# The Educational Experiences and Outcomes of Young People who Stammer

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# ABSTRACT

Previous research has indicated that stammering negatively impacts the educational outcomes of people who stammer (PWS). However, data examining the educational achievement of young people who stammer (YPWS) compared to peers in the current UK education system is limited. Further, whilst studies provide some insight into the school experiences of PWS their findings are based on the retrospective views of older adults.

This thesis therefore aimed to explore the educational achievement of YPWS and their lived experiences of stammering in secondary school and continuing education (i.e. at college/university). Mixed methods were used in two consecutive studies. The first study investigated their educational achievement and the second focused on listening to the voices of YPWS to understand their experiences of living with their stammer in education.

Thirty-five young people aged 15-25 years who self-reported stammering and who were current or recent students in UK education were recruited via a range of sources. In the first study a survey investigated their history of stammering, educational choices and school results. Their educational achievement was compared with government statistics reporting pupils' educational achievement in England. To provide a deeper understanding of their lived experiences the second study used interpretative phenomenological analysis to explore data from individual semi-structured interviews with a sub-sample (n=16) of YPWS.

The academic achievement of the YPWS was comparable to pupils in England but their educational choices and activity were negatively impacted by their stammer. Three super-ordinate themes emerged from the interviews: 'Living with being a YPWS in education: the struggle', 'Being a YPWS in education: the impact', and 'Learning to cope: the journey'. This research reveals the valuable insights that YPWS provide and the importance of listening to

their perspectives. The implications of the findings for YPWS and the professionals who work with them in health and education are discussed.

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# CHAPTER 1. INTRODUCTION TO YOUNG PEOPLE WHO STAMMER AND THE CURRENT INVESTIGATION

## 1.1 Overview

This chapter introduces the phenomenon of stammering, providing key definitions and details about types of stammering. It describes the characteristics and prevalence of stammering and relates these demographics to young people who stammer (YPWS), then describes possible treatment approaches for YPWS. The second part of the chapter outlines the potential impact stammering can have on the activity and participation of people who stammer (PWS) and the current educational context for YPWS in secondary school and continuing education (i.e. college/university) which has led to the research initiative for the current investigation. Finally, the structure for the remainder of thesis is outlined.

## 1.2 What is stammering?

**1.2.1 Definitions of stammering.** Stammering, also referred to as stuttering, affects the fluency of speech and is "characterised by a high frequency or severity of disruptions that impede the forward flow of speech" (Guitar, 2014, p.19). Similarly, Bloodstein (1993) suggested "stuttering is a communication disorder in which the forward flow of an individual's speech may be characterised by the occurrence of disruptions or disfluencies" (p.1). These definitions describe the speech behaviours noticed by listeners, but Ward (2006) argued these conventional definitions do not encompass all aspects of stammering. He suggested stammering consists of two main threads: the observable features of the disrupted speech output and the individual's reactions and experiences relating to those disruptions.

**1.2.2 Types of stammering.** Developmental stammering typically occurs in young children between the ages of 2-5 years with an average age of onset of 33 months (Bloodstein & Ratner, 2008). It coincides with a time when young children are developing their speech and language skills (Yairi & Ambrose, 2005) and is thought to have a genetic origin (Guitar, 2014). This early onset stammering can be transient, when the child spontaneously recovers within 18 months with no or limited intervention, or persistent, whereby the child continues to stammer (Guitar, 2014). Although adolescents and young adults who continue to stammer will have their own individual trajectory, their stammer is typically more established and less likely to change without intervention (Guitar, 2014).

Researchers have suggested a number of risk factors which contribute to whether a child persists in stammering (Yairi & Ambrose, 2013). Kelman and Nicholas (2008) developed a multifactorial model, based on evidence from the literature, which identified predisposing factors which appear to be significant to the onset and development of stammering, as well as factors that contribute to severity and persistence of stammering. Predisposing factors include the child's physiological make-up (e.g., genetic influences and speech and language skills such as delayed development), while factors that contribute to the severity and persistence of stammering include psychological factors (e.g., the child's temperament) and environmental demands, involving the child's communicative interactions with others. They proposed that "for each child there will be an individual combination of factors that contribute to his vulnerability to stammering and the likely prognosis" (Kelman & Nicholas, 2008, p.5).

