Aspirations of Government for People with Learning Disabilities and the Reality

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DECLARATION

This work is being submitted in partial fulfilment of the requirements for the degree of BSc (Hons) Health and Social Care and has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

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STATEMENT 1

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Acknowledgements

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Abstract

There is a lack of academic research on the aspirations of the Government for people with learning disabilities and there is little research on the reality of lives of people with learning disabilities. The policies regarding people with learning disabilities are recent when comparing with other healthcare professions. This raised the questions whether the Government implemented these policies due to the incident of bad practice in Winterbourne View. The intention of this study was to research into the aspirations of the Government for people with learning disabilities and whether they are met. In order to approach this study, qualitative research was the most appropriate as it is a primary research method. Four people from two different organisations who works with people with learning disabilities from North Wales participated within the study. The participants were involved in semi-structured interviews, where thematic analysis was used to identify themes within the data. It was discovered that good practice is important in both policies and practice, which can be difficult to implement at all times. Communication for people with learning disabilities is improving, however, there are elements which could be address such as language available in technologies. It was found that practitioners are the weakness within the practice for people with learning disabilities. Many different barriers were discovered, such as forming relationship and understanding the need of people with learning disabilities. Further research needs to be conducted on the reality of lives of people with learning disabilities to understand whether the policies set are effective.
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Chapter 1: Introduction

According to the Welsh Government (2016) there were 14,729 people with learning disabilities registered in Wales in 2016. The UK Population 2016 states that the population of Wales in 2016 was 3.168 million, therefore 1 in 215 people in Wales were classified as having learning disabilities. Meeting the needs of people with learning disabilities is a significant social issue, but first it is necessary to consider definitions.

"Conceptualisation, definitions and measurements have important implications for targeting and policy" (Laderchi, Saith and Stewart, 2003: 269). Definitions have implications that effect all aspects of society; therefore, they are of significant importance to the function of society.

The terms ‘learning disabilities’ and ‘learning difficulties’ are both commonly used. Contradictions over the definition is a contemporary debate. Some people, groups or organisations prefer ‘learning difficulties’, whereas others prefer ‘learning disabilities’. This project will refer to learning disabilities as explained by Hardie and Tilly (2012), ‘learning disabilities’ is a term used in both health and social care to define people with profound learning disabilities. ‘Learning difficulties’ can suggest the same definition, but it can also categorise children and young people who have difficulties regarding education, for example dyslexia.

More specifically, and although referring to ‘learning difficulty’, Williams and Evans (2013) provide a definition that can be usefully applied:

‘A person with learning [disabilities] is someone who has been labelled as having difficulties in cognitive understanding, but is someone with rights, including the right to maximum control over decisions that affect them, and who may need help and support to claim and exercise those rights.’ (Williams and Evans, 2013: 7).

People with learning disabilities are considered as vulnerable adults. It is important that both government and community support people with learning disabilities. Following the abuse at Winterbourne View, the Department of Health (2013) have developed the Good Practice Project, with the purpose of identifying the best practice procedure for
people with learning disabilities; hopefully avoiding the repetition of the atrocious practice and care at Winterbourne View. This incident occurred in 2011 (Department of Health, 2012 (d)), therefore it is a contemporary study, which highlights how recent the policies in care for people with learning disabilities were developed, compared with other social supports. The Winterbourne View case was a catalyst for the development of these policies.

Reviewing and assessment of such policies and their impact are as important as the policies themselves. Government, local authorities and other organisations should cooperate to ensure the success of the changes, by regularly assessing, promoting and maintaining both health and well-being in society. Recently, The Social Services and Well-being (Wales) Act (2014) was published and came into force in Wales in April 2016 (Welsh Government, 2016 (g)). This Act has influenced the care industry greatly, and is perceived positively across the country.

Academic research into the effectiveness of policies and legislation and whether their impact matches aspirations regarding people with learning disabilities is very limited. It appears as a field that has received very little academic attention. Governmental documents that evaluate the policies are available, but they are of different significance to academic research. Therefore, this research will mainly include primary research involving interviews, which will be further explained and discussed in the Methodology chapter.

The researcher has an interest of building a career involving people with learning disabilities. Most work experience the researcher has attended links with this field of work. This has also developed the researcher's awareness of the social significance of the subject.

The aim of this project is to analyse the policies implemented concerning people with learning disabilities, policies that mainly regards the goals and aspirations that are set for the people themselves. Therefore, the research focuses on the comparison between the aspirations of the policies and the practice, as perceived by professionals working with people with learning disabilities. For greater understanding of the policies and their
management, it is necessary to review relevant literature, documents and policies that discusses such matters.
Chapter 2: Literature Review

Moule and Hek (2011) explains that literature review is a process of searching into literature concerning a certain topic. The purpose of a literature review is to examine into the topic thoroughly and it ‘is an essential stage in any research process’ (Moule and Hek, 2011:53). The Literature review was approached through researching into different types of materials, including research papers, government documents, academic books and policies. These materials were critically evaluated, and their significant to this research is clear in this chapter.

2.1 Definition/ Terminology

This chapter will begin by exploring the definition and terminology of people with learning disabilities and how this may have an effect on the identification of the number of people with learning disabilities.

2.1.1. Definition in the United Kingdom

In the United Kingdom (UK) there is a confusion and inconsistency regarding which term should be used when referring to people with learning disabilities or difficulties as referenced to in the introduction. Some use learning disability, whereas others use learning difficulties. Organisations who work with people with learning disabilities, such as Mencap and the British Institute of learning disabilities (BILD), use the term learning disabilities as they believe learning difficulties holds a different definition.

According to Williams (2006) there is no specific definition for learning disability. Both Mencap (2016) and BILD (2016) defines learning disability as individuals having difficulty with daily activities and lower intellectual ability in, for example, understanding complex information. Whereas, learning difficulty refers to individuals who have difficulties in a specific learning such as dyslexia, which does not affect their intelligence (Mencap (2016) and BILD (2016)).

People First is an advocacy organisation which is run by and for people with learning disabilities. This organisation uses the term learning difficulties as they believe that people with learning disabilities prefer the term ‘difficulties’ (People First, 2017).
However, there is stigma attached to the term learning disability which could affect the number of people identified as having a learning disability. An example would be families not seeking support to detach themselves from the stigma. To avoid this, the Government has recently changed their definition or terminology from Special Educational Needs to Additional Learning Needs (Welsh Government (2016) (i)). This term could be applicable to most of the society, as we all need support which shows equality. The term Additional Learning Needs is less strong than Special Educational Needs, which could decrease the stigma attached and allow people to feel more comfortable in receiving support. This illustrates that the revision of terminology is more inclusive.

2.1.2. Definition in America

In America the term learning disability is used to define what the UK states as learning difficulty. This means that learning disability in America is defined as individuals who have a disorder in understanding the process of language and literacy (Learning Disabilities Association of America, 2017). The term intellectual disabilities is used in America for what the UK defines learning disabilities. This helps support the contention that terminology is contested.

2.1.3. Identifying People with Learning Disabilities

The terminology makes it harder to identify individuals with learning disabilities as there is a stigma associated with learning disabilities which, in turn, means that not all those affected seek support. This could influence the number of people identified with learning disabilities in Wales. According to the Welsh Government (2016) (h) there were 14,729 people in Wales registered with learning disabilities in 2016, as mentioned in the introduction. These people will have different types of learning disabilities which will vary between mild, moderate, severe and profound. By having different terminology for learning disability, it does not mean it has different meaning to different people, as they are referring to the same group of people. Therefore it should not affect the number of people with learning disabilities identified in Wales.

Alborz, McNally and Glendinning (2005) explains that some people with learning disabilities are identified at birth, whereas others may not be identified until school
years when intellectual developments deviates. Therefore, identified numbers depends on monitoring and diagnosis arrangements, and if these are not effective, again, not all people affected will be identified.

2.1.4. Social and Clinical Model

Williams and Evans (2013) explains that there are two types of models that categorise people with learning disabilities; a social and a clinical model. The clinical model focuses on the ‘problem’ of cognitive understanding, whereas the social model focuses on their rights and how their daily lives might be affected which results in the need of support. It also focuses on what might be done to improve the autonomy and well-being of those people. According to Williams and Evans (2013) most people with learning disabilities would reject the clinical model and prefer the social model. This project will focus on the social model, as the aspirations of the Government are set out in policies, which concentrates on the rights of individuals. Policies also consider all the elements around the individuals, which is social model orientated.

2.2 The Purpose of the Study

The purpose of this study is to explore the government’s aspirations and to compare this with the reality ‘day to day’ of lives of people with learning disabilities. This examines whether the policies of the government are realistic for people with learning disabilities. The policies only came into force recently, therefore there are not many research papers that relate to this project. However, there are similar studies which are mainly based in England. This research concentrates on practice in a rural area in North Wales. Although it concentrates on Wales, it will refer to some policies used in England. Therefore, this project uses primary research through interviews of professionals working with people with learning disabilities.

