A Qualitative Analysis of Life Skills needed for Independence in Adulthood – Perspectives from Young People with Moderate Learning Difficulties, their Parents and their Teachers.

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# **Abstract**

The Special Educational Needs and Disability Code of Practice (DfE, 2014a) advocates for the participation of children and young people (CYP) and their parents in planning and decision-making during the transition processes involved in preparing CYP for adulthood. Specific reference is made to developing independence. Supporting adults with Special Educational Needs (SEN) to be independent can improve their quality of life as well as reduce the financial and emotional burden placed on society and families associated with providing services and care to support their needs.

The aim of the study was to explore one area of independence, life skills, for young people (YP) with moderate learning difficulties (MLD) from the perspective of the YP themselves, their parents and their teachers. It sought to understand which life skills were important to the YP, and if and how these life skills had been developed when the YP left school.

A multiple case study participatory design, known as the Mosaic Approach, which involved the use of qualitative methods, was used to study ten cases. Participatory research tools supported the YP to share their views and meaningfully contribute to the research. Thematic analysis was used to undertake within-case analyses and a more involved integrative cross-case analysis on the YP data along with the data from the parents and teachers.

Findings indicated that important life skills were consistent with existent life skills models but interacting factors, such as the YP's state of mind and parental and societal perceptions of SEN, impacted on the development of these skills. YP were less proficient with life skills required in the community such as independent travel and money management. Both parents and teachers were involved in teaching life skills to the YP suggesting a need for increased joint working between schools and families.

Implications for practice are discussed, particularly for educational psychologists who can support schools to develop life skills training through pupil participation, collaborative working with families and early intervention.

## **Declaration of word count**

The word count (exclusive of appendices and list of references) is 38,448 words

# **Declaration of own work**

I, Sneha Shah, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signed

Sneha Shah June 2016

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# **GLOSSARY OF TERMS**

This thesis frequently makes reference to terms that may be unclear to the reader or have multiple meanings. This glossary provides definitions of the terms as they are used in this thesis.

<u>Terms</u>	<u>Definitions</u>
Moderate Learning Difficulty	Pupils with attainments significantly below expected levels in most areas of the curriculum, despite appropriate interventions. Their needs will not be able to be met by normal differentiation and the flexibilities of the National Curriculum.
Young People	People in the age range of 17 and 22 years old who are about to leave, are leaving or have left compulsory education.
Independence	Greater choice and control over the support needed for daily living; greater access to housing, education, employment, leisure and transport opportunities and participation in family and community life.
Life skills	Skills or tasks that contribute to the successful independent functioning of an individual in adulthood.
Transition	Young people leaving school from post-16 educational provision into adulthood.
Interim college	An educational provision for students aged 19 years and older who have special educational

needs. They would be working at P and Entry levels with the aim of progressing onto a mainstream course at college.

Oyster card A smartcard that holds credit for travel on public

transport around Greater London.

Residential School trips where young people are away from

home overnight (normally between 1 to 4 nights),

organised and run by the school's educational

staff.

## 1. Introduction

#### 1.1 Context

Historically, policy and practice about people with learning difficulties (LD) has focused on their lack of abilities and their dependence. This has emphasized a 'can't do' attitude and highlighted the individual's dysfunctions (Aldridge, 2010). In the last few decades, there has been a move away from this view of incompetence and low expectations to consider how to empower people with LD and support them to participate and be included (PMSU, 2005). Empowering people with LD increases their ability to advocate for themselves and make decisions about their circumstances to improve their quality of life. This was the vision behind the Government's White Paper 'Valuing People' (DH, 2001) which reflected society's changing expectations and attitudes about people with LD. 'Valuing People' focused on four key principles: rights, independence, choice and inclusion. In 2009, Valuing People Now (DH, 2009) set out ways for putting that policy into practice by introducing personalisation and individual budgets to enable people with LD to have more control over their lives.

This has been taken one step further with the Children and Families Act (2014b) and the Special Educational Need and Disabilities (SEND) Code of Practice: 0 to 25 (DfE, 2014a), that formally recognize children and young people (CYP) with *all* types of Special Educational Needs (SEN) have the right to be supported in making decisions for themselves. The SEND Code of Practice states clearly that CYP with SEN and disabilities should be provided the support, information and skills to help them gain independence and prepare for adult life (DfE, 2014a). Under this new legislation, CYP who have the most complex level of need will have a comprehensive Education, Health and Care (EHC) plan until the age of 25, which will bring together education, health and social services as well as Children and Adult services. Through the EHC plan, the Local Authority (LA) now has a duty of care to ensure that transition planning for adulthood begins in Year 9 and is reviewed annually,

taking into account the aspirations and ambitions of YP and their families. The transition planning must include:

"support to prepare for independent living, including exploring what decisions young people want to take for themselves and planning their role in decision making as they become older" (p.126, DfE, 2014a).

Planning for adulthood for CYP with SEN should begin before the transition period and ideally, should start when the SEN is identified, which could be at birth (DfE, 2014a). Ensuring CYP with SEN are as prepared as possible for adulthood when they leave school increases their chances of being successfully included in society and helps them to make valuable contributions to the community. The cost of supporting people with SEN in adulthood, especially the growing LD population, is becoming increasingly difficult to sustain in the current economic climate. With cuts to budgets, Local Authorities (LAs) are under pressure to be fiscally conservative while still ensuring people with SEN are provided with the services and care they need (Sully & Bowen, 2012). Developing independence in adults with SEN can reduce their reliance on these costly services. Therefore, there is need to understand how best to support CYP with SEN to develop the skills to be independent once they leave school and transition into adulthood.

Educational psychologists (EPs) are well placed in schools to support educational professionals and families of CYP with SEN to develop independence to prepare for adulthood. Through their role, EPs can work with schools to impact change at a systemic level, by using their knowledge and application of psychological theory. Theories on developmental psychology and the psychology of change can help schools prepare vulnerable CYP for adulthood through appropriately differentiated curricula (Atkinson, Dunsmuir, Lang & Wright, 2015). EPs' skills in consultation and listening to CYP and families can enable them to help schools elicit the views of YP and parents during the transition process and encourage collaborative working (White & Rae, 2016). Additionally, as EPs work in schools and LAs,

they can contribute meaningfully to LAs practice and policies around transition planning (Atkinson et al., 2015.)

My motivation to carry out this research stemmed from my work as a trainee Educational Psychologist, working with young people (YP) with moderate learning difficulties (MLD) and their families and hearing about their frustrations of the transition process when they moved between schools. I was curious to explore their experiences of the transition to adulthood in an area I perceived to be of fundamental importance: 'independence for living' skills. With the changes in legislation stipulating this as an area of focus, I wanted to explore, through the first-hand experiences of the YP themselves, what this actually meant for the YP and their families.

#### 1.2 Rationale and Research Aims

This study explores the perspectives and experiences of YP with MLD, their parents and their teachers about the life skills that would support independence in adulthood. It is particularly centred on YP who have recently left or are leaving school in order to understand what life skills they have developed and how the school and parents supported the development of these skills. The research also aimed to explore the views of parents and teachers to gain an understanding of how the development of life skills could be supported in different contexts. The study intends to contribute to educational practice by developing a better understanding of the life skills for independence that are important for YP with MLD and considers how educational psychologists can work with schools and families to develop these life skills before the YP leave school.

The concept of MLD has long been debated in educational and social policy and literature. It is a problematic concept that is difficult to define because it constitutes a heterogeneous group, which includes pupils with a wide range of abilities. Historically, CYP were identified as having MLD if they had IQ scores that fell between 50 and 70 (Burton, 1996). The Warnock Report

(DES, 1978) shifted societal attitudes and perceptions of MLD towards acknowledging the environmental factors that impact on a child's learning and thinking about how provision can best support children. MLD is currently understood by the definition used in the English school census that refers to significant general difficulties in literacy and numeracy learning. In 2015, 28.3% of pupils with SEN were recorded as having MLD as their primary need, making it the largest group of SEN (DfE, 2015). The SEND Code of Practice refers to MLD as a continuum of learning difficulties but does not specify the boundaries between MLD and other forms of LD, highlighting the lack of clarity and understanding in its definition. There is great variation between and within LAs in how MLD is identified and supported. Despite the continued use of this term and the high proportion of children identified as having MLD, research with this population remains a neglected area (Fletcher-Campbell, 2005). Therefore, this research will focus on YP with MLD, particularly exploring their views and experiences.

Under the old SEN Code of Practice (DfES, 2001), statutory advice was limited to preparing young people for higher education and employability without any mention of how young people with SEN would develop skills in 'independence for living' (known hereafter as 'independence'). With the changes in legislation arising from the SEND Code of Practice (DfE, 2014a), professionals from education, social and health care are now charged with planning and working together with CYP with SEN and their families until the age of 25, to ensure they are supported in their transition to adulthood. Statutory guidance within the SEND Code of Practice now identifies 'independence' as a key area of support for preparing young people for adulthood. However, there is no clear indication of what independence means for CYP with SEN and how they can be best supported to achieve it.

Independence is a complex and multi-faced concept that varies for different populations of SEN and can encompass issues such as self-advocacy, choice and control (PMSU, 2005). The understanding of what independence means for people with MLD was drawn together from outcome studies undertaken in the 1970's that suggested that the four primary outcomes that

were important for students with MLD were productive employment, self-sufficiency and independence (including empowerment), life skills competence and opportunities to successfully participate within the community (Patton et al., 1996). However, research that informed this understanding did not include the views of students with MLD themselves about what aspects of independence are important to them. Exploring independence as a whole is beyond the scope of this study. There has been much research on employment and empowerment of people with LD but proportionately fewer studies on life skills in recent years (Alwell & Cobb, 2009). Therefore, this is an important area for further research.

Theoretical models about life skills were developed in the 1970's and 80's when government legislation and initiatives highlighted the need for students to be taught through functional curricula to support their transition to adulthood. Prior to this, children with MLD were taught using curricula based on normal child development, but with skills learnt at a slower pace (Trach & Rusch, 1988). Outcome studies identified that adults with MLD were underemployed, had restricted social lives and struggled with day-to-day living (Cronin & Patton, 2007). This led to a surge of research in the area of life skills for students with MLD. Models of life skills formed the foundations from which functional life skills curricula were developed and these are still used today to teach students with MLD. However, these models were based on research that only sought the views of educational professionals. Clark (1994) stipulated that understanding what life skills are important requires seeking the views of students and their parents. Yet there have been no studies, to my knowledge, seeking the views of students with MLD and only two studies seeking the views of parents of CYP with MLD.

For life skills to be functional, they need to be relevant to the individual's natural environment and context (Brown et al., 1979). The majority of the research on life skills has been conducted in the USA and therefore may not be relevant to the UK population. Additionally, these models were based on contexts three decades old and may in large part be out of date in relation to the current social, cultural and technological environment that we live in.

These factors all highlight the need for the current research that explores the views and perspectives of students with MLD and those of their parents, in modern, UK-based contexts and environments that are relevant to them.

The United Nations Convention on the Rights of Persons with Disabilities (UN, 2007) stated that people with SEN should have the same rights, opportunities and life chances as other citizens, and should be included in decision-making that pertains to factors affecting their lives. In recent years, a growing emphasis on getting the views of YP with SEN has emerged in research, government policy and as a driver for practice (Clark, 2005; Germain 2004). Understanding what is important for YP with SEN begins with hearing their "voice". In keeping with this view, research should allow YP to express themselves to the extent that they can and wish to. This was important to the current research that aimed to seek the views of YP with MLD in a meaningful way. It was acknowledged that YP with MLD may not be able to express their views through the traditional means of verbal or written expression. Therefore, it was important to consider alternative methods with which they could communicate their views as well as giving them the ability choose and make decisions about their participation. To do this, participatory research methods were used.

Participatory research methods involve using a range of approaches and techniques that allow the population being studied to express their views as 'experts' in their own lives and be an integral part of research process (Fargas-Malet, McSherry, Larkin & Robinson, 2010). These methods have been developed and used with CYP to help them share their lived experiences, which can then form the foundations on which practice is developed (Clark & Moss, 2011). This aligns well with the role and practices of EPs, that promote inclusion and pupil participation in education planning, through use of child-friendly approaches (White & Rae, 2016). Participation of CYP does not mean that adults are excluded from research. Rather, including adults and CYP's 'voice' in research provides a richer and more thorough picture of the topic being studied. Therefore, parents and teachers were included in this study to gain their perspectives and develop an

understanding about how life skills were being taught at home and school and to consider how life skills could be developed in both these contexts during and after the YP left school.

Using a participatory research approach, the principle aim of this study was to obtain the perspectives of YP with MLD about the life skills for independence that they feel are important to them and furthermore how these could be achieved. A second aim was to seek the views of parents and teachers of these YP with MLD about life skills that they see as important and how these can be achieved. The final aim is to understand how the YP's school provision, during the transition to adulthood, supported them to develop these skills.

This research seeks to contribute to academic knowledge by developing a better understanding of what 'independence' means to YP with MLD as they prepare for adulthood. The use of participatory research tools may help schools and educational professionals working with this population to consider alternative ways to get the views of YP and to involve them in developing a functional curriculum. By getting the views and perspectives of parents and teachers, this research aims to identify ways that professionals can best support families of YP with MLD to develop the life skills YP need to increase independence in adulthood.

## 2 Literature Review

#### 2.1 Overview

This chapter provides an overview of literature in relation to MLD and life skills for independence. Firstly, the continuum of learning difficulties will be discussed, and difficulties in categorising MLD within this continuum will be considered. A definition of MLD for the purpose of this study will be established based on literature and educational psychology practice. Secondly, the concept of 'independence for living' as it pertains to current legislation will be discussed. 'Independence', defined as giving young people the choice, control and freedom over their lives (DfE, 2014a), will be evaluated in relation to what this means for different populations and how to explore this complex and multi-faceted concept with people with learning difficulties. Thirdly, the focus of this research, life skills, will be explored as a component of 'independence' by providing a definition and examining current models of life skills. Fourthly, the transition process and how a functional curriculum can support this process will be considered. The strengths and challenges of teaching life skills through a functional curriculum will be explored. Finally, teaching methods of life skills will be critically analysed. The literature review will inform the framing of the main research questions which will then be clearly stated.

## 2.2 Defining Moderate Learning Difficulty

The term moderate learning difficulty (MLD) is used in the UK and is synonymous with other terms used in the literature such as moderate learning disability, mild and moderate intellectual disability, mild and moderate mental retardation and mild and moderate intellectual impairment. The concept of MLD has been and still remains a contentious topic in educational literature and policy. Categorisation and terminology of MLD has evolved over the last 100 years with changing social and political views and

understanding (Norwich, Ylonen & Gwernan-Jones, 2014). Yet, there still remains uncertainty and debate about how it is defined and identified.

The term Moderate Learning Difficulties (MLD) was introduced in the Warnock Report (DES, 1978). This terminology replaced 'educationally subnormal to a moderate degree' or ESN (M), which was the term used since 1945 as one of the eleven categories of educational handicap (Norwich & Kelly, 2005). Prior to this, children with difficulties in learning were referred to as mentally defective, feeble-minded, mentally retarded, backward and slow-learning (Norwich & Kelly, 2005). Negative labels and perspectives such as these devalued and stigmatised learners, and implied that difficulties lay within the child, in line with a medical model of disability (Norwich et al., 2014). The Warnock Report began the shift in thinking towards a more social model of learning disability that considered the child's environment and how it was impacting on their ability to learn.

Historically, children were identified as having a learning difficulty based purely on their scores on intelligence tests. IQ scores falling within the 50 to 70 range identified a child as having MLD and IQ scores below 50 identified a child as having severe learning difficulties (SLD) (Burton, 1996). The use of IQ tests as a means of identifying learning difficulties has been surrounded by much debate (Norwich & Kelly, 2005). IQ tests have been criticised for being academically orientated and culturally biased. In the 1980's Tomlinson (1982) found that a disproportionate number of children from socially deprived and Black Afro-Caribbean backgrounds were being categorised as having a learning difficulty. This highlighted the impact that social disadvantage rather than within-child factors played in identifying learning difficulties. Since the Warnock Report it has been well accepted that using IQ scores alone does not provide a subjective means of identification. Recent legislation and educational guidance, such as the SEND Code of Practice does not refer to the use of intelligence measures as identification procedures. IQ scores provide little information about the child's needs and the provision required to support them, which was the philosophy behind the Warnock Report. In UK legislation this was addressed by introducing the

system of Statements for children with SEN, which formally stated their needs and provision (Norwich & Kelly, 2005).

The Warnock Report suggested a continuum model of learning difficulties from Profound and Multiple Learning Difficulties (PMLD) to SLD through to MLD and to Specific Learning Difficulties (SpLD), which are the terms used today (Copeland, 2002). There are no set definitions, boundaries and cut-off points between these terms adding to the problematic nature of identifying children with MLD. Warnock also suggested the term 'mild learning difficulties' which is not used by practitioners, yet the MLD category may have absorbed what this category represented by including some children who are referred to as 'low attainers' (Norwich & Kelly, 2005).

To collect data for the school census, the government provided the following criteria to identify pupils with MLD:

- •their attainments are significantly below expected levels in most areas of the curriculum
- •additional educational provision is in place
- despite appropriate interventions and differentiation, their needs are not being met
- •they have a greater difficulty than their peers in acquiring basic literacy and numeracy skills
- associated difficulties may include: speech and language delay, low self-esteem, low levels of concentration and underdeveloped social skills (DfES, 2003).

In 2015, 23.8% of pupils in England on SEN support or with a Statement/EHC plan were recorded as having MLD as their primary need, making it the most common type of need (DfE, 2015). Despite the fact that MLD constitutes the largest group of SEN, it has attracted the least amount of research interest when compared to other areas of need, for example autism, specific learning difficulties and emotional and behavioural difficulties (Fletcher-Campbell, 2005). Some studies have found a prevalence of MLD in

families from a low socio-economic status and poverty. Norwich and Kelly's (2005) study in one LA found that 16% of the pupils had *only* MLD identified as a need on their Statement and the remaining 84% of the pupils had at least one other area of need. This highlights the differences in the characteristics and needs of children identified as having MLD. The heterogeneous nature of this group further exacerbates difficulties in developing a clear and distinct definition of MLD. The study also found that there was often little distinction between how MLD and SLD were described on a child's Statement. The broad range of abilities within this group means that different LAs, and even different professionals within the same LA, will have varying judgments about if a child has MLD or not.

The SEND Code of Practice recommends that MLD is now identified by taking a holistic view of the child and by considering how biological, social and environmental factors interrelate and impact on the child's learning. However, in most LA's, including the one where this study was conducted, attainment measures remain synonymous with identification of MLD, in line with the positions of the SEND Code of Practice (Norwich, 2004).

Guidance from the Centre for Evaluation and Monitoring (CEM) suggests the criteria as shown in Figure 1. P scales are performance scales used to assess the progress of CYP who have SEN and whose abilities do not yet reach Level 1 of National Curriculum in England.

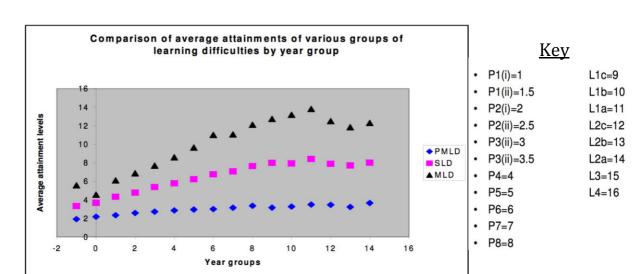


Figure 1: CEM Criteria for Definitions of Learning Difficulties

The criteria suggest that the average attainment levels for pupils with MLD at each Key Stage fall between the following levels:

- P Scales 4 and 7 in Key Stage 1 (year groups 1 & 2)
- P Scale 7 and National Curriculum in England Level 2c in Key Stage 2 (year groups 3 to 6)
- National Curriculum in England Levels 2c and 2a in Key Stage 3 (year groups 7 to 9)
- National Curriculum in England Levels 1a and 2a in Key Stage 4 (year groups 10 and 11) and post-16 provision (year groups 12 to 16)

Decisions about whether a pupil gets a Statement/EHC plan or attends a special school is influenced by low attainment scores, response to interventions and having a significant SEN (Yule, 1975 as cited in Norwich et al., 2014).

## 2.3 'Independence for Living'

The concept of 'independence' has recently been identified in the legislation as a key area of importance for CYP with SEN. It is referenced to in the SEND Code of Practice (DfE, 2014a) as an aspect of preparing for adulthood: 'independent living'. This is defined as:

"young people having choice, control and freedom over their lives and the support they have, their accommodation and living arrangements, including supported living." (p.122)

This is a significant change from the earlier version of the SEN Code of Practice (DfES, 2001) under which there was no statutory advice or guidance about developing independence for pupils with SEN. Prior to 2014, YP would receive advice from the Connexions Service from Year 9 for careers advice and progression to work, but developing skills in independence was not mentioned. Independence is a multi-faceted concept that can mean different things for different groups of people. In the UK, the White Paper 'Valuing People' (DH, 2001) stated that one of the key principles for the Government's agenda was promoting 'independence' for people with learning difficulties.

The need for people with LD to develop independence has stemmed from the increasing financial burden placed on adult social services to support people with LD (Sully & Bowen, 2012). In 2010, £6.5 billion was spent to provide care and support for people with LD and their families (DH, 2010). The number of people with LD in England is continuing to rise due to increased survival rates of infants and longer life spans of adults. Therefore, the cost to the state to support people with LD is also likely to continue to increase (Aldridge, 2010). However, LAs have been faced with budget cuts making it increasingly difficult to provide adequate services for this population. Promoting independence for people with LD through community networks can have significant benefits to people with LD, their families and society. Adults with LD who are independent can contribute to society in many ways including through employment, which can increase their selfconfidence and sense of self (Aldridge, 2010). Increasing independence can also prevent the needs of people with LD from escalating and requiring costlier services in the future (Sully & Bowen, 2012). Additionally, independence can reduce the dependence and reliance on families of adults with LD which can place a financial and emotional burden. This highlights the importance for professionals working with YP with LD to understand how to

promote independence for this population and help them to develop these skills to prepare them for adulthood.

In 2009, 'Valuing People Now' (DH, 2009), the key principle of independence was reaffirmed but referred to as 'independent living' and described as:

"This does not mean doing everything on your own or having to do everything yourself. All disabled people should have greater choice and control over the support they need to go about their daily lives; greater access to housing, education, employment, leisure and transport opportunities and to participate in family and community life." (p. 30)

Although it is encouraging to see that Government guidance is addressing independence as a key issue for people with LD, this description does not provide a clear and thorough definition for the meaning of independence for this population. As it refers to *all* disabled people, it is unclear if these are factors that are specifically related to or important for people with LD.

Most of the research exploring what independence means for people with LD came from outcome studies conducted in the USA in the 1990's. There are four main outcomes that have been recognised as being important for students with MLD: productive employment; self-sufficiency and independence (including empowerment); life skills competence and opportunities to successfully participate in the community (Patton et al., 1996). However, it is unclear if these have been determined through the views of the students themselves or through statistical data analysis. In this study I will be focusing on one area of independence: Life Skills.

## 2.4 Life skills as a component of independence

Research in the last three decades has affirmed the ability of most YP and adults with MLD to live and work successfully in the community (Smith & Puccini, 1995). A diverse and extensive range of acquired life skills has been

attributed to improved independence, community participation, interpersonal relationships, home and family activities and quality of life for people with MLD (Patton et al., 1996). Patton et al. (1996) state that YP with MLD need to be explicitly taught the required life skills to be successful in adulthood.

Developing life skills goes beyond being able to gain employment or live alone. In fact, Luftig & Muthert (2005) found that most (95%) of YP with LD lived with their parents after they left school. It was unclear if this was due to financial reasons, the lack of independent living facilities, or by choice. It is therefore important to think about life skills that will promote independence.

#### 2.5 Definition of life skills

Most of the literature exploring life skills for people with SEN spans from the 1970 to the 1990's. Following the Education for All Handicapped Children Act in 1975, educators in USA were faced with the challenge of understanding what and how to best teach children with SEN. A seminal piece of work at this time was a paper by Brown and colleagues (1979) challenging the assumption that CYP with SEN should be taught following models of normal human development. Until this time, CYP with SEN were taught through traditional developmental models that believed that handicapped children developed along the same trajectory and went through the same developmental stages as non-handicapped peers, but at a slower pace (Trach & Rusch, 1988). Brown et al. (1979) refuted this premise, suggesting that handicapped adolescents develop differently and that they should be taught skills that are functional to prepare them to "function ultimately as independently and as productively as possible in non-school and post-school environments" (p.85).

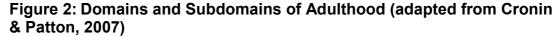
This led to a surge of research and literature exploring the skills for life that students with SEN needed to learn to be successful in adulthood. The research base and consequent theories that emerged from it were predominantly from the USA. There were numerous and varied ways in

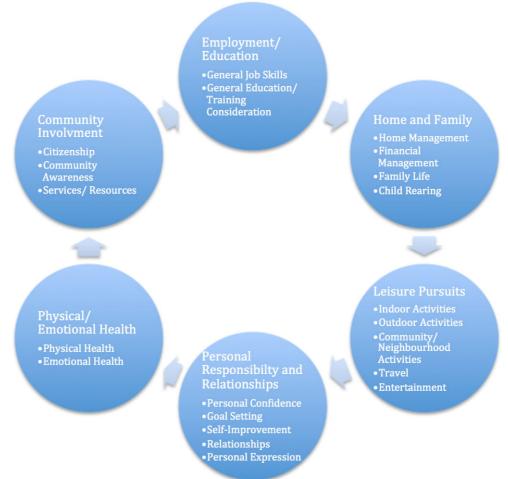
which these skills were described in the literature, as identified by Cronin's (1996) review of the life skills terminology. Cronin reviewed the various descriptions and presented the following definition of life skills that was succinct and clear. This definition will be used in this study:

"Life skills are those skills or tasks that contribute to the successful independent functioning of an individual in adulthood" (Cronin, 1996, p. 54).

#### 2.6 Models of life skills

Models of life skills have been identified using a top-down approach which starts by identifying the areas of adult functioning, then determines the life skills needs to be successful in these areas and ultimately leads to curriculum targets to teach these skills. Cronin and Patton (2007) identified six areas of adult functioning which they termed as domains and subdomains (**Figure 2**).





From these domains of adulthood, Cronin and Patton (2007) determined the areas of life skills which are suggested as being the life skills that CYP with SEN need to learn. There are a number of problems with this. Firstly, to identify the life skills, they state that they used their own teaching experience, experiences of professionals and education staff, views of their colleagues and observations of students, parents, teachers, siblings, friends and strangers. The views of the students, their parents and their teachers have not been included, yet this model has formed the basis of many life skills curricula for CYP with SEN. With increasing emphasis on gaining the views of CYP and their parents it is imperative that what we are teaching to students with SEN is in fact based on the life skills *they* feel are important for their future.

Secondly, the adult domains and life skills identified in Cronin and Patton's model were based on the experiences of adults without SEN. Although there is some merit in using this model, it cannot be assumed that the adult domains, and thus the life skills that normally developing adolescents and adults deem important, will be the same for adolescents and adults with SEN.

One model of life skills is the Life Centered Career Education (LCCE) (Brolin, 1978). Career education is defined as "education that focuses on facilitating growth and development for all life roles, settings and events" (Brolin, 1991, p.9). Brolin's model organises 22 'student competencies' into 3 domains: Daily Living Skills, Personal-Social Skills and Occupation Skills. Each competency has subsequent sub-competencies that, in regards to this study, would be considered life skills. Brolin's model has advantages over Cronin and Patton's model because it was based on research on CYP with SEN, therefore providing a better foundation on which to determine what life skills would be important for this population. Nevertheless, these research studies (eg. Brolin, 1973) were based on the views of teachers and once again did not seek the views of the students themselves or their parents.

