but also often had their claims

turned down without a good excuse. Cheetham et al. (2018) suggested that advocates have been working with individuals to appeal and have supported them to have their income reinstated. Participants in the Cheetham et al. praised the role of advocacy in dealing with a demeaning system.

Furthermore, the November 2018 visit to the UK of the United Nations Special Rapporteur, Professor Philip Alston, reported extreme poverty and human rights violations taking place in today's UK society against people with disabilities (United Nations Human Rights Council, 2018). Professor Alston reported a catalogue of practices that further disempower already marginalised people and criticised the system's total focus on its goals, targets and agenda rather than seeing the individual and their point of view (United Nations Human Rights Council, 2018). Furthermore, the UN Rapporteur expressed concerns about the long term impact that Brexit might have in individuals already living in extreme poverty and the potential of many more people falling in this category.

All the above reports portray a negative and at times hostile environment for people with learning difficulties full of negative influences. It can be argued that the importance and need for advocacy is bigger when people are facing a negative or even hostile environment. As discussed above advocacy has been demonstrated to be particularly important and valued by people with learning difficulties during challenging times. This notion is discussed further when theorising about the development of the Advocacy Partnership model in section 7.4.

## **2.16. Negative Influences**

The following section looks at different social theories that can be used to better understand the need for advocacy. The theories of Street-Level Bureaucracy (Lipsky, 1980) and Service Forum Incoherency (Brandon, 2005) have been used to provide a better understanding of how health and social care policies and procedures, that are there to support people with learning difficulties, can turn out to be negative influences that put further barriers and hinder rather than aid their empowerment.

Brandon (2005) demonstrated that the notion of street-level bureaucracy (Lipsky, 1980) plays an important role in implementing policies, such as government policies, directly affecting disabled people, at the front line level. Street-level bureaucrats are interpreting the abstract theoretical top-down policies and implementing them according to their service culture and professional discretion. Brandon (2005) theorised about the disparity often identified between an organisation's posture, which is publicly portrayed as positive, versus the same organisation's actual culture, which can be found to be negative and far removed from its posture. Brandon (2005) used the term service "forum incoherency" to describe when the organisation's posture and actual culture are found to be well apart. Although Brandon (2005) explored and identified service forum incoherency in a day centre, supporting people with learning difficulties, the same analogy can be applied to other organisations.

For instance, according to McInnis et al. (2012) following UK government initiatives, up to 50% more individuals with learning difficulties could have been identified as entitled for support by community learning disabilities teams in England by 2018. Initiatives to provide more support for people with learning difficulties can be seen as something positive however at the same time under the same administration the Local Government Association reported that up to three-quarters of the councils' learning disabilities teams faced financial pressures (McInnis et al., 2012). Newcastle Council for Voluntary Services (2018) suggested that Gateshead and Newcastle councils, in the North East of England, faced a real term cut in government funding of 50.5% and 48.8% respectively between the years 2010/11 and 2017/18. It is not hard to imagine that this had an impact on the actual services received or expected to be received by people with learning difficulties.

Malli et al. (2018) reported that people with learning difficulties have disproportionately experienced negative outcomes as a direct result of government budget cuts despite UK government claims that "we are all in it together". People with learning difficulties have been disproportionately

adversely affected by being out of employment for longer, lose personal income, seen an increase in hate crime against them, lose social support via tightened eligibility criteria and increasingly face social isolation (Malli et al., 2018). On top of that, charities, community and voluntary organisations supporting individuals with learning difficulties, including advocacy organisations, faced increased demands for their services however they have seen their funding reduced leaving them unable to meet all the demand (NCVS, 2018).

People with learning difficulties, particularly in a time of austerity and neoliberal politics, increasingly faced street-level bureaucrats with a set of agendas that were often against their views and wishes. Services that were there to support people with learning difficulties often developed even further forum incoherencies by on the one hand suggesting, in their posture, that they provided a person-centred service to people with learning difficulties and on the other hand, in their culture, finding ways to implement cuts that often, go against the agenda of the people who were using the service. These service incoherencies observed particularly during challenging times are perceived by people with learning difficulties as negative influences that get in the way of them achieving their goals and fulfilling their needs and wishes. Those negative influences make the need and importance of advocacy even bigger and make advocacy perceived as even more valued and appreciated by people with learning difficulties.

## **2.17. Advocacy in Other Parts of the World**

So far the thesis concentrated mostly on advocacy practice in England and Wales, and the UK in general, however, interesting developments have also been taking place in different parts of the world. Moreover, it helps to put advocacy into context by also looking at the developments in the rest of the world and comparing those to the practices in England and Wales. The chapter continues with looking at advocacy research and practice in other parts of the world including Scotland where a particular focus is placed. The

similarities and differences are introduced and discussed in order to put advocacy into a wider context.

### ***2.17.1. Advocacy in Scotland***

Since the Scottish parliament, following devolution, legislated for the health and social care sectors there have been some differences in the advocacy provision in Scotland. The Scottish Independent Advocacy Alliance (SIAA) is the national body governing advocacy practice. Scotland, unlike England and Wales, has a national body that regulates but also deals with the funding of advocacy organisations as it receives funding from the central Scottish government (SIAA, 2018). Funding in England and Wales is mostly commissioned by local authorities but also by health authorities and charities.

Although the types of advocacy are the same the legislation that underpins and relates to advocacy practice in Scotland is different. SIAA (2018) indicated that there are a number of different pieces of legislation talking about or giving the right of access for advocacy to a person. Advocacy in Scotland is linked to different pieces of legislation such as the Mental Health Care & Treatment (Scotland) Act 2003, the Adult Support and Protection (Scotland) Act 2007, the Patient Rights (Scotland) Act 2011 and the Social Care Self-Directed Support (Scotland) Act 2013. SIAA (2018) points out that apart from the associated legislation there are different government policies related to advocacy in Scotland. Policies include the National Care Standards (Standard 19) and the Keys to life, improving quality of life for people with learning disabilities (2013).

Although many pieces of legislation and policies are different, in Scotland, advocacy research and theory remain mostly linked to the British Social Model of Disability. SIAA apart from providing information to the public about advocacy and supporting advocacy organisations has also funded research studies about advocacy and its outcomes. The thesis refers to the work from several research studies from Scotland such as Stewart and MacIntyre (2013), Miller (2011) and Bocioaga (2014).



The Scottish Independent Advocacy Alliance appears to make a great deal of a difference as it is an independent organisation receiving funding from the government to inform the public, support the organisations and promote the causes of advocacy. This is a major difference between advocacy in Scotland and England/Wales where there is no defined umbrella organisation and different advocacy organisations tend to compete for scarce funding rather than working together to serve a common cause.

### ***2.17.2. Advocacy in the USA***

As it was mentioned earlier in the chapter advocacy and particularly self-advocacy has a long tradition in the US. The service user and survivors' movements in the 1960s and 1970s inspired the development of various self-advocacy movements supporting the cause of people with learning difficulties. Caldwell (2011) carried out research with 13 self-advocacy leaders across the US to explore their life stories and perspectives on their disability identity. Caldwell reported that self-advocates expressed a strong sense of identity connection with the disability movement as well as with the broader rights movements. The self-advocates also reported a strong sense of social justice and interdependency.

Kendrick (2002) suggested that the US advocacy scene for people with learning difficulties covers a wide variety of advocacy types such as self-advocacy, peer advocacy, citizen advocacy, legal advocacy, systems advocacy to name a few. Kendrick (2002) argued that advocacy in the US is not only different in terms of focus and types but there are also major differences between different states, therefore, making it even more difficult to define and measure advocacy. Hawley (2016) claimed that funding for advocacy in the US can be very diverse too ranging from local, state and national fundraising, grants from foundations, corporate contributions, fees, memberships, donation awards and so on. One main difference with advocacy in the UK can be easily seen to be the lack of dependency of the advocacy sector to the state whether local or central. However, another main difference is that in the US some advocacy organisations charge individuals for their services compared to the UK where advocacy remains largely free

for the person that uses the service. These differences demonstrate that although US advocacy projects are fully independent from the state they show signs of struggle for survival. Hawley (2016) concluded that US advocacy faces a challenge to start rebuilding itself following a rapid decline.

### ***2.17.3. Advocacy in Australia***

Although it is difficult to compare advocacy in a European country such as the UK and a country as large and widespread as Australia this section is going to provide some key points. According to Henderson and Bigby (2016), Australia following the psychiatric survivor movement in the 1970s saw a number of self-advocacy groups develop to resist and fight for the rights of people with learning difficulties. Peter (2002) suggested that formal advocacy for people with learning difficulties is quite new in the Australian socio-political context. The Australian government established the Disability Services Act 1986 which included some provision of funding for a variety of different advocacy types. The different types of advocacy are broadly the same with the UK with the exception of parent advocacy services which is an area underfunded in the UK. Henderson and Bigby (2016) argued that self-advocates have expressed that although there is more funding available now for advocacy, back then advocacy and self-advocacy were more radical and there was a stronger sense that they can achieve more. Henderson and Bigby (2016) argued that governmental indifference and ad hoc funding has hindered the growth of the self-advocacy movement in Australia.

### ***2.17.4. Advocacy in Sweden***

Sweden, as mentioned earlier in the chapter, was at the forefront of advocacy development with the work of Nirje on Normalisation in the 1960s. Mineur et al. (2017) claimed that although the notions of normalisation and inclusion have been guiding principles in the Swedish health and social care context, for so long, people with learning difficulties still faced injustice and exclusion in society. Mineur et al. (2017) argued that only since self-advocates with learning difficulties no longer accepted the subordinated role assigned to them by society that things really started to change. Tideman and Svensson (2015) suggested that it was the participation in self-advocacy

groups that aided increases in health and well-being through new roles and identities that strengthened the control of everyday life. Mineur et al. (2017) highlighted that self-determination and expressing opinions and preferences are fundamentally important to people with learning difficulties. Mineur et al. (2017) also pointed out that self-advocates reported that group membership has resulted in a change of self-perception with participants feeling more skilled, social and confident. Milneur et al. (2017) concluded that self-advocacy is important in the lives and identity of people with learning difficulties. Tideman and Svensson (2015) also concluded that although support is still needed that should be channelled in different ways in order to avoid mistakes of the past and the restrictions of institutions to not be replicated in the new Swedish welfare system.

## **2.18. The future of Advocacy**

Stewart and McIntyre (2013) suggested that the introduction of legislatively mandated access to advocacy, in England and Wales, has the potential to create a division between those individuals eligible who will be much more likely to access advocacy support compared to others who are not eligible. For instance, people that are detained under the Mental Health Act in psychiatric settings have the statutory right to an IMHA whereas people who are voluntary informal patients in the same settings do not something that makes them less likely to receive advocacy support. A general issue identified is whether local authorities, as well as other funders, will continue to provide funding to different types of advocacy when they only have the statutory requirement to provide certain types of advocacy to certain groups of people and in certain situations. Another issue identified is that certain local authorities, as well as advocacy projects, are better at securing funding to provide a good advocacy service whereas in different areas that is not the case. Moreover, Stewart and McIntyre (2013) noted that some concerns have been expressed around the difficulties in recruitment of peer advocates as well as volunteers such as citizen advocates.

Manthorpe et al. (2005) highlighted that in some areas advocacy services are in short supply and that a combination of short term funding and insensitive evaluation could mean that there will be no access to advocacy services at all for certain groups of people such as for parents with learning difficulties. Manthorpe et al. (2005) also suggested that potentially paid advocates could be given a higher status from professionals thus undermining the role of volunteer, peer or self-advocates. Rapaport et al. (2006) argued that there is a fear that certain types of advocacy particularly based on volunteers such as citizen as well as peer and self-advocacy will be reduced and potentially replaced by casework and paid advocates as they are easier to control and more accountable. Moreover, they reported that smaller schemes are likely to face difficulties in sustaining the extra costs for monitoring thus increasing the risk of being replaced by larger organisations. It was however highlighted that access to advocacy should be improved and that every person with a learning disability should have a right to advocacy.

Finally, Manthorpe et al. (2006) suggested that the developments of common standards as well as of multidimensional evaluation tools that explore the stakeholders' and particularly the peoples' that use the service perspectives are vitally important. They concluded that the pressure on funders to demonstrate accountability will disadvantage advocacy types that are more difficult to evaluate therefore different models of evaluation may need to be developed for different types of schemes to prevent that from happening.

## **2.19. Summary**

The review of the literature surrounding advocacy and its outcomes in the chapter highlighted gaps in existing knowledge around both advocacy theory and practice. The literature indicated that there is a lack of research exploring these outcomes and impact. The gap in the literature is even bigger when exploring advocacy outcomes and impact from the point of view of people with learning difficulties using advocacy. Historically research has often focused on advocacy services and particularly their outputs rather than outcomes and on the point of view of other stakeholders rather than of the

service users. The literature review highlighted that more research is required in order to explore in depth the views, wishes and perspective of the people with learning difficulties that use advocacy about advocacy.

Moreover, the review of the literature pointed out that advocacy theory has failed to explore in depth the relationship between advocacy practice and the empowerment of people with learning difficulties. Finally, the chapter discussed developments in advocacy in the rest of the world. Scotland's advocacy appears to be strengthened by a policy that encourages cooperation between advocacy projects rather than competition. Advocacy in Sweden underlined the importance of learning from the past and not repeating the same mistakes in the current and future reforms. Advocacy in US and Australia highlight that lack of leadership and support can lead in rapid decline and loss of momentum for advocacy services. The chapter concluded by looking at the future prospects of advocacy research and practice. Advocacy research and practice ought to concentrate on promoting advocacy's uniqueness as by focusing on becoming part of the mainstream health and social care services can lead to losing its main advantages and role altogether. The literature review supports the need for this thesis to address existing research shortfalls and develop a greater understanding of advocacy to inform the design of future services.

### **3. Methodology**

#### **3.1. Overview**

The chapter reviews the methodological approaches that were adopted in the study. The research aims of the study are discussed along with the philosophical and theoretical position underpinning the research. The chapter looks into the ontology and the epistemology of the research study. The disability studies research paradigm is then discussed. The chapter continues by looking into the participatory and narrative research approaches that principles of which were used in the study. Furthermore, the research design of the study is outlined starting with the data collection methods used and the sampling method. The chapter continues by exploring the ethics process but also the challenges in this type of research. The methodology chapter concludes by looking into the approach used in the analysis of the data collected from the participants and the reflexivity approach used.

#### **3.2. Methodological Approach**

Methodology is concerned with how we get to know the world and gain knowledge from it (Guba and Lincoln, 1994). The present study is informed by the social constructivist methodology in order to produce knowledge around advocacy and its outcomes from the point of view of the people that use the service. The study also utilised principles of the participatory research philosophy for conducting research by involving people with learning difficulties, who have used advocacy services, in the preparation and implementation of the research process. The participatory research theory and practice is discussed, in greater detail, in section 3.7. Diagram 1 is outlining the methodological approaches used in the study and can be found in Appendix 1.

The study also used principles of the narrative research method in relation to data collection as well as analysis. The narrative research method principles were used in order to allow the participants that were involved in the study to express themselves more freely compared to other methodologies which put

more restrictions and prerequisites (Atkinson, 2005). Narrative analysis was utilised to gain a more accurate and complete representation of how people that used the service are experiencing advocacy involvement and what they think its outcomes are. It has been argued that using narrative interviewing allows research respondents to express different aspects of their experience and feel empowered (Elliott, 2005). Furthermore, different methods were used to collect qualitative data for different purposes. Focus groups were used to explore the main research questions from the service users' perspective and narrative interviews were used to investigate the research questions and advocacy further. The study used thematic and narrative research methods for data analysis from the focus group and the in-depth interviews respectively. The triangulation method strategy was also employed in order to explore the topic of research using different methodologies and different stances and thus get a more in-depth insight into advocacy, the topic under investigation. According to Pitre and Kushner (2014) triangulation of methods allows the study to explore more fully the complexity of participants' data compared to studying them only from one standpoint. Moreover, the triangulation method allows the study to cross-check the consistency of the data from various sources and multiple methods at different times (Guba and Lincoln, 1994). The narrative research method is discussed further in section 3.9.2.

The recruitment of people with experience of using advocacy services with an interest to take an active research role in the study as well as participate or simply participate in the study was from the North East of England advocacy organisation where I was working. The advocacy organisation is a charity which has been providing different types of advocacy services to a wide range of people in the North East of England for over 20 years. The advocacy organisation's executive committee (which included a number of service users with disabilities) had expressed their approval of the research study further to the approval being granted by the Northumbria University Ethics Committee.

Furthermore, all the relevant policies and procedures of the University as well as of the charity were followed and the full informed consent of the people that participated was sought prior to any data collection. The study considered in depth all the ethical implications and sought all the relevant approvals before the commencement of any data collection or other active research processes. This advocacy organisation was chosen primarily because I was a practitioner there and I had the opportunity, over the past few years of my involvement there, to get to know as well as talk with a number of people using the service and also have a level of familiarity with them. That level of familiarity could be seen as an advantage because interviews have been described as a rather artificial environment to collect data from (Llewelyn and Northway, 2008). Since the participants were already familiar with me they were more comfortable and therefore more inclined to feel a sense of trust and rapport and to have a more in-depth conversation in the interview and thus produce richer data. Overall a large number of people that have used the advocacy service, we contacted, suggested that they would be interested in taking part in research looking into advocacy outcomes.

A stratified sampling method was used which allowed the selection of groups of people that displayed some variation but also were fairly homogeneous (Ritchie and Lewis, 2003). Participants were male and female adults of working age, with learning difficulties, who had been involved in at least one advocacy partnership. A number of participants had experience of working with more than one types of advocacy. For instance, several participants have been members of a self-advocacy group but also, at some point, have worked with an independent advocate before. Moreover, it was decided that service users who were working directly with me were excluded from participating but were still able to take part in the research training workshops if they wished. This issue is further considered in the challenges section (3.8.4). It was considered that some participants might have felt obliged or not comfortable to fully participate in an interview about advocacy with the person that has been working with them as an advocacy partner. Additionally, the potential power imbalance created between myself who had



the role of the researcher but also the “practitioner” and the participant who is also a “service user” would have been too great. After all the study, similar to advocacy principles, was looking to minimise the power imbalance that is often experienced by people with learning difficulties working with professionals. Moreover, I give a reflective account of the dual role experience and its challenges in the relevant section (3.14).

### **3.3. Research Aims and Questions**

The main aim of this PhD research study was to explore the theoretical and practice outcomes and impact of the advocacy partnership. More specifically the study explored advocacy outcomes from the perspective of the people that use and have experience of advocacy. The study to achieve this worked closely together with a group of self-advocates with learning difficulties who were my co-researchers throughout all the stages of conducting this study. The study aimed to carry out the research with people with learning difficulties rather than for them or on them. This was a very important aim of the study right from the beginning as the idea of the PhD study came from my work with the self-advocacy group members that later became my co-researchers. The study actively tried to extend the mainstream researcher-participant relationships and work together in carrying out this research. Additionally, it was the aim of the study to carry out the research according to the principles of advocacy. The principles of inclusion, empowerment, participation, as well as of promoting self-advocacy, were considered as central in the implementation of the research study. The chosen methodological approaches encompassed all the principles that valued and promoted the voice of people with learning difficulties.

It was not the aim of the advocacy outcomes research PhD study to review or evaluate advocacy work against its principles, aims and objectives but rather to work together with the group of self-advocates and advocacy partners to explore their point of view. The advocacy outcomes study explored the views, experiences, meanings, perceptions and feelings of people with learning difficulties around advocacy and its outcomes. The

research study working together with self-advocates and advocacy partners produced, within the constraints of a doctoral study, new discourses and knowledge. The study utilised the participatory research approach and some of advocacy's main principles in the way the research was carried out with people with learning difficulties rather than on them or for them. The participatory research approach adopted in the study is discussed in more detail later in the chapter (section 3.8).

The use, of the principles of advocacy, demonstrated one of the main differences between the advocacy approach and other approaches supporting individuals to achieve their goals and targets such as health and social care support, social work and advice organisations' approaches. Advocacy's main principles include empowering individuals to self-advocate and putting people first. These main principles reflect the difference in the primary aims between advocacy and other approaches. However, it is beyond the scope of this study to examine in detail all of the principles of advocacy or wider outcomes of advocacy work that are not directly related to the people that use the service. More specifically, the study was not intending to examine the impact of advocacy on other services, the community or on policies and procedures unless these issues were brought up by the individuals taking part in the study. It was not the main aim of the study to provide a comprehensive exploration of all potential indirect advocacy outcomes but rather focus on the outcomes that are important and relevant to the group of people, with learning difficulties, who used the service and participated in the research.

Critical social theorists argue that it is not enough to generate knowledge around social structures but rather the knowledge should be used to bring positive social change (Ransome, 2010) since it is a strong belief that a more civilised or better society is attainable and humanity should strive to achieve that. The research study sought to contribute to a better understanding of advocacy and also to the development of advocacy theory. The study sought to add to the existing body of knowledge around participatory research in this field. It has been noted, in the literature, that little research interest was

shown on advocacy theory and practice and that further research was needed to develop and explore them (Macadam et al., 2013). Furthermore, the study aimed to discuss recommendations, including from the findings, concerning advocacy theory and practice in order to improve them. The study aimed to examine the notion that advocacy can empower disabled people. More specifically, the study sought to explore the following questions:

- What is the relationship between advocacy theory and practice and the empowerment of disabled people?
- What recommendations can the study produce which can be used for the development of advocacy practice impact?
- Does current advocacy practice contribute towards positive or negative outcomes for the people using the service?

The research questions were the product of the initial literature review but also of the discussion of the main research issues with the self-advocates who formed the steering group for this study. The work with the steering group of self-advocates with experience of different types of advocacy was a fundamental part of the study. Without their knowledge, skills, commitment and determination this study would have not been made possible. The discussions and debates we had over the lengthy period of this research process informed me and challenged me and in a sense changed my way of thinking as a researcher and advocacy partner. Further details about the work with the steering group are discussed later in this chapter (sections 3.8.2 and 3.8.3) and also in the conclusion chapter (section 7.7).

### **3.4. Philosophical Position**

Social constructivism is a philosophical position suggesting that knowledge which is typically taken for granted, such as the objectivity of the scientific method, is mainly derived from social interactions (Robson and McCartan, 2016). Social constructivism and its proponents have come under criticism for suggesting that scientific facts are also socially constructed (Khalifa,

2010). According to social constructivism theorists, scientific facts whether true or false depend on the social conditions at the time when they were established. Latour and Woolgar (1986) suggested that the objectivity of a scientific fact is the consequence of scientific work rather than the cause. Latour and Woolgar (1986) argued that if for example the scientific community and its practices were different then what was discovered would be different as well. According to the social constructivist paradigm, research is inherently subjective and cannot be objective as proponents of the positivist scientific methodology claim. Khalifa (2010) proposed that social constructivism offers a broad analysis of realism and relativism in science and provides evidence suggesting that particularly social scientists should not hold a positivist view of science. Social constructivism suggests that there are no set rules that enable the scientist to certify the validity of research and knowledge. Social factors such as professional characteristics and intellectual authority play an important role in shaping and evaluating knowledge creation.

The social constructivist paradigm is compatible with the aims and the types of questions that this study has set to explore. Moreover, the philosophy of social constructivism and the focus on the importance of social interactions and the development of identity are also in accordance with our study. The advocacy outcomes study recognised the potential imbalance of power between myself (Manos) the PhD student/researcher and advocacy practitioner and the participants who have used advocacy services and shared their views, thoughts, attitudes and experiences of advocacy. However, the study apart from only recognising the potential imbalance of power also took steps to minimise its impact. Firstly the study adopted the social constructivist methodological standpoint which recognises the impact of the imbalance of power in research rather than encourages it. Secondly, the narrative research method was used in collecting and analysing the data. The narrative research method allows the participants to express their views, experiences and feelings in a critique-free way and also it accepts that there are more than one realities, therefore, being non-judgemental (Elliot, 2005). Thirdly the study used the participatory research philosophy which shares

some of the control of the knowledge production with the group of participants who actively contributed and co-produced the study thus having a greater input and minimising the imbalance. Finally, I gave a reflexive account of the experience as well as the challenges faced whilst involved in the study, later in this chapter (section 3.13) and also in the conclusion chapter (section 7.7). Thus further recognising and minimising the imbalance of power within the study.

### **3.4.1. *Ontology***

Ontology is concerned with what kind of being is the human being and what is the nature of reality (Guba and Lincoln, 1994). De Gialdino (2009) suggested that the ontological position of a research project deals with the value and the relationship of those involved in the research. The research process and design, as well as the worth of the findings, should be open to discussion, critical exploration and reflection. According to Bergold and Thomas (2012) research in the field of disability, whether carried out by a disabled researcher or not, cannot be seen as more legitimate purely based on the basis of experience of disability alone. Bergold and Thomas (2012) also proposed that it is how the research is carried out, how are the participants involved and the consideration placed upon the ethical issues as well as the critical reflexivity that have to be seen as important factors. Those key factors need to be critically explored at each stage of the research process. Critical research requires taking into account the specificities of the particular topic of research as well as of the socio-political context. The exploration of the historical context, as well as self-reflexivity, is required in order to maintain a critical awareness of the topic under research. The social basis of knowledge, as well as a commitment to political emancipation, is also essential. de Gialdino (2009) proposed that political and policy agendas even when research is anti-exploitative and anti-oppressive can be important factors of how the research is perceived.

The study demonstrated its commitment to anti-exploitative and anti-oppressive research by carrying out the exploration with the people who have first-hand experience of using advocacy. Moreover, the study showed a

commitment to the empowerment and politics of people with learning difficulties by co-creating knowledge and narratives from the research with and by people with learning difficulties. The ontological approach of the study is one that sees the participants of the study as important and valued. The ontological approach of the study aimed to counter balance the traditional researcher-participant relationship.

According to Barnes (2004) research in the field of disability should lead to social liberation by radically transforming the participant-researcher power relations. Oliver (1990) suggested that research should tackle oppression by altering the relations between knowledge and action. Oliver and Barnes (2012) argued that emancipatory research in disability should have at its core how disability is experienced from different perspectives. The adoption of such an ontological approach in disability research allows the analysis to not only discuss disability but also to focus on how disabled people experience it and how their expertise can intervene in policy making by confronting scientific experts in different fora, something which has been described as ontological politics (Barnes and Mercer, 2010).

The study's ontological position focused on the expertise and value of the experiences and viewpoints of the participants and co-researchers in the study. The study aimed to transform the mainstream researcher-participant relationship into a partnership where the research is carried out together and the knowledge is co-produced. The study aimed to utilise the expert viewpoint of people with direct experience of using advocacy in order to influence relevant policies by providing recommendations from the findings of the study. The co-produced knowledge with the self-advocates and advocacy partners, with learning difficulties, as co-researchers provided challenges and alternatives to dominant modernist views of people with learning difficulties with negative connotations.

Moreover, the study adopted a critical approach to the research process and included the element of reflexivity which was seen as rather important. The study by taking all the steps outlined in the previous section demonstrated

not only an awareness and recognition of the power imbalances in carrying out research and producing knowledge but also took a stance in counteracting those imbalances. Furthermore, the study recognised the importance of being in line with the causes of people with learning difficulties and the politics of the disability movement. The study counteracted the power imbalance by aiding the empowerment of people with learning difficulties that have used advocacy services to have a voice to express their views and experiences of advocacy in the research arena. Moreover, the study by directly working with the steering group of people with learning difficulties using participatory research was open to critical discussion, exploration and reflection at each stage of the research process.

### **3.4.2. *Epistemology***

Epistemology is concerned with the relationship between the inquirer and the known (Guba and Lincoln, 1994). Several research approaches are seen as essentially qualitative research approaches. The qualitative research approach is derived by a number of different paradigms such as critical, hermeneutic, pragmatic, phenomenological and post-modernist traditions. Qualitative research approaches are also linked with the idiographic approach. On the other hand, quantitative research has been described as a product of realist and positivist epistemologies. Realist and positivist epistemologies aim to establish objective knowledge and are linked to the nomothetic approach (Khalifa, 2010). Guba and Lincoln (1994) suggested that the nomothetic and idiographic divide emerged in the nineteenth century and was seen as the basis of the scientific inquiry. Postmodernism emerged much later on in the second half of the 20<sup>th</sup> century. Epistemologies in the area of qualitative research are rather varied and can be distinguished in three main frameworks: phenomenology, critical realism and constructivism (Silverman, 2006). Phenomenology focuses on the subjective experience of the person. Critical realism emerged from realism and suggests that data can provide information about reality but do not necessarily directly represent it. Constructivism mainly has to do with how phenomena are viewed and how knowledge is formed. According to Guba and Lincoln (1994), the different

frameworks are human constructions and basic belief systems based on epistemological, ontological, and methodological assumptions.

According to Schwandt (2000) there are three major epistemological paradigms for qualitative inquiry which have come as a reaction to positivist causal explanations: philosophical hermeneutics, interpretivism and constructivism. Interpretivism focuses on the human subjectivity in the attempt to gain knowledge about topics in an objective manner. Similar to interpretivism, philosophical hermeneutics focus on object-oriented methods, however, come to a different understanding. Constructivism is different as places the focus on the construction of meaning particularly from a social, cultural and historical point of view to understand human experience. Schwandt (2000) claims that constructivism is concerned with the meaning not with the individual in mind but rather collective constructs of meaning shaped by interaction using language and other social processes. According to constructivism, qualitative research can unfold an understanding and meaning through the active involvement of the researcher in the formulation of meaning.

The advocacy outcomes study accepted that belief systems should be open to criticism and different interpretations. Contrary to the medical model of disability that has been utilising positivist quantitative methodologies the study used a qualitative research approach. It can be argued that knowledge and belief systems are based on human constructions or inventions of the human mind and thus they are subject to human error. According to the constructivist viewpoint philosophical position adopted human constructions cannot be unarguably right and according to Guba and Lincoln (1994) proponents of any given belief system rely on persuasiveness and utility rather than proof when arguing their views.

De Gialdino (2009) suggested that there are many ways of studying what has been described as epistemological otherness which can be seen as the difference between the perspective of the participants and the perspective of the researcher. Different social science perspectives take different



approaches about how this separation can be bridged. According to positivist perspectives, the researcher and the analysis should maintain technical neutrality from the subject of research. Fawcett and Hearn (2004) claimed that truth and objectivity in the research process are unachievable myths. Ritchie and Lewis (2003) suggested that constructivists challenge the epistemological basis of positivist research as they suggest that dominant research practices (such as positivism but also phenomenology) have marginalized specific groups of people such as people with learning difficulties or people with experience of using mental health services, as both researchers and researched. Zuckerman (1988) suggested that there are many valid versions of the social reality and that experiences from marginalised groups can be seen as a starting as well as a finishing point. Bergold and Thomas (2012) proposed that there should be an emphasis placed on qualitative research methods and a focus on the experiences of people from marginalised groups as well as direct involvement in the research process.

The study's main aim was to explore advocacy, its outcomes and impact with the people that use the service. As it has been described in the literature review mainstream research has to a large extent excluded and othered the views of people with learning difficulties. The study aimed to not only include the voices of the people with learning difficulties but to co-produce together the research and knowledge. The epistemological stance adopted in the study was one that allowed and encouraged the co-production with people with learning difficulties.

The study adopted the social constructivist epistemological viewpoint of qualitative research inquiry. The study accepts that there is not only one reality and that knowledge and meaning are constructed based on social but also cultural interaction. Language and other social processes play an important role in the construction of knowledge. It is the study's belief that the way mainstream research has been carried out, excluding the expert viewpoint of people with learning difficulties in areas where they can provide valuable insight, has been at least counterproductive. The involvement of

people with learning difficulties who have direct experience of advocacy can provide a greater understanding of the topic under investigation.

The advocacy outcomes study put the beliefs into action by demonstrating a commitment in carrying out the research with people with learning difficulties a group of people that has been historically largely ignored by mainstream research (Gray and Jackson, 2002). The study carried out the research on advocacy outcomes with people with learning difficulties rather than for them or on them. By doing so, the project explored advocacy outcomes from the point of view of the people that count most, the people that use the service and have direct experience and knowledge from actually using the service. Thus gaining an invaluable insight but also at the same time promoting and encouraging the direct involvement in the production of knowledge and the empowerment of a group of people that has been pushed towards the margins of society (Goodley, 2011). Furthermore, the study by adopting this stance provided challenges to the mainstream methods and ideologies of carrying out research.

### **3.5. Theoretical Framework**

Qualitative research is primarily dealing with individuals and their subjective experience instead of factors and statistics involved in quantitative research (Silverman, 2006). Qualitative research identifies the central role that language and discourse play in showing the various facets of different points of view. It is focused on creating knowledge such as finding out how it could be living in an institution for the biggest part of your life or what are peoples' views around using a service (Morse and Field, 1995). Kim (2014) suggested that the social constructivist paradigm recognises qualitative research as a tool to uncover meaning and gain an understanding of the researcher's active exploration of the construction of meaning.

Social constructivist research is considered a creative and transformative activity which involves an empathic researcher-participant relationship. The social constructivist theoretical framework was adopted as it is a framework

compatible with the aims of the study as well as the methods used. The social constructivist approach focuses on the social constructs of the participants, their meanings, their realities and their expressed identities. The account from the participants as well as their views, feelings and thoughts were seen as valid and important.

Social constructivist theorists have scepticism towards dominant ideologies and the reality they represent. Social constructivist proponents have been influenced by the work of post-structuralist and postmodernist authors such as Foucault, Butler and Goffman. Several theorists have linked the critical and social constructivist theoretical framework with theories exploring disability and impairment of the body and the mind. According to Galis (2011), social constructivism is a meta-theory which focuses on exploring individuals' realities and how those realities are being constructed from social interactions with other people, social contexts and perceptions of the world. The social constructivist approach provides an understanding of peoples' functioning, in society, which is determined by how they interpret and experience their culture within society as well as by the understanding of the meanings the individuals associate with those experiences (Greene and Lee, 2002). The social interaction within a person's cultural environment can create meaning and knowledge which is influenced by the various institutions comprising that cultural environment (Willig, 2012).

According to social constructivist theorists the members of society who hold the power, within, construct the dominant beliefs, values and norms followed by the mainstream of that society (Greene and Lee, 2002). Moreover, the people who do not demonstrate the dominant beliefs, values and norms are considered abnormal and as deviating from mainstream society thus pushed towards its margins (Kim, 2014). Social constructivism focuses on the importance of the social environment in influencing peoples' behaviour and perception of themselves within their social environment. Kim (2014) also highlighted that the social constructivist approach is interested in the construction of identities as well as social realities.

### **3.5.1. *Postmodernist Views***

Postmodernist authors such as Lyotard (1979) have claimed that it is possible to alter the mainstream ideology of modernist times and change the world by adopting a new direction in research. Goodley and Rapley (2002) argued that modernist views such as the “acquiescence bias” suggested that people with learning difficulties are not to be trusted in reporting even their own beliefs, actions and feelings. Goodley and Rapley (2002) pointed out that what, for other groups of people, may have been seen as disagreement in the case of people with learning difficulties was seen as incompetence thus discrediting any beliefs and views people held. It is the belief of the advocacy outcomes study that the co-production of knowledge with self-advocates and advocacy partners with learning difficulties provide challenges and alternative viewpoints to such dominant mainstream ideologies. The co-creation of knowledge constructs with people with learning difficulties can alter the negative views that excluded them and give research a new more inclusive direction.

Day (2007) suggested that people with learning difficulties, that have been dehumanised for so long, in the post-modernist Britain finally became visible with initiatives such as Valuing People (2001) however that visibility made them also potential targets. Corker and Shakespeare (2002) claimed that theorists in disability studies and proponents of the social model of disability in the UK failed to encompass post-modernism in their thought and that is to the detriment of disability studies. Roets, Goodley and Van Hove (2007) suggested that postmodernism proponents claim that definitions of people with learning difficulties, with negative connotations, can be contested by creating more positive roles and putting forward their chosen identities. Goodley and Rapley (2002) argued that materialist views that the impairment of disabled people is inevitably biological can be challenged in a postmodern world and can be seen as an aspect of disabled peoples’ lives that can be theorised as a politicized vision of disablement.

The study encompassed some of the postmodernist viewpoints and by carrying out research together with people with learning difficulties not only

provided challenges to negative modernist ideologies but also contributed to the creation of more positive roles and identities for people with learning difficulties. The study rejected the modernist positivist viewpoints favoured by the medical and personal tragedy models of disability. The medical and personal tragedy models of disability favoured explanations that see disabled people as victims. On the contrary, the advocacy outcomes study adopted a postmodernist viewpoint demonstrating that people with learning difficulties are not victims but rather competent and skilful researchers that can speak up and express their point of view loudly and clearly.

### **3.5.2. Poststructuralist Views**

Roets et al. (2007) suggested that self-advocates, with learning difficulties, should be involved as producers of knowledge and discourses to challenge and change the current narratives, with negative connotations, around learning difficulties. Tamboukou and Ball (2003) proposed that poststructuralist viewpoints can be useful as a theoretical framework, to achieve that, and cited Foucault (1986) extract stating that *“I believe too much in truth not to support that there are different truths and different ways of speaking the truth”* (Tamboukou and Ball, 2003, p. 14). Walmsley (2002) claimed that self-advocates have to fight against dominant modernist knowledge/power systems every day however that have not stopped them to be able to share and shape their lives. Goodley and Rapley (2002) argued that much can be gained from a poststructuralist social view of people with learning difficulties that have been labelled and been objectified by various groups of professionals including researchers. Goodley (2000) highlighted that notions held for people with learning difficulties as ‘lacking’ have been challenged from the work of self-advocates with learning difficulties who demonstrated that even people with severe learning difficulties can be active contributing members of self-advocacy groups.

Poststructuralist views suggest that the emphasis should be put on collective activities as well and not only on modernist views of individualism as by focusing on inter-dependence the formation of autonomy becomes evident. Moreover, Liasidou (2012) claimed that post-structuralism rejects

'metaphysical dualisms' that involve dichotomous perspectives such as normality/abnormality and personal/social. Liasidou (2012) argued that post-structuralism challenges those views by suggesting that for instance, the notion of impairment is neither true nor real without taking into consideration the concept they have been developed or emerged from. Poststructuralists hold that negative views of people with learning difficulties that are seen as essential from the positivist viewpoint can be better understood and challenged in terms of social relations. The advocacy outcomes study carried out research together with self-advocates and advocacy partners co-producing knowledge and discourses together thus sharing some of the principles of the poststructuralist viewpoint. Self-advocates and advocacy partners put forward their truth and their expert points of view and shared those with the academic and the wider community. By doing that they put forward a positive identity for people with learning difficulties and provided challenges to views with negative connotations that led to their exclusion.

### **3.6. Disability Studies Research Viewpoint**

Barnes and Mercer (2010) have argued that non-disabled researchers cannot bring authenticity in the research process and that they cannot fully adopt the emancipatory agenda proposed by the social model of disability. Shakespeare (2006) noted that although many people experience impairment, only a minority share the social identity of disability. Moreover, Shakespeare suggested that certain marginalised groups such as disabled people, people of colour or people who have survived psychiatric services, that have directly experienced oppression, can generate the most fundamental challenges to mainstream views. Furthermore, Shakespeare (2006) claimed that 'others', even people who can be seen as supporters of the marginalised groups, cannot be seen as long-term allies because they have not been affected enough. Oliver and Barnes (2012) argued that supposed allies may not be appropriate to generalise challenges to mainstream views as they may alter the nature of the movements. Walmsley (2002) highlighted that research involving people with learning difficulties often needs the support of non-disabled academics to represent their

theories something that came in contrast with the social model of disability calls for disabled researchers being in the core of disability research.

De Bruin (2017) suggested that a danger associated with those views of research is that it entails possibilities of marginalization of certain groups of people if only a number of people who have direct experience of a field can research it. The author also noted that there are several problems with the proposition that fight against oppression can only be represented by one standpoint alone which speaks “the truth” about disability rather than from different voices united. Hood et al. (1996) argued that it is how the research is conducted, how the ethical issues are being addressed, and how the participants are being involved in doing research, rather than being preoccupied with forms of experience that make the research worthy.

Shakespeare (2006) suggested that there is a difference between personal commitment to the social model of disability, research accountability and emancipatory research. Emancipatory research has a specific agenda, which is political in nature and can often be seen as a disadvantage and be ignored by policymakers and the government as being ideologically prejudiced. Participatory research differs from emancipatory research mainly around the ownership of research. Proponents of emancipatory research, such as Oliver and Barnes (2012), have suggested that the ownership and control of the research should rest with the disabled people. In contrast, participatory research allows non-disabled researchers to play a central role in research, sometimes because other contributors may have little knowledge or experience around research (Stone and Priestley, 1996). De Bruin (2015) claimed that disability research should aim to have some notional independence, at the same time as being committed to the principles of the disability movement, which could be achieved by equalizing the research relationship which involves sharing with participants some control over the research process.

Walmsley (2002) proposed that part of the literature for participatory research has been produced from non-disabled researchers for example

Cocks and Cockram (1995). Goodley (2000) argued that participatory research has advantages but also disadvantages such as requiring more time for doing it well something that sits uneasily with the pressure on researchers to find funds and deliver outcomes quickly but also requiring a different kind of publication and dissemination. Goodley and Clough (2004) pointed out that the advantages of participatory research include breaking down traditional researcher/participant relationships with the power imbalance counteracted by involving participants as co-researchers. Moreover, participatory research offers the opportunity to explore the expert views from people who have lived experience of the topic thus managing to have a more in-depth investigation of the topic.