Acquired stammering usually has a late onset, and may be neurogenic (typically diagnosed in adults following a neurological event or trauma such as a stroke or brain injury) or psychogenic (diagnosed in late adolescence and adulthood following a stressful incident or a lengthy period of stress experienced by an individual). Although acquired stammering is most generally associated with adults it can manifest in children and young people following a neurogenic or psychogenic episode, but this is less common (Bloodstein & Ratner, 2008; Guitar, 2014).

**1.2.3 Characteristics.** Van Riper (1982) used the term 'core behaviours' to describe the basic speech features of stammering, which include repetitions, prolongations and blocks. Guitar (2014) suggested that repetitions are the most common core behaviour among children beginning to stammer and these consist of either an individual speech sound, syllable or whole word that is repeated a number of times before the speaker is able to move onto the next sound. Prolongations are described as "the unnatural stretching of a sound" (Ward, 2006, p.5). The speaker continues to make the sound, but the movement of his articulators ceases. Van Riper (1982) suggested prolongations appear later than repetitions, but Yairi (1997) reported that prolongations as well as repetitions may be heard from the outset. Guitar (2014) described blocks occurring when the flow of air or voice is stopped unexpectedly by the speaker with the articulators often remaining in a fixed position, so nothing is uttered. Guitar (2014) suggested that blocks are usually the last core behaviour to emerge, but Yairi (1997) reported that blocks may appear in children's speech close to onset of stammering. These overt core behaviours are referred to as primary stammering (Guitar, 2014; Ward, 2006).

Guitar (2014) also described secondary stammering features which consist of learned behaviours which become associated with the primary stammering. These secondary

behaviours appear to develop in an attempt to manage the primary stammering and consist of “escape behaviours and avoidance behaviours” (Guitar, 2014, p.9). People who stutter (PWS) may use escape behaviours (e.g., body, head and hand movements; tongue thrusting; eye blinking; stamping of foot; losing eye contact; and using interjections such as err and um) during a stammered word to try and help them to finish the word.

Sheehan (1975) proposed an analogy between stammering and an iceberg which can be used to help PWS identify the nature of their stammer. It recognised the overt features of stammering, observable to others, which appear above the waterline (e.g., prolongation of speech sounds). However, it also highlighted the covert features, hidden and invisible to others, such as the feelings of embarrassment and anxiety which are massed below the waterline. Many PWS have described these uncomfortable feelings as well as the negative self-belief they develop in response to their adverse experiences of stammering (Blood, Blood, Tellis & Gabel, 2001). The feelings and attitudes of PWS are therefore seen by many researchers and clinicians as equally important to consider as speech behaviours, in order to understand the entirety of the stammering disorder (Guitar, 2014; Stewart & Turnbull, 2007).

YPWS are likely to have experienced stammering for a number of years so consequently they are often referred to as intermediate to advanced stammerers (Guitar, 2014; Schwartz, 1993). Guitar (2014) suggested that YPWS exhibit overt core behaviours, such as sound repetitions, prolongations and blocks, but secondary behaviours are usually more evident with increased tension accompanying speech blocks. However, some YPWS may have developed efficient avoidance behaviours so that they appear as fluent speakers (Guitar, 2014). During adolescence it is reported that YPWS usually become more aware of their stammering and negatively perceive the reactions of others towards them which increases their fear of speaking and use of avoidance strategies (Bloodstein, 1995; Schwartz, 1993).