2.3 Policies

2.3.1. Social Services and Well-Being (Wales) Act 2014

The Social Services and Well-Being (Wales) Act 2014 came into force in Wales on April the 6th 2016 (Welsh Government, 2016 (g)). The purpose of this legislation is to provide a legal framework for people who need care or support. People with learning disabilities
are included in this Act. Its aim is to improve their well-being. As well as those who receive care, carers who need support are included. Carers may need support financially and emotionally, as the industry is very demanding in many aspects. It is also intended to transform the social services provided in Wales (Welsh Government, 2016 (g)).

According to Welsh Government (2016) (g) there are 3 major changes within the Social Services and Well-Being (Wales) Act 2014 that shapes the whole legislation. The first change is the way people are being assessed for their needs. The way the services are being delivered is another change. Finally, the new legislation allows the individuals to have more say in the services they receive (care and support). The legislation works closely with communities to promote a range of assistance to reduce the need for planned support (Welsh Government, 2016 (g)). This would allow individuals to be more involved within their own community. Linking with the medical and social model, the Social Services and Well-being (Wales) Act (2014) focuses on the social model in terms of opinions and how things are viewed rather than the clinical model.

2.3.2. **Social Services Improvement Agency – Opportunity Assessment**

The Social Services Improvement Agency (SSIA) (2014) have introduced a new programme which identifies new aims in improving services for people with learning disabilities. To achieve this the SSIA want to co-operate with local authorities in Wales and the NHS in order to improve the allocation and efficiency of funding. SSIA (2014) have set aims to improve the quality of life of people with learning disabilities, ensuring that the use of funding is more effective, and to follow the policies set by the Welsh Government.

As explained above, Social Services and Well-Being (Wales) Act (2014) aims to change the assessment of needs of people with learning disabilities. Following this Act, The SSIA (2014) have introduced the Opportunity Assessment in Wales. The Opportunity Assessment is implemented to set benefits to both people with learning disabilities and the Welsh Government (SSIA, 2014). People with learning disabilities’ wishes should be listened to, and short and long term goals should be set to achieve these wishes. SSIA (2014) explains that these goals should be achievable in terms of time and pace of the
individual. This indicates that the Government have realised that every person with learning disabilities abilities is different as are their needs. The benefits for the Welsh Government is that capital is potentially distributed more efficiently.

The SSIA (2014) have recommend that the 'Progression Model' should be used in services in Wales for people with learning disabilities. This model concentrates on the individual's needs and their ability to reach their goals. At the end of each goal, they will review the process and decide whether the outcomes are positive and how to make changes in ensuring the individual reaches their needs.

(SSIA, 2014).
This Person Centred Development Approach is promoting the Social Services and Well-Being (Wales) Act 2014.

2.3.3. Valuing People Now

Valuing People Now is set by the Government for services and individuals who works with people with learning disabilities (Department of Health, 2009). This policy closed in March 2011 (Learning Disabilities Today, 2013). The aim of this report was to identify the aspirations, wishes and needs of people with learning disabilities and to address them. By doing this the Government were working towards encouraging people with learning disabilities to make their own decisions and choices over their own lives (Department of Health, 2010). Guess, Benson and Siegel-Causey (2008) cited in Mitchell (2012) explains that people with learning disabilities were not allowed to make decisions before, as they were seen as having a lack of understanding on knowing what decisions are considered risky. Although this policy has a historical significance it is still relevant as it is under the umbrella of the Social Services and Well-Being (Wales) Act 2014. Valuing People Now was more directly related to people with learning disabilities, whereas, Social Service and Well-Being (Wales) Act (2014) is related to everyone. However, it helps identifying some of the specific aspirations that are still relevant for people with learning disabilities today.

2.3.4. Valuing People

Valuing People Now report is an update to Valuing People 2001, this shows that a realisation of the importance of reviewing and updating policies. According to Gardner, Morey and Routledge (2001), this report has set out 11 key objectives which is set by the Government for people with learning disabilities.

1) Maximising opportunities for disabled children  
2) Transition into adult life  
3) Enabling people to have more control over their own lives  
4) Supporting carers  
5) Good health  
6) Housing  
7) Fulfilling lives
However, the Welsh Government (2016) (i) has introduced the Additional Learning Needs (ALN) Transformation Programme for the educational needs of people with learning disabilities. This is introduced as a new model to replace the previous Special Educational Needs (SEN) model which was introduced more than 30 years ago. The changes include overcoming barriers to allow individuals to reach their full potential, identify the needs and wishes of individuals when planning and deliver the support, and understanding the importance of identifying needs (Welsh Government, 2016) (i)). As mentioned earlier additional learning needs will potentially eliminate the stigma attached to the term. In contrast to Valuing People Now (which comes under the Social Services and Well-Being (Wales) Act 2014, and developed from Valuing People 2001), the educational aspect for people with learning disabilities did not update often enough.

2.3.5 Social Care Code of Practice

Social Care Wales (formerly Care Council for Wales) has created a framework for social care workers called the ‘Social Care Code of Practice’. This identifies the standards required from professionals for conduct and practices. This framework raises awareness of the importance of good practices. The framework was recently reviewed, resulting in a new code that was implemented in 2015, the 'Code of Professional Practice for Social Care' (Care Council for Wales, 2015 (a)). The reason for reviewing this framework is that a lot has changed in terms of policies in Wales within the last 12 years (Care Council for Wales, 2015 (b)). The Code of Professional Practice for Social Care is shaped by the Social Services and Well-Being (Wales) Act, which emphasises the importance of promoting good practice (Care Council for Wales, 2015 (b)).
2.4 Good Practice

Pritchard (2001) explains that good practice applies to everyone especially to vulnerable adults who might not have the capacity to protect themselves. It is a framework to protect individuals from harm.

Good practice begins with a person-centred approach i.e. taking account of the wishes of a person needing care and support, whilst considering their families and carers. Therefore, the Department of Health introduced a new project where people with learning disabilities and their families can influence the shape of the practice (Department of Health, 2013). Gibbons (2007) explains that the Welsh Assembly Government also contributed towards the policy and practice for people with learning disabilities. They have noticed by receiving suggestions from organisations who work with people with learning disabilities it improves the effectiveness of the policy and practice, whilst making it more realistic for people with learning disabilities. In order to create a framework for the service the Welsh Assembly Government worked alongside The Learning Disability Advisory Group (Gibbons, 2007). However, these policies are considered dated due to the force and significance of the Social Service and Well-Being (Wales) Act 2014 in Wales. Although these policies are still relevant, as all the principles now come under the Social Service and Well-Being (Wales) Act 2014.

According to the Social Services and Well-Being (Wales) Act (2014) under Section 24, it is a duty to ensure that all carers or supporters’ own needs and wishes are being assessed in terms of education, training or any leisure activities. This would be the beginning of promoting good practice; by meeting the needs of the carers it will improve the service for people with learning disabilities.

However, Mansell (2010) (e) discovers that some parents of people with learning disabilities prefer to have carers or staff who develop a good relationship with people with learning disabilities rather than have up to date training. One mother explained that having a warm and good relationship with a person with learning disabilities is the most important service a carer could provide (Mansell, 2010 (e)). This suggests that anyone can be trained to become a carer, however not everyone can develop a good relationship with the service user.
Mansell (2010) identifies different elements on what is considered to be good practice for people with learning disabilities:

1) Person-Centred

2) Treating the family as experts.

3) Quality of relationship between the staff and the individual.

4) Package of care.

5) Cost-Effectiveness.

(Mansell, 2010 (e)).

These elements were discovered by interviewing individuals and families of people with learning disabilities. All of these principles are now considered under the Social Services and Well-Being (Wales) Act 2014.

Mansell refers to people with learning disabilities as people with profound intellectual or multiple disabilities (PMLD) (Mansell, 2010 (e)). This term refers to an individual who has more than one disability, this could include a sensory impairment as well as physical disability. Alborz, McNally and Glendinning (2005) also state that people with learning disabilities are more prone to other types of disabilities. Therefore, PMLD is seen as one of the most vulnerable group of people within the community as they require additional support or assistance (Mansell, 2010 (f)). Mansell’s report is set to follow and analyse the Valuing People Now’s Report.