It was beyond the scope and potentially not feasible for a research study conducted as part of fulfilling the criteria for the PhD award to be an emancipatory research project. The advocacy outcomes study recognised the importance of emancipatory research and its alignment with the disability movement agenda. The study demonstrated a commitment to the causes of people with learning difficulties and to a certain extent to the political causes of disability studies. However, the study opted for the participatory research approach which is also a methodology that has certain benefits. The advocacy outcomes study worked together with a group of people with learning difficulties by promoting their active involvement in co-producing knowledge, discourses and narratives. People that have direct experience of advocacy expressed their views, feelings and experiences about advocacy and contributed to the development of its theory and practice. The study demonstrated that such a project that can aim to produce good quality research and knowledge is possible.

### **3.7. Participatory Research**

The PhD study adopted principles of the participatory research philosophy by working with a steering group of self-advocates in the preparation and implementation of the research process. Participatory research as defined by Cornwall and Jewkes (1995) is carried with the people that the research is



about rather than only acknowledge them. It has been argued that the participation of service users in active research roles can “turn the passivity into activity” and can be a powerful strategy to develop better services for the people who use it (Cocks and Cockram, 1995). According to Cocks and Cockram (1995), participatory research encourages participants to have direct input in the research process and aims to produce positive practical outcomes for the participants. Positive practical outcomes for the participants, in participatory research, can include providing research training in the form of workshops amongst others. The study followed the participatory research principles by carrying out the research with a steering group formed of self-advocates who have also been using other different types of advocacy. The steering group members received research training in the form of workshops which supported them to actively contribute and be partners in the research study and the knowledge production. The approach that was followed with regard to the training for the steering group was the challenging inequality model (Warren and Boxall, 2009). Warren and Boxall (2009) proposed that the challenging inequality model views researchers with and without learning difficulties as able to learn together. The challenging inequality model recognised that both groups of researchers need support and training to carry out quality research.

Participatory research has been important in the field of enquiry exploring learning difficulties research and its importance may be attributed to its links with self-advocacy. Northway, Howarth and Evans (2014) suggested that participatory research is seeking to include the views of people with learning difficulties thus promoting self-advocacy. Walmsley (2002) noted that a number of publications have been created by, and developed for people with learning difficulties for example (People First, 1993b and 1993c). Furthermore, several chapters have been co-written by people with and without learning difficulties, for example (Atkinson and Cooper, 2000). Moreover, conferences routinely involve people with learning difficulties as speakers and delegates. Atkinson (2002) suggested that participatory research has been influential in research circles and grew alongside self-advocacy. Participatory research also showed that people with learning

difficulties are able and willing to be included in research as co-researchers and participants as well as be actively involved in knowledge production (Cook, 2012). The self-advocacy movement encouraged and gave the confidence to people with learning difficulties to speak up as well as take part and be actively involved in the research process. Atkinson (2002) also suggested that people with learning difficulties involved as consultants, co-researchers or participants of research can lead to promoting self-advocacy and speaking up. French and Swain (2000) claimed that disabled people can be empowered by telling their stories and being involved in research. Macadam et al. (2013) argued that self-advocacy and taking on research roles may be intertwined as speaking up can be empowering similarly to researching and producing knowledge.

Atkinson (2002) suggested that participatory research is an important part of learning difficulties field of research and is widely accepted. Participatory research typically involves people with learning difficulties taking up not only the roles of participants but also the roles of consultants, partners, interviewers and co-researchers. It has the potential to be inclusive, enabling and empowering by engaging people with learning difficulties in the various stages of the research process. Involvement can include identifying the focus of research, designing and implementing the fieldwork, interpreting the results and disseminating the findings. French and Swain (2004) suggested that participatory research changes the social relations of research and that taking part in the research process can have positive outcomes. Atkinson (2002) also suggested that participatory research builds on the good practices of qualitative research such as the sympathetic researcher who works with the people and encourages as well as supports participation at all the stages of the research process.

### **3.7.1. Research and disempowerment**

Oliver and Barnes (2012) argued that a lot of people with learning difficulties have had previous bad experience, when dealing with different institutions such as during education, including in some cases being abused. In addition, Carlson (2009) suggested that research has played a key role in the

oppression of people with learning difficulties by legitimating their institutionalisation and their exclusion from mainstream society. Corker and Shakespeare (2002) noted that studies, particularly until the 1980s, have systematically excluded marginalised groups such as people with learning difficulties from research as they were viewed as story-less. Nind (2008) claimed that oppressive research practices have been evident in research with people with learning difficulties where their views and experience were ignored as they were treated as subjects. Furthermore, a lot of people with learning difficulties have suffered institutional oppression and generally felt powerless across a number of situations in their lives such as dealing with social services or health authorities. Goodley (2000) suggested that even individuals with mild learning difficulties who have been active in self-advocacy groups, speaking up for themselves and others, are aware of the power lying on the side of supporters without learning difficulties who are often responsible for facilitating the groups.

Therefore it is not unlikely that some people with learning difficulties, who wish to be actively involved in research as participants or part of the steering group, saw the researcher, at least initially, as another person that may wield power upon their lives. Thus it is possible that some participants and co-researchers may have tried to please the researcher and give answers that were seen as positive, an effect that is generally observed in research participants with or without learning difficulties (Morse and Field, 1995). Furthermore, because of past experience, people with learning difficulties may refrain from expressing opinions and views that could be seen as negative as they may be fearful of negative consequences. It is thus very important that the researcher spends time and develops a positive relationship with the research participants and particularly with co-researchers in order to build a trusting relationship.

The advocacy outcomes study utilised a number of ways to tackle the potential challenges discussed above. First of all the idea of the current research study came from the interaction with the established self-advocacy group, that later became the steering group for the study, and also from the

interest shown from its group members. I have been working for a number of months, with the self-advocacy group that later became the steering group for this research project, prior to the conception and implementation of the study. Additionally, I had been an advocate at the advocacy organisation, have spent time, and had a positive relationship, with most individuals prior to them taking part in the study. Therefore a level of familiarity and to a certain extent trust and rapport was established beforehand thus making the interactions less uncomfortable and more fruitful. The self-advocates that acted as the study's steering group have played a key part in the development and implementation of this research study.

Furthermore, Simons et al. (1989) noted that people with learning difficulties until the 1980s have not been included even as participants, let alone co-researchers, in research that was exploring learning difficulties. It was only after the rise of participatory research and the self-advocacy movement in the 1990s that people with learning difficulties started to be actively involved in research as participants and co-researchers (Walmsley, 2002). Goodley (2000) suggested that research has provided empowering opportunities for self-advocates to share experiences of resilience, resistance and self-determination.

### ***3.7.2. How we worked with the group***

We had a number of meetings with the steering group, including workshops explaining the research process, prior to agreeing the terms of reference. All the members of the steering group agreed the terms of reference, discussed and set the agenda for the next meeting at every meeting. Ritchie and Lewis (2003) suggested that it is important that members of the steering group and the researcher take time to understand their relationship and roles and allow space and time to come up with different suggestions around the study and the research process. It is worth mentioning that I had developed an initial research plan that was open to discussion and change, something that did happen. It took time however for the research relationship, between the members of the steering group and myself, to develop and the research to turn into a co-production rather than the researcher simply consulting with

the steering group members. All group members were given the opportunity and were encouraged to actively be involved in the research process and we all worked as a team. The presence of mutual support (Keyes and Brandon, 2012) between the steering group members with learning difficulties was evident in every meeting with members of the group supporting mutually each other in developing the ideas and suggestions under discussion. The steering group took an active role in the formulation of the research questions as well as of the material of the study, the interpretation of the findings, the conclusions and the formulation of the recommendations.

Northway et al. (2014) suggested that although participatory research has certain benefits and can transform the nature of research it also has some drawbacks such as being immensely demanding in terms of the researchers' time as well as personal involvement. Morrison and Dearden (2013) proposed that participatory research needs careful facilitation with time allocated to training in order to make the contributions more meaningful and valued and not tokenistic. Nind (2008) argued that people with learning difficulties tend to not have experience around the research process however a lot of people have participated in advisory and other groups that share similar principles and aims. Braun and Clarke (2006) claimed that less interpretative methods including thematic analysis can be seen as more suitable for participatory research compared to more theory generating methods such as grounded theory. In terms of the ownership of the knowledge although, as in most academic social research at the PhD level, I planned and initiated the research process, with the support of the supervision team, the steering group members felt increasingly part of the study as the participation grew.

### **3.7.3. Steering group**

Members of the steering group were also members of a pre-existing self-advocacy group that had been running for over two years prior to the commencement of the study. The self-advocates with learning difficulties also had experience of using other types of advocacy services. The steering group was formed in the early stages of the research study to allow for direct

input from the group to all the different stages of the study. The steering group initially was meeting fortnightly and after the group have started to be more established and functional it was meeting monthly for the whole duration of the study. The steering group met regularly at the foundation's premises and although the number of attendees was not fixed a strong core of five members who regularly attended the sessions was established. The group received research training to actively participate in the decision making around the research design as well as the planning and implementation of the research study. Different methods were examined and considered to find the most appropriate methodology for the study to follow.

Although a research plan has been devised and submitted for the Initial Project Approval from Northumbria University this had to change to encompass the direct input from the steering group and the changes in the research questions. The group made the decisions regarding the research questions, to be explored in the study, as well as regarding how the study was going to be implemented. The group came up with different ideas which were then discussed and all the decisions were made collectively. The research training provided to the steering group followed the challenging inequality model described by Warren and Boxall (2009). The challenging inequality model sees researchers with and without learning difficulties working, learning and accessing support together to carry out quality research. Nind et al. (2015) suggested that the challenging inequality model involves examining and problem-solving together when facing a decision. We together with group members had discussions around the research training resources and after that, we were discussing real research problems and reaching decisions together.

The steering group also collaborated in producing all the research materials including the invitation letter which explained the main parts of the study to prospective participants. The invitation letters, the information sheets and the consent forms for the focus group and the participants' interviews can be found in appendices 4-9. Furthermore, the steering group also worked on producing accessible information sheets and consent forms that explained

the study and what was expected from them to prospective participants. The group worked together and produced the schedule of the semi-structured interviews as well as the case vignettes that were included in the guide. The semi-structured interview guide can be found on appendix 10.

We also worked together and analysed the data by identifying the themes as well as the important points presented in the data. Different themes were presented and were discussed before collectively making the decisions about which themes were kept and which were discarded. The group contributed to the decision making around the need for more extensive data and the timing when data saturation has been reached. Moreover, the steering group worked together to formulate the discussion and conclusions. The steering group decided together about the main points that should be highlighted in the discussion and conclusion chapters. The self-advocacy group has been involved in presenting and disseminating the findings in an easy read format in order to make them more accessible to people with learning difficulties that use advocacy services and might have faced difficulties understanding the report. The group also contributed to the key points of the research report, following extensive discussions, as well as to the recommendations for advocacy practice and the Advocacy Partnership model produced by the study (figure 11).

The self-advocates and I worked as a team throughout the study. Everyone in the group was given the opportunity and was encouraged to participate in order to get everyone involved. It was a collaborative work as every person was complementing each other's ideas before reaching the final result. Consistent with the mutual support model of peer support (Keyes and Brandon, 2012) members of the steering group with learning difficulties supported each other in different ways. Members of the group were supporting each other mutually to learn as well as come up with ideas for the purpose of progressing with the research. Buettgen et al. (2012) suggested that an important aspect of the participatory process for people with learning difficulties is developing new skills and knowledge which can increase confidence and own capabilities. This appeared to have worked well in the

steering group as group members reported that they learned new skills. Working together with the steering group, however, had some limitations and challenges mainly because this study was part of the assessments for the award of the PhD. Although I worked together with the group on all the stages of the research study, the writing up of the thesis as well as other critical elements of the PhD award assessments such as the Initial Project Approval, the Ethics application and the annual progression documentations were my own work. The next section discusses a number of other challenges and difficulties faced whilst carrying out the study.

#### **3.7.4. Challenges/Difficulties**

Perez and Treadwell (2009) suggested that although participatory research is seen as an ethical method with several benefits it also raised some ethical challenges. The fact that I was involved in the study as a researcher but have also been working in the advocacy organisation brought up some additional issues. A number of measures were taken to minimise the challenges. The participants were fully informed that taking part, or deciding not to, would have not at all affected their rights in any way. Iacono (2006) claimed that power issues are very important and relevant to consent as it is important that the individuals are clear that if they consent to participate but later wish to withdraw there would be no penalties or loss of the services they receive. Furthermore, other measures were taken to ensure the impartiality and trustworthiness of the data as described in the earlier sections. Additionally, I kept a reflexive account of the issues that came up during the course of the study and of how I and the group dealt with them.

Nind (2008) noted that finding people with learning difficulties to take an active part in research or participate in the study can prove difficult and also suggested that members of self-advocacy groups are a good starting point, something that this project followed. Furthermore, Nind (2008) argued that an additional difficulty for recruiting people with learning difficulties for a study is the range of gatekeepers such as social workers and health professionals, parents or carers who may feel that participation in research is not a good idea for people with learning difficulties. Instead of leaving the



individual to make up their own mind. It has also been claimed that the gatekeepers may discourage people from participating or even fail to pass on relevant information about the project.

Another challenge was the decision around methods of communication in the focus group and interviews. It was decided, with the steering group, that the primary method of communication would be spoken words although other methods were not excluded they were seen as complementing verbal communication. The interviews were audio recorded, with the agreement of participants, something which allowed taking some notes regarding other forms of communication such as facial expressions and body language. Roets et al. (2007) suggested that recruiting participants that use words to communicate was their preferred option as they were unable to develop appropriate data collection tools for people who do not use words as well as meeting the project's deadlines. They also suggested that qualitative research uses data mainly in the form of words and therefore participating in such a study requires a degree of verbal ability to respond in questions, something that creates barriers for some people with learning difficulties.

Cornwall and Jewkes (1995) also proposed that potentially there could be unintended negative consequences such as when disempowered groups of people feel empowered through participation and come across further oppression when the existing dominant power structures are being challenged. Cornwall and Jewkes (1995) also argued that the involvement of disempowered groups of people can increase their awareness of oppression and thus increase unhappiness. They also noted that although participatory research methodology is associated with a commitment to action research it may not necessarily lead to the desired outcome.

A further challenge for the advocacy study was whether it was possible for a non-disabled researcher to conduct participatory, non-exploitative, qualitative research with people with learning difficulties. According to Ritchie and Lewis (2003), there are some questions around the appropriateness of researching 'others' such as in research projects where a non-disabled researcher

carrying out research with people with learning difficulties or on black people by white people. Gilchrist et al. (2010) suggested that it is possible for a member of a dominant group in one setting in society to also be an 'other' in a different setting in society. This relates to the present research study as I, the main researcher although non-disabled, am from an ethnic minority background and do not belong to the mainstream White British part of society. Although the experiences of "otherness" that I have may not be the same, as those of people with learning difficulties, there are a number of similarities. There are times, when you are not part of the mainstream group of society, when you feel as different and as not belonging to this society. Moreover, there are experiences that make you feel that you are pushed towards the margins of society. I believe that although the experiences are not the same across all minority groups a certain extent of understanding exists that potentially can aid the exploration of experiences of a different group more deeply. Gilchrist et al. (2010) also argued that being from a different ethnic, cultural or linguistic background can also involve frequent experiences of being the 'other' or a 'foreigner', thus experiencing similar feelings of oppression, in relation to social power relations, felt by people with learning difficulties.

### **3.8. Research Design**

The PhD study chose a qualitative research design to best meet its aims and objectives. The qualitative design allowed the study the flexibility to explore an under-researched area. Moreover, the research design chosen facilitated rather than hindered the active involvement of participants with little research experience. Although within the boundaries of a doctoral research project, the study worked with an established group of self-advocates in order to explore advocacy outcomes from the point of view of people with learning difficulties that have used the advocacy service.

The research design did not adopt any purist approach however it was informed by principles of different research approaches. Principles of the participatory research philosophy were used to guide the research

partnership and best explore advocacy outcomes involving people with learning difficulties who had used different types of advocacy. Participatory research approach has been demonstrated to be an inclusive design which promotes co-production (Cook, 2012). Participatory approach design counters the power imbalance in the research process and promotes inclusion by actively encouraging the active involvement of all the participants.

Principles of the narrative research approach were utilised in the data collection and data analysis stages of the study. The narrative research design values human subjective experiences and does not put obstacles in the active involvement of participants. The narrative design principles enhanced the exploration of advocacy outcomes by encouraging participants to express their views, perceptions, experiences and feelings in a space free of judgement and pre-requisites. The following sections have a closer look at the practical aspects of the study. A flow diagram illustrating the different stages of the research process of the study is included in Appendix 2.

### ***3.8.1. How data were obtained***

A focus group was used to explore the main research questions from the service users' perspective and provided some initial themes to be further investigated in the interviews. Thematic analysis was used to identify the initial themes from the focus group to be further examined in the interviews. The initial themes from the focus group, together with discussion with the steering group, were used to finalise the case vignettes to be utilised in the in-depth interviews. Ritchie and Lewis (2003) suggested that case vignettes can be employed to encourage the participants to define a situation in their own words. Gilbert (2008) noted that focus groups can be useful at a preliminary stage of a study to provide greater insight into a topic and inform the development of the content to be used in interviews.

The study used the narrative research method (Elliott 2005) for data collection from the in-depth interviews. The in-depth interviews were used in order to explore the research questions, the meanings surrounding advocacy

and the identity of the participants as a group of self-advocates and advocacy partners with learning difficulties. The interviews were employed to provide a wealth of data representing the views of the people using advocacy and what they think were its outcomes using different types of questions as well as vignettes (Mason, 2002). The individuals that took part were able to express their views on what advocacy meant to them and what impact advocacy had in their lives. The study was open to ideas and influence from the steering group and participant involvement which provided the guide for the in-depth interviews together with the themes from the focus group. We decided the research questions as well as the questions to be used in the focus group and the schedule at the interviews together with the steering group. As a result of the input from the steering group, the focus group's schedule and interviews topic guide were finalised after the ethics approval and were submitted for ethics review at a later stage, however before the commencement of data collection. The focus group and the interviews took place mainly at the advocacy organisation's office and at the foundation's premises, where the self-advocacy group was based. The interview topic guide can be found in appendix 10.

### **3.8.2. Narrative Method**

According to Atkinson (2005), the narrative method is suitable for research with people with learning difficulties as it encourages participation and people sharing their distinct personal histories and wealth of experience in a critique-free interview. Elliott (2005) suggested that the narrative method focuses on the stories that participants with learning difficulties were willing to share but also on the meanings they attached to advocacy. Atkinson (2002) suggested that placing the focus on the meaning of the story helped to make sure that the narrative was an experience that mattered. Kondrat and Teater (2009) argued that views, from dominant ideologies, perpetuated the objectification of people with learning difficulties by proposing that they are powerless and story-less. Roets et al. (2007) claimed that personal and even intimate narratives of people with learning difficulties merit being listened to and understood in their cultural contexts. The life stories of people with learning

difficulties require attention as well as theoretical analysis and reflection in order to avoid being misinterpreted and objectified in professional discourse.

Atkinson (2005) suggested that interpretive methods such as narrative research can be used to reflect the experience of oppression. The oppression should be addressed and the prevalent cultural images that gave inferior status to people with learning difficulties should be challenged. Walmsley (2002) claimed that the reproduction of such constructions strengthened the hegemonic discourses and continued to dehumanize and stigmatize the oppressed. The narrative research method provided a power balance between the researchers and participants which allowed the exploration of their respective shared actions and social roles in their struggle towards defeating oppression. Strier (2007) proposed that by using the narrative method researchers strive towards a more egalitarian endeavour and thus promote genuine participation. Furthermore, it has been claimed that using the narrative interviewing technique promotes carrying out research with participants and encourages them to express different aspects of their experience and feel empowered (Elliott, 2005). It has also been argued that the narrative method makes research more accessible and interesting for the participants and avoids negative ethical and power consequences by not accepting that there is only one reality (Mason, 2002).

The study listened to the participants' stories that they were willing to share and viewed them within their context. The study by adopting this methodology and philosophical viewpoint distanced itself from previous oppressive research practices that gave an inferior status to data from people with learning difficulties. The participants' stories were treated with respect and they were valued as they offered an invaluable insight on what advocacy is and how it was perceived by people with learning difficulties that used the service. Furthermore, the study used the narrative research method to aid the empowerment of people with learning difficulties by facilitating their active participation in the study and also the expression of their views, beliefs and experiences as well as their identities which produced new discourses and knowledge. The study by using the narrative research method

demonstrated that it valued the contribution from the participants and also that it attempted to counteract the power imbalance between the researcher and the participants. Moreover, the narrative approach informed the interviews by actively promoting the construction of an identity of the participants with learning difficulties based on their discourses. Ultimately the narrative approach actively promoted the empowerment of the participants with learning difficulties by providing an opportunity for their views, lived experience and discourses to be listened to and be acknowledged.

### **3.8.3. Interviews**

Qualitative research largely involves collecting data via the medium of the semi-structured interview. Curry et al. (2009) suggested that the interview's schedule should be focussed, open and brief but also allow the exploration of participants' experiences through the generation of new questions. Nind (2008) argued that studies involving interviews with people with learning difficulties report interview length of around an hour or less compared to similar research involving interviews with stakeholders such as family, carers or care staff that report length of around an hour or more. Ritchie and Lewis (2003) discussed the appropriateness of qualitative research using interviews for people with learning difficulties and suggested that although verbal ability may play a part in explaining the different lengths in reported time of interviews, this has not been investigated by research. They also claimed that another possible explanation is that researchers are constructing shorter interviews for participants with learning difficulties or use fewer prompts to reduce bias effects.

McVilly et al. (2006) discussed a number of issues that should be taken into account when compiling interviews involving people with learning difficulties. They suggested asking simple open questions to minimize issues such as social desirability, suggestibility and acquiescence. Furthermore, they proposed that the development of questions should ensure that they are non-leading and that the interviewer minimizes any tendencies to shape answers. Beail and Williams (2014) noted that some people with learning difficulties

may be reluctant to answer questions relating to services they receive or to criticize services, perhaps, for fear they may be withdrawn.

The interviews took place at the venue where the participants were feeling more comfortable with, mostly at the advocacy organisation's office or at the foundation's premises where participants have been before and felt a sense of familiarity. Although the interview process can be seen as rather artificial and not natural or comfortable the advocacy outcomes study tried to counteract those negative aspects with making the participants feel as much at ease as possible. Apart from having the choice of the interview's venue participants were also encouraged to take the time to make themselves comfortable and talk about any issues, they may had, with the interview facilitator to make sure that they were content with the process. The study had the advantage of the established familiarity between the participants and myself who acted as the interview facilitator for the in depth interviews of the study. This helped the participants feel more at ease with the whole process, feel more relaxed and potentially this was reflected in the quality of the data produced.

The participants after making themselves comfortable and had any questions answered completed the informed consent form assisted by the interview facilitator. Full details of the process followed and information about the issues surrounding the informed consent are discussed section 3.12.1. Following the completion of the consent form and having any final questions answered the process included talking about participants' lived experience involving advocacy. The participants were encouraged to talk freely about their lived experience of advocacy and also about the meaning of advocacy to them and the most important outcomes for them. A number of vignettes were also included in the interview process and those can be seen in appendix 10. The vignettes included stories about fictional people who come across different issues. The participants were encouraged to discuss in the interview what the advocate could do to support the person. In order to further explore self-advocacy, the participants were asked about what they would do if they were facing the same problem and also what they would do

if they were the advocate. All of the participants were given opportunities to express themselves freely in the interview process and highlight the issues that they were seeing as important.

The participants in the study were explicitly told that any services received would have not been affected by taking part in the research or withdrawing from it without giving an explanation. Moreover, it was made explicit and it was highlighted that all the data that were collected were anonymised and therefore the participants could not be identified. The participants were allowed to have as much time and information as they required to make an informed decision without feeling obliged to participate.

Bunning et al. (2009) carried out qualitative research with people with learning difficulties using an alternative data collection method to interviews through the use of communication aids such as symbol cards. The authors suggested that for people who have very severe and profound learning difficulties the use of qualitative research has limits to what can be achieved. However, this method was beyond the scope of the study which decided that verbal communication was the primary means of communication and of data collection. Other means of communication were seen as complementary to spoken language. It can be argued that it was a potential limitation of the study not involving people who had limited verbal ability or potentially profound learning difficulties. The section continues by exploring some of the methodological advantages and limitations of the advocacy outcomes study.

#### **3.8.4. Advantages and limitations**

There are a number of measures that the study has utilised in order to ensure the rigour and trustworthiness of the data collected. With regards to the credibility of the study, a suitable well established qualitative research method has been used (narrative method) because it aided the participants' expression of views without restrictions or prerequisites. Moreover, the philosophy adopted by the study accepted that there are no pre-fixed ways of



seeing matters and also that there are more than one realities and meanings that can be accepted and valued.

Furthermore, the study sought and received approval from the Northumbria University Ethics Committee but also from the advocacy organisation's Executive Committee. In addition, I used a reflective commentary account in relation to the practitioner-researcher role and the potential power imbalance and how this was counteracted. Fox et al. (2007) suggested that practitioner researchers ought to be aware of the power imbalance issues between the researchers and the participants within the research. The same can be true for practitioners who provide a service and the people receiving a service. In my situation this could have potentially created a great imbalance due to my dual role as a researcher in this study but also a practitioner working for the advocacy scheme. In order to minimise this potential great imbalance of power and to counteract it people, who I have been working with as an advocate, were not invited to take part in the study. However, since it would have been unfair to penalise the people, I was working with, they were offered the opportunity to attend the research workshops if they wished to do so without participating in the actual data collection. Furthermore, the active involvement of participants in the research process was a further factor that counteracted the power imbalance in the research process. A group of self-advocates with learning difficulties acted as the steering group and co-researchers for the study thus playing an active role in the knowledge creation.

According to Shenton (2004) terms such as validity and reliability have an uneasy relationship with qualitative research and terms such as trustworthiness, confirmability and credibility are preferred. Shenton (2004) suggested that some qualitative researchers have embedded credibility checks into their methodologies by utilising an analytical auditor or confirming the understandings with the participants referred to as participant validation. Stalker (1998) claimed that, although some researchers have rejected participant validation, it can be seen as an important and ethical tool particularly in research involving people with learning difficulties.

Furthermore, it was noted that participation validation may potentially be more effective when the results stay close to the participants' words such as in the thematic or contents analysis as opposed to more interpretive methods. The study tested the trustworthiness, confirmability and credibility of the data collected by checking them again with the participants but also by making sure that the questions, as well as answers, were understood correctly. Moreover, the study stayed close to the actual words used by the participants and extensive quotations, from the data collected from the interviews, have been presented in the findings section to strengthen that. Additionally, the study's chosen analysis methods, discussed later in the chapter, again stayed close to the participants' actual data thus minimising any associated risks.

### **3.9. The Sample**

The recruitment of advocacy service users for the study was primarily from the North East of England advocacy organisation where I was a practitioner. I liaised with the advocacy organisation's staff member who was managing the database in order to send invitation letters to all the people that have used the service and that met the recruitment criteria. The advocacy organisation's staff member, responsible for managing the database, identified the potential participants from the whole of the database of service users using the inclusion criteria, people with learning difficulties of working age with some verbal ability, not in a non-instructed advocacy partnership. Furthermore, I liaised with the advocacy organisation's staff member and together sent the invitation letters along with the information sheet to the identified prospective participants. A total of 67 invitation letters along with information sheets were sent out to the prospective participants. There were no letters sent out to people that were working with myself in order to avoid potential conflicts as described in the previous section. When one participant was expressing an interest to participate in the study or wanting to find out more information he/she was directed to contact myself or have their preferred contact details passed on so I can contact them directly. A total number of 16 service users expressed an interest to participate however

three decided not to participate due to the commitments required. As the participants were coming forward following the invitations as self-selecting the possibility for some level of associated bias cannot be excluded. However, the participants were divided into three different levels of advocacy experience to minimise such associated bias. The details of the different levels of experience can be found in the following paragraphs and on table 2 (page 128). The invitation letters, information sheets and consent forms for the focus group and interview participants can be found in appendices 3-8.

Although the study endeavoured to be as inclusive as possible following advocacy's principles this was not always achieved. People who were involved in a non-instructed advocacy partnership were not included because this type of partnership most likely signified that the person was lacking the capacity to provide informed consent to take part in the research study. The ethical questions such as the issue of assessing the individual's mental capacity to provide informed consent to participate are discussed in section 3.12. Moreover, people with no verbal communication were not included because, as agreed with the steering group, it was beyond the scope of the study and its resources, given the time restrictive nature of a study for a PhD. The chosen method of data collection was in-depth interviews a method with certain advantages but also with the limitation of mostly allowing people with some verbal ability to participate. The issues discussed above are potential limitations of the study and are also being discussed further in the conclusion chapter section 7.6.2.

A purposive stratified sampling method was used which allowed selecting groups of people that display some variation but also are fairly homogeneous (Ritchie and Lewis, 2003). According to McVilly et al. (2006), qualitative research approaches tend to adopt purposive sampling however that is not to be confused with an opportunistic way of sampling. Holloway & Wheeler (2010) defined purposive sampling as selecting participants based on experience relevant to the research topic or group membership. Smith (2008) suggested that deciding how many participants are needed can be difficult as in qualitative research participants are involved to represent a perspective

rather than the whole of the population. Smith (2008) proposed that for research at the doctorate level four to ten in-depth interviews are recommended.

The participants of the study were female and male adults of working age, with learning difficulties, who had been involved in one or more types of advocacy partnerships. The study recruited a total of 13 (7 female and 6 male) participants. The age of participants varied from 23 years old to 57 years old. The advocacy types were separated into professional/case advocacy, citizen advocacy, peer and self-advocacy. Participants had varying levels of experience with 4 participants having been involved in advocacy for less than 6 months, 4 participants between 6 months and a year and 5 participants over a year advocacy involvement. All participants took part in the in depth-interviews and were in agreement for their data to be audio recorded, anonymised and used for the purposes of the advocacy outcomes research study. Table 2 provides information about the different advocacy types, gender and the different levels of experience of the interview participants.

Table 2. Advocacy type, levels of experience and gender of the participants

Participant	Advocacy Experience	Advocacy Type	Gender
1	< 6 months	Professional Advocacy	Female
2	< 6 months	Professional Advocacy	Male
3	< 6 months	Professional Advocacy	Male
4	< 6 months	Professional Advocacy	Male
5	6-12 months	Case/Self Advocacy	Female
6	6-12 months	Case/Citizen Advocacy	Female
7	6-12 months	Case/Citizen Advocacy	Female
8	6-12 months	Citizen Advocacy	Male
9	>12 months	Citizen Advocacy	Female
10	>12 months	Self-Advocacy	Female
11	>12 months	Peer/Self Advocacy	Female
12	>12 months	Peer/Self Advocacy	Male
13	>12 months	Peer/Self Advocacy	Male

Regarding the focus group, a smaller number of participants were recruited. Fraser and Fraser (2001) suggested that the traditional 6-10 participants' group size can be seen as problematic in focus groups involving people with learning difficulties. A focus group size of 4-6 is seen as appropriate as can allow more time for each participant to contribute. Participants at the focus group were 5 (3 male and 2 female) self-advocacy group members of working age. No members of the steering group that were involved in the focus group took part in the study as interview participants.

### **3.10. Rationale**

Ward and Trigler (2001) proposed that qualitative methods can be used to provide an opportunity for people with learning difficulties to express their experiences in their own words and explore the issue under study. Mcvilly et al. (2006) suggested that qualitative research with its inductive methods is more valuable when the knowledge is less specific, or where there is difficulty in the systematic control of the issues or constructs under evaluation. Qualitative methods have been important in bringing the unknown, about experiences of people with learning difficulties, into the known (Nind, 2008). Moreover, although qualitative research studies are in the minority, they are on the increase.

Juritzen et al. (2011) claimed that often people with learning difficulties are viewed as a vulnerable participant group within research leading to their exclusion from research something that can bring additional harm. Juritzen et al. (2011) brought up as an example that the care that vulnerable groups of people receive can escape research scrutiny, therefore, increasing vulnerability. Gill (2006) suggested that the assumed vulnerability of disabled people is socially constructed and also that the key aspects of this vulnerability are due to treatment and barriers from a social environment that devalues human difference. Furthermore, Gill (2006) proposed that vulnerability is about the lack of power that many disabled people are facing in their day to day living, the inequality and the barriers they are experiencing in aspects of their lives. Smith (2008) argued that exclusions from research

due to ethical guidelines can be seen as marginalisation or discrimination. Kondrat and Teater (2009) highlighted that people with learning difficulties themselves can best answer questions regarding their lives and that exclusion of their voices from research raises ethical questions and leaves a gap in the knowledge surrounding these topics.

The study shared the view that people with learning difficulties that have used advocacy services have the expert knowledge to inform research about advocacy. Moreover, the people that used the service can best provide an in-depth evaluation of what worked well and what did not for them. The study worked with a group of people with learning difficulties in order to advance the knowledge, surrounding advocacy, from the expertise that self-advocates and people that have used advocacy services were able and willing to share. The study shared the view that their expert opinions, viewpoints and experiences should be respected and valued and not taken out of context to be used against them.

### **3.11. Ethics**

No data were collected prior to obtaining the ethics approval from the Northumbria University Research Ethics Sub Committee and from the advocacy organisation's executive committee. There was no risk identified for potential harm to either the participants or the researchers that took part in the study. There was no intention to explore sensitive issues within the focus group or interviews however due to the nature of the topic (advocacy work) it was seen as possible that some of the participants might share something that could cause distress to themselves or others. All participants were therefore offered the contact details of a local counselling service in case they wished to discuss any issues that may have arisen from taking part in the study. Moreover, extra time to talk was offered when required regarding any concerns or when any of the participants may have required any further information or further clarifications. The participants were informed that any information they shared would remain confidential as their name would be removed from the data. The only exception when

confidentiality would have needed to be broken was if something, shared in the interviews, was suggesting that someone was being hurt or was being at immediate risk of harm. However, there were no incidents that required confidentiality to be broken and thus no personal data needed to be removed from the data set collected from the interviews. The section continues by looking at the different ethical issues that the study faced.

### **3.11.1. Informed Consent**

The study was explained to the participants verbally and also via an easy read information sheet that was presented to all the participants. After the study was explained to the participants verbally alongside the information sheet the participants were presented with the information about consent and the relevant consent form. Again the information about consent and the content of the consent form were presented verbally and in the easy read format which included pictorial information. The participants were explicitly asked whether they understood each piece of information and they were encouraged to ask questions and to clarify when something was not clear. Only after the information about the study and consent was understood participants were asked to provide their consent.

Participants who advised that they understood the information were asked to explicitly express their consent in taking part in the study. The opportunity was given again to all participants to ask any further questions about the information on the study or the consent as well as about the implications of participation. Moreover, extra time was offered to the participants to make sure that they had all their questions answered satisfactorily before making their decision. Participants were asked to explicitly give their consent verbally but also by signing the consent form. It was made clear to all participants that they could have withdrawn at any time from taking part, if they wanted to, without giving a reason for that even after they have given their consent or after participation, without facing any consequences.

Furthermore, the interviews and the assertion of capacity to provide informed consent to participate were conducted using some of the principles that were

suggested by Cook and Inglis (2012). Cook and Inglis (2012) proposed that improving the understanding of people with learning difficulties around research could be achieved by using simplified language, multiple methods of presentation, repeating the information, using visual aids as well as case vignettes and role-play scenarios. The study in order to enhance the understanding of participants used simplified language (jargon-free), different methods of presentation including verbal presentation as well as written, easy read with text and pictures.

Moreover, the study used case vignettes to enhance the understanding and the conversation and also involved role play as the participants were asked to think themselves as the advocate and what they would do if they were the advocate in one of the scenarios presented in the case vignettes. Furthermore, Cook (2012) reported that studies with people with learning difficulties highlighted that active participation of prospective participants in the research process enabled the individuals to have a better understanding and thus more fully and actively participate. The study also followed this recommendation as participants also played an active role in the research process.

### **3.11.2. *Mental Capacity Act 2005***

Jepson (2015) discussed the implications of the Mental Capacity Act (MCA) rules that researchers had to follow in order to assess the capacity of the prospective participants to provide informed consent. Jepson (2015) described how a researcher has to follow the principles of the MCA to fulfil the requirements of ethical research practice. Nind (2008) suggested that although it has been widely recognised that people with learning difficulties should be involved in research about them the access to research opportunities for people with learning difficulties had been restricted by gatekeepers who did not always act according to the first principle of the MCA which states that capacity should be assumed unless it is proved otherwise. Cook (2012) proposed that people with learning difficulties are able to give their informed consent for taking part in research however the information needs to be presented in an accessible, to them, way. Moreover,



Cook (2012) noted that participation rates for people with learning difficulties were higher when the individuals were contacted directly rather than relying on third parties to seek consent.

Jepson (2015) suggested that good practice in regard to accessing the consent of participants in research is the same for people with learning difficulties as it is for any other human participant. Jepson highlighted that most participants with learning difficulties are capable of gaining an understanding of verbal or written information about research and make their own mind whether or not they wish to participate. Some participants may not be able to read or write and some may struggle to understand some of the information communicated by researchers in spoken explanations. In these situations, it may be helpful to provide the consent form and information sheets in accessible ways, which people can take away and review before deciding whether to take part.

The study followed the Mental Capacity Act (2005) guidelines and thus the capacity for consenting and taking part in the study for the people who chose to take part was assumed. However, for the study to fully comply with the sections 30 to 33 of the MCA, in case of fluctuating capacity, additional safeguards were employed. Firstly participants who were involved in non-instructed advocacy partnerships and thus their capacity to provide informed consent for taking part in the study was not likely were not included in the invitation list. Secondly, data from participants who during the course of the study may have lost their capacity to consent would have been deleted and removed. Thirdly the explicit verbal consent of all the participants along with the signed consent form were obtained before taking part in the focus group or the interviews and before collecting any data. Additionally, signs were sought that each individual taking part in the study was able to understand the information relevant to making a decision, retain that information, use or weigh the information and finally being able to communicate their decision. This was in accordance with the MCA outlining that a professional assessment is not required providing that the fundamental criteria described above were met.

Moreover if concerns were raised around an individual's capacity to provide informed consent to take part further assurances were being sought. The researcher would have asked questions to make sure the person could understand, retain and weigh all the relevant information as well as communicate their decision. Additionally, if further doubts were present the advice of a person near the participant (e.g. family member or carer) would have been sought. The advice would not have been in the form of consenting for the participant, something out of the scope of the study as only participants who could consent were involved, but rather in the form of assent. If the person near the participant expressed valid concerns regarding the ability of the person to provide informed consent to take part in the study the participant was not included in the participants' list and any data collected were removed from the data set.

### **3.11.3. Data Protection**

Electronic data, including research data, were stored on a password-protected computer and the data will be kept for a maximum of 3 years after the end of the study, or no longer than necessary, at which point they will be safely destroyed along with any other data in different formats. The personal data that could make the participants identifiable have been separated from the raw data, when anonymised, and pseudonyms have been used to protect the identity of the participants. More specifically sensitive personal data, such as name and age, will be safely destroyed at the end of the study. The sensitive personal data were separated from the research data when participants' responses were coded in order to be anonymised. The research data will be kept for no longer than necessary in order to allow the data to be used in potential future research publications.

Furthermore, the study complied with the 7 principles of the Data Protection Act (2018), the General Data Protection Regulations (2018) as well as with the University's policy on the secure storage and retention of research records. It is clearly set in the Data Protection Act's and in the GDPR principles that data should not be retained for longer than it is necessary. The research data were accessible to the research participants, should they

wished to access them, for part of the duration of the study until the data were anonymised. After the data were anonymised, it became impossible to identify one participant's research data as the sensitive personal data were separated. All the raw data will be deleted securely following the permitted period after the end of the study.

### **3.12. Analysis**

Thematic analysis was used to analyse the data derived from the focus group. Braun and Clarke (2006) suggested that thematic analysis can be used to elicit themes from focus group data and finding out a group's conceptualization of the phenomena under study. Thematic analysis entails examining the data to identify clusters of meaning which comprise themes. The themes from the focus group, together with discussion with the steering group, were used to consider the case vignettes which were employed in the narrative interviews. In depth, interviews were utilised to explore the research questions exhaustively. The interviews were chosen to provide a wealth of data representing the views as well as meanings and perceptions of the people using the service around advocacy and its outcomes. Participants shared their views, feelings and experiences and those were facilitated by using different types of questions as well as vignettes and role-play to enhance conversation (Mason, 2002). Ritchie and Lewis (2003) suggested that case vignettes can encourage the participants to define a situation in their own words.

The data derived from the in-depth interviews were analysed according to Mishler (1995) framework which proposed that narrative analysis can be separated into three entities meaning, structure and performative context. The analysis focused primarily on the content of the narratives and evaluated the meaning of the content. Different patterns were explored within the data to get a deeper understanding of the meaning communicated by the participants. The patterns identified from the content and the meaning of the data formed themes that were discussed with the steering group and are presented in the findings chapters (4 and 5). For example the analysis of the

content examined specifically what the participants has shared in the interviews and identified meanings from what was expressed but also from the different patterns that emerged from the participants' accounts.

Harter et al., (2005) contrasted narrative analysis which seeks to unveil meaning from the content of what participants have shared with different practices in the health and social care field where the professional only uses the parts from the person's narrative that suite their interests. Harter et al. (2015) highlighted that this takes the person's narrative out of its context and is used to validate the professional's point of view rather than the person's. The analysis of the data in the advocacy outcomes study was sensitive to the potential detrimental effects of this practice and sought to keep the meanings identified from the content of the participants' accounts within context. The study focused on the whole of the content of the narrative and sought to find relevant meanings rather than taking parts of the narrative out of context. Moreover the study concentrated on what the participants highlighted as important.