**1.2.4 Prevalence.** It is estimated that the overall prevalence of stammering at any given time is approximately 1% of the population in the UK and USA, which is also reflected within other western countries (Bloodstein & Ratner, 2008). Differences in prevalence rates are reported which may be due to the use of varied methodologies and intrinsic differences in the populations sampled, but a number of studies suggest that the prevalence of stammering is highest in young children, ranging from 2.5% of children aged 2-5 years old in the USA (Proctor, Yairi, Duff & Zhang, 2008), 1.4% of children in Australia aged 2-10 years (Craig, Hancock, Tran, Craig and Peters, 2002) and 1.2% of school aged children in the UK (Andrews & Harris, 1964). Few studies have examined adolescent prevalence rates of stammering. One, conducted by Craig et al. (2002) in Australia, used telephone calls to confirm stammering in a sample population of over 4,000 by measuring the speaker’s

percentage of stammered syllables. They found a lower rate (approximately 0.5%) for young people aged 11-20 years compared to younger children. This lower rate reflects the reported pattern of spontaneous recovery from stammering which typically occurs in early childhood and also the tendency for therapy to be offered for children with persistent stammering prior to adolescence (Lincoln & Onslow, 1997; Yairi & Ambrose, 1992).

Prevalence data suggests there is a difference in the number of males to females who stammer with males being more vulnerable to persistent stammering than females (Bloodstein & Ratner, 2008). However, among very young children, similar ratios of 1.6:1 and 1:1 are reported (Kloth, Kraaimaat, Janssen & Brutten, 2002; Yairi, 1983). Most studies indicate the ratio of males to females who stammer increases with age with a ratio of 3:1 for schoolchildren and 4:1 for YPWS aged 11-20 years old (Craig & Tran, 2005; Guitar, 2014).

Stammering has been reported across cultures and races for over 40 centuries and some have suggested it is a universal disorder (Guitar, 2014). However, Bloodstein and Ratner (2008) reviewed studies relating to prevalence of stammering in different cultures and found variances. Their review revealed similar prevalence levels in the USA, UK and other countries adopting a Western culture but a lower prevalence or absence of stuttering in many non-Western societies (Lemert, 1962; Morgenstern, 1953; Snidecor, 1955; Stewart, 1960). However, data collected by Morgenstern (1953) found a very high number of PWS in the Ibo and Idoma tribes of West Africa and an intolerance towards stammering. This finding could be reflective of the competitive and ambitious tribal culture which aims for high standards of educational success and status (Bloodstein & Ratner 2008). Accordingly, Bloodstein and Ratner (2008) suggested clinicians and researchers working with PWS should be mindful of how the beliefs and standards of a particular culture may impact how stammering is regarded and accepted by a society.

**1.2.5 Treatment approaches.** There are a number of therapy approaches for YPWS but these are mostly based on adult therapies so fail to take account of the physiological, psychological and social changes occurring for YPWS during the adolescent stage of development (Weisz & Hawley, 2002). During adolescence YPWS may find it difficult to seek the support they require because they are reluctant to receive therapy within school or take time out from school to attend appointments (McNeil, 2013). For some, their stammer may not be a significant problem at this point and they may have other priorities in their lives (McNeil, 2013). Hearne, Packman, Onslow and Quine (2008) explored the views of 13 adolescents who stammered and found that some had not been particularly motivated to receive treatment for their stammer, which is in keeping with a general lack of motivation characteristic of this stage of development. Hearne et al. (2008) also reported that life

changes such as starting university or work were more likely to be a catalyst for adolescents to pursue therapy and that adolescents described the importance of being ready to engage in therapy. Holmbeck et al. (2000) contended that the period of adolescent development is a time when therapy intervention can have a positive lasting influence. Hearne et al. (2008) also suggested that although adolescents may not show interest in receiving therapy during their adolescent years, this period may be the last opportunity to prevent stammering becoming a life-long condition.

Baxter et al. (2015) conducted a systematic review of non-pharmacological interventions for developmental stammering, and identified a wide range with the potential to assist some PWS, but there were significant individual differences in response to treatments. The authors suggested that increased knowledge is needed to understand the processes of treatment which effect change and to identify core therapy outcomes that can be measured to analyse therapy effectiveness across different approaches. The two main treatments for stammering include fluency shaping and stammer more fluently approaches. Fluency shaping involves replacing stammered speech with a different pattern of controlled fluent talking which usually involves rate control techniques such as prolonged speech (Guitar, 2014). The stammer more fluently approach focuses on supporting the client to become less sensitive about their speech by increasing their understanding and awareness of stammering and by modifying moments of stammering (Van Riper, 1975). It also addresses anxiety associated with stammering by responding to the fears and avoidance behaviours experienced by PWS (Bloodstein & Ratner, 2008).