2.4.1. Decision Making

Mitchell (2012) researched into parents’ point of views regarding allowing their child with learning disabilities to make decisions. Mitchell (2012) discovered that some parents felt that it is important to encourage people with learning disabilities to make their own decisions, while others felt that it depends on their level of understanding. It was identified that parents’ needs of protecting their child was influencing the decision of allowing people with learning disabilities to make their own decisions (Mitchell, 2012).
The Department of Health (2008) explains that making decisions is an important part of everyone's lives when transitioning into an adult. When people with learning disabilities are transitioning into an adult, they move from children services to adult services. Mitchell (2012) explains that practitioners face difficulties in ensuring that people with learning disabilities’ wishes and choices are met, when their parents have different wishes for their child. Thompson and Pickering (2001) state that practitioners must work with other professionals as well as allowing the service user and their family involved in decision making.

By allowing people with learning disabilities to make their own choices without causing harm to self or others, the Department of Health (2008) have identified steps in maintaining good practice, when a person with learning disabilities is transitioning into an adult:

1) Ensure the individual's needs are at the centre of the assessment.

2) A clear structure on planning. This includes easy communication to allows everyone to understand.

3) The aims are still there when a person with learning disabilities is transitioning from a children's services to adult's services.

4) Acknowledging that they still need support and services when are adults.

5) Identifying what will help or support the individual to transition into adult.

6) Everyone around the individual understands their roles and responsibility in supporting the person centred-care.

(Department of Health, 2008).

Having a voice would come under the decision making process. Section 3 of the Code of Professional Practice for Social Care Workers the Care Council for Wales ‘[promotes] the well-being, voice and control of individual and carers while supporting them to stay safe’ (Care Council for Wales (2015) (a)).
2.4.2. Access to Healthcare

According to Department of Health “We know that people with learning disabilities have worse health care and die earlier than others” (Department of Health, 2013:3). Supporting this evidence, Michael (2008) produced a report called ‘Healthcare to All’ which states that people with learning disabilities have greater needs in health, however find access to healthcare harder than the general public. Within the report Michael (2008) identifies many different issues which have an influence on the efficient of the delivery of healthcare for people with learning disabilities.

The first issue is many parents or carers of people with learning disabilities feel that the practitioners does not consider their opinions or suggestions, even though they understand the need of the individual more than anyone (Michael, 2008). This suggests that practice does not match the aspiration, which links to the purpose of this project ‘Aspirations of Government for People with Learning Disabilities and the Reality’.

Another issue identified is that the General Practitioner lacks knowledge regarding people with learning disabilities, therefore failing to understand what support the individual needs (Michael, 2008). This shows that the General Practitioners need to realise that equality in treatment does not mean the same treatment for everyone.

However, Alborz, McNally and Glendinning (2005) categorises access to healthcare into two different elements; Physical access to the service and gaining the access to the service. Physical access looks at the geography of the service, and whether the individual can access it. Whereas gaining access may be easy for the individual to access the service, however, does not access the right treatment or healthcare. This distinction can apply to people with a disability in that physical access to services is possible but gaining access is restricted, for other reasons e.g. GPs failing their gatekeeping duties. Mencap (2007) identifies that 75% of GP’s admitted that they have had no training on how to support or treat people with learning disabilities. This statement also shows that the aspiration of Government is not met.
2.4.3. Equality

The Human Rights Act 1998 sets out rights for everyone. In this Act under Article 14 everyone has the right for protection from discrimination (Equality and Human Rights Commission, 2016). This article explains that everyone should be treated fairly and equally. However, it does not mean that everyone should receive the exact same treatment, as some may be disadvantaged under different circumstances such as pregnancy or disability (Equality and Human Rights Commission, 2016). As the difference in needs are not recognised, this can lead to indirect discrimination.

Looking back to Alborz, McNally and Glendinning (2005) access to healthcare, it could show an indication of indirect discrimination as people with learning disabilities may not be accessing the services they need due to the lack of recognition. As well as a potential breach of article 14, this could be in breach of the Equality Act 2010. That Act prohibits indirect and direct discrimination based on ‘protected characteristics’. Disability is one of those characteristics and would include people with learning disabilities.

Parrish (1998) explains that the NHS Executive introduced a document called Signposts for Success. The aim of this document was to give guidance to different services on how to maintain good practice. This document emphasized the importance of the quality of services (Parrish, 1998). This included ensuring that every person surrounding the individual are working in cooperation; a person-centred service. These people can include family, carers and professionals. This document has similar purpose to the SSIA Progression Model; a person centred focus.

2.5 Bad Practice

2.5.1. Barriers Which May Cause Bad Practice

Michael (2008) emphasizes that all issues are not leaning towards the practitioners. One major issue is the communication barrier for people with learning disabilities. They might have difficulty in expressing their worries or pains, which makes it harder for the practitioner to identify and deal with certain issues.

Williamson (2004) identifies four different barriers, which affects the health service for people with learning disabilities. These barriers are: personal, physical, organisational
and professional. Difficulties in communication comes under personal (Williamson, 2004), and according to the Department of Health a good practice for people with learning disabilities is using a form of communication that is easy and effective for the individual to understand.

2.5.2. Real Life Case Studies

In 2011 a programme was broadcast by the BBC Panorama called ‘Undercover Care: the Abuse Exposed’. This highlighted horrific graphics and real life cases of people with learning disabilities being abused by their own carers in Winterbourne View Hospital in South Gloucestershire. Many reports and investigations were conducted to look into the Winterbourne View case. One major report was created by the Department of Health called ‘Transforming Care: A National Response to Winterbourne View Hospital: Department of Health Review Final Report’. Department of Health (2012) (c) identified that many mild and severe warnings in Winterbourne View were ignored, and these were ignored by more than one person and department.

Within this report the Department of Health (2012) (c) identified that people with learning disabilities are staying in hospitals or residential homes longer than needed. There is no evidence that they receive bad care, however, it explains that they can fulfil a happier life somewhere else. The Department of Health (2013) explains that one form of good practice is ensuring that people with learning disabilities are happy with where they live and with their own lives. This shows that the Government responded with actions and implemented a new policy.

However, Ockenden (2014) explains that an investigation was undertaken into a Mental Health Unit in North East Wales following serious allegations. These allegations included lack of care, not following the duty of care guidance and letting the patients walk around unsupervised. This illustrates that policies can be written and it is easy to set principles on what is expected from people, however, these principles need to be put into practice. It is important to maintain the quality of the practices and that is why assessment, review and inspection are fundamental.

Department of Health (2012) (c) have set an aim where the health and care commissioners such as Care Quality Commission should carry out an assessment on
services rather than on units. This would include assessments on the community and ensure the individual and others around that individual is safe from harm. Following the Winterbourne View incident, Care Quality Commission (2012) carried out inspections in 145 different settings, which included 68 NHS trusts, 45 private healthcare settings and 32 residential homes. This promotes good practice following a bad practice as the Care Quality Commission realised the importance of ensuring that such delivery of care is not repeated in other settings.

To conclude, the definition of learning disabilities does have different terminology, however they all refer to the same group of people. The terminology should not affect the number of people identified with learning disabilities. Many policies for people with learning disabilities are all recent, however, many of them are now historical and dated, as the Social Services and Well-Being (Wales) Act 2014 was introduced and dissolves preceding acts. This Act is a framework which compiles all other policies under one umbrella. It refers to everyone, which also includes people with learning disabilities. These policies are the Governments’ aspirations; however, they need to work in practice in order to be effective. Person-centred care is the key element to promote good practice. This includes multi-disciplinary team working to support the individual by also considering the individuals needs and wishes. These aspirations are not always effective in practice as cases such as Winterbourne View still arise today. However, this incident was a catalyst for many policies, which shows that the Government are working towards their aspirations in improving the quality of life of people with learning disabilities.
Chapter 3: Methodology

This chapter considers the methods of obtaining data, mainly through primary research. It also discusses the implementation of the research.

3.1 Definition

Braun and Clarke ((2013, pp31-32) define ‘methodology’ as ‘referring to the framework within which [the] research is conducted’. It enables a ‘series of decisions about [the] research’. For example this includes ‘How can participants be selected?’ and ‘What methods of data collection and analysis are appropriate?’ Therefore, it concentrates on the methods used in order to carry out the research (Khan, 2008).

3.2 Quantitative and Qualitative data

There are two types of data in research; qualitative data and quantitative data. Qualitative data concentrates on opinions and open-ended results, whereas quantitative concentrates on the statistics (Creswell, 2014). This means that qualitative data can vary between individuals or situations, however, quantitative data will more limited, as statistical data is uniform and confined. It is also a more accurate data. Qualitative data can be collected through the use of interviews, focus groups, questionnaires or observation. Quantitative data can be collected through the use of questionnaires, recording data, and measurements.

3.3 Primary Research

This research undertaken is primary research as it collects original, raw data. Primary research is necessary in this project as it compares aspiration with the reality, and this required the researcher to do their own investigation. To do this the researcher chose semi structured interviews. The reasons for that choice are explained more in depth later in this chapter.