Secondly, it looked at the structure of the narratives and thirdly on the context of how their performance. The analysis investigated the structure to understand better the context and the reasons behind the choice of structuring the narrative in a particular way. The structure of the narrative can indicate that the participant wished to achieve particular aims through their communication such as a sense of collective identity.

Labov (2007) pointed out that the narratives shared by participants in the interviews tend to be structured in an abstract or messy rather than linear or tidy way. It was highlighted though that this does not mean that this type of structure lacks in information, messages or meaning. Labov (2007) argued that the researchers carrying out the analysis ought to follow the particular structure of the narrative as this can reveal important information and deep ideas. Labov (2007) suggested that the how a narrative is told and structured can include important meanings similar to what the narrative itself says.

Finally, the performative context element of the narratives can unveil further deeper understandings by exploring questions such as how the narrative was performed in its specific context. The analysis examined the performative context of the narratives also to look at the identities demonstrated by the participants through the performance of the narratives. Participants performed their narrative not only to provide information but also developed accounts that demonstrated a collective identity for people with learning difficulties. The findings from the analysis of the structure and the performance of the narratives are discussed primarily in chapter 5 but also chapter 4.

McCormack (2000) argued that the analysis of the data should pay particular attention not only in the content and the structure of the narratives but also in their performative context. McCormack (2000) suggested that the interpretive process should not separate the participants' accounts content and structure from their performative context because that can have the danger of misinterpreting their accounts. In the advocacy outcomes study analysis the input from the direct involvement of the steering group of self-advocates with learning difficulties played a very important part. The steering group was directly involved in the decision-making around the themes identified from the data. This involvement made sure that the analysis of the data stayed close to the performative context of people with learning difficulties.

McVilly et al. (2006) suggested that qualitative researchers seek to collect rich data from participant interviews which are seen as extensive, detailed accounts of personal experience. Furthermore, McVilly et al. (2006) noted that verbal ability can play an important role in the extent to which a detailed account is given and that researchers should expect that some people with learning difficulties may have an issue with the level of description in an interview setting. Thus they suggested that interviews involving people with learning difficulties may not produce as rich data however that should not mean that the data are of less value. Smith (2008) proposed a different definition of richness in terms of the number of themes in the data and

argued that research has not explored whether learning difficulties have an impact upon the number of themes extracted.

The study collected rich in-depth data containing a wealth of information from the participants' views, feelings, meanings, perceptions and experiences and the data were highly valued as they provided a unique and important perspective. The data were particularly insightful and reflected the expert view of participants who have direct experience of the advocacy partnership and its outcomes. The data offered apart from insight into advocacy also a representation of the identity of people with learning difficulties.

Braun and Clarke (2006) argued that some forms of coding and analysing are common to all different qualitative methods and although they are informed by different epistemological underpinnings they result in similar looking findings. Snilstveit et al. (2012) suggested that visual inspection of the results section, of qualitative studies, reveals text and quotations from participants which can be seen as evidence to support that the main themes were found in the data. The process of the identification of themes often involves a detailed line by line analysis of the raw data from participants' interview transcripts. This process involves identifying codes which are grouped into themes across participants' transcripts and across individual interviews.

Thematic analysis often takes the participants' words at face value and is moving away from the individual by searching for common themes whereas the narrative method focuses more on the individual and their story (Braun and Clarke, 2006). Thematic Analysis can also be performed by entering transcripts into qualitative software packages such as NVivo 11 which can help identify the themes across transcripts by organising, reducing and managing the text. Another way for identifying themes is commonality however some qualitative researchers prefer to avoid this as it relates to quantitative methodology. Nind (2008) suggested that it is important for the analysis not to lose the emotional tone included on participants', with learning difficulties, accounts.

The study, adopting social constructivist principles, accepted that there are no universal truths that need to be uncovered but rather different realities that should be accepted and valued. One of the methods that the study used in order to elaborate on its stance is providing reflexive accounts later in this chapter (3.14) but also in the conclusion chapter section 7.7. Furthermore, the study in order to achieve its aims utilised the narrative methodology which is compatible with social constructivism principles and facilitates the active participation of people with learning difficulties in research by not putting barriers and by accepting their point of view as valid and valued.

#### **3.12.1. Focus Group Data**

The focus group session was used as the pilot to test the materials produced as well as the topic guide and the case vignettes. The focus group was run to carry out a discussion about the materials and the topic as well as their relevance to people with learning difficulties. The participants were able to express their views on what advocacy means to them and what impact advocacy had in their lives. The focus group took place at the foundation's premises where the self-advocacy group was based in the North East of England. It was decided, with the steering group, that the primary method of communication would be spoken words although other methods, were not excluded, they were seen as complementing verbal communication. The focus group was audio recorded, with the agreement of participants, something which allowed taking some notes around other forms of communication such as facial expressions and body language.

NVivo 11 qualitative analysis software package was used to better manage the data. The software package assisted in the themes being elicited as it reduced the data and assisted in organising them. Moreover, the data from the focus group apart from being coded in NVivo were also visually inspected line by line to identify themes from specific to more generic. NVivo was not used to quantify the data or the themes identified and NVivo tools such as the query were not used. Furthermore, the initial themes identified were discussed, debated and the final themes were decided together with the

steering group. The steering group together discussed the findings from the focus group data after and determined the final version of the material and the topic guide to be used in the in-depth interviews.

### **3.12.2. Narrative Interviews Data**

The data were organised using NVivo 11, qualitative analysis software package, which has been found useful in managing large sets of data. Gilbert (2008) suggested that the NVivo software package is suitable for organising narrative interview data as it can assist in the reduction of the data something which makes identifying different themes easier. NVivo was used to organise the material however it was not used to analyse the data. The transcripts were coded (and later themes were identified) in NVivo, however, the transcripts were also inspected visually again to identify themes from more specific to more generic.

Please find below an example of the coding of the raw data from the interview participants. The extract from the raw data is presented alongside the identified code in the same colour. The code is largely based on what the participant is sharing in the interview process. More examples can be found in appendix 3.

*Peter: “Advocates are not pushing their own point of view to you like other professionals do. Not telling me what to do, putting their ideas into my head, but I was able to tell what I wanted and then we were working together with the advocate to do something about that. With the current economic climate, you may not get always what you want but with the support of an advocate you can try and fight for that and speak up for yourself. You fight for your rights and for what you believe in. You don’t really fight but when you are passionate you speak up. I am passionate about the students getting a new pool. After school hours will also be available to the adults as well.”*



*Codes identified: Advocacy is different, Working together is important, Advocacy can be important, and Self-advocating, speaking up and standing up for your rights aid empowerment.*

NVivo was not used to quantify the data or the themes identified and NVivo tools such as the query were not used. Concentrating on the quantitative aspects of the participants' responses would not allow the co-researchers to immerse themselves in the data and seek a deeper understanding of their meanings, structure and performative context. Additionally, the richness of the data and the personal experiences of the participants could potentially be reduced or lost. The study valued and aimed to explore the participants' responses as individuals but also as a group of people with expert knowledge over advocacy, the topic under investigation.

I carried out all the transcribing from the interviews, soon after the interviews, in order to have an opportunity to reflect on the interview process, get to know the data better and also to make any additional notes to the ones taken whilst carrying out the interviews. I firstly inspected and familiarised myself with the data before coding the data. After coding the data I reviewed the coding against the transcript to make sure that it was accurate and representative. Following that step I created different clusters of coding that started to form themes. At that point all the different clusters were discussed with the steering group and together we came up with the themes.

Furthermore, the analysis of the data continued by carrying out a six-step process for examining the data. The first step involved reading again the material in order to build up a better understanding and further the level of familiarity with the data. The second step included looking at the content of the narratives and trying to look for potential clusters of meaning as well as patterns within and between the data from the participants. The meaning from the content of the narratives was seen and interpreted within its performative context. This was seen as important because that allowed for

the different patterns of meaning to be identified from the content but also to always remain within the performative context.

The third step was comprised of exploring the structure of the narratives to gain a better understanding of the context as well as the reasons why participants chose to structure their narratives in that particular way. Participants structured their narrative in that way in order to achieve their aims through the communication of what is important for them. Although the structure was not linear and could be described at times as abstract or messy following the structure can lead to hidden meanings and deep ideas.

The fourth step within the analysis included examining the performative context of the narratives. This was done in order to better understand how the participants chose to perform their narrative within their specific context. By investigating the performative context element of the narrative the analysis achieved to not only explore the meanings provided by the participants but also to research their attitude and approach to taking part in research. The participants demonstrated that they are more than able, willing and determined to be active participants in being involved in research and knowledge production.

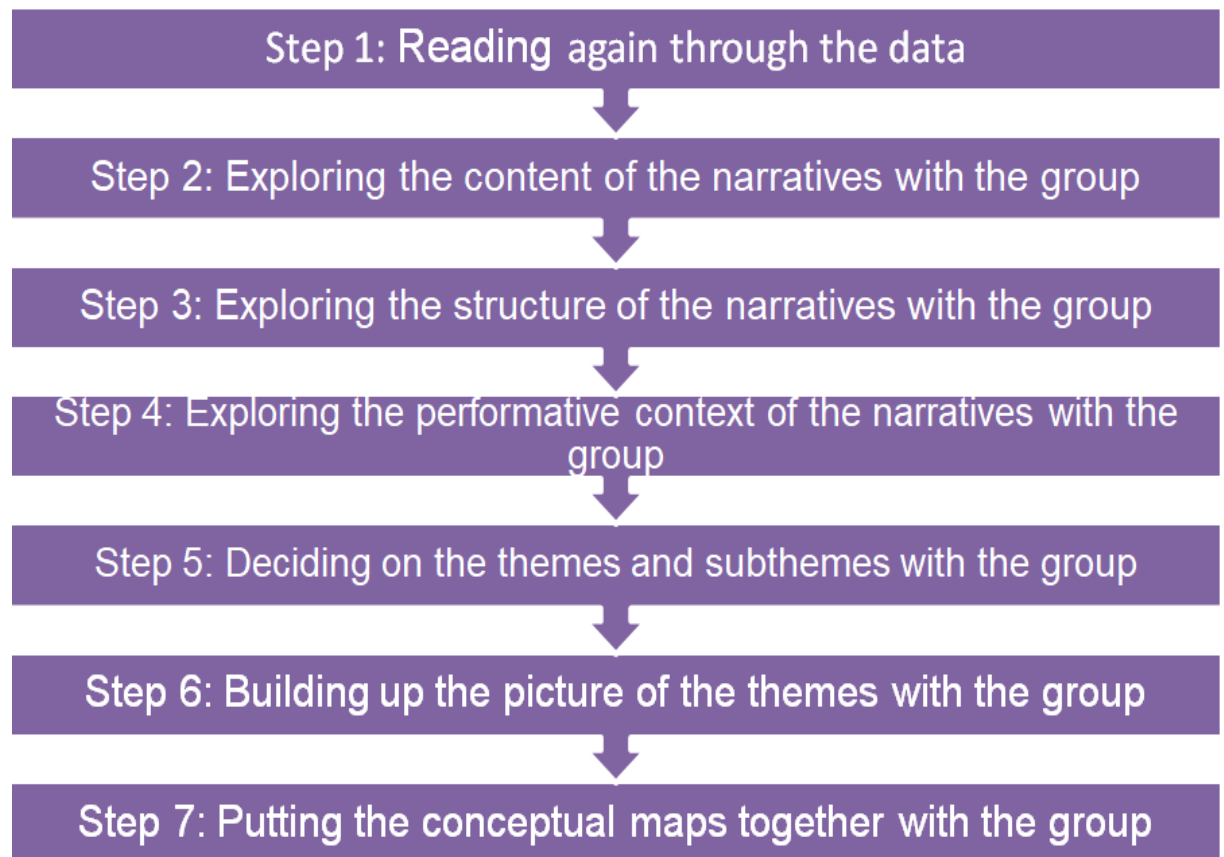
The fifth step involved starting to build up a picture containing different potential themes and concepts found within the material. The themes, coming from different angles following the different steps of the analysis so far, were discussed and reviewed with the steering group who had the important role of discarding some potential themes that were not seen as relevant enough to advocacy with people with learning difficulties. The steering group decided which themes were included in the next stage. The steering group direct involvement in the analysis and the interpretation of the data made sure that the identified themes remained within context.

The sixth step involved working with the steering group to weave the narratives together and forming the final structure of the advocacy outcomes themes. This stage included making the decisions with the steering group

and physically placing cards, with the themes, along a large piece of cardboard apart from discussing and debating. The step also involved deciding with the steering group on the themes, sub-themes and slowly along the process completing the shape of the grand conceptual map. The analysis and the interpretation of the data involved the examination of the content as well as of the structure and the performative context of the narratives.

The seventh and final step involved putting together the diagrams produced with the main themes and their sub-themes as well as the grand conceptual map (appendix 11). Putting together the diagrams that represented the different main themes and sub-themes was carried out and decided together with the steering group of self-advocates with learning difficulties. The seventh step also included writing up the findings section. Although in an ideal participatory research project the steering group should have a great involvement in all parts of the project this was not, to a full extent, possible in the advocacy outcomes study. The main reason for this is the constraints placed upon a PhD study requiring the written work submitted to be the product of the student. Although the steering group was not directly involved in the writing up of the findings their involvement and contribution was very important and added an expertise that made the analysis and the interpretation of the data reflect the authentic voice of the participants to a large extent. The seven steps of the analysis process can be seen together in table 3.

Table 3. The seven steps of the data analysis.



### **3.12.3. Approaches to the Data Analysis**

The analysis saw the account of the participants, their views, feelings and thoughts as vitally important. The data collected from the focus group were analysed using thematic analysis. The thematic analysis was used to identify themes from the focus group data and also to find out the group's thoughts, views and feelings on advocacy. The thematic analysis involved examining the data and identifying clusters of meaning which comprised the themes. The participants' words were taken at face value and they were not only used for identifying common themes. The approach used valued the account of the participants with learning difficulties and aided their empowerment by focusing on their views, thoughts and feelings around advocacy and in general around the issues that were important for them.

Riley and Hawe (2004) suggested that the social constructivist approach of narrative analysis places an emphasis on the performative and interactional context as the interview is seen as a place where interactive functions are

being performed. The social constructivist perspective focuses on the response of the research participants within the context of the interview. Moreover, the power relations between the participant and the interviewer are seen as an important and integral part of the process of co-construction in the interview. Analysing the performative context of power relations is one way of describing and understanding it. The advocacy outcomes study analysed the researcher's personal position, as well as the theoretical and methodological frameworks. The study sought to address those issues by providing a reflexive account of the study particularly in terms of the power relations but also in terms of my personal position in the following section and in section 7.7.

Gilbert (2008) suggested that the narrative enquiry explores how people make sense of the world however the narratives may require interpretation when used as data in social research. The narrative analysis emphasises also on the structure of how something is being said including non-verbal cues such as pauses, topic changing and other aspects of conversation, rather than only focusing on what has been said. Ritchie and Lewis (2003) proposed that attention to the thematic content and the narrative structures are not abandoned however the main interest is in the process of co-construction of meaning.

It can be argued that not dedicating a section only in analysing the non-verbal communication cues is a limitation of the study. The reason for not analysing non-verbal communication cues is that not enough data were collected as the primary method of data collection was via verbal communication. Furthermore the same holds true for the data collection surrounding the performative context of the participants' narratives. Although some information were noted down regarding the performative context of the participants' narratives the data were not sufficient to dedicate specific sections to their analysis but rather they were seen as complementary to the verbal communication data collected. One design solution that could have greatly improved the data collection of both the structure and the performative context data from the participants' accounts would have been to

record the interviews with the participants. However this was beyond the scope of the current study and potentially this is a recommendation that could be utilised in a future study. The issues surrounding this proposition will be discussed in greater depth in section 7.3 recommendation for future advocacy research.

The study however utilised the Weick (1999) sense-making framework as an analytical tool within which the qualitative data were further explored. The participants' accounts were analysed by exploring them in a holistic way taking into consideration not only the performative context of the interview but also of the participants social and cultural. The data collected from the participants were considered important at both the individual but also the social level. The examination and interpretation of the participants' accounts according to the sense-making theory looked at past meanings and personal schema which provide the basis for future meanings and actions (Mills et al., 2010).

### **3.13. Reflexivity**

Reflexivity is seen as playing an important role in many qualitative research approaches as it considers the extent to which the researcher contributes in the formulation of the study and the findings (Ritchie and Lewis, 2003). Nind (2008) suggested that reflexivity can be divided into personal and epistemological. Personal reflexivity includes an account of the researcher's own past and history and how this may influence the findings. I gave a personal statement about myself, my background as well as my involvement and work with people with learning difficulties as a practising advocate and how that might have impacted upon the data collection and research findings. Furthermore, I kept a reflexive account throughout the research process and my involvement with the steering group and the participants with learning difficulties, thus shading light into the positive sides as well as the challenges of conducting participatory research with people with learning difficulties. The reflexive account along with the personal statement and the

challenges of the research study are discussed in the following section and in section 7.7.

According to Bergold and Thomas (2012), epistemological reflexivity involves exploring how the assumptions of the research approach employed form the study and what was the potential impact on the reporting of the findings. Bergold and Thomas (2012) noted that some qualitative studies do not make clear their epistemological position or what paradigm their study is influenced by either in terms of analysis or data collection and that is something that can be seen as a weakness.

The advocacy outcomes study discussed its epistemological position in section 3.4 but also provided a reflexive account of the study and the methodological approaches adopted in section 7.7. Moreover, I provided a personal reflexive account and a statement discussing how the data and findings may have been influenced by my position in section 7.7.3. The reflexive account also provided information about the positive aspects but also the challenges of carrying out participatory research.

### **3.13.1. Reflexive Account**

One of the main principles and aims of participatory research is to counteract the power imbalance evident in mainstream researcher-participant relationships. Participatory research is also a mean to include voices with lived experience from often excluded and marginalised groups. People with learning difficulties as described in the literature review chapter have been excluded from research concerning their interests because they were often described as story-less. A group of self-advocates was actively involved in the outcomes study research process and knowledge production. However, due to the nature of the research study, a number of challenges were faced during the planning and implementation stages. Reflexivity is an important part of qualitative studies and over the course of the study, I kept a reflexive account, part of which, is presented below.

One of the main issues that I faced when reflecting upon the study was over the use of participatory research and the involvement of self-advocates with

learning difficulties that I work with. As I mentioned earlier in the thesis I started working as a co-facilitator with the self-advocacy group a while before deciding to carry out this study as part of studying for a PhD. Together with the group we decided that this project would have been an exciting venture that we should look into. Prior to even sending a research proposal to be considered by my now principal PhD supervisor Professor Toby Brandon I have tried a number of different avenues for securing the funding necessary to carry out this research project as a co-production. However, despite several attempts, and particularly following the financial crisis and the years of austerity, it became apparent that the only way possible to turn this research project into reality was by studying for a PhD. Although the research proposal received positive feedback and was shortlisted to the final stages in different grant applications and from different funders it became apparent that such a project was not in the priorities of any of the funders particularly during a time of such financial restraint and budget cuts.

I contemplated this idea a lot before reaching the final decision and it was only the willingness, eagerness and determination of the self-advocacy group to be included and have their voices listened to that made me overcome my reservations. The self-advocacy group has been supportive of this idea throughout the study and their dedication to the cause of this study without any obvious external reward was monumental. The internal motivation of all the self-advocates to demonstrate their abilities, skills and willingness to be involved in the research project and have their voices heard was more than apparent in every steering group meeting. During difficult times when I might have become even slightly doubtful of this study's value it was only taking me until the next steering group meeting to be reassured and re-energised by the enthusiasm, the skills and the talent of my fellow co-researchers. After the steering group was established and we were carrying out the research together I felt the tension between carrying out a participatory research project within the limitations of a PhD study to lessen. Only then I became increasingly confident that this was a valuable study that can showcase how self-advocates can be included in research and evaluation work and produce



high-quality results and new knowledge to be shared with the rest of the community.

### **3.14. Summary**

The methodology chapter outlined the philosophical position and the methodological approach adopted within the study. The social constructivism theoretical framework underpinning the study reflects the values and philosophical viewpoint of advocacy itself. Moreover social constructivism was compatible with the research methodologies employed in the study. There was no single purist methodology that was adopted by the study but rather an eclectic approach utilising principles of participatory and narrative methods.

Participatory research approach promoted the active involvement of people with lived experience, who had however little previous experience, in the research and knowledge production processes. Moreover, principles of narrative method were utilised to avoid adding obstacles and pre-requisites but rather aided the empowerment of the participants with learning difficulties to share their perceptions, lived experience and meaning.

Furthermore, issues surrounding ethics were discussed. Contrary to some previous assumptions, it was showed that people with learning difficulties can demonstrate the mental capacity to provide an informed decision regarding their participation in a research study. Finally, the chapter looked at the analysis of the data, in particular the content and meaning of what was communicated by the participants. The meaning and content as well as the structure and performative context of the data were transformed into themes that will be presented in the following two chapters.

## **4. Advocacy Outcomes**

### **4.1. Overview**

The following chapter present the main findings from the advocacy outcomes study. A number of themes have been identified from the analysis of the content, meaning, structure and performative content of the participants' accounts. The participants with learning difficulties shared their experiences, views, feelings, thoughts and perceptions about advocacy and its outcomes. The themes are presented visually using conceptual maps to allow a better understanding of them and to make them easier to follow. Direct quotations from the participants' interviews are used to describe the themes identified in order to provide a more accurate representation of the views expressed by the participants. The themes identified in the findings section have been discussed and been selected together with the steering group made up of people with learning difficulties. All main themes identified are looked at and explored individually along with their associated sub-themes identified.

### **4.2. Presentation of the findings**

The findings section presents the themes that emerged from the data collected and consequently analysed in the study. Conceptual maps have been used to present the themes visually and make them easier to follow. Direct quotations, from the data, are used to keep the narratives close to what the participants shared. A conceptual map that presents all the advocacy outcomes main themes can be seen in figure 1. Then all the main themes are looked at individually, in different sections, along with their sub-themes. An individual conceptual map is presented for every main theme identified together with the associated sub-themes. Direct quotations for every theme and sub-theme are also presented. Moreover, each theme is discussed further individually and in relation to other themes. The grand conceptual theme map presenting all the themes and sub-themes can be seen in appendix 11.

Pseudonyms have been used, when analysing and presenting the findings, in order to protect the identity of the participants. Where different participants have suggested the same view one representative quotation is shared to minimize repetition. The findings are presented without reference to the literature or theory, something that is taking place in the discussion and conclusion chapters (6 and 7).

### 4.3. Advocacy Outcomes Findings

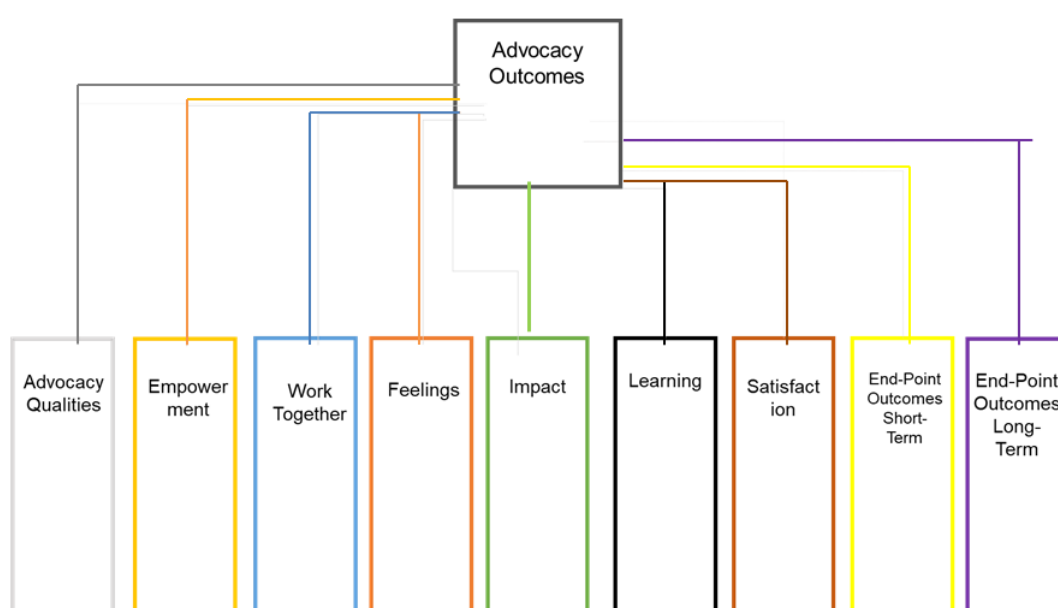


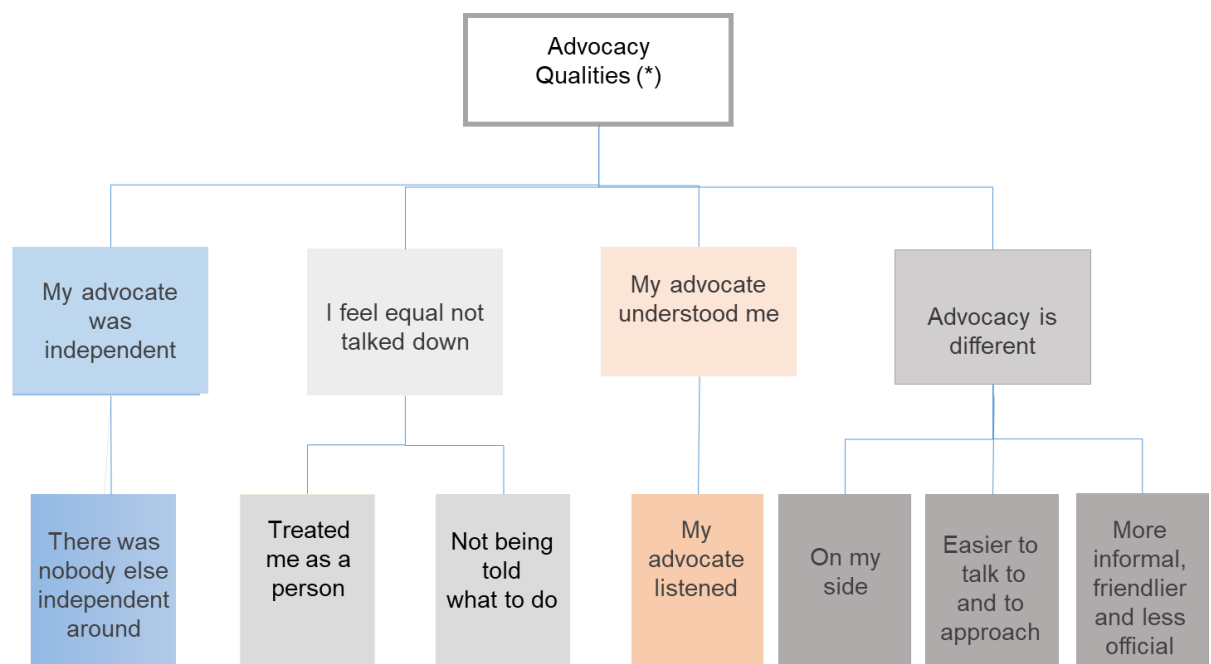
Figure 1. Advocacy Outcomes Main Themes identified.

#### Advocacy Outcomes

The advocacy outcomes main theme conceptual map presents all the themes that have been identified from the analysis of the content, meaning, structure as well as performative content of the data collected from the thirteen individuals who participated in the in-depth interviews. The nine main themes identified and presented here are subsequently looked at individually together with their associated sub-themes and direct quotations from the interviews with the participants as examples, later in the chapter. The first outcome that looked at is advocacy qualities followed by all the other main themes as presented in the main theme conceptual map above.

The different themes and sub-themes presented demonstrate the different views, feelings, perceptions and lived experience that the participants have shared in the interviews particularly in relation to advocacy. The main themes are presented in a colour coordinated way in order to make them easier to follow.

#### 4.4. Advocacy Qualities



(\*) Process outcomes

Figure 2. Advocacy Qualities Outcomes main theme identified.

The advocacy qualities conceptual map looks at the main qualities that participants suggested that advocacy has. A number of participants expressed that their advocates have been different compared to other professionals they came across. Participants shared different practical examples demonstrating how and why they felt that their advocate was different and what advocacy meant for them.

A number of participants talked about their own personal experiences in relation to the stories outlined on the vignettes. Participants also talked about their perceptions of advocacy before or after the discussion about the vignettes. Many participants suggested that they felt listened to and understood by their advocate and that was not necessarily the case when dealing with other professionals.

Feeling equal and not talked down was also quoted as an important quality outcome of advocacy work. Independence was a quality of advocacy that was highlighted by the participants as something valued and important as not many other professionals they have worked with were independent. Each sub-theme identified is discussed in greater detail, with direct quotations from the interviews with the participants, below.

#### Advocacy is different

A number of participants expressed that their advocate came across as different compared to other professionals in their lives. For example, Sarah suggested that her advocate is

*“friendlier and less official, more informal and easier to talk to”. “This is a good thing as is easier to approach if I want to talk about something”.*

Sarah expressed that working within the advocacy partnership was different, in a positive way; compared to other experiences she had working with other professionals. A similar view was expressed by Peter who suggested

*“Advocates are not pushing their own point of view to you like other professionals do” “Not telling me what to do, putting their ideas into my head, but I was able to tell what I wanted and then we were working together with the advocate to do something about that”.*

Peter highlighted that one of the reasons why the advocacy partnership was so much valued and important is because working with other professionals can be a negative experience. Peter made an important point that someone telling him what to do and put ideas in his head is something negative and

unwanted however this is how Peter experienced working with some other professionals. Participants also shared in the interview that they felt that their advocate was fighting their corner. Jane shared that her advocate

*“listened to me and helped me fight my corner, it is good to have someone on your side”.*

Susan suggested

*“I felt sometimes not really listened to; you want someone to be on your side”.*

Jane and Susan explained how advocacy was perceived as a positive experience, by feeling you have someone on your side, versus negative experiences when you feel not listened to.

#### My advocate understood me

Participants expressed in the in-depth interviews that their advocate understood them. For example, Susan when discussing the story involving advocacy in the vignette suggested

*“the advocate listened to the person and tried to do something about what they were wanting”.*

Peter shared in the interview

*“somebody listened to me and that was important”.*

Peter also commented about the story in the vignette,

*“John worked together with the advocate rather than being told what to do or the advocate doing it for him”.*

Peter highlighted why the advocacy partnership is seen as important because it provides a relationship where the person can be and feel in control rather than having to be told what to do or somebody just doing something for them. Pat suggested,

*“I think it is really good if you can have an advocate to understand you and offer help”.*

Pat commented when discussing the vignette

*“the advocate helped Paul to get something that he needed and also helped him to stand up for himself and ask for things rather than be afraid and stay quiet”.*

Pat made an important point that advocacy can provide a critique-free environment where the person can express and explore their views and wishes rather than be afraid and stay quiet.

#### I feel equal not talked down

Sarah shared her personal negative experience working with a social care professional and that was contrasted with the positive experience that Sarah had working within the advocacy partnership. Sharon also highlighted how advocacy is perceived when talking about the vignette

*“the person was not afraid of asking and not felt that he has been put down”* when talking with his advocate.

The participants highlighted that advocacy is about feeling equal the opposite of feeling talked down by professionals trying to impose their point of view and agenda on to them. Karen suggested how the people perceive advocacy when talking about the vignette

*“made him feel like a person and not as a child and he did not make him feel that he was put down and not listened to”.*

Moreover, Karen talked about her perception of working with her advocate

*“I felt like an equal and not as if I was told what to do”.*

Karen shared her negative experience working with a professional where Karen was made to feel uncomfortable and talked down rather than encouraged to express and explore her views and wishes. Participants expressed in the interview that when working with an advocate they felt more equal and not talked down. For example, Sarah suggested that her advocate

*“does not push her own point of view as other professionals do.” “The advocate did not take over and made him feel equal. Social workers tend to talk down to you and that they know better than you”.*

#### My advocate was independent

A number of participants suggested that they perceived their advocacy partners as independent and that this was something highlighted to be rather

positive. People were having the opportunity to talk with someone independent and discuss with them more freely. George suggested,

*“Sometimes for months my advocate was the only person, I met, independent from my care service.”*

George also shared that

*“there was nobody else independent around and it is important to be able to talk to someone independent about something, it is very important. Someone from the outside who maybe has a different point of view. An outside interest trying to help you to solve any issues.”*

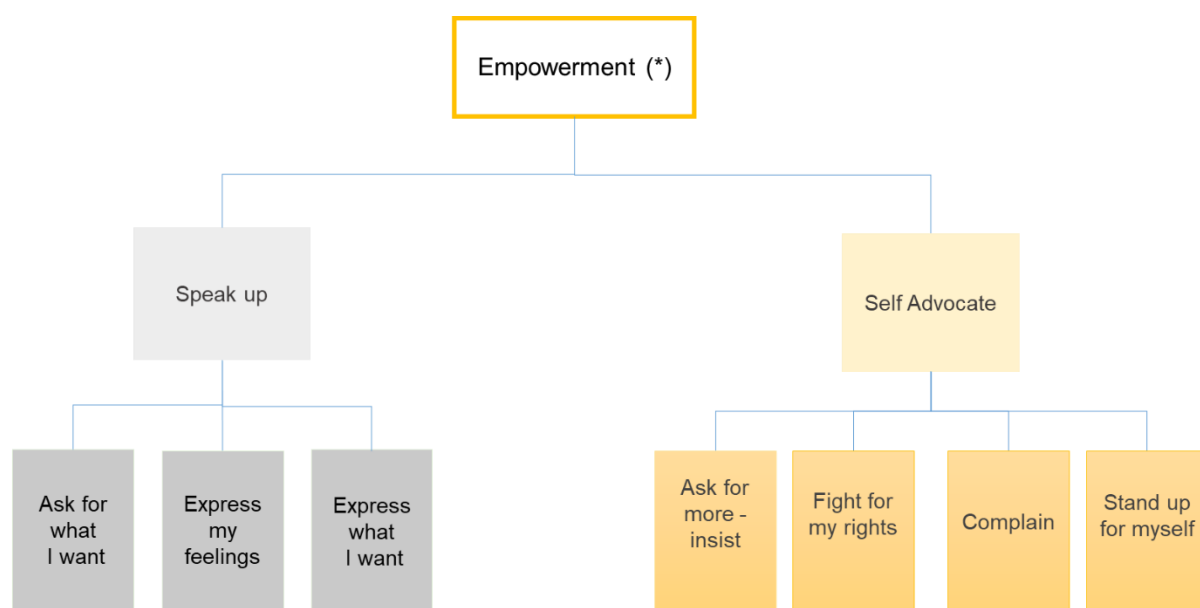
George highlighted that advocacy was important to him as his advocacy partner was the only person George was working with that was independent from other services and that was very important for him. Ken highlighted

*“It is really good to talk to an independent person about any problems or issues you may have and they listen and together trying to come up with a way to try and sort out the issues”.*

Ken also clarified why it is important and positive to have an independent person working with you in an advocacy partnership. It can be seen as rather important that a number of participants expressed that advocacy has been different. Participants highlighted that working with an advocate was a more positive experience compared to potentially a more negative experience working with other professionals.



## 4.5. Empowerment



(\*) Process outcomes

Figure 3. Empowerment Advocacy Outcomes main theme identified.

The empowerment conceptual map looked at the participants' accounts' meaning and content expressing that the advocacy partnership supported them to feel empowered. A number of participants expressed that working within an advocacy partnership aided their empowerment to speak up and self-advocate. Participants shared different examples demonstrating how and why working within an advocacy partnership helped them to take control of the situation, plan and take action to correct the issues concerning them.

Several participants shared their stories as well as examples from friends or family members and their experiences around advocacy. Participants also talked about and discussed the stories outlined in the vignettes but also expressed their views, meanings, perceptions and feelings around advocacy at the in-depth interviews. A number of participants expressed that working with an advocate encouraged them to feel empowered to self-advocate and speak up. Moreover, the structure of the participants' performance showed

evidence that advocacy was aiding their empowerment. Determined, resilient and empowered participants performed with a great deal of self-determination to self-advocate and provide challenges to often hostile hegemonic systems.

Particularly participants that were also members of a self-advocacy group suggested that they were encouraged by other peers to speak up and self-advocate but also they encouraged other peers to speak up and self-advocate. The benefits of mutual support were highlighted in the participants' accounts. Although a number of participants expressed that they felt empowered to speak up and self-advocate this cannot be said for all of the participants. Several participants highlighted their own efforts to speak up and self-advocate without explicitly connecting this outcome to advocacy.

The two main themes identified speak up and self-advocate are discussed further in this section along with the identified sub-themes stand up for myself, complain, fight for my rights, ask for more-insist, express what I want, express my feelings and ask for what I want.

### Speak Up

A number of participants suggested that working with an advocate or, in the case where the participant was a member of a self-advocacy group, with peer advocates encouraged them to speak up.

For example, Karen suggested,

*“my advocate helped me to speak up. Helped me find the right information and write letters in which am not good at.”*

Karen provided an insight into the practical support that the advocacy partnership can provide in order to aid speaking up. Brian who is also a peer advocate and a self-advocacy group member suggested about the story in the vignette and about his work as a peer advocate,

*“the advocate tried to represent him and helped him to speak up. That is what I sometimes do as well however it is hard at times to do that.”*

Brian describes the mechanisms of advocacy, peer and self-advocacy where within the advocacy partnership the person is supported to speak up. Brian highlights that he is a peer and self-advocate and this is not an easy job however it is a job that he wishes to talk about. Charles expressed his experience when facing a change of accommodation. Charles shared

*“my advocate helped me to speak up and find another place that I would like rather than go to a place I did not like. We arranged and met with my advocate and I was able to say that I did not like the place.”*

Charles gave a practical example of how the advocacy partnership worked for him to challenge a decision and speak up to try and make better arrangements. Charles also demonstrated his self-determination to not accept what was on offer and fight for his right to make his own choice.

James, also a self and peer advocate, described, when discussing the story in the vignette, how working with an advocate can empower an advocacy partner but also his experience as a self and peer advocate. James suggested that

*“an advocate can help a person to speak up because a lot of people with disabilities as well as able-bodied people can face problems and feel down and need someone to listen to them and support them to express themselves and to speak up. I am not better than anybody else but I am trying to put my case across strongly.”*

James gave an example where the advocacy process is described when the advocacy partners provide support but also when James decides to speak up and self-advocate. James performance in his interview demonstrated that he is self-determined to speak up and self-advocate and also showed an identity with a lot of qualities for people with learning difficulties.

A number of participants suggested that sometimes they would use an advocate whereas other times they feel they could self-advocate, speak up

and achieve what they want without the support of an advocate. Jason shared how he is self-advocating and speaking up

*“I suppose I could ask the social services but I don’t think they would help much. But I don’t know because if you do not ask you do not get what you want. I would ask if there was any money available. Try somewhere else, but don’t know where, I would have to try and find out where, I suppose.”*

Jason demonstrated that above all the choice to speak up is a personal one and Jason’s structure of his performance highlights his self-determination to fight and achieve his goals. Jason’s structure described how he is determined to persevere by trying again and again to find as many different avenues and ways to achieve and meet his needs as well as defend his rights.

#### Self-Advocate

Participants expressed in the in-depth interviews that working with an advocate encouraged them to self-advocate. For example, Sharon when discussing the story involving advocacy in the vignette suggested

*“If I was Jo I would ask to arrange some more holidays, and I would take Jane on holidays with me, and I would also take Mary with us and George. As I like them.”*

Sharon demonstrated a sense of companionship when Sharon suggested that she would not only self-advocate for herself but also fight to access opportunities for her fellow self-advocates from the self-advocacy group. Moreover, Sharon demonstrated the mutual support between the self-advocates but also the affection she is feeling towards her fellow members of the self-advocacy group. Judy expressed how she is self-advocating,

*“I would continue onto them until I get what I want”.*

Judy highlighted that people with learning difficulties have been self-advocating and providing challenges to systems that have been at times unfriendly or even hostile to them thus demonstrating great levels of self-

determination. Judy's performance portrays a positive identity for people with learning difficulties that challenges the views expressed by dominant ideologies describing people with learning difficulties in a negative light.

Peter shared his view on working with an advocate and on self-advocacy

*"You fight for your rights and for what you believe in. You don't really fight but when you are passionate you speak up."*

Peter demonstrated that people with learning difficulties are passionate for their beliefs and have been fighting hard and strongly to defend their rights in at times hostile environments. Peter similar to Judy demonstrated a sense of strong, passionate and positive identity for people with learning difficulties. Susan shared her personal experience and how she self-advocated when faced a certain issue;

*"I wanted to stay at home and I did not want to go to a care home. I did not like that, as it was horrible and I had to complain. The advocate helped me to write a letter and complain."*

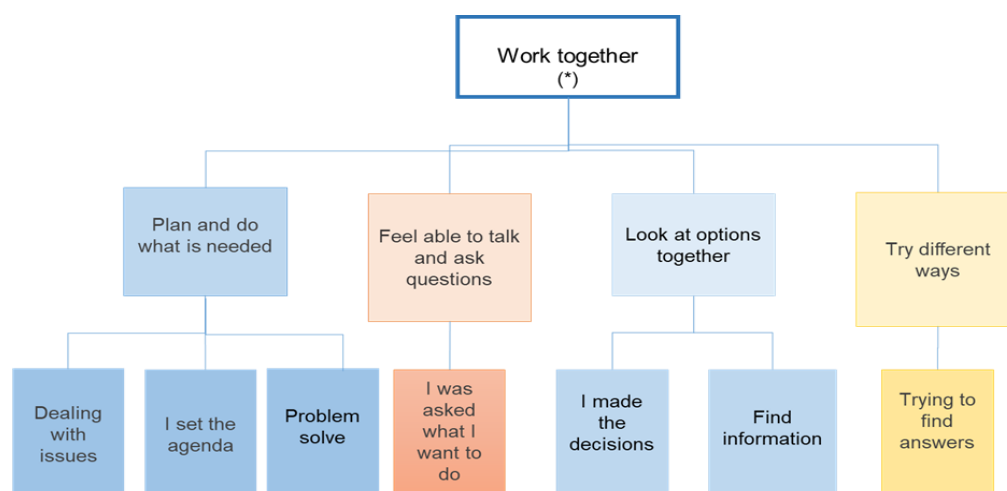
Susan shared her feelings about a decision and the actions she took to self-advocate but also brought up how her advocacy partner supported her in that process. Similarly, Sarah also shared her view

*"I have learned that if you believe that you are unhappy there are ways to talk about it and bring it all out and complain and make your feelings known."*

Sarah described how she is managing to self-advocate and bring change as well as make her feelings known when not happy with something.