A combined treatment approach is adopted by many speech and language therapists (SLTs) who provide intervention for YPWS and this is seen as beneficial for adolescents (Hancock & Craig, 1998; Hancock et al., 1998). In the UK, combined approaches are often offered in a group setting for YPWS and have been found to be effective (Fry, Millard & Botterill, 2013; Fry, Botterill & Pring, 2009), but data from these research studies is limited due to small sample sizes and a lack of participants across some age groups. Some researchers have suggested that adolescents have a preference for group therapy and find interaction with peers to be beneficial (Blood et al., 2001; Hearne et al., 2008). However, Liddle, James and Hardman (2011) surveyed SLTs in the UK regarding group therapy provision for school aged children who stammer (CWS) and found a majority of SLTs perceived a lack of parent and child motivation for group therapy. The authors suggested this may reflect a child's anxiety regarding group therapy. Although this study concerns school-aged CWS it does not clarify the age range of the school children so its findings may not apply to adolescents who stammer.

The Teens Challenge Programme is a UK integrated group treatment for YPWS which aims to promote confidence in communicating, positive thoughts towards speaking, speech management strategies, developing problem-solving abilities and self-help skills (McNeil, 2013). This is achieved through a residential course involving group work and outdoor activities. Questionnaire data and feedback from the group participants, collected by the programme's author, have suggested positive therapy benefits but to date there is no published evidence to support the programme and it is unclear as to how the individual elements of the programme of therapy support a YPWS or whether it is the combined approach that is crucial (McNeil, 2013).

The McGuire Programme is another intervention which was developed by a person who stammers and is available for adolescents and adults who stammer (AWS) (McGuire, 2016). It is delivered by PWS as a residential intensive group intervention. It aims to support PWS to achieve fluent speech through diaphragmatic breathing and promotes openness and acceptance of stammering. Many PWS who have been through the treatment promote its benefits to others through its website, the BSA and conference presentations. The developers of the McGuire Programme also provide an annual evaluation audit based on their own success criteria, which involves the programme coaches giving ratings of their students' progress. The latest audit in 2014 indicated an overall success rate of 72% (324 out of 449 people were rated successful) (McGuire, 2016). However, there is no empirical research which evaluates its effectiveness.

Research findings have also reported the positive role of self-help support groups for PWS (Boyle, 2013). PWS have described how belonging to a support group is beneficial in terms of sharing their thoughts and feelings with others within a safe context and helping them to accept their stammer as part of their self-identity (Boyle, 2013; Yaruss, Quesal and Murphy, 2002). However, this previous research only concerns AWS and there is a dearth of information regarding the existence and possible value of support groups for YPWS. In the UK a number of self-help groups have been established by members of the BSA and these groups can be accessed through the association. However, many of these seem inactive and they only appear to target the adult population. An on-line group for young people has also been set up to provide mutual support but though this is called the Young BSA Group, the group caters for 18-30 year olds.

## 1.3 The potential impact of stammering on activity and participation of PWS in education.

**1.3.1 Disability.** Stammering is regarded as a disability under the Equality Act 2010 if it has considerable negative impact on the person's ability to participate in routine everyday activities such as communicating with others. However, in line with the 'social model of disability' (Oliver, 1983) some PWS do not see themselves as disabled by their stammer and believe it is society's prejudices which debilitate the individual (Pierre, 2012; Tyrer, 2013). A recent worldwide 'stammering pride' movement has arisen which promotes a stuttering community where the experience of stammering is shared and accepted by PWS and stammering is not seen as a deficiency. It encourages a belief that individuals should be proud of themselves as a person who stammers (Meredith & Harrison, 2014). Research has suggested that knowledge and understanding of stammering and disability culture should be considered in the education of student speech and language therapists. (Boyle, Daniels, Hughes & Buhr, 2016).