3.4 Data Method and Implementation

Collecting qualitative data is the most relevant method for this project as it researches into people’s opinions and perspectives. Collecting qualitative data may be time consuming for the researcher however, an advantage of using qualitative research is
that it gathers personal opinions or experiences, and in-depth information on the subject. It draws on different elements within the topic that the researcher may not have considered.

According to Harrell and Bradley (2009) there are two main types of methods of collecting qualitative data; semi-structured interviews and focus group. To collect data in this research, the researcher used semi-structured interviews. Interviews are one-to-one discussions between the interviewer and interviewee. Semi-structured interviews involve a list of questions to be covered in the interviews (Cohen and Crabtree, 2006). They provide a framework in which the interview takes place. This helped keep the interviews on track and focus on relevant matters.

Positively for this research, semi-structured interviews allow flexibility; for example, regarding other topics which the participants may want to introduce that the researcher did not initially consider, or with regard to follow-up questions that might arise from a particular answer. This kept the subject more open and allowed the researcher to draw on more detailed information.

Conducting focus groups was considered as a research method for this project, however it was overruled by semi-structured interviews. The reason for this is that there are many disadvantages of using focus group. Firstly, the practical management side. It would have been difficult to arrange a time that was appropriate for everyone to meet and to create transcribed notes of everyone talking at once. While focus groups may be considered more effective in gaining broader information, some participants may feel somewhat conservative in terms of expressing some opinions or points in front of others. This would have had an effect on the validity of the research. Flick (1998) explains that another limitation of using focus groups is that it is difficult to manage the group to concentrate on one topic without introducing another non-relevant topics.

3.5 Sample

According to Moule and Hek (2011) a sample is a selected section of the population where data can be collected. This means that the participants has to come under a specific sample to participate in the research. The criteria for this research was:
a) They have to be over 18 years of age.

b) They have to be in a professional role that involved people with learning disabilities.

Purposive (judgemental) sampling was used to recruit staff who work with people with learning disabilities. These people were recruited from two organisations the researcher identified as working closely with people with learning disabilities. Moule and Hek (2011) explains that purposive sampling is effective to collect data from a specific sample. Purposive sampling is the most appropriate approach to select participants in this research as it required a specific group of people. Teddlie and Yu (2007) explains that purposive sampling is working with a small group of people and concentrating on the depth of the information received from the participants.

There are disadvantages of using this method. As the researcher was familiar with both organisations, the participants involved may have felt that they could not be truthful with their answers or share their experience in case any information was disclosed to the organisation. To avoid this issue, the participants were assured at the beginning of the interview that all data will be kept confidentiality and no names will be mentioned at any time in the research.

These approvals were done through email as it is the most efficient way. The emails included a small description of the research and its purpose.

When selecting participants for the research, an email was sent to both organisations inviting individuals to participate with the research. Within the email an information sheet was attached (see appendix 2), explaining the purpose of the study, what the involvement of the participant meant for the research and how the data was to be used after the interviews. These participants chose voluntarily to participate.

By having the participants choosing to be involved in the research voluntarily, it reduces the potential for bias. This would improve the validity of the research. Validity is when the analysis of data is what was expected at the beginning of the research (David and Sutton, 2011). However, if individuals are concerned that the data received would not be kept confidentiality, the participants may not give their truthful opinions which could have an effect on the validity of the results.
Questions were constructed before the interviews, which were piloted with the supervisor (see appendix 4). Moule and Hek (2011) explains pilot study as a data collection technique, which is tested before the research. This researcher did not use these questions exactly, however, it allowed the researcher to plan the structure of the interviews. Another advantage of using this technique was that it enabled the researcher to better identify topics to be covered and to exclude unnecessary data.

Each participant had a choice of engaging the interview in either Welsh or English; all of the participants preferred engaging in Welsh. This allowed the participants to feel more relaxed when being interviewed. The researcher used a phone and a tablet to record the interviews. Marshall and Rossman (2011) states clearly that the reason for using two separate devices is to make sure the interviews are successfully recorded. That proved to be good advice, as one device failed to record the last 5 minutes of an interview.

3.6 Collecting the Data

Semi-structured interviews took place in two separate organisations. The first organisation provides a range of services for people with learning disabilities. This includes a craft centre, furniture shop, gardening, and accommodation. The second organisation provides education for people with learning disabilities at the age of 18 and older. Here, they support people with learning disabilities in developing independent living skills. Both of these organisations are appropriate for the research as they both work closely with people with learning disabilities, however, they are confined to two different fields: 1) daily lives of people with learning disabilities and 2) education and development for people with learning disabilities.

Before the interviews, each participant were given an information sheet (see appendix 2) to allow them to have an insight on the purpose of the interview and what the discussion was regarding. The information sheet was available again for the participants in each interview and it was read at the beginning of the interview to remind the participants of its purpose. Once participants were comfortable with this they were given a consent form (see appendix 3), which needed to be signed and dated. Mauthner et al (2002) explains that ethics committees require consent forms to be signed by the participants, especially in health services research. This research would come under this
category. Both researcher and participant received a copy of the signed informed consent form.

All of the interviews were conducted in one day. The researcher did two interviews in one organisation in the morning and the other two in another organisation in the afternoon. Initially, the aim was to interview three participants in each organisation. However, the researcher decided it was more convenient to do two interviews in each organisation as plenty of information was gathered. There were also practical considerations. It is time consuming to arrange a time to conduct and to transcribe the interviews. All interviews were conducted in a closed and quiet room. Each interview lasted around 20 to 30 minutes. During this time the participants had the opportunity to share their views and experiences of the Government’s methods to set aspirations for people with learning disabilities.

The purpose of the interviews was to gather information on:

1) Staff’s opinion on the definition of people with learning disabilities.

2) The perception of good practice for different people.

3) If the Government work closely with people with learning disabilities, and their parents or carers/staff.

4) If people with learning disabilities receive equal access to healthcare services as the rest of the public.

5) Whether people with learning disabilities have a voice.

6) If staff for people with learning disabilities feel that the services provided by the Government for people with learning disabilities is improving or worsening.

Talking about people with learning disabilities may be a sensitive subject for some people. This made it hard to word some questions as some may be offended. The researcher tried to minimise the risk of this by, for example, starting each interview by asking the participant which term they preferred: ‘learning disabilities’ or ‘learning difficulties’.
3.7 Data Analysis

The interviews were translated and transcribed in English, which are kept in a password protected file. This allowed only the researcher to have access to the interviews. To analyse the transcriptions the researcher used thematic analysis.

Thematic analysis is a qualitative method of analysing data through identification of themes (Braun and Clarke, 2006). Using thematic analysis, the researcher needed to identify patterns raised in the interviews and compare the results between both organisation (Marshall and Rossman, 2011). In order to do this, Marshall and Rossman (2011) emphasises the importance of categorising each information. Braun and Clarke (2006) identifies six different steps in thematic analysis. These steps are:

1) Familiarizing yourself with the data
2) Generating initial codes
3) Searching for themes
4) Reviewing themes
5) Defining and naming themes
6) Producing the report. [In this research the ‘report’, of course, is the dissertation].

(Braun and Clarke, 2006)

In stage one, the transcripts were read repeatedly, in order to become familiar with the data. Javadi and Zarea (2016) emphasizes that it is important that the transcriptions are correctly spelled and written. It is crucial to make sure that, for example, the commas are placed correctly as it can change the whole meaning of the sentence (Javadi and Zarea, 2016).

Stage two was not used in this research. The research was not considered largescale enough to create codes. Therefore, it went straight to stage three; to identify initial themes. Stage three was similar to stage one, in that the researcher read the data repeatedly, however, themes needed to be identified within the data. It was also important to attempt to establish relationships between the themes (Javadi and Zarea, 2016).

Stage four involved reviewing the themes that had been identified at stage three. This was challenging, as identifying specific themes could prove difficult. Sub-themes were often constructed, which limited the ability to establish relationships between different themes. This stage was time consuming and required a lot of effort. The researcher followed Javadi and Zarea (2016)’s recommendation and created a map of the themes, which clarified different themes and assisted in the categorisation of the themes.

Once the themes were identified, stage five of the thematic analysis was to name each theme and define it. This stage is key, as it limits the data, keeping it narrow and confined rather than allowing broad information to be collected as one. Javadi and Zarea (2016) explains that it is important that the definition and the title of the themes are short and clear for the readers.

In the final stage, the relationship between each theme were established, and this then provided the foundation for the discussion that follows. Themes also need to be written in a way that convinces the readers that these themes exist within the data found from the interviews, for example, by backing up with effective evidence. The evidence can be examples and quotes from the interviews. The quotes are written in Welsh, as all the interviews were conducted in Welsh, and the researcher has translated these quotes to English. Javadi and Zarea (2016) emphasizes the effectiveness of thematic analysis for a qualitative project as it is clear and straightforward.