Feeling empowered and also feeling more confident to self-advocate are two important outcomes. A number of participants emphasized that feeling empowered and being confident to self-advocate is really important. Participants mentioned that they would first try to self-advocate and the same they would suggest to a peer before asking the support of an advocate. A positive, strong, passionate, resilient and self-determined identity for people with learning difficulties is portrayed by many participants.

## 4.6. Work Together



(\*) Process outcomes

Figure 4. Work Together Advocacy Outcomes main theme identified.

The work together main theme concentrated on the meaning, structure and performative content of the participants' accounts that explored the importance of working together within the advocacy partnership. Participants shared different practical examples, their personal experiences but also talked about the stories in the vignettes during the in-depth interviews regarding how they perceive working together within an advocacy partnership. Participants highlighted with their performative content how they view their relationship with their advocacy partner.

According to the content and the meaning of the participants' views the main themes of working together included the sub-themes of plan and do what is needed, feel able to talk and ask questions, look at options together and try different ways. The themes identified along with the sub-themes were dealing with issues, I set the agenda, problem solve, I was asked what I want to do, I made the decisions, find information and trying to find answers are discussed in more detail, with direct quotations from the interviews with the participants.

### Plan and do what is needed

A number of participants suggested that working with an advocate supported them to plan and do what is needed to achieve their goal identified at the beginning of the partnership. For example, Karen shared in the interview about her partnership with her advocate

*“It is not always easy to have someone you can talk to and try and do something about things. It can be very difficult. I am always worried with the cuts that there will not be even the basic support available”.*

Karen apart from expressing her views about the advocacy partnership also shared her worry, performed in an animated way to give emphasis, that even this type of positive partnership or other basic support can be stopped because of the budget cuts implemented. The meaning extracted from Karen’s content highlighted that the advocacy partnership was something important and valuable to her. However Karen also expressed her concern/worry that the cuts and austerity will probably affect her negatively. Karen’s powerful performance however emphasised that despite her concerns she had great self-determination to continue to speak up and fight for her rights. The following quote shows Sharon’s account of her experience when “working together” with her advocate

*“My advocate helped me to get organised and plan some actions and do them. My social worker did not help me. Advocacy was totally different, helped me find courage in myself and start doing something about my situation.”*

Sharon focused more on the more practical aspects of the advocacy partnership and explained how she worked together with her advocacy partner. Moreover, Sharon noted that her social worker did not help her and that her experience working with the social worker was the opposite of working with the advocate. Ken discussed in the interview how the advocate helped Paul in the story shared in the vignette. Ken suggested

*“the advocate helped to get something that he needed and ask for things. Paul met regularly with his advocate and together made a plan about tackling the issue and dealing with it”.*

Ken also expressed that from his personal experience

*“It is very hard to try and get things these days. You have to plan it for months ahead and try and organise it very well.”*

Ken apart from talking about how he worked with the advocate to achieve his target also talked about his self-determination and perseverance in order to work hard and achieve what he wants. Ken with his performance highlighted a positive identity for people with learning difficulties full of self-determination, resilience and perseverance to achieve their goals against systems that are not always listening and are not always willing to offer their support.

It can be argued that trying to get something done within health and social care should not be this way as the systems supporting people with learning difficulties should be responsive to the needs of people with learning difficulties. However, the reality described by several participants is that every small achievement for the person to get their wishes and needs met is a slow, hard but also a rewarding process too. On the other hand, it was demonstrated that the negative influences of not responsive and rigid systems when it comes to meeting the peoples' needs and wishes can be transformed in efficient and creative when implementing their own agenda and not that of the person.

#### Feel able to talk and ask questions

A number of participants expressed that when working together with an advocate they felt they were better able to express their views and ask questions if they did not understand something. For example, James shared that he felt that he was better able to express his views

*“I was asked what I want to do. With my advocate, I can set up the agenda of the meeting rather than talk with the other person about what they want to talk. We meet up and talk about different things such as about finding a good place to move to. I can phone my advocate and speak to them.”*



James made a very important point of something which could have been thought as a given however his experience of working with different professionals was so negative as in the past he was not even asked what he wanted to do. James, on the contrary, shared that working with the advocate was a much more positive experience where he felt able to talk about what he wanted not what the other person wanted.

Charles shared a personal experience when working together with his advocate

*“I got in contact with my advocate and together we planned and found out about things and tried to find a suitable place. My social worker and key worker from the house were also involved. We went to one place but I really did not like that and although my social worker suggested that it was a nice place I did not like it as it was on a busy road, it was noisy and there were a lot of other people living there.”*

Charles shared his experience and by doing that described the advocacy partnership process. Charles outlined how he worked with his advocate to plan and take action in order to speak up and express his views and wishes and fight for them. Charles demonstrated that his social worker was trying to persuade him that this was a good choice. Charles however also demonstrated that he was determined to not accept something that he did not like and fight for what he wished for and for his choice.

#### Look at options together

A number of participants expressed that when working together with an advocate they were supported to look at different options. Charles shared what he would do as an advocacy partner, when discussing one of the stories in the vignettes. Charles suggested that he would

*“ask the person where they would like to go and then work together to find different options such as talking to different travel agents.”*

Charles highlighted that working together in the advocacy partnership was one of the most important elements potentially one of the most effective.

Charles pointed out that by working together the advocacy partners can achieve more. Similarly, Judy when discussing one of the vignettes shared what she would do as an advocate

*“I think I would try and help the other person by asking her what she would like and look at the different options”.*

Judy shared that her notion of working as an advocate required her to ask the person and look at options together with the person she was working with. Judy highlighted that this forms an important part of the advocacy partnership. Brian a member of a self-advocacy group and peer advocate shared his personal experience and his view of what an advocate should do

*“I have supported another person to try and sort out their holidays. We have together tried and organised a trip to London with some support from staff. An advocate can also help to try and organise something like that by looking in different options and try to arrange something”.*

Brian suggested from first hand-experience that working together and looking at different options together is an important process in the advocacy partnership that can be effective. Brian performative content indicated that he was proud of his achievements as an advocate something demonstrating a confident, competent and effective advocate working with his partner and achieving their goals.

Pat pointed out that it is the advocacy partner that always makes the decisions and also that this is very important. Pat when discussing the vignette suggested about the advocacy partner,

*“treat Jo as a person rather than telling them what to do. Possibly can offer opportunities for Jo to try and find other people to go with in order to not be on her own if that is what she wants.”*

Pat highlighted that an advocacy partnership should look to really listen to the views and wishes of the partner and together the partners can tackle the issue and try and achieve the target.

### Try different ways

Participants also suggested that their experience working together with an advocate involved trying different ways to achieve different things. George shared his thoughts around working together with an advocate

*“I believe that I have certain things that I need and that I want and sometimes I may not be able to achieve them but I would try and do that and also an advocate can sometimes help you to achieve those”.*

George demonstrated with this example his self-determination, resilience and perseverance to try and make a difference no matter how difficult the circumstances and how many the negative influences. George pointed out that sometimes he may not achieve his target but he would certainly give it his best try. George also highlighted that advocates can be seen as helpful allies at times. Participants noted that together with their advocate they plan and do what is needed to sort out a problem. John suggested,

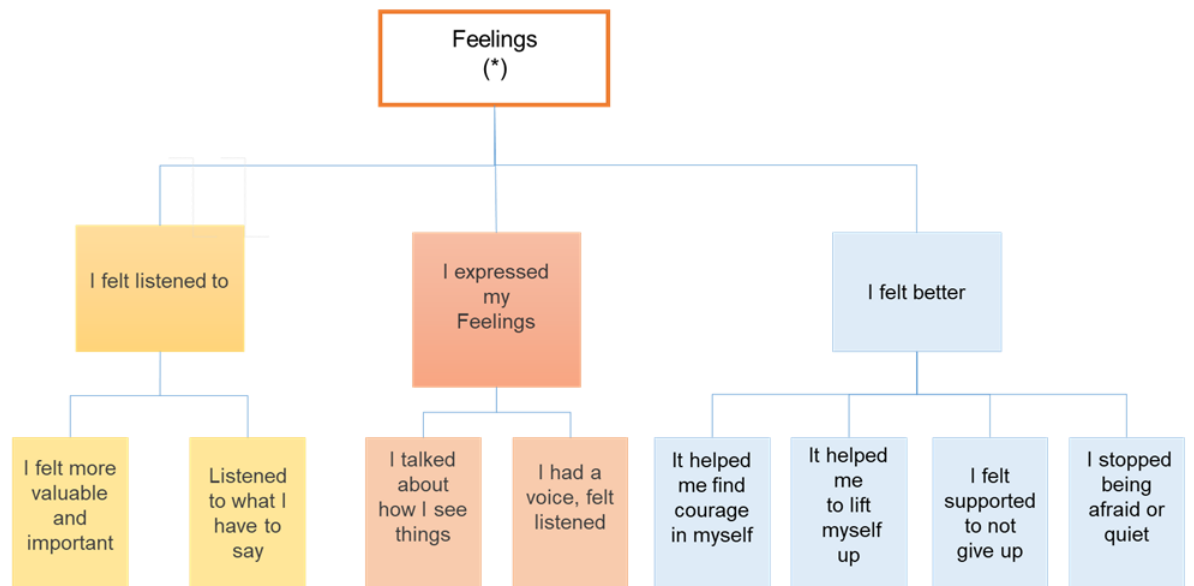
*“I feel I can talk to my advocate about things and ask questions”. “We always look at the options together and I make the decisions”.*

John highlighted his self-determination by suggesting that no matter how well he works with other people he is always the one making the decisions. Peter also shared his thoughts around working together with an advocate

*“with the current economic climate you may not get always what you want but with the support of an advocate you can try and fight for that and speak up for yourself”.*

Peter highlighted that although the advocacy partnership may not always achieve the desired goal it is still a worthy journey as it encourages self-advocacy and fighting for your rights. Working together as opposed to, for instance, the advocate doing what is needed was also highlighted. A number of participants pointed out that this is expected from the role of the advocate to work with the person, therefore forming an important part of the advocacy role. It has also been suggested that working with the advocate has several positive outcomes.

#### 4.7. Feelings (Personal Outcomes)



(\*) Personal outcomes

Figure 5. Feelings Advocacy Outcomes main theme identified.

The feelings main theme was derived from the meaning, structure and performative content of the participants' accounts on the feelings associated with the advocacy partnership work. A number of participants indicated that they felt more listened to and more able to express their feelings when working within an advocacy partnership. Participants shared that their perception of advocacy mostly involved positive feelings. Some participants expressed that they even felt better after working with an advocate. The participants reported positive feelings as an outcome of the advocacy partnership.

The themes identified in relation to feelings along with the associated sub-themes are discussed in greater detail with direct quotations from the interviews with the participants in the following sections.

I felt listened to

A number of participants suggested that when working with an advocate they felt listened to and not ignored. Sharon shared in the interview

*“working with my advocate made me feel better as my advocate listened to what I had to say instead of just telling me what to do”.*

Sharon not only reported that she had positive feelings when working with her advocate but also highlighted that on other occasions when working with professionals felt that she was told what to do a feeling she perceived as negative. Other participants also expressed, as Sharon did, that they didn't like to be told what to do but rather they wanted to be listened to, make their own choices and make up their own mind. Jane similarly expressed positive feelings about the work with her advocate. In the words of Jane

*“I felt more valued and important”. It felt as if no one was listening before”.*

Again Jane illustrated that working within an advocacy partnership yielded positive feelings for her such as feeling valued and important. Jane also shared that she felt that no one was listening to her before and that was not a positive feeling but a negative one. Jane highlighted that being listened to is really important and appreciated and if someone is not listening to you it makes you feel devalued. Sarah shared her personal experience of her work with her advocate and how she found the experience. Sarah suggested in the interview

*“my advocate helped me to make choices for myself rather than other people to make them for me. I am making the decisions for myself now but it was not always like that.”*

Sarah's performative content also highlighted the important positive feelings associated with making your own decisions for your own destiny. This is a fundamental need and right as feeling that you are not making the decisions about your own life can be disempowering. Sarah demonstrated that with her resilience and self-determination along with advocacy managed to feel empowered and make her own decisions something very important for her.

### I expressed my feelings

A number of participants shared that being able to better express their views, wishes and feelings was a very positive outcome of the advocacy partnership work. For example, Judy reported in the interview

*“My advocate helped me to express me feelings and what my view was rather than accept what I was told without having a say. I am much happier with that.”*

Judy reported that being able to self-advocate, make her own choices and express how she was feeling was very important for her. Judy described this as an outcome of the advocacy partnership that made her feel happier. Moreover, Judy also mentioned that she was not happy when she was not listened to and was expected to just accept what was on offer without even have a say. Jane also shared her personal experience and how she felt working with an advocate. Jane suggested in the interview

*“I am now feeling more confident to ask for things and disagree with people if needed”.*

Jane reported increased feelings of confidence which was an important outcome for her. Jane highlighted that she was feeling more empowered to disagree and ask for things. Similarly, James suggested,

*“when working with my advocate or somebody who knows me I can express how I feel what my emotions are”.*

James highlighted the importance of having someone on your side but also the importance of feeling being safe or encouraged in a way to express how you feel and your emotions about something without feeling that you will be judged and be criticised about how you feel.

### I felt better

Several participants suggested that they experienced some positive feelings from the advocacy partnership. Sharon shared

*“advocacy was totally different, helped me find courage in myself and start doing something about my situation.”*

Sharon pictured advocacy as something very positive and welcomed in her life. Sharon suggested that advocacy encouraged her to find courage in herself and deal with some issues. Sharon also highlighted that although she was dealing with a difficult situation she had the resilience to manage this. Sharon's performance demonstrated a positive identity of resilience for people with learning difficulties who against external negative influences manage to find courage, speak up and self-advocate. Furthermore, Sarah suggested,

*"I myself have shot myself in the foot sometimes and if it was not for my advocate then I don't know what I would have done. I dig myself too deep and I could not lift myself up."*

Sarah shared her personal story and experience and highlighted that although she was in a very difficult situation she had the resilience and self-determination to deal with any issues and try and overcome them. Sarah also suggested that her advocate was very supportive and important in this journey. Sarah by sharing her story highlights an identity of resilience and self-determination for people with learning difficulties. Pat commented when discussing the vignette

*"the advocate helped Paul to get something that he needed and also helped him to stand up for himself and ask for things rather than be afraid and stay quiet".*

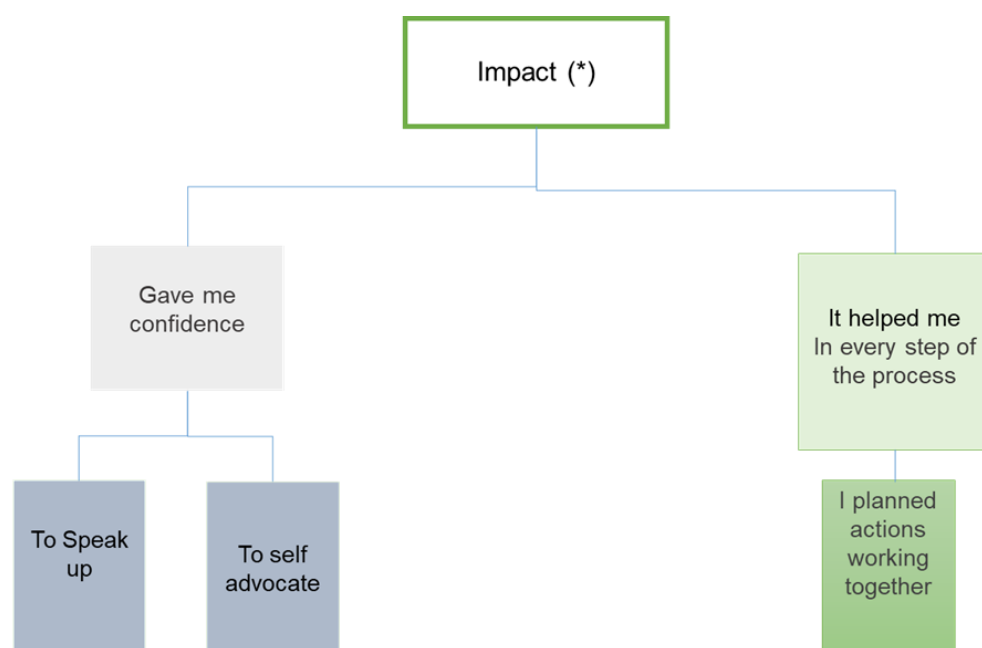
Pat highlighted that the advocacy partner supported Paul to be empowered, self-advocate and feel better. Peter talked about the story in the vignette

*"John worked together with the advocate rather than being told what to do or the advocate doing it for him".*

Peter outlined the process of the advocacy partnership which involves working together and ultimately the person making their own decisions and self-advocating.

Different feelings have been highlighted as an outcome from working within an advocacy partnership. A number of participants suggested that working with an advocate increased their confidence but also made them feel better, have more courage and encouraged them to not feel afraid or stay quiet but to speak up and self-advocate. Being able to express feelings and felt listened to were also quoted as important outcomes.

#### 4.8. Impact (for individuals)



(\*) Impact for individuals outcome

Figure 6. Individual Impact Advocacy Outcomes main theme identified.

The impact main theme focused on the participants' accounts meaning, structure and performative content in relation to the impact of advocacy in the person's life. A number of participants suggested that working within an advocacy partnership had the positive impact of giving them more confidence to speak up and self-advocate. Participants also suggested that advocacy helped them in every step of the process and that encouraged them to see things in a different light.



Participants suggested that advocacy aided their building up of confidence to speak up when not happy with something and to self-advocate to achieve their goals. Participants also highlighted that advocacy had a positive impact on them by supporting them to plan actions together and carrying them out. The themes identified from the participants' accounts as the impact for the individuals along with the sub-themes are discussed in greater detail below.

### Gave me confidence

A number of participants shared experiences which suggested that advocacy improved their confidence to speak up and self-advocate. For example, Pat shared her view of advocacy

*“Advocacy definitely gives you confidence and helps you move forward, gives you skills that can help you to do more things for yourself.”*

Pat pointed out that the advocacy partnership had a positive impact for her by facilitating an increase in confidence and providing support when she person needed it. However Pat also highlighted that the most important aspect of advocacy impact was that it aided people to self-advocate. Furthermore, Susan suggested,

*“I didn’t want to be in such a position but I was not well and needed some help to feel more confident and be able to do things for myself and advocacy helped me to do that and feel better”.*

Susan shared her powerful personal story and pointed out that advocacy had a positive impact on her life because she felt encouraged during the time she needed some support. Susan also mentioned that the advocacy partnership work had the positive impact of supporting her to feel better. Susan's performance also demonstrated a positive identity of resilience for people with learning difficulties in sometimes disempowering situations due to a number of negative influences.

Judy also shared her personal experience

*“it was hard to start with however the work with the advocate made a big difference it made me feel useful and that I could do something to help myself. It also helped me to build up my confidence, as I was feeling useless.”*

Judy also shared her personal story and highlighted that advocacy had such a positive impact because Judy was feeling disempowered. Judy pointed out that advocacy encouraged her to build confidence to speak up and self-advocate. Judy demonstrated her resilience and self-determination to speak up and self-advocate against a disempowering system and at the same time reinforced a positive identity for people with learning difficulties.

Furthermore, Ken shared his personal experience

*“It helped me not only for this specific problem but gave me the confidence to do more for myself. It gave me choices and was able to do something about the situation that I was in”.*

Ken highlighted that the positive impact of advocacy for him was not only that he felt supported dealing with a specific issue but rather, more importantly, that he used that to speak up and self-advocate also across different issues.

#### Helped me in every step of the process

Participants suggested that advocacy helped them in different steps of the process. Jane shared her personal experience of working with an advocate

*“They wrote letters to social workers on my behalf. I was telling them what I wanted and they were making it more presentable as I am not good at writing letters. They put it in a formal letter cause I could not write what I wanted to say. But I was definitely expressing my views and agreed the letters with the advocate before sending them out”.*

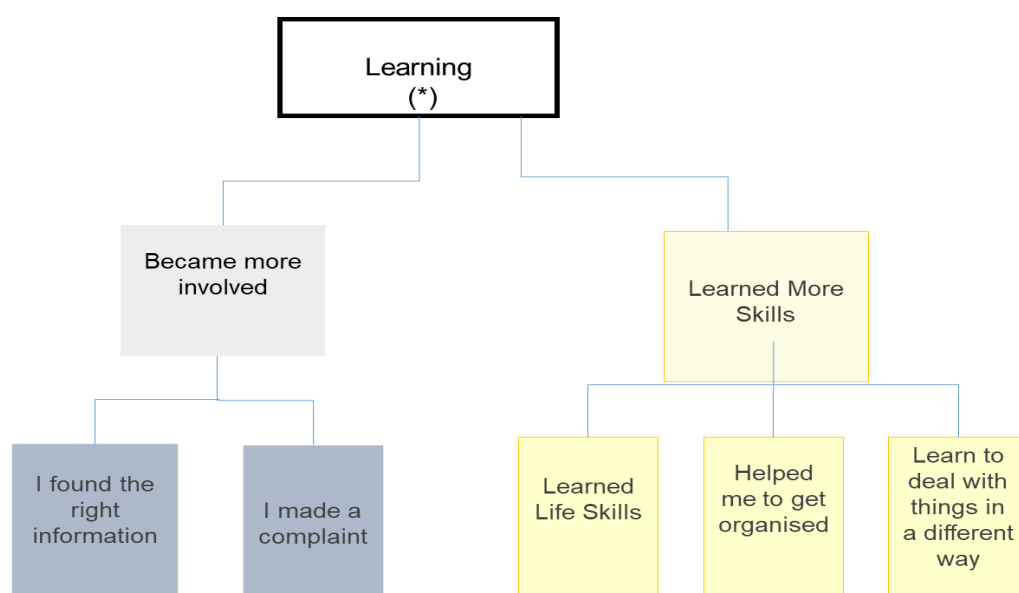
Jane pointed out that although the advocacy partner was supporting her to write a letter she was in control of what was happening and she was making all the decisions. Jane additionally demonstrated the process of the

advocacy partnership and the steps that she took in order to deal with specific issues in her pursuit to achieve her goals. Moreover, Charles suggested,

*“I had to move to a new place. I got in contact with my advocate and together we planned and found out about things and tried to find a suitable place... We went to one place but I really did not like that and although my social worker suggested that it was a nice place I did not like it as it was on a busy road it was noisy and there were a lot of other people living there... my advocate helped me to speak up and find another place that I would like rather than go to a place I did not like... I made a list of all the things I would like to have in the new place and also the things I would not like... The advocate helped me put across my point to my social worker... I visited different places and supported me to make a decision and found the best option available”.*

Charles's account structure was very detailed and in-depth. He narrated his personal advocacy partnership journey and how he worked with his advocacy partner in every step of the process. Charles described that from the beginning of the partnership they were planning the actions together and putting the actions into motion. Charles performance demonstrated his resilience, perseverance and self-determination, along with the advocacy support, to achieve his goals. Charles however also highlighted that he felt that his social worker was not on his side since he was encouraged, through means of persuasion, to accept an offer for a place that he did not like. Charles concluded that supporting him to make the choice himself rather than simply accept an offer was the most positive impact for him.

## 4.9. Learning (Process Outcomes)



\* Learning for individuals outcome

Figure 7. Learning Advocacy Outcomes main theme identified.

The learning from the process conceptual map looked at the outcomes that relate to learning from the advocacy process. A number of participants' accounts indicated that they have learned from the advocacy process and from working within an advocacy partnership. Participants shared practical examples demonstrating how learning occurred and what this meant for them. They proposed that learning and improving current skills such as life skills but also working with the person to improve organisation skills was important and valued. It was also reported by participants that they have learned to deal with things in a different way as a result of advocacy. Moreover, several participants talked about their experiences in relation to the stories outlined in the vignettes but also about their views of advocacy before or after the discussion about the vignettes.

The themes derived from the participants' accounts content and meaning along with the sub-themes, are presented below with direct quotations from the narrative interview data.

### Became more involved

Participants expressed that their advocate supported them to become more involved and through that learn from the advocacy process. James when discussing the vignette, involving advocacy work, suggested

*“Paul also joined a gym and got more involved in his local community.”*

Moreover, Brian, a self-advocacy group member, talked about the self-advocacy group

*“I like what we do in the group. We have been doing quite good work there. Been involved in different things.”*

Brian highlighted what the self-advocacy group membership meant for him. Brian's performance of his narrative demonstrated a sense of pride in his identity as a self-advocacy group member and of the work that has been taking place there. Sharon shared her personal experience

*“I feel more involved in decisions since I started working with my advocate. I ask for more things and I make the decisions for my life. I now live independently with some support from staff in my own flat whereas before, most of the decisions were made for me.”*

Sharon pointed out that advocacy encouraged her to be more involved in decisions and that led to her choosing to become more independent. Sharon contrasted that with the feelings of disempowerment when she was not being involved in the decisions as they were made for her. Sharon also demonstrated her resilience and self-determination to speak up and self-advocate for her wishes, choices, rights and needs to be met.

Ken suggested that advocacy supported him to learn to try and look into finding options and information. In Ken's words

*“Sometimes we look into things and try and find available options for an issue together maybe search on the internet about information.”*

Ken shared that advocacy had supported him to improve his problem-solving skills by looking for alternative options. Ken demonstrated that he is an able problem solver by looking for different options and for the right information to best deal with issues. Sarah also expressed her lived experience

*“I have learned that if you believe that you are unhappy there are ways to talk about it and bring it all out and complain and make your feelings known.”*

Sarah demonstrated her self-determination and willingness to self-advocate and to speak up when not happy with something. Sarah highlights the value of making your feelings known and act to change things when you are not feeling happy with something.

#### Learned more skills

A number of participants suggested that they learned some skills from the process of the work within the advocacy partnership. For example, Charles suggested,

*“my advocate helped me to learn life skills compared to before when everything was done for me”.*

Charles highlighted that advocacy supported him to improve his skills and learn new. Charles contrasted this with times in his life that he felt excluded when things were done for him leaving him disempowered and not feeling in control of his own life.

Karen shared her personal experience on how she plans to use her skills

*“I would like to help my family as they really struggle with their budgeting skills and that is something I feel I can help them with. Put some money away for a rainy day.”*

Karen’s narrative demonstrated that she is a skilful person who was able and willing to share her knowledge and skills to help others. Karen highlighted that she valued being able to help others in her life.

Brian, a peer advocate and member of the self-advocacy group shared his views on how to learn more skills. Brian suggested,

*“you learn with experience, the only way to learn life skills is to throw yourself at the deep end and basically no disrespect you will either sink or swim”.*

Brian who is an experienced peer and self-advocate demonstrated confidence in his performance and argued that the best way of learning is through experience. Brian pointed out that this may involve making mistakes but that is how people learn real-life skills. Brian made an important point that people with learning difficulties have often been denied the human right of learning by making their own mistakes as powerful systems have taken away that from them. Moreover, Brian when discussing the vignette shared his experience as a peer advocate. Brian shared

*“If you want to be an advocate you have to be persistent as it is not easy to achieve things. It is like the Berlin wall, one thing at a time, not all at once. You learn the skills with experience”.*

Brian highlighted that learning and achieving your goals comes from experience and that you have to persevere and be determined in order to achieve your goals and learn in the process. Brian also demonstrated a sense of pride for his work as a peer and self-advocate. Participants also suggested that working with an advocate supported them to improve their organisation skills. For example, Sharon expressed,

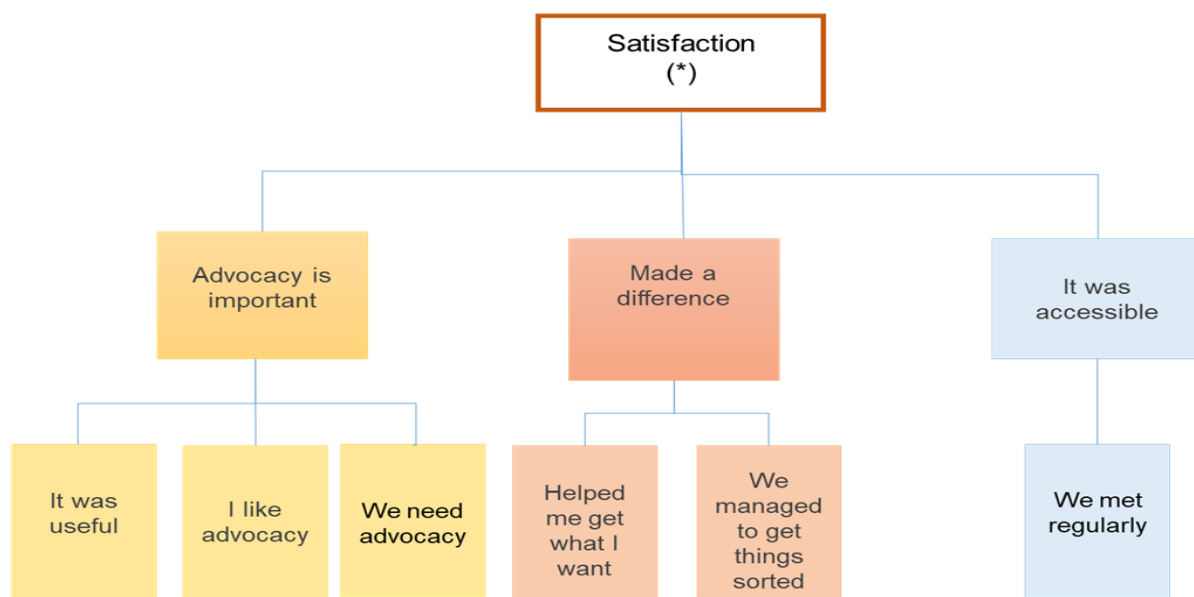
*“My advocate helped me to get organised and plan some actions and do them.”*

A number of participants proposed that they learned to deal with things from their work within the advocacy partnership. For example, Charles suggested,

*“my advocate helped me to find different ways to deal with things and look at different options.”*

Charles highlighted that learning through working within an advocacy partnership is an important outcome of the advocacy process.

## 4.10. Satisfaction Outcomes



(\*) Personal outcomes

Figure 8. Satisfaction Advocacy Outcomes main theme identified.

The satisfaction conceptual map presented what the participants valued about advocacy. A number of participants suggested that they liked advocacy as it made a difference in their lives despite not always achieving what they wanted. Moreover, other participants expressed that advocacy was important, useful and that it is a service that is needed.

Participants also mentioned that advocacy was accessible as they met regularly with their advocates. They shared a number of practical examples from their personal experiences but also discussed their views and thoughts about advocacy in the interviews. The themes and sub-themes are introduced along with direct quotations from the participants' views, in greater detail in the following sections.



### Advocacy is important

A number of participants suggested that they feel that advocacy is important and a service that is useful and needed. George when discussing the vignette, involving advocacy work, in the interview, shared

*“Some people sometimes think that they do not have the power but the advocates can sometimes, if they are trained right, help the person to argue their case.”*

George pointed out that advocacy is particularly important for people who feel that they do not have the power to argue their case and a well-trained advocate can assist them in doing so. George also highlighted that advocacy is not the only way and that people often choose to self-advocate and fight their own battles without the advocacy support.

Sarah commented

*“not much support out there, some people are on their own. It was a long time before I was seeing someone else apart from my care worker. I see my social worker only when there is a review.”*

Sarah highlighted that advocacy is particularly important and needed because the right support is not available at the current climate. Sarah pointed out that people not having the support they need makes it more difficult to speak up. At those times, working with an advocate can be particularly important and valued. Peter also shared his view of advocacy

*“It is a good service a valuable service that people find useful and want to use it. I think it should continue as it is important and without advocacy, a lot of people would be left without someone to support them to have a voice.”*

Peter also echoed what Sarah pointed out by also proposing that advocacy is particularly important and valued because people do not have the right support they require to argue their case. By inference, if people had the support they required then they would have been better able to self-advocate and not necessarily choose to work with advocacy to better argue their case.

Brian who is an experienced peer and self-advocate shared his view about the advocacy service

*“If somebody asked me if I should get in touch with an advocate I will tell them that I can give them the contact details and then it will be your decision if you want to get in touch with them and work with them”.*

Brian pointed out that advocacy should be an option available for people that feel that they would benefit from advocacy. However, Brian emphasised that advocacy should be a choice for people who can decide whether they would like to use advocacy or not. Brian also highlighted the importance of self-advocacy in the lives of people with learning difficulties.

#### Made a difference

Charles shared his personal experience when talking about the vignette in the interview. Charles suggested

*“people are entitled to their own decisions... everybody is entitled to make a decision about what is best for them”*

Charles highlighted that people should always be encouraged to make their own decisions and that everybody is entitled to decide what is best for them. It is a basic human right however that at times has been taken away from people with learning difficulties. Peter also shared his point of view,

*“I think that advocacy helps a lot in different ways and also a lot of people including myself. Helped me to bring myself back up and sort things out for myself.”*

Peter demonstrated how advocacy played a part in himself feeling more empowered to self-advocate and sort things out for himself something that made a difference in his life.

### It was accessible

A number of participants expressed that they were satisfied working within an advocacy partnership because they found advocacy accessible. Ken when discussing the vignette suggested,

*“Paul met regularly with his advocate and together made a plan about tackling the issue and dealing with it.”*

Ken also shared his personal experience around working with his advocate

*“I like my advocate, we meet regularly and is friendly.”*

Ken explained that he valued advocacy because he enjoyed the friendly approach of the advocate and the fact that they met regularly.

When talking with Sarah about the story in the vignette she suggested,

*“The advocate did not take over and made him feel equal. Social workers tend to talk down to you and that they know better than you. Advocacy is totally different.”*

Sarah expressed that she particularly valued advocacy because the advocacy partner was not trying to take over from the person and strive to have an equal partnership. Sarah also suggested that advocacy is valued because it is different compared to professionals who tried to take over and talked down to the person proposing that they know best.

Karen described her personal experience working with her advocate

*“We meet regularly and spend time together finding out information about different issues and things. We put it in the calendar when she comes when we arrange the next meeting. It’s been good working with Tracy we have been working together for some time now.”*

Karen provided an insight into her advocacy partnership with her advocate. Karen explained what she valued about advocacy and why it was good working within an advocacy partnership. George, when talking about advocacy based on the vignette in the interview, suggested that if he was the advocate

*“I would look at what activities there were and see how I could access them. See who could help with that.”*

George demonstrated that he is a skilful self and peer advocate by indicating what he would do to advocate for another person. Brian also shared a personal experience of a problem faced in the self-advocacy group he was involved in

*“We have faced the problem with the activities when we had a problem to go out... we asked for someone to take us out. We managed to access the activities.”*

Brian shared an achievement of the self-advocacy group he attended. Brian demonstrated that self-advocacy members advocate for each other and for the benefit of the group as well as the wider community. Brian also highlighted that self-advocacy group-work can be very successful. Brian’s performance demonstrated a skilful identity for self-advocates with learning difficulties who speak up, problem solve and achieve their goals for themselves and their community.

#### 4.11. End-Point Outcomes Short-Term

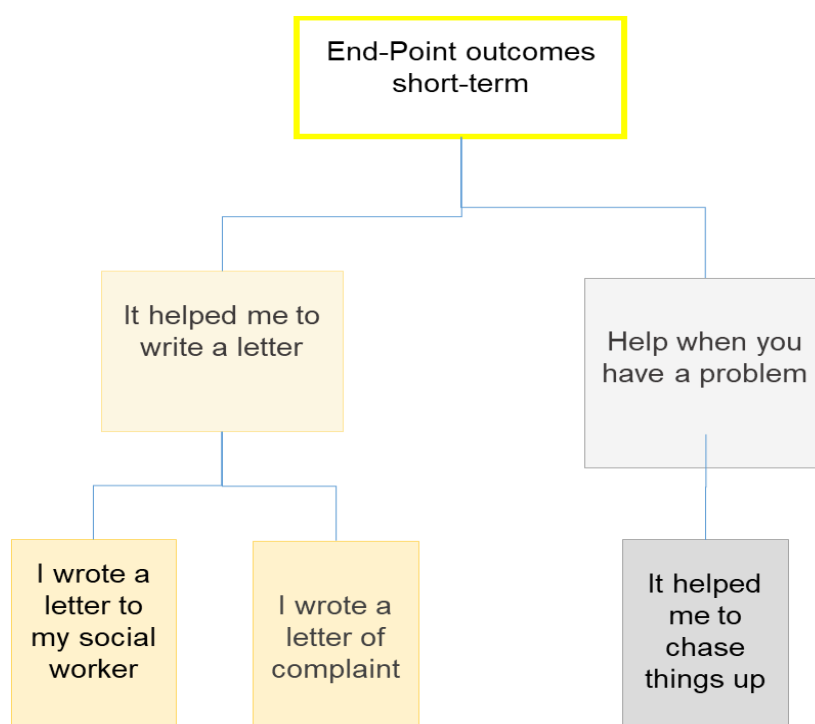


Figure 9. End-Point Advocacy Outcomes Short-term main theme.

The short term end-point outcomes conceptual map focuses on the more measurable aspects of advocacy outcomes. The end-point advocacy outcomes are easier to measure, compared to the process advocacy outcomes presented previously in the chapter. The main reason for this is because people either meet their end-point goals partly, fully or not at all. The theme of the short-term end-point advocacy outcomes concentrated on the practical aspects of the advocacy partnership. For instance, participants' accounts indicated that practical aspects were often their end-point goal from the advocacy partnership. Participants shared that their advocate supported them to write letters and to chase things up in order to sort out issues important to them and their main goal from the advocacy partnership. Moreover, participants expressed that their goal involved raising a complaint and that is what they managed to do with some support.

#### Helped me to write a letter

A number of participants suggested that their advocate supported them to write letters, to complain and self-advocate. Karen shared,

*“my advocate helped me to speak up. Helped me find the right information and write letters in which am not good at.”*

Karen highlighted that end-point advocacy outcomes such as filing a complaint and writing letters to argue your case are an essential, important and valued part of advocacy. Susan shared her personal experience and how she self-advocated when faced a certain issue

*“I wanted to stay at home and I did not want to go to a care home. I did not like that, as it was horrible and I had to complain. The advocate helped me to write a letter and complain.”*

Susan outlined how advocacy supported her to self-advocate and make her case against a decision that she was not happy with. Susan demonstrated also her determination to not just go along with a decision she was not agreeing with by doing that she provided challenges to the dominant system that was not listening to her. Jane shared her personal experience

*“They wrote letters to social workers on my behalf. I was telling them what I wanted and they were making it more presentable as I am not good at writing letters. They put it in a formal letter cause I could not write what I wanted to say. But I was definitely expressing my views and agreed the letters with the advocate before sending them out”.*

Jane talked about how advocacy supported her to speak up and self-advocate by writing letters to professionals a strategy that was found to be important in expressing how she was feeling about certain things. Jane made clear that although her advocate was supporting her she was always in control of what was communicated.

#### Help when you have a problem

A number of participants suggested that their advocate helped them to deal with a problem. Ken shared his personal experience

*“It is really good to talk to an independent person about any problems or issues you may have and they listen and together trying to come up with a way to try and sort out the issues”.*

Ken pointed out how advocacy was an important resource of credible information when dealing with specific problems or issues. Ken made the point that it was important and much appreciated being able to talk to someone independent about your issues or problems. James also suggested,

*“an advocate can help a person to speak up because a lot of people with disabilities as well as able-bodied people can face problems and feel down and need someone to listen to them and support them to express themselves and to speak up.”*

James highlighted that advocacy is welcomed in the lives of people with learning difficulties when people choose to involve advocacy. James pointed out that all people at one point or another in their lives may feel down and could benefit from advocacy and someone listening to them and supporting them. On the other hand, James argued that long term advocacy is not

necessarily a good option for many people. John also shared also his personal experience,

*“I feel I can talk to my advocate about things and ask questions”. “We always look at the options together and I make the decisions”.*

John highlighted that although he feels comfortable talking with his advocate he is always the person making all the decisions. John also expressed that he valued working within an advocacy partnership to look at options and explore questions in order to try and achieve his short-term end-point outcomes.