**1.3.2 International Classification of Functioning, Disability and Health (ICF).** In 2001 the World Health Organization (WHO) produced the ICF as a framework for considering the holistic nature of health and wellbeing. The ICF has two parts: Functioning and Disability, and Contextual Factors (WHO, 2001). The first part is further separated into Body Functions and Structures, and Activities and Participation, which together describe the structures and systems within the body and the daily life activities that contribute to positive health experiences. The second part is separated into Environmental and Personal Factors which act as barriers and facilitators to health. This framework has been adopted by health professions around the world and provides a useful way of identifying impairments and disability, including disorders of communication (Threats, 2006). It has been found to be useful when applied to describing the key components of stammering because it provides a broad structure capturing not only the specific physical speech impairment or health condition but the wider implications of stammering (i.e. the subsequent impact stammering can have on an individual's daily experiences and overall participation in life) (Yaruss, 2007). For individuals who stammer the severity of the impairment does not necessarily predict the effect it will exert on their life experiences but rather the influence of contextual factors, such as their environment and personal reactions, are vital for understanding the individual's whole, lived experience of stammering.

**1.3.3 Past research: The educational outcomes and experiences of PWS.** A number of qualitative studies describing the narratives of PWS highlighted participants'

shared belief that stammering had restricted their lives in terms of their education (e.g., negatively impacting on participation in class) (Butler, 2013; Crichton-Smith, 2002; Daniels, Gabel & Hughes, 2012). However, these research findings were based on the views of adults who stammered (AWS) and involved retrospective accounts of individuals' experiences of the education system.

Bloodstein and Ratner (2008) reviewed the mixed findings from quantitative studies that explored the educational achievement of children who stammer (CWS) compared to children who do not stammer on standardised achievement tests for Maths and English. For example, whilst McDowell (1928) reported no difference in the educational achievement of the two groups (mean age not stated), Williams, Melrose and Woods (1969) found the median scores for 11-12 year old CWS to be significantly lower than those of their fluent peers. DuPont (1946) compared the educational achievement of chiefly male CWS with published norms for language and maths and found significantly lower scores for 8-11 year old CWS on language and for 11-14 year old CWS on Maths. However, all of these studies focus on the academic achievement of young CWS and there is limited empirical data on whether a difference exist between the educational achievement of YPWS and their fluent peers aged 16 years and over. Also, the studies reported here are of children at school in the USA many years ago and are unlikely to reflect the academic achievement of YPWS in the current educational system in either the USA or the UK.

Since the current research commenced, two studies have been carried out to investigate the educational outcomes of PWS. The first by O'Brian, Jones, Packman, Menzies and Onslow (2011) found a significant negative association between stammering severity and educational attainment but there was a wide age range of participants (i.e. 18-73 years old) who would have had varied educational experiences according to their age and the educational system to which they were exposed. The second by McAllister, Collier and Shepstone (2012), followed up a group of 50-year-old individuals who were reported as stammering at age 16, and found no difference in the highest qualification achieved compared to a control group, but there was a lack of information regarding the nature of the qualifications studied by the individuals who stammered.

Thus, the review of previous studies shows that the educational outcomes and experiences of YPWS have been examined in different ways. For this current investigation educational outcomes refers to the educational achievement of YPWS in secondary school and continuing education (i.e. at college and/or university) measured by their qualifications attained; the number and choice of subjects studied and also their post 16 choices in relation to their engagement with further education and/or employment. The term educational

experiences is used to capture the views of YPWS about their lives and progression in secondary and continuing education.

This review also reveals an absence of research investigating: 1) the views of YPWS regarding their educational outcomes and experiences in the current UK education system; 2) differences between the outcomes (i.e. examination results) of YPWS and fluent peers; 3) the nature and choices of qualifications studied by YPWS; and 4) the further education and employment plans of YPWS.