3.8 Ethical Considerations

In research, it is important to recognise the ethical considerations and the issues that arise. Moule and Hek (2011) emphasises that professional bodies set guidance or principles, which should be followed. Moule and Hek (2011) has identified 4 key principles which are relevant for all research;

1) The Principle of Veracity

2) The Principle of Justice

3) The Principle of beneficence (or Non-Maleficence)

4) The Principle of fidelity and Respect'
The veracity principle protects the participants' rights to withdraw from the research at any time. The justice principle emphasises the importance of equality, this is set to avoid discrimination. The beneficence or non-maleficence principle explains the researcher's duty of protecting the participants from harm, and to ensure the importance of the participant's involvement. Finally, the fidelity and respect principle covers the rights of participants, which includes: confidentiality, safeguarding, privacy and dignity.

According to Mauthner et al (2002) ethics in a qualitative research is not just about gaining ethical approval (in the researcher’s case from the Applied Community Sciences and Protection Ethics Panel), but also following the ethical guidelines. The Applied Community Sciences and Protection Ethics Panel approved this research (see appendix 1).

As to ethical guidelines followed by the researcher, the Cardiff School of Health Sciences (CSHS) provides ethical framework, which aims to protect the staff, students and participants (James and Lewis, 2016). The general principles mentioned by Moule and Hek (2011) can be identified in this framework. In the ethical framework, the CSHS has 7 different ethical principles which needs to be followed; Non-maleficence, Beneficence, Dignity and Autonomy, Confidentiality and Anonymity, Impartiality, Legal, and Non-Discriminatory. James and Lewis (2016) briefly explains these principles:

- Non-Maleficence – Protects everyone involved in the research from harm.
- Beneficence – Ensuring that every step within the research has a purpose.
- Dignity and Autonomy – Showing respect towards the participants and organisations.
- Confidentiality and Anonymity – Keeping the participants and organisations anonymous.
- Impartiality – To be open minded about the outcomes of interviews.
- Legal – Follow appropriate legislation.
- Non-Discriminatory – Ensure equality treatment for everyone.
Some of these ethical principles were used in the project, especially for conducting interviews, however, many of them correlate together. When selecting the participants, they volunteered to be involved. This followed two principles of the CSHS ethical framework, the non-maleficence and dignity and autonomy.

Before conducting the interviews, participants received an information sheet and then had a consent form to sign if they wished to participate. The information sheet followed the beneficence principle as it explained to the participants the purpose of interviews regarding the research. Whereas, the consent form followed the non-maleficence principle as it seeks to protect the participants from harm. Within this consent form it emphasised the participants’ rights to withdraw at any time.

By conducting the interviews in a familiar environment, it followed the non-maleficence principle as it sought to protect them from harm, but also, the dignity and autonomy principle as it shows respect towards the participants and their organisations.

The participants had a choice of conducting the interviews in either Welsh or English. This covered the dignity and autonomy, and the non-discriminatory principle as it showed respect towards participants by ensuring they were comfortable but also to maintain equality.

All recordings of the interviews and transcription notes are kept in a password protected file. This limited the number of people that can access the data; only the researcher is aware of the password. Moule and Hek (2011) also emphasised the importance of maintaining the participant’s anonymity throughout the project. To ensure this all participants will be coded as A, B, C and D. This followed the confidentiality and anonymity principle of the CSHS ethical framework.

Following this chapter will be the findings chapter. All of the data will be transcribed and analysed in order to identify themes. In this chapter, the themes will be titled and defined.
Chapter 4: Findings and Discussion

This chapter will discuss the findings from the interviews. As explained in the Methodology section, thematic analysis will be used to analyse different themes. Moule and Hek (2011) emphasises on the importance of selecting the themes carefully. These themes will be compared with the discoveries from the literature review. This stage is the last stage of the thematic analysis (Braun and Clarke, 2006). Before exploring the themes discovered within the data analysis, it will briefly explain the background of participant’s organisations and evaluate the terminology the participants preferred.

4.1 Background of participants

Each participant had different experiences of working with people with learning disabilities. Also, it is important to note that all of the participants have worked longer in this field of work than other fields. One participant started their own organisation over 21 years ago which provides services for people with learning disabilities. Before establishing this organisation, they worked with the social services for physical disabilities then moved towards learning disabilities. Another participant of this research is working within this organisation, who started as a volunteer support worker for people with learning disabilities over 15 years ago.

The other 2 participants are involved within a department for people with learning disabilities in a college. One participant is the coordinator of this department, who used to work for the Careers Wales for people with learning disabilities, who had duties of going around different schools. The other participant within this college used to teach people with learning disabilities before moving forward to manage the department for people with learning disabilities. This participant has professional experience of working with people with learning disabilities, but also has personal experience as they have a child who has learning disabilities.

Five different themes were analysed within the analysis of the data, the most common, and the widest theme found was good practice. This theme could also be sectioned into sub-themes.
4.2 Terminology

At the beginning of each interview the participants were asked which terminology they preferred ‘learning disabilities’ or ‘learning difficulties’. All participants acknowledged that the Government uses the term learning disabilities today. However, only one participant preferred this term as it covers everyone. Two participants use learning difficulties, not only because they prefer it, but also it is the term they are more familiar with. Another participant referred to people with learning disabilities as ‘workers’, as they are employed within the organisation. This demonstrate that although the Government attempts to make a definition or term official, reality sometimes resists, as opinions and personal objectives influences such statements.

4.3 Good Practice

Each participant had different beliefs on what they considered as good practice. Pritchard (2008) believes that every worker should promote good practice professionally and morally. Further to this point, Pritchard (2008) gives an example of where workers will say that they have too much paper work or simply did not have the time to complete certain tasks. Pritchard (2008) emphasised that good practice should not be seen as something extra or additional to the duty of the role.

4.3.1 Policies

Policies are developed through developing goals, aims or objectives which the organisations must strive to achieve (Carver, 2009). Many of these goals are promoting good practice and well-being, which all comes under the recent Social Services and Well-Being (Wales) Act 2014. However, as explained in the literature review, written policies are only effective if they work in reality. To get a better understanding of the effectiveness, reviews must be conducted by asking the public opinions on their thought and feelings toward a certain policy. The policies within this project concentrates on people with learning disabilities, therefore, people with learning disabilities are the priority in ensuring they are satisfied with the set policies.
Within the data analysis, both positive and negative reviews were conducted. A major positive aspect was that some of the policies documents are available in 'easy read' format, which includes images as a form of communicating.

This indicates that it is promoting equality by allowing people with learning disabilities who may have difficulty in reading or understanding complex communication, to understand the aim of the policy. This supports Williamson (2004) statement within the literature review of the importance of using a form of communication to allow individuals to understand. Therefore, the aspiration of ‘Promoting independence where possible’ in Social Services and Well-Being (Wales) Act (2014) Section 6 (3)(b), is met in reality here.

According to one participant the government do occasionally contact parents or carers to ask for thoughts and feelings regarding the services provided.

‘Pan mae nhw’n cysylltu, mae  yn dod i’r tŷ, i’r fam ac fan hyn’ TRANSLATED TO

*They do contact, a letter is sent to [people with learning disabilities], to the parents and to [the carers]’ (Participant C).

In contrast to this another participant emphasised that their child who has learning disabilities has never had the opportunity to share own thoughts and feelings.

‘Dwi’n cael holidaur i ofyn ei farn o. Ond dyna ydi’r unig darn dwi wedi cael yn gofyn iddo, erioed. Erioed wedi cael barn y llywodraeth ar dim byd o gwbl’ TRANSLATED TO

‘The [private] organisation do send a questionnaire on the services, which I have completed with [them]. That is the only thing I have ever had on asking [their] opinion, ever. I have never been approached by the Government’ (Participant D).

However, as the policies are developed for a wide populous, it is important to remember that people of this population might have different needs that can differ greatly from one to another. Therefore, developing policies that are suitable for everyone is a nearly impossible task.

4.3.2 Integration

It was found that some participants involved believed that being a part of the community promotes good practice, where they believe that community inclusion is not
only beneficial for the individual with learning disabilities, but also for the health of the community itself.

‘Mae pawb yn dysgu efo’u gilydd ac yn help i’w gilydd. Mae’r myfywyr yn yr adran yma yn codi calonau pawb ac yn hapas, a bodlon eu byd. Mae gan y ddwy ochr lot i rhoi i’w gilydd. TRANSLATED TO

‘Everyone learns together and are helping each other. I think the students in this department lifts everyone hearts and are always happy. And both sides have a lot to give for each other’ (Participant B).