#### 4.12. End-Point Outcomes Long-Term

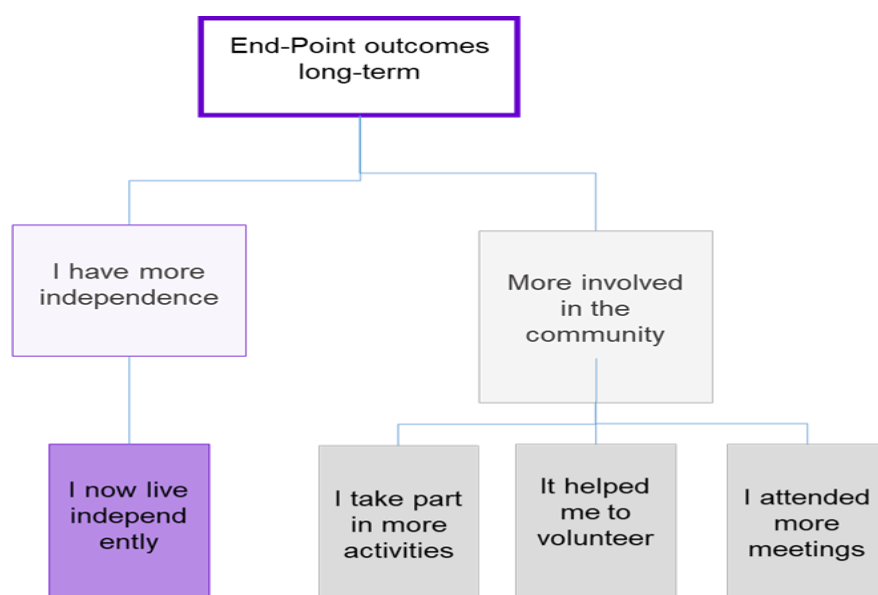


Figure 10. End-Point Advocacy Outcomes Long-term main theme.

The long-term end-point outcomes conceptual map focused on the longer-term measurable aspects of advocacy outcomes. A number of end-point advocacy outcomes were highlighted as valued and important by the participants. End-point outcomes were a lot of the time the reason why participants started working within an advocacy partnership in the first place. Different participants suggested that working within an advocacy partnership increased their involvement in their community including taking part in more

activities, taking up more volunteering work and attending more meetings. Participants also expressed that advocacy supported them to achieve more independence an end-point outcome that was particularly important and valued. Participants shared different practical examples of their experiences working within an advocacy partnership. Each of the themes identified, along with the associated sub-themes, is discussed in more detail with direct quotations from the interviews with the participants.

#### I have more independence

A number of participants proposed that working with an advocate helped them to increase their independence. Sharon shared her personal experience,

*“I feel more involved in decisions since I started working with my advocate. I ask for more things and I make the decisions for my life. I now live independently with some support from staff in my own flat whereas before, most of the decisions were made for me.”*

Sharon expressed that advocacy supported her in her pursuit to be more independent and to make the decisions in her life contrasting that with time in the past where she was not making the decisions something that was negative. Sharon demonstrated her resilience, self-determination and perseverance to increase her independence. Sharon portrayed with her performance of her narrative a resilient, self-determined identity that persevered to speak up and self-advocate to try and achieve her goals and to be more independent. Sharon’s positive identity can be contrasted with and counteracts modernist views of people with learning difficulties full of negative connotations.

#### More involved in the community

Sarah shared her personal experience from working with her advocacy partner. Sarah suggested that her advocate supported her to be more involved in meetings. In Sarah’s words

*“it is good going together in meetings and supporting you there. Helps you get more involved in meetings.”*



James indicated that the advocate helped Paul to be more involved in his community by taking part in more activities. James suggested in the interview

*“Paul joined a gym and got more involved in his local community.”*

James highlighted a long-term end-point advocacy outcome that was positive such as being more involved in your community. Charles shared his personal experience, Charles suggested about his peer advocacy experience

*“people are entitled to their own decisions, for instance, I try to encourage the students to do their physio exercises however everybody is entitled to make a decision about what is best for them. I am working as a volunteer with them or as a friend as I have gone through the same problems sometimes.”*

Charles who was a peer and self-advocate highlighted the importance of being able to make your own mind and decision even that may be at times, from most peoples' point of view, not the “right” decision. Charles highlighted the important point that sometimes people with learning difficulties have the right to make their own decisions however powerful systems sometimes have taken away from them this important right. Charles suggested, when discussing one of the stories in the vignettes that as an advocate he would

*“ask the person where they would like to go and then work together to find different options such as talking to different travel agents.”*

Charles demonstrated that he was a skilful and able peer advocate who was willing to share his knowledge, experience and skills. Charles highlighted a number of advocacy's principles in his practice thus demonstrating that he was a competent advocate with an in-depth understanding of advocacy. Jane also suggested that she became more involved in her community and takes part in more activities. Jane shared

*“I do a lot of activities, I do a lot of swimming, I am a volunteer at the local hospital”.*

Jane demonstrated that she was an important and valued member of her community who was willing and able to bring positive change. Jane similarly to other participants shared not only her views, feelings, perceptions and meanings surrounding advocacy but also ample examples of positive aspects of her identity. An identity for people with learning difficulties full of positive qualities contrasting and counteracting views, from modernist ideologies, of people with learning difficulties with negative connotations.

#### **4.13. Summary**

The advocacy outcomes findings chapter presented and explored the different themes derived from the content, meaning and performative context of the participants' accounts. Nine main themes were identified from the narrative interviews data. Conceptual maps presented all the main themes, themes and sub-themes in a visual way and these were discussed in different sections in the chapter alongside quotes from the participants.

The meaning and content from the participants' views, experiences perceptions and thoughts highlighted a number of advocacy outcomes that were seen as important and valued. However the participants' accounts apart from only showcasing the importance of advocacy's outcomes also, and maybe even more importantly, demonstrated a positive identity for people with learning difficulties.

More specifically the structure and performative context of the participants' narratives clearly demonstrated that people with learning difficulties have the abilities, resilience, knowledge, skills, self-determination and willingness not only to advocate for themselves and others but also to share their knowledge and experiences and thus create new knowledge and inspire other people to do the same. Participants' narratives contributed to the creation of an identity, for people with learning difficulties, full of positive qualities that contrasted and counteracted the identity with negative connotations put forward by dominant modernist ideologies.

## 5. Further Exploration of Advocacy Outcomes

### 5.1. Overview

Chapter 5 further explores the advocacy outcomes derived from the content, meaning, structure and performative context of the accounts of people with learning difficulties using a bottom-up approach. The chapter focuses on the sub-themes extracted directly from the participants' data rather than exploring the main themes identified. This is rather important because it provides a further understanding of the participants' views, ideas, thoughts and perceptions of advocacy. Additionally, in chapter five, we make sense of the data and explore advocacy meanings on a deeper level. The meaning of advocacy is further explored at the sub-theme level. The patterns from the data reported in the interviews are also identified, explored and discussed. The importance of human relationship within the advocacy partnership is articulated and explained. Finally, the notion of the advocacy journey is explored, a notion that has been highlighted in the participants' responses. Chapter five examines concepts and perceptions of advocacy that have not been covered by the introduction of the findings in chapter four. The advocacy outcomes themes are presented again in figure one below.

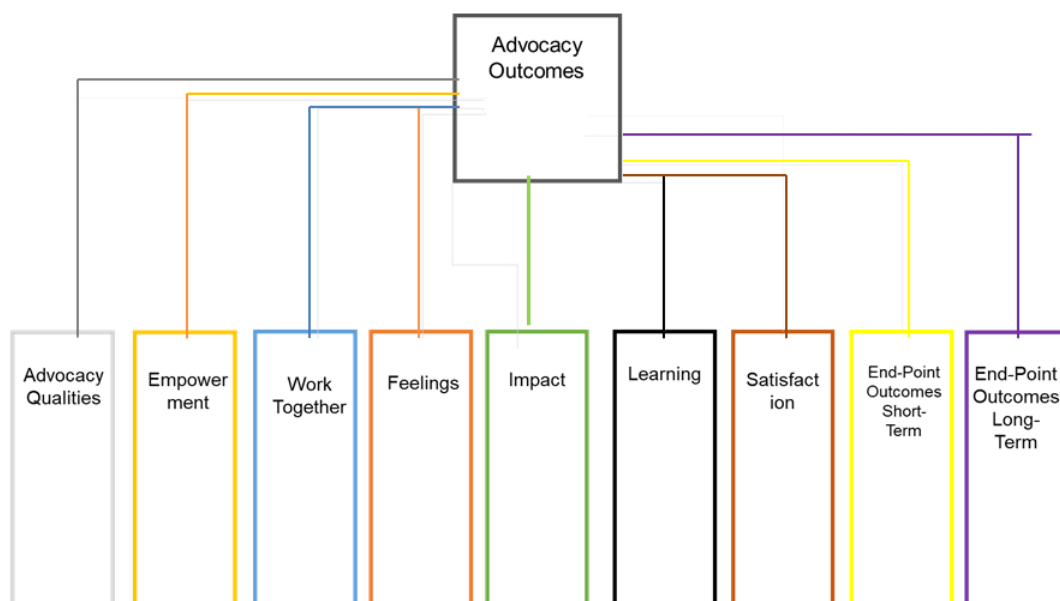


Figure 1: Advocacy Outcomes Main Themes.

## **5.2. Making sense of the data**

Making sense of the data represents an essential part of the social constructivist research approach. The social constructivist research point of view sees the structure, performative context of the interview and the interaction between the participant and the researcher as rather important. Sense-making of the data is a valuable framework and analytical tool within which the qualitative data can be explored (Weick, 1999). The data collected from the participants were considered important at both the individual and the social level. The exploration of the individual's performance in the interviews along with the social and cultural context allowed a more holistic approach to the interpretation of the data. According to the sense-making theory the past meanings are stored in the form of personal schema and they also provide the basis for future meanings and actions (Mills et al., 2010). The sense-making theory also has a similar view of the social context of constructs with the social constructivist approach. The advocacy outcomes study used some of the sense-making theory's principles to gain a greater insight into the participants' attempts to make sense of the advocacy relationship and also the meanings they attribute to this. The sense-making exploration of the data is presented in the following sections.

## **5.3. Exploration of the Top Findings**

A number of sub-themes came up consistently from the analysis of majority of the participants' data. The step by step analysis of the data with the steering group acknowledged that some sub themes were present throughout most of the other themes. The steering group came up with three top findings that were seen as the most characteristic and defining of all the themes. "Felt listened to", "on my side" and "Speak up" were the three top findings that the analysis, with the steering group, showed as most important. The analysis of the participants' accounts content, meaning, structure and performative context highlighted that the majority of participants demonstrated that they "felt listened to" within the advocacy partnership and this was perceived as rather important by the participants. They expressed that their advocacy partner listened to them and to what they had to say.

Furthermore, many participants reported that they felt that their advocacy partner was “on my side” again something valued and perceived as very important. It was also widely shared that their advocacy partner was helping them to fight their corner.

### **5.3.1. Exploration of Top Finding 1 “Felt listened to”**

Participants throughout the interviews consistently expressed that their advocacy partner listened to them something that made a difference and was perceived by them as very important. This can be seen as a top finding and a defining characteristic of advocacy. For instance, Susan expressed in the in-depth interview that the advocate listened to the person and that was very important. Susan expressed when talking about the story in the vignette that

*“the advocate listened to the person and tried to do something about what they were wanting”.*

Peter also commented in the interview

*“somebody listened to me and that was important”.*

Peter shared his point of view about the story in the vignette,

*“John worked together with the advocate rather than being told what to do or the advocate doing it for him”.*

Peter highlighted the importance of feeling listened to within the advocacy partnership and feeling equal compared to being told what to do or someone else doing it for you when you feel down. Peter suggested that was very important as someone telling you what to do can be seen as negative and patronising. Peter’s animated performance at the interview indicated that this matter was very important to him and close to his heart.

Moreover, many participants suggested that they felt listened to and not ignored. Some of these comments from people with learning difficulties propose that they have felt not listened before when working with another professional. Sharon was explicit in suggesting in the in-depth interview that her advocacy partner made her feel better by listening to her. Sharon shared,

*“Working with my advocate made me feel better as my advocate listened to what I had to say instead of just telling me what to do”.*

Sharon indicated that her experience working with an advocate was positive compared to some of her experiences working with professionals, which have been negative for her. Jane also expressed a similar experience and point of view as she described her experience of working within an one-to-one advocacy partnership as positive compared to her experience working with other professionals, which was described as negative. Jane suggested,

*"I felt more valued and important. I felt as if no one was listening before".*

Again, this account by Jane indicated that she felt not listened to before something that changed when she worked within an advocacy partnership.

Jane also shared that working within an advocacy partnership made her feel more confident to express her point of view and challenge decisions rather than accept what is offered to her without question. Jane suggested,

*"I am now feeling more confident to ask for things and disagree with people if needed.*

Jane also expressed that her advocacy partner

*"listened to me and helped me fight my corner".*

Jane outlined a number of positive outcomes from the advocacy partnership. Jane suggested that she became more confident to challenge people and not agree with something she is given but speak up and ask for what she wants/needs. Ken pointed out that advocacy partners listen to problems or issues that you have and together try to find a solution. Ken highlighted

*"It is really good to talk to an independent person about any problems or issues you may have and they listen and together trying to come up with a way to try and sort out the issues".*

James suggested that it is important to have an advocacy partner as they can listen to you and support you to express yourself and speak up. James mentioned,

*"People can face problems and feel down and need someone to listen to them and support them to express themselves and to speak up".*

Again, here with these suggestions from the participants it becomes apparent that there is a shared feeling that an advocate can listen to you and support you to express yourself.

### **5.3.2. Exploration of Top Finding 2 “On my side”**

“On my side” was also seen by the steering group analysis as a top finding. On my side was a very significant theme that was present in most of the participants’ interviews. Participants consistently expressed that they felt that their advocate was on their side. Participants shared their views and experiences indicating that working within an advocacy partnership was a positive experience which supported them to further self-advocate and speak up. Several participants suggested that they felt that their advocacy partner was always on their side supporting them to fight their corner. Participants’ views and experiences however also suggested that working with other professionals was not always positive and not always on their side or even at times felt like they were against them. Advocates did not set the agenda but rather worked together with the person’s agenda.

Susan shared her negative experience of working with professionals in the past when she felt not listened to. Susan suggested that you want to have someone on your side rather than someone not listening to what you say.

*“I felt sometimes not really listened to; you want someone to be on your side”.*

Jane shared her experience of working with her advocacy partner and suggested that she felt that the advocate was on her side and that they were helping her to fight her corner. Jane suggested that her advocacy partner

*“listened to me and helped me fight my corner, it is good to have someone on your side”.*

Overall advocates were described as someone on their side standing by them and supporting them to fight their corner within a more equal partnership.

Peter shared his perception of advocacy

*“advocates are not pushing their own point of view to you like other professionals do”. “Not telling me what to do, putting their ideas into my head, but I was able to tell what I wanted and then we were working together with the advocate to do something about that”.*

Peter suggested that he experienced working with an advocate in a positive way as the advocate did not set the agenda but worked with him and with what it was important for him. Peter also expressed that when working with a professional he was not able to set the agenda but rather the discussion was led into what the professional had in mind. Peter shared that he felt that the professional he was working with was not on his side and was trying to put ideas into his head and tell him what to do. Peter suggested that he persevered with the support of the advocate and was able to express his views and wishes and do something about it. Similarly, many participants indicated that when working within an advocacy partnership they felt more equal and not talked down. Sarah shared that the advocate

*“does not push her own point of view as other professionals do”. The advocate did not take over and made him feel equal. Social workers tend to talk down to you and that they know better than you”.*

Sarah expressed that previous experience working with a social worker was not positive for her as she felt she was talked down. In contrast, Sarah suggested that her advocate made her feel equal and did not take over. Sarah with her performance clearly demonstrated that she provided a challenge to the system that was not listening to her views and wishes. Sarah was not afraid to ask for more, to self-advocate and to try and achieve her goals and meet her needs. Furthermore, Sharon highlighted when talking about the vignette

*“the person was not afraid of asking and not felt that he has been put down”*

when talking with his advocate. Sharon again offered a similar account of how she felt working with an advocate versus previous experiences she had



working with professionals. Karen talking about the vignette and her experience proposed that the advocate

*“made her feel like a person and not as a child and he did not make him feel that he was put down and not listened to. I felt like an equal and not as if I was told what to do”.*

Karen expressed that the outcomes from her work with the advocate were positive as she described working with her advocate making her feel as an equal person and not negatively as a child being told what to do or put down and not listened to.

### **5.3.3. Exploration of Top Finding 3 “Speak up”**

“Speak Up” was also seen as a top finding following the analysis of the content, meaning, structure and performative context. Speak up has been a key message in all of the participants performances. Speak up can be seen as a top defining characteristic advocacy outcome. Participants expressed that they felt that their advocacy partner supported them to stand up and speak up for themselves. Participants with learning difficulties, that have used advocacy services, suggested that this was a very important outcome of the advocacy partnership. Advocacy encouraged them to express their point of view and how they were feeling as well as ask for more and fight for their rights. Furthermore, they shared a number of their stories expressing the meaning that advocacy has for them. The advocacy partnership journey was strongly associated with increased levels of speaking up and self-advocating. Many participants brought up that being encouraged by their advocacy partner to stand up and speak up was a very important outcome. Pat commented when discussing the vignette

*“the advocate helped Paul to get something that he needed and also helped him to stand up for himself and ask for things rather than be afraid and stay quiet”.*

Pat indicated that if the advocate was not there to support Paul he potentially could have been afraid and stayed quite. This is very important because being afraid and stay quiet is something negative. Pat highlighted the

importance of speaking up and asking for more but also of providing challenges to a system that is not listening and at times can feel intimidating. Peter provided another great demonstration of speaking up and its importance. Peter suggested

*“You fight for your rights and for what you believe in. You don’t really fight but when you are passionate you speak up.”*

Peter highlighted that being passionate and fighting for your rights and what you believe in is very important. It is also very to not accept things as they are and do something to change them. Peter an experienced peer and self-advocate highlighted the importance of speaking up but at the same time also demonstrated his passionate approach to life and advocacy.

Susan pointed out the importance of persevering and doing something when not happy. Susan shared her personal experience and how she self-advocated when faced a certain issue

*“I wanted to stay at home and I did not want to go to a care home. I did not like that, as it was horrible and I had to complain.”*

Susan demonstrated that she did something about a negative situation she experienced when she decided to write a complaint about something she was not happy with. Susan provided a challenge to the system that tried to tell her what to do and tell her how she was supposed to behave and where to live. Similarly, Sarah also shared her view

*“I have learned that if you believe that you are unhappy there are ways to talk about it and bring it all out and complain and make your feelings known.”*

Sarah demonstrated her self-determination to do something when not happy. She made a complaint and made her feelings known. Susan also associated advocacy with speaking up thus indicating that advocacy was perceived as a positive influence.

Brian who is a peer advocate and a self-advocacy group member suggested about the story on the vignette and about his work as a peer advocate.

*“The advocate tried to represent him and helped him to speak up. That is what I sometimes do as well however it is hard at times to do that.”*

Brian highlighted the importance of advocacy but also of peer advocacy as he suggested that he was carrying out this role as well. Brian pointed out that this task can be hard at times and it is not something straightforward. Moreover, Brian expressed that although being a peer advocate can be hard work it is also valuable and important. Charles also shared his experience when facing a change of accommodation decision. Charles mentioned,

*“my advocate helped me to speak up and find another place that I would like rather than go to a place I did not like. We arranged and met with my advocate and I was able to say that I did not like the place.”*

Charles talked about a specific situation he was facing when trying to find a different place for himself. Charles suggested that the advocate was helpful in trying to find another place. He highlighted that he would not accept a place that he did not like and by doing that demonstrated the standing up and speaking up attitude displayed by people with learning difficulties. Charles by not accepting what he was offered and by asking for more provided a challenge to the system proposing that he should accept what he was given. How Charles structured and performed his narrative demonstrated his self-determination along the positive influence of the advocacy partner managed to stand up for his rights and find another place that he liked rather than just accept what was on offer.

James described how working within an advocacy partnership can empower an advocacy partner. James suggested that

*“an advocate can help a person to speak up because a lot of people with disabilities as well as able-bodied people can face problems and feel down and need someone to listen to them and support them to*

*express themselves and to speak up. I am not better than anybody else but I am trying to put my case across strongly.”*

James expressed how he perceived advocacy according to his experiences and point of view. James highlighted the importance of listening to someone and doing something to support them to speak up and express themselves as people with or without disabilities can face problems and feel down sometimes. Moreover, James demonstrated that he is trying to put his case across strongly something that he sees as important.

A number of participants suggested that sometimes they would choose to engage in an advocacy partnership whereas other times they feel they could self-advocate, speak up and achieve what they want without the support of an advocacy partner. Jason shared how he is self-advocating

*“I suppose I could ask the social services but I don’t think they would help much. But I don’t know because if you do not ask you do not get what you want. I would ask if there was any money available. Try somewhere else, but don’t know where, I would have to try and find out where, I suppose.”*

Jason here expresses how it is important for him to stand up, speak up and self-advocate otherwise you would not be able to get what you want. Jason demonstrated his problem-solving skills and his perseverance to try and achieve what he wants.

Participants expressed in the in-depth interviews that working with an advocate encouraged them to self-advocate. For example, Sharon when discussing the story involving advocacy in the vignette suggested

*“If I was Jo I would ask to arrange some more holidays, and I would take Jane on holidays with me, and I would also take Mary with us and George. As I like them.”*

Sharon expressed here how it was important to try and do things your way rather than accept what you were offered. Sharon demonstrated that she

self-advocated to make her own choices rather than leave it to someone else to make decisions for her. Judy expressed how she was self-advocating,

*“I would continue onto them until I get what I want”.*

Judy described her way of self-advocating. Judy highlighted that it is important to stand up, speak up and self-advocate to get what you want otherwise you would not achieve that. Moreover, Judy showed her self-determination and perseverance to continue until she got what she wanted. Judy's performance demonstrated a positive attitude against negative influences that can get in the way of Judy achieving her choices, wishes and meeting her needs.

#### **5.4. The Meaning for the person**

As suggested earlier in the chapter making sense of a person's meaning is a very important part of the social constructivist research approach. This section achieved this by further analysing the content, meaning, structure and performative context of what the participants with learning difficulties were willing to shared, using a bottom up approach. Further to what was discussed in chapter 3 regarding the analysis of the data the Mishler (1995) framework was utilised to explore the meaning, structure and performative context of the data. The meaning of the content was evaluated by looking at the narratives and trying to extract the deeper meaning for the participant. The section continues by exploring factors that potentially influenced the meanings expressed by the participants in the interviews.

The advocacy partnership was reported to be something positive that was being welcomed in the lives of many of the participants in this study. The advocacy partnership was described as something that you can rely on and you can trust. Furthermore, since many participants have also mentioned that they had negative experiences when working with other professionals it became an even more important positive relationship. The advocate was perceived as someone that has good listening skills but maybe even more importantly someone that tries to work with the person, to plan and to act

together to achieve the agreed goal in an often not so good situation. The advocate works together with the person and encourages the person to stand up, speak up and self-advocate. The advocate was perceived as friendlier, more approachable and less formal compared to professionals involved in the person's life. It can be argued that the advocacy partnership, was not described, as there for the long run or as a friend that is always there. But rather it was narrated as a partnership that can be there to counteract the negative influences and the barriers placed in front of people with learning difficulties to prevent them from achieving their choices and wishes and what they aim for.

Another important meaning identified was that advocacy have been perceived as an attitude and as a commitment or a way of seeing and doing things differently. The advocacy partnership was narrated as a journey rather than something static. Advocacy was described as a notion that was evolving as the advocacy partnership progressed rather than remained the same or being repetitive. Advocacy was described as a journey to a place where asking for more, being supported and encouraged to do so is the norm. The advocacy partnership journey came into contrast with relationships with other professionals where the person's voice was not really listened to and the agenda of the professional or of their service was more important compared to the person's views, wishes and choices. Advocacy was described as the journey that encouraged the person to ask for a more fulfilling and empowered way of life where asking for more, challenging and expressing your views particularly when not happy is the norm and not the exception.

How advocacy partners and self-advocates structured and performed their narratives demonstrated a resilient, self-determined identity confident to ask for more and fight for their rights, in the health and social care arena and in general. However, when the barriers and negative influences were so many, advocacy has demonstrated that it could be an ally to the causes of people with learning difficulties in their struggles with a system that seems, at least at times, to be against them although it has been developed to support them. The meaning that each individual gave to advocacy seem to have a lot of

similarities and common themes. The following section looked into identifying the patterns that were common in different participants' perception of advocacy.

### **5.5. Exploration of Patterns**

Patterns were explored and identified within the data to get a deeper understanding of the meaning communicated by the participants. The content of the data was also examined to get a better understanding and to make sense of the qualities of the narratives. The study also looked at the structure of the narratives and on how they have been performed. The analysis investigated the structure to understand better the context and the reasons behind the choice of structuring the narrative in a particular way. The structure of the narrative indicated that the participants wished to achieve particular aims through their communication such as a sense of collective identity for people with learning difficulties. Finally, the performative element of the narratives unveiled further deeper understandings by exploring questions showing why the narrative was performed in the chosen way.

Overall advocacy was perceived by people with learning difficulties, that have used the service and took part in the in-depth interviews, as something positive. Both in the advocacy outcomes findings section as well as in the further exploration section most of the views, opinions, perceptions, meanings and experiences expressed appeared to portray advocacy as something important but also something that is welcomed in the lives of people with learning difficulties. A pattern that became rather clear, from a lot of the views and experiences expressed, was that advocacy is on the same side as the person who uses the service. This was even more important because a number of participants expressed that not all the services they work with seem were on their side.

Many participants shared views and experiences that working with professionals was not always a positive experience. Participants expressed

their feeling that the professionals wanted to push their own points of view and agendas rather than listen to the person and act according to the person's agenda. This appeared to be a contradiction when professional services designed to support individuals, with learning difficulties, and provide a person-centred service were potentially not listening to the views and wishes of the people who actually use the service. However many participants proposed that and this view was consistently supported using different examples from different experiences and different people.

Potentially this was one of the main reasons why people with learning difficulties saw advocacy as such a positive and important service. It appeared that fundamental elements, of what makes a good service, were not met by some of the professional services that were provided to people with learning difficulties. Advocacy seem to be meeting those fundamental elements and that was why potentially it was seen as something positive and important that was valued and welcomed in the lives of people with learning difficulties.

Another important pattern was that participants have been consistently talking about their advocates supporting them to stand up, speak up and self-advocate. Again this pattern highlighted that advocacy was potentially perceived as so positive and important because some professional services involved in peoples' with learning difficulties lives have been experienced as negative. Participants with learning difficulties suggested that, the professional working with them was trying to push their own ideas to them and also to put thoughts on their mind then it could be inferred that this was a very negative experience. When an advocate was supporting the person with learning difficulties to challenge that and sometimes get what they wish then it can be understood why this service was seen as so positive and important. The above suggestion can also lead to the inference that if the professional services were closer to what they described themselves as then probably the need and also the impact of advocacy would have been lesser. However, following a number of years of austerity and a number of cuts across different important professional services the need for advocacy appeared to



be higher and stronger. Many participants have highlighted that and it can explain why so many professionals failed to be seen as allies and on the side of the people with learning difficulties. The analysis of the data also examined the performative aspect of the narratives and focused on the identity that was demonstrated by the participants through the performance of the narratives. Participants by performing a narrative they did not only provide information but also developed accounts that demonstrated a positive collective identity for people with learning difficulties.

### **5.6. The Journey**

It can be argued that advocacy has been demonstrated, by the participants, to be above all a human relationship. A human relationship that was based on trust, confidence and working together to achieve one or more agreed goals. A very important element of the advocacy partnership that was demonstrated by the participants was feeling listened to. Feeling listened to is a fundamental principle of all human relationships and its importance should not be underestimated. Participants, however, have reported on a number of occasions that they have felt not listened to when working with other professionals and that made them feel devalued and disempowered. Participants consistently reported that they did feel listened to within the advocacy partnership. Being listened to appear to form the basis of the process of the advocacy partnership that was reported by participants to be so valued and important.

Feeling the advocacy partner to be on their side was indicated, by the participants, to be another very important element of the advocacy partnership. This has been reported as very important and valued because it was perceived as the element highly associated with developing trust in the partnership and consequently aiding an increase in confidence and empowerment. It can be argued that after these fundamental human relationship elements have been satisfied then the advocacy partnership can aid an increase in empowerment which is positively associated with an increase in speaking up and self-advocating.

It can be argued that all the advocacy outcomes that have been reported to be important and valued by the participants are interlinked with each other. Particularly without the first two basic elements of the human relationship met, feeling listened to and feeling the other person on your side, it is unlikely that all the other positive outcomes would be realised, at least not to the same extent. Therefore, if the basic human relationship elements, of feeling listened to and having someone on your side, were not there then the advocacy partnership would not be as effective and would not have been perceived as so important and valued.

Self-advocates and advocacy partners in our study demonstrated their resilience, perseverance and self-determination in difficult circumstances. Participants have clearly demonstrated that they were able and willing to self-advocate and speak up for themselves and others. However, as a number of participants highlighted there are times that everyone can feel disempowered, particularly in an environment with many different negative influences and barriers. The advocacy partnership has been demonstrated to be an ally to the person in those circumstances.

It can be argued however that it is the journey of this partnership that allowed firstly the basic human relationship elements to be satisfied and then the advocacy partnership to be built upon those fundamental human relationship elements. Without the advocacy journey and the feelings that are associated with it, advocacy outcomes would have had less value. Without those fundamental elements satisfied, the advocacy partnership would have not been the same. Therefore advocacy is more than a resource of finding information but rather primarily a human partnership that, particularly in difficult times, can be an ally and partner or counter force to the negative and disempowering influences of dominant systems. The importance of the human relationship within advocacy partnerships is further explored within the discussion chapter to follow.

### **5.7. Summary**

Chapter 5 presented findings that were more focused on the sub-themes rather than the main themes identified from the data. A bottom-up approach was adopted in looking at the data by concentrating on the micro elements of the participants' accounts rather than the macro in the pursuit of uncovering the essence of what advocacy is for the people that use it. Three top findings were identified that best represented what advocacy meant to the participants "felt listened to", "on my side" and "speak up". The importance of the partnership experienced primarily as a positive human relationship was emphasised.

Moreover, the chapter further explored the structure and the performative context of the participants' accounts as well as their content and meaning. The structure and performative context of the participants' accounts portrayed a collective identity for people with learning difficulties full of positive qualities. Additionally, the patterns in the data described advocacy as a journey and something that evolves rather than remaining static. A journey that aids the person's empowerment but also, along the way, counteracts negative influences contributing to disempowerment.

## **6. Discussion**

### **6.1. Overview**

The following chapter is going to discuss the findings presented in the previous two taking into consideration research findings from the literature as well as from relevant social theories. The study's main aim was to explore advocacy outcomes from the perspective of the people who use the advocacy service rather than of other stakeholders. The participants expressed and discussed their views, experiences, perceptions, meanings and feelings around advocacy work in qualitative interviews. The findings highlighted the importance of not only the end-point outcomes of advocacy work but also of the process outcomes along the advocacy journey. Moreover, the chapter explores the meaning of advocacy and what difference can advocacy bring in the lives of people with learning difficulties. It finishes by looking at the lack of research from the point of view of people who use services and with considering and discussing future directions for advocacy, its outcomes and wider research in this area.

### **6.2. Discussion of the Main Findings**

The findings sections, of the thesis, highlighted the importance of the process advocacy outcomes along with the end-point outcomes. Both process outcomes and end-point outcomes were perceived as important and were valued by people with learning difficulties that use advocacy. The study also highlighted that the process outcomes are present and valued even when the person using advocacy has not reached their primary goal set at the beginning of the partnership. The chapter relates those and the rest of the findings with the current literature around advocacy and social theories in the areas of disability studies, learning difficulties and social policy.

It has been well documented that advocacy and its outcomes have received limited research attention however most of the projects that did so from the point of view of different other stakeholders rather than from the view of people who use the service (Ridley et al., 2018). Several studies examined

advocacy outcomes from the point of view of social services professionals (Rapaport et al., 2006), from the point of view of professional advocates (Forbat and Atkinson, 2005 and Carver and Morrison, 2005) from the point of view of parents (Fazil et al., 2004), from the point of view of mental health professionals (Jugessur and Iles, 2009) and commissioners of advocacy (Hussein et al., 2006 and Rapaport et al., 2005).

Only a few of those studies involved people who have directly used advocacy services and explored their views, experiences, meanings and perceptions. For instance, Thomas et al. (2017), Thomas et al. (2016) and Oliver et al. (2006) explored advocacy's outcomes and impact involving children and young people. Bocioaga (2014), Bright (2008), Wright (2006) and Murphy (2001) investigated the impact of independent advocacy on the lives of older advocacy partners. Newbigging et al. (2015b), Palmer et al. (2012), Ridley et al. (2018) and Eades (2018) examined advocacy and its outcomes with people who have experience of using mental health services and people detained under the powers of the Mental Health Act (2007). Darwin and Pickering (2007), OPAAL (2009) and Barnes and Tate (2000) carried out qualitative research studies that explored advocacy with disabled adults who had been victims or alleged perpetrators of anti-social behaviour.

The number of research studies that have explored advocacy from the point of view of people with learning difficulties is even scarcer. Tarleton et al. (2006) carried out research with a group of parents with learning difficulties to explore the issues they faced as well as the advocacy outcomes from their point of view. Tarleton (2007) also conducted a study looking at the experiences and views of people with learning difficulties on advocacy and its outcomes.

Self-advocates with learning difficulties have also been involved in advocacy research exploring the self-advocacy membership outcomes. However, there is a difference between looking into the outcomes of self-advocacy membership and our study exploring the outcomes of different advocacy types. Goodley and Armstrong (2001) explored the meaning and significance

of self-advocacy in the lives of people with learning difficulties using two qualitative methods ethnography and narrative inquiry. Llewelyn and Northway (2008) explored self-advocacy's meaning and definition from the perspective of the group members with learning difficulties. The research concluded that advocacy had different meanings for different groups of people with learning difficulties in different situations. Gilmartin and Slevin (2009) conducted an inclusive study with self-advocates employing a phenomenological approach to explore their experiences and feelings. Caldwell (2011) used in-depth interviews, following a life story approach, with 13 leaders (10 with learning difficulties) of the self-advocacy movement in the United States. Finally, Clarke et al. (2015) investigated the experiences of six members of a well-established self-advocacy group with learning difficulties.

The themes identified from our research with adults with learning difficulties are discussed compared and contrasted alongside findings from the different studies directly involving people who have used advocacy services rather than from people who have indirect experiences. This is an important point as it has been highlighted that involving people who have used the service is linked with better outcomes for the service as well as the empowerment of the people who take part in research and the production of knowledge (Beresford et al., 2011). It is beyond the scope of this study to discuss, in-depth, findings of advocacy outcomes from different stakeholders as those findings would not be comparable with the findings from our study. In line with the main aim of our research, it is very important to look closely at and explore advocacy outcomes from the point of view of the people who have used advocacy.

The term "our" study is used in this chapter in order to help differentiate, in the discussion, between the advocacy outcomes study with adults with learning difficulties and the rest of advocacy outcomes research studies. In addition, this term is used to emphasize the participatory approach that was utilised in this research project. The study explored the advocacy outcomes and impact from the point of view of the people that use the service that has been highlighted as an important methodology, with great potential, that has

been largely ignored by mainstream research. It was one of the main aims of the study to bridge this gap in the literature around advocacy and its outcomes. Moreover, the study used the participatory approach in order to be compatible with the main principles of advocacy, empowerment and inclusion. The participatory and co-production principles adopted in the study are discussed in more detail in the methodology chapter (chapter 3).

The nine main themes that have been identified from the analysis of the in-depth interviews with the participants are presented in figure 1 below. The chapter continues by exploring each of the main themes, presented in figure 1, alongside the evidence from other studies that investigated the perspective of people that have used advocacy.

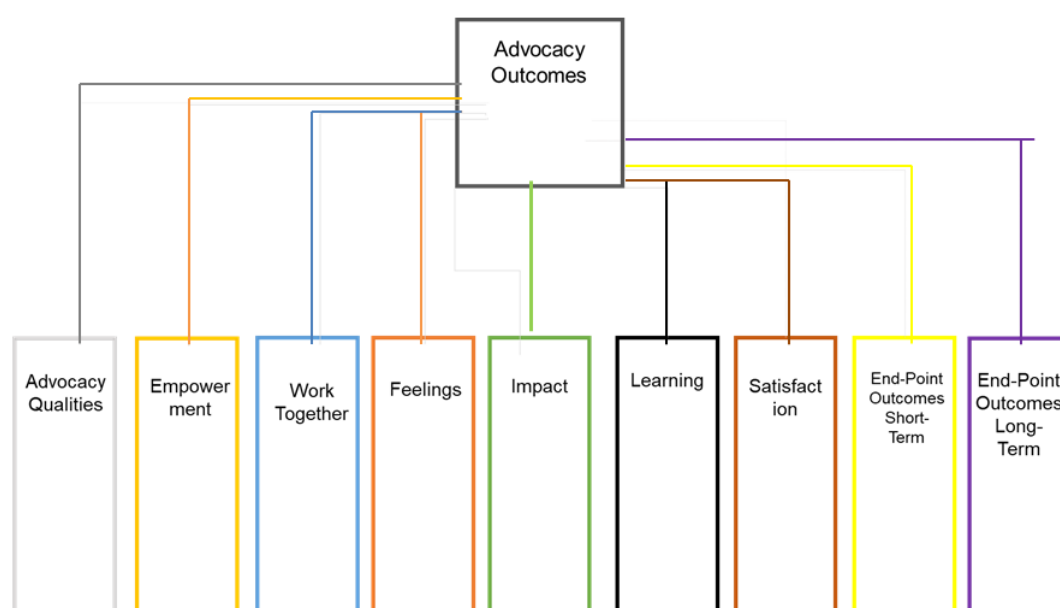


Figure 1: Advocacy Outcomes Main Themes identified.

### 6.3. Advocacy Qualities

The advocacy qualities theme highlighted that advocacy and advocacy partners were perceived as different compared to working with professionals. Participants shared a number of different personal stories and practical examples demonstrating how and why they felt that advocacy was different and what advocacy meant for them. Participants reported that they felt

listened to and understood within advocacy partnerships however this was not always the case when working with professionals. Thomas et al. (2016) also suggested that young people who participated in the study reported feeling listened to by their advocate. Young people, besides that, reported feeling a sense of being let down by other professionals when they did not deliver their promises a feeling that was also reported several times by the 13 adults with learning difficulties in our study. Being listened to, having an opportunity to express their views, increased ability to self-advocate and improved self-confidence were key advocacy outcomes across both studies. Wright (2006) study shared that participants felt valued by their advocate, that their advocate was there for them and that there was a sense of trust in their relationship with their advocate. Advocacy qualities that were also highlighted by the participants in our study.

Participants in our study suggested that independence was a very important quality of advocacy. Participants expressed that they were not working with other professionals that were independent. Professionals in their lives had an agenda and that was not always an agenda that was shared by them. Moreover, participants expressed in the interviews that they felt that their advocacy partner was on their side and someone that was fighting their corner. In that sense, the advocacy partnership was different as their advocacy partner was someone they could talk openly to, someone more approachable and friendlier and was not someone that they were seeing as an official.

Furthermore participants, in our study, also reported feeling equal and not talked down and this was highlighted as an important quality of advocacy work. Participants shared that they were not being told what to do, within the advocacy partnership, and that was not always the case when dealing with other professionals. Participants even suggested that they felt they were being treated as a person in the advocacy partnership as some professionals made them feel they were not being treated as an equal person but at times less than a person and more like a number.



The advocacy qualities theme highlighted the differences between advocacy and its outcomes and professional services that also claim to be on the person's side. Participants clearly indicated that advocacy came in contrast with professional services as advocacy stands on the side of the person and aid their empowerment rather than promote its own agenda as other professional services often do. According to the participants this is a main difference that makes advocacy as important and valued.

#### **6.4. Empowerment**

The empowerment theme study highlighted participants' perceptions suggesting that advocacy supported them to feel empowered. Participants expressed that the advocacy partnership aided them to feel empowered to speak up and self-advocate. Particularly participants that were also members of a self-advocacy group reported that mutual support was present as they were encouraged by other peers to speak up and self-advocate and they encouraged other peers to speak up and self-advocate.

Participants in Bocioaga (2014) study suggested that process outcomes such as empowerment, sense of well-being, increased levels of confidence and self-esteem are very important. The findings reported by Bocioaga (2014) were very similar to the findings reported in our study. Older advocacy partners valued advocacy outcomes something consistent with the findings from the research with people with learning difficulties. Apart from finding end-point advocacy outcomes important older participants also placed particular value on the process outcomes, particularly feeling empowered to speak up and self-advocate. Bright (2008) also carried out interviews with older people who have worked with advocacy. Participants from the Bright (2008) study highlighted a number of positive process outcomes such as increased levels of empowerment, increased levels of sense of self-worth, self-confidence and emotional well-being. Wright (2006) participants reported a number of process outcomes including increased levels of empowerment, self-confidence, self-worth and emotional well-being.

Participants in our study similarly shared their stories and practical examples demonstrating how and why working with an advocate made them feel more empowered to do something and choose to take action. Some participants also chose to share examples from friends or family members and their experiences around advocacy. Participants suggested that advocacy aided them to speak up for themselves, complain, fight for their rights, ask for more/insist, express what they want, express their feelings and ask for what they want.

Palmer et al. (2012) study involved participants, with experience of using the IMHA service. Palmer et al. (2012) participants, similar to the participants in our study, highlighted a significant increase in self-reported empowerment, self-efficacy and wellbeing. Ridley et al. (2018) also suggested that mental health advocacy partners reported that advocacy was acting to empower partners and was supportive in improving involvement as well as changing care and treatment and aiding personal development. The Palmer et al. (2012) and Ridley et al. (2018) findings were compatible to our study particularly in terms of trustworthiness and empowerment.