**1.3.4 Current educational context.** The education of young people and their educational outcomes is seen as key to the future success of young people in relation to work prospects and financial rewards (Abbott, 2012). The importance of education has been reflected in UK Government policy during the last two decades particularly since the 14-19 reform programme was introduced in 2005, which sought to ensure all young people had the necessary education and training to prepare them to "succeed in life" (Department for Education and Skills, 2006, p.16). An independent review of 14-19 vocational education suggested that many young people were not pursuing programmes of study which successfully led them to appropriate higher education or employment (Wolf, 2011). The review also highlighted that fewer than 50% of students achieved satisfactory passes in Mathematics and English by 16 years of age and recommended that further education should meet this need. To address the review, changes have been implemented in England to increase the education and training opportunities for young people by raising the compulsory education leaving age of 16 years old from 2015, so that young people now have to choose one pathway from three options: to continue with full-time education or training, to participate in an apprenticeship, or to combine working with continuing education and training (Department for Education, 2014a) (DfE). This means that young people are spending longer in education which could have implications for YPWS if stammering is associated with negative educational experiences (Butler, 2013; Crichton-Smith, 2002; Daniels et al., 2012).

**1.3.5 Personal context: clinical experience.** As a speech and language therapist (SLT) working with people who stammered I became aware of the number of young people who stammered who experienced difficulties with their stammer at school in regard to speaking aloud in class. Some mentioned their frustration at not being able to answer questions they knew the answers to due to their fear of stammering, which caused them to remain silent. Others described stammering when they tried to join in with reading and class discussions and the embarrassment they experienced. YPWS also attended speech and language intervention for help with preparing for oral examinations, usually in relation to

English or modern language subjects. They often talked about being afraid of failure due to not being able to express themselves coherently because of their stammer. For many their anxiety associated with these oral tasks was apparent. As a result, therapy focused on support strategies for class activities and oral presentations and liaising with the school teacher, with the young person's agreement, to offer advice. For formal examinations, I would also submit a letter providing information to the teacher and to the examination board to explain and support the young person's stammering needs.

These personal experiences led me to undertake a Master's degree in 2007 which investigated teachers' training experiences in dysfluency and the resources they used to support children and YPWS at school. This study provided me with insight regarding teachers' perspectives about dysfluency resources and teacher training. Whilst reviewing the literature I became aware of research which suggested that PWS are at risk of negative outcomes in relation to education (Butler, 2013), employment (Klompas & Ross, 2004) and psycho-social adjustment (Smith, Iverach, O'Brian and Kefalianos, 2014).

## 1.4 The current investigation and research aim

Stammering affects approximately 0.5-1% of young people in the UK and prior research suggests the impact on their lives and learning can be significant (Butler, 2013; Crichton-Smith, 2002; Daniels et al., 2012). However, there is a lack of information about the experience of stammering from the perspective of YPWS and about the educational outcomes achieved by YPWS. The current educational context requires that students remain at school longer (Department for Education, 2014a) and recent health policies recognise the need for health and educational professionals to address not just the impairment but also to support the life activities of individuals experiencing difficulty (e.g., with communication skills) (WHO, 2001). However, it is not possible for SLTs and teachers to support YPWS unless more is known about their outcomes and experiences. Thus, this research aims to:

*Explore the educational outcomes and experiences of young people who stammer*

In order to address this aim it was vital to engage YPWS aged 15-25 years old who were students in the current UK education system or who had completed their education in the last year. This was important to enable the reporting of young people's current or very recent perspectives of their educational journey and to investigate their educational outcomes in terms of the subjects studied and qualifications achieved by the YPWS in the present UK education system. To gain an insight into the academic performance of YPWS and to seek their views concerning their educational experiences two studies were undertaken. The following research questions guided the two studies:

Study One: What are the educational choices and outcomes of YPWS in secondary school and continuing education?

Study Two**:** How do YPWS perceive their educational experiences of secondary school and continuing education?

The first study utilised a quantitative survey method to investigate the educational choices and outcomes of YPWS. The second study then used using qualitative interviews to explore the perceptions of their educational experiences.

## 1.5 Structure of thesis

This thesis is comprised of eight chapters. The introduction presents an overview of the phenomenon of stammering with a particular focus on its potential impact on YPWS in education. It provides the background to the research initiative and outlines the aim of the current thesis and the two studies carried out.

Chapter two provides a review of the current literature in the areas relevant to the investigation. These include typical adolescent development, young people's relationships, current educational markers of achievement for young people in the UK and the potential factors influencing their educational achievement. It then