‘Wrth fod yn rhan yn y gymuned y coleg I gyd, mae nhw yn dod I adnabod y pobl yn y gymdeithas. Mae yna pobl sydd ddim efo anableddau yn trin nhw’n barchus ac yn dysgu lot wrth fod yn ffrindiau gyda nhw’ TRANSLATED TO

‘By being a part of the community, within the whole college, I feel that people are starting to get to know other people in the community. People who do not have disabilities treats them with respect and learns a lot by being friends with them’ (Participant D).

Both statements show strong opinions towards the importance of integration. Cummins and Lau (2003) states that integration improves the quality of life for people with learning disabilities. However, it is also beneficial for the future generation to adapt attitudes towards people with learning disabilities (Cummins and Lau, 2003). This is a long-term process; however, this would further develop the quality of life of people with learning disabilities.

The literature review emphasised on the importance of reducing stigma for people with learning disabilities, integration would enforce this, therefore, allowing the aspiration of improving the quality of life to be met.

4.4 Person-Centred Care

The progression model emphasises on the importance of person-centred care. Therefore, everyone surrounding the individual must promote their well-being. Participant A discussed a time which the person-centred care was not promoted. An individual with down syndrome was rushed to the hospital, and a practitioner decided not to give resuscitation due to ‘poor quality of life’. Participant A appealed against this decision, arguing that the quality of life of this individual was excellent. This act demonstrates a lack in promoting well-being, and a failure for the government’s aspirations.
4.4.1 Decision Making

Decision making regarding people with learning disabilities can be a complicated debate. Although promoting decision making promotes good practice, other factors need to be considered. Maintaining good practice is key for people with learning disabilities, safety is also a characteristic of good practice. Mental Capacity Act (2007) has a code of practice which enables people with learning disabilities to make their own decisions. If they lack in capacity, the Mental Capacity Act (2007) states that sufficient planning should be completed in regards to their best interest.

‘Bod nhw yn cael eu hawliau, yn cael dweud a gofyn yn eu dewis nhw. O fewn rheswm wrth gwrs, mae yna adegau gyda perygl!’ TRANSLATED TO

‘They have their rights, so they can say and ask what they would like to do. Make choices within reason of course, we have to be careful of their safety too’ (Participant C).

This statement clarifies the distinction of the importance of both making choices and to reduce risk of harm for the individual. One participant explained that an advocate can support an individual with learning disabilities to make their own decisions and can also ensuring they maintain their rights. Advocacy will be further explained later in this chapter.

While it is important to be concerned about safety, the carers and parents needs to be careful that they do not make all the decisions on behalf of the individual.

‘Fel arfer mae yn hawdd iawn siarad dros nhw’ TRANSLATED TO

’Sometimes it is easy to speak over them’ (Participant D).

Common occurrence of such a situation can cause the individual to become less independent, therefore not given the opportunity to make their own choices or decisions. This could then lead to lack of promoting good practice which is the most important element of working with people with learning disabilities.

It is important to promote decision making, the department for people with learning disabilities in the college has made recent changes in how they conduct arrangements for the individual before beginning college, which is now called a ‘one page profile’. Previously, assessments were carried out with numerous staff as well as the person-centred care in the same meeting. Although beneficial for the staff, it was not so
beneficial for the person-centred care, as often they were conservative to contribute due to the number of people in the setting. Recently, these meetings are conducted between the individual and an advocate, who discusses the individual’s best interests. These interests will be assessed to ensure that the individual achieves their goals, as well as maintaining a safe environment.

4.5 Communication

Leonard, Graham and Bonacum (2004) clarifies that effective communication is important to deliver safe care to patients. This includes communication between people with learning disabilities and people surrounding the individual. When analysing communication within the findings, there are different elements which influences its effectiveness.

4.5.1 Technology

The department for people with learning disabilities within a college referred to the effectiveness of the use of technology in communicating. Bryant, Bryant and Raskind (1998) explains that some people with learning disabilities may need assistive technologies to help them with communicating such as hearing aids. This links with PMLD as mentioned in the literature review. The participants discussed the use of technologies which helps people with learning disabilities in education and communicating through the use of tablets and Computers.

‘Does yna rhai ddim ar gael yn Cymraeg, ond yn Saesneg’ TRANSLATED TO
‘They are only available in English and not Welsh’ (Participant D).

‘Mae gen ni [myfyriwr] yn fan hyn sy’n blincio i gyfathrebu a mae hwna yn trigio’r cyfrifiadur i siarad’ TRANSLATED TO

‘We have a [student] who communicate through blinking, this is linked to the computer’ (Participant D).

Both statements show different aspects of effectiveness of technology in communicating. By not having the technologies available in Welsh it limits the number of people who can use the technology. This would then indicate an indirect discrimination as not everyone receives equal opportunity. Therefore, the aspiration of equality is not promoted.
However, looking at the second statement it shows a great advantage in using technology as a method for communication. Technology which allows an individual to communicate through blinking promotes independence and improve their quality of life.

Although both shows two different scales of effectiveness, it shows the importance of adapting and using technology every day in supporting individuals.

Participant B and D emphasised the importance of 'adapting to learn with the modern world'.

‘Dydw i ddim yn gwynod os mae diffyg hyder y staff i defnyddio’r offer ydi o, ta [y myfyriwr] sydd yn ffeindio ffordd rownd y offer ydi o’ TRANSLATED TO

‘... I am not sure if it’s the lack of confidence in staff with using the computer or if [the student] is trying to avoid using it’ (Participant D).

This statement indicates that some people may need to build confidence in using technology to allow people with learning disabilities to develop their independence.

4.5.2 Advocacy

Advocacy is an important part of the lives of individuals who have learning disabilities. It promotes their rights and supports their independence (Grant et al, 2010). Therefore, advocacy is a social model. Every participant involved had strong views on the importance of maintaining advocacy as a key element in the lives of people with learning disabilities.

Mae'r person adfocatiaidd wedi bod yn help, mae yna engreiffiau o bethau ella fuasai pobl eisiau mwy o help neu mwy o waith arno, a dyna lle mae adfocatiaidd yn allweddol' TRANSLATED TO

‘Advocacy here has been helpful, there are examples where people may need more help or support in and that is where the advocacy comes in’ (Participant B).

‘[Mynediad gwell] os gan y nhw adfocatiaidd efo nhw’ TRANSLATED TO

‘[Better access to services] by having advocate with them’ (Participant C).

Fuasai byth yn methu defnyddio’r gwasanaethau oni bai bod yna rhywun yn ei gefnogi ac yn dweud ar ei ran’ TRANSLATED TO

‘[They] would never be able to have access to the services without the supports and someone to advocate for [them]’ (Participant D).

All these statements demonstrate the effectiveness of advocacy in reality, as it improves the services for people with learning disabilities.
4.5.3 Barriers

There are many barriers within everyday communication, some of these barriers were identified within the findings. Other barriers are less common, and would affect people with learning disabilities more often than it would for the rest of the population.

Three participants gave different examples on barriers of communication.

‘Yn aml iawn mae nhw eisiau plesio pobl, felly dydi nhw ddim am gwyno’ TRANSLATED TO:

‘Very often they want to please people, therefore they are not going to complain’ (Participant A).

‘Dwi wedi gorfod stopio nhw, na dweud yn iawn beth sydd. Ti’n gweld weithiau arnynt bod dydyn nhw ddim yn deall’ TRANSLATED TO

‘I’ve had to stop them and encourage them to say what is wrong. Sometimes a lot of them do not understand the question’ (Participant C).

‘Lot o problemau sy’n gwynebu [fy mhlentyn] ydi’r cyfathrebu yn saesneg ... y problem yw defnyddio’r gwasanathau ac mynediad gan bod nhw’n saesneg’ TRANSLATED TO

‘The problem that faces [my child] is the language barrier... the problem is that the services and access are in English’ (Participant D).

These barriers may seem small, and easy to tackle, however, when they are not recognised the delivery of service becomes poorly. Abbott and McConkey (2006) explains that communication difficulties may increase the chance of developing social exclusion.

Referring to the title of this project, these statements provides evidence that the aspirations of Government are not always met in terms of effective communication. Relationships may be the cause of this problem, this will be analysed more in depth later in this chapter.

4.6 Healthcare

Healthcare is an appropriate theme to be raised in the analysis of findings as many factors seemed to affect the delivery of health care services. Many issues raised in the literature review discussed the access to healthcare for people with learning disabilities. Similar issues could also be identified from the interviews.
4.6.1 Practitioners

Practitioners are very important within the person-centred care for people with learning disabilities (Dowling, Manthorpe and Cowley, 2006). According to two participants there have been changes to the practitioners that are available for people with learning disabilities in their area since they started working in this field.