Gilmartin and Slevin (2009) participants reported feeling empowered to speak up both at the individual and collective level. Participants reported that being a member of the self-advocacy group was really important and valuable for them. The Gilmartin and Slevin (2009) study concluded that, based on the evidence of clear benefits from the membership, opportunities should be provided for adults with learning difficulties to attend and participate in self-advocacy groups. The self-advocacy groups were described as having the potential to empower people with learning difficulties, who have experienced feeling disempowered, and the potential to bring positive change and make a real difference to the members' lives. Clarke et al. (2015) also concluded that empowerment was a central theme brought up by the group members who reported that being a member of a self-advocacy group helped them to speak up and feel empowered. Their findings were consistent with the findings from our study exploring the views,

feelings and experiences of adults with learning difficulties on different types of advocacy.

Newbigging et al. (2015b) used focus groups and interviews with people who have experiences of using mental health services and some of them being detained under the powers of the Mental Health Act (2007). The study explored the participants' views and experiences around advocacy and its outcomes. The difference in the findings from our study to Newbigging et al. (2015b) was that the participants, in their study, expressed a feeling of advocacy helping them to come to terms with their situation rather than feeling empowered. The participants did not express feelings of empowerment, something that was reported from participants in our study as well as the majority of the studies discussed in this chapter. Participants in the Newbigging et al. (2015b) study felt that advocacy helped them to come to terms with their situation which is far from feeling empowered.

The difference in the findings can be explained, at least partly, by the profound levels of disempowerment experienced by people detained under the Mental Health Act who have their freedom removed in the hospital wards. As Goffman (1961) suggested, the different elements of control used by total institutions, such as surveillance, supervision, privilege and punishment, are focused on disempowering the individuals to prevent resistance and promote discipline. Some parallels between the total institutions and their functions described in Goffman (1961) and detention, under the powers of the Mental Health Act, at the present day psychiatric hospital wards can be drawn as evidenced by the levels of disempowerment reported by the Newbigging et al. (2015b) participants. It can be argued that the extreme levels of disempowerment experienced by the participants in the Newbigging et al. study are an explanation why the participants did not feel empowered unlike other participants in studies exploring advocacy who clearly did.

## **6.5. Work Together**

The work together theme looked at the main aspects that participants identified as important in the advocacy partnership. Participants expressed their personal experiences in relation to working together such as planning the actions that are required to tackle any issues and carry them out together to try and get a result. The participants suggested that they felt able to talk comfortably and ask questions without feeling they would be criticised or be judged about what they say. Participants shared that they found and discussed information and looked at different options together with their advocacy partner. Members of self-advocacy and peer-advocacy groups particularly highlighted that they were working closely together with their peer advocates. They reported mutually supporting each other to speak up and self-advocate but also working together to find the right information and share their knowledge and experiences.

Participants at the Bocioaga (2014) study expressed that their advocacy partners were available when they wanted to talk to them and also listened to their views and needs again similarly to the responses from our study. A number of participants in our study suggested that working together with their advocacy partner increased their confidence and also increased their courage and supported them to not feel afraid or stay quiet. Being able to speak up, express feelings and feel listened to were also highlighted as important outcomes.

Tarleton (2007) carried out a study with parents with learning difficulties, who reported that when working within an advocacy partnership they felt being treated with more respect by the child protection professionals. Tarleton (2007) study reported that participants felt that they were emotionally supported by their advocates and also felt that the advocates were challenging the child protection professionals in an appropriate way. In addition, parents suggested that all those feelings were present despite advocates not being able, most of the time, to change the situation they were in. All these outcomes reported in the Tarleton (2007) study have also been

highlighted in our study and again it is demonstrated how important process outcomes are in advocacy. Tarleton (2007) concluded that the advocates employed strategies commonly used when working with adults with learning difficulties, strategies which have been found to be effective. Ward and Tarleton (2010) proposed that the development of specialist advocacy services supporting parents with learning difficulties is beneficial and should be promoted by national guidelines.

Furthermore, a number of participants, in our study, mentioned that working together was an expectation from the advocacy partnership as this is one of the main principles of advocacy. Advocacy partners were expected and did work together in order to achieve the desired result which has been outlined at the beginning of the advocacy partnership. Working together as an outcome has been highlighted as important by the majority of the participants and it was contrasted with and opposed to other experiences which could be described as negative. Participants have reported feeling that felt not listened to and not understood by other professionals who wishes to promote their own agenda rather than listen to the person's.

Participants suggested that, within the advocacy partnership, they felt involved and their views, wishes and feelings were listened to. Moreover being a member of a peer or self-advocacy group was reported to involve working together to deal with issues, set the agenda, problem solve, being asked what you want to do, make decisions together, find information together and try to find answers together.

## **6.6. Feelings**

The feelings advocacy outcome theme focused on the feelings that the participants associated with the advocacy partnership. Participants reported a number of mostly positive feelings such as feeling positive because they have been listened to. Participants also suggested valuing not feeling ignored by their advocate, in contrast to the feeling they had sometimes when working with professionals.

Something which may seem like an obvious expectation from a service was highlighted as important from participants who have experienced feeling ignored by professionals, in their lives. Participants reported that they felt that their views, wishes and opinions were valued within the advocacy partnership and that made a positive change. OPAAL (2009) participants also reported that they felt listened to in the advocacy partnership and also it was suggested that their views, wishes and opinions were valued and that made them feel more empowered. Furthermore, some of the participants reported that they were satisfied with advocacy despite not meeting the identified target at the beginning of the process.

Participants also reported feeling more able to express their feelings as they felt more empowered to open up and share their views something that did not feel the same when dealing with some professionals who made them feel talked down and belittled. Participants suggested that they felt encouraged to express their feelings and their point of view. Participants additionally reported feeling more positive about themselves and also having an overall positive effect in their lives. Some participants even suggested that the advocacy partnership supported them to increase their overall well-being and feel better about themselves and in general. Palmer et al. (2012) participants also highlighted the importance of the feelings of trust in their relationship with their advocates something that was also highly valued by our study's participants.

Barnes and Tate (2000) participants reported feeling being listened to by someone who understood them was important and they also felt more confident. The majority of participants suggested that advocacy provided them with a voice however some participants described it as a quiet voice. With the exception of the reported feeling of being less angry and of the advocacy voice being quiet the findings from Barnes and Tate (2000) were similar to the findings from our study. Another major difference between the findings in the two studies is that although there were a number of positive outcomes related to advocacy reported, from the Barnes and Tate (2000) study, empowerment was absent. Similar to the Newbigging et al. (2015b)

study participants at Barnes and Tate were inpatients detained in a hospital. On top of that, Barnes and Tate (2000) participants were detained in a secure forensic psychiatric hospital feeling even more disempowered and advocacy did not change those feelings. Again the Goffman (1961) account of the total institutions and their functions, that were designed to make people feel disempowered, appear to be applicable to the secure psychiatric hospital in Barnes and Tate (2000) study. This provides a possible explanation of why the participants in the secure hospital reported different feelings compared to other participants not detained in hospital explored in this chapter.

### **6.7. Impact**

The impact advocacy outcome theme focused on what the participants highlighted as the effects from their experience of working within an advocacy partnership. Participants proposed that advocacy had the positive impact of supporting them to become more involved, to speak up and self-advocate. Participants also suggested that dealing with issues in a different way was a positive impact of advocacy. Participants expressed that advocacy's positive impact included supporting them to build up their confidence and to become more effective in speaking up for themselves and self-advocating.

Eades (2018) reported an increase of self-reported self-determination for the majority of the participants which was described as a positive impact. Bocioaga (2014) also reported advocacy's positive impact in services and relevant systems however this was beyond the focus of the advocacy outcomes study which concentrated on the impact directly relevant to people with learning difficulties. Caldwell's (2011) interviews with self-advocacy leaders highlighted a positive impact which included gaining confidence, speaking out and finding a voice through their participation at the self-advocacy group meetings. Membership in a self-advocacy group encouraged individuals to form a connection with other disabled group members and formulate their disability identity as well as a sense of community, also

described as important impact. Self-advocacy leaders expressed also that the group helped them to accept and embrace differences as well as understand limitations and be ok with that as well as develop a sense of pride in contrast to negative labelling and disability oppression. However, individuals also expressed that they felt contrasting feelings between their sense of pride to be disabled and labelling such as mental disability or mental retardation, with so many negative connotations, that are still commonly used in the United States. They also drew a parallel with the sense of pride of physically disabled people who however do not have labels as stigmatising as theirs and can therefore fully embrace their sense of pride over their identity.

The findings derived from the structure and performative context of the participants' accounts also demonstrated a sense of unified identity for people with learning difficulties full of positive qualities such as resilience, perseverance and self-determination. Participants in our study provided a valuable insight into advocacy's outcomes impact from their unique privileged position of lived experience. Participants highlighted why advocacy is seen as important and valued as a service by people with learning difficulties.

## **6.8. Learning Outcomes**

A number of learning outcomes were identified from the participants' data. Participants reported that they have learned a lot from the advocacy process and from working within an advocacy partnership. They shared a number of their stories demonstrating how learning occurred and what this meant for them. The participants proposed that they learned new skills as well as enhanced current skills such as life skills and organisation skills. They shared that within the advocacy partnership they felt supported to learn to try and look into finding different options, information and alternatives in different parts of the process. Participants suggested that they learned different skills such as making complaints, becoming more involved in different stages of



decision making processes, finding the right information, planning actions together and working together in every step of the process.

Clarke et al. (2015) suggested that being part of a self-advocacy group was an important theme and was positively associated with increased learning opportunities, self-development and empowerment. Membership of a self-advocacy group was linked with learning new skills and knowledge, development of more positive relationships, sense of self, social identity, interpersonal learning, self-determination and building resilience. The self-advocates also highlighted in the interviews the challenges faced by the group members such as some members getting emotional, shouting or even being patronizing at times.

The positive elements of belonging to a group such as empowerment, learning, having a sense of belonging as well as mutually supporting each other were also highlighted in our study. However the negative elements were not brought up by the participants. The difference in the findings can potentially be explained by the fact that Clarke et al. (2015) study focused solely on the experiences of members of a self-advocacy group whereas our study explored experiences across different types of advocacy work. The group members at Clarke et al. (2015) made decisions and plans collectively and learned from each other. Increased confidence was also reported by members and that everyone had the opportunity to express their views and wishes as well as feelings and discuss different topics, themes also highlighted in our research study. These findings are consistent with the experiences expressed by the participants in our study.

Participants demonstrated that they were willing to learn and to expand their knowledge as well as valued becoming part of the research process and knowledge production themselves. Participants demonstrated an identity highly motivated to learn but also to generously share their knowledge and valuable lived experience.

## **6.9. Satisfaction**

The satisfaction outcome theme encompassed what the participants liked about advocacy and what they were satisfied with. Participants expressed that they liked advocacy for a number of reasons. Most importantly however advocacy partners valued advocacy because it made a difference in their lives despite not always achieving what they wanted. Participants suggested that they were satisfied with advocacy and that it is an important, useful and much-needed service. Participants outlined that advocacy was accessible and that they liked they met regularly with their advocacy partners. Participants shared their stories, experiences and a number of practical examples but also discussed their views and thoughts on what they liked about advocacy in the interviews.

Thomas et al. (2016) suggested that young people highlighted feeling high satisfaction rates with advocacy an outcome that was consistent with the findings of our study. Oliver et al. (2006) also reported that the majority of young people, asked, suggested that they had high levels of satisfaction from the advocacy service they used. The majority of OPAAL (2009) participants also reported that they were fully satisfied with the advocacy support and only one reported that they were not satisfied. Wright (2006) participants reported that they valued the advocacy service even when the agreed end-point outcome goal was not reached, something that was consistent with what was reported by the participants in our study.

Murphy (2001) study reported that participants felt satisfied with advocacy and expressed that advocacy had a positive effect on them and expressed that their expectations of the advocacy service have been met. Participants that have used the mental health advocacy services in Newbigging et al. (2015b) reported satisfaction from the advocacy process but not necessarily in regard to end-point outcomes such as improved care and treatment under the Mental Health Act. Palmer et al. (2012) participants also reported satisfaction for both the process outcomes and the end-point outcomes from their work with the independent mental health advocates.

Darwin and Pickering (2007) carried out qualitative research that looked into the experience of advocacy by disabled adults who had been victims of anti-social behaviour. They reported that the people who worked with advocacy expressed that they were satisfied by the service and felt supported. They also highlighted that they felt that the advocacy standards were excellent. The Darwin and Pickering (2007) findings were consistent with the findings from our study with participants reporting in both studies that they felt supported and satisfied with advocacy.

Gilmartin and Slevin (2009) participants suggested that being a member of a self-advocacy group enhanced the quality of life of its members by feeling more fulfilled, feeling a greater sense of self-determination, positive identity, personal development and autonomy. Members of self-advocacy groups, in our study, also suggested that they were satisfied with being a member of the group and with what they did in the group. Self-advocacy group members highlighted that they were satisfied with the work that was taking place in the group and also found it valuable. Moreover, a number of participants in our study reported that they felt advocacy was important, valued and a service that can be seen as an ally to people with learning difficulties.

#### **6.10. End-Point Outcomes Short-Term**

The short-term end-point outcomes focused on the short-term measurable aspects of advocacy outcomes. Participants proposed that advocacy involvement helped them with practical aspects and supported them to resolve them. For instance, several participants shared that their advocate helped them to write letters or to chase things up to sort out an issue. Moreover, participants reported that their advocates helped them to make a complaint and speak up. Bocioaga (2014) participants reported that hard or end-point outcomes such as advocacy supporting them to maintain their independence or regain control of their circumstances, completing forms, making complaints and navigate complex systems were important and valued. Bright (2008) participants also pointed out a number of short-term end-point outcomes including being supported to obtain the appropriate equipment such as a specialist mattress and physical adaptations which can

help to remain living within your home for longer and thus have more choice, control and more independence. Participants in our study indicated that practical goals were so important that, some of the times, they were the reason why they engaged within an advocacy partnership in the first place.

Tarleton et al. (2006) study with parents with learning difficulties suggested that advocacy was helpful particularly with writing letters which is a short-term end-point outcome also found in our study. Wright (2006) participants highlighted end-point outcomes which included increased income via improved access to financial entitlements and more independence via being supported to obtain appropriate equipment and physical adaptations. Participants, in our study, listed a number of positive end-point outcomes from the advocacy partnership such as writing letters with requests, expressing their views, wishes and needs as well as letters of complaint thus also at the same time increasing the relevant skills in expressing themselves. Participants shared also practical examples of actions they planned and carried out together in the advocacy partnership to tackle specific issues and problems.

Palmer et al. (2012) suggested that the participants reported satisfaction for both the process outcomes and the end-point outcome something not found in Newbigging et al. (2015b) study. The differences in findings between the Palmer et al. (2012) and Newbigging et al. (2015b) may be attributed to the fact that Palmer et al. explored an innovative specialist advocacy service which adopted a proactive approach compared to the mainstream IMHA service involved in Newbigging et al. (2015b). Palmer et al. (2012) reported that the proactive approach was closer to the main principles of advocacy suggesting that action needs to be taken to support individuals to express their views and secure their rights. This approach is similar to the recommendation from Newbigging et al. (2015b) who argued that a proactive opt-out rather than opt-in approach could increase the accessibility of the specialist advocacy service and potentially the end-point outcomes but also the feelings of empowerment experienced by the people that used the advocacy service.

### **6.11. End-Point Outcomes Long-Term**

Nearly all of the participants in our study reported that advocacy supported them to meet a number of their long-term end-point outcomes. They suggested that advocacy supported them to attend more meetings, be more involved in community activities and having more independence. Participants shared different practical examples of the end-point advocacy outcomes from their experiences of advocacy.

Thomas et al. (2016) suggested that young people valued advocacy because it supported them to reach their goals and solve specific issues something which again is consistent with our study's end-point advocacy outcomes. Young people demonstrated that they valued their relationship with their advocate irrespective of the actual outcome of the advocacy work something that highlighted the importance of the advocacy journey's process outcomes, something also evident in our study's findings. Moreover, young people in Oliver et al. (2006) expressed that end-point advocacy outcomes such as achieving more contact with family and friends, remaining in a placement of their choice and obtaining access to housing and welfare benefits were also very important, again consistent with the long-term end-point outcomes shared by the participants with learning difficulties in our study.

Barnes and Tate (2000) participants also highlighted positive end-point outcomes such as advocacy supporting them to access useful information, making formal complaints, making transfer requests, getting in contact with others, supporting them to access benefits and buy goods. Participants also reported that advocacy supported them when attending tribunals and review meetings. Overall the findings from the Barnes and Tate (2000) study were consistent with the findings from our study, thus emphasising the importance of end-point and process outcomes. Participants in our study additionally shared personal stories and expressed that advocacy helped them to live independently.

Parents in Tarleton et al. (2006) study also suggested that their advocate helped them to speak up and argue their points across, a finding highlighted a number of times in our study. Tarleton et al. (2006) study wrote a list of positive steps advocates were taking to support and empower the parents however they also noted that there was a shortage of independent advocacy services available for the parents.

After discussing all the main themes that were identified in our study, with people with learning difficulties, the chapter continues by discussing the findings from the bottom-up further exploration of the advocacy outcomes which focused mainly on the sub-themes rather than the main themes identified.

### **6.12. Top Findings**

Apart from the nine main themes identified, in our study, three sub-themes were also highlighted as the top findings which were the most representative of what advocacy and its outcomes meant for the participants. The analysis of the data and the discussion with the steering group recognised “felt listened to”, “on my side” and “speak up” as the top outcomes, from the participants’ accounts content, meaning, structure and performative context. Participants consistently suggested that they felt listened to in the advocacy partnership and that this was very important for them. They highlighted that feeling listened to and working together with their advocate was rather important and made a difference compared to being told what to do by a professional or someone else doing something for them. Participants shared that this was very important as someone telling them what to do was seen as negative however unfortunately something that they have experienced before. Participants expressed that they did not like feeling being told what to do by professionals and highlighted that they also did not like feeling talked down or being ignored.

Participants with learning difficulties suggested that, at least on some occasions, they had felt not listened to before when working with a

professional. Participants expressed that their advocacy partner made them feel better by listening to them compared to just telling them what to do. They shared that their experience working with an advocate was positive compared to some negative experiences of working with professionals. It was also highlighted that the advocacy partnership contributed to them becoming more confident to challenge people and not agree with what is on offer when they are not happy with it.

Almost all the participants expressed that they felt that their advocacy partners were on their side. They shared views and experiences suggesting that working with an advocate was a positive experience that helped them to self-advocate and speak up more. Many participants reported that they felt that their advocate was always on their side supporting them to fight their corner. The views and experiences shared by the participants also indicated that at times in the past, when they worked with other professionals, they did not always feel that they were on their side but sometimes they felt they were against them.

Bocioaga (2014) study reported that participants expressed a sense of relief that the advocate was on their side supporting them to deal with problems, ensuring their voices, views and wishes are listened to. Participants from Wright (2006) study also reported that participants expressed that they felt their advocate was on their side and encouraged them and helped them to find solutions. Additionally, participants, in our study, mentioned that the advocates did not set the agenda and did not try to push their views and opinions but rather worked together with them. They shared experiences suggesting they were feeling that professionals, they were working with, were not on their side and they were trying to put ideas into their head and tell them what to do. The participants also reported that they persevered with the support of their advocate and were able to express their views and wishes and do something about the issues they were facing. Similarly, many participants shared, in the in-depth interviews, that advocacy felt more equal and not talked down and that the advocate did not try to take over.

Furthermore many participants expressed that they felt that their advocacy partner supported them to stand up and speak up for themselves. Participants with learning difficulties that used advocacy suggested that this was a very important aspect of the advocacy partnership. They shared that their advocate supported them to express their point of view and how they were feeling. They also suggested that their advocate helped them to ask for more and fight for their rights. Additionally, participants shared stories relating to their perceptions of advocacy and the meanings they associated with it. They expressed perceptions of advocacy strongly associated with speaking up and self-advocating for one's self. Many participants proposed that advocacy was giving people the confidence to self-advocate, stand up and speak up for themselves without any support. They also shared that without the advocacy partnership potentially they could have been less inclined to speak up and self-advocate. This argument was seen as particularly important because not speaking up, being afraid and staying quiet were reported by participants as rather negative attributes.

Tideman and Svensson (2015) reported that membership, in self-advocacy groups, increased speaking up, health and well-being and provided a sense of control in the lives of people with learning difficulties. Participants, in our study, also emphasized the importance of peer and self-advocacy as peer and self-advocates mutually support each other to speak up and take action about any issues they have as well as encourage each other. Mineur et al. (2017) reported that self-advocacy group members highlighted that they sometimes were supported by their co-workers but other times they supported their co-workers, making it mutual and reciprocal. Participants, in our study, shared that they perceived as rewarding encouraging and supporting other people, with learning difficulties, but also being encouraged and supported to speak up particularly in self or peer advocacy group settings.



### **6.13. What is the Meaning of Advocacy?**

The chapter so far concentrated on exploring our study's themes and outcomes and discussing them, comparing and contrasting them with other advocacy research studies from the literature. It continues by focusing more on the structure and performative context of the participants' accounts. The meaning of the content was examined by looking at the narratives in an attempt to identify the deeper meaning of advocacy for the participants. The chapter also discusses the findings, from our study, and relates them to current theories of disability and social policy.

Overall, the advocacy partnership has been reported to be something positive that is being welcomed in the lives of people with learning difficulties that have used advocacy. Advocacy has been reported to be something that you can rely on and you can trust. Furthermore, since many participants have mentioned that they had negative experiences when working with professionals, the advocacy partnership became an even more important positive relationship. The importance of the human relationship element of the advocacy partnership was also highlighted. Advocacy partners described a number of advocacy qualities that are also basic elements of a positive human relationship. The advocacy partnership was described as involving being listened to, feeling safe and being encouraged to express your views and thoughts and work together to plan and take action when something is not right. .

It has been highlighted that advocacy can produce positive outcomes even when the main target, agreed at the beginning of the partnership, was not achieved. Moreover, advocacy partners were described as different compared to professionals. Advocacy was perceived as friendlier, more approachable and less formal compared to professionals involved in a person's life. Advocacy partners were described as allies in the life of disabled people during often challenging times. Particularly since it has been demonstrated that not all professionals involved in their lives were seen as allies.

Llewelyn and Northway (2008) explored advocacy's meaning and definition with people with learning difficulties who have experiences of using advocacy. The research concluded that advocacy had different meanings for different groups, of people with learning difficulties, in different situations. All participants, however, highlighted the importance of relationships within advocacy. One key point was that empowerment was not always achieved despite being advocacy's main goal alongside longstanding positive relationships which was supported by the findings. These findings gave support to the notion that advocacy cannot be empowering in all circumstances as highlighted by the group of participants being detained in mental health hospitals (Newbigging et al., 2015b and Barnes and Tate, 2000).

Our study, however, did not support this notion as all the participants, to some extent, proposed that they felt that advocacy aided their empowerment. One plausible explanation, for the difference in findings, could be that the people that expressed that they did not feel empowered were detained in mental health hospitals. As Goffman (1961) highlighted total institutions utilise a number of methods in order to disempower and control people. A parallel can be drawn between Goffman's (1961) total institutions and modern-day mental health hospitals as both appear to potentially have disempowerment as an outcome. Thus, it can be argued that people detained in mental health hospitals were extremely disempowered and advocacy could not support them to reverse that and feel empowered.

Another important meaning identified was that the advocacy partnership was a different way of working rather than a fast solution or a snapshot. The advocacy relationship was described as a journey rather than something static. Advocacy was likened to a journey that unfolds as the advocacy partnership progresses rather than remaining the same or being repetitive. The advocacy partnership was described primarily as a positive, trusting human relationship, without this basic characteristic the partnership is unlikely to flourish. The partnership evolves as the partner is becoming more

confident and develops more skills. Always the ultimate goal is the partnership to lead to the empowerment of the partner to speak up and self-advocate without the need and the presence of advocacy.

Finally, advocacy's meaning was strongly linked to asking for more, not be expected to do as you are told and being supported and encouraged to do that. It was highlighted by a number of participants in our study and across different studies that people who use advocacy do not always feel like that when working with other professionals. The peoples' voices were not always really listened to and the people did not always feel they were working together with the professional that was there to support them. The participants in ours and other studies did not feel that the professionals working with them, to support them, were there to listen to their voice, share their views, encourage them to be actively involved, speak up and feel empowered. To the contrary, participants expressed that they felt that, at times, working with professionals made them feel talked down and disempowered. Participants felt that they were not supported to speak up, that they were not listened to and that they were not able to work with the professionals in an equal way. Participants reported feeling that professionals' ideas, views, targets and priorities were seen as more important compared to their ideas, views, targets and choices.

#### **6.14. The importance of Self-Advocacy**

Participants in our study highlighted the importance of self-advocacy as well as of speaking up for one's own self but also for other people with learning difficulties. Participants with learning difficulties demonstrated that they have been facing barriers and certain difficulties, however, they felt able to overcome some of those barriers. Participants with learning difficulties showed that they were able and willing to make their own decisions and choices and not just accept something they were not happy with, something that was valued as very important for them.

Participants and self-advocates in our study with their active involvement and participation in the production of narratives and knowledge also challenged the modernist and ableist views of people with learning difficulties. Participants also demonstrated the importance and value of mutual support between peer and self-advocates a partnership which was highly valued. Participants in our study showed that they have interesting stories, views and valuable lived experience that they are willing to share and thus provide positive views and representations of people with learning difficulties.

Moreover the structure and performative context from the participants' accounts, highlighted that they can take the role of the peer and self-advocate, mutually support each other, and not only be a partner in the receiving end of an advocacy partnership. They also highlighted that offering support can be a mutually beneficial partnership as it is important not only to receive but also to give in order to be involved in a reciprocal partnership. The potential of self-advocacy for shifting the power dynamics of an advocacy partnership was also highlighted as an important element of self-advocacy.

Participants in our study set a clear example that people with learning difficulties can be actively involved in research by clearly demonstrating their perspectives and their achievements, by sharing their stories and taking an active part in research and the creation of knowledge. Participants demonstrated that they were able, willing and more than capable of actively participating in research and knowledge production if they have the opportunity.

The importance of self-advocacy highlighted in our study was also identified and demonstrated in the Goodley and Armstrong (2001) study where similar experiences and views were shared by the participants in their study. Goodley and Armstrong (2001) claimed that the self-advocacy study outcomes came into contrast with dominant negative constructions related to learning disabilities such as dependency on others and lack of ability. The dominant ableist and modernist constructions were challenged by the

participants in our study by consistently deconstructing them and replacing them with more positive ones highlighting their perspectives and their achievements. Goodley and Armstrong (2001) study's reported findings were in many ways similar to the findings from our study.

Clarke et al. (2005) concluded that the change and the outcomes that take place in the self-advocacy group at the individual level are often carried on into the wider community and bring about a positive change such as breaking down barriers, constructing positive identities and integrating fully as equals.

However, self-advocacy groups project the wider insecurity of the voluntary sector being constantly under threat of funding cuts and with them come under threat the associated positive individual and collective outcomes. The need for secure funding and commissioning for self-advocacy groups has also been highlighted to remove barriers to inclusion and enhance the quality of life and promote equal treatment, equal citizenship and equal participation.

### **6.15. What difference does Advocacy make?**

As discussed in previous sections advocacy has an even more important role to play in difficult and challenging times for people with learning difficulties. Our research highlighted that advocacy can support individuals to express their views, speak up, be listened to and ultimately feel empowered and self-advocate. Our findings suggested that advocacy supported people with learning difficulties to ask for more, express their disagreement and challenge in a sometimes negative and hostile environment. The study reported that overall advocacy was seen, by people with learning difficulties that have used the service, as something positive. Both in the advocacy outcomes findings section as well as in the further exploration section most of the views, opinions, thoughts, perceptions and experiences expressed by our participants portrayed advocacy as important but also welcomed in the lives of people with learning difficulties. Participants expressed views and experiences portraying advocacy as a service being on the same side as the person who uses the service. Advocacy organisations appeared to have

postures, such as their main aims and principles, which were close to the actual organisations' cultures thus according to Brandon's (2005) theory demonstrate service forum coherence rather than incoherence.

Participants expressed views and experiences that working with professionals was not always a positive experience. They shared feelings that the professionals wanted to push their own points of view and agendas rather than listen to the person and act according to the person's agenda. This seems to be a contradiction, or a service forum incoherence, when a professional service designed to support individuals with learning difficulties is not listening to their views and wishes. Many participants consistently supported this view using different examples from their personal experiences. Potentially this is one of the main reasons why people with learning difficulties saw advocacy as such a positive and important service. It can be inferred that fundamental elements of good service provision were not met by some of the other professional services that were supposed to provide support for people with learning difficulties. Advocacy seems to be meeting those fundamental elements and therefore is seen as something positive, important and valued.

Participants suggested that professionals, in at least some instances, were not seen as allies and not on their side. This can be seen as a contradiction since all these services have been developed to support people with learning difficulties and be person-centred. Many participants suggested that they saw their advocates as different compared to the professionals involved in their lives. The advocates have been described as more approachable, friendlier and less formal compared to professionals.

The above suggestions also demonstrated that if the professional services were closer to what they described, themselves as, then probably the need for and also the impact of advocacy would have been lesser. If professionals and their services were real allies to people with learning difficulties listened to their views, wishes and needs and acted accordingly then the need for advocacy potentially would not have been as powerful. However, following

several years of austerity and neoliberalism the need for advocacy seem to be higher and stronger than ever before as the service incoherence (Brandon, 2005) for many organisations grew further apart.

Advocacy made a difference, advocates were seen as allies to people with learning difficulties working together with the person to strive towards positive changes both in terms of process as well as of end-point outcomes.

#### **6.16. Lack of Research**

The lack of research on advocacy and its outcomes from the point of view of the people who use the service is well documented in the literature (Newbigging et al., 2015b, Thomas et al., 2017, Macadam et al., 2013, Perry, 2013, Ridley et al., 2018). However, this lack of research comes despite being recognised as a key element of the measurement of the effectiveness of any advocacy service in the literature for some time now (i.e. Brandon and Brandon, 2000). Brandon and Brandon (2000) highlighted that the impact for individuals, that have used the advocacy service, is the most important consequence or measure of the effectiveness of any advocacy. Furthermore, Action for Advocacy (2009) highlighted the importance of the involvement, of people that have used advocacy, in any meaningful examination of advocacy outcomes. Action for Advocacy (2009) argued that for advocacy to be better understood the views and experiences of people who use the service need to be further explored. Moreover, Ridley et al. (2018) suggested that it is important that this gap, of research produced from the lack of the point of view of people who use the service, needs to be addressed. Ridley et al. (2018) concluded that focusing on the perspective and the experiences of people using advocacy can bring valuable insight into the real advocacy impact and outcomes for the people who use this service.

The lack of research is particularly evident with people with learning difficulties who use advocacy. Greig (2015) suggested that past, disempowering, assumptions made about people with learning difficulties need to be challenged by motivated self-advocates who can show that those

assumptions were wrong. Self-advocates and advocacy partners participating in research and sharing their stories can be a way of empowerment and proving those assumptions wrong.

Townsley et al. (2009) also highlighted that, despite the documented high levels of anti-social behaviours towards disabled people and people with learning difficulties in particular, there is still very limited research on how to reduce it. Townsley et al. (2009) suggested that there is very limited evidence basis about the impact of independent advocacy regarding disabled victims of crime. Moreover, there were even fewer studies looking into the experience of advocacy and its outcomes from the point of view of disabled victims of anti-social behaviour. The same is true for disabled people who are described as alleged perpetrators of anti-social behaviour.

A number of reasons have been identified in the literature to explain why there is little systematic research into advocacy, its outcomes and impact in different fields. Stewart and McIntyre (2013) suggested that the difficulty to effectively measure the impact of advocacy outcomes for people who use the service can be partly attributed to the wide range of schemes with differing aims and objectives. Miller (2011) highlighted that advocacy is only one of a number of different influences in a person's life, making it difficult to determine any positive changes directly attributed to advocacy. Action for Advocacy (2009) argued that potentially some people using advocacy may find it difficult to express their views around advocacy outcomes for them. Wood and Selwyn (2013) pointed out that the changing policy landscape around advocacy provides little guidance as to what outcomes should be monitored and how. In addition, Wood and Selwyn (2013) suggested that the competitive and constantly moving commissioning and tendering processes of advocacy service provision makes projects reluctant to share information with researchers as well as with each other.

Our advocacy outcomes study aimed and managed to bridge this lack of research on advocacy from the point of view of people with learning difficulties that have used the service. The research was carried out with the



people that have used advocacy making sure that their authentic voice is included and promoted. Our study apart from providing valuable evidence from the research also demonstrated an inclusive way of carrying out the research.

Moreover, Roberts et al. (2012) noted that the funding for advocacy for people with learning difficulties has been declining steadily in recent years. Roberts et al. (2012) suggested that the decline in funding came despite the importance of the advocacy services for people with learning difficulties being recognised by commissioners and also despite the advocacy service being seen as a successful and worthy as well as good value for money service. Good examples of advocacy quoted from Roberts et al. (2012) included improved access to health and social care services, development of systems to tackle hate crime, training professionals and be involved in important services reforms.

Wetherell and Wetherell (2008) also pointed out a lack of systematic evidence however also suggested that despite the lack of empirical evidence or monitoring frameworks around advocacy and its outcomes, the literature has been able to identify some positive outcomes associated with advocacy. Roberts et al. (2012) commented that advocacy is supporting individuals with learning difficulties to have a voice, achieve equality, gain rights, be empowered, have more choice and control, access and challenge services. Roberts et al. (2012) argued that the reduction in funding has been shown to have affected, as expected, the quantity as well as the quality of the advocacy services provided to people with learning difficulties. Roberts et al. (2012) concluded that further research on advocacy outcomes was required in order to further demonstrate good practice.

Our advocacy outcomes study provided further evidence indicating that advocacy is important and valued by people with learning difficulties that use the service. Our study was particularly important because most advocacy research with people with learning difficulties was carried out in the late 1990s to mid-2000s. Since then a lot has changed in the way the society and

advocacy operate. Our study took a fresh look in the topic, explored advocacy and provided important evidence by directly carrying out the research with the people that use the service rather than for them or on them.

### **6.17. Lack of Evaluations**

However, apart from the lack of advocacy outcomes research, it has also been suggested that advocacy organisations have not been consistent in recording and reporting outcomes particularly from the point of view of the people who use the service (Townsend et al., 2009). Thomas et al. (2016) explored six advocacy projects working with young people and suggested that advocates and their managers felt that it was really important to effectively monitor and record outcomes. However, Thomas et al. (2016) also highlighted that it was particularly striking for them that the commissioners of the service were not very clear about how different advocacy outcomes should be recorded but rather focused on outputs such as demographics. The practical challenges that advocacy projects were facing in recording the outcomes included limited feedback received back from the people that used the service, lack of capacity within the organisation and potential conflict with the principles of advocacy such as being non judgemental (Action for Advocacy, 2009). Newbigging et al. (2015a) also argued that some advocacy projects have cited a lack of capacity within their schemes to regularly and systematically collect data on advocacy impact and outcomes.

NDTi (2016) suggested that the advocacy sector has been examining ways of measuring outcomes for a number of years and that the lack of a nationally recognised method is not the result of advocacy sector's lack of willingness to do that. However, it is widely acknowledged that concisely measuring advocacy outcomes is a complex task as there are a number of factors and challenges that the advocacy projects are facing. Bauer et al. (2013) also noted that despite numerous attempts, to measure advocacy outcomes, there is still no single recognised evaluation method that advocacy projects use. Macadam et al. (2013) highlighted that in evaluations

more focus was placed on advocacy principles rather than on the outcomes for the people who use the service.

NDTi (2016) proposed that it was a prerequisite of an effective advocacy service to be able to deliver good outcomes for the people who use the service and that the most important aim of advocacy was supporting people to achieve their goals and ultimately self-advocate. Thomas et al. (2016) suggested that the best way to create an effective way of collecting the outcomes is to co-produce a method with the people who use the service. Furthermore, MacKeith and Graham (2007) claimed that generally exploring the outcomes from the point of view, of the people that use the advocacy service, should become part of a general wider shift of focus onto the person and their outcomes. As it is widely acknowledged that without the shift of focus, the outcomes measuring tools may just become another form which is bureaucratically completed by practitioners.

## **6.18. Implications for advocacy research, practice and policy**

Our research on advocacy outcomes with people with learning difficulties that use the service demonstrated a number of points that have implications for advocacy research, practice and policy. The implications identified will be discussed in the following sections.

### **6.18.1. *Implications for advocacy research***

The advocacy outcomes research study showed that people with learning difficulties are able and willing to share their lived experience and actively contribute to carrying out research and producing knowledge particularly in a topic of direct relevance to them such as advocacy. People with learning difficulties demonstrated that they are experts by experience in this topic and that their authentic voice can contribute to a better understanding of advocacy. It can be argued that the lack of involvement of people with learning difficulties in the area of advocacy and research in general has been based on unfounded evidence. Advocacy research and research concerning people with learning difficulties, in general, ought to actively involve them to

build a more complete view of the topic. Furthermore our study highlighted that process outcomes need to be looked at more closely as they have not received enough research attention. Additionally, advocacy research should also focus on exploring advocacy outcomes in general and not only on principles of advocacy.

The study showed that the involvement of people with lived experience enhanced the levels of understanding of the topic under investigation. The study also demonstrated that researching with people with learning difficulties can de-construct views about them, with negative connotations, by producing new positive constructs about their identity. It can be claimed that participatory research with people with learning difficulties is an essential type of research that provides great benefits and has to be prioritised. As it was demonstrated in the literature review research has not included people with learning difficulties even in topics concerning them. Our study, along with other research studies using participatory principles, demonstrated that people with learning difficulties can be willing and able co-producers of knowledge. Prioritising participatory co-productions research projects can further inform different topics of enquiry by including the authentic voice of people with learning difficulties.

#### **6.18.2. *Implications for advocacy practice***

Our advocacy outcomes study highlighted a number of implications for advocacy practice. The participants in our study showed that they were highly motivated to learn, share their experiences and be actively involved in the research and knowledge making processes. Advocacy practice can also work together with people with learning difficulties, as well as other groups of people, that use the service in order to organise regular service evaluations and monitoring strategies. Our study demonstrated that the best strategy to go about monitoring, evaluating or improving the service is via directly involving the people that use the service, their views, wishes and experiences.

It is demonstrated in the literature and was highlighted by our study that a service can become more relevant, effective and person-centred by meaningfully actively involving the people that use the service in its evaluation and act on the feedback. The authentic voice of the people that use the service can guide advocacy and any other organisation, providing services to people with learning difficulties, to better service planning and delivery that is more relevant to the people that actually use it.

Participants in our study showed that they are passionate and determined to be included, be listened to and make a difference for themselves and their community. Additionally, the study demonstrated that involving people that use the service to express their views and perceptions about it can be an empowering positive experience in itself.

Furthermore, advocacy practice should focus more on trying to meet the process advocacy outcomes highlighted in our study and not only focus on end-point outcomes. Advocacy organisations need to demonstrate that they offer a service that produces good process outcomes because as demonstrated by our research they are of equal if not of greater importance compared to the end-point outcomes.

### **6.18.3. *Implications for advocacy policy***

Apart from having implications for advocacy research and practice our study also has implications for social policy surrounding advocacy. Our study demonstrated that people that use advocacy clearly reported that they value different forms of advocacy. Participants valued that their advocacy partners listened to them and supported them to fight their corner and several other positive advocacy outcomes described in the previous two chapters. However, participants also demonstrated that they valued the independence of advocacy and the advocacy partnership not having an agenda but rather listening to and acting together with the partner.

However with the majority of the funding made available for advocacy directed to statutory advocacy services the independence and lack of agenda come increasingly under threat. Advocacy was shown to produce its best outcomes when partners worked together to achieve the targets agreed together and not pre-determined targets that have been defined by third parties. The study's implication for policymaking is that funding should continue to become available to different forms of non-statutory advocacy services that do not have pre-determined targets.

Moreover, the study highlighted the importance and value of peer and self-advocacy as a number of participants argued their benefits compared to working with a professional advocate. It is important for policy therefore to encompass the importance for increased opportunities for different non-statutory advocacy services including peer and self-advocacy ones. It is of paramount importance that funding increasingly becomes available to organisations that support and provide peer and self-advocacy services as these are types of advocacy with high value and effectiveness, as clearly demonstrated by the participants in our study.

Additionally the study highlighted that process outcomes are of equal if not greater importance compared to end-point outcomes. The findings from our study implied that policy makers and commissioners of services should focus on advocacy services that promote good process outcomes as well as end-point outcomes. Policymakers should focus not only on hard measurements, outputs and numbers but also on the process qualities of the services. Evaluating the services by the people that use the services should also be prioritised.

### **6.19. Summary**

The chapter discussed the findings of the study by comparing and contrasting them with evidence from the literature review. The meaning, importance and value of advocacy for people with learning difficulties were also discussed. Advocacy is seen as important and valued by people with

learning difficulties that use advocacy services. This is stressed particularly in these difficult times when the external barriers to empowerment are increasing. Advocacy partners are seen as allies that promote involvement and empowerment.

Moreover the chapter discussed the importance of the findings and related them to social theories. The lack of advocacy research as well as evaluation from the point of view of the people with learning difficulties that use the service was highlighted. The implications of this project for future research, practice and policy are discussed. The need for the active inclusion, of the authentic voice of people with learning difficulties, in advocacy research, evaluation and policy was emphasised to provide a more complete view of advocacy.