Brolin's model was disseminated to educators and quickly gained popularity as the curriculum of choice throughout the USA for educating students with SEN. Once it had been implemented in schools for a few years, Bucher, Brolin and Kunce (1987) carried out a study to gain the views of parents of students with MLD and SLD who had been taught using the LCCE curriculum. The parents were asked to score their child's level of competence on objectives from the LCCE curriculum. The study found that the LCCE competencies significantly related to employment levels for students with MLD however there was a relatively low level of employment success. Additionally, the results showed that students with SLD were reported as having more competencies than those with MLD. Although this research sought the views of the parents, there were some limitations with the study. Firstly, as the researchers themselves state, the participants did not represent the ethnic, cultural and socio-economic diversity of the MLD and

SLD population. Secondly, it did not address whether the parents felt the competencies within the LCCE were appropriate nor did it obtain qualitative parental views about objectives within the curriculum, which would have provided a much deeper understanding about why students may be more competent in some areas compared to others. Finally, parental reports alone on competency may not give a true picture of student competence. Had they asked the students themselves how competent they felt within each area, the triangulation of data would have provided a far richer picture.

The LCCE model is based on competencies and life skills that are thought to be important for students with all types of SEN. Lewis and Taymans (1992) referred to the fact that much of the research in the 1980's focused on life skills for students with mental disabilities, but less was known about the specific life skills of individuals with LD. It should not be assumed that all individuals with an SEN will have the same needs and strengths, especially since it is well established that even within individual categories of SEN, CYP have vast differences in their characteristics. Lewis and Taymans (1992) compared what they called 'autonomous functioning skills' in adolescents with and without LD. They found that adolescents with LD had significant differences in the execution of Management activities compared to the comparison group. The Management subscale measured the ability to manage interactions in the environment, including community resources and self-management, and align with the Community Involvement and Personal Responsibility and Relationships domains from Cronin and Patton's model. Difficulties in this area support the implementation of life skills teaching in schools for YP with LD.

The authors stated that low Management scores could be due to a variety of reasons including the severity of the condition, parental and teacher over-protectiveness, lack of confidence or necessary skills and dependence on adults (Lewis & Taymans, 1992). All these factors would have revealed interesting information about why these adolescents with LD struggled with these skills but the research did not include qualitative data to explore these factors. The research presented other limitations. Firstly, the study sought

the views of parents of adolescents with LD but did not include the voice of the adolescents themselves. Secondly, the adolescents' age range was quite broad, ranging from 14 to 18 years of age. Although this gave an indication of the skills that adolescents with LD may execute in their teens, it does not provide adequate information about the skills that they may struggle with in early adulthood. Finally, within two school settings from which the adolescents were selected, LD was defined using a discrepancy model: evidence of a severe discrepancy between achievement and intellectual ability. In this way many children who would be classed as LD in today's society may not have been included in the sample.

In 1997, Loyd and Brolin presented a modified version of the LCCE for individuals with moderate disabilities. This appears to be the most relevant model for the current research and will be examined next. However, it should be noted that the modifications were made based on views of parents, practioners and agencies and once again did not include the voice of the individuals with moderate disabilities themselves.

The LCCE Modified (LCCE-M) includes 3 domains, 20 major competencies and 75 sub-competencies. Sub-competencies will hereafter be referred to as life skills. The 3 domains are Daily Living Skills, Personal-Social Skills and Occupational Guidance and Preparation. In recent decades there has been a profusion of research examining vocational and employment-related skills for children with MLD. This area will not be addressed in the current research and the Occupational Guidance and Preparation domain will be omitted. Table 1 shows the life skills from the LCCE-M.

Table 1: Domains, competencies and life skills from the LCCE-M model

Domain	Daily Living Skills							
Competency	Managing money	Selecting and maintaining living environments	Caring for Personal Health	Developing and Maintaining appropriate intimate relationships	Eating at home and in the community	Cleaning and purchasing clothes	Participate in leisure/ Recreational activities	Getting around the community
Life Skills	machine	Select appropriate community living environments Maintain living environments Use basic appliances and tools Set up personal living space	<ul> <li>Perform         <ul> <li>appropriate</li> <li>grooming and</li> <li>hygiene</li> </ul> </li> <li>Dress         <ul> <li>appropriately</li> </ul> </li> <li>Maintain physical fitness Recognize and seek help for illness</li> <li>Practice basic first aid\practice personal safety</li> </ul>	Demonstrate knowledge of basic human sexuality     Demonstrate knowledge of appropriate dating behavior	Plan balanced meals Purchase food Prepare meals Demonstrate appropriate eating habits Demonstrate meal clean up and food storage Demonstrate appropriate restaurant dining	Wash/dry clothes     Buy clothes	Identify available community leisure/ recreational activities     Select and plan leisure/ recreational activities     Participate in group leisure and recreational activities     Select and participate in group travel	Follow traffic rules and safety procedures     Develop and follow community access routes     Access available transportation

Domain	Personal-Social Skills									
Competency	Acquiring Self- identify	Exhibit socially responsible behavior	Developing and maintain appropriate social relationships	Exhibiting independent behavior	Making informed decisions	Communicating with others				
Life Skills	Demonstrate knowledge of personal interests and abilities     Demonstrate appropriate responses to emotions     Display self-confidence and self-worth	Demonstrate appropriate behavior     Identify current and future personal goals     Demonstrate respect for other's rights and property     Demonstrate respect for authority     Demonstrate ability to follow directions/instructions     Demonstrate appropriate citizen rights and responsibility     Identity how personal behavior affects others	Develop friendships     Maintain friendships	Set and reach personal goals     Demonstrate self-organisation     Demonstrate self-determination	Identify problems/     conflicts     Use appropriate     resources to assist in     problem solving     Develop and select best     solution to problem-     solve/conflicts     Demonstrate decision     making	Demonstrate listening and responding skills     Demonstrate effective communication     Communicate in emergency situations				

Although this model of life skills has merit in that it has been developed through a top-down approach, many researchers alluded to the fact that life skills need to be functional for the population it refers to. Clark (1994) referred to functionality as "the usefulness of something or usefulness for somebody" and that what may be functional for one person may not necessarily be functional for another person. Additionally, for life skills to continue to be functional and relevant to the population they refer to, they must continue to be examined and explored as social and political contexts evolve and change. Brown, Nietupski and Hamre- Nietuspki (1976) alluded to the changing nature of life skills by stating that for life skills to be ultimately functional they must be "an ever changing, expanding, localized and personalized cluster of factors that each person must possess in order to function as productively and independently as possible in socially, vocationally and domestically integrated adult community environments" (p.8).

Yet despite this understanding of the evolution of life skills in relation to changing contexts, there has been no research to determine if the life skills from earlier models are still relevant or appropriate. For example, in the LCCE-M model of life skills, there is reference to 'selecting appropriate community living environments' as a life skill, In the current economic climate, most YP with LD live at home with their parents after leaving school, as found by Luftig and Muthert (2005), and therefore it is important to explore if this still remains an important subdomain and life skill for YP with LD.

Another life skill from the LCCE-M is 'using vending machines' (from the managing money subdomain) may have less relevance in today's society as these types of machines may be outmoded. Finally, with increasing technological advances, for many YP in today's society, using technology for example computers and smartphones, is an integral part of their everyday life, yet this does not appear within the LCCE-M model.

If life skills are to be functional to the individuals' natural environment (Brown et al, 1979), it is important to remember that most of the research on life skills

has been conducted in the USA and therefore may have lesser relevance to the UK population. It cannot be assumed that the natural environments of people living in USA mirror onto the environments of people living in the UK. It is therefore important that research is conducted in the UK to better understand what life skills are pertinent for YP living in the UK in relation to their specific environments.

Finally, Clark stated as far back as 1994, that to determine what a functional skill is, requires an understanding of what is important for current and future needs from the perspective of the parents and students. Despite this there have been only two studies gaining the views of the parents and no studies exploring the views of students with LD on this topic. Both the studies seeking parental views were carried out over a decade ago. The first study carried out by Epps and Myers in 1989 sought the views of parents with severe and profound difficulties and did not include parents of students with moderate difficulties. As the distinct needs for students with MLD will differ from those with more severe forms of LD, with consequent differing views of the parents, the findings of that study will not be reviewed.

The second study explored the views of parents with moderate, severe and profound difficulties to understand how they valued different areas for their child's development. Hamre-Nietupski, Nietupski and Strathe (1992) found that parents of students with moderate difficulties rated functional life skills as the most important area for development followed by academic skills and then friendship/social relationships. Although this study has merit in that it sought the views of parents, there are some limitations with the methodology. Firstly, the study used a survey with a Likert Scale to gain the views of the parents and did not include qualitative measures to determine why the parents rated the areas for development as they did. This was a limitation that the researchers identified and suggested future studies should include interviews to better understand the pattern of responses (Hamre-Nietupski et al., 1992). Despite this recommendation, there still remains a scarcity of research using qualitative methods. Secondly, the survey only included seven items within each area of development, providing very narrow criteria

on which parents judged importance. From the LCCE-M model it is evident that life skills for students with MLD are extensive and therefore it is not clear if these seven items provided adequate scope for parents to accurately rate these three areas. For this reason, the current research aimed to address this issue, by seeking the views of the YP and their parents of MLD to understand what life skills are important for them.

## 2.7 Characteristics of Participatory Research

Participatory research grew from action research in the 1960's as a style of research that served to empower the community and the populations whose lives the research aimed to impact. Participatory research moved away from doing reach *on* participants to doing research *with* participants, with the aspiration to strengthen the link between theory and practice, and contribute to social change. Within the framework of pure participatory research, target groups would strongly influence the research process, through selection of the research topic, development of research tools, decisions regarding design, conducting the research and interpretation of the data (Anastasiadis et al., 2014).

Research can be viewed on a continuum, in relation to participation. Wright and colleagues (2007) developed a stepped model of participation (Figure 3).

Figure 3: Stepped Model of Participation (Wright, Block & Unger, 2007)

Level 9	Community-owned initiatives	Goes beyond participation		
Level 8	Decision-making authority	Participation		
Level 7	Partial delegation of decision-making authority			
Level 6	Shared decision-making			
Level 5	Inclusion	Preliminary stages of participation		
Level 4	Consultation			
Level 3	Information			
Level 2	Instruction	Non-participatory level		
Level 1	Instrumentalisation			

They proposed that participation went up in levels, from non-participation to going beyond participation. At levels 1 and 2 (Instrumentalisation and Instruction), the researchers define the research problem and make decisions about the research, and the views of the target population are not sought. At levels 3, 4 and 5 (Information, Consultation, Inclusion) participation progressively increase. The target group's views are sought and they may be asked for advice on the topic to be studied, but they have no control over whether their views will be taken into account. Levels 6, 7 and 8 (Shared decision-making, Partial delegation of decision-making authority, Decision-making authority) involve high levels of participation from the target group. There will be a high level of collaboration between them and the researchers and they will have increasingly more power and authority over the decision-making processes. The final level, 9 (Community-owned initiatives) are projects that are initiated, organised and implemented by the target group, making them the sole decision makers.

Researchers hoping to conduct research that involves a high level of participation can encounter some challenges. Participatory research can take a long time, often a few years, to complete and requires members of the

target population to be willing to commit to a high level of involvement with the research process (Bergold & Thomas, 2012). The target population in the current study was YP with MLD. Wilkinson (2001) highlights that research is a skill and CYP need to be trained to conduct research. Ensuring a sufficient amount of time is taken to train CYP is important and not necessarily a straightforward process. Furthermore, the YP and their parents may have concerns about the research taking time away from other aspects of their lives such as academic studies or leisure activities.

Taking these factors into considerations, the current research had to make some compromises on the level of participation it could realistically achieve. The current research was time limited and conducted by one researcher, rather than a team of researchers. Therefore, full participation from the YP with MLD in the research, such as involving them at all stages of the decision-making process, was not possible. However, efforts were made by the researcher to keep the YP central to any decision-making about the research process and ensure that the YP's views were heard and shared in a meaningful way. As a way of compromise, participatory research methods were used to include and involve the YP with MLD to the highest level possible, and elicit their voice.

### 2.8 Eliciting the voice of the young person

Recent trends in research have highlighted the needs for CYP's views to be included in research, to ensure their 'voice' is heard and increase the impact that research can have in making valuable changes in their lives. Hart's (1992) ladder of CYP's participation (Figure 4) links to Wright's stepped model of participation (discussed above) by associating participation with the degree of control afforded to stakeholders.

Figure 4: Ladder of Participation (Hart, 1992)

8	Child-initiated, shared decisions with adults	Degrees of Participation
7	Child-initiated and directed	
6	Adult-initiated, shared decisions with children	
5	Consulted but informed	
4	Assigned but informed	
3	Tokenism	Non Participation
2	Decoration	
1	Manipulation	

The current research fell within the fifth rung of the ladder, whereby the researcher planned the research but involved the YP through participatory research methods. By inviting the YP to share their experiences through a range of methods that moved away from the predominant use of spoken language "increases their skills and by having their opinion taken into account, provides as sense of empowerment. By letting children decide what is important to them we have a basis for a joint analysis based on a more equal power relationship between adults and children" (p.5, Wilkinson, 2001).

There is scarcity of studies seeking the views of YP (within the age range of 17 to 22 years) with SEN using participatory methods. The few studies that have been done have included children as well as YP, with age-ranges from 5 to 18 years old. These will be reviewed below.

Cameron and Murphy (2002) used Talking Mats to support YP with LD make choices at times of transition. The YP were presented with a 'mat' on which were a range of emotions which represented things they like/want, things they were not sure about, and things they did not like/want. The YP were then asked to select options (presented as pictures) pertaining to six topics and place these under the respective emotions to create a picture of their views. Some researchers (Franklin & Sloper, 2009; Germain, 2004;) have used Talking Mats in conjunction with photographs to elicit the views of YP with LD. Germain provided the YP with disposable cameras for a week and asked them to take photos of their activities. The YP were provided with

instructions of how to use the camera with Makaton symbols with words written underneath that were stuck to the back of the camera. The developed photographs were then sorted by the YP under the Talking Mat emotions to express how they felt about each activity. Other researchers (Preece, 2002; Preece & Jordan, 2010) have sought the views of YP with Autism Spectrum Condition and used visual supports such as photographs, visual cards and objects of reference in different ways for different CYP depending on their need. The visuals were used either to aid recollection, prompt discussion or to explicitly express the CYP's views.

### 2.9 Transition to adulthood

There has been a growing body of research, through follow-up studies, that has found that children who leave special educational provisions have poor outcomes in adulthood compared to their non-disabled peers. This was a large cause for concern given that government policies had long been stressing the need to educate children with SEN. The majority of the adult outcome studies have focused on employment outcomes and have found that YP who leave SEN provision are often under- or unemployed and have low pay (Halpern, 1993). Limited research in other areas of adult adjustment has found that this population also lacked engagement with the community, had limitations with independent functioning and restricted social lives (Halpern, 1993). In an attempt to address these concerns, government legislation was introduced to consider the transitional needs of children with disabilities before they left school.

Under the SEN Code of Practice (DfES, 2001), the co-ordination of transition planning from Year 9 onwards was the responsibility of the Connexions Service, in conjunction with schools (Abbot & Heslop, 2009). The LAs' involvement with YP would cease when they left school at 16. The Connexions Service worked with CYP with LD from the age of 13 until 25 with the aim of increasing participation in learning and ensuring that they had the opportunity to learn the skills required to be successful in their adult lives (Hudson, 2003). The Connexions service was disbanded in 2010 under the

Coalition Government. Despite this provision, research highlighted that this period of transition was extremely stressful to YP with LD and their families due to the uncertainty and inconsistency they faced as a result of the lack of coordination between services and professionals (Abbot & Heslop, 2009; Foley et al., 2012; Hudson, 2006). Furthermore, Tarleton and Ward (2005) found that the lack of information about services and support available for YP with LD and their families also acted as a barrier to successful transitions.

The advent of the SEND Code of Practice (DfE, 2014a) has aimed to address these issues by bringing together children's services and adult services under the remit of the LA with the hope that this will lead to more coordination between services and improve the transition process for YP. Additionally, to develop co-ordinated approaches, professionals must now work together with YP and their families to plan for and secure better outcomes in adult life. It is well established that the involvement of families in the transition process is an essential component of successful transitions (Foley et al., 2012). Working together with families during the transition process can help professionals understand the skills parents need to support YP in making choices and having control of their own lives after they leave school.

Transition into adulthood for young people with LD is a complex and multifaceted process that has become an important concern internationally for service providers and researchers (Foley et al., 2012). Compared with YP without LD, the experience of transition into adulthood for those with LD is "characterised by wider scope, longer duration and attenuated experiences" (Hudson, 2003, p.72). It is well accepted by most professionals now that transition planning is a critical part of preparing for adulthood. The stage of transition is a real opportunity for local authority departments to work together with YP and their families to prepare them for 'independence' in adulthood. However, this opportunity is often not taken up. Many YP are not aware of their rights to independent lives and are not given all the options at transition (Mencap, 2012). There is an informed view that it is more often the case that uncertainty for YP and their families about what lies ahead that limits

expectations as opposed to the lack of belief in what the YP themselves feel they can achieve (DfE, 2011).

"The ultimate outcome of the transition planning process is to maximize the chances that an individual will deal successfully with the multi-faceted demands of adulthood, thus leading to higher degrees of personal fulfilment." (Patton, Cronin & Jairrels, 1997, p. 295). Therefore, transition planning must assess the individual's needs, plan for them and address them through appropriate teaching of the knowledge and skills required.

### 2.10 Functional Curricula

A key component to transition planning is the curriculum that is taught. Prior to the 1970s, children with MLD were taught through a simpler version of the normal educational curriculum (Davis & Rehfeldt, 2007). In the 1990s, as transition planning gained momentum in public and educational policy, practioners began to develop more comprehensive approaches to teaching through vocational curricula.

Wehmen (1997 as cited in Davis & Rehfeldt, 2007) identified that any educational programmes needed to be functional and practical for individuals with MLD. It was important that the curriculum taught individuals the skills needed to be as independent as possible in adulthood. Additionally, functionality had to be assessed in line with future environments and be relevant within the context they are being taught (Patton et al., 1997). Traditional curricula based on academic attainment were replaced with contemporary curricula that centred on teaching skills to support independence and daily living at home, work or in community settings in adulthood (Davis & Rehfeldt, 2007). These curricula were referred to in many different ways: functional, ecological, life skills curricula, amongst others, but they all stemmed from the same premise.

There has been a limited amount of research on the outcomes for CYP with MLD who are taught through a functional life skills curriculum, yet professionals continue to advocate that teaching of functional life skills is crucial for successful transition to adult life for YP with MLD (Bouck, 2010). Halpern (1994) has suggested that this should not be surprising as many transition-planning goals are part of a functional life skills curriculum.

Despite the surge of functional life skills curricula in the 1990s, there has been a decline in their use in schools in recent years (Alwell & Cobb, 2009). There appear to be two main reasons for this. Firstly, over the last 20-30 years the political context has shifted to promote inclusion for children with SEN through legislation such as the Children's Act and Every Child Matters (DfES, 2003) agenda. Secondly, there has been a growing emphasis for academic accountability within schools. The government's White Paper, The Importance of Teaching (DfE, 2010), has made all schools directly accountable for the education they provide as measured by school attainment. Thus the national curricula focus for all students in secondary education appears to have transferred back onto academic achievement and away from functional life skills (Alwell & Cobb, 2009). It should not be discounted that much has been gained through the inclusion movement and an increased focus on academic achievement. Children and YP with disabilities now have the right to access mainstream education with the emphasis on educators to support their needs and document strategies to promote social inclusion, meaningful participation and academic learning (Alwell & Cobb, 2009).

However, there continues to be controversy and philosophical dilemmas about whether inclusion and mainstream schooling really does support the needs of CYP with MLD. The tension occurs when we weigh up participating in mainstream schools (where the curriculum focuses on academics) against teaching functional life skills to support success in adulthood (Alwell & Cobb, 2009). The academic curriculum in mainstream secondary schools often does not promote the development of skills that will lead to independence in adulthood. YP with LD are often required to complete courses that do not

fulfil their practical, functional and life skills needs (Smith & Puccini, 1995). Functional life skills curricula seem to be largely at odds with the values in the ECM agenda (Bouck, 2010). The competing demands between mainstream curriculum and a functional curriculum for YP with LD can often result in YP with MLD having less than satisfactory experiences of school.

Even when life skills are incorporated into mainstream education for YP with LD, it raises issues about how they are taught. Firstly, YP will often not receive the same level of expertise from teaching staff in mainstream settings compared to teaching staff working in a special school. Cronin's (1996) review of the literature found that mainstream teachers often have a lack of practical and specialist training in life skills of YP with MLD in adulthood, including understanding what life skills will be needed and how to teach them Additionally, teachers often do not have the time or skills to develop an individualised life skills programmes for YP with MLD. This can make it difficult for YP with LD to generalise the life skills that are learnt in school to the outside world when they leave school because they are often not based on YP need-specific practical skills training (Cronin, 1996).

Secondly, where school ethos and systems do not whole-heartedly accommodate a life skills or functional curriculum, YP with MLD who are 'included' in mainstream are often at the biggest disadvantage. These YP are often separated from their peers by being taken out of class to work independently. Research indicates that they are often taught by educators who have the least knowledge and skillset about working with these children (Webster & Blatchford, 2013). Additionally, when they are kept in class with their peers, they may be included in classes that do not support their learning needs (Patton et al., 1996).

As educators, professionals and policy makers continue to wrangle with this conundrum, there appears to be a re-emphasis on assessing the individual needs of each child and considering the best provision for them, whether that be in mainstream or special school.

If it is accepted there is a link between functional life skills acquisition and successful adult outcomes for children and YP with MLD, it remains that high-quality life skills instruction should be included in the curriculum (Alwell & Cobb, 2009). Cronin (1996) stated that "the essence of life skills acquisition cannot be weighed in terms of degrees, diplomas, or other documents; rather it is demonstrated in their level of independent living, community adjustment and enhanced quality of life" (p.53). By this merit, functional life skills curricula should be available for all children and YP with MLD.

To achieve the best outcomes for YP with MLD to be 'independent', researchers have suggested that life skills and concepts should be taught throughout school programmes, starting from the early years (Cronin, 1996). However, life skills should be incorporated into the curriculum, rather than taught in isolation, and taught in community settings so that YP with MLD can generalise these skills from school to adult life. Teaching vocational skills and social skills as part of areas of life skills can also help with generalisability because YP will understand how to use these skills in different contexts, not just in the classroom.

The advent of the recent SEND Code of Practice (DfE, 2014a) has addressed this need by including independent living skills as an aspect of transition to adulthood. Although this signifies changes occurring in terms of transition planning to adulthood, there has been no emphasis on what changes need to occur in the curriculum to support this. Therefore, there is less information and understanding about what specific knowledge and skills need to be included and taught in the curriculum to ensure children with SEN are prepared to deal with the demands of adulthood (Patton et al., 1997). Furthermore, the curriculum content should be developed to adequately support the needs of YP in the future and finding out what these needs are should begin with asking the YP themselves. Additionally, parents should be included in understanding the importance of teaching life skills to their YP with MLD from birth. Parents can be trained in the concepts and teaching of life skills to support their YP at home on a day-to-day basis, to become more independent. Additionally, this can encourage a positive, supportive

relationship between parent and YP, which promotes what the YP can do as opposed to a reliance on the parent (Cronin, 1996). One key question then is, what are the best methods through which life skills can be taught to YP with MLD?

### 2.11 Teaching Life skills

In recent years there have been a number of systematic reviews that have identified studies that have looked at the teaching of life skills to students with disabilities. Alwell and Cobb (2009) conducted a systematic review looking at studies that examined the following areas of life skills: recreational and/or leisure, maintaining a home and/or personal care and participation in the community. They did not look at social or communicative life skills which is a domain that will be considered in the current research. They found that the majority of the research (92%) had been published between 1989 and 1999. Only 4 studies (8%) were published between 2000 and 2003. This highlights the decline in research studies on life skills between 1999 and 2003. The review did not identify studies post-2003 and therefore it is not clear if this trend continued. Furthermore, only 1 study from the studies reviewed used qualitative methods. If we are to gain a deeper understanding about the underlying reasons and opinions of how and why teaching methods help or hinder the acquisition of life skills, it is important that more qualitative research is done in this area. The one qualitative study done by McGill and Vogtle (2001) looked at the views of the students with physical disabilities on learning how to drive. Although this study sought the views of the students themselves, students with physical disabilities are likely to have very different needs to students with LD, and therefore it cannot be assumed students with LD would share the same views.

When we consider that the characteristics of students with disabilities vary according to each disability, it is important not to generalise the findings of research from people with different disabilities. Cronin (1996) conducted a review of the literature looking specifically at teaching methods of life skills for

students with LD. She made a number of recommendations regarding the leaching of life skills for students with LD. Firstly, it was suggested the life skills training should be taught from the Early Years, on a daily basis and should be an on-going part of the curriculum. This means that it should not be taught in isolation or in blocks of teaching as often occurs in mainstream education. Secondly, she reiterated the long-standing notion that life skills are best taught in the natural environment, where the life skills would normally take place, as opposed to simulated environments. Thirdly, it was acknowledged that there were challenges to teaching life skills which included the school's lack of commitment to a life skills curriculum, difficulty with obtaining appropriate resources and the lack of training on life skill teaching for staff. Finally, an important recommendation was that parents should have an understanding of life skills training so that they could help their children learn these skills and develop their independence. Despite this paper being published in 1996, many of these recommendations have not been taken on board when implementing life skills curricula in schools.

Shurr and Bouck (2013) conducted a more recent systematic review looking at the research on the curriculum for students with moderate and severe learning disability. However, they only looked at studies on which the research or practice was carried out in a US school setting. It is unclear if this was due to limited research from other countries or simply due to their exclusion criteria. Either way, this highlights the need for more studies to be conducted in the UK. Shurr and Bouck (2013) focused on seven areas of the curriculum: functional life skills, interaction, communication, sensorimotor, cognitive- academic and other. They found that almost half (43%) of the articles focused mainly on functional life skills, with a 4% increase of studies in this area from 1996-2000 to 2006-2010. It appears that researchers are responding to the dip that occurred in the mid-2000's on studies focusing on life skills teaching as identified by Alwell and Cobb (2009). However, a 4% increase does not constitute a large number of studies and there is certainly room for further research in this area. Additionally, in over 50% of studies, the setting in which the studies took place could not be determined. If, as been precisely stated, the context is important in determining the relevance of the life skills and teaching methods, it is difficult to know if the findings from these studies can be generalized across similar settings. Only 4 studies were carried out in special schools but studies in mainstream schools showed an increase to 8% from 1996-2000 to 2006-2010. This aligns with the recent legislative emphasis towards inclusion for children with disabilities. However, as has been mentioned earlier, the contention between meeting the needs of YP with LD in mainstream schools versus special schools indicates that there is a need for studies in special schools to understand how to best support curriculum development in mainstream schools.

There have been numerous studies that have looked at how various teaching methods have been used to teach specific life skills. Most of these studies have been quantitative in nature and have not explicitly sought the views of students, parents or teachers. Examining each of these studies individually is beyond the scope of this review. Instead a few studies will be discussed which either look at life skills instruction as a whole or those that used qualitative methods. Additionally, some studies that relate to specific teaching methods will be examined.

Only one recent study was found that looked at how much life skills training YP with LD received in school. The study was conducted by Bouck in 2010 as part of a secondary analysis of the National Longitudinal Transition Study-2 data in the USA. Bouck (2010) found that individuals with mild LD received no life skills training at school whereas over half the individuals with moderate to severe LD had some life skills focus in their special education class. However, there were some limitations with this study. Firstly, the data used to address the research questions came from a parent/youth survey. Therefore, it is not clear if the 'self-report' is that of the parent or the CYP with LD. This diminishes the validity of the research data as it may have been the parent who completed the survey for the CYP and inadvertently expressed their own views. The views of CYP with SEN are often 'lost' amongst the voice of the parent, who with good intentions, can easily influence or incorrectly assume what their child or YP wishes to express. It is important

therefore to involve the YP directly in research to gain their views and hear their 'voice'.

Secondly, although this research identified which individuals with LD received life skills training in school, it did not identify what constituted as life skills training in school and what aspects of that training were useful and what aspects remain unavailable. The current study aims to address these gaps by trying to find out which life skills support and develop 'independence for living' in adulthood as well as try to understand what aspects of the curriculum provide the instructional knowledge that YP require.

Teaching and training of life skills have been found to work best with YP with LD in number of environments and through a variety of methods. Teaching in community based and simulated environments will now be discussed, and studies carried out in these environments will be examined. This will be followed by a discussion on the teaching methods based on instruction prompts and studies using this method.

### 2.11.1 Community-Based instruction

It has been well established in the literature that the best way to teach life skills is in the natural environment that they will be used. This is also known as community-based training (Davis & Rehfeldt, 2007). Community-based training provides the best opportunities for YP to generalize the learnt skill once they leave school. Only one study was found that employed qualitative methods to examine community based instruction on teaching life skills to YP with LD.

Dereka (2004) explored the views of teachers in adult training centres in Greece. The study found that teachers showed a preference to visiting shops, especially supermarkets, to teach life and social skills. Fewer visits occurred to cinema and public buildings. During the visits to the supermarkets, students had the opportunity to choose products, pay for their items and take the receipt. The prevalence of visits to the supermarket was

linked to the inclusion of cooking lessons in the curriculum. The study highlighted a number of difficulties the teachers faced when trying to teach students life skills through community-based instruction. Firstly, the teachers reported that they found it difficult to know how best to make the visits to the community useful for the students. Secondly, teachers said that parental cooperation hindered successful acquisition of life skills because parents did not perform the life skills with students at home and parental over-protection and disappointment prolonged students' dependence on their parents. Thirdly, teacher's felt that the students' cognitive difficulties were impeded by their ability to acquire the life skills. Finally, teachers reported that a lack of time and resources (for example, teaching assistants) prevented them from carrying out community-based instruction as often as possible. It is likely that teachers' perceptions and attitudes will factor into the amount of time and effort they invest in community-based instruction if they feel it will be difficult to manage the students in the community compared to in school (Dereka, 2004). It is important to ascertain if similar challenges exist for community based instruction in the UK context and explore this through the views of teachers as well as parents and YP.

### 2.11.2 Simulated Environments

It is often difficult to implement training of life skills in the community for practical and logistical reasons. An alternative training method involves using simulated or artificial environments that closely resemble the natural environment with regards to the physical features of the space and training materials (Davis & Rehfeldt, 2007). When YP are taught in simulated environment, it has been recommended that they are provided opportunities to practice their skills in the natural environment too to ensure they are able to generalise the skills.

Collins, Stinson and Land (1993) compared instruction in community based and simulated environments for teaching safety skills to students with MLD. They found that being taught in a simulated environment first did not significantly affect students' ability to acquire the skill in the nature

environment. This suggests that if time and resources are scarce to provide community based instruction from the outset, teaching in safety skills in a simulated environment first may be a more feasible option. However, as this study only investigated safety skills, it is not apparent of these findings apply to other life skills. Additionally, the study only had a small sample size of 8 students. Four students were used for Experiment 1, which was then replicated with four more students, but the students in Experiment 2 had a different, younger age range which diminishes the re-test reliability.

## 2.11.3 <u>Instructional Prompts</u>

Instructional prompts are provided from least to most intrusive order. The first and least intrusive type of prompt is verbal instruction. Verbal instruction is when the adult provides a verbal cue to direct the student behaviour. The next type of prompt is gesture whereby the adult makes a movement, often pointing, to direct the student to the next step that needs to be performed. The third prompt is modelling. A modelling prompt is done when the adult demonstrates how the task should be performed. Modelling can be done effectively by direct demonstration, through watching a video or by using props (eg. dolls). The final and most intrusive prompt is a physical prompt whereby the adult provides hand-over-hand instruction to show the student how to perform the task (Davis & Rehfeldt, 2007).

The process of teaching life skills through a stepped approach using instruction prompts has been termed in the literature as system of least prompts (SLP). Studies examining the use of SLP with students with MLD have found that this is a successful intervention for teaching laundry skills (Miller & Test, 1989), table cleaning skills (Smith, Collins, Schuster & Kleinert, 1999) and leisure skills (Collins, Hall & Branson, 1997). All of these studies used a small sample size (4 to 8 participants) and were conducted in a one-to-one setting. Although these studies showed positive findings for the use of SLP, life skills are rarely taught in one-to-one settings where there are few distractions and teachers are able to focus solely on the YP performing the task. This questions the practicalities of using SLP in a busy classroom

where teachers are teaching more than one student. It is therefore important to gain the views of teachers and YP about what teaching methods work best in real life settings.

In more recent years with the rise in technological advances there have been a number of studies examining the use of video prompting for the teaching of life skills. For YP with MLD it has been found that video prompting is effective in teaching cooking skills (Graves, Collins, Schuster & Kleinert, 2005). Video prompting can reduce the amount of time and input required by teachers as well as be used in a classroom setting with multiple students at once making it a practical alternative to teacher-led SLP. In the study by Graves et al. (2005), teachers were required to play the videos for the students and it may have been worth teaching the students to play the videos themselves.

All of the studies exploring instruction prompting have been carried out in the USA and have used quantitative methods. It is important to determine what teaching methods are being used in the UK to teach life skills to YP with MLD and understand what methods work best from the perspective of the YP, their parents and teachers themselves. Additionally, as it is known that YP with MLD will live with their parents, the YP are likely to be learning life skills from their parents as well as from staff at school. There has been no research to explore the extent to which life skills are taught by parents nor which teaching methods parents employ. This has implications for practice as it is well established that parental involvement in the YP's teaching is beneficial and it would be assumed that this would be even more so in the teaching of life skills which are predominantly used in settings YP encounter when they are with their parents (that is, in the home and community).

### 2.12 Summary

MLD constitutes the largest group of SEN in England (DfE, 2015). The provision of care and services for people with MLD is costly and places large financial burdens on the state, as well having an emotional toll on the families

and carers of this population. Therefore it is not surprising that supporting YP with MLD to be as independent as possible in adulthood is an important priority for the UK government and educational professionals. Despite this, research with the MLD population is scarce compared to other areas of SEN, providing a much smaller evidence-base on which policy and initiatives are founded. This highlights the importance and need for more research with people with MLD.

The recent changes of government guidance and legislation through the SEND Code of Practice (DfE, 2014a) have advocated for schools and professionals to work together to provide YP and their families with the information and skills to help them gain independence and prepare for adult life. Understanding what independence means for people with different types of SEN was based on research in the 1980's looking at adult outcomes. Researchers identified life skills as an important area to support independence in adulthood for people with MLD. However, the models of life skills, that underpin much of the life skills curricula taught today, were developed before the 1990's and were based on the views of educational professionals. There is no research seeking the views of the YP themselves and only two studies seeking the views of parents to determine what life skills are important to the YP themselves. Furthermore, most of the research carried out in this area has been conducted in the USA. It is well established that life skills have to be functional and relevant to the context and environment that an individual lives in. Therefore, there is a real need for more UK-based and current research to be carried out in this area.

The move towards including families and CYP in the EHC needs assessment encourages professionals working with YP with MLD to find creative and innovative ways to gain their views and keep them in the centre of any future planning. However, there is very little research obtaining the views and perspectives of YP with MLD and therefore a poor understanding of how this can be best done to ensure the YP can make a meaningful contribution to decisions made about their lives. The use of participatory research methods in the current study hopes to provide suggestions for educational

professionals in seeking the views of YP with MLD during the transition process.

This study will explore the perspectives of YP with MLD, their parents and teachers. Due to the paucity of research seeking the views of YP with MLD about 'independence' to prepare them for the transition to adulthood, the study will focus on a sample of YP who are in the final year of leaving post-16 education or have left post-16 education in the last three years. The study took place in one school. This was important because pupil and staff perceptions can vary between different contexts. Additionally, focusing on one school context increases the relevance of this research to educational psychology professional practice, as educational psychologist work often entails supporting schools at the systemic, group or individual level in one school context. The overall objective of this study was to gain a deeper insight what life skills for independence were important for YP with MLD and their parents and how they could be supported to develop these skills, and for this information to inform educational professional practice.

#### 2.13 Main Research Questions

The main research questions underpinning the research were:

- 1. What competencies for independence are important for YP with MLD when they leave school from the perspective of the YP, their parents and teachers?
- 2. What life skills for independence are important for YP with MLD when they leave school from the perspective of the YP, their parents and teachers?
- 3. What teaching methods support the development of these life skills for independence from the perspective of the YP, their parents and teachers?

4. What are the facilitators and barriers to the teaching and learning of life skills for independence?

In this research, competencies refer to the overarching areas of ability that adults need in everyday life. Life skills refer to specific skills needed to achieve each competency and that will have local relevance. It is expected that the findings from this research will show that the competencies from earlier models will be similar to the competencies that are important for YP with MLD in this study. It is possible however, that the life skills will differ to earlier models because of local relevance and functionality, which will be impacted on by the context, environment and society in which the YP with MLD in this study live in. In light of previous research, community based teaching methods may be the most effective teaching method, as they appear to improve maintenance and generalizability of the skills. But due to budget constraints in the current economic climate, I expect teachers and parents will express the feasibility of this method as barrier to the teaching of life skills for independence.

# 3 Methodology

#### 3.1 Overview

In this chapter I will describe the methodology used for this research. Firstly, I will explain my epistemological position and how it relates to the research design. Secondly, I will describe my research design based on a qualitative, multiple case study, followed by a discussion of the participatory research approach, the Mosaic Approach (Clark & Moss, 2011) and the development of the research tools. I will then go on to discuss how the participants were selected and how the exploratory work, pilot and main study were carried out. Ethical considerations when conducting research with a vulnerable population will be addressed. Finally, a description of the how the data was analysed through Thematic Analysis is considered (Braun & Clarke, 2006).

### 3.2 Philosophical Stance

The ontological and epistemological perspective adopted in this study is that of a social constructionist paradigm, which asserts that reality and knowledge is socially constructed (Burr, 2003). In a social constructionist paradigm, the epistemological perspective is taken that knowledge is constructed through purposeful social interactions and the dynamics of social relationships with others (Burr, 2003). As such, there is no single objective reality or point of view. Rather, different versions of knowledge exist based on each person's unique and subjective experiences (Burr, 2003). In this research, the understanding of 'independence' is constructed through the young people's subjective perceptions of their experiences.

Social constructionism provides a different perspective with which to view the world "that allows the unique differences of individuals to come into focus while at the same time permitting the essential sameness that unites human

beings to be identified" (Ashworth, 2003 as cited in Roots, 2007, p.19). This purports that the views of others do not necessarily have to be shared by individuals' but simultaneously, reality cannot change. In this manner, each individual perceives their reality to be true because they experience it; however this reality is still removed from each person, as they do not have the power to modify it (Gergen, 1999).

Social constructionism posits that knowledge is ultimately grounded in conversation, and language is the means by which social realities are constructed together. People "socially construct reality by [their] use of agreed and shared meaning communicated via language" (Berger & Luckman, 1966 as cited in Speed, 1991, p. 400). For these reasons, participatory research fits well within the social constructionist paradigm, as it promotes the co-construction of reality, between the researcher and participant, through means of communication. Hence, human relationships are fundamental to the research methodology (Baldwin, 2012). In this way social constructionism acknowledges the role of the researcher in the research process and postulates that the researcher is integrally linked to the shared interpretation of knowledge and meaning through the data collection process, analysis and interpretation (Baldwin, 2012).

### 3.3 Rationale for the Research Design

As the research aims and research questions are exploratory in nature, a qualitative design was employed. Qualitative methods can be used to gain an in-depth insight into participants' views and experiences (Legard, Keegan & Ward, 2003). They enable researchers to understand how people construct their social worlds by getting to personal accounts of their experiences (Flick, 2009). Using qualitative research methods gives participants a "voice" with which to share their experiences'; to enhance knowledge about the research topic (Mcleod, 2001). It was felt that a qualitative design was best suited to the current research as it aligned with the researcher's epistemological

position and ensured that the views of the YP could be explored in a meaningful way using participatory research methods.

### 3.3.1 Participatory Research Methods and the Mosaic Approach

It was important to use participatory methods for the participants in this research, to give them the choice over the ways in which they wished to communicate their views. In using participatory methods, especially with a vulnerable population, it is important to take a sensitive approach to the ethical issues in this research. A more thorough description of the ethics considerations (such as gaining informed consent, confidentiality and anonymity, safeguarding and ensuring participants were free from psychological harm and their right to withdraw) is provided in Appendix 1. The research adhered to the British Psychological Society Code of Ethics and Conduct (2009) and Ethical Approval was sought form the Departmental Ethics' Committee at the Department of Psychology and Human Development at the UCL Institute of Education before data collection began.

The Mosaic Approach is a participatory approach that has been used with disabled children, young people and adults to recognise and access the expertise they have in their own lives. This approach respects and values the views and experiences of participants and uses different means to gather this information. It is therefore an approach that was consistent with the aims of this research.

The Mosaic Approach gives participants the opportunity to reflect on their views and experiences and to co-construct meaning with the researcher (Clark & Moss, 2001). It identifies participants as 'experts in their own lives' who, through the use of different modes of communication, can construct knowledge and make meaning. The researcher creates an environment for 'listening' which is "an active process, involving not just hearing but interpreting, constructing meaning and responding" (Clark & Moss, 2001, p. 9). The Mosaic Approach has been predominately used by researchers and practioners to gain the views of children. It had been used with children in a

range of contexts including social work (Quarmby, 2014) and hospitals (Randall, 2012).

As this research was focused on the YP's lived experiences, the starting point for understanding what to explore came from the discussions with the YP themselves. The Mosaic Approach is based on using multiple modes of communication to gain the views of the participants. Interviews with children in the Mosaic Approach are referred to as 'conversations' and this term will be used in the current research in reference to the interviews with the YP. In Clark and Moss' (2001) original study, they used map-making, photobooks, tours, conversations and interviews as 'tiles' of the Mosaic. Studies using the Mosaic Approach since, have adapted these methods to make them appropriate for use with different populations. In the current study, the premise of using different 'tiles' to create a detailed picture of the YP was key. Interviews, conversations and multi-modal research tools (text, photographs, symbols) all formed 'tiles' of the Mosaic. The research tools were adapted to be relevant and age- appropriate for the YP in this study and are discussed in more depth later.

The Mosaic Approach has two stages:

Stage 1: YP and adults gathering data documentation to develop pieces of the mosaic.

Stage 2: piecing together the information or 'mosaic pieces' for dialogue, reflection and interpretation.

### 3.3.2 Research design

In this study I used a multiple case study design. Case study research has been defined as "the in-depth study of instances of a phenomenon in its natural context and from the perspective of the participants involved in the phenomenon" (Gall, Borg & Gall, 1996, p. 545). Case study research was chosen because it was important to assimilate information from various sources to develop an understanding about the contextual and complex factors integral to each case (Yin, 2003). In this way case study research

aligns well with the Mosaic Approach which uses a variety of sources to create a complete picture. The case studies combined a variety of data collection methods such as conversations with YP, participatory tools, interviews with parents and teachers. Using multiple sources of data within a case study enables the research to examine convergence in evidence (sometime called triangulation) which increases the understanding of the findings (Yin, 2003). The case study approach allows the researcher to explore functional life skills for YP with LD as they pertain to the YP within their particular context. Ten in-depth cases studies were undertaken.

#### 3.4 The Research Process

The research involved 4 main stages: sample selection; piloting and exploratory work; data gathering and interview phase and analysis. Each of these stages in now discussed in turn.

## 3.4.1 Stage 1: Sample Selection

# Sample Selection

Identifying sample using inclusion criteria Sending out opt-in letters to parents of YP

Sending out opt-in letters to teachers of YP who gave consent to participate.

Purposeful criterion was used in this study. Qualitative research generally has small sample sizes which lends itself to exploring a phenomenon indepth. Purposeful sampling is the process by which cases that are information rich are selected and studied in-depth. "Information rich cases are those from which one can learn a great deal about the issues of central importance to the purpose of the research" (Patton, 2002, p. 46).

The participants were recruited from the post-16 provision of a special needs day school in the Local Authority I was working in. This enabled me to gain access more easily to the participants and it also made the research relevant to the Local Authority. The school agreed to participate following discussions with the link EP and the Deputy Head for Inclusion at the school. The post-16 provision used the ASDAN (Award Scheme Development and Accreditation Network) curriculum which included elements of life skills teaching. The school was attached to an interim college that YP were selected to attend after they left the school depending on their need. The interim college also used the ASDAN curriculum.

A multiple case-study design was selected over a single case study of the school as the focus of the research was on the YP's perspectives rather than aspects of the school. It was important to develop a case-study for each YP because although they all had MLD identified on their Statement, the heterogeneousness of this group would mean that their experiences of MLD would be different form one another. Case studies enabled the researcher to gain an understanding of their individual experiences as well as compare across cases.

## 3.4.1.1 Study Sample

The inclusion criterion for selecting the participants was developed in line with the research objectives. Firstly, as I aimed to understand how the life skills curriculum supports YP with MLD, the YP had to have MLD identified on their Statement. YP who had other needs or diagnoses in addition to MLD on their Statement were also included in the sample. Secondly, it was important to explore the experiences of YP who had attended the school over a period of time so the YP had to have attended the school for at least one year. Thirdly, as the parents' views were pertinent to the understanding the experiences of the YP while they were at school, it was important that the YP had been living at home while attending the school.

Therefore, my research specific inclusion criteria included:

- MLD identified on the YP's Statement
- Attended the special needs school for at least 1 year.
- Be living at home with a parent while attending the school.

Four groups of participants were recruited for this research:

- 1. YP currently in their last year of school
- 2. YP who left the school in July 2014
- 3. YP who left the school in July 2013
- 4. YP who left the school in July 2012

The aim for each case study was to include the YP, their parent and their teacher.

In summary, the pupils participating in the study had MLD identified on their Statement and this was checked to ensure their eligibility for and inclusion in this study. The advantages of using this inclusion criterion was that a bigger sample population could be used and a holistic approach included parent and carer views. The disadvantage was that the results may vary widely due to different levels of MLD causing varying views of 'independence'.

For the first group of participants, who were currently still attending the school, information letters and consent forms were sent out to five parents of YP who qualified for the research, via the Deputy Head of Inclusion (Appendix 1). Parents were asked to return the consent letter back to the school in a sealed envelope to protect anonymity. For the remaining three groups (i.e. YP who had left the school) letters were sent out by post to twenty parents (8 from the 2014 cohort, 8 from the 2013 cohort and 4 from the 2012 cohort) with postage-paid envelopes to be returned to the researcher. The information letters included an opt-in clause. A pictorial leaflet with information explaining the research was sent out with the letters for parents to discuss the research with the YP and gain their consent to participate (Appendix 2). Two parents returned the consent forms however, in one case it was clear the parent had not understood the information letter as English was not their first language, and they were therefore not included in the study. Follow-up telephone calls were made to the remaining 18 parents two weeks after the letters were sent out to increase recruitment rate. Subsequently seven parents agreed for them and their YP to participate.

Eleven YP and their parents were initially recruited to take part in the study forming the basis of 11 case studies. However, following this, one case study did not take place because they had moved abroad. Two YP had attended or were currently attending the interim college.

Information letters were then sent out to the teachers who had taught the YP while they attended the post-16 provision at the school (Appendix 3). Some teachers had taught multiple YP and it was important to conduct separate interviews relative to each YP. Three teachers agreed to take part in the research with one teacher being interviewed for 2 YP. Initially two of these teachers agreed to be interviewed for other YP they had taught (3 of the remaining YP) but later declined due to their school workload and time constraints. One teacher that had taught 2 of the YP had moved abroad and the school could not provide contact information. One teacher declined to participate. Table 2 illustrates the information for each case study:

Table 2: YP participant information

Pseudonym for YP*	Year YP left school	Identified SEN	Attended Interim college	Teacher interview included in case study
1. James	2015	MLD & Autism Spectrum Disorder	No	Yes
2. Julia	2015	MLD	No	Yes
3. Gina	2014	MLD	Yes	Yes
4. Lola	2014	MLD & Autism Spectrum Disorder	Yes	Yes
5. Noel	2014	MLD	No	No
6. Reena	2013	MLD	No	No
7. Rita	2013	MLD & Autism Spectrum Disorder	No	No
8. Adam	2013	MLD	No	No
9. Terry	2013	MLD	No	No
10. Mike	2012	MLD	No	No

<sup>\*</sup>names have been changed to maintain anonymity

### 3.4.2 Stage 2: Developing the Mosaic Approach and Exploratory Work

# Developing the Mosaic Approach and Exploratory Work

Informal observations in the school and interim college
Informal discussions with staff
Exploratory work to develop research tools

### 3.4.2.1 Developing the Mosaic Approach

An important piece of the Mosaic Approach is for the researcher to develop a thorough understanding of the YP and the school setting. This was done by taking time to familiarise myself with the school and interim college through visits to the settings. I had discussions with the Deputy Head of Inclusion, Head of the post-16 provision, Head of the Interim college and teaching staff and spent two days at the school and one day at the interim college with the YP to get a sense of their educational experiences. I was informed that most of the teaching staff and the structure of the curriculum and school day had not changed over the last 4 years therefore most of the YP in this study would have experienced a similar school environment. However, I was aware that inevitably each year group of students would have been exposed to subtle differences in their school environment.

An important part of this familiarisation included getting an understanding of how the YP's MLD would affect the research process, including finding out what may help me build rapport and engagement with the YP. Furthermore, it helped me understand what their literacy and language needs were to evaluate how to best use the research tools with each YP and enable me to explain the research to the YP in the a clear and respectful manner. The visits also provided an opportunity to develop good relationships with the staff, with the hope of effective collaboration at the later stage. Field notes were taken from these visits from the researcher's perspective.

## 3.4.2.2 Exploratory work

Although the research aims and design were decided before the YP's participation began, it was important that the research was conducted in a participatory manner. This goes farther than simply employing user-friendly materials, but also involving YP in consciously influencing the direction of the research (Thomas & O'Kane, 1998). This was done through the exploratory work, which aimed to pilot a range of research tools by trialling the use of different approaches and gaining experience of using the tools. Researcher experience was important for the participatory nature of the research to ensure familiarity with the research tools so that the researcher could focus on actively listening to the YP during the conversation. The exploratory work was conducted in one 30-minute session with one YP who matched the inclusion criteria.

The session included activities directed at exploring the concept of life skills for independence through visuals to support their understanding of the abstract term of independence. The research tools were then used to explore their views. The session began by discussing what was important to them through a 'road map' illustration (Appendix 5) to think about what activities they felt were important to do by themselves to be independent. The 'road map' was used to discuss what the YP considered important aspects of independence now and in the future and how they could be supported to achieve this. The YP decided on 'stops' along the way that symbolised different ages/stages of their lives (e.g. in school, leaving school, after college etc.). They were given the option of using visual aids (pictures, symbols, drawings etc.) to place on the 'road' to create a visual map or have a verbal discussion. A range of research tools was then used to explore their views.

Participatory research tools have been used in research to get the views of young children. Puppets have been used with story-telling by giving children an unfinished story to complete (Carr, 2000). This method was adapted for the YP in this study whereby a scenario was read out to the YP and they

were asked to use the puppets to demonstrate what would happen next. The puppets within this study were used as 'intermediaries' to address issues around life skills with the YP (Clark, 2005). The same scenario was presented with a role-play activity. The YP and the researcher each took on a role and acted out a scene. Role-play has been shown to be a powerful tool to help children share their views and experiences (Cousins, 1999; Finch, 1998). Drawing materials have also been used to get children's perspective (for example, Docket & Perry, 1999) by listening to what they have to say about their drawing which can provide insights into their understanding (Fargas-Malet et al, 2010). Timelines were used to provide a visual representation of the YP's life. Ranking exercises are another tool used with older children whereby pictures or photographs are ranked in order of importance (O'Kane, 2000).

Finally, studies using photographs have found this to be a creative and fun form of communication for children and young people (Germain, 2004; Lancaster, 2003) and can be used as one piece of the Mosaic to facilitate the interview process (Clark & Moss, 2011). The YP were given the option of using disposable cameras for one week with which to document their daily lives and take pictures of things they felt were important to them. The researcher explained how to use the cameras, when the cameras would be collected, appropriate settings and contexts in which to 'take' photographs and when the researcher would come and meet the YP for the conversation. This information was discussed with the YP using symbol-supported instructions with a copy provided to the parents too (Appendix 6). The researcher modelled how to use the camera on a 'practice' camera and the YP were then given an opportunity to use it as well. Two copies of the photographs were developed: one set was provided for the YP to use as a means of communication in the conversation if they wished to and one set was given to the YP to keep. The following research tools were trialled in the exploratory work:

- Puppets
- Role play
- Drawing materials

- Timelines
- Ranking exercise with symbols
- Using a disposable camera

The session ended with a debrief where the YP was asked about their experiences of working with and using the research tools. The YP was asked if they felt there was too much or too little choice in the number of research tools available. Field notes were taken from the exploratory work which informed the selection of research tools (in terms of the YP's language needs as well as age-appropriate material) for the main study. Life skills that the YP indicated were important for independence were printed as phrases with symbols to be used in the ranking exercise. Feedback from the YP indicated that the research tools were easy and enjoyable to use and that the number of options was appropriate. He mentioned that the time line was similar to the 'road map' illustration which he felt was clearer. The time line was subsequently excluded from the range of research tools and the road map included instead.

### 3.4.3 Stage 3: Development and Piloting of Schedules

# **Development and Piloting of Schedules**

Development of interview and conversation schedules Pilot of interview schedules with YP, parent and teacher

### 3.4.3.1 Development of interview and conversation schedules

The exploratory work informed the first stage of developing the conversation and interview schedules for the YP and their parents and teachers, through understanding what elements of independence are important for this group. Questions on the interview and conversation schedules were formulated based on previous research with consideration given to areas that would inform the practice. Conversation questions for the YP aimed to address their perceptions of current and future life skills and the support they felt would help them to develop these skills. The conversations questions were open-

ended to enable the researcher to use them with whichever research tools the YP chose to use. Interview questions for the parents aimed to address their perceptions of the life skills they felt were important to their YP and understand how these skills had been or could be developed. Interview questions for the teachers aimed to address which life skills the YP had developed when they left school, how these skills had been taught at school and what more could have been done to develop other important life skills for the YP.

### 3.4.3.2 Piloting of interview and conversation schedules

The second stage involved piloting the conversation schedule with the YP and interview schedules with parent and teacher. The participants from the first case study recruited were willing to act as a pilot. Feedback from the pilot indicated that the YP found the use of the research tools supported their ability to answer the questions. He also indicated that photographs taken with the camera were predominately taken at home and in public and this informed the instructions for the use of the camera in the main study. Instructions for the camera in the main study stated that photos should be taken at home and in public but not in school/college. This also resolved the difficulty with gaining consent from all the parents of students enrolled in the school/college to have their photos taken. The parent and teacher suggested that prompts would have helped them think of areas pertaining to life skills and how these had been taught in the curriculum. Prompts they suggested or topics discussed in their interview were included in the revised schedules (see Appendix 5 for revised interview schedules). Feedback from the teacher indicated that they found it was difficult to remember YP who had left the school more than 2 years ago unless the teacher had had a particularly good relationship with the YP.

## 3.4.4 Stage 4: Data Gathering

# **Data Gathering**

Interviews with parents and teachers
Involvement with YP
Member-checking with YP, parents and teachers

### 3.4.4.1 Interviews with parents and teachers

In-depth interviews were conducted with the parents and teachers to allow for the depth and detailed responses that is required in this study. Interviews were chosen over questionnaires to establish a personal interaction and encourage participants to talk candidly about their experiences. Interviewing also lends itself to the small sample size of this research and enabled me to get a rich, detailed response. A semi-structured approach to interviewing enabled flexibility to participants' conversation patterns (Rubin & Rubin, 2005). One parent interview was excluded from the data set because it was felt that the parent had not been able to engage sufficiently in the interview process as English was not the parent's first language.

### 3.4.4.2 Involvement with YP

I met each YP 4 times:

to use it.

Session 1: Build rapport, get consent, give the YP the camera if they chose

Session 2: Collect the camera

Session 3: Conversation

Session 4: Member-checking

The first session involved having an informal conversation with the YP for them to become familiar with me. In order to establish rapport, I started by asking the YP about things that are relatively unthreatening, through problem free talk (e.g. questions about daily events, routines and feelings) (Cameron, 2005 as cited in Fargas-Malet et al., 2010). Then the symbol supported information sheet was read through with the YP and consent sought for their

participation; this was repeated in the third session prior to the conversation. It was important to build rapport with the YP to help them to feel comfortable during the conversation. Additionally, as this population was vulnerable, it was hoped that meeting the YP and explaining the research a number of times before the conversation would alleviate any feelings of anxiety the YP might have. Furthermore, the YP were given the option to attend the sessions with their Teaching Assistant to help them feel more comfortable. One YP chose to attend the first session with her Teaching Assistant and then came alone for the subsequent sessions.

Once rapport was built and the YP had given their consent to participate, the YP were asked if they would like to use a camera to take photos of activities they like doing by themselves. All of the YP opted to use the camera. A symbol-supported information sheet was used to explain to the YP how and where to use the camera (i.e. in public and at home), with examples of activities in each setting (see Appendix 6). Use of the camera was then modelled for the YP by the researcher using a duplicate camera. The YP then had an opportunity to practice using the camera with the researcher supporting them if necessary. The researcher informed the YP when the camera would be collected and when the conversation would take place. The YP were also told that they would receive copies of pictures taken. The symbol-support sheet was personalised for each YP with the day of the camera collection and the conversation. Parents/carers of each YP were given a copy of the symbol-supported information sheet to go through with the YP at home.

The conversation with the YP took place at the school, the interim college, the college they were currently attending or at their home. When the conversations were at an educational setting they were done in an activity or resource room as this provided a quiet, convenient location. The conversation started by explaining to the YP that there are no right or wrong answers to alleviate feelings of being pressured to give the 'right' answers. The information and consent form were reviewed with the YP again and the YP were given a copy of the photos they had taken. It was explained to the

YP that they could keep the photos regardless of if they took part in the study or not. The second copy of the photos was provided as one of the choices of materials for the YP to express their views through (see below).

YP's choice over their participation is central to the study so it was made clear that they could withdraw from the study at any time. The YP were provided with a red 'Stop' sign card, a blue 'Stop' sign card and an 'I need help' visual card, which were placed next to the YP. They were informed that they could use language or give the researcher the card during the conversation to indicate if they did not want to take part in the research anymore, if they wanted to take a break or if they needed help to answer a question respectively. They were then asked if the conversation could be recorded and put in charge of the Dictaphone with the choice to switch it off whenever they wished. This was all explained to the YP using colour symbol-supported language presented in large print on A4 paper (see Appendix 7).

In the conversations, the YP were shown the following range of materials and techniques:

- Puppets
- Role play
- Drawing materials
- Road Map illustration
- Ranking exercise with symbols
- Photos they had taken

Each YP was presented with the same range of materials and were given the freedom to choose any activity or just answer questions (Thomas & O'Kane, 1998). This gave them the choice and control on how they want to express themselves, and assisted them in talking about more complicated, sensitive and abstract issues (Fargas- Malet et al., 2010). It also allowed them, to some extent, to direct the course of their interviews, within the overall themes of the research (Thomas & O'Kane, 1998). For each activity chosen, the interviewer used an open-ended conversation schedule with prompts, to

explore the YP's views. The YP were asked to choose 2 or 3 activities depending on how long each activity took and their levels of engagement. The YP's level of engagement was determined by the researcher, using their skills as a trainee Educational Psychologist which enabled the researcher to attune to the YP's mood through assessing the YP's behaviour, non-verbal cues, distractibility and compliance. To ensure consistency was achieved in the YP's conversations, the structure of the conversations was the same for each YP and the prompts in the conversation schedule, although possibly phrased slightly differently, always addressed the same areas in each activity and across YP participants (see Appendix 8).

Certain activities were suggested as being particularly helpful such as the ranking exercise that explored the opinions of the YP in terms of what life skills that they had developed and were important to them. The ranking exercise was based on Talking Mats and involved giving the YP a set of symbols cards pertaining to a variety of life skills. These life skills were derived from the LCCE-M model and more life skills symbols were included following the exploratory work where the YP was asked to add, by drawing or writing on blank cards, any other life skills he felt were important and relevant. All of these symbol cards, as well as more blank cards for the YP to add additional life skills, were presented to each YP and they were asked to rank them in relation to whether they could do the skill a) without help or minimal help, b) with some help c) with a lot of help or not at all. This was done by placing a green, amber and red smiley face in front of the YP and explaining that the smiley faces corresponded to the 3 criteria above respectively. The YP were then asked to place each life skills symbol card under the appropriate smiley face. A picture was taken of their responses (Appendix 9). At the end, the YP were asked which life skills they would like to be able to do by themselves by moving cards from the amber face and red face groups to the green face group.

Table 3 shows how many YP did each activity.

Table 3: Number of YP that chose each activity

Activity	Puppets	Role play	Drawing	Road Map	Photos	Ranking Exercise
Number of YP	1	2	1	1	8	8

Participant's choices were recorded and used to stimulate discussion. Brief notes were taken by the researcher during the conversation to record the YP's choices and actions. One YP chose not to have their conversation audio recorded. Comprehensive field notes were written for this conversation that were then analysed.

#### 3.4.4.3 Member-Checking

To improve the validity of the interviews with the participants it was important to undertake member-checking measures (Lincoln & Guba, 1985). Member-checking was done with the YP, parents and teachers to develop agreement of what was said in the conversation and interviews. Parents and teachers were sent transcripts of the interviews via email to check, clarify and provide feedback on. Member-checking with the YP was done by identifying themes in their conversation, developing a symbol-supported script to verify the themes and meeting them in the final session to discuss this (an example is provided in Appendix 10). The YPs were informed that they were allowed to change their views or add additional information. One YP clarified her views on one topic while another YP added further information about a range of topics. Where the YP provided additional information or clarified their views, this was included in their transcript.

#### 3.4.5 Stage 5: Analysis

# **Analysis**

Transcribing interviews and conversations
Within-case analysis: identify themes within cases using thematic analysis
Discussions with other researchers about coding
Cross-case analysis: Identify themes across cases

With qualitative research, the fluidity and emergent nature of data collection means there is far less distinction between the data gathering and data analysis processes (Patton, 2002). Analysis often begins as the data collection progresses; patterns begin to emerge and hypotheses form that guide later stages of data gathering. It was important to use a method of analysis that was consistent with the methodology and enabled me to retain the richness and depth of the participants' views while still finding meaning in their responses (Mcleod, 2001). For this reason, I decided to use Thematic Analysis to analyse the data in this study.

Thematic Analysis is a method of discerning patterns and themes in qualitative data by encoding the qualitative information obtained (Boyatzis, 1998). Thematic Analysis is not a linear process and occurs throughout all the phases from data collection through to writing up the results (Braun & Clarke, 2006). Nor is it a passive process. The researcher is inherently involved in seeking out patterns in the data. Meaning can only emerge from qualitative texts when the researcher actively engages with the text and tries to understand what can be found within them (Mcleod, 2001). The researcher is actively involved in identifying patterns and deciding which patterns are of interest and which themes to report in the findings (Taylor & Usher, 2001 as cited in Braun & Clarke, 2006).

Data analysis began in the conversations with the YP and the interviews with the parents and teachers. In the conversations with the YP, opportunities for the YP to interpret and analyse the data was done through selecting research instruments that enable the YP to choose the subjects for discussion and decide what they want to say about them (Thomas & O'Kane, 1998). The use of participatory methods enabled the YP to discuss meanings together with the researcher and thus analyse the findings and change practice together.

In the interviews, analysis of the data began when I conducted the interviews and started to notice patterns within and between the participants' responses. Patton (2002) states that "ideas for making sense of the data that emerge

while still in the field constitute the beginning of analysis; they are part of the record of field notes" (p. 436). Field notes were taken after observations, the piloting phase and the YP conversations.

#### 3.4.5.1 Transcribing interviews and conversations

The interview and conversation data was recorded and transcribed verbatim by the researcher from the audio recordings. It was important for the researcher to conduct the conversations and interviews and transcribe them because it provided opportunities for immersion and familiarisation with the data, which is an integral part of qualitative analysis (Boyatzis, 1998). The transcription conventions as shown in Flick (2009) were followed. The transcripts give a verbatim account of the interviews but are not overly concerned with complete exactness. 'Um's and 'ahh's were left out where they do not change the context of the narrative. This is because Thematic Analysis does not require the same level of detail in the transcripts as other analysis methods such as conversational analysis (Braun & Clarke, 2006). Nevertheless it was imperative that the core information from the interviews and conversations was relayed as accurately as possible. Also, an advantage of the researcher interacting with the participants during the interviews and transcribing the interviews was the ability to give a more accurate narrative of the participants' "voice" through recollection of their tone and emotion during the interviews.

## 3.4.5.2 Case Study Analysis

Thematic Analysis is well suited to this study because it enables the researcher to explore themes and patterns within and across cases (Braun & Clarke, 2006). When using thematic analysis to analyse multiple case studies, themes and patterns are initially identified within each case. Withincase analysis is then followed by thematic analysis across the cases, known as cross-case analysis (Creswell, 1998; Yin, 2003). NVIVO software was used during the analysis process to organise and code the data.

#### 3.4.5.3 Within-case analysis

Ten separate thematic analyses were conducted, one for each case. The first stage of the analysis was familiarisation with the data. This started when I transcribed the conversations and interviews and began to notice patterns emerging within cases. I then immersed myself in the data by reading and rereading the transcripts.

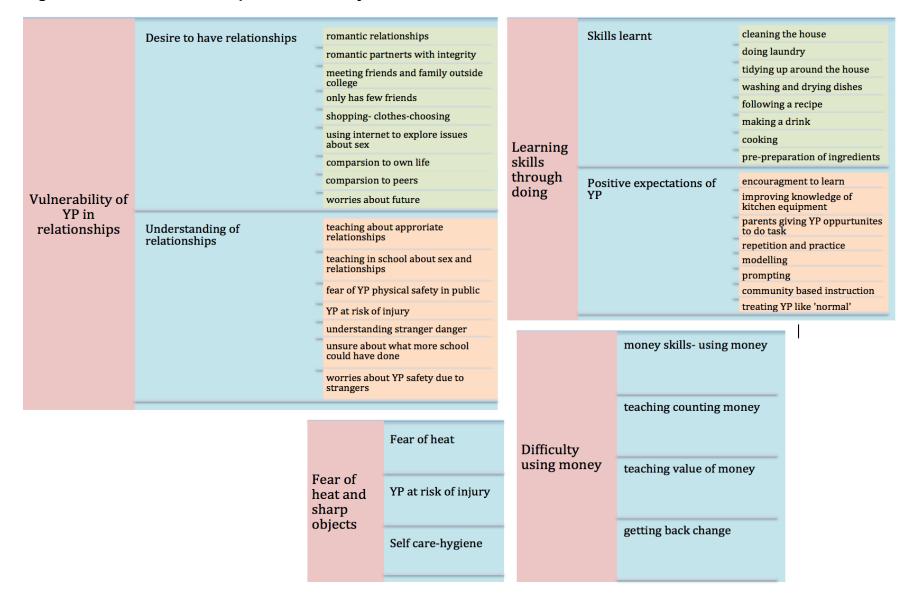
The next stage involved the formal coding process in which the transcripts were systematically worked through and ascribed codes. As the research was participatory and concerned with understanding the perspectives of the participants, an inductive coding approach was used. Codes refer to "the most basic segment, or element, of the raw data or information that can be assessed in a meaningful way regarding the phenomenon" (Boyatzis, 1998, p.63). Codes can often overlap and are sometimes ambiguous which demonstrates the flexibility of thematic analysis as well the challenges of using qualitative analysis methods (Braun & Clark, 2006). Each transcript was coded separately and information that was regarded as digressing from the interview questions or clearly not being relevant to the research questions was not coded (Guest, MacQueen and Namey, 2011). Extracts of data were coded as many times as was relevant. Appendix 11 shows an extract from a coded parent transcript and a coded YP transcript.

To improve rigour of the analysis process and the validity of the findings, the codes were discussed with other skilled qualitative researchers. A sample from a YP and parent transcript was independently coded by 3 Trainee Educational Psychologists and codes were then compared and discussed. Discussions highlighted the importance of contextual factors in the photos and therefore YP transcripts and photos were coded together.

Once the transcripts were coded, extracts from each code were examined to gain an overall impression of the code and codes were then refined. Refining codes included splitting and linking codes, whereby one code could be separated into two codes or a number of codes could be combined to form

one code respectively (Wilkinson, Joffe & Yardley, 2004). NVIVO was used to develop a list of codes that appeared in the data for each case. The codes for each case were read again to identify relationships between them and from this themes began to emerge. Initially codes from all the data sources within each case were grouped together and seeking similarities in the codes identified emerging themes. This was done for each case and an example of a thematic map is shown below.

Figure 5: Initial Thematic Map for Case Study 6



However, of primary importance to the researcher was keeping the YP's voice at the centre of the research and ensuring their views did not get lost within the data. By combining the codes from all the data sources to develop themes within each case, it was felt that it was difficult to distinguish the YP's voice. Therefore, there was much deliberation and trailing of different methods of analysis including by not limited to analysing the YP's data, parents' data and teachers' data separately. In the end, in order to keep the YP's voice central but to ensure the robustness of the cases, the codes of the YP were combined into themes for each case. Codes from the parent and teacher data in each case were then compared to the YP themes and included where they shared similarities. By this method of analysis, it was apparent that some of the themes from the parent and teacher data might not be included in the final case study themes. Therefore, a separate thematic cross-case analysis was conducted on the parent and teacher data, which highlighted the similarities and differences between the YP data and the parent/teacher data.

All of the themes were then reviewed to ascertain if extracts within each theme cohered and had enough data to support them. Themes that did have enough data to support them were discarded. The final themes were subjected to further review to ensure they were concise and distinct and that the data extracts reflected the meaning of each theme (Braun & Clarke, 2006). This was done for each case study. Thematic maps showing the final themes and subthemes for two case studies are shown below:

Figure 6: Final Thematic Map for Case Study 6

	YP	fear of cutting	Teaching methods	YP	modelling
Risk of getting hurt		fear of swimming alone			prompting
	YP and parent	fear of heat using kitchen appliances			community based instruction
		YP at risk of injury		Parent	encouragment to learn
		fear of YP physical safety in public			repetition and practice
	Parent	fear of grooming			parents giving YP oppurtunities to do task
	stranger danger				treating YP like normal
	YP and parent	meeting friends outside college		YP	money skills-using money
			Using money	Parent	teaching counting money
Relationships	Parent teaching about relationships romantic relationships using internet to explore issues about sex				teaching value of money
					getting back change
		romantic partners with integrity			

Figure 7: Final Thematic Map for Case Study 10

Travel	YP	reading for directions support with traffic rules aspiration to drive aspiration to travel independently travelling by walking		
	YP and parent	family member drives YP travelling by bus travelling by train help reading tube map		
	Parent	using freedom pass crossing the street safely travelling with adult travelling independently to do tasks close to home		
	YP	Using a bank card Using money learning how to count money		
Using money	YP and parent	getting back change aspiration to use money independently		
	Parent	parent giving exact amount of money knowing how much things cost understanding monetary value		

Socialising	YP	meeting friends in college	
		visiting public places with cousins	
	YP and parent	meeting family and friends outside college	
	Parent	difficulty organising meeting friends	
		having a friend group	
Health	YP	difficuly with physical exertion	
	YP and parent	going to the doctor	
		difficulty standing due to health	
Health	Parent	difficulty standing due to health	
Health	Parent	difficulty standing due to health missed learning due to poor health	
Health	Parent		

#### 3.4.5.4 Cross-Case analysis

The within-case analysis was followed by a thematic analysis across the cases (Creswell, 1998; Yin, 2003). Using themes that were established in the within-case analysis, a thematic analysis was utilised for the cross-case analysis. The emergent themes from all the cases developed into categories that formed broader concepts for consideration and began the process of synthesis (Miles & Huberman, 1994). Integration of the data involved expanding, collapsing, merging and creating categories that best represented interpretations of meaning (Miles & Huberman, 1994). Themes that were retained were identified from the integrated analysis of the YP data and integrated analysis of the parent/teacher data and similarities and differences between the data were explored.

The whole process is summarised here as

Figure 8: Research Process

# Stage 1

## Sample Selection

Identifying sample using inclusion criteria

Sending out opt-in letters to parents of YP

Sending out opt-in letters to teachers of YP who gave consent to participate.



# Stage 2

# Developing the Mosaic Approach and Exploratory Work

Informal observations in the school and interim college
Informal discussions with staff
Exploratory work to develop research tools



# Stage 3

# **Development and Piloting of Schedules**

Development of interview and conversation schedules Pilot of interview schedules with YP, parent and teacher



# Stage 4

## **Data Gathering**

Interviews with parents and teachers
Involvement with YP
Member-checking with YP, parents and teachers



# **Analysis**

Stage 5

Transcribing interviews and conversations

Within-case analysis: identify themes within cases using thematic analysis

Discussions with other researchers about coding

Cross-case analysis: Identify themes across cases

#### 3.5 Validity and reliability in qualitative research

Ensuring the quality of research is essential if findings are to be utilised in practice (Noble & Smith, 2015). In quantitative research, the validity and reliability of the research can be established by using tests and measures. However, in qualitative research these methods cannot be applied and qualitative research is often criticised on its trustworthiness. Some researchers (e.g. Lincoln & Guba, 1985; Miles and Huberman, 1994) go so far as to reject the notions of validity and reliability within qualitative research, suggesting that these concepts are rooted in a positivist paradigm. Lincoln and Guba (1985) offer alternative terminology for determining the trustworthiness of research:

- Credibility instead of validity
- Dependability instead of reliability.

They proposed that to maximise the trustworthiness of qualitative research, the following techniques could be operationalized:

- Triangulation- using different data collection modes and/or using and comparing multiple data sources to corroborate evidence.
- Prolonged observation and engagement in the field- spending a sufficient amount on the site, using 'persistent' observation to determine and identify factors that are relevant to the research.
- Peer debriefing- the researcher exposes themselves to experienced peers who probes and questions the methodological, ethical, interpretive and any other relevant factors of the research.
- Member checking- researcher checks the accuracy, interpretations and meanings with the participants of the research.
- Audit trail- the researcher provides a clear explanation of the research processes, decisions and activities to show how the data was collected recorded and analysed. An external auditor can review the following to check the inquiry:
  - 1. Raw data
  - 2. Data reduction and analysis notes

- 3. Data reconstruction and synthesis products
- 4. Process notes
- 5. Materials related to intentions and dispositions
- 6. Instrument development information

#### 4 Results

#### 4.1 Overview

This chapter presents the findings of the research. Firstly, case summaries provide an overall sense of each case, while keeping the YP's voice central within the case. Secondly, themes that emerged from the integrated analysis of the YP's data are described. Thirdly, themes from the integrated analysis of the parents' and teachers' data, that were similar and different to he YP data, are described. Discrepant themes are included to highlight areas that parents and teachers felt were significant but that did not necessarily appear in the YP's conversations. Themes are illustrated using extracts<sup>1</sup> from the participants' transcripts.

#### 4.2 Case summaries

Case summaries were created for each of the cases. Three of the case summaries are presented below. The remaining case summaries can be found in Appendix 12. The three case summaries selected to be presented in this section were chosen to highlight the similarities, differences and general areas of importance raised by the YP, their parent(s) and teacher regarding life skills for independence. The YP in each of these 3 cases had different educational experiences once leaving school, which provides an interesting illustration of life skill development from the different perspectives. The case studies will be presented as follows:

1) Gina: left school in 2014 and attended the interim college for one year before enrolling in a specialist education facility within a local college, that she currently attended.

<sup>&</sup>lt;sup>1</sup> Extract sources will be identified as YP-young person, P-parent, T-teacher. Where names of YP and the school are mentioned in the extracts, they will be substituted with [YP] and [school] respectively.

- 2) Lola: left school in 2014 and was currently in her second year at the interim college.
- Terry: left school in 2013 and enrolled in a residential training hotel and catering college, where she was in her final year of a 3-year course.

#### 4.2.1 Case 1- Gina

Gina's case was developed through various data sources. These included an interview with her mother, an interview with her former teacher at Whitemore<sup>2</sup> School and a conversation with Gina. During the conversation with Gina, she chose to use the drawing materials and photos to express her views, followed by the ranking exercise.

Gina was 21 years old at the time of the conversation. She left Whitmore School when she was 19 years old and spent one year at Whiteside (the interim college). She was studying at Hopkins College at the time of the conversation.

Gina said that she enjoyed watching TV, listening to music, playing on the trampoline and football by herself. Her teacher and mother mentioned that she would acquire information from TV and especially enjoyed watch programmes such as Casualty where she learnt about the job of a paramedic.

Gina had an aspiration to be a paramedic and said that she could learn firstaid skills through the club IPOP to help her to achieve this. This was reiterated by her mother and teacher. Her mother mentioned that she had previously participated in a club for first-aid.

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<sup>&</sup>lt;sup>2</sup> The name of the school, interim college and localities have been changed to further preserve anonymity.

Self-care skills were an area of difficulty for Gina. She said that she was able to brush her teeth by herself but needed help from her mother to bathe, put on face cream and do her hair. She said that her mother helped her with the sponge and the soap when bathing. This was reiterated by her mother who said Gina needed help with applying soap appropriately.

Gina said she enjoyed going out to visit different places such as Central London. This was mentioned by her mother too who said Gina enjoyed going to the cinema and museums. Gina said that she could walk down to McDonalds to meet her friends but couldn't travel on the bus or tube independently. She talked about going on trips to Madame Tussauds when she was at Whitemore School and how the teachers would help her to-up her Oyster card.

Cooking was an activity that Gina enjoyed doing, and she said at Whitemore School she would chop the vegetables for stir-fry and mix the ingredients to make chocolate cake in a cookery room. Her teacher described her as being "pretty good and confident" in the kitchen and said she had the ability to make simple meals. He also mentioned that she had a good understanding of food hygiene. Gina talked about making rice at home with the help of her Uncle and making Spaghetti when she went away on Residential with the school. Gina's mother said Gina would help her in the kitchen by serving the food or helping with the pre-preparation of ingredients but stated that she (Gina's mother) worried about Gina's safety in the kitchen.

Gina appeared to need some emotional support when she went out in public. She said her mother helped her to be 'brave' when she went to the doctor. She also mentioned her worries about walking on the street alone saying, "When I'm walking down the street I get scared easily. I get scared of naughty boys. The boys might have a gun." Gina's mother talked about Gina lacking confidence in public and hiding her head in front of people. Her teacher mentioned that the school had supported her to develop an understanding and management of her emotions by using an emotions key ring.

#### 4.2.2 Case 2- Lola

Lola's case was developed through an interview with her mother, an interview with her former teacher at Whitemore School and a conversation with Lola. Additionally, an observation of Lola at Whiteside interim college and an informal conversation with her teacher at the college were recorded in the field notes. During the conversation with Lola, she chose to use the photos and the role-play activity to express her views, followed by the ranking exercise.

Lola was 20 years old at the time of the conversation. She left Whitemore School when she was 19 years old and was currently in her second year at Whiteside. Lola had a diagnosis of Autism and referred to this when explaining why she thought some activities might be harder for YP to do by themselves.

L: Because he might be autistic. It is difficult for him to learn. He might have been ill as a baby. He might have a weak body.

I: What happens?

L: It's hard for him. Cooking, walking, shopping, he needs someone to hold his hand

Friendship appeared to be important for Lola. She took photos of black and white pictures of members of the Royal Family and referred to them as her friends, who she said she met at her house. During the role play activity, Lola stated that the YP would like to be able to go a restaurant with their friends by themselves. In contrast, her mother said that Lola didn't 'crave' other's company and would be happy to be by herself. Lola's mother stated that Lola did not have any friends or a social life outside the home. Her teacher said that she developed friendships with two students while at Whitmore School.

Lola was able to do many activities around the house with some help. She talked about a YP wanting to be able to cook, clean, tidy the beds, dust, hover, wash dishes and do laundry by themselves. Specifically, she said that

she wanted to be able to housework by herself and that her mum would teach her these skills. Her mother explained that Lola would make herself simple snacks and drinks, set the table, sweep the floor and do the dusting. However, she would not take the initiative to do the laundry or washing up. Lola's mother did not have any expectations for Lola to cook for herself while she lived at home. Similarly, her teacher mentioned that Lola would be able to do simple cooking tasks like make toast and tea.

Another skill that Lola said was important for her to learn how to do by herself was to use money. She talked about wanting to 'run a shop' and learn 'how to sell things and use money'. Lola explained that Maths lessons had helped her learn how to use money and talked about her school experience:

In primary school, I learnt all the different coins, how much things cost, how to speak to customers, work experience in the supermarket.

Lola's teacher expressed that Lola would be able to go shopping by herself and understand the skills integral to this such as making a list, knowing how much money she had to spend, how to wait for and get back the correct change.

An area of need for Lola was emotional support which she alluded to by saying that she "can't cope without my mum" when carrying out activities such as travelling and shopping. Lola's mother echoed this sentiment by talking about Lola's strong attachment to her. Her mother also discussed Lola's difficulty to "control her feelings" and manage changes in routine. Her teacher also talked about Lola's need for support with emotional regulation explaining that when Lola was in a calm state of mind, she was able to perform a larger range of life skills.

#### 4.2.3 Case 3- Terry

Terry's case study included data sources from an interview with her father and his partner and a conversation with Terry. Terry's teacher had moved abroad and was un-contactable. Terry had good language skills but was a bit shy. I met with Terry once in person prior to the conversation and spoke to her on numerous occasions over the phone to build rapport. The photos and ranking exercise were used to aid the conversation.

Terry was 22 years old at the time of the conversation and it had been two and half years since she had left Whitemore school, at age 19 years. Terry attended a residential catering college that was attached to a hotel, which she joined when she left Whitemore School. She had aspirations to get a job in catering in Whitemore School's canteen.

Terry was able to do many activities around the house by herself. She talked about being able to do the laundry, set the table, take out the rubbish and recycle, wash and dry dishes and clean around the house, including doing the vacuum cleaning. Her parents affirmed this by stating that she was able to do these activities independently. Her parents mentioned that she had some difficulty with hygiene, such as brushing her teeth and bathing properly, but this was because she did not like the sensation of water on her face and not because she did not know how to perform the skill.

Terry had good skills in cooking and said she was able to peel, cut and roast vegetables and make meals like noodles, curries and steak. She said she could use the oven. Her parents said that she could follow simple recipes at home and bake cookies.

#### 4.3 Integrative analysis of YP data

This section presents the results from the integrated analysis of the YP data. Table 4 shows the themes and subthemes that emerged from the analysis. The themes and subthemes are discussed using illustrative extracts and photos<sup>3</sup> from the YP data.

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<sup>&</sup>lt;sup>3</sup> Photos sources will not be indicated to preserve the YPs' anonymity.

Table 4: Themes and subthemes from the integrative analysis of YP data

Themes	Subthemes
1. Travel	Finding way around the community
	Accessing and using public
	transport
	Using travel passes
2. Safety	Risk of YP to themselves
	Risk of others to YP
3. Money	Counting money
	Purchasing Items
	Using bankcards
4. Housework	Doing laundry
	Cleaning the home
	Throwing rubbish and recycling
Meal Preparation	Buying food
	Cooking
	Using kitchen appliances
	Table setting
6. Personal Care	Hygiene in the kitchen
6. Personal Care	Hygiene and grooming
	Dressing
	Buying clothes
7. Teaching Methods	Managing health
7. Teaching Methods	Community based instruction
	Training environment instruction Repetition and practice
	Modelling and Prompting
Social and Leisure activities	Socialising
o. Coolal and Loisure delivities	Participating in clubs
	Organising social and leisure
	activities
	Using technology
	Comp technology

Table 5 shows the summary of the data from the ranking exercise, showing how many times a particular life skill (ie. clothes shopping) was ranked within each of the categories (with a lot of support, with some support, with little or no support).

Table 5: Ranking exercise- Number of life skills YP placed in each category

Life Skill	Number of YP				
LIIE SKIII	With a lot of support	With some support	With little or no support		
Using the Computer	0	1	7		
Doing housework	2	2	4		
Cooking	0	5	3		
Food Shopping	2	3	3		
Clothes Shopping	1	5	2		
Going to the doctor	2	5	1		
Playing sport	0	4	4		
Meeting friends	1	1	6		
Using money	3	4	1		
Travelling	3	4	1		

Table 6 shows the life skills that the YP said that they would like to be able to do by themselves in the future.

Table 6: Ranking exercise- life skills that YP said they would like to do independently

Life Skill	Number of YP
Using the Computer	0
Doing housework	1
Cooking	3
Food Shopping	1
Clothes Shopping	3
Going to the doctor	2
Playing sport	1
Meeting friends	1
Using money	4
Travelling	2

## 4.3.1 Theme 1: Travel

The first theme was travel. This was an area that most YP felt they had not developed, with 3 YP saying they needed a lot of support to travel by

themselves and 4 YP saying they needed some support to travel. The YP referred to using different modes of transport including walking, using buses, travelling by tube or train and driving.

#### 4.3.1.1 Finding way around the community

Some of the YP talked about how they were able to find their way around the community. However, this predominately involved travelling to places that they were familiar with or to locations that were close to their home. Two YP mentioned that they travelled by walking:

There is Lodgeway station near my house. I walk down to the station. I can walk because I live in Lodgeway High Street (YP 7)

I'd walk '.....' to my friend's house (YP 9)

For most of the YP travelling to college by the college bus was the only way they travelled around the community by bus independently. The college bus picked them up from their homes and dropped them to college and vice versa. It did not require the YP to plan their journeys which was an area of difficulty, as referred to in the previous subtheme:

I take the college bus not the red bus (YP 6)

Only one YP talked about wanting to learn how to drive in the future as they were currently reliant on their brother to help them access the community by car. However, they alluded to being apprehensive about driving by themselves:

Sometimes I might like to drive, my brother drive for me. I would like to try it one day. But I need someone to be with me or my mum or my sister or my brother... someone to be with me in the car. I can't go by myself (YP 10).

#### 4.3.1.2 Accessing and using public transport

The YP talked about using a range of different types of public transport, yet most of the YP could not access and use public transport by themselves. Using buses was the only form of public transport that some YP said they could use by themselves and when they did, they could only use buses on familiar routes:

[I] also know what bus number to take to the college. Like I know if we live in Woodside it's the 3X2 straight from here and then the same bus back. (YP 5)

A reason that almost all the YP referred to as a barrier to them using public transport was the risk of getting lost. The skills required to use public transport such as planning a journey, knowing where to alight and map reading were areas of difficulty many of the YP discussed when using the bus, tube and train. This meant that most of the YP needed an adult with them when travelling:

My sister she tells me where to get off [on the train]. So I can't do it by myself. I have to do it with my sister or my mum. She helps me where to find a map '....' I can probably try go by myself, but I need someone to be with me. In case I get lost (YP 10)

#### 4.3.1.3 Using travel passes

Travelling in the local environment on public transport required knowing how to use a travel pass. Apart from walking, this restricted many of the YP's ability to travel independently around the community. Three YP discussed how they had difficulty with various stages involved in using a travel pass (Oyster) such as putting money on the pass and scanning the pass to pay for their journey:

I find it difficult scanning my Oyster card in the bus. My teacher helped me put money on my card. (YP 3)

#### 4.3.2 Theme 2: Safety

The second theme was safety. Within this theme the YP referred to a risk to their safety from themselves and from others. Safety or the lack thereof was a reason that many of the YP felt they could not perform activities by themselves. There was an indication that worries about their safety limited the development of many life skills.

#### 4.3.2.1 Risk of YP to themselves

When talking about the risk posed to themselves, all of the YP referred to getting physically harmed when performing an activity. Predominantly, the physical harm was associated with activities in the kitchen, especially with getting cut or burnt. The YP described how the risk of getting cut with knives meant they would allow parents to perform these tasks for them at home:

Well everyday my mum cuts the fruit for me.... because you have to be careful of sharp knives. Because if you cut yourself there will be blood. (YP 5)

Similarly, three YP said that they would not use kitchen appliances such as ovens and stoves by themselves due to the risk of getting burnt. Interestingly, a few YP talked about using kitchen appliances at school or college but not at home. Conversely one YP mentioned they could use the appliances at home because they were gas not electric:

Not electric [oven] but the normal one. Not electric one. But the electric one can burn in your face. When I cook some tea at home my sister use gas one. [Its] more dangerous. (YP 10)

One YP was worried about the dangers associated with swimming and drowning if she went by herself. She indicated that this was the reason that she needed someone to come with her:

Someone has to come [swimming] with me because it might be dangerous. What happens if I have drowned? There is someone there to take me out of the pool. So that's why someone has to come with me (YP 6)

#### 4.3.2.2 Risk of others to YP

Three of the YP talked about the how other people could potentially pose a risk to the YP by physically harming the YP. This risk was only discussed in relation to travel and impacted the YP's ability to travel independently. The YP talked about 'bad' people in the community abducting them, suggesting that the YP lacked the understanding and skills needed for self-protection:

No I can't go by myself because if anything happens to me. Like if bad people or strangers and stuff like that and that's why a support worker would be better (YP 5)

#### 4.3.3 Theme 3: Money

The third theme was money. Using money was an area that most YP had difficulty with, and of these, 4 YP said they would like to be able to use money by themselves. The need for adult support when using money greatly restricted the YP's independence. YP struggled with counting money and the use of money and bankcard to purchase items.

#### 4.3.3.1 Counting money

Almost all the YP discussed how they found it difficult to count money. The YP referred to needing to count forwards and backwards when using money and how this affected their ability to use money without support:

I need help with that. A lot of help '...' Counting up and then giving it to local people (YP 9)

Four YP referred to getting help from their parents to help them count money as they found this aspect of using money difficult:

He helps my by like counting how much money to give yea. I can't count backwards '....' That's why, sometimes you needs to need count forward sometimes you needs to count backwards but this is the one I find a little bit hard. (YP 6)

### 4.3.3.2 Purchasing Items

Most of the YP talked about needing support from parents to make purchases. This included a variety of items but mainly involved difficulty with purchasing food in shops.

[Using money.] A bit difficult. My mum does the food shopping. She helps me pay for the toys. (YP 3)

Where YP said they could make purchases by themselves, this involved being given small amounts of money by their parents. Often the YP were given the exact amount of money required for the purchase so they did not need to count out the money or get change:

Sometimes my dad gives the exact money I need and I go [to the shop] (YP 9)

Additionally, these purchases were made in local shops and parents could immediately check that the YP had received the right amount of change:

When I go to Tesco, opposite my house I give the money. The guy gives me the change back and I have to give the money back to my sister. (YP 10)

#### 4.3.3.3 Using bank cards

One YP talked about how he was able to use money, but found it difficult to use a bank card to pay. However, he did not specify what aspects of using a bank card were difficult for him:

the hard bit is to pay by card. That's the hard bit. It's hard. I can't pay by card. I can use a coin or a note (YP 10)

#### 4.3.4 Theme 4: Housework

The fourth theme was housework. Almost all of the YP said they were able to do some form of housework, either by themselves or with a little bit of support. The YP were able to do a variety of different types of housework.

#### 4.3.4.1 Doing laundry

Most of the YP talked about knowing how to do laundry which included sorting clothes, washing clothes in the washing machine and drying clothes by hanging them out. One YP was able to carry out the sequence of actions by themselves but most needed some help from their parents to operate a washing machine:

mum tells me that open '....' the washing machine and then take, put all the dirty clothes in the plastic bag, put it in the washing machine. Put a little bit of ...soap, or any kind of soap in and then close the washing machine and then switch it on. (YP 6)

#### 4.3.4.2 Cleaning the home

Many of the YP were able do some aspects of cleaning around the house which included cleaning their room, bathrooms, vacuum cleaning, tidying up around the house and making their bed. When they performed these activities they often did it by themselves, without adult support. However, half of the YP said they needed some help from their parents which may be an indication that they could not do the full range of cleaning activities in the house.



I am folding a tea towel up. And then I put it away. I can tidy up. I just tidy up some of the house

#### 4.3.4.3 Throwing rubbish and recycling

Two of the YP talked about taking out the rubbish by themselves and recycling. They appeared to take the initiative with this activity and had a good understanding about how to sort and recycle rubbish item:

sometimes I throw the, if we have rubbish or anything I throw it in the bin.... in the house in the dustbin, first in the house and then outside, in the dustbin. So the blue ones are for recycling and the black ones are for rubbish. (YP 5)

#### 4.3.5 Theme 5: Meal Preparation

The fifth theme was meal preparation. Within this, the YP discussed the skills they were able to do which included buying food, cooking, using appliances, table setting and hygiene in the kitchen.

#### 4.3.5.1 Buying food

All the YP talked about buying food from supermarkets or local shops and most said they would do this activity with their parent. Although this was partly due to difficulties with travelling to the shop, there were other aspects of buying food that they found difficult. These included knowing what to buy, making a shopping list and locating items:

Food shopping, with mum and I can help. Because like we have a shopping list, we can write what we need. We are going to have to look for it in the supermarket. If its not there, because sometimes in Tesco you know they've moved everything around. But before it was in the place that that it was in before but not anymore (YP 5)

Two YP were able to buy food by themselves. One YP said they could buy simple items like bread and milk from the local shop but doing a full household shop was a skill that none of the YP had yet mastered independently:

I can do some of that [food shopping] by myself. I sometimes like get a few things that we need from local shops and then my dad and me go out to get the rest of the things that we need from, from different shops (YP 9)

#### 4.3.5.2 Cooking

Cooking was a skill that was important for most of the YP. It was a skill that most of the YP said they could do with some support but many wanted to be able to cook independently. Six YP said they were able to make simple meals and drinks by themselves at school and at home:

Making '...' a cup of tea. I know how to make tea. You put tea bag in, hot water, then you put the milk and then sugar. (YP 5)

Sometimes I cook some Iranian food at home, some English food here, at college. Like for example I make pasta, fish. (YP 6)

Five YP talked about the pre-preparation of ingredients, which included chopping vegetables and measuring out ingredients for baking. These were skills that the YP would do with support when making more complex meals at home and at school.

[School] do cooking in the cookery room. They teach me how to get equipment. We use equipment to chop vegetables. We make stir fry. We make dessert. The dessert was chocolate cake. We had to put flour, eggs and baking power and baking soda (YP 3)

### 4.3.5.3 Using kitchen appliances

Four YP were able to using kitchen appliances such as the microwave, oven and hob. This, however was limited to turning on the appliances and not necessarily knowing how long to cook food for:

This is me putting the cup in the microwave. So I open the door, put the cup in, close the door for the microwave and press the button. (YP 5)

#### 4.3.5.4 Table setting

Two of the YP talked about setting the table by themselves, which included knowing the appropriate kitchenware to use for different meals.



That's the table. I set it

### 4.3.5.5 Hygiene in the kitchen

The YP understood how to be hygienic in the kitchen and could wash and dry dishes, put them back into the cupboard, load the dishwasher and clean work surfaces:

I can [wash dishes] by myself. I wash them in the sink. I let them dry by themselves and then I put them in the cupboard. (YP 7)

### 4.3.6 Theme 6: Personal Care

The sixth theme was personal care and included hygiene and grooming, dressing, buying clothes and managing their own health by doing exercise and going to the doctor.

### 4.3.6.1 Hygiene and grooming

Almost all the YP were able to look after themselves in relation to aspects of hygiene and grooming, including bathing, combing their hair and brushing their teeth:



This is me in the bathroom pretending to brush my teeth with the toothbrush....just put toothpaste on the brush and brush your teeth '...' hairbrush in a bathroom pretending to get ready.

#### 4.3.6.2 Dressing

Most of the YP were able to physically dress and undress by themselves but some needed support in choosing appropriate clothing to wear for different occasions, for which they sought help from their parents:

like when I go swimming I can change, I can shower by myself. When I come out of the pool I shower and get changed. If we go and see a performance or something...like my mum will chose that for me '...' my mum helped me to chose like shirt and jeans (YP 5)

#### 4.3.6.3 Buying clothes

Most of the YP needed support with buying clothes. They enjoyed going shopping for clothes and many of the YP wanted to be able to do this by themselves. They talked about requiring help from their parents with choosing appropriate clothing in terms of size and colours:

I need help with '...' choosing the right size. My dad helps me. (YP 9)

#### 4.3.6.4 Managing health

Managing health included looking after their health by doing exercise and going to the doctor. Five YP performed some form of exercise including PE in

college, going to the Gym or playing in the park. It was a skill they said they needed little to no support with. Two of the YP went to the gym on a regular basis but would have an adult with them.

That's my gym. It's in Roxey. '...' I do the machines and listen to music. (YP 7)

Almost all the YP needed help when going to the doctor. The YP said they got help from their parents who would book the appointments and come with them to the appointments to support the dialogue between the doctor and the YP:

Like mum makes the appointments. Mum comes with me. The doctor explains what happened, like what happens to me. Like I tell the doctor. In case she needs to ask questions to the doctor. (YP 5)

### 4.3.7 Theme 7: Teaching Methods

The YP discussed various teaching methods that they felt had helped them acquire life skills. These included community based instruction, training environment instruction, repetition and practice, and modelling and prompting.

### 4.3.7.1 Community based instruction

Half of the YP mentioned going out into the community with their teachers and how this had helped them to begin to develop some of the skills needed for grocery shopping, using money and travelling. These included making a shopping list, choosing food items, paying for groceries, and using their Oyster card on public transport:

I did it with school '...' you can have shopping list and mum told me to buy this and this I bought it and paid for it by myself. (YP 5)

#### 4.3.7.2 Training environment instruction

Three YP mentioned learning how to cook in a cookery room at school. They felt that this had helped them learn skills in meal preparation, including knowing what ingredients and kitchenware to use for different meals, making meals and maintaining hygiene in the kitchen:

[school] do cooking in the cookery room. They teach me how to get equipment. We use equipment to chop vegetables. We make stir-fry. We make dessert. The dessert was chocolate cake. We had to put flour, eggs and baking power and baking soda (YP 3)

One YP talked about learning about hygiene in the kitchen and how, once their teacher had taught them how to mop the floor, they were then able to do it by themselves:

The plate and all the washing some plates as well, cleaning with the mop as well '...' one time in school... I needed a bit of help with the teacher or staff but now '...' I can do it by myself. (YP 10)

#### 4.3.7.3 Repetition and practice

Performing activities repeatedly was a teaching method that many of the YP referred to that helped them to develop life skills such as traveling on the bus and doing housework. One YP talked about practicing and repeating activities by themselves:

Like if you go different places you have to look on the map how many stops to get off basically. [I: And can you do that by yourself?] Yea because I done that so many times (YP 5)

However, most of the YP said they needed teachers or parents to show or teach them how to do an activity numerous times to help them learn to do it independently:

My staff. They showed me how and taught me. Many times (YP 9)

#### 4.3.7.4 Modelling and prompting

Four YP discussed how parents and teachers supported them to develop life skills by initially showing them how to do an activity and then verbally prompting them when they performed the activity at subsequent times. This was used for travelling, using appliances, doing housework and grocery shopping. The YP felt this teaching method helped them to begin to do these skills more independently:

My mum '...' taught me [shopping]. She showed me then she told me, she reminded me. She told me put the equipment on the counter and the counter will video what you bought and then finish and pay. (YP 6)

#### 4.3.8 Theme 8: Social and Leisure activities

The eighth theme was social and leisure activities, which appeared to be important to the YP as all the YP mentioned this theme. The subthemes within this theme were socialising, participating in clubs and using technology, organizing and planning social and leisure activities.

#### 4.3.8.1 Socialising

Most of the YP said they could socialise and meet friends and family by themselves, as illustrated by the ranking exercise. The YP said they would go out and meet their friends for meals, go to the cinema, go bowling or just 'hang out'.

[I go to] to café' and like to have dinner we will go out. I do that by myself. I go and see [my friends]. I just hang out with them....Play a game, Uno. (YP 9)

#### 4.3.8.2 Participating in clubs

Three YP talked about participation in clubs. The YP enjoyed attending clubs as it provided an opportunity to meet friends as well as partake in activities of interest:

[I] go to the club called Action for Kids and it's a charity, it an office basically so I like office work and stuff like that. I see lots of people, when I do drama I see lots of people from outside so like I meet [YP] and people like that. With my friends because we do drama together. (YP 5)

#### 4.3.8.3 Organising social and leisure activities

Although most of the YP enjoyed socialising and participating in clubs, most of them needed their parents to help them to organise these activities; including helping them arrange to meet their friends and enrolling them in clubs. Only one YP talked about occasionally arranging social activities by herself:

I first ask my staff if I could meet [my friends] and then, and then I'll go and see if I can hang with them. And then I go hang out with them. Sometimes I do call them and sometimes my staff call them. (YP 9)

#### 4.3.8.4 Using technology

The ability to use technology including computers, TVs, game consoles and phones was an important skill for many of the YP, to help them enjoy leisure time and connect with friends. The YP were quite adept at using media equipment such as TVs and game consoles by themselves. However, only two YP referred to being able to use a phone (landline or mobile) independently:

[I can make phone calls] to my mum, my dad, my brother or the house telephone number, for the house. That's me using the house telephone so if someone calls I pick up the telephone. (YP 5)

From the ranking exercise, seven YP said they were able to use a computer independently. However, when the YP discussed what they used the computer for, they mainly referred to being able to do simple activities such as logging in, browsing the Internet or looking at pictures. None of the YP mentioned using computers for more complex tasks.

I can use the computer by myself. I like going on the computer. I like looking at pictures, wallpaper and things. (YP 7)

# 4.4 Integrative analysis of parent and teacher data

Through an integrative analysis of the parent and teacher data, themes emerged that had similarities and differences to the YP data. There were nine themes that emerged that were similar to the YP data and five themes that only occurred in the parent/teacher data. The similar themes will be discussed first followed by the discrepant themes.

# 4.5 Similar themes between parent/teacher data and YP data

This section identifies the themes that emerged from the parent and teacher integrative analysis and compares them to the themes from the YP integrative analysis. There were seven themes that shared similarities with the YP themes: travel, safety, money management, housework, meal preparation, personal care and teaching methods. The final two themes, leisure activities and relationships link to the final theme in the YP analysis but are discussed as separate themes in the parent/teacher analysis. Table 7 shows the themes and subthemes from the integrative analysis of the parent/teacher data. The themes and subthemes are then described in turn with supporting extracts.

Table 7: Themes and subthemes from the integrative analysis of parent/teacher data that are similar to the YP data

Themes	Subthemes
1. Travel	Finding way around the community
	Accessing and using public
	transport
2. Safety	Keeping safe in the home
	Keeping safe in the community
Money management	Understanding monetary value
	Getting back change
	Budgeting
A Have sweet	Banking skills
4. Housework	Doing laundry
	Cleaning the home
	Throwing out rubbish and recycling
5. Meal Preparation	Looking after pets Buying food
o. Mour reparation	Cooking
	Using kitchen appliances
	Table setting
	Hygiene in the kitchen
6. Personal Care	Hygiene and grooming
	Dressing appropriately
7. Teaching Methods	Instructional Prompts
	Community based instruction
	Training environment instruction
	Residential
Leisure activities	Participating in clubs
	Using technology
	Visiting public places
9. Relationships	Meeting friends
	Developing and maintaining
	friendships
	Romantic relationships

# 4.5.1 Theme 1: Travel

The first theme was travel. Similarly to the YP data, parents and teachers discussed how the YP were able to find their way around the community and access and use public transport.

# 4.5.1.1 Finding way around the community

When the parents talked about the YP being able to find their way around the community, they most often referred to the YP walking to places that were close to their home or places that were familiar to them:

But he's learnt, like we teach him, if you want to go to the shop like if he wants something, he says can I go mummy today.... He's just lately got that confidence where he can go in the shop and get it. And the thing is because it's local they kind of know [him] (P 5)

However, as one parent pointed out, finding their way around the community, whether by walking or by bus, required careful planning and support from others, otherwise the YP would get lost:

She occasionally would go and visit her friends with careful mapping of where she needs to go round. She relies extensively on her phone. If she is going to visit her friend '...' she would have to arrange to meet Nicola at a particular point because she can't navigate how to get to Nicola's house. So she would meet up with Nicola at the bus stop and '...' then she would constantly ring Nicola I'm now on the bus '...' I'm going to be there in so minutes and where are you and '...' so without a phone you become really lost (P 9)

# 4.5.1.2 Accessing and using public transport

Many of the parents stated that traveling by public transport was difficult for the YP and this meant that the YP had to travel with their parents. The parents referred to travelling by bus and tube as an area of difficulty because the YP would not know which bus or tube to take and where to alight. This was often due to difficulties with reading bus numbers and tube maps:

When we are in the bus '...' I have to do it for her... sometimes when we get to Broaders Park she might see 113 and she will say, because there is 1 and 3 there she will get confused and say "Mum is it that bus?" and I'll say "No [YP] remember its 1 and 3" (P 3)

[H]e wouldn't know the tube exactly how it ends. He wouldn't know where to get off (P 10)

Some of the teachers and parents talked about how travel training was important for the YP to continue to do, to become independent travellers. However, as this teacher states, travel training would need to be done in incremental steps and independent travel would still be limited to familiar places:

Travel, I think she could with support she could do it, but she wasn't at the stage where she left us as an independent traveller. But I think if things are done in a small and routine way, '...' [YP] could make small journeys to regular places on a single bus '...' I definitely imagine her being able to do that in the future. (T 3)

# 4.5.2 Theme 2: Safety

The second theme was safety. For seven parents, a big worry was the risks that the YP faced in the home and when they went out in the community. This was a theme that also arose from the YP data that showed they had similar worries. The parents worried about the YP's physical safety as well as their emotional safety.

### 4.5.2.1 Keeping safe in the home

Similar to the YP, the parents talked about the risks associated with physical harm to the YP. Most of the parents talked about physical harm in the home associated with cooking, such as cutting themselves with a knife or getting burnt when using kitchen appliances. This often meant the parents would either not allow the YP to perform these activities or would only allow the YP to do these activities when an adult was present:

[YP] can not cook or she is dangerous to herself in the kitchen (P 7)

And we have a hot tap '...' I've told him only do it if someone is here (P 5)

One parent talked about how the YP was afraid to use sharp objects such as a scissor and razor and therefore the parent would be required to help the YP with aspects of grooming:

She is scared about the scissors, she is scared about the nail cutting. Still she need help all the time '...' For the removal she need all the time help....the cleaning of herself, shaving (P 6)

# 4.5.2.2 Keeping safe in the community

One of the many areas of concern in relation to safety, which almost all the parents talked about, was how to keep the YP safe in the community. Parents were worried about their YP being physically and emotionally harmed when they went out in the community. Physical risks included crossing the road and being physically harmed by strangers due to the YP's vulnerability. In relation to crossing the street, some parents stated that the YP lacked a sense of danger and therefore their impulsivity or distractibility would put them at risk:

if we're walking down the road '...' she wouldn't think twice about running across the road. (P 4)

Two parents discussed how the YP lacked knowledge in or would not be able to consistently use their knowledge of road safety when crossing the road:

The only problem is crossing the roads because he forgets to look on both sides and if I remind him, then he will forget for the next one. (P 5)

Three parents talked about the risk of physical harm because of the YP's vulnerability. There was a sense that the parents' own anxiety about the YP's safety prevented the parents from letting the YP travel by themselves. The parents discussed worries about the YP getting lost, mugged and danger from strangers:

Couple of times she missed the stop and I would be very anxious if she went out on her own '...' I think she probably could do it but there's just so many strange people around '...' I wouldn't like her to do it on her own. (P 7)

Another risk that the parents talked about was the emotional harm to the YP. This was not an area that was raised by the YP but was discussed by a few of the parents. Emotional harm included getting conned and being mistreated by others. Two parents talked about the risk of their YP getting swindled because of the YP's difficulties in understanding monetary value:

So he has no concept of how, um, I have a £10 and I went to the shop and I spent a £5 so they should give me £5 change. So my worry is always that people can con him. (P 5)

One parent was worried about the YP being mistreated by the opposite sex because the YP was vulnerable due to her trusting and suggestible nature and lack of sexual maturity:

[YP] is very, very easy going to the other people, especially men you know she has some attraction to the men '...' She doesn't know the meaning of these things, she is very clear person, and then I explain '...' you shouldn't do that '...' I don't want anyone to use you. (P 6)

### 4.5.3 Theme 3: Money management

The third theme was money management and occurred in most of the parent and teacher data. Parents and teachers both mentioned how the YP found it difficult to use money because of a lack of understanding of monetary value and not knowing how much change to get back. These subthemes had similarities with the YP subthemes of counting money and purchasing items. A few of the parents and teachers made reference to more complex money management skills: budgeting and banking.

# 4.5.3.1 Understanding monetary value

Three parents discussed how their YP did not yet have an understanding of monetary value. This was the reason that many parents were reluctant for their YP to use money independently. However, this was an area that many parents hoped the YP would be able to learn in the future:

If I give '...' him coins he doesn't know that, he thinks that you've given him less. I don't let him handle money because he doesn't understand money '...' Money, concept of money is really big thing that we are hoping he will learn (P 10)

### 4.5.3.2 Getting back change

Almost all the parents and teachers talked about how the YP had difficulty with getting back the correct amount of change. They stated that although the YP would understand they had to give money to make a purchase, they would not be able to do the mathematical calculations involved in knowing how much change they were due:

I mean she wouldn't have a clue if somebody didn't give her the right change but she knows that she has to give the money and if there's change it's given back to her. (P 7)

#### 4.5.3.3 Budgeting

One parent and one teacher talked about the YP's ability to budget. The teacher spoke positively about how one of the YP was able to budget her money in order to know how much money she had to spend when she went shopping:

knowing that she has enough money '...' in her purse to pay for her things '...' that is a fair bit of skills and she is capable of doing that (T 4)

In contrast, one parent talked about more complex monthly budgeting in relation to understanding how much money was in a bank account and appeared to have higher aspirations for what they expected the YP to be able to do:

Budgeting it's a whole comprehensive thing that she needs to have to be able to do that. In terms of budgeting, she doesn't know how to keep a tab on it so if you put money in an account, you have to make sure you use a specific amount otherwise she'll go over (P 9)

### 4.5.3.4 Banking skills

One parent and one teacher talked about banking skills including the ability to open and manage a bank account. The parent said the YP was able to use cash machine to take money out but had difficulty with checking bank statements:

She doesn't check the statement because it's too difficult for her to add up the entries and so on so she just doesn't want to do that. (P 9)

#### 4.5.4 Theme 4: Housework

The fourth theme was housework. Almost all the parents talked about the YP's ability to do housework. As the parents talked about the same range of housework skills as the YP (doing laundry, cleaning the home, throwing out rubbish and recycling and looking after pets) these will not be discussed as individual subthemes. Instead, specific references to how housework was done by the YP will be discussed.

Most of the parents discussed how the YP were not yet able to complete all the steps involved in doing aspects of housework, such as laundry and cleaning the house, by themselves. Two parents described how the YP would be able to put their dirty laundry in the washing machine and turn in on

but would not be able to add the detergent or know which washing programme to select;

he does take his clothes and put it in the hamper and in the kitchen so we can put it in the washing machine for him '....' because he wouldn't know how to operate the washing machine (P 10)

Similarly, although many of the parents described how the YP would help with cleaning around the house, there was a sense that the YP did not know how to thoroughly keep a house clean:

she could sweep the floor but '...' it wouldn't be any help and she sometimes gets a feather duster '...' but nothing practical really (P 4)

### 4.5.5 Theme 5: Meal Preparation

The fifth theme was meal preparation. Again as the subthemes are the same as the YP data (buying food, cooking, using kitchen appliances, table setting and hygiene in the kitchen), these subthemes will not be discussed individually. Aspects of meal preparation that the parents and teacher mentioned the YP found particularly easy or difficult will be discussed.

The parents and teachers talked about how the YP were able to make simple meals and drinks, set the table and wash and dry dishes by themselves. Some of the parents said the YP could do grocery shopping by themselves when this involved shopping for familiar brands or simple food items. As one parent describes, this skill was developed by recognising the brands the family regularly used at home and performing the activity with the parent on previous occasions:

Just going with me and gradually finding out where in the supermarkets things are. And she even knows which brand, she won't just come back with the wrong ... like for cornflakes for example, she knows to get Kellogg's cornflakes and not the own brand ones. I think that's just visual because she is very visual and she'll see them in the cupboard and she knows the ones that we have. Same with cat food '...' But that again is just looking at the same thing every week (P 7)

Although the parents and teachers referred to the YP's ability to make simple meals, half of the parents stated that the YP did not know how to make more complex meals. Interestingly, three of the parents said that they were aware that the YP cooked at school or at the interim college but that the YP did not cook at home. This was often due to the parent cooking for the YP because there was an expectation that the YP was not required to cook at home or that they would perform the task incorrectly or incompletely:

I mean when she is at college I think she is more independent than when she is at home because I've always cooked the meals for her (P 4)

sometimes he says can I help but that just means he will come and stir something. He doesn't have the patience. But his idea is it just means I just want to do this mixture and put it in the oven '...' but in the college he loves it. He does it. (P 5)

In a similar vein, one teacher talked about the YP's ability use kitchen appliances but the parent of the same YP felt that the YP could be danger to herself in the kitchen. The YP's inability to use some kitchen appliances like the cooker and oven at home was also mentioned by two other parents.

I mean she had a good grounding in [knowledge of using kitchen equipment], kettles and ovens and that. (T 3)

[YP] can not cook or she is dangerous to herself in the kitchen so I don't have to let her if, when I'm cooking she can come sometime, ask me if she can help me. (P 3)

### 4.5.6 Theme 6: Personal Care

The sixth theme was personal care. Within this theme, the parents and teachers discussed two subthemes: hygiene and grooming, and dressing appropriately.

### 4.5.6.1 Hygiene and grooming

Parents reiterated what the YP said, in that the YP could bathe and perform personal hygiene skills such as brushing their teeth and combing their hair themselves. Two parents talked about the YP being able to go into the community by themselves for other aspects of grooming such as getting haircuts and nail treatments. However, this was to places where the owners knew the YP:

She goes to the hairdressers on her own. She gets a haircut. I just drop her there and I say to the hairdresser I'll be back in half an hour and she's quite happy to sit there. Because they are very good, they know her, they know her difficulties and she also goes sometimes and gets her nails done as a treat. (P 7)

#### 4.5.6.2 Dressing appropriately

Both the parents and teachers stated that the YP were able to dress and undress themselves. A skill that was more difficult for the YP, from the parents' perspective, was choosing appropriate items to wear on a day-to-day basis. One parent referred to the YP choosing inappropriate shoes to wear to college. Another parent described how the YP would not know how to wear appropriate clothing for different seasons or occasions:

he can't chose '...' if it's in the morning and it's sunny he will just go and get a t-shirt and go. He would know its morning, its nice and sunny but does not mean it's summer (P 5)

# 4.5.7 Theme 7: Teaching Methods

The seventh theme was teaching methods. The parents and teachers highlighted teaching methods that had been useful in helping the YP learn life skills. The parents and teacher talked about the teaching methods used in school, while only the parents talked about how they themselves had helped the YP learn some life skills.

The teaching methods used at school that were discussed included community based instruction, training environment instruction and going on residential. Instructional prompts were used at school and at home.

### 4.5.7.1 Instructional prompts

Like the YP, parents and teachers talked about how the use of instructional prompts, including modelling and prompting, helped the YP develop skills through repetition and practice. All of the parents referred to using modelling and prompting methods themselves or by teachers at school to teach the YP life skills such as cooking, travelling, cleaning around the house, doing laundry and bathing.

Five parents said they had taught the YP some life skills at home through modelling and this had helped them learn how to do the skills by themselves;

I think most of that she's learnt here. I don't think it was from school really '...' by showing her how to do things and then letting her do it (P 7)

An example of how a parent taught the YP to bathe properly through modelling is given below:

Well he can shower himself. Before that I had to wash him properly '...' because he couldn't wash himself properly before. So I said to him when you wash open the flannel up, put loads of it on and then go like that and go like that (P 9)

Four parents and two teachers stated that the YP would need to be prompted many times and required practice in doing life skills. For some life skills, the YP would then be able to complete the life skill by themselves when prompted, but that would not mean that they would take the initiate and do it by themselves the next time they had to perform the life skill:

he has a freedom pass but it's never topped up. He knows how to use it. I've gone so many times with him

so I tell him what to do '...' It's like a constant repeating things for him to remember. (P 10)

### 4.5.7.2 Community based instruction

Seven parents talked about community based instruction as a teaching method done by the school or interim college that helped the YP develop skills such as grocery shopping, travelling and visiting public places. Most of the parents felt that this teaching method, when done regularly, was a key aspect in enabling the YP to learn how to do skills in the community.

They go shopping, they go to the post office, they go on the tube and on the bus '...' now they go everyday '...' what's been the best thing here is that they are in their small little group, they go off and do loads of different things.(P 4)

Two parents talked about how learning the skills in the community meant that they then felt comfortable to let the YP perform the life skill by themselves:

They did take them to the shops. They used to take him every week, once a week to Tesco and tell them to buy something and then they would be able to buy and go to then counter and pay for it. So that also did help so that I can still send him. (P 10)

### 4.5.7.3 Training environment instruction

Two parents described how cooking was taught through a training environment which was done in a step-by-step approach. Parents felt this enabled the YP to get practical experiences of performing the life skills of cooking:

They did a lot of cooking '...' that was good because they had to do things like going out to buy the ingredients for what they were making. (P 7)

However, the parents did not appear to know specifically how the YP were being taught in the training environment nor did they talk about how these skills were being utilised and generalised by the YP at home.

#### 4.5.7.4 Residential

Five parents referred to the school taking the YP on residentials, which helped the YP develop their independence because they were away from home and had to do many life skills, such as getting ready, by themselves.

Obviously being away from home for that length of time is very beneficial. (P 10)

Sometimes they take them for 1, 5 days to see how students are doing for themselves. They teach her so many things, going to the tour '...' sometimes they have to let her lead the way because sometimes they have to find out that she is the one that know (P 3)

Three parents felt that residentials helped the YP reduce the dependence that they had on their parents when they were at home but that the YP felt anxious about being away from home for those few days:

If he has to go away for residential for 2 days he doesn't like it. He is fine all day, evening comes he doesn't like it (P 5)

One parent said that there was a need for more residentials so that the YP could build confidence about being away from the parent:

They could have gone on more trips '...' just making her realize that she could survive away from home and she can survive without seeing me. (P 4)

### 4.5.8 Theme 8: Leisure activities

The eighth theme was leisure activities. As in the YP data, the parents and teachers talked about the YP's leisure activities. This included participating in clubs and using technology. Parents also talked about the YP visiting public places which was not discussed by the YP. As the first two subthemes were similar to the YP data these will not be discussed individually.

The parents reiterated that the YP were able to use technology for leisure activities such as watching DVDs, using the iPad, using computers and listening to music. They also talked about the YP participating in a variety of clubs that enabled the YP to engage in activities they enjoyed such as drama, first aid, cheerleading, dancing and office work. As one parent mentioned, participating in clubs gave the YP a sense of achievement and enjoyment:

It's called Roadhouse. So it's for special needs kids. And they were really good and he would go there and they would teach him something about first aid, he would get that certificate and he would be so happy. (P 10)

One teacher talked about how more placements in clubs would have been beneficial because it gave the YP a chance to practice life skills in the community:

She did go to Broaders and they learn how to use the photocopier and they learn some office skills which is great. But yea I think more placements like that. (T 3)

#### 4.5.8.1 Visiting public places

Four parents talked about the YP enjoying visiting public places such as famous landmarks, games arcades, museums, the local high-street and the cinema in their leisure time. Two parents talked about the YP being able to do this themselves, when the place was close to home. For most of the parents, this was an activity they did with their YP because they knew the YP enjoyed it but would not be able to do alone:

[YP] she likes going out. [YP] would like to go the cinema, she would like to go outside London, to go to Trafalgar Square, look around, see things. Like yesterday we went to X museum for her to look around, see the planes and everything '...' I have to go with her. (P 3)

# 4.5.9 Theme 9: Relationships

The ninth theme was relationships. The YP only talked about friendships whereas the parents and teachers talked about friendships and romantic relationships. In this theme there were three subthemes that emerged which were: meeting friends, developing and maintaining friendships and romantic relationships.

# 4.5.9.1 Meeting friends

Four parents talked about how their YP were able to go and meet friends by themselves. The parents said they would drive the YP to meet their friends at various locations and then leave, so this was a skill that some YP were able to do completely independently. The parents seemed pleased that the YP had friends and encouraged the YP to meet them by themselves.

She sometimes goes to the cinema with a friend. We will take her there and pick her up afterwards but she will be in the cinema with a friend. There will be no adults there. We've done that with going out for a meal as well. (P 7)

# 4.5.9.2 Developing and maintaining friendships

However, four parents discussed that the YP did not have many friends or that they would like the YP to have more friends. It appeared this was due to difficulties with developing and maintaining friendships with peers by themselves:

She hasn't got any friends, girls also even because from the other learning difficulties she can't cope with them. She is very chatty girl she wants someone '...' to talk about matter which she has got a question but she is very lonely. (P 6)

One aspect of developing and maintaining friendships was organising social activities, which was a skill that many YP relied on their parents to do for them:

to be able to sort of go out with friends '...' on her own and at the moment we always sort of organize it '...' but she's getting better but they just don't have the means to sort of foster a friendship. (P 7)

#### 4.5.9.3 Romantic relationships

Three parents talked about wanting their YP to have a romantic relationship in the future. Yet two of these parents felt that at present the YP did not have a good understanding about romantic relationships:

He would say, 'oh I learnt this day. We had a lesson about growing up and relationships.' But you can tell that he didn't quite understand. (P 5)

One parent discussed her concerns about this lack of understanding causing her YP to behave inappropriately:

she said something about some relation with the boys in the college and I think the boys are very touchy and she ask her to touch her private parts and she did...She doesn't know the meaning of these things (P 6)

### 4.6 Discrepant themes between parent/teacher data and YP data

In this section, I will identify themes from the parent and teacher data that were different to or not evident in the YP data. There were five themes that emerged in this manner: YP's state of mind, language and communication, perceptions of SEN, school experiences and parents doing tasks for the YP. Table 8 shows the themes and subthemes which will each now be described in turn with extracts from the transcripts.

Table 8: Themes and subthemes from the parent/teacher data that were discrepant to the YP data

Themes	Subthemes
10. YP's state of mind	Understanding and managing
	emotions
	Developing confidence
	Having intrinsic motivation
11.Language and Communication	Expressive skills
	Receptive skills
12. Perceptions of SEN	Parental perceptions of SEN
	Societal perceptions of SEN
13. School experience	Positive experiences
	Negative experiences
14. Parents doing tasks for YP	

# 4.6.1 Theme 10: YP's state of mind

YP's state of mind was the tenth theme. Many of the parents and teachers talked about the YP's emotional state of mind and how this impacted on the YPs ability to do a variety of life skills. This included understanding and managing their emotions, developing confidence and having intrinsic motivation.

### 4.6.1.1 Understanding and managing emotions

The parents and teachers discussed how the management of the YP's emotions in the community could hinder the YP's ability to do life skills. Two teachers and one parent talked about the YP's feelings of anxiety and panic impacting on their ability to perform life skills independently:

She could quite easily get flustered and that when she can panic a little bit and that when it spirals out of control quite quickly (T 3)

Well she really does struggle with independence. She gets very, very anxious and that clouds over everything that happens. (P 4)

Helping the YP to emotionally regulate by providing strategies and resources was considered an important aspect to help the YP to acquire life skills. Two teachers talked about how they supported the YP:

she is more than able to do all these tasks if she is calm and regulated well '...'.the ticket to her independence is someone helping her to be emotionally regulated. (T 4)

We spent a long time with [YP] trying to help her with strategies to try and regulate herself basically to try and stay calm '...' so we made her a key ring. She felt she needed it and she would come and tell us, she would use the symbols. (T 3)

# 4.6.1.2 Developing Confidence

Confidence was another area that parents talked about that affected the YP's ability to do things in public. Four parents talked about the YP lacking in confidence, which restricted them from going out and talking to people in the community:

Well obviously starting from childhood. She always lacked confidence in certain areas. She needs nurturing in so many areas. (P 9)

Two parents talked about how they would like their YP to have more confidence in the future, to enable them to perform life skills in the community by themselves:

I would like to see her to go to the shop, buy something for herself and then come back, to be proud that she did it, instead than go out there, feel like somebody's looking at her, watching her, because she is not really comfortable (P 3)

### 4.6.1.3 Having intrinsic motivation

Some of the parents and teachers discussed how the YP's intrinsic motivation affected their ability to engage in and perform life skills tasks consistently by themselves. Enjoying and being motivated by a particular task helped the YP develop this life skill:

She would probably be able to do little tasks like cooking task, like really easy cooking tasks '...' So

anything like making a cup of tea, hot chocolate is motivating for her. (T 4)

Similarly, parents talked about whether or not the YP performed a task was contingent on their levels of interest. Where the YP had an interest in a doing a particular life skill, they would do it independently:

Sometimes, when he can bother '...' He does wash up sometime '...' when he feels like it. Oh he does put the washing in the washing machine '...' Well when he feels like it. (P 8)

In contrast, if YP lacked interest or did not feel a life skill was valuable to them, they were less likely to learn how to do the life skill independently. One parent described how the YP lacked interest in doing things outside the home and having friends, which meant it was harder for the parent to teach these life skills to the YP:

Lack of any real interest in doing anything outside of the home. She doesn't have any sort of desire to do anything or see anything or go anywhere particularly without me '...' she doesn't really have any life outside of the home and she has no friends or no social life. She doesn't have any desire for it, which is the trouble. (P 4)

#### 4.6.2 Theme 11: Language and communication

The eleventh theme was language and communication. Within this parents and teachers talked about the YP's expressive and receptive language skills.

#### 4.6.2.1 Expressive skills

Parents and teachers talked about the YP's expressive skills being a limitation for doing life skills by themselves in the community. This included difficulties with speech content and clarity. One teacher talked about the YP's need to develop her communication skills to enable her to be more independent in the community:

Moving toward the actual practical steps of being able to be outside and communicate with people that we meet, if we are out shopping for things, like that. (T 3)

Two parents talked about how the YP would avoid or limit interactions with people in the community because of their difficulties in expressive language:

He doesn't interact with other people. I mean he might be okay here, in college but outside he won't be able to. He talks to people '...' but he don't talk to them proper like we do (P 8)

Two parents talked about the YP speech clarity making it difficult for unfamiliar people to understand the YP:

We've kind of pushed her with her speech because she can be very, not unintelligible but sometimes her words all sort of run into each other. Because quite often when she sees people that don't know her they'll have problems understanding what she's saying because of her speech. So that's been a big issue with her because.... her speech could be a little bit unclear. (P 7)

### 4.6.2.2 Receptive skills

Some parents and teachers talked about the YP's difficulty with receptive skills, which include reading for meaning and the ability to process information. Two parents talked about the YP's difficulty with understanding spoken language:

I mean you can sit with him and talk to him for hours. He loves it but he doesn't take it all in. He understands, he will use those phrases but he won't know what it really means (P 5)

One teacher talked about the YP's difficulty with understanding and processing written text as being a barrier to independence:

I definitely think the understanding word, written text, the actual process of looking in one was a big step and then two once you've understood what do I need to do then. So I definitely think she would find 2 or 3 step instructions quite difficult to process. So it was that processing that would hold her back (T 3)

### 4.6.3 Theme 12: Perceptions of SEN

The twelfth theme was perceptions of SEN. This included how the parents felt themselves about the YP's SEN and also their experiences and feelings about how they thought society perceived their YP's SEN.

# 4.6.3.1 Parental perceptions of SEN

Parents talked about their YP's SEN being a debilitating factor for the YP to acquire life skills. Many of the parents and one teacher also mentioned that they felt the YP's SEN restricted their ability to acquire skills. One parent talked about the YP's SEN restricting the YP from reaching their aspirations:

I know that every mum hopes well for their children but when you have somebody like [YP], in her head she is a very intelligent person but because of her disability she can't do the things she wants to do. I've seen her, she's the kind of child that knows what she wants but, because of her disability, she can't get there. (P 3)

Other parents and one teacher discussed how the YP's SEN set limitations on the YP's ability to acquire life skills because of cognitive difficulties. Two parents talked about reading:

At home I try to make her ready but she can't do all of them. Weakness is weakness you know. She has got this one. (P 6)

The teacher talked about the YP's processing and communication difficulties, as a result of the YP's SEN, being a barrier to the YP developing some life skills:

It was just the nature of her learning disability '...' the need for extra processing time and communication skills would definitely come into the mix there as well. So it was that processing that would hold her back but I think that was just inherent in her condition and not entirely something that can be taught. (T 4)

### 4.6.3.2 Societal perceptions of SEN

Many of the parents discussed the judgment they and their YP felt from members of society because of the YP's SEN and how this affected the YP's involvement in the community. This was a theme that only emerged from the parents' data but shed light on an area that the YP may not have been able to articulate. One parent talked about how their YP felt uncomfortable when they thought people in society were looking at them:

So when people see you different of course they will look at you. But for her she doesn't feel comfortable '...' I would like to '...' let her know that they are not judging you '...' But I've tried to explain. (P 3)

Three parents discussed how they felt that the public were judging them or their YP when the went out in the community together:

Its quite hard as a parent when you are out with her and she looks perfectly normal and then all of a sudden something dreadful happens and one parent to cope with it and also to for other people looking at you (P 4)

I think if you know her it's fine but for people that don't they might think she is a bit standoffish or whatever but it's purely because of her obviously the learning difficulties. (P 7)

One parent talked about how they felt their YP had been discriminated against because of their SEN when trying to get a job and how this made the parent feel:

The biggest problem we've got '...' several times we've attempted to get a holiday job or a part time volunteer job. And it's disgraceful what goes on around here. You go into the shop and they look at her because the eye gaze on her, because of her special needs, she doesn't have a particularly fixed gaze and the moment you recognize that the gaze isn't as precise as you wanted, they just decline. Yeah, and how they stigmatize in society '...' All the shops tell me...you know our customers are very sensitive and the moment they realize they have got special needs or disabled people working here, they will go away. It's very narrow-

minded opinion. And these are the sort of problems they are going to encounter. (P 9)

### 4.6.4 Theme 13: School experience

The thirteenth theme was school experience. Parents mainly talked about the positive relationship and experiences they had with the school. A few parents discussed how they felt the school could have provided a greater focus on the life skills curricula and made the teaching more individualised and challenging.

### 4.6.4.1 Positive experiences

Almost all the parents held positive feelings about the school and shared positive experiences. Three parents talked about the school and interim college having regular contact with the parents, keeping good and open home-school communication links and helping the parents develop academic skills at home:

I always get feedback on how she was doing '...' every time I have problem with [YP] I always talk to [Teacher] '...' I worked with [school] together to support [YP] in any way that she wanted '...' Like when they say '...' they need parent support when they are teaching children '...' all those rules that they giving to [YP], everything they ask her to do, I make sure that she is on it. (P 3)

I'm in constant contact with '...' her tutor and they write a diary everyday so we know what she is doing. So I feel that even though I don't come up here really too or very often I still feel involved and I feel I can anytime email or message them. (P 4)

A few parents talked about the school and interim college providing a supportive environment for the YP and helping the YP to learn and develop the life skills. Many parents felt the school could not have done any more in terms of what they taught the YP:

I think they pretty much did everything that they could. No, we were very happy with [school]. The teachers were absolutely lovely and she came on in leaps and bounds (P 7)

# 4.6.4.2 Negative experiences

Some parents talked about how the school could have done more to support the YP. Three parents discussed how the life skills teaching was not given enough emphasis in the curriculum:

I know that they have curriculums and in post-16 they used to have more focus on life skills, they used to take them out and about in the community '...' but I still don't feel it was 100% based on the life skills, like whatever they are doing (P 5)

Two parents felt that the curriculum was too simple, not individualised enough or that the YP was not being challenged:

But the trouble is the life skills they teach in there are so mundane. Because basically hygiene, road safety awareness, using sport facilities '...' But transition into becoming independent is more complex than that (P 10)

### 4.6.5 Parents doing life skills for YP

The fourteenth theme was parents doing life skills for the YP. Almost all the parents mentioned doing some life skills for the YP such as cooking, doing laundry, cleaning the house and reading information. Parents consistently reported that they performed tasks for the YP instead of letting them do them by themselves because parents had constraints on their time and the YP would take longer to do the task or would do it incorrectly:

But there is time when I have to just do it when he is not at home because you can't just leave it like that. And then another problem is because I work as well you have to do a time schedule, you come home and '...' I'll just grab all the laundry and I'll put them in the wash (P 5) Some parents said they would do the task for the YP because this is what they had been doing for a long period of time and therefore they kept doing it:

Every time I go with him I just never remember. I just do it myself but maybe I should try it and go to the shop give him money and see what he does. (P 10)

In summary, this chapter describes the findings of the research through identifying the themes and subthemes that emerged firstly from an integrative analysis of the YP data and secondly from an integrative analysis of the parents and teacher data, that highlights similarities and differences to the YP data.

### 5 Discussion

#### 5.1 Overview

In this chapter the findings will be discussed in relation to the research questions. It will begin by addressing the research questions through a discussion of the over-arching themes that emerged from the case studies, taking into account the findings from the YP and their parents and teachers. The implications for EP practice will be discussed followed by the limitations of the current study. Finally, recommendations will be made for future research.

This study aimed to examine the perceptions and experiences of YP with MLD and their parents and teachers, about life skills for independence that were important for the YP when they left school, to be successful in adulthood. It also explored the factors that helped or hindered the development of these life skills from the perspectives of the YP as well as those of their parents and teachers.

#### 5.2 Research Question 1

What competencies for independence are important for YP with MLD when they leave school from the perspective of the YP, their parents and teachers?

The importance of this study was to gain the views of YP with MLD, their parents and teachers about what life skills for independence are important for them when they leave school. In accordance with recent legislation, namely the Children Act (2004) and the SEND Code of Practice (DfE, 2014a), involving CYP and parents in developing intervention to best support them is best done through seeking their views directly. Although there has been a surge in literature exploring the views of CYP with SEN in recent years, their remains scarcity in research seeking their views in relation to life skills for

independence. In fact, most life skills curricula have been developed based on models of life skills that have been informed by the views of educational professionals and policy makers.

Clark (1994) highlighted the need for exploring the views of students and their parents to understand what their current and future needs were. This should therefore be the starting point in this top-down approach; to ensure that the eventual curriculum that is developed is based on what the CYP with SEN themselves feel are their ultimate goals in adulthood. Yet, adult domains have been identified based on research outcome data and there is a limited amount of qualitative information about what people with SEN actually value in relation to aspects of adulthood (Cronin & Patton, 2007). The current study identified areas of competency and life skills that were important for the YP with MLD themselves and their parents. There still however remains a need for more research in this area, using participatory methods to gain the views of adults and YP with MLD, to determine whether the adult domains currently being used are consistent with the adult domains that are important to them.

There was considerable agreement and overlap between the competencies that the YP thought were important for them when they left school and those that their parents and teachers thought were important. Competencies refer to the overarching areas of ability that adults need in everyday life. Life skills refer to specific skills needed to achieve each competency and that will have local relevance. The findings indicate that YP, parents and teachers felt that the areas of competency that were important were housework, meal preparation, personal care, friendships, participating in leisure activities, travel and money management. These themes align with the competencies from the Daily Living Skills domain and one competency from the Personal-Social Skills domain from the LCCE-M model (Loyd & Brolin, 1997) as is shown in Table 9.

Table 9: Comparison of competencies and themes

	Competencies	
Domain	LCCE-M model	Current research themes (subthemes)
Daily Living Skills	Managing money Selecting and maintaining living environments Caring for personal health Eating at home and in the community Cleaning and purchasing clothes	Money management Housework (cleaning in the house, throwing rubbish and recycling) Personal Care Meal preparation  Housework (laundry) and Personal care (buying clothes)
	Participating in leisure activities Getting around the community	Participating in leisure activities Travel
Personal-Social Skills	Developing and maintain appropriate social relationships	Friendships

The findings in this study showed that YP with MLD and their parents gave equal importance to competencies in the Daily Living Skills domain and the friendship competency. This contrasts with the findings from the study by Hamre-Nietupski et al. (1992) who found that parents of YP with MLD rated 'functional life skills' (domestic functioning, community functioning and leisure/recreational) higher than friendship/social relationship development. This highlights the need to seek the views of YP themselves as well as understanding the different needs of YP living in varying contexts.

It is possible that the changing social context in the new technological era has had an influence on friendships being seen as a more important competency in the current research. YP are now much more aware of their peer's social interactions due to the prominence of social media. In fact, recent studies with adults with LD have found that having friends is important for this population and that many adults with LD often describe themselves as being lonely. This was addressed in the government's paper Valuing People (DH, 2001) that highlighted "helping people [with LD] to sustain friendships is consistently shown as being one of the greatest challenges" (p.81). The current economic climate of austerity has led to funding cuts for

services provided to people with LD. Research by Mencap (2012) found that 57% of people with LD no longer had access to day care facilities due to closure of facilities and an increase in charges for access to these facilities, leaving many people with LD 'stuck at home'. As many young people and adults with LD now live at home with their families as opposed to in supported living accommodation (Luftig & Muthert, 2005) this has a significant impact on the number and quality of opportunities for social interaction with peers that YP with LD will experience once they leave school. Additionally, YP with MLD have more developed social skills than YP with more significant LD, and therefore it is unsurprising that this was an area of competency that was important for the YP in this study.

A competency that was important for both the YP and the teachers and parents was safety. Within the LCCE-M model this is categorized as a life skill. However, within the current study this was an important area that had many elements and it could therefore be argued that this should be a competency in its own right. Keeping oneself safe is an important aspect of independence for YP as they move into adulthood. As YP learn to be less dependent on adults, they are likely to encounter more risk which is an important and natural part of human development (Mechling, 2008). Within the current study, YP and parents identified crossing the road, safety in the home and safety in the community as important aspects of keeping safe.

Crossing the road safely has been identified as an area of need for YP with MLD in a number of studies (Branham, Collins, Schuster & Kleinert, 1999; Collins et al., 1993; Matson, 1980a). Safety in the home for YP with MLD has been addressed in relation to fire safety (Matson, 1980b), first aid (Gast & Winterling, 1992), product labels (Collins & Stinson, 1994) and handling broken materials (Wintering, Gast, Wolery, & Farmer, 1992). In the current study, the YP, parents and teachers were concerned with safety in the home pertaining to using sharp tools and heat appliances, which has not been explored in the literature. This once again highlights the need to seek the views of YP themselves to understand what areas of safety they feel are important and consider how best to support them to develop these skills.

YP and their parents talked about their physical safety in the community, while only the parents talked about concerns with the YP getting swindled. The simple fact that this was not raised by the YP highlights the problem that the YP are unaware of this danger. It is well established that YP with LD are vulnerable and can be easily coerced due to difficulties with making appropriate judgments (Matson, 1984). Watson, Bain and Houghton (1992) taught children with MLD how to respond to the lures of strangers. This appears to be an important area that needs to continue to be addressed for YP with MLD and therefore there should be more research in this area.

One competency that was identified as important by the parents of the YP but not by the YP in this study was romantic relationships. Many studies have found that adults with LD value intimate relationships but there has been no research to explore the views of YP about this. The findings from this research found that this was not an important area for the YP. This could be in part due to the age of the YP in this study. The trajectory of social skills development for YP with MLD is slower than that of their 'normally-developing' peers and therefore the YP in this study may not yet been ready to pursue intimate relationships. Additionally, parents raised concerns about the vulnerability of the YP in intimate relationships, which could have influenced parents' lack of encouragement to develop romantic relationships.

Two areas of competency were identified as being important in the current study from the perspective of the parents and teachers but not the YP. These competencies were YP's state of mind and communication with others. Within the competency of YP's state of mind, parents identified three areas that were important to them for their YP: self-confidence, emotional regulation and intrinsic motivation. These align with some of the life skills within the acquiring self-identity competency. This echoes the findings of Kolb and Hanley-Maxwell (2003) who found that parents of adolescents with high incidence disabilities felt it was important for their YP to have more self-confidence and positive feelings about themselves.

In summary, the themes identified in the current research aligned well with areas of competencies that occur in established models used for curriculum development for students with MLD, such as the LCCE-M. This study showed that the views of YP and their parents reflect similar priorities as those identified by the designers of earlier models. Competencies such as money management, housework, travel, personal care, meal preparation and participating in the community remain areas that YP with MLD wish to be able to do independently to be successful in adulthood. Friendships featured heavily as an area of competency for the YP, with less emphasis on other social relationships such as intimate relationships. Learning about safety was identified as an important area of need with many specific skills associated with it, yet only occurs in the LCCE-model as one life skill, therefore it is proposed that safety should be identified as a competency. Finally, two areas of need identified by parents and teachers but not the YP were YP's state of mind and communication that aligned with the LCCE-M competencies acquiring self-identity and communicating with other respectively.

### 5.3 Research Question 2

What life skills are important for YP with MLD when they leave school from the perspective of the YP, their parents and teachers?

Within the competency of money management, the YP predominantly talked about the life skills of counting money and making purchases. Both the YP and their parents and teachers discussed how this was an area of difficulty for the YP. Dealing with money has been identified as challenge for YP with disabilities in the literature (Denny & Test, 1995). Lowe and Cuvo (1976) successfully taught students with MLD how to count coins in American currency. Other studies have focused on the use of pocket calculators to purchase items (Wheeler, Ford, Nietupski, Loomis & Brown, 1980). However, the use of pocket calculators now seems out-dated and with the advances in technology it may be more relevant to teach students how to use calculators on their phone to count money or pay by bank cards to make purchases. Use

of banks cards may be a more viable option for students with MLD who are struggling to count money. This presents other problems such as remembering their PIN and protecting the YP from fraud. In contrast, only the parents and teachers discussed the life skills of budgeting and banking skills. These skills were not important for the YP and it could be argued that they should therefore have a lesser emphasis in the curriculum.

The life skills within the travel competency were important for the YP and parents and teachers, and yet this skill had only been partially developed by the YP. YP felt they could access the community by walking, however parents stipulated that this was only to areas that were close to home or that the YP was familiar with. Using and accessing public transport was a skill that most YP, their parents and teachers felt they had not developed yet. The skills required to travel had a significant impact on many other areas of the YP lives and their ability to be fully independent. Many of the YP talked about how they could meet friends, participate in clubs, buy food and clothes and do exercise by themselves but needed to be driven to or taken to the venues by an adult. YP with MLD are often restricted to walking or being transported by others if they do not learn to use public transport, because many will not be able to drive themselves (Mechling & O'Brien, 2010).

Most of the studies that were conducted on teaching the use of public transport were done in the 1970's and 80's when YP with MLD lived in institutional settings. The importance of gaining the views of the YP in this study can therefore not be discounted, as it highlighted the modes of transport they wanted to use in their environment, which may be much different from those of institutional environments. There also appears to be a scarcity of research examining how to teach YP how to use different modes of transport. One study that looked at teaching YP to use the bus identified some difficulties with generalising this skill because the YP were not able to travel alone (Mechling & O'Brien, 2010). This may be one of the reasons that the YP in the current study had not developed these skills, as there was no mention of the YP traveling independently; they always travelled with an adult. Additionally, parents' worries about the YP's safety meant that parents

would also always travel with the YP which could be increasing the YP's dependence on adults in relation to using public transport, which can create a self-sustaining cycle.

Most of the YP, their parents and teachers reported that the YP could perform some of the life skills associated with housework and meal preparation. YP and parents asserted that the YP had more developed life skills in these areas than the parents did. This was especially the case with meal preparation where the YP said they could buy groceries, cook simple meals and clean the kitchen which they did at school and at the interim college, and this was reiterated by the teachers. Yet, parents often stated that the YP had not developed these skills. Studies have found that YP with MLD are able to generalize skills such as shopping for groceries, cooking and table cleaning (Graves et al., 2005; Morse, Schuster & Sandknop, 1996; Smith et al., 1999) learnt at school to home and other settings. So this begs the question, why were the YP in this study not performing these skills outside school? A possible explanation could be to do with the risks involved with performing these skills, that the YP and parents alluded to, such as getting swindled when shopping or physically harmed in the kitchen as discussed earlier. However, Smith et al. (1999) found that students with MLD were able to learn safety skills through observational learning, suggesting that the YP would be aware of and know how to avoid potential dangers. YP in this study were aware of dangers and appeared to be able to successfully negotiate them as shown by their ability to perform these life skills at school, therefore this does not seem like a valid reason for them not to be doing these tasks outside school. Rather, it may have been the parental expectations of the YP that hindered them from doing these life skills when they were with their parents. Parents would often do the life skills for the YP. This poses a serious risk of the YP not being able to maintain the skills learnt at school once they leave school because the parents do not give them the opportunities to perform the skills independently. This issue will be addressed and discussed further later.

Similarly, life skills involved with housework appeared to be an area that the YP said they could do but parents indicated that the YP could not perform all aspects of housework by themselves, especially doing laundry and cleaning the house. There was more reference of these skills being taught to the YP by the parents than at school. Miller and Test (1989) found that YP with MLD were able to learn and generalise laundry skills taught in school laundry rooms through instructional promoting. There is no research on teaching house cleaning skills to YP with MLD. Many of the parents referred to using instructional prompts to help their YP learn laundry and house cleaning, yet said these skills had not yet been mastered. One reason for this could be the YP's reliance on the parent to provide the prompts, thus preventing the YP from attempting the steps in the task independently (Miller & Test, 1989). It may be useful to include the teaching of laundry and house cleaning skills in a training environment at school to help the YP to develop independence in these skills. There is also a need for research examining how best to teach YP with MLD life skills related to cleaning in the house.

To summarise, counting money and making purchases were skills that were important for the YP. All aspects of travel were considered important because the ability to travel independently was associated with being able to do other skills independently. From parental reports, life skills related to housework and meal preparation appeared to be less developed outside school, and this could be attributed to YP's reliance on parents. There is a need for more emphasis on travel training and money skills in schools as well as supporting parents to let the YP do life skills outside school so that these skills leant in school can be generalised and maintained.

### 5.4 Research Question 3

What teaching methods support the development of these life skills for independence from the perspective of the YP, their parents and teachers?

The YP, parents and teachers all discussed the teaching methods that had been and could be effective in developing life skills for the YP. Community based instruction was important in teaching skills such as counting money, purchasing items, buying groceries, finding their way around the community and accessing and using public transport. Community based instruction has been acknowledged as the best way to teach life skills because it ensures the skills can be generalised to the students' natural settings (Davis and Redfelt, 2007). It was encouraging to see that this method was being used and the YP were being taken out into the community to develop these skills. However, parents and teachers reported that there was a need for more community based instruction, yet restrictions in time and opportunities limited this. This was consistent with findings from previous research (Dereka, 2004). Furthermore, as Government agendas continue to emphasis academic attainment as measures of CYP's progress and school evaluation, schools are more likely to direct resources towards academics in classroombased settings rather than the teaching of life skills through community based instruction. Therefore the aims and motivations of schools may often be at odds with what is most beneficial for the YP.

Some of the life skills within the meal preparation competency such as cooking, using appliances and hygiene in the kitchen were taught through training environment instruction. These were skills that the YP were able to do, and this is likely to be because they had opportunities to perform these skills in the natural environment at home. This supports studies that have shown that YP with MLD are able to maintain and generalise food preparation skills across settings (Hall et al., 1992; Schuster et al., 1988) The generalisability of these skills may be because the materials used to perform meal preparation skills will be similar in the training environment and the natural environment, and where there are some differences YP with MLD would be able recognise the function of similar materials (Lancioni & O'Reilly, 2002). However, despite the YP being able to do these skills, they were not often given opportunities to do them by themselves at home, as discussed earlier. Helping parents understand how best to teach life skills to their YP would presumably support the generalisation of these skills to the multiple

settings the YP will eventually need to use them in. Nevertheless, it is important to consider if the teaching of other life skills, such as doing laundry and cleaning the house, can be included in the curriculum through learning in training environments with materials that are as similar as possible those in the YP's natural environment.

Modelling, prompting repetition and practice were teaching methods used by teachers and parents that YP said helped them develop life skills. These teaching methods are referred to in the literature as instructional prompts, which need to be carried out in a graded approach and on a regular basis (Davis & Rehfeldt, 2007). Parents and teachers did not refer to using these methods in a graded approach but more on an ad-hoc basis. Parents and YP said that parents used instructional prompts to teach most of the life skills including those in the household competency, meal preparation competency, travel competency, personal care competency and crossing the road safely. Previous studies have demonstrated the successful use of instructional prompts to teach YP with MLD skills in table cleaning (Smith et al., 1999), food preparation (Hall et al., 1992), doing laundry (Miller & Test, 1989) and grocery shopping (Gaule, Nietupski, & Certo, 1985). All the studies that identified this as a successful teaching method used educational staff to provide the instructional prompts. There is no research to determine how parents use these prompts with their YP. Yet this study highlighted that this is the predominant way in which parents support their YP to learn life skills. It is not surprising that parents are teaching their YP to develop life skills outside school considering repeatedly reporting that they are worried about the future of their children. If the gold standard of educational practice relies on evidence based research and involving the CYP and their families in the development of practice, it is important that more research is conducted to identify ways in which parents are scaffolding the teaching of life skills to their YP.

In summary, community based instruction was considered a useful teaching method to teach skills required in the community. However, time and resource constraints often mean that this type of instruction does not happen as much as it should in schools. Training environment instruction was used to teach cooking and it may be worth examining if other domestic skills can be taught in this way in schools. Teachers and parents used instructional prompts on a regular basis to teach the YP a range of skills. It would be worthwhile to increase collaborative working between teachers and parents so that these skills can be taught in unison inside and outside school.

#### 5.5 Research Question 4

What are the facilitators and barriers to the teaching and learning of life skills for independence?

The findings of the research show that the development of life skills for independence for YP with MLD is complex and has many inter-related factors. How these factors interact can impact on the development of life skills for independence. For the YP with MLD in this study there were a number of factors that either served to facilitate or present barriers to the teaching and learning of life skills for independence.

#### 5.5.1 Parental attitudes to SEN

Parental attitudes to their YP's SEN were a factor that appeared to inhibit parents giving the YP opportunities to develop their life skills. Many parents seemed to feel that their YP's SEN inherently affected their ability to develop life skills. This led to parents doing tasks for the YP rather than letting them make an attempt. Additionally, parents often held the belief that the YP would never be able to do certain life skills independently and this was a result of aspects of their SEN (e.g. cognitive levels). This was highlighted in another study that found the parents of children with MLD had low expectations for their children and believed that they would lead restricted lives (Epps & Myers, 1989).

Another factor that prevented parents from providing opportunities for their YP to attempt tasks was the belief that the YPs were vulnerable and

therefore they did not let the YP face some types of risk. Lewis and Taymans (1992) found that YP with LD that lived at home with parents who worked were more independent because they had to assume more selfresponsibility, whereas when parents were at home they would be more overprotective of the YP. Although parental demographic data was not collected in this study, a few parents alluded to having jobs, but still discussed risk and time constraints as reasons for doing tasks for the YP. Interestingly, teachers did not hold this view and offered more opportunities that involved risk in school. YP themselves mentioned that they were allowed to attempt riskier tasks at school than at home such as cutting with a knife, using heat appliances, paying for groceries and travel. Taking risks is important in developing independence and therefore parents could be inadvertently increasing their YP's dependence and learned helplessness by not providing these opportunities. Furthermore, if parents do not believe their YP cannot perform certain life skills because of their SEN, these perceptions are likely to affect the YP's belief in themselves too. It is therefore important raise parents' expectations of their YP and educate them about how best to support their YP to develop life skills by allowing risk-taking.

#### 5.5.2 Parental Involvement

It has been well established that parental involvement in the education and transition process of CYP enhances the quality of education and preparation for adulthood for CYP (Foley et al., 2012). In this study parents stated that a positive aspect of their YP's educational experience was the communication between school and home. Parents were regularly informed about what the school was doing and felt they could contact the teachers. Open lines of communication between home and school have found to build effective relationships and identify areas of strengths and difficulties for CYP. However as already noted, parents are actively involved in teaching their YP life skills outside of school through the use of instructional prompts. Added to this, YP spend a considerable amount of time with their parents in the evenings and at weekends and with and through parents they are engaging with and accessing the community. If, as it appears in this study, some life skills are

developed through parental input, parents should be provided with a better understanding of the life skills curriculum and how they can best be taught (Cronin, 1996). Where parents have been taught life skills concepts and how to teach these to their YP, this has increased parents' awareness to life skills within daily tasks, increased the independence of YP and developed positive interactions between parent and YP (Cronin, 1996). There is therefore a need to include parents more actively when teaching life skills for YP with MLD when they are in school and as well as when they leave school.

#### 5.5.3 The YP's state of mind

The YP's state of mind in relation to developing self-confidence and understanding and managing emotions was discussed by parents and teachers as factors that inhibited the YP's ability to successfully participate in the community. YP lacked self-confidence which diminished their ability to go out in public and speak to members of the public. This had a direct impact on the YP's development of life skills such as managing their health, purchasing items and using public transport. Self-confidence or self-esteem and managing emotions are included in the theory of emotional intelligence (Goleman, 1995). Self-esteem falls within the dimension of self-awareness. Developing self-awareness begins by understating, controlling and expressing thoughts and feelings (Taylor & Larson, 1999) and therefore both the subthemes the parents discussed in this study are linked. Parents and teachers talked about how some YP were supported to regulate their emotions when in the community, yet they could not do this independently. Teaching YP how to manage their emotions in public through utilising a range of strategies is therefore an important part of the life skills curriculum, and may be beneficial for all YP as it may enhance their self-confidence. Kolb and Hanley-Maxwell (2003) found that parents of students with LD held similar views; that there was a need for adolescents with LD to learn strategies for self-control to support their interactions with others.

Parents in this study referred to motivation and interest in a task contributing to the YP's ability to perform or learn how to do a life skill by themselves.

Previous research has found that parents of YP with LD report that motivation plays a part in their YP's ability to successfully reach academic and personal goals (Kolb & Hanley-Maxwell, 2003). Therefore, it is unsurprising that motivation is a factor in the development of life skills for this population. Furthermore, researchers have found a direct links between the amount of effort an individual applies to a task and their ability to accomplish the task (Elder, 1996). This provides a strong argument for teachers to ensure that the YP are involved in deciding what life skills are important to them, so that they have the motivation to learn them.

#### 5.5.4 Societal perceptions of SEN

Parents addressed the issue of societal perceptions and judgments from society regarding the YP's SEN. They stated that this had a negative impact on the YP's feelings towards being involved in the community such as reducing their self-confidence to go and interact with members of the community. It also directly influenced the number of opportunities the YP had access to in the community. Despite recent legislative context moving towards the inclusion of people of SEN, it appears cultural attitudes of SEN have been slower to shift. Some people still seem to hold attitudes and assumptions about people with SEN that can then limit their full inclusion into the community. This can have repercussions that impact on the YP at many different levels. As parents highlighted, feeling judged because of the YP's SEN can prevent parents from taking the YP into the community and more importantly make the YP themselves reluctant to go out into the community. Success and independence in adulthood hinges on YP being active and valued members of the community therefore addressing societal perceptions of SEN are pivotal in helping YP with MLD feel fully included in society. Additionally, as has been stated previously, community based instruction is considered the best teaching method to for life skills and therefore increasing YP's exposure to the community should not be to the detriment of their sense of self. Parents should also feel comfortable and confident in helping their YP to learn skills in the community without feeling judged and excluded.

In summary, parental and societal perceptions of the YP's SEN can serve to hinder the YP's ability to develop life skills for independence because the YP can become reliant on the parent or lose self-esteem about interaction with members of the community. Motivation and self-confidence are powerful factors in supporting YP with MLD to learn life skills and therefore life skills should be relevant and important to the YP. YP should have more exposure to the community to encourage full inclusion into society. Parents should be involved in teaching life skills to their YP through developing stronger homeschool links and collaborative working.

To conclude, the findings from this research have been discussed in line with the research questions. The similarities and differences of competencies and life skills between existing models and the data from this research have been explored. Teaching methods were identified from the perspectives of the YP, their parents and teachers that were used to develop the life skills for the YP. Finally, the facilitators and barriers to the learning and teaching of life skills were addressed.

#### 5.6 Credibility, dependability and transferability of the research

Considering the needs of the population in the current study, there arose a number of threats to the credibility and dependability of the research. As the YP with MLD had a range of abilities, including their understanding and use language, it was important to ensure that the operational techniques suggested by Lincoln and Guba (1985) were carefully considered and implemented to ensure trustworthiness of the data. To highlight how this was done Table 10 shows the strategies that were employed in relation to each technique:

Table 10: Strategies employed to ensure trustworthiness

Strategies employed in the current research to ensure trustworthiness  • Case studies using multiple data sources- YP,
parent and teacher (where possible).
Alternative methods of collecting data-
interviews, conversations, role play, ranking
exercise, photos, puppets, drawing and
'roadmap'
Numerous and varied observations and
conversations in the post-16 provision and
interim college to familiarise myself with the
environments and understand the needs of the
YP.
Exploratory work to pilot research tools
Regular meetings with Research Supervisors
where decisions about each stage of the
research process were discussed.
Independent coding of sample YP and parent
transcripts by 3 skilled qualitative researchers,
followed by a comparison and discussion about
the codes.
Transcripts sent back to parents and teachers
to check accuracy and amendments made
where necessary.
Themes from each YP's conversation were
compiled into a symbol-supported script to
verify with each respective YP in face-to-face
meeting. Changes were made to YP transcripts
to reflect any clarification or change of their
views.

Audit trail	Clear explanations of research processes,
	decisions and activities evident in this thesis.
	Availability of raw data, process notes and
	research diary for review.

The findings from this research are not intended to be representative of all YP with MLD, but can contribute to our understanding of what life skills for independence are important to this population in a particular social context. Their perceptions and views can provide some insight into how transition planning can prepare YP with MLD and their families for 'independence' in adulthood.

The current research was undertaken in one school. The findings highlighted that for YP with MLD from this school and their families, the life skills for independence that were important to them were consistent with models of life skills that have been used to develop functional curricula for students with MLD. These findings are consistent with previous research in this area. However, this research highlighted the need for parents to have a better understanding of, and be more involved in, teaching life skills for independence to their YP. It also highlights the need for YP with MLD to have more community opportunities and integration to develop these life skills for independence. The findings from this study may be used to consider how to support other subsamples of children from the same school or other YP with MLD in similar contexts. This study can contribute to the current research knowledge about the types of issues that YP with MLD and their parents have in relation to life skills for independence and preparing for adulthood.

#### 5.7 Implications

From an EP professional perspective, this research highlights the need for EPs to support educational professionals in providing advice, services and information during the transition process that fit around the YP and their families (White & Rae, 2016). EPs can achieve this through their use of

evidence based practice, consultation skills and multi-agency working, thus improving service delivery for this population. EPs are well placed, in a range of schools and different contexts, to conduct research that explores life skills for independence for CYP with SEN in the UK. By adding to this body of research, EPs can then make evidence-based suggestions to educational professionals on how best to support CYP with SEN to develop life skills for independence that are relevant to them.

EPs can work with schools at a systemic, group and individual level. At a systemic level, educational psychologists may be able to work with senior management teams in schools to help them develop models of participatory practice that subsequently can be used to develop adapted functional life skills curricula that are modified for the needs of groups of YP with different types of SEN (White & Rae, 2016). EPs working with different schools in this way, in different parts of England, could lead to life skills curricula being functional and appropriate to the varying contexts the YP live in, and therefore provide the maximum value for the YP with SEN. EPs can also support schools to develop ways of working collaboratively with parents to teach life skills. This could be done by conducting training with parents about life skills training or facilitating joint working between teachers and parents by modelling work discussion groups.

At a group level, EPs can help educational staff to seek the views of different groups of CYP with SEN in meaningful, creative ways like the Mosaic Approach, using cameras, role-play and other tools that are appropriate for the needs of the CYP. Understanding what life skills are important, which life skills have not yet been learnt and how best the skills can be taught, can help to inform practice. Technology is fast becoming embedded into secondary curricula and there is a potential for simple technology systems to be used to support YP with MLD to manage their lives and be independent. However, in this study the YP did not seem to engage with technology much and therefore this might not be an appropriate or useful way to support them. Exploring issues such as these with other groups of SEN will enable

professionals to ensure teaching methods can be customised for their suitability.

Participatory tools can also be used by EPs at an individual level to seek the views of CYP with SEN and support schools to create tailor-made and individualized transition plans that focus on teaching relevant life skills for each YP. EPs can act as advocates for CYP with SEN and their families and help them feel valued and empowered (White & Rae, 2016). This could help YP build their self-esteem by knowing their views are important and create more opportunities for them be included in decisions made about their lives (Atkinson et al., 2015).

Finally, this study contributed to a body of research that supports the vision of the SEND Code of Practice by exploring an aspect of independence from the perspectives of YP with MLD and their parents. This research has identified competencies and life skills that are important for YP with MLD and ways in which educational professionals can develop these skills. To ensure that all YP with MLD and their families are getting the appropriate education and support to ensure a successful transition to adulthood in this the area, future government policy may need to explicitly highlight some of the educational provision that should be compulsory in the curricula for this population.

#### 5.8 Research limitations

A limitation of the current study was the low participation rate of teachers. Teachers mentioned heavy workloads and time constraints as reasons for not participating in the research. It is possible that the school and the teachers did not fully engage with the research because they did not commission the research and they may have felt that the research would not necessarily benefit them or contribute to their practice. Perceptions about me as the researcher, being a trainee Educational Psychologist may have meant that the school believed that the research was simply being conducted as a

course requirement and therefore lacked importance and value. Alternatively, the school and the teachers may have perceived the research as an examination of their current educational practice and methods and therefore been reluctant to fully engage with it. A higher level of teacher participation may have provided a richer and more detailed picture about the support that schools can provide to help YP with MLD to develop life skills for independence.

#### 5.9 Future research directions

The findings of this study have provided an insight into the life skills for independence that are important to YP with MLD and their families. There would be benefit in further research exploring this area. Replications of the current study in similar and different contexts would enhance practioners understanding about how local contexts impact on the type of life skills for independence that YP with MLD need when they leave school to prepare them for adulthood. Future research could also explore life skills for independence for other populations of SEN to determine if models and curricula of life skills are appropriate and suitable for them.

There is a need for more research with CYP with MLD, as this remains an area with the least amount of research interest, despite MLD being the largest group of SEN. Future research with this population will develop a deeper insight and understanding into how to support people with MLD throughout their schooling process and their transition into adulthood. Additionally, in line with the SEND Code of Practice statutory guidelines, future research should seek the views and perspectives of CYP with MLD and their families. Whether this serves to consolidate earlier research findings or highlight differences in the findings, it will add to the research knowledge base and inform practice. Incorporating CYP's views in research ensures that they are kept central to decision-making processes made about their lives and that they are able to contribute to changes in policy and practice.

Reflections from the current research recommend that when working with this and similar sample groups, researchers may benefit from taking consideration of some of the following methodological factors. It may be helpful to:

- conduct observations within settings for the researcher to familiarise themselves with the YP's environments and evaluate their language needs,
- pilot the research tools to ensure they are relevant to the study sample (i.e. motivating, not to childish, culturally and contextually appropriate),
- take time to build rapport with the YP to help them feel comfortable with the researcher and the research process. This could include having a member of staff they are familiar with present at the research meetings,
- ensure the environment, where the interviews are conducted, have minimal distraction to help the YP remain focused and engaged,
- provide clear explanations using simple language and visuals about the nature of their involvement and the structure of the interview,
- have an awareness of their engagement and mood during the interview, being flexible in your approach and provide follow-up opportunities to finish the interview if need be,
- provide multiple opportunities to YP to give their consent to participate and use methods that support their language needs to ensure that the YP are clear about the research, their participation and ways in which they can withdraw from the study. This may include providing information to their parent/carer to support them with these decisions,
- reduce and attempt to relieve any feelings of anxiety the YP may feel
  as a result of participating in the research. This could include
  informing them of when they will be seeing the researcher next or
  giving them copies of materials they have produced,
- when giving the YP cameras to use, provide clear explanations of how and when to use the cameras so as not to cause the YP risk or harm.

Exploring the views of CYP, parents and teachers provides different perspectives on a topic, and therefore future research should aim to include these groups. Further research using qualitative methods could seek the views of CYP, parents and teachers to explore other areas of independence such as choice and self-determination, to provide a broader understanding of how these factors impact on CYP with MLD's transition into adulthood. Furthermore, to develop more collaborative working between school staff, families and EPs, research exploring the perspectives and experiences of EPs working with CYP with MLD during the transition to adulthood will be useful. These studies should aim to identify collaborative ways of working that will help EPs support schools in seeking the views of YP with MLD, include parents in the transition process and develop individualised transition plans for the YP.

Finally, there is a need for more longitudinal studies in understanding what life skills for independence are important for YP and adults with MLD and their families at later stages of their lives. These studies will provide an insight into whether YP and adults with MLD value and require different life skills for independence as they get older and help educational practitioners to support them to develop these skills before they leave school.

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### 7 Appendices

#### 7.1 Appendix 1: Ethical Considerations

#### Informed consent

The Mental Capacity Act (2005) states that people over the age of 16 must be assumed to be able to have the capacity to make their own decisions unless they have a specific impairment that causes them to be unable to make specific decisions. In this research, it was important to consult with the parents of the YP to get their consent for the YP's participation as well as getting consent from the YP themselves. Parents were given detailed written information about the nature of the research, and the extent of the YP's participation was outlined to ensure that they understood the aims and purpose and what the young person would be required to do. Information was included about the YP's use of cameras. This was to ensure they were able to provide fully informed consent for themselves and the young person.

To support the YP's understanding about the decisions they made about participation, a few strategies were employed. Firstly, the information about the research was presented through the use of symbols and simplified text. A simplified information sheet (with symbols) was sent out with the parents' information letter, for the parents to discuss with the young people. Secondly, repetition can support understanding for YP with MLD so the researcher went through the information sheet again with the YP on two separate occasions before the conversation. The researcher read the text aloud to the YP while pointing to the corresponding symbols. Consent was sought from the YP by asking the YP to point to a pictorial representation of "Yes" or "No". Finally, the YP were provided with a "Stop" and "Help" sign while going through the consent form to give them the opportunity to ask any further questions or choose not to continue. School staff participants were also given detailed written information about the research and again, written informed consent, was sought (Flick, 2009).

#### Confidentiality and Anonymity

To ensure anonymity, participants were assigned a pseudonym, and all data and audio-recorded data from interviews, was stored under this. During the write up of the Thesis, identifying information such as family name and details was changed (Cohen, Manion & Morrison, 2007). Photographs used in the research had faces obscured. Participant information was kept securely for family contact and correspondence only and at the end of the research, any identifying information will be destroyed. All information collected from the YP, parents and school staff was strictly confidential and returned in a sealed envelope. Only the researcher and research supervisors had access to the data.

Research indicates that children and young people with learning disabilities are more vulnerable to abuse (Morris, 1998). Confidentiality was not permitted to be maintained if the researcher suspected or had self- disclosed

information from the YP, of abuse, threats to health, etc. (see below). This was made clear to the YP by use of accessible language and checking their understanding.

## <u>Safeguarding and Ensuring Participants are Free from Psychological Harm or Distress</u>

It was hoped that the participants would not experience any undue anxiety, discomfort or embarrassment as a direct result of the study, however due to the nature of the research, participants may experience emotional reactions. Considerations were taken regarding factors that may elicit an emotional response from participants and what to do if this should occur.

Parents may find reflecting on and talking about their YP's life potentially distressing or they may worry about the future holds for their YP. The researcher would be sensitive to this by acknowledging this emotion, being empathetic to them and allowing them the time and space to reflect (Legard et al., 2003). The researcher also reminded them they could choose not to answer any questions. The same was done for the teachers. The researcher informed the YP of relevant staff in their educational provision that were aware of their participation and who they could contact and speak to if it was felt they had experienced any anxiety, discomfort or embarrassment. The researcher would inform the relevant staff if this occurred and follow up with the staff to check that the YP has discussed this with them and/or these feelings have been relieved.

Furthermore, the participation of vulnerable YP has been carefully considered, as part of the safeguarding procedures. It is possible that participants may disclose information concerning their involvement in activities that represent a threat to themselves or others (e.g., child abuse, domestic violence, substance abuse). If this occurs, then the appropriate agencies and persons will be informed, in accordance with the Children's Act, 1989.

#### Right to Withdraw

All participants were informed that they are under no obligation to take part in the research and that if they wished to withdraw at any point in the study they were free to do so without explanation and with no adverse consequences.

It was made clear to the young people that they could withdraw from the study by using a red "Stop" sign in the conversation or by telling a member of school staff or their parent to inform the researcher of their wish to withdraw. A blue 'Stop' sign was provided during the conversations with YP for them to ask for a break. This was explained to them through the use of simple language and symbols to support their understanding.

Participants were informed that if they chose to withdraw from the research, any audio recordings, interview transcripts and photos of participants from interviews would be destroyed straight away.

#### 7.2 Appendix 2: Parent information letter and consent form



#### Dear Parents,

My name is Sneha Shah. I am a doctoral student at the UCL Institute of Education, training to be an Educational Psychologist. As part of my studies I am researching about young people with learning difficulties and their views on the skills required for 'independence for living' in adulthood. I am also looking at how parents can support these skills and what help they may need to help their son or daughter.

I would greatly value the participation of you and your son/daughter in this research. For your son/daughter, it would involve participating in an interactive conversation. During this conversation of between 20-40 minutes, your son/daughter would be asked questions about the things they feel are important for them to do by themselves.

Your son/daughter will also be given the option to take pictures of the things that are important to them, using a disposable camera (which I will provide). I will be giving your son/daughter clear guidance on what to photograph and when. They will be able to choose to use the photographs in the conversation I will have with them, if they wish. They will also do some sorting activities, drawings and acting out different points of view. Your son/daughter will be able to choose how they communicate (by talking, drawing, photographs etc). If they use the camera, they will receive a copy of the photographs at the end of the conversation. If the pictures they make are used in the study faces, including their own will be obscured.

Your views are also very important. It will help if I can identify what help and support a young person might need and what can be done to support you as you support your son/daughter. A conversation with you of about 40 minutes would allow me to do this. The time would be arranged to suit you and the conversation would take place at X School in July 2015, during the school day between 9:00am and 5:00pm.

In this conversation with you, I plan to ask you some questions about what you feel are important living skills that would enable your son/daughter to become more independent when they leave school. I would also like to ask you about how you feel schools could help your son/daughter to develop these skills and what strategies you feel would help you, as parents, to support these living skills for independence, at home.

If you take part in the project, I will need to get your permission to tape-record the conversation (to make sure I don't miss anything important!). You can refuse to answer *any question with out having to give a reason*. When the tape recording is

turned into writing your name will be removed. It will be anonymised to protect your confidentiality and kept securely. You will also *be able to withdraw from the research at any point without giving a reason*. Any materials, including photographs, will be destroyed. All of these points will **also** *apply to your son's/daughter's conversation notes and records*.

An anonymised summary of the results of the research will be shared with X School to help them develop their support for children at the school including your son/daughter. You will also receive a summary of the research to keep you informed about what the study found out.

Taking part in this research is important if we are to better support children's independence skills. I hope you will agree for you and your son/daughter to join the project!

Thank you. Yours Sincerely,

Sneha Shah

Sneha Shah Trainee Educational Psychologist UCL Institute of Education X Borough Council Dr. Karl Wall (Research supervisor)
UCL Institute of Education

Email: xxxxx@ioe.ac.uk Email: xxxxxl@ioe.ac.uk Telephone: 07xxxxxxx Telephone: 020 xxxxxxx

If you would be willing to take part in this study please complete the consent form, put it in the envelope provided, seal it and return it to the school/college. Alternatively you can email a scanned copy to me at <a href="mailto:xxxxxx@ioe.ac.uk">xxxxxx@ioe.ac.uk</a>. Please include dates and times that would be convenient for you to have the conversation.



# PARENT CONSENT FORM RESEARCHER COPY – Please return this copy to the school/college

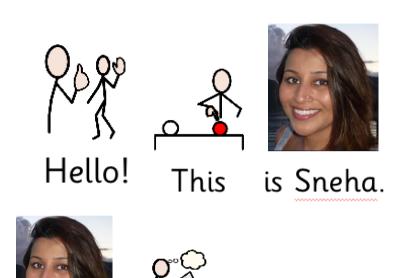
I have read the information sheet about the research.	☐ (please tick)
I would like my son/daughter to take part in the study.	☐ (please tick)
I understand that participation is voluntary and that I can withdraw my participation at any point.	☐ (please tick)
I understand that I can contact Sneha Shah (xxxxxx@ioe.ac.uk/ 07xxxxxxxxx) to discuss this study at any time.	☐ (please tick)
I give consent for my son/daughter to take photographs. during this study.	☐ (please tick)
Name of son/daughter: Date of birth:	
Contact email:	
Contact phone number:	
Possible Dates and Times:	
Name of parent (please print):	
Signature: Date:	<del>-</del>
Researcher's signature: Date:	



## PARENT CONSENT FORM PARENT COPY – Please retain this copy for your records

I have read the information sheet about the research.	☐ (please tick)
I would like my son/daughter to take part in the study.	☐ (please tick)
I understand that participation is voluntary and that I can withdraw my participation at any point.	☐ (please tick)
I understand that I can contact Sneha Shah (xxxxx@ioe.ac.uk/ 07xxxxxxxxxx) to discuss this study at any time.	☐ (please tick)
I give consent for my son/daughter to take photographs. during this study.	☐ (please tick)
Name of son/daughter: Date of birth: _	
Contact email:	
Contact phone number:	
Possible Dates and Times:	
Name of parent (please print):	
Signature: Date:	
Researcher's signature: Date:	_

#### 7.3 Appendix 3: YP information letter and consent form





Sneha studies at the Institute of Education.





She has a question.











What do young people want to do by themselves when they



grow up?





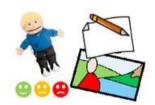






To help her with this question, she

wants to do some





activities with you.









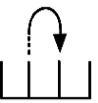


Sneha will come and meet you at school/college.











If you do not want to do the activities then it is ok.











Do you want to do some activities with Sneha about what







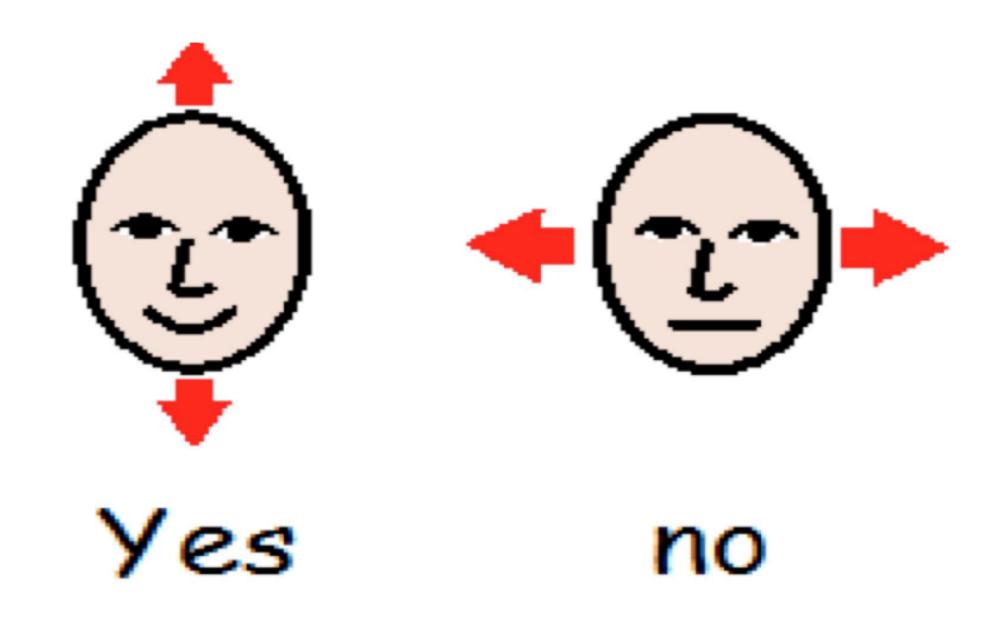




you would like to do by yourself when you



grow up?



#### 7.4 Appendix 4: Teacher information letter and consent form



Dear Mr/Mrs/Ms	
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My name is Sneha Shah. I am a doctoral student at the UCL Institute of Education, training to be an Educational Psychologist. As part of my studies I am researching about young people with learning difficulties and their views on the skills required for 'independence for living' in adulthood. I am also looking at how teachers/family workers can support these skills and what help they may need to support these young people.

Your views are very important. It will help if I can identify what help and support a young person might need and what you feel are important aspects for them to develop these skills. A conversation of about 40 minutes would allow me to do this. The time would be arranged to suit you and the conversation would take place at X School in July 2015, during the school day between 9:00am and 5:00pm.

In this conversation with you, I plan to ask you some questions about what you feel are important living skills that would enable the young person you work with to become more independent when they leave school. I would also like to ask you about how you feel schools could help parents to develop these skills and what strategies you feel would help them support young people with these living skills for independence, at home.

The YP may take photographs of you as a means to gain their views. If the photographs are used in the study, faces will be obscured.

If you take part in the project, I will need to get your permission to tape-record the conversation (to make sure I don't miss anything important!). You can refuse to answer *any question with out having to give a reason*. When the tape recording is turned into writing your name will be removed. It will be anonymised to protect your confidentiality and kept securely. You will also *be able to withdraw from the research at any point without giving a reason*. Any materials, including photographs, will be destroyed.

An anonymised summary of the results of the research will be shared with X School to help them develop their support for children at the school including the young person you work with. You will also receive a summary of the research to keep you informed about what the study found out.

Your taking part in this research is important if we are to be able to better support children's independence skills. I hope you will agree to join the project!

Thank you.

Yours Sincerely,

Sneha Shah

Sneha Shah Trainee Educational Psychologist UCL Institute of Education X Borough Council Dr. Karl Wall (research supervisor)
UCL Institute of Education

Email: xxxxxx@ioe.ac.uk
Telephone: 07xxxxxxxxx

Telephone: 020 xxxxxxx

If you would be willing to take part in this study please complete the consent form, put it in the envelope provided, seal it and return it to the school/college. Alternatively you can email a scanned copy to me at xxxxx@ioe.ac.uk. Please include dates and times that would be convenient for you to have the conversation.



# TEACHER CONSENT FORM RESEARCHER COPY – Please return this copy to the school/college

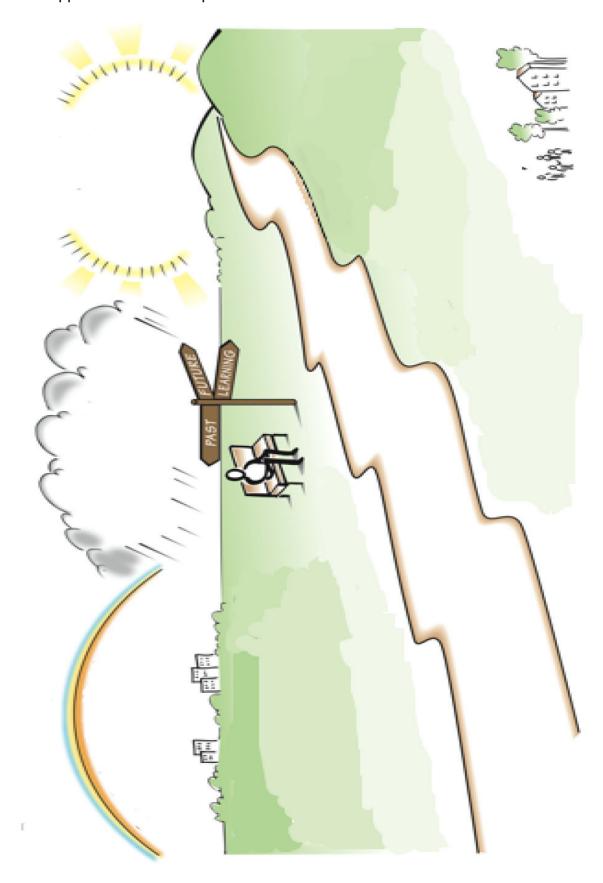
I have read the information sheet about the res	earch.	(please tick)
I would like to take part in the study.		(please tick)
I understand that participation is voluntary and can withdraw my participation at any point.	_	(please tick)
I understand that I can contact Sneha Shah (xxxxxx@ioe.ac.uk/ 07xxxxxxxx) to discuss this study at any time.		(please tick)
Name of young person you work with:		
Your contact email:		
Your contact phone number:		
Possible Dates and Times:		
Your Name (please print):		
Signature:	Date:	
Researcher's signature:	Date:	



# TEACHER CONSENT FORM TEACHER COPY – Please retain this copy for your records

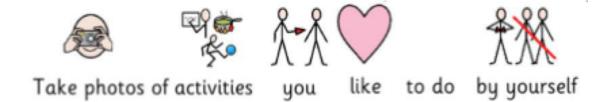
I have read the information sheet about the rese	earch.	(please tick)
I would like to take part in the study.		(please tick)
I understand that participation is voluntary and can withdraw my participation at any point.	_	l (please tick)
I understand that I can contact Sneha Shah (xxxxxx@ioe.ac.uk/07xxxxxxxx) to discuss this study at any time.		l (please tick)
Name of young person you work with:		
Your contact email:		
Your contact phone number:		
Possible Dates and Times:		
Your Name (please print):		
Signature:	Date:	
Researcher's signature:	Date:	

# 7.5 Appendix 5: Road Map Illustration



### 7.6 Appendix 6: Camera instructions for YP





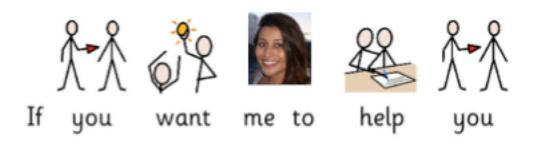


Take photos at home and in public.

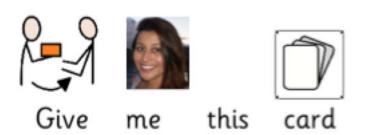


### 7.7 Appendix 7: Instructions and visual cards for YP Conversation











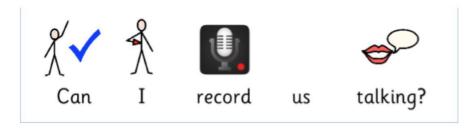
I don't want to take part anymore



I want a break



I need help please.





### 7.8 Appendix 8: Interview Schedules

### Parent Interview Schedule

- 1) In your view, what does independence mean for your son/daughter?
- 2) How did you come to this view?
- 3) What (functional) life skills for independence does your son/daughter have at the moment? What is s/he able to do by themselves? *Prompts: In the home, outside the home, in public, in college, outside college.*
- 4) What (functional) life skills for independence would you like your son/daughter to develop in the future? What things would you like for him/her to be able to do by herself? Prompts: In the home, outside the home, in public, in college, outside college.
- 5) What life skills do you think your son/daughter would like for him/herself? What do you think is important for you son/daughter to be able to do by themselves in the future. What life skills are important for your son/daughter to learn?

  Prompts: In the home, outside the home, in public, in college, outside college.
- 6) What did the school do to support him/her to develop those life skills? How did the teaching help him/her to develop those life skills? What aspects/elements/parts of the curriculum supported him/her to develop these skills?
- 7) What else could the school have done to develop you son/daughter's life skills for independence? What more do you think could have been done to help him/her develop those life skills to become more independence? What else do you think would have helped him/her in terms of like the curriculum and how they supported him/her?
- 8) Was the training provided by the school useful? What other training would you have valued?

Prompts: What does that mean? What do you mean by \_\_\_\_\_? What would does that look like? What does/would that entail? Can you tell me a little bit more about that? Could you elaborate a bit more on that? How do you help her? How do you support her? Can s/he do that independently, by themselves? Does she need supervision? Who does s/he go with? How do they get there? What else? What about other aspects of travel/hygiene/self-care/things around the home/using money?

## YP Conversation Questions/Prompts

1.	What things/activities can you do by yourself? ➤ At home, outside home, in public, outside college.	
2.	<ul> <li>What things/activities would you like to do by yourself when you are older?</li> <li>At home, outside home, in public, outside college</li> </ul>	
3.	Who can help you?	
4.	How can they help you?	
5.	How did X School help you to learn to?	
6.	How did they teach you?	
7	How did you learn to ?	

### 7.9 Appendix 9: Example of Ranking Exercise response



### 7.10 Appendix 10: YP Member-checking



## 7.11 Appendix 11: Example of coded transcripts

### Example of coded parent transcript

Interview Transcript	Initial codes
P7: In the house she pretty much does all of her own, she doesn't do her own laundry but she puts it in the laundry basket and she'll tell me, "oh I haven't got any socks left or whatever" but she doesn't actually, she has done it, she has put stuff in the washing	Doing laundry
machine and, but she doesn't do things like ironing. We always make sure at the weekend that she does things like setting the table for breakfast, doing the washing up she does all that, she is very good at tidying up, she tidies up after her dad which saves me the hassle.  Cooking she did a lot of cooking when she was at college so but on a daily basis at home	Parent giving YP opportunities to do task Setting the table Washing and drying dishes Tidying up the house
she'll make we make cakes every so often but she doesn't sort of do the cooking. She gets her own breakfast in the morning and she gets her own, she has a salad every evening before her meal, so she does that.  I: And she'll prepare that herself? [P7: Yeah.] Okay, what else is she able to do by herself in terms of the functional life skills for independence?	Making simple meals
P7: Well just obviously things like getting dressed and you know, cleaning her teeth all sort of personal hygiene things. Listens to music, goes on the computer she got an iPad	Getting dressed and undressed Personal hygiene Leisure activities-media
she does all that sort of independently. I don't, she's more technically able than I am to be honest. So yeah that's about it really in the house. I mean she doesn't have a great deal of friends so that's obviously an issue and has been for a while so.	Only few friends

## Example of coded YP transcript

Interview Transcript	Initial codes
YP10: I put all the different clothes on the floor and then I sort it out. And then I put it in the washing machine. And then I switch it on. And then I wait for it to finish and then I put it on the hanger. And then that's it.	Doing laundry
I: Oh, well done! Fantastic! What else can you do by yourself?	
YP10: I can tidy up. I just tidy up some of the house and then I'll like washed it off and I just tidy up around the house, and that's it.	Tidying up the house
I: Good. That's really good! So we've got washing up, doing the laundry, tidy up; what else do you do by yourself, even things outside the house.	
YP10: That's it.	
I: That's it, yeah. Is there something, things that you needed a bit of help with? What kind of things did you need a bit of help with?	
YP10: I don't know.	
I: You don't know, okay is there things that you can't do by yourself yet?	
YP10: I can do a lot of things by myself.	
I: Okay what else can you do by yourself then, we've got three things but there are other things that you can do by yourself?	
YP10: Hoovering	Vacuum cleaning

#### 7.12 Appendix 12: Case Summaries

#### Case 4- Noel

Noel's case study was made up of an interview with his mother and a conversation with Noel. Noel was 20 years old at the time of the conversation. Noel had left the school when he was 19 years old and was in his second year at Hopkins College. Noel had good conversation skills and was eager to take part in the research and share his views.

Noel had aspirations to get a job in catering. He could make simple meals by himself although he said he was supervised and more cautious when using kitchen appliances at home than at school. He wanted to try cooking more at home. He could do many skills around the house by himself such as cleaning his room, making his bed, cleaning the bathrooms, washing the dishes and taking the rubbish out to be recycled.

Noel was very friendly and enjoyed interacting with people. He had a regular volunteer job at the local supermarket where he would help customers pack their shopping and occasionally take money at the till. His mother said that customers would often come into the supermarket specifically to meet Noel. Noel attended a few clubs and enjoyed meeting and socializing with his peers from the college at the clubs. His other social activities included going out with his brother and his support worker to the gym or the cinema.

Noel was quite adept at using different forms of technology such as the "huddle" to watch TV or DVDs, the computer to search the internet and listen to music and mobile phones and landlines. He said he could use the telephone to make and answer calls.

Noel wanted to be able to travel independently and knew how to use his travel card but was worried about getting lost or being mistreated by strangers. He could make familiar journeys on public buses to go to college by himself and said he had learnt how to do this by doing it many times. He wanted to do more training to become an independent traveller. His mother said that he knew how to cross the road safely but would often get distracted which would put him at risk.

Using money was an area of difficulty for Noel and he said that he could not yet count money. He would go to the shopping with his mother. He enjoyed shopping for clothes but said he needed help from his mother to help him choose the right sizes. He also needed some help in choosing appropriate clothing to wear on a day-to day basis, which his mother reiterated.

#### Case 5- Reena

Reena's case study was developed through an interview with her mother and a conversation with Reena. Reena left the school when she was 20 year old

and was currently in her third year at the Hopkins College. She was 21 years old at the time of the conversation.

Reena was a friendly girl who enjoyed meeting her friends and had begun to develop an interest in having romantic relationships. Her mother was concerned that she was quiet naïve and did not yet have a good understanding of sexuality and therefore could be mistreated by members of the opposite sex. Similarly, Reena shared her concerns about being travelling alone to meet her friends outside college because she was worried about danger from strangers. She wanted to learn how to travel independently by having more travel training.

Reena enjoyed going grocery shopping with her mother. She said she could get the shopping trolley, select food and put it on the counter but needed help to pay for items. She explained that she had difficulty with counting money and getting back the correct change. Her mother and uncle would help her to pay for things.

She enjoyed cooking and could make pasta and fish at college. She helped her mother cook at home. She was scared of getting cut with the knife and getting burnt so needed help to boil the kettle and put oil in the pan because it was hot and "spitting". She wanted to learn how to cook by herself. Her fear of getting cut meant that her mother helped her with aspects of hygiene such as shaving and cutting her nails.

Reena said she could do housework such as washing and drying clothes and plates and clean the house, although she needed help to sort the clothes when doing laundry. Her mother mentioned that Reena was very neat and would clean and tidy her room by herself.

#### Case 6- Rita

Rita's case study included the following data sources: an interview with her mother and conversation with Rita. Rita was in her third year at Hopkins College. She had left the school when she was 18 years old and was 21 years old at the tie of the conversation.

Rita was quite independent in the house. She said she could wash, dry and put away the dishes, set the table, feed the pets and take out the rubbish for recycling. She could also make simple meals and hot drinks and would help her mother with the cooking. This was confirmed by her mother who said she had leant these skills because was encouraged to do them by herself at home as well as being taught how to cook in school. Rita said she enjoyed baking cakes and muffins.

Additionally, Rita could go shopping for clothes and groceries by herself. She said she would walk down to the high street to shop for clothes. Rita's mother mentioned that Rita would walk down to the local shops and get her hair and nails done by herself. Her mother also said that Rita was able to shop for groceries independently including knowing which brands to buy.

Rita enjoyed socializing with her friends. She participated in a few clubs where she would meet peers from college as well as come of her other friends. She said she went bowling and out to eat at KFC and McDonalds with her friends. Her parents would give her the money and drop her off at the location. Her mother reiterated this but said she would like Rita to be able to organize social activities by herself. Rita also regularly went to the gym by herself or played football and basketball in the park with her dad.

Rita said she could use her travel pass and would travel on public buses and tubes with her friends. She mentioned that she sometimes needed help from her parents when travelling into London. She would need her parents to drive her to some locations such as the gym and the clubs. She would also walk to the doctors with her mother whose help she needed to make appointments and converse with the doctor.

#### Case 7- Adam

Adam's case study was made up of an interview with his mother and father and a conversation with Adam. He was 22 years old at the time of the conversation. Adam left the school when he was 19 years old and had just completed his second year at Hopkins College. Adam was shy and had difficulties with his expressive language skills. He chose to express his views through his photographs and the ranking exercise.

Adam said he could wash dishes, clean worktops, tidy his room and do grocery and clothes shopping by himself. His parents mentioned that he would often perform these tasks when he "could be bothered." They also talked about Adam's lack of confidence in public which hindered his ability to pay for his shopping by himself.

Adam said he enjoyed going to the seaside with his parents and hoped to get a job as a supervisor. His parents also hoped that in the future Adam would get a job, have a group of friends and have a wife. Adam's mother mentioned that he didn't like interacting with people and didn't have many opportunities for socialising with his peers outside school and college because the few friends he had lived far away. Adam would go to the arcade by himself or watch DVDs at home.

Adam expressed that he needed help with using money and cooking. He wanted to learn how to cook by himself. He said he could learn these skills by being shown how to do them by his parents and teachers. His parents had taught Adam how to shower and make his own lunch by modelling these skills many times. His parents also mentioned that he had learnt how to use his travel pass on the tube by being taken on the tube regularly while he was at school. They would have like more community based experiences to help Adam develop his interaction and travel skills.

#### Case 8- Mike

Mike's case study comprised of an interview with his sister who was his legal guardian and a conversation with Mike. Mike was born in Africa where his parents still resided. Mike left the school when he was 19 years old. He was 22 years old at the time of the conversation. Mike was a friendly and mature young man. His speech clarity was poor but repeated phrases to make himself understood during the conversation.

Mike was able to do many things around the house by himself including cooking simple meals such as noodles, using kitchen appliances, doing the laundry, washing the dishes and cleaning the house. However, due to health reasons, he would not often clean around the house because he got tired easily. His guardian said that Mike could not yet do his own laundry because he did not know how to operate the washing machine. Mike said he had learnt his cooking and cleaning skills in the kitchens at school and at college and this had helped him to do these skills independently.

Learning how to travel independently, including learning how to drive was important for Mike. He was able to walk down to his local high street by himself and use public buses to make familiar journeys. He would travel on the bus to visit family that lived nearby. Mike knew how to get to the train stations and use his travel pass but said that he needed help from his family to travel by train and tube because he found it difficult to read maps and alight from trains.

Mike enjoyed visiting and socializing with his cousins. He would travel by car with his cousins, who would drive him, and they would go to shopping malls or restaurants together. Mike had a good understanding of locations and where his family members lived. He said that he needed to travel with an adult at night because travelling during this time would be dangerous.

Mike had regular hospital appointments. He would go to the local hospital by himself. For hospital appointments in London, he would need to go with his guardian who would arrange the appointments and support him when speaking to the doctor. His guardian mentioned that Mike needed help expressing himself because of his poor speech clarity and his difficulties in understanding.