‘Rydym ni wedi bod yn lwcus ar hyd y blynyddoedd gan bod yr un doctoriaid wedi bod yma tan rhyw 3 neu 4 mlynedd yn ôl. Locums ydi rest ohonynt rwan [ac] dydi o ddim yn gweithio i pobl efo anableddau dysgu’ TRANSLATED TO

'We have been lucky over the years as we have had the same doctors here, until around 3 or 4 years ago. We now have locums .. [and] it does not work for people with learning disabilities’ (Participant A).

‘Oedd gen ti psychiatric nurse iddyn nhw ac oedd yr nyrs yna yn medru asesu gyntaf, ond dydi o ddim yr un fath wan’ TRANSLATED TO

‘You had psychiatric nurse for them specially and the nurse could assess them before seeing a doctor, but it is not the same now’ (Participant C).

It is believed that financial difficulties have had an effect on the number of practitioners available for people with learning disabilities, which affects the delivery of the services. Such changes impact the formation of relationships between people with learning disabilities (the service users) and the practitioners. ‘Good communication benefits both doctor and patient’ (Charlton, 2007: 30). Charlton (2007) explains that forming a relationship increases the patient’s satisfaction.

This may be happening in one organisation, however, a participant in another organisation explains that the same community nurse has visited the college for years, which has allowed the students with learning disabilities to familiarise and form a relationship with them.

‘Mae gen ti nyrsys sydd wedi dod i fewn o [pentref agos], a gen ti nyr syr lleol sydd yn gweithio gyda pobl ifanc ac anhawsterau dysgu’ TRANSLATED TO

'[There are] nurses from a town nearby and you have a local nurse who is used of working with people with learning disabilities ... The students know the local nurse’ (Participant B).

Participant B believes that living in a rural setting provides community inclusion, therefore a relationship with the practitioner is naturally established.
Will this statement mean that the college will have a change in service if the practitioner who has been working with them for years leaves? There are advantages and disadvantages of having the same practitioner for an individual with learning disabilities. An obvious advantage would be that the practitioner would be familiar with the service user, therefore trust and understanding would become natural. This could also benefit communication between the practitioner and the individual with learning disabilities. The disadvantage of forming an effective relationship is when the practitioner leaves, it might make it harder for the individual with learning disabilities to form a new relationship.

4.6.2 Acknowledgement

Within the literature review it was discovered that many parents or carers feel that practitioners do not listen to their opinions (Michael, 2008). In comparison to the data analysis, it is shown that the participants feel that the practitioners are more likely to talk with parents or carers than to the people with learning disabilities themselves. This would link with the above discussion of forming a relationship between people with learning disabilities and the practitioners. If the practitioners do not engage with people with learning disabilities themselves, how do they provide an effective and efficient service?

‘Mae nhw’n tueddol i siarad efo’r gofalwyr ac dim efo’r person’ TRANSLATED TO
‘They do tend to speak with the carers and not with the individuals themselves’ (Participant A).

‘Gan bod nhw methu egluro’n iawn ar beth sy’n bod, does ganddynt dim yr amser i wrando arnynt’ TRANSLATED TO
‘As they cannot explain very well on how they feel, the practitioners do not have the time to listen to them’ (Participant C).

This statement indicates two separate issues which could affect the acknowledgement of people with learning disabilities from the practitioner's point of view. Firstly, that people with learning disabilities may have difficulty in expressing their emotions and feelings. Secondly, that practitioners simply may not have the time to establish a
relationship with the individual. Both issues correlate with each other, if the appointment timescale is not long enough, the person with learning disabilities do not have enough time to be able to express their emotions.

4.6.3 Physical and Gaining Access

Physical and Gaining Access was mentioned in the literature review, the analysis of data within the interview drew on this. It was discovered that people with learning disabilities do have the physical access, but only with the support of an advocate or having someone alike. However, when looking at the accessibility in terms of gaining, it became more complex. Mencap (2007) explains that 75% of GPs lack in training in terms of dealing with people with learning disabilities. This suggests that the delivery of the services provided for people with learning disabilities is affected negatively, as some participants felt that occasionally, practitioners simply do not understand the need of people with learning disabilities. This would explain Michael’s (2008) statement on the failure of understanding the support that the individuals need.

With the limited qualified practitioners available to deal with people with learning disabilities, it affects the healthcare service system for people with learning disabilities. As mentioned in the literature review, people with learning disabilities have shorter life expectancy than the average living age, therefore such medical inexperience could influence this factor. There is also an opportunity to question equality here, as well as to question the government’s aspirations. It seems as if the aspirations are not met here, therefore suggesting that it is a failure in terms of the government’s role in this matter.

4.7 Improving or Worsening?

At the end of each interview every participant was asked if they believe that the services for people with learning disabilities were improving or worsening. Both participants who work for a private organisation who provides daily services to people with learning disabilities felt it was worsening. In contrast to this both participants who work within the department for people with learning disabilities in a college felt it was improving.

Referring to the project title it is difficult to clarify whether the aspirations of government and the reality are met as both organisations have different views on the
way the aspirations of services are developing. Different issues could influence their opinions. The private organisation would develop their own policies around legislation, whereas the college would follow a set guidance developed directly by the government, which is an opportunity to understand the changes more directly.
Chapter 5: Conclusion

The purpose of this project was to evaluate the Government’s aspirations for people with learning disabilities and to compare with the reality. It was an opportunity to explore policies and whether they were used effectively in practice. The Winterbourne View case occurred due to the failure of implementation of policies in practice, and it was this case that founded the base of the research. Developing the research was difficult, and somewhat limited due to the lack of academic literature surrounding this field; the well-being of people with learning disabilities.

Qualitative research was the most appropriate method to use in this study. This was conducted through the use of semi-structured interviews. To analyse the data drawn from semi-structured interviews, thematic analysis was used, in order to identify relevant themes (Braun and Clarke, 2006). Four main themes were identified which consisted of many sub-themes under each category. These themes evaluated whether the aspirations of the Government for people with learning disabilities were met in practice.

Each participant had different experiences with people with learning disabilities which contributed well to the research in analysing different aspects of the lives of people with learning disabilities. The four main themes were: Good Practice, Person-Centred Care, Communication, and Healthcare.

The project discovered that the good practice for people with learning disabilities was the main theme. Every policy is implemented to ensure that the well-being of people with learning disabilities is promoted (Carver, 2009). This project emphasised that policies applies to everyone, however, due to different levels of abilities, they can be difficult to implement in reality. The study explored whether people with learning disabilities has a voice. It was analysed that the Government do contact parents or carers of people with learning disabilities, however, people with learning disabilities themselves are not contacted. Every participant believed that integration is key to good practice, which links with Cummins and Lau’s (2003) point that integration is beneficial for the community. One organisation from this research proved this aspiration to be achieved, as integration is one of their fundamental principles.
This study discovered that not everyone involved within the person-centred care always promotes good practice; following the case when practitioner did not want to resuscitate someone due to ‘poor’ quality of life. However, someone else within the person-centred care appealed against this and accomplished. Every decision must be based on the individual’s interest (Mental Capacity Act, 2007). It was discovered that the participants believed in the importance of promoting decision making as long there is no risks of harm. Therefore, the aspiration of Mental Capacity Act (2007) is met.

The project drew on communication, which found that technology is an efficient way for some people with learning disabilities to communicate. The participant emphasised on the use of computers which allowed people with learning disabilities to become independent. However, the research suggests that technologies could still improve, such as to offer technology through the medium of Welsh, as it brought inequalities to those who cannot communicate in English. Furthermore, it was discovered that advocacy is a positive element in people with learning disabilities lives as it not only improves their services, but also allows them to have easier access to the services. Although, both forms of communication had positive outcomes, it was explored that poor communication causes poor relationship, which then leads to social exclusion (Abbott and McConkey, 2006).

The last theme discussed within this study was healthcare. Practitioners was the main focus here, which was raised from the semi-structured interviews. The participants had concerns regarding the relationship between the practitioner and the service user, which was damaged through the constant change in community medical staff. The research suggests different sources for the damaged relationships. Firstly, that the practitioners were more likely to talk with the carers of people with learning disabilities, rather than their parents or themselves. Secondly, that the practitioners simply do not have the time to form relationship. Lastly, that the practitioners do not fully understand the needs of people with learning disabilities.

Finally, it was discovered that there were mixed reviews on whether the services are improving or worsening. Therefore, it is difficult to give a clear response to this project’s title, however, there are areas in which the research could be furthered, in order to improve the services and the quality of life of people with learning disabilities.
This project is important as it explores the policies regarding people with learning disabilities, and whether the implementation of the policies are effective. It concentrates on a vulnerable group, where academic research into the group is limited. Due to the lack of academic papers, this project was naturally guided to research primary sources. It was an opportunity to see first-hand whether the policies are realistic in terms of the day-to-day lives of people with learning disabilities.

The project will now move onto the recommendations chapter, which will evaluate the limitations of the study and provide recommendations on how to improve for further research. It will consider the implications that may rise if the project was researched again.
Chapter 6: Recommendations

The intention of this chapter is to explore the recommendations and limitations regarding a situation where this research would be conducted again. Whilst suggesting changes, it will also consider the implications to these changes.

The first limitation raised in this study was the sample size. Four participants were appropriate for this project; however, it was not enough to prove the hypothesis of this study. An advantage of using only four participants was that they came from two different organisations. As both organisations offer different types of services for people with learning disabilities, it offered a more broad range of data, therefore more broad findings. To re-conduct the research, more participants would be recommended, to hopefully offer more reliable results.

To improve this study, the researcher could seek information from people with learning disabilities themselves. However, this requires a further ethical approval as people with learning disabilities are seen as a group of people who are vulnerable. By interviewing people with learning disabilities themselves it would improve the insights on practice as they are the ones who experiences the services.

The amount of literature regarding the Governments aspirations and the reality of people with learning disabilities may be limited, however, while researching for this study a few literatures were discovered which discussed elements that were appropriate to this study. For example, the implications for people with learning disabilities to access healthcare. Therefore, further research needs to be conducted in terms of addressing the Government aspirations within the policies and Acts, and to compare them with the reality; to identify if they are met or not. This will be a form of analysis, to determine whether they are effective for people with learning disabilities, which will further improve the Government aspiration of promoting the well-being of people with learning disabilities.

Word Count: 12,722
Reference List:


Social Services Improvement Agency (SSIA) (2014) *Transforming Learning Disability Services in Wales*. Available at:


Appendix 1

Ethical Approval
Dear Applicant

Re: Application for Ethical Approval: Aspirations of government for people with learning disabilities and the reality

Ethics Reference Number:

Your ethics application, as shown above, was considered by the Applied Community Sciences Ethics Panel on 23/11/2016

I am pleased to inform you that your application for ethical approval was APPROVED, subject to the conditions listed below – please read carefully.

Standard Conditions of Approval

- Your Ethics Application has been given a Project Reference number as above. This MUST be quoted on all documentation relating to the project (E.g. consent forms, information sheets), together with the full project title.
- All documents must also have the approved University Logo and the Version number in addition to the reference and project title as above.
- A full Risk Assessment must be undertaken for this proposal, as appropriate, and be made available to the Committee if requested.
- Any changes in connection to the proposal as approved must be referred to the Panel/Committee for consideration without delay quoting your Project Reference Number. Changes to the proposed project may have ethical implications and so must be approved.
- Any untoward incident which occurs in connection with this proposal must be reported back to the Panel/Committee without delay.
If your project involves the use of samples of human origin, your approval is given on the condition that you or your supervisor notify the School of your intention to work with such material by completing Part One of the form entitled “Notification of Intention to Work with Human Relevant Material or Human Bodily Material” which must be obtained from the PD (Sean Duggan), BEFORE any activity on this project is undertaken.

This approval expires on 23/11/2017. Please set a reminder on your Outlook calendar or equivalent if you need to continue beyond this approval date. It is your responsibility to reapply / request extension if necessary.

Yours sincerely

Professor George Karani
Chair of Applied Community Sciences & Protection Ethics Panel
Cardiff School of Health Sciences

Tel : 029 20416855
E-mail : gkarani@cardiffmet.ac.uk

Cc: Evans, Huw

PLEASE RETAIN THIS LETTER FOR REFERENCE
Appendix 2

Information Sheet for Participants
Participant Information Sheet

Project Researcher: xxxxx

Title of Project: WORKING TITLE: Aspirations of government for people with learning disabilities and the reality.

Aim of Project: The aim of this project is to evaluate government policies and aspirations for people with learning disabilities and compare it with the reality, as perceived by people working with people with learning disabilities. It will also assess the effectiveness of support for people with learning disabilities.

Background to Project: The project researcher is studying Health and Social Care (BSc) in Cardiff Metropolitan University and has a personal interest with working with people with learning disabilities. Linking with personal interest the researcher has had work experience with people with learning disabilities.

Participation in the Research Project: The researcher will carry out semi-structured interviews. Participants involved will have knowledge or experience of daily lives of people with learning disabilities and the government policies. You have been identified under this category. The interview will explore your views on whether aspirations of government for people with learning disability are met in practice.

You are a volunteer in the research. You can withdraw from the research at any time with no explanation. Your knowledge and experience will be valued and contribute towards the research project.

Are there any risks?: As the interview involves discussion about the experiences of a vulnerable group, some participants may have strong opinions that will make them sensitive. The participants will be informed at the start of the interview that they may leave or stop the interview at any time.

What happens to your interview results?: Any relevant data or information from the interviews will be used within the research project. All data will be used anonymously and will follow the rules of confidentiality.

Confidentiality:

The interviews will be audio recorded which will be password protected. Transcribed notes will also be stored securely, and you can have a copy if wanted. Only the project researcher and the supervisor will have access to these.
Personal details such as names will also be kept securely. These details will be kept away from recordings and transcribed notes. On the transcribed notes individual names and the names of any organisations will be replaced by a coded reference, which only the project researcher and her supervisor will know the participants.

You will be given a copy of this participant information sheet and a consent form.

Contact Details:

xxxxx

Email: xxxxxoutlook.cardiffmet.ac.uk

Supervisor details

Huw Evans

Email: hdevans@cardiffmet.ac.uk

Tel: 029 2041 6887
Appendix 3

Template of the Consent Form
Consent Form

PARTICIPANT CONSENT FORM

Reference Number:

Participant name or Study ID Number:

Title of Project: WORKING TITLE: Aspirations of government for people with learning disabilities and the reality.

Name of Researcher: xxxxx

Participant to complete this section: Please initial each box.

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

3. I agree to take part in the above study.

4. I agree to the interview consultation being audio recorded

5. I agree to the use of anonymised quotes in publications

_______________________________________   ___________________
Signature of Participant                              Date

_______________________________________   ___________________
Name of person taking consent                         Date

_______________________________________
Signature of person taking consent

* When completed, 1 copy for participant & 1 copy for researcher site file
ORGANISATION 1

My title of my project is ‘Aspirations of Government for People with Learning Disabilities and the Reality’ First:

1) Which term do you prefer? Learning disabilities or learning difficulties? *WHY*

2) What do you think the aspirations of Government for People with LD are?

3) What are your views of good practice? *Can you give examples of good practice?*

4) Do you believe that people with LD have a voice? *If so, How?*

5) Do you work along with the Government?

6) Do you think that people with LD find it harder to access healthcare than the general public?

7) ‘Study suggests that many parents or carers feels that the practitioners do not listen to them even though they understand the need of the individual’. Do you agree with this? Please explain.

8) Do general practitioners understand the need of people with LD? *Please explain.*

9) *Physical (Access to healthcare) and Gaining (Receiving the right healthcare) Access.* Do you believe this is an issue in Gwynedd?

10) Are you familiar with the Social Services and Well-Being (Wales) Act 2014? *If so, what is the extent of your knowledge?*

11) *Aim of ‘Valuing People Now’ is to identify the aspirations, wishes and needs of people with LD.* Do you know if anyone has been contacted by the Valuing People Now and share an opinion?

12) Do people with LD have the opportunity to make their own choices?

13) Do you know if Government (eg local or Welsh government) are contacting people with LD to see if they are happy with their services and what they would like to change?

14) Now having had our discussion, and going back to my project title, do you think the aspirations of Government to people with LD met in reality? *If so, how? If not, why?*
ORGANISATION 2

My title of my project is ‘Aspirations of Government for People with Learning Disabilities and the Reality’ First:

1) Which term do you prefer? Learning disabilities or learning difficulties? 
   WHY?
2) What do you think the aspirations of Government for People with LD are?
3) What are your views of good practice? 
   Can you give examples of good practice?
4) Do you believe that people with LD have a voice? 
   If so, How?
5) Do you work along with the Government?
6) Do you think that people with LD finds it harder to be a part within the community?
7) What are the differences between the practices you use now and the ALN?
8) Physical (Access to services) and Gaining (Receiving the right services) Access. 
   Do you believe this is an issue in Gwynedd?
9) Are you familiar with the Social Services and Well-Being (Wales) Act 2014? 
   If so, what is the extent of your knowledge?
10) Aim of ‘Valuing People Now’ is to identify the aspirations, wishes and needs of people with LD. 
    Do you know if anyone has been contacted by the Valuing People Now and share an opinion?
11) Do people with LD have the opportunity to make their own choices?
12) Do you know if Governments (eg local or Welsh government) are contacting people with LD to see if they are happy with their services and what they would like to change?
13) Now having had our discussion, and going back to my project title, do you think the aspirations of Government to people with LD met in reality? 
   If so, how? If not, why?