## **7. Conclusion**

### **7.1. Overview**

The final chapter starts by answering the main research questions, identified by the steering group, at the beginning of our project. The chapter continues by looking at the theoretical implications of the advocacy outcomes study. The chapter then introduces and discusses a model of advocacy that represents the advocacy partnership and its mechanisms. Questions are answered with regard to the utility of our study and model in relation to people with learning difficulties' theory, their activism and politics as well as the policies affecting them. Reflections then are offered around the whole research process and the methodology along with personal reflections. The chapter then makes some recommendations for future research in the area of advocacy and learning difficulties and draws some conclusions concerning the future of advocacy. The thesis is completed by drawing some final comments and reflections on the work.

### **7.2. Conclusions on the Research Questions**

The research questions were identified following discussions and direct input from the self-advocacy group which acted as the steering group for the study. The research questions set the main targets of what the research wished to explore with the participants with learning difficulties. Self-advocates, in the group, demonstrated that people with learning difficulties are able and willing research partners that can contribute with valuable expert knowledge and inquisitive questions. The section continues by answering the questions from what has been learned from the advocacy outcomes study.

#### ***7.2.1 What is the relationship between advocacy theory and practice and the empowerment of disabled people?***

The findings from our study demonstrated that advocacy is seeking to address the power imbalance between the expert professionals who provide the service and the people "in need" of receipt of the service by the experts.



Advocacy demonstrated to be an ally of people with learning difficulties that stood shoulder to shoulder with them and shared the power rather than keeping the power in the hands of the expert professional. Advocacy partnerships have been successful in doing that by working together to achieve the goals agreed and to aid the empowerment to speak up and self-advocate. Participants clearly highlighted and demonstrated that they have felt empowered to express their views, feelings, thoughts and perceptions and to self-advocate as well as construct a positive identity for people with learning difficulties. Advocacy has been demonstrated to be different from professional services and an ally to people with learning difficulties something that has been highlighted by participants on a number of occasions.

Our study provided evidence that the advocacy partnership is a relationship which yields mostly positive outcomes as indicated in the lived experiences shared by participants in the interviews. The advocacy partnership was shown to be primarily a positive human relationship, which particularly during challenging times, can be a supportive ally working together with people with learning difficulties. Although challenging experts, such as health and social care professionals, seems a daunting task advocacy makes it much more achievable (Goodley and Ramcharan, 2010). Our study demonstrated that advocacy partners have worked together and gained confidence by learning new skills and techniques. They have also managed to show resistance and challenge propositions brought up before them and asked for more. Participants highlighted forms of everyday resistance and resilience where they have felt empowered to stand up, speak up, challenge dominant ideologies and prove them wrong. People working side by side in advocacy partnerships were empowered and took action to achieve their goals, asked for more and succeeded in tackling exclusion.

Participants with learning difficulties, in our study, challenged the dominant views which have been used to justify marginalising, excluding and othering people with learning difficulties. They contributed to alternative and more positive views of people with learning difficulties and towards a society with

less disablement and prejudice. The people that took part in our study highlighted that their label is not the important point but rather what they say, their voices, views, attitudes, perceptions and opinions which were meaningful and valued. Their informative and valuable stories and lived experience were a positive step towards their empowerment, the empowerment of other people with learning difficulties and the creation of more positive attitudes and less negative ones such as exclusion and stigma.

A number of parallels can be drawn between the advocacy practice, theory, inclusive participatory research and co-production as they all have as main aim the promotion of the voice of people who have often been excluded or silenced by dominant systems and ideologies. In the case of advocacy, the dominant system is the established health and social care bad practices and a disabling attitude of society that needs to be changed. The same analogy can be made for social theories such as the Social Model of Disability and Critical Disability Studies which promote the emancipation and empowerment of disabled people by encouraging people to carry out their own research and be actively involved in knowledge production, in contrast to theories that promoted the exclusion of people with learning difficulties.

Advocacy, similarly to the Social Model of Disability and Critical Disability Studies, is having a positive impact towards the change of negative attitudes in society. Furthermore, inclusive and participatory research approaches seek to change the power dynamics within the research process. Similarly to health and social care bad practices, mainstream research has excluded and disempowered people with learning difficulties for too long and participatory research is seeking to change this by shifting power to the people who have been silenced, excluded and were seen as story-less. Participatory research has been demonstrated to be potentially empowering for its participants as it offered them the opportunity to have their voices and views expressed, listened and valued as well as to contribute to the production of new discourses and knowledge.

Moreover, co-production in the health and social care sectors has been seen as a positive approach which recognises and values the active involvement, of people who use the services, in the service development as well as in health and social care priorities and policy decision making. Co-production is based on the principles of equality, diversity, accessibility and reciprocity and puts an emphasis on active citizenship, community support networks and voluntary effort (Scie, 2018). Co-production aims to share the power by directly involving diverse groups of people that have been previously excluded from decision making processes about health and social care changes. The notion of experts by experience has been increasingly recognised as a very important one and valuable to provide insight and knowledge on decisions.

Goodley (2005) noted that different authors have emphasized the self-determination, empowerment and independence of people with learning difficulties in the self-advocacy movement. Goodley (2005) went further to suggest that self-advocates have also been demonstrating a great form of resilience in response to a disabling society. Goodley (2005) highlighted that the self-advocacy movement was a moving force supporting people with learning difficulties to voice their views and be empowered. Goodley however also proposed that for something to really change and people with learning difficulties to be truly empowered a shift in power should happen. People with learning difficulties ought to be given the opportunity to speak up and self-advocate individually, in groups and in different fora. Self-advocacy should become the norm and not the exception and then there would be less need for advocacy to support individuals to speak up, be empowered and be listened to.

It can be concluded that the development of advocacy, its theory and practice have a direct relationship with the empowerment of people with learning difficulties. Although there is no unified theory related to advocacy the study demonstrated that advocacy supports people to be empowered, to self-advocate and speak up. The study also contributed to a better understanding in relation to what makes advocacy different from professional

services. Advocacy was portrayed as friendlier and less official but also on the side of the person that uses the service. Developing services accordingly can also lead to more effective practices that better aid the empowerment of people with learning difficulties.

However as theorists such as Goodley (2005) proposed for something truly to change there is a need for a drastic shift in power in order to allow people with learning difficulties to take control and be truly empowered. When the shift in power takes place there will be less need for advocacy and self-advocacy as then they will be the norm rather than the exceptions. People will be just arguing their point of view rather than self-advocate and they will be listened to and not be ignored. Only then it could be suggested that advocacy would have reached its potential regarding the empowerment of people with learning difficulties and only then we could talk of a fairer, more inclusive and just society.

***7.2.2. What recommendations has the study produced which can be used for the development of advocacy practice impact?***

The participants in our study clearly indicated that they valued advocacy because it was different and supported them to speak up and ask for more. Advocacy would become more effective in its practice and have more impact by being even more advocacy-like and reinforce the aspects that make it different and not another professional service. Advocacy has to listen even more to the people that use the service and make the service even more relevant to them. Advocacy needs to continue to be on the side of people using the service, continue to be speaking the truth to power rather than become part of the same system that is fighting against. Because if advocacy is to only be defined by statutory requirements and funders' priorities then it will move further away from what the people truly want from advocacy and thus become less effective.

Furthermore, it is important that different types of advocacy are supported to offer a variety of services that are closer to the people who use the service. It

is of paramount importance that self-advocacy is supported to continue to expand and involve more people with learning difficulties as it has been demonstrated that it is a form of advocacy that can truly empower its members and people with learning difficulties in general. Goodley (2011) argued that there are inherent dangers with “professionals” supporting people with learning difficulties to be empowered as this is potentially reinforcing the victim status. Moreover, this potentially reinforces negative viewpoints suggesting that empowerment is something that is given from the powerful to the weak.

Brolan et al. (2012) proposed that advocacy is about power as it strives to, first of all, share the power with the person that uses the service rather than take the stand of the expert that is telling the individual what to do and how to do things. Advocacy is seeking to support individuals to be empowered and also to gain some of the power back from a system that has disempowered people with learning difficulties. Jenkins and Northway (2002) suggested that advocacy is trying to influence those with power standing side by side with people who have less power. Fereday et al. (2010) highlighted that advocacy has the potential of conflict with those in positions of power and advocates are often seen by those in power as pushy and aggressive. Carver and Morrison (2005) argued that advocates have been often described and considered as trouble makers by some health and social care professionals and other staff that may perceive the advocacy partners’ views and arguments as criticism. Silvera and Kapasi (2002) proposed that advocacy is deeply rooted in an understanding of unequal power relationships between the people that use the service and the services that support them, and is associated with viewing the world from the point of view of the person that uses the service.

Advocacy has been demonstrated, in our study, to support people to be empowered to speak up and self-advocate. Different types of advocacy have supported individuals to self-advocate, express their views and wishes and to have their voices listened to. However, some potential dangers have also been identified with the increase in numbers of statutory advocacy services

as well as the increase of advocacy service contracts with the targets and aims determined by funders and organisations rather than the people who use the service. The main danger with these developments is that they can lead advocacy to become increasingly part of a system that has failed to empower people with learning difficulties for so long. It is a danger that can lead advocacy to increasingly lose track of its main advantage, its essence and what makes it different standing side by side with people who use the service. Advocacy shares the person's agenda rather than being another professional service putting its own or its funders' agenda telling people what to do and not truly listening or strive to empower them. If advocacy increasingly becomes part of the mainstream health and social care system it is likely that it will gradually lose part of its force and main reason for existence. As it will become embedded in a system that supported people to speak up and self-advocate against.

In conclusion, our study has produced several recommendations that can be used to further develop advocacy and its impact. The study highlighted that advocacy is valued by people with learning difficulties that use the service because it is different from professional services. Advocacy has been demonstrated to be on the side of the person fighting against a system that has oppressed and pushed people with learning difficulties towards the margins of mainstream society. Advocacy in order to continue to be an effective ally against such systems and further develop its impact needs to listen and share even more the point of view, struggles and causes of people with learning difficulties. It has also been highlighted that if advocacy is driven towards becoming another professional service, which is part of the mainstream health and social care systems, then it will lose its main strengths and advantages and will lead itself to ultimately losing its real purpose of existence.

### ***7.2.3. Does current advocacy practice contribute towards positive or negative outcomes for the people using the service?***

Participants in our study challenged negative viewpoints and discourses as they clearly demonstrated that they are not story-less. They clearly showed that they were able and willing to share their stories, views, wishes, attitudes, perceptions, meanings and lived experience and create knowledge and powerful discourses. Participants highlighted that they are empowered, skilful, competent co-producers of knowledge rather than powerless and story-less victims of their “mental impairment” labels assigned to them by a dominant modernist ideology. They shared their stories where they stood up, spoke up for themselves, asked for more and fought for their rights and entitlements.

Furthermore, the study demonstrated that advocacy was seen as an ally by people with learning difficulties and a supporter in their struggle with powerful institutions and systems. It was shown that advocacy can play a big part in the struggle of people with learning difficulties towards reclaiming voice, power and identity. Advocacy was also demonstrated to counteract some of the negative disempowering effects that can be experienced by individuals involved in health and social care systems. It has been shown to share the power with the individuals rather than the practitioner keeping all the power thus leaving the person that used the service feeling disempowered. All these were positive advocacy outcomes for the individuals that took part in the study but also by inference for people who use different types of advocacy.

Different types of advocacy have been demonstrated to have different advantages and disadvantages (for a summary see Table 1). The study attempted to view advocacy not as different types but rather as a unified entity with at least some common core principles. This was not done to deny the benefits and drawbacks of certain advocacy types but rather to demonstrate a different approach. Concentrating on different principles and elements of advocacy was quoted as one of the main reasons why advocacy outcomes research studies have been so scarce. Our study wished to show

a different way of carrying out advocacy outcomes research where the focus is on the perspective of the participants rather than the type of advocacy.

The study also highlighted that advocacy needs to be driven by the individuals using the service rather than the professional, the organisation or any other stakeholders including commissioners and funders. If the advocacy partnership is led by the professional advocates and the demands of their services and their funders' agendas then advocacy faces the danger of becoming just another professional service not fighting for the empowerment of people with learning difficulties.

Goodley (2005) criticised policymakers and funders for attempting to formalise and professionalise the self-advocacy movement and also for setting many aspects of the political agenda for people with learning difficulties without them. Goodley (2005) highlighted that policymakers, funders and professionals need to be led by the self-advocacy movement otherwise there is a danger that the whole movement will be redefined in ways that contrast its main aims and identity.

In conclusion, different types of advocacy have been demonstrated, by the participants of this study, to contribute towards positive outcomes for the people that use the service but also people with learning difficulties in general. Participants in our study shared their stories, thoughts, views and opinions about advocacy and indicated that advocacy is seen as an ally to their causes that can contribute to better outcomes for people with learning difficulties. The study however also highlighted that advocacy needs to continue to work together with people who use the service and share even more their agenda rather than having its own agenda imposed by funders and commissioners. Advocacy, in order to continue to work towards providing even better outcomes for the advocacy partners, needs to stay true to its principles and share even more power with the people who use the service. Only by doing this advocacy can really reach its potential and offer the best outcomes to people who use the service and people with learning difficulties in general.



### **7.3. Theoretical Implications**

The study contributed in different ways to advocacy theory and research, involving people with learning difficulties but also to social theory research in general. It can be argued that the advocacy outcomes research study provided support for the Critical Disability Studies view of learning difficulties. Critical Disability Studies scholars such as Goodley (2011) have argued that learning difficulties should not be seen as different from other disabilities for instance physical. Goodley (2011) proposed that all disabilities including physical and learning should be seen as a continuum rather than on a binary basis.

This view comes into contrast with the Social Model of disability view which suggested that disabilities are different and are either physical or learning. Oliver and Barnes (2012) argued that the Social Model of Disability supported the emancipatory research approach where disabled people have full ownership of the research. The emancipatory research approach may work well however it has some disadvantages. Emancipatory research can be seen as not fully inclusive because people with little, or no, research experience struggle to take full control of research and knowledge production. On the contrary, the advocacy outcomes study demonstrated that people with learning difficulties with little research experience, utilising a participatory research approach, were able, willing and motivated to be active co-producers of research and knowledge. Our study showed that people with learning difficulties that had no previous research opportunities managed to be actively involved and meaningfully contributed to the research process. Participants in our study were determined to be involved and demonstrated many different important qualities that were even further developed.

In terms of advocacy theory, our study highlighted the importance of the process outcomes in the advocacy partnership. The importance of the human relationship within the advocacy partnership was also highlighted. Our study showed that self-advocates and advocacy partners perceived

advocacy as an ally that can be useful particularly in challenging times. Moreover, our study was carried out with advocacy partners and self-advocates with lived experience and they were active participants and co-producers of advocacy research and knowledge. Advocacy and other social research exploring topics that are relevant to people with learning difficulties ought to work with them to gain a deeper and more complete view of a topic.

The authentic voice of people with learning difficulties can only enhance the research process and knowledge production around the topic under investigation. Able, skilful and motivated people with learning difficulties are willing and determined to share their lived experience, take up active research roles and contribute to knowledge production. The study demonstrated that by successfully carrying out the research with the people that use the service and by producing new narratives and knowledge. Moreover, people with learning difficulties that participated and took up active research roles contributed to the construction of a new identity full of positive qualities for people with learning difficulties. This view comes into contrast with the modernist view of people with learning difficulties with negative connotations.

The Critical Disability Studies theoretical viewpoint reflects the approach that has been adopted by our advocacy outcomes research study. The study focused on the participants' lived experience within the social context of the advocacy partnership. It can be argued that there is a need for advocacy and self-advocacy to continue to grow. A similar need exists that requires inclusive disability studies theory and research to continue to explore and inform knowledge around relevant topics. At times when hate crime, exclusion, stigma, oppression and even abuse of people with learning difficulties (e.g. Panorama, 2011 and 2019) appear to be increasing rather than decreasing the point of view of the people needs to continue to be voiced as loudly as possible. Advocacy partners and self-advocates have an important role to play in highlighting what is important for people with learning difficulties via different channels. Advocacy can be seen as an ally striving to reduce bad practices and promote inclusion.

The study also demonstrated that advocacy aided the empowerment of people with learning difficulties that use the service. Advocacy partners and self-advocate highlighted that advocacy plays an important part in their life particularly when they are facing external barriers such as not being feeling listened to or not having the professionals that they work with on their side. Participants in our study demonstrated that advocacy provides a number of different varied outcomes that are seen as important and valued by people with learning difficulties.

#### **7.4. Advocacy Partnership Model**

The advocacy outcomes study, right from the beginning, aspired to carry out research looking into advocacy outcomes by using a different approach compared to previous studies (for a comprehensive literature review of the area of advocacy please refer to chapter 2). For the past twenty years very little research has been carried out on advocacy involving people with learning difficulties. A main reason for that being the widely held modernist views that people with learning difficulties are not credible and trustworthy sources of their own stories, experiences, views and beliefs.

Another main reason noted has been that there was no clear accepted definition for advocacy, due to a lack of consensus between the different types of advocacy which prioritise different principles compared to other types. Most definitions of advocacy however have been stressing out the importance of enabling people to have a voice, choices, safeguarding autonomy and self-determination, be listened to in decision-making processes and have their interests represented and rights protected (NDTI, 2018). A third reason highlighted by Thomas et al. (2017) was that advocacy research mostly concentrated on examining the principles as well as the differences between the types rather than concentrating on evidence around the outcomes of advocacy. Our study took the view that different types of advocacy have much more in common than differences and therefore the exploration of different types of advocacy should not be focused on the

differences between the types but rather on what the outcomes are for the people who use the service.

The data collected, the analysis of the data, the findings as well as their discussion and presentation were co-produced with the self-advocates with learning difficulties that were part of the steering group. The following proposed advocacy partnership theoretical model is the fruit of the collaborative work of many years. The advocacy partnership model (figure 11 below) represents the main mechanisms involved in advocacy and describes how the advocacy partnership works. The model is comprised of elements that came up from the analysis of the data, but also from the literature review and the long discussions and meetings that were held with the steering group of self-advocates. The advocacy partnership model represents the whole advocacy experience as viewed by the people with learning difficulties that use advocacy. The model shows what the advocacy partnership means for people with learning difficulties in a visual way.

From the one side (left side of the figure), there are the advocacy partners and the advocacy partnership (circle) which has as the main focus trying together to achieve the agreed desired end-point outcome(s) of the advocacy partnership (rectangle at the right side of the figure). In the middle of the figure is the blue arrow which symbolises the advocacy partnership work or journey. The advocacy journey has been shown to encourage the person and aid their empowerment to achieve their end-point goals (rectangle). The advocacy partnership model also symbolises that the advocacy journey produces a lot of “process” outcomes which are outlined with the blue font letters underneath the shapes regardless of the actual end-point outcome.

However in contrast, the model also represents that the advocacy partnership journey faces a number of negative influences that can often counteract the person’s and the partnership’s efforts. The red arrow in the model going on the opposite direction symbolises the external negative influences or barriers that can hinder the person’s empowerment to achieve their goals, outlined in the red font above the blue shapes. The two arrows

(blue and red) go in the opposite directions symbolising the struggle that people with learning difficulties face against external barriers to meet their goals. Although the vast majority of the positive influences (blue font) as well as the negative ones (red font) are derived from the advocacy outcomes research some, such as hate crime have been identified from the literature.



**Figure 11: The Advocacy Partnership/journey model**

#### **7.4.1. The importance of Advocacy**

Participants in our study as well as in other studies demonstrated that the advocacy outcomes that come from the advocacy process are highly important and effective. The participants showed that even when an advocacy partnership failed to meet the desired goals there was still a lot of value in advocacy. The advocacy partners during the advocacy journey and

their common aim of trying to meet the agreed goals come across several barriers or negative influences from various sources that they try to overcome. The advocacy partners by trying to deal with the barriers and negative influences and reach their goal, during the advocacy process, learn new skills, develop existing ones and mutually support each other. All this added value is captured in the participants' stories, views, opinions, meanings, perceptions, feelings and beliefs. The participants came up with a list of key advocacy outcomes that are explored analytically in the findings and discussion chapters and are presented in the Advocacy Partnership model in figure 11 above.

The Advocacy Partnership model, however, has another important element which is the negative influences that are not directly related or controlled by or within the advocacy partnership. The negative influences are either pre-existing or come along during the advocacy process or journey and make pursuing the desired outcome more difficult but also make the partners more determined and the cause of the advocacy partnership more important, valued and worthy. The negative influences are very important in the advocacy partnership model and cannot be underestimated. It can be argued that the negative influences, outside of the partners' control, represent some of the main reasons why advocacy is so important and has such a big part of a role to play in the lives of people with learning difficulties. It can be claimed that without the negative influences the need and requirement for advocacy would not be as strong and important. As people with learning difficulties would be able to more easily attain and work towards achieving their desired goals themselves.

Self-advocates and advocacy partners have clearly demonstrated that they have the skills and motivation to speak up and to be listened to. However, the need for advocacy becomes greater when the negative influences increase and interfere even with the voice of able, skilful, motivated and determined people. If systems and policies were there to make sure that everyone was listened to or at least that the negative interferences weren't as great then there would have been less need for advocacy services.

Goodley and Ramcharan (2010) argued that there would be no need for advocacy services or even terms such as advocacy or self-advocacy as people would just be listened to. People with learning difficulties have demonstrated that they are more than able and willing to have a voice and express it loudly and clearly. Systems and services need to be willing and structured in a way that they listen and value the input from people with learning difficulties rather than people having to go through a number of additional barriers.

However, modernist systems are not designed, by default, to listen to peoples' views, wishes, wants and choices. They are designed in such a way that expert professionals are the ultimate decision-makers with the expert knowledge that can determine important decisions about how people, for instance with learning difficulties, should live their lives. The mainstream health and social care services, similar to mainstream research, have often not trusted and not seen as credible the voices, choices, views and wishes of people with learning difficulties. The peoples' agendas, often, have not been respected and agendas determined by bureaucrats and experts have replaced the persons' real agendas. During the last decade when the effects of neoliberal politics and austerity have intensified the reality of people with learning difficulties only became worse, the same was true for other marginalised groups of people. People with learning difficulties, however, continued to provide challenges to modernist systems, with everyday resistance, creation of positive discourses, self-determination, resilience, mutual support and perseverance.

The main question that arose is: does advocacy have a role to play in the lives of peoples with learning difficulties? The question to this answer as highlighted by the people with learning difficulties themselves and represented by the Advocacy Partnership model is yes. As long as those external negative influences are present, particularly to such an extent as they are today in 2021, advocacy has a role to play in peoples' lives. As can be seen from the visual representation of the advocacy partnership model (in figure 11) all the negative external influences (blue font words) have to be

counteracted by positive influences (red font words). Advocacy has been demonstrated to be a useful and valuable ally that is on the side of the person when so many negative influences are present. The struggle for a fairer society with more justice and empowerment ought to continue in order to bring positive change. When the society has moved on to listen to all its citizens, be inclusive rather than exclusive, equality and equity have been established and the negative influences described in the advocacy partnership model have disappeared or at least lessened then there would be less of a need for a strong advocacy movement or there would be no need for advocacy at all. Until then, however, the struggles of advocacy partnerships and the advocacy journey ought to continue to strive for better outcomes and a fairer more inclusive society overall.

## **7.5. The Utility of the Advocacy Outcomes study**

Goodley and Runswick-Cole (2016) suggested that every theoretical account in social sciences should be subject to a number of questions about its utility. They proposed that the main questions include: how relevant is the study and its analysis to the lives of disabled people? How can this study and its analysis inform policies related to disability? And finally how is the study connected with disability activism and the politics of disability? The chapter now continues by answering those questions about the utility of the study and its relevance to the causes of people with learning difficulties related policies and the politics and activism of people with learning difficulties.

### ***7.5.1. Is the Advocacy Outcomes Study relevant to the lives of people with learning difficulties?***

The study has been demonstrated to be relevant to the lives of people with learning difficulties as it explored types of services that a lot of people use or have an interest in. Different types of advocacy, including peer and self-advocacy, play a role in the lives of thousands of people every year. There are very few statistics available regarding the total uptake of different advocacy services however the indication is that the total is well in the thousands. For instance, the Department of Health (2015) published the 7<sup>th</sup>



(2013-2014) annual review of the Independent Mental Capacity Advocacy (IMCA) service where 2628 referrals have been made for people with learning difficulties. Although this is not a representative or an accurate number of people receiving the service, it indicates that a statutory advocacy service is receiving a high number of referrals. However, it needs to be noted that the IMCA service is a very specific type of advocacy and it does not represent the number of advocacy partnerships across the different types of advocacy services.

Furthermore the study apart from only carrying out research on an area which is relevant to people with learning difficulties it did so in a way that involved people with learning difficulties that have experience of the advocacy partnership. Participants were people who had lived experience of using different types of advocacy and they shared their views, beliefs, ideas, perceptions, experiences and attitudes towards advocacy. The participants shared their stories, their lived experience and expertise and contributed to the wider knowledge of the area of advocacy work thus providing people, who may wish to consider using advocacy, an in-depth insight. Additionally, participants had the opportunity to be involved and learn more about the research process.

The study was also relevant to people with learning difficulties in general, rather than only to people who use advocacy, because it demonstrated a type of study where people with learning difficulties carried out research and produced knowledge. Moreover by carrying out the research people with learning difficulties produced positive discourses for the whole community by challenging modernist descriptions of people with learning difficulties with negative connotations. People with learning difficulties as co-researchers demonstrated that they are able and willing to produce good quality research and explore different meanings on different areas such as advocacy. This type of research can be used more widely in larger scale but also in smaller-scale research projects as well as specific service evaluations and other critical exercises. People with learning difficulties demonstrated that they are critical thinkers and that apart from sharing their stories and experiences they

are more than capable and willing to also critically appraise data collected as well as analyse the data, identify themes and discuss them.

### ***7.5.2. Can the Advocacy Outcomes Study inform policies relevant to the lives of people with learning difficulties?***

The study demonstrated a way that policies can be informed directly from the people concerning them. Participatory research, the main principles of which were used in our study, is a research approach that can be used to directly inform policies. Contrary to dominant modernist views, the participants in our study demonstrated that people with learning difficulties can be trustworthy and credible sources of a wealth of information and knowledge about a wide range of areas. The participants actively took part in all the stages of the research study and showed that they can be valuable contributors.

The recommendations produced from the study can be used to inform policies relevant to advocacy but also can be used from the advocacy services to improve their effectiveness and relevance to the lives of people with learning difficulties. The Advocacy Partnership Model produced at the end of the study (figure 11) demonstrated the importance of advocacy but also the specifics of its mechanisms that make it an important and valuable service. The model can be used to inform policies that are relevant to people with learning difficulties by influencing the development, funding and commissioning of advocacy services, and services in general, that maximise their effectiveness and their relevance to people with learning difficulties. Moreover, the Advocacy Partnership model can inform the policies and procedures of different organisations that are involved in the lives and support people with learning difficulties.

However, organisations need to not only inform their relevant policies and procedures but also their culture. As it has been demonstrated by Brandon (2005) organisations not only need to have their policies and procedures right but also make sure that they implement those policies thus reducing their service from incoherencies. The organisational policies, procedures and practices need to change to make their systems better able to listen and

take on board the views wishes and input from people with learning difficulties. These changes in the systems are needed to make a fairer society, remove a number of negative influences and barriers and strive towards a more equal society. As participants demonstrated with powerful discourses and narratives, they live in a society that is often pushing them towards exclusion rather than inclusion. A society in which empowerment does not seem to be on the agenda of every service in the life of people with learning difficulties. This was shown to be one of the main reasons why advocacy was seen so favourably and so differently compared to other services in the lives of people with learning difficulties. Other services in the lives of people with learning difficulties should use the example of the advocacy partnership model to inform their policies and try to maximise their positive influences and minimise the barriers and obstacles placed in front of people with learning difficulties.

### ***7.5.3. How is the Advocacy Outcomes Study connected with the activism and the politics of the people with learning difficulties?***

Participants in the study clearly demonstrated that they are providing everyday challenges to the modernist systems that have oppressed them and pushed them towards the margins of society. Participants demonstrated that they are activists that challenge the norms by sharing their powerful stories, creating positive discourses and knowledge and by doing all these they are empowering themselves and others to do the same and project a positive identity for people with learning difficulties. Participants challenge the negative stereotypes used by a system that often has not listened to them and has not valued their positive contributions.

The study by carrying out the research together with the participants connected with the learning difficulties activism and disability politics. People with learning difficulties' main movement is self-advocacy which has achieved a lot and continues to do so. The study worked with self-advocates and a self-advocacy group in order to carry out together participatory research that explored advocacy outcomes from the point of view of the people that use the service. The study demonstrated that the advocacy

partnership can work well and produce good quality outcomes. The partnership between the self-advocacy group, the self-advocates, the advocacy partners and myself the PhD student/advocate appeared to have worked well as a study within the constraints of a PhD thesis and produced good quality research.

The partnership also demonstrated that research with people with learning difficulties should not be the exception, as it was demonstrated by the literature review, but should be prioritised and become much more common and part of the mainstream research particularly for social sciences. Modernist ideologies that portrayed people with learning difficulties as being story-less and thus powerless have been proven to be wrong. Empowered self-advocates produced new narratives and discourses that demonstrated a positive identity with qualities, abilities, trustworthiness and credibility for people with learning difficulties. More participatory research is required to demonstrate even clearer that people with learning difficulties can and should be the main producers of knowledge at least about themselves and areas of interest to them. As Foucault (1981) suggested discourses and knowledge are power and whoever produces the discourses and the narratives can exercise the power. People with learning difficulties demonstrated that they are empowered to create their discourses and knowledge.

Self-advocates producing positive discourses and narratives empower more people with learning difficulties to do the same and all the challenges to the modernist ideologies can replace the negative connotations and portray a positive identity for people with learning difficulties. It is of utmost importance however that the new production of research is driven with and by the people with learning difficulties rather than for them or on them as it was the case with the modernist way of thinking. The positive identity development is driven by people with learning difficulties and the negative labelling is rejected and can be replaced. The positive identity of people with learning difficulties is replacing the modernist notions of the need for institutions, control and punishment. The institutions and modernist ideologies' views and

systems are replaced by views, narratives and knowledge produced by people with learning difficulties.

## **7.6. Recommendations for Advocacy Practice and Policy**

An important contribution from the findings of our research study, putting forward the point of view of people with learning difficulties that use advocacy, is that the process outcomes play a major role in the advocacy partnership. The participants in the study clearly demonstrated that advocacy was seen as important and valued not only because of the end-point outcomes but also because of the process outcomes that were a vital element of the advocacy partnership. Participants highlighted that even when the advocacy partnership did not meet its main goals it was still valued because it offered some outcomes that were achieved in parallel with trying to meet the main targets, agreed in the beginning. Participants showed that working together in the advocacy partnership was beneficial for the partners as it led to different positive outcomes such as learning skills, increased positive feelings and empowerment. Participants expressed that they were satisfied with the advocacy partnership and perceived it as important and valued because it made a difference regardless of the end result. However, the end-point outcomes and results that the advocacy partnership achieved were also seen as important outcomes but far from the only positive outcomes of the advocacy partnership. The section will continue by discussing recommendations for advocacy practice and policy.

### ***7.6.1. Recommendations for Advocacy Practice***

A main contribution and recommendation from our study is that advocacy projects need to concentrate even more on meeting the views, wishes and expectations of the people that use the service rather than the project's priorities, which are often set by funders. Although this is something that can be difficult or nearly impossible to achieve in the present day and age of competitive contracts and tendering it is potentially the only way forward that will make advocacy even more effective. As by focusing on the views, wishes, needs and priorities of the people that use the service is the only

way to have the best advocacy process outcomes apart from end-point ones. Our research study clearly demonstrated that advocacy process outcomes can add extra value to the advocacy partnership and they are outcomes that are particularly valued by the people who use the service.

Additionally, advocacy projects need to, not overlook or omit, regularly collecting data and evaluating their work with the people that use their service. Our research demonstrated that effective advocacy practice is interlinked with what the people that use the service see as important and it is not something static. Advocacy evaluation with and by the people that use the service is an important and powerful way to demonstrate the value of advocacy and make sure that advocacy is meeting its main objectives and aims. Data collection and monitoring is a useful process and should become an essential part of advocacy provision without the need to separate it from the advocacy journey. Obviously, feedback collected would require to be acted upon in order to make the service more aligned to the peoples' views, wishes and expectations.

Furthermore another recommendation that comes from the findings of our study is that advocacy organisations need to focus even more on delivering better advocacy process outcomes which reflect the views and wishes of the people that use the service. This is important because participants highlighted them as valuable. Advocacy services should not only concentrate on measuring outputs but also on the quality of the process outcomes delivered. It was demonstrated by our study that being on the person's side and working together to promote the person's agenda aids the empowerment of the person to speak up and self-advocate.

In summary, the study provided the following recommendations in regard to advocacy practice:

- Advocacy services should be more focused on the person and their own personal goals and targets

- Focusing on other pre-determined agendas and targets can potentially hinder rather than promote the advocacy partnership's effectiveness
- End-point advocacy outcomes are seen as important and valued and therefore should continue to be promoted and monitored
- Advocacy process outcomes are particularly valued by people even when end-point outcomes haven't been reached and therefore should also be prioritised something which is not the case at present
- Advocacy evaluation by and with the people that use the service is an essential and effective way of evaluating the service routinely and should become standard practice
- Feedback collected by the evaluations should be acted upon regularly

#### ***7.6.2. Recommendations for Advocacy Policy***

Apart from the advocacy organisations the advocacy policymakers, funders and commissioners need to also realise and appreciate that advocacy is most effective for the people that use the service when there is no agenda or targets set for them without them. This needs to be reflected in the relevant policies that can promote the development and sustainability of different advocacy organisations including peer and self-advocacy groups. Moreover, resources need to be distributed on projects that offer the best value and are most effective rather than only based upon meeting specific targets in terms of numbers and outputs. Advocacy projects, such as statutory advocacy services are providing specialist services, which are useful and needed however serve very specific purposes and have very restricted focus and remit. If funding was only to be directed towards statutory advocacy leaving all other types and areas significantly underfunded, then the future and scope of advocacy would be largely restricted and reduced.

New policies and approaches to funding need to be developed to look beyond the statutory requirements and narrow contractual targets and open the funding up more to different types of advocacy including peer and self-advocacy which have seen funding reduced dramatically. Self-advocacy and peer advocacy services have been highlighted as very important and

valuable by people that use advocacy. A number of important advocacy outcomes have been pointed out as coming from peer and self-advocacy work such as working together, feelings of empowerment but also satisfaction. Moreover the analysis of the structure and performative context of the participants' accounts demonstrated a great sense of pride and the portrayal of an identity full of positive qualities for people with learning difficulties that are members in peer and self-advocacy groups.

In summary, the study provided the following recommendations in regard to advocacy policy:

- Process outcomes are important and valued by people that use advocacy even more than end-point outcomes. Therefore policymakers need to include good process outcomes in their standard measures and requirements.
- Advocacy is most effective for the people that use the service when there are no targets or agenda set for them without them. Policy should make available funding also for services with targets that are not pre-determined (such as statutory) to allow for flexibility and choice which were found to fully utilise the advocacy partnership.
- Increasingly more funding should become available to different effective advocacy types such as peer and self-advocacy groups. Those types have been demonstrated to provide not only a valuable service but also a great sense of pride and identity full of positive qualities for people with learning difficulties.
- A different approach to funding advocacy projects should be adopted in order to encourage and promote collaboration rather than competition between different stakeholders

### **7.7. Reflecting back on the study**

The advocacy outcomes study's final chapter looked at answering the original research questions but also questions about the utility of the study in relation to people with learning difficulties. It continued by exploring the theoretical implications of the study particularly in relation to the theories



talking about the empowerment of people with learning difficulties. Furthermore, the Advocacy Partnership model was developed and discussed alongside recommendations for advocacy theory and practice. The chapter will now continue by reflecting back on the study, the chosen methodology but also by discussing some personal reflective thoughts.

#### **7.7.1. *Reflecting back on methodology***

The main aim of this PhD study was to explore advocacy, its outcomes, theory and practice impact with people with learning difficulties rather than for them or on them. This was a very important aim as the study from its very beginning was about working together and learning as well as producing knowledge together. Our work with the self-advocacy group prior to the conception of the study, as well as during and afterwards, was catalytic for the study's formulation, development and implementation. The group had been running for at least a couple of years before I became involved as a co-facilitator and then as a co-researcher. The self-advocacy group had several highflying achievements at local, regional and national level. A number of people taking part in the self-advocacy group were experienced self and peer advocates and some have also worked with advocacy partners. However, apart from the high levels of experience and achievements, there was a strong sense of desire and willingness to learn more but also to share the knowledge explored within the group with the wider community. It was realised that this group's meetings were very important and significant and that this good work should be shared more widely to raise awareness about advocacy and to educate other people about what working within an advocacy partnership entails.

The choice of methodology was one that embraced and facilitated the approach of working together in an advocacy-like partnership. The objective right from the beginning was not only to advocate for ourselves or only for each other but to produce knowledge that can be shared with the wider community. The first decision after the formation of the steering group, the agreement of the terms of reference, and the research training workshops was to determine the methodology that would be most suitable and

appropriate for meeting our main aims but also following our principles. The methodology chosen promoted rather than hindered everyone's participation as much as possible in the process of carrying out the research. Firstly, it was decided that qualitative methodology would be used as it allowed more flexibility in carrying out the research and exploring advocacy, a topic that was not well researched and understood.

This decision was a justified one as the qualitative research methodology aided the data collection and the collective analysis of a wealth of information. The wealth of information allowed us to build a picture of advocacy and look at all the different details rather than have pre-determined characteristics of advocacy and test them, something which would have been the case if quantitative research methodology was chosen. Moreover, this decision was justified because the methods used encouraged the active participation of people with learning difficulties in the research process in a critique-free environment. This was also an important point as the principles, of inclusion and sharing of the power, present in advocacy were followed by the type of research that was adopted. It was a research study that acknowledged the power imbalance and also shared the power of those that carried out the research with the ones that participated and actively contributed. It was an important aim of the study that everyone invited was encouraged and felt welcome to engage and actively participate.

Furthermore, a conscious decision was made to not follow a purist research approach from any of the methodologies utilised but rather to use an eclectic approach. Different principles from different approaches were used rather than a single homogenous approach in its pure form. One of the main methodological approaches that a lot of its principles were adopted was the participatory research approach. The participatory approach encouraged the active participation of all the group members and promoted the expression of the point of view of a group of people that has been underrepresented in research (Walmsley, 2004).

Principles of the narrative research design were used particularly in the data collection and analysis stages of the study. The narrative research method provided a critique-free opportunity for the participants to express their subjective experiences views and opinions, which were valued. Narrative analysis was used to gain a more accurate and complete representation of how people, that use advocacy, experienced and perceived the advocacy partnership and what they thought the true advocacy outcomes were for them. More specifically the content, meaning, structure as well as the performative context of the participants' accounts were analysed.

Different research methods were employed to collect data for different purposes. Focus groups were used as a pilot and in order to examine the main research questions from the perspective of the people that use the service. In-depth interviews were used in order to explore the research questions further. The study used thematic and narrative research methods for data analysis from the focus group and the in-depth interviews respectively. The data collection methods allowed the development of narratives in relation to advocacy outcomes from people who have been using this service.

Llewelyn and Northway (2008) suggested that they rejected using one to one interviews as although they provide a wealth of information they were not seen as an ideal inclusive method of collecting data. Llewelyn and Northway (2008) proposed that the interview process puts the researcher in an overpowering position that could be daunting to participants and it is likely to not allow them to open up to someone who is not already familiar to them. In the case of our research, however, this was not the case. I carried out the interviews and was also involved and familiar with the majority, if not all, of the participants as I was working as an advocate for the advocacy organisation, participants were recruited from. Therefore, the participants were feeling familiar and more relaxed in an interview with someone they already knew and to some extent trusted.

Focus groups have been praised as a more equitable and relaxed atmosphere where discussions and interactions between participants can take place more naturally and data can be generated more effortlessly (Kitzinger and Barbour, 1999). Fraser and Fraser (2001) also reported that participants tend to feel empowered and supported by the group and are often willing to share their feelings and insights in the presence of people they see as being like them in some way. Our experience with running the focus groups was a positive one as well as a productive one. Participants reported a number of positive outcomes from the focus groups but also a wealth of information and good quality data were collected.

The philosophical integrity of the research has been maintained something that was also a main aim of this study. The social constructivist theoretical framework underpinning the study claimed that there is no fixed external reality and therefore cause and effect cannot be inferred (Brown and Brooks, 1990). Instead, Brown and Brooks (1990) pointed out that a fluid social reality is co-constructed. This framework allowed us to explore and focus on the individuals' point of view rather than seek to uncover cause and effect relationships in the social environment of the advocacy partnership. The subjective nature of individuals' views and experiences have been encouraged and promoted by using this theoretical framework. Additionally, the person was placed in the centre of this research process and the power was shared. The research and the creation of knowledge were co-produced by actively co-constructing the knowledge.

This approach came into contrast with previous deterministic explanations that excluded people with learning difficulties from the research and knowledge production processes. The social constructivist viewpoint proposes that there are multiple realities and not only one as suggested by the positivistic viewpoint (McLeod, 2002). The epistemological position was also compatible with the principles of social constructivism. Lincoln and Denzin (2000) suggested that according to the social constructivist paradigm the participants and the researcher co-create understanding and knowledge.

### **7.7.2.     *The study's limitations***

Although the study had some positive aspects, a number of limitations were also identified. It was one of the main aims of this study to be as inclusive as possible in carrying out the research. This endeavour of the study, however, was not fully achieved. Some people have not been included in the study for different reasons.

People who were described in the Mental Capacity Act (2005) as lacking the mental capacity to provide informed consent to participate in the study were not included. The study followed the main principles of the Mental Capacity Act (2005); however, it was not always possible to exhaust all practicable steps to make sure that a person that could have participated managed to do that. The study had neither the resources nor the time to exhaust all practicable steps. The study followed, however, a number of inclusive research principles such as from Cook (2012) and Jepson (2015) to make sure that as many people as practically possible participated.

Despite all the efforts, the recruitment criteria for inclusion in the study had some exceptions. For instance, people involved in non-instructed advocacy partnerships were not included in the invitation list due to the high likelihood that they would, according to the Mental Capacity Act (2005), lack the capacity to provide informed consent to participate. It was logistically and practically impossible, for a PhD study, to have the time and resources to attempt to involve all people with learning difficulties that have used advocacy in the scheme we recruited from. Additionally, inviting people who most likely would not participate in the study potentially could have caused inconvenience and potential disappointment to the people invited to a study they were most likely not going to participate.

Goodley (2000) highlighted that people with profound learning difficulties have been contributing members in self-advocacy groups. People with profound learning difficulties could have contributed valuable insight into a research study exploring advocacy. However, as discussed above it was neither practical nor the main focus of the study to explore advocacy using

different methods apart from focus groups and interviews that require a level of verbal communication.

Furthermore, apart from people who were involved in non-instructed advocacy partnerships people with no verbal communication were also not invited. This was the case because the chosen methods of collecting data were focus groups and interviews that mostly require a certain level of verbal communication. Most likely a study using a method involving different formats of communication such as pictures, signs or talking mats would have yielded good quality rich data. However, it was neither practical nor the main focus of our study to commit time and resources in finding or developing such a methodology. The use of focus group and in-depth interviews as data collection methods also meant that there was less focus placed on the non-verbal elements of the communication such as body language, gestures and facial expressions. Although some data were collected it was felt that the amount was not enough to allow for a meaningful analysis. Video recording the focus groups and the interviews could potentially provide rich data in terms of non-verbal communication. A future study could use video recording to add further depth and richness into the data collected and the analysis.

Furthermore, video recording the interviews with the participants would have allowed further rich qualitative data to be collected and analysed. More specifically collecting audio and visual data from the interviews would have facilitated the more in depth analysis of the structure and the performative context of the participants' accounts. This would have been a very practical and valuable way of fully utilising the rich data that the participants with learning difficulties produced. However this was practically impossible given the scope and the restrictions placed upon a research study at the doctoral level with limited resources and time available to reach different milestones. Not collecting audio-visual data from the interview is a limitation of the study however also an opportunity for a future project involving people with learning difficulties using a participatory research approach.

Working together with the steering group as part of a doctoral study also posed some challenges and can be seen as a limitation. Working collaboratively with a steering group of self-advocates was very constructive and productive however its scope was somewhat restricted because this co-production study was carried out as part of the assessments for the award of the PhD. Although I worked together with the group on all the stages of the research study, the writing up of the thesis as well as other critical elements which formed part of the assessments had to be completed individually rather than collectively. Ideally, a co-production study should have involved all partners in all the stages of the research including writing up the reports however this is a limitation of working together within the constraints of a doctoral study.

### **7.7.3. *Personal Reflections***

The advocacy outcomes study demonstrated that a group of self-advocates with learning difficulties can co-produce good quality research, powerful discourses and narratives. Self-advocates that actively contributed to the study reported that everyone worked in equal terms in the group and everybody's views were respected and promoted. In addition, mutual support was present, between the group members but also disagreements which were also fine. The group had critical and fruitful discussions over how the study can best meet its objectives. Self-advocates also commented that participating and co-producing research was positive and powerful and an opportunity that will be welcomed in the future too. Overall there was a positive sense of learning and achievement in the group together with critical thinking and important decision making. Self-advocates commented that it was important that experiences and knowledge from the group were shared to inform and empower more people.

The study would not have been made possible without the hard work and commitment of the self-advocacy group that worked alongside me for the duration of the study. Few obvious explicit rewards were present apart from the satisfaction that was shared with fellow group members following long discussions and arguments as well as achievements. The willingness,

motivation, drive and ambition of the self-advocacy group, to share the good work that has taken place within the group but also to search for answers in the questions that were identified at the beginning of the project, have been unparalleled. The study was a journey for me and the group and although it was a long, hard and bumpy ride the memories of the group's productive work but also the fun times will always be with us.

As a group member as well as researcher and advocacy partner, I was always aware of the power issues and the potential power imbalance. This was not much the case in the self-advocacy group environment where everyone was seen and treated as an equal. I was always taking my turn to make the cups of tea the same as every other group member and also to wash up afterwards. The one to one interviews, involved a greater potential for power imbalance, however, some precautionary measures were employed to counteract the imbalance. Apart from acknowledging the power imbalance it was also included in the criteria for participation that people that I was working with as an advocacy partner were not included in the invitation letters list for participation in the study. However all those people were encouraged to take part in the workshops if they wished to do so. This was done in order to avoid a risk of great power imbalance by taking part in an interview that the person was asked questions about advocacy by the researcher who was also their advocacy partner.

The advocacy outcomes study and the research process has influenced my way of thinking as both an advocacy partner as well as aspiring early career researcher. The work together with the self-advocacy group was inspiring for me to learn more about what advocacy really was for the people that were using the service. More importantly, the work with the self-advocacy group also provided us with even more of a determination to prove wrong the negative modernist views of people with learning difficulties.

I have a sense that what is obvious to me as an advocacy partner and participatory researcher and to similarly minded colleagues in advocacy and the academia has not been truly reflected in the wider health and social care



practice as well as academic research community and the associated knowledge production systems. A number of academic and practice disciplines such as psychology, psychiatry, nursing and social work have not uncovered fully the true potential of working together with people with learning difficulties and gaining from their expertise based on lived experience. Carrying out participatory research and co-production with people with learning difficulties can yield high-quality findings, new discourses, narratives and bridge gaps in existing knowledge in different areas.

Furthermore, in the applied health and social care world, there are still processes and systems that contribute to the oppression and exclusion of people with learning difficulties. Changing those systems should be taking place and people with learning difficulties need to be partners and leaders in the decisions to be made about how to plan for and implement the changes in the systems. The academic community also needs to change and be more inclusive particularly in the social sciences, but also in other disciplines, where the potential of involving people with learning difficulties has far from been reached. The potential is there and is waiting to be utilised in order to produce high-quality research that will construct expert knowledge from the most credible and trustworthy sources the people with learning difficulties themselves. The knowledge constructed can inform theories, policies and practices that can contribute to better functioning health and social care systems and processes. Moreover carrying out research with people with learning difficulties rather than for them or on them to inform theories, policies and practices can “disrupt” in a positive way systems that have been demonstrated by this but also other research studies to be dysfunctional.

#### **7.7.4.     *The study's Contribution***

The Advocacy Outcomes study has been the only study that carried out research with adults with learning difficulties exploring different types of advocacy. Participants were having the opportunity to express their voice, views, feelings, meanings and perceptions. Participants shared their stories

and lived experience in a study that was co-designed and carried out with people with learning difficulties rather than for them or on them.

It was one of the main aims of the advocacy outcomes research study to bridge the gap, of the lack of the viewpoint of people using advocacy, in advocacy research. Although carrying out research with people with learning difficulties that have used advocacy, to explore advocacy has been widely recognised as valuable and important, the research in that area has been scarce. On top of that, most advocacy research about people with learning difficulties was carried out in the late 1990s to mid-2000s. Since then a lot has changed in the socio-political scene, in advocacy and society in general. Someone would have thought that the challenges and the difficulties as well as barriers faced by self-advocates and advocacy partners, with learning difficulties, so many years ago would have been a long lost memory. However as discussed in the study self-advocates and advocacy partners with learning difficulties continue to face barriers however they also continue to be willing, motivated and determined as ever to be listened to as well as to share their knowledge and occupy the spaces that they rightly deserve.

Our study's aim was to explore the advocacy practice and impact with the most important people who have lived experience and who provided valuable insights into what advocacy was and what difference it made. It was outlined in advocacy's main principles, shared by all advocacy projects, that advocacy was about putting people first and aiding people that use the advocacy service to be empowered and self-advocate. The study managed to carry out a high quality research project with people with learning difficulties and produce new constructs and knowledge not only about advocacy and its outcomes but also about people with learning difficulties and their identity full of positive qualities too.

The research findings of the advocacy outcomes study contributed to a better understanding of advocacy and also to the development of theories surrounding advocacy. The study also added to the existing body of knowledge around participatory research in the area of advocacy something

that has not been researched in the past. The advocacy outcomes research study can be an example of how to work with people with learning difficulties in order to not only produce together research but also to strive to bring social change that matters in the real social world.

The study also demonstrated that modernist views, that people with learning difficulties should not be involved in research as they have little or no valid experiences and stories to contribute, are simply not true. Thus more research with and by people with learning difficulties can and should be carried out in order to gain an even better understanding of fields of enquiry such as advocacy but also other areas of social interest. People with learning difficulties have illustrated that they are more than able and willing co-researchers as well as participants. People with learning difficulties provided challenges as well as disruption to dominant ideologies as well as constructed new knowledge, discourses and narratives. The study developed apart from theoretical contributions also practical recommendations that can be useful to inform practices and policies relevant to people with learning difficulties. Recommendations were provided for advocacy service development, monitoring as well as commissioning and funding that can improve the advocacy experience and effectiveness.

The study apart from the recommendations for advocacy policy and practice development also produced the Advocacy Partnership model which represents how advocacy partnerships work and how outcomes are achieved. The Advocacy Partnership model can be used to gain a better understanding of the advocacy processes and also to improve outcomes for the people that use advocacy and services in general.

#### **7.7.5.     *Dissemination of the findings***

Furthermore, the advocacy outcomes study apart from discussing the theoretical implications and practical recommendations will also strive to disseminate the findings to a wider audience and to events and publications accessible for people with learning difficulties. The study will not only disseminate the findings in relatively inaccessible (to people with learning

difficulties) forms of publication such as peer-reviewed journal articles but also to publications such as the Community Living magazine that has a proven record of engaging self-advocacy and advocacy partners with learning difficulties. Moreover, the study has already disseminated its findings to advocacy organisations, conferences and training events and is also planning to present the findings in the National Advocacy Conference. The National Advocacy Conference also has a track record of engaging self-advocates and advocacy partners with learning difficulties both as attendees but also as presenters.

Finally, the advocacy outcomes project has plans to disseminate the findings to other conferences but also different self-advocacy and advocacy organisations as well as other organisations working with people with learning difficulties. This will be done to showcase the inclusive participatory research practices that were utilised in the study. Moreover, the findings will be disseminated to highlight the benefits of working collaboratively, carrying out research and evaluations as well as creating knowledge together.

### **7.8. Future of Advocacy**

Valuing People Now (Department of Health, 2009) proposed that self-advocacy, professional/representation advocacy and peer advocacy have been identified as really important forms of advocacy. Department of Health (2009) highlighted that people with learning difficulties see advocacy as important and expressed a commitment to continue to support advocacy in the future. However, since then, the development of different advocacy services has been disproportionate with statutory advocacy services receiving the lion's share of funding from local authorities compared to other types of advocacy. The large number of cuts to the local authorities' funding can explain this development, at least partly. Local authorities' reduction in budgets potentially left them with little choice other than primarily meeting their statutory obligations and cut or reduce funding to other non-statutory services such as non-statutory types of advocacy. This development has drawn criticisms as it came with inherent dangers for the future of advocacy.

The reduction in funding of non-statutory advocacy services threatened even the existence of smaller advocacy projects, which did not provide statutory advocacy, and some were driven to closure.

Moreover, as this chapter highlighted, different types of advocacy have been shown to have different advantages and disadvantages however all are important and serve an important role in the lives of people with learning difficulties. Statutory advocacy services have a specific agenda which is not always shared fully by the person who is using the service. Therefore this type of advocacy, although it serves an important specific role, it has some important disadvantages. Statutory advocacy duties and roles are enlisted in relevant legislation such as the Mental Health Act (2007), Mental Capacity Act (2005) and Care Act (2014). Statutory advocacy services, therefore by definition, are not types of advocacy that can share fully the agenda of the people using the service and therefore truly empower people with learning difficulties. Statutory advocacy is designed to support and to empower people to be involved in specific health and social care decisions and processes. Additionally, statutory advocacy services, although important, are aligned with current processes in the health and social care systems. Therefore within this context, the advocacy partners are not able to work together without prerequisites and across any area thus the advocacy partnership cannot fully empower the person using the service.

Goodley and Ramcharan (2010) raised some questions about the future of advocacy by arguing that potentially the independence of advocacy can be compromised when asked to become overly critical of a statutory organisation they receive funding from. Goodley and Ramcharan (2010) also highlighted that advocacy organisations have to manage limited resources, therefore, they have to make choices and decisions about what type of advocacy they should prioritise usually at the expense of another area of need. The statutory funding to advocacy organisations also poses the risk of placing the demands of the statutory service first before the demands of the person who uses the service. Additionally, competitive tendering for contracts has also brought a lot of priorities and agenda from funders thus

leaving the advocacy organisations that take up these contracts with little space of promoting the agenda of the people that use the service, if that is something different.

It can be argued that different types of advocacy need to be funded in order to promote advocacy that can serve its principles and truly empower people with learning difficulties. Only then advocacy can reach its full potential in becoming a real force for change and making a real difference to the lives of people with learning difficulties and society in general. Because if advocacy is fully tied to statutory and contractual requirements then it will gradually lose its main advantages and main reason for existence.

As discussed in chapter 2 advocacy came to the health and social care scene with radical ideas to bring change and have a real impact in the lives of people with learning difficulties. A difference that the mainstream health and social care services have failed to bring. Advocacy was demonstrated to be valued and effective because it was perceived as different. If advocacy was to become just another role in the mainstream health and social care systems it will no longer be as effective and valued to the and therefore it will restrict its own potential and future.

## **7.9. Further Research**

Our study highlighted that people with learning difficulties are able and willing partners of producing research and creating knowledge which has been shown to be a powerful tool. Participants with learning difficulties demonstrated that were empowered, had their voices listened to and reinforced a positive identity that challenged and disrupted the negative connotations of mainstream ideologies that perceived, people with learning difficulties, as story-less. Participants in our research study showed that they can create powerful discourses and narratives that can empower themselves as well as other people with learning difficulties. The findings from our study confirm the Foucauldian point of view that dominant ideologies can be challenged and be discredited.

Further research in the area of advocacy with people with learning difficulties however should continue to be carried out together with people who have experience of using the service to examine what is important in the advocacy partnership. As Goodley and Ramcharan (2010) suggested research with and by people with learning difficulties should become the norm rather than the exception.

Research with and by people with learning difficulties, as opposed to for them or on them, can make a positive difference by producing high-quality research, knowledge constructs and discourses. Participants with learning difficulties have demonstrated that they can provide expert views on services that they have used but also provide accounts that can bring light onto what are the important outcomes for them and for other people who use those services. Furthermore, participants with learning difficulties have not often been included in research that is important to them and that is something that has to change in order to make services as well as research and the knowledge produced more relevant to them and more inclusive. Participants shared different views about what was important to them and also about how a service can be more effective and more relevant to them and other people using it. The participants and the steering group with learning difficulties made a valuable contribution and made the project a success.

The discourses produced not only represented the participants' point of view and lived experience but also reflected the experiences of people with learning difficulties that are important and valued. Moreover, the discourses produced challenged, disrupted and deconstructed dominant modernist ideologies which suggested that people with learning difficulties do not have a story to tell or should not be trustworthy or credible representatives of their own stories and experiences. The study challenged those modernist views and produced evidence that contrasted them. More participatory research with and by people with learning difficulties is required to create more knowledge but also to produce more challenges.

### **7.10. Final Comments**

The advocacy outcomes study, within the constraints of a doctoral programme, has managed to co-produce, with people with learning difficulties, powerful discourses and narratives that challenge ableist and disablist modernist viewpoints. People with learning difficulties demonstrated that are willing and able to produce good quality research and knowledge, share their stories and be listened to. The participants clearly demonstrated that the negative connotations associated with the labelling of learning difficulties, or “learning disabilities” as preferred by the medical model, can be challenged and new positive discourses and narratives can be constructed with and by people with learning difficulties. The new positive discourses and narratives produced by people with learning difficulties are essential for a move towards creating a fairer, inclusive society where positive discourses are not required in order to counter argue the negative and dehumanising effects of the labelling of people with learning difficulties (Inglis and Swain, 2012). The next step after that as Goodley (2011) theorised would be for people with learning difficulties to not have to be labelled and dehumanised but rather to be accepted and be valued. Goodley (2011) suggested that this will come by truly empowered self-advocates who would not need to be seen as self-advocates but as equal members of the society that can express their voices without being disempowered and marginalised by an ableist majority. Different types of advocacy have been shown to be a partner and ally to people with learning difficulties, their causes and struggle to achieve empowerment and disregard the labelling of tragic victim assigned to them by the medical model of disability.

Furthermore, the advocacy outcomes study confirmed the value of advocacy in supporting people with learning difficulties to be empowered to self-advocate, speak-up, be listened to and challenge systems of power. The study explored the full breadth and width of the advocacy outcomes and impact from the point of view of the people that use the service, in detail, in the findings and discussion chapters. The participants shared their lived experience, stories, views, perceptions, beliefs, meanings and attitudes



towards advocacy and created powerful discourses explaining how advocacy works for them.

The study also examined the challenges faced by advocacy projects and also made recommendations for the development of advocacy policy and practice as well as future research in that area. Advocacy projects ought to continue to put the agenda of the people that use their service first in order to be even more effective. The advocacy organisations need to also involve even more the people that use their services in the evaluation and running of the service to make them even more relevant. Additionally, funders and commissioners need to realise that the real value of advocacy is not utilised by simply looking at the number of outputs and end-point outcomes but also at the process outcomes where the true value of advocacy has been highlighted to be.

As a conclusion, our study argued that people with learning difficulties can produce and generate high-quality research, powerful discourses and knowledge. The study brought challenges to the modernist ideologies and structures that gave labels with negative connotations to people with learning difficulties. It also showed that positive social change and justice can become a reality. This makes the research study even more powerful since it is a strong belief in social theory that research is not powerful enough without the potential for social change, for a fairer and more equal society, something that was clearly evident in our research.

The advocacy outcomes study also produced the Advocacy Partnership model which explains the advocacy process or journey. The Advocacy Partnership model demonstrates that advocacy has an important role of an ally to play in the lives of people with learning difficulties particularly during challenging times such as our times. The Advocacy Partnership model represents the advocacy partnership as well as the processes and dynamics involved. The advocacy partnership has been demonstrated to be powerful with the potential of bringing positive change. Advocacy strives for a fairer and more inclusive society where everyone's voice is listened to and no one

is excluded and pushed towards the margins of the society. A society where people with learning difficulties are not talked down and their views, wishes and voices are listened to and their needs are met. Advocacy has been demonstrated to be an ally of people with learning difficulties. An ally that stands side by side with the person with learning difficulties in the struggle for achieving better outcomes, protection of rights, protection from harm and abuse and pursuing fulfilling lives. A society where advocacy is not required as the systems in place are available and everyone's voice is listened to. A society where everyone is respected and is entitled to the same rights and opportunities as everybody else.

However, as demonstrated by the study and the Advocacy Partnership model (figure 11) our society is far from reaching the levels of fairness, equality and equity aspired by activists with learning difficulties as well as self-advocates and advocacy partners up and down the country. The Advocacy Partnership model demonstrates apart from the advocacy partnership also the negative influences and barriers that get in the way of people with learning difficulties achieving their rightfully desired outcomes. Until a fair, equal and more equitable society is reached advocacy has a big role to play as an ally on the side of people with learning difficulties. The struggle and fight for justice, equality, equity and a better, fairer, more inclusive society continue.

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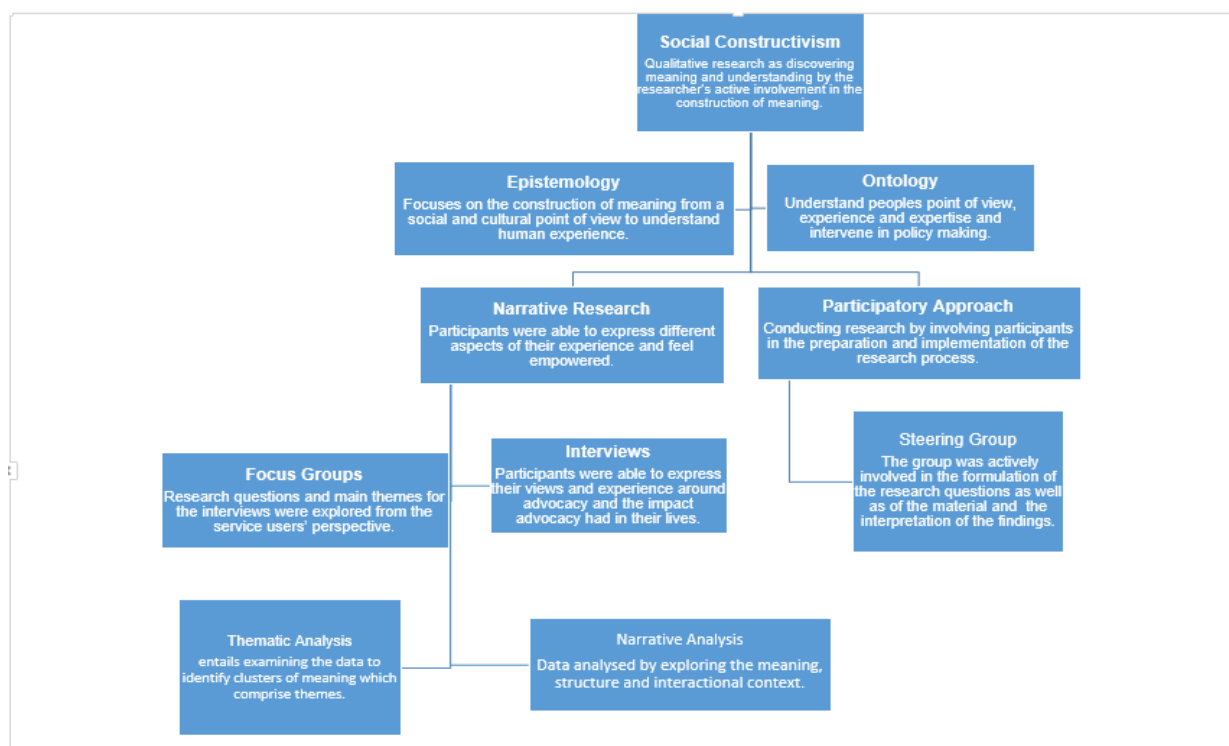
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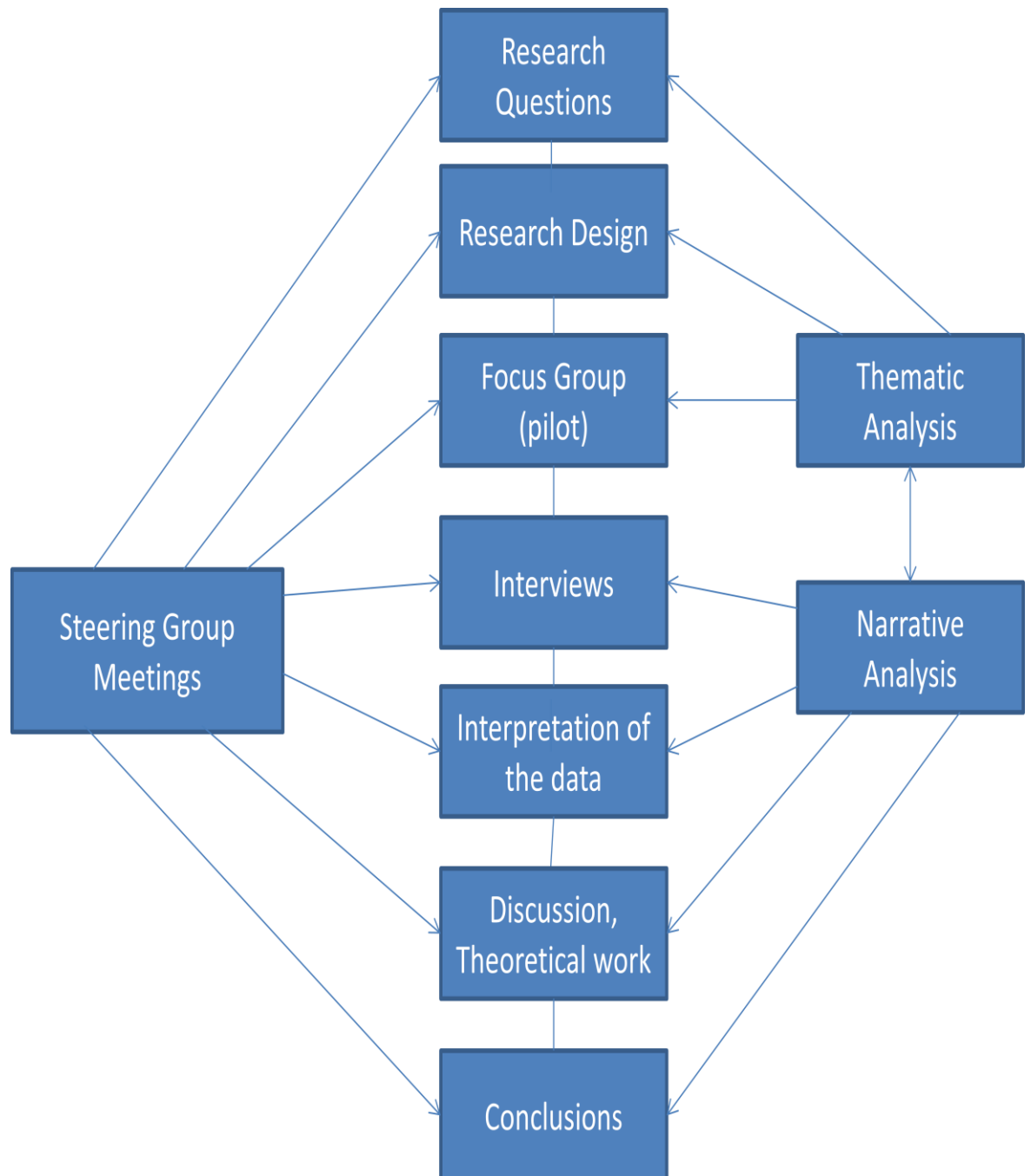
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## Appendices

### Appendix 1. Diagram visually representing the Methodologies used in the study



**Appendix 2. Flow Diagram illustrating the stages in the research process of the study.**



### Appendix 3. Example of coding from the raw data from the participants.

Extracts from the raw data from two of the participants (Peter and Sarah) followed by the associated coding and the emergence of themes. Peter's and Sarah's raw data and the associated coding are colour coordinated in order to make it easier to follow.

*Peter: "Advocates are not pushing their own point of view to you like other professionals do. Not telling me what to do, putting their ideas into my head, but I was able to tell what I wanted and then we were working together with the advocate to do something about that. With the current economic climate, you may not get always what you want but with the support of an advocate you can try and fight for that and speak up for yourself. You fight for your rights and for what you believe in. You don't really fight but when you are passionate you speak up. I am passionate about the students getting a new pool. After school hours will also be available to the adults as well. A lot of people would not or cannot look outside of the box. I am not any different to anybody else but through experience in life, you learn to do things. You learn how to approach a problem or a situation in a different way. I always try and use different ways and those include simple ways."*

Coding and the emergence of themes from Peter's data

Advocacy is different compared to working with other professionals.

Working together is important within an advocacy partnership because the partner is still in charge.

Advocacy can be an important ally particular in challenging times for people with learning difficulties who face a number of negative influences.

Self-advocating, speaking up and standing up for your rights aid the empowerment of people with learning difficulties and demonstrate they are challenging dominant systems.

*Sarah: “Advocates are friendlier and less official, more informal and easier to talk to. This is a good thing, easier to approach if I want to talk about something. The advocate listens to the person and helps them to fight their corner. The advocate does not push her own point of view as other professionals do. The advocate did not take over and made him feel equal. Social workers tend to talk down to you and that they know better than you. I myself have shot myself in the foot sometimes and if it was not for my advocate then I don’t know what I would have done. I dig myself too deep and I could not lift myself up. Not much support out there, some people are on their own. It was a long time before I was seeing someone else apart from my care worker. I see my social worker only when there is a review. I have learned that if you believe that you are unhappy there are ways to talk about it and bring it all out and complain and make your feelings known. My advocate helped me to make choices for myself rather than other people to make them for me. I am making the decisions for myself now but it was not always like that.*

Coding and the emergence of themes from Sarah’s data

*Advocacy is different compared to working with other professionals.*

*Working together is important within an advocacy partnership because the partner is still in charge.*

*Advocacy can be an important ally particular in challenging times for people with learning difficulties who face a number of negative influences.*

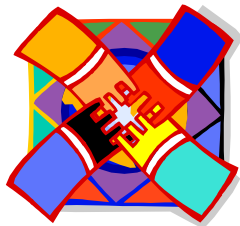
*Self-advocating, speaking up and standing up for your rights aid the empowerment of people with learning difficulties and demonstrate they are challenging dominant systems.*

#### **Appendix 4. Invitation letter – Focus Group.**

My name is Manos Gratsias and I am a PhD research student at Northumbria University.



You are invited to take part in this research study to help finding out more about how people, like you, who use advocacy view and feel about the advocacy service. You have been selected to take part because you have been using advocacy services. The advocacy organisation has given permission for this letter to be sent out to you.



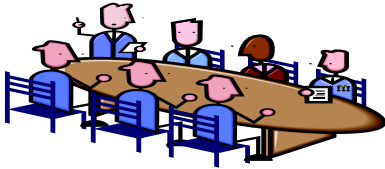
Advocacy organisations are interested to find out your views to help them improve their service provision and make it more relevant and effective for the people who use it.



The Health Authority that supports Advocacy organisations may also be interested in your views and feelings around advocacy.

The study has been approved by the University's Ethics Committee before asking you to take part to make sure it is safe to participate and the research is worth doing.





As part of the research you will be asked to take part in a group discussion, called Focus Group, to discuss how you view and feel about advocacy



If you decide that you would like to participate please let a member of the research team know.



If you decide not to take part that is fine. In any way you can change your mind at any time without giving a reason and will not affect you.



Please feel free to ask questions and for any further information.

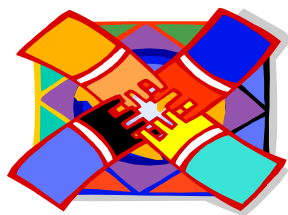


## **Appendix 5. Invitation letter – Interviews.**

My name is Manos Gratsias and I am a PhD research student at Northumbria University.



You are invited to take part in this research study to help finding out more about how people, like you, who use advocacy view and feel about the advocacy service. You have been selected to take part because you have been using advocacy services. The advocacy organisation has given permission for this letter to be sent out to you.

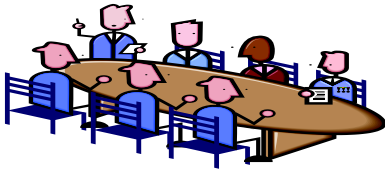


Advocacy organisations are interested to find out your views to help them improve their service provision and make it more relevant and effective for the people who use it.



The Health Authority that supports Advocacy organisations may also be interested in your views and feelings around advocacy.

The study has been approved by the University's Ethics Committee before asking you to take part to make sure it is safe to participate and the research is worth doing.



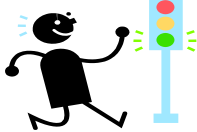
As part of the research you will be asked to take part in an interview to discuss how you view and feel about advocacy



If you decide that you would like to participate please let a member of the research team know.



If you decide not to take part that is fine. In any way you can change your mind at any time without giving a reason and will not affect you.



Please feel free to ask questions and for any further information.



## **Appendix 6. Information sheet for focus group participants.**



### **What is the study about?**

The study is about finding more information about how people who use advocacy view it, their feelings and experience. How advocacy has made a difference? Does advocacy help people who use the service?

### **Why I have been asked?**

You have been asked to take part in the study because you have used/are using the advocacy service. Your views are important and can make a difference on how people view the service.



### **What I am being asked to do?**

You are being asked to take part in a group discussion (focus group) with other people who also use advocacy. A researcher will ask some questions in the group discussion. You are asked to express your views, experience and feelings on advocacy. The focus group will not take more than two hours.



Up to 2 hours

### **What happens if I do not want to participate?**

You do not have to take part in the study. It is entirely up to you and you will not be treated any different if you choose not to.



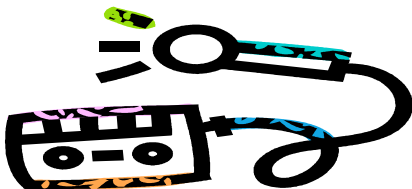
### **What would happen if I agree and then change my mind?**

It is fine for you to change your mind. You would not have to give any reason for that. You will not be treated any different if you change your mind.



### **How will the data be collected?**

An audio recorder will be used to collect the information shared. All the information shared will be noted to allow the researcher to analyse the views shared. The data will be kept for a maximum of three years after the end of the study before being disposed of.



### **Will anybody be able to tell what I have said?**

Your name and any other names mentioned will be removed from the information collected. Everything that is said will remain confidential, unless something very

important is shared such as anyone is being hurt or being at risk of getting hurt, then I will have to tell someone. I would talk to you, in private, about it first though. Everyone taking part in the group discussion will be asked not to repeat what has been said during the discussion.



### **What will happen to the data that is gathered?**

The information collected will be read by the researchers and be analysed. At all times they will be stored safely and only people that need to will have access to them.



### **How will the research report be shared?**

All participants that wish to can receive a study report. The report will be available to different formats including easy read to make its access easier. A report will also be given to the university as part of the PhD award assessment.



### **Who do I contact if I want to ask more questions about the study?**

If you would like any more information you can contact the research team at Northumbria University (details at the top of this letter) or ask the person who gave you this information sheet. You can also contact the main researcher by phoning 01912156480, **emailing or sending a letter to me or my supervisor (see contact details below).**



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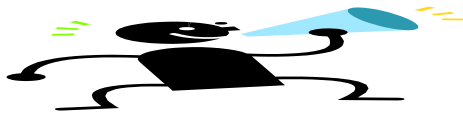


## **Appendix 7. Information sheet for interview participants.**



### **What is the study about?**

The study is about finding more information about how people who use advocacy view it, their feelings and experience. How advocacy has made a difference? Does advocacy help people who use the service?



### **Why I have been asked?**

You have been asked to take part in the study because you have used/are using the advocacy service. Your views are important and can make a difference on how people view advocacy.



### **What I am being asked to do?**

You are being asked to take part in an interview with one of the researchers and express your views, experience and feelings on advocacy. The interview would probably not take more than an hour.





### **What happens if I do not want to participate?**

You do not have to take part in the study. It is entirely up to you and you will not be treated any different if you choose not to.



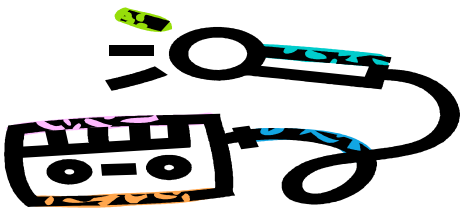
### **What would happen if I agree and then change my mind?**

It is fine for you to change your mind. You would not have to give any reason for that. You will not be treated any different if you change your mind.



### **How will the data be collected?**

An audio recorder will be used to collect the information shared. All the information shared will be noted to allow the researcher to analyse the views shared. The data will be kept for a maximum of three years after the end of the study before being disposed of.



### **Will anybody be able to tell what I have said?**

our name and any other names mentioned will be removed from the information collected. Everything that is said will remain confidential, unless something very important is shared such as anyone is being hurt or being

at risk of getting hurt, then I will have to tell someone. I would talk to you about it first.



### **What will happen to the data that is gathered?**

The information collected will be read by the researchers and be analysed. At all times they will be stored safely and only people that need to will have access to them.



### **How will the research report be shared?**

All participants that wish to can receive a study report. The report will be available to different formats including easy read to make its access easier. A report will also be given to the university as part of the PhD award assessment.



### **Who do I contact if I want to ask more questions about the study?**

If you would like any more information you can contact the research team at Northumbria University (details at the top of this letter). You can also contact the main researcher by phoning 0191 215 6480, emailing or sending a letter to me or my supervisor (see contact details below).



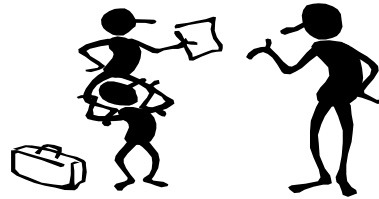
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**toby.brandon@northumbria.ac.uk***



## Appendix 8. Informed consent form – focus group.

Participant Number:





***Title of study:*** *Advocacy Outcomes, exploring the theoretical and practice impact of Advocacy work, using a Narrative approach.*

**Thank you for reading the information about our research project. If you would like to take part, please read and sign this form.**

The consent form can also be presented in different formats such as audio or with an oral presentation.

### Consent for the current study

PLEASE TICK THE BOXES IF YOU AGREE WITH EACH SECTION:

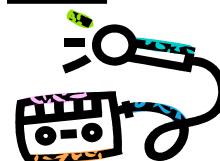
- |  | Agree   | Disagree                 |
|--|---|--------------------------|
| 1. I have read the information sheet for the above study and have been given a copy to keep. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. | <input type="checkbox"/>  | <input type="checkbox"/> |
|  |  |                          |
| 2. I understand that my involvement is voluntary and that I am free to withdraw at any time without giving any reason, without my rights being affected.   | <input type="checkbox"/>  | <input type="checkbox"/> |
|  |  |                          |

3. I agree to the focus group being audio recorded and I understand that my name, and any other names mentioned, will be removed from the transcripts of the Focus Group.

Agree

☐

Disagree

☐

4. The Focus Group will last up to two hours. After the Focus Group I know how to contact the research team if I need to.

Agree

☐

Disagree

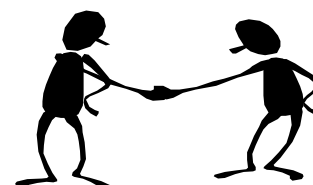
☐

5. I agree to participate in this study.

Agree

☐

Disagree

☐

---

Participant:

Date

Signature

Name.....

.....

Surname.....

Researcher:

Date

Signature

Name.....

.....

Surname.....

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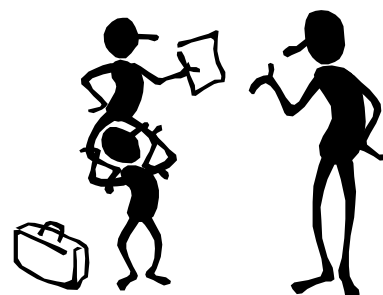
Tel: 0191 215 6480

[emmanouil.gratsias@northumbria.ac.uk](mailto:emmanouil.gratsias@northumbria.ac.uk)



## Appendix 9. Informed consent form – interviews.

***Title of study:*** *Advocacy Outcomes, exploring the theoretical and practice impact of Advocacy work, using a Narrative approach.*





Participant Number:

**Thank you for reading the information about our research project. If you would like to take part, please read and sign this form.**

The consent form can also be presented in different formats such as audio or with an oral presentation.

### Consent for the current study

PLEASE TICK THE BOXES IF YOU AGREE WITH EACH SECTION:

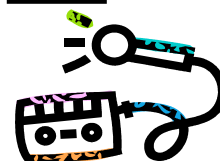
- |  | Agree   | Disagree                 |
|--|---|--------------------------|
| 6. I have read the information sheet for the above study and have been given a copy to keep. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. | <input type="checkbox"/>  | <input type="checkbox"/> |
|  |  |                          |
| 7. I understand that my involvement is voluntary and that I am free to withdraw at any time without giving any reason, without my rights being affected.   | <input type="checkbox"/>  | <input type="checkbox"/> |
|  |  |                          |

8. I agree to my interview being audio recorded and I understand that my name, and any other names mentioned, will be removed from the transcripts of my interview.

Agree

☐

Disagree

☐

9. The interview will last up to an hour. After the interview I know how to contact the research team if I need to.

Agree

☐

Disagree

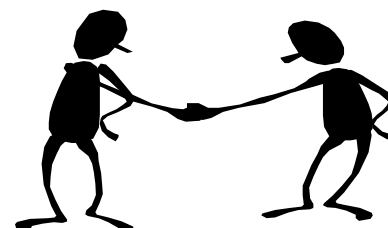
☐

10. I agree to participate in this study.

Agree

☐

Disagree

☐

---

Participant:

Date

Signature

Name.....

.....

Surname.....



Researcher:

Date

Signature

Name.....

.....

Surname.....

---

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## Appendix 10. Semi-structured Interviews Topic Guide - Vignettes

### Interview Topic Guide - Vignettes

#### Mel's Case

Mel would like to have some extra support to access some additional activities. Mel feels that she should have that extra support because she has not been accessing enough activities and she feels that she will benefit from the extra activities.



- What the advocate could do to support Mel?



- What would you do if you were facing the same problem?



- Do you have a story working with an advocate?

## Jo's Case

- Jo would like to go on a holiday but he does not like to go where his friends are going. Jo would like to arrange something different as he does not like to go to the same place.



- What the advocate could do supported Jo?



- What would you do if you were facing the same problem?



- Do you have a story working with an advocate?

## Appendix 11. Grand Conceptual Theme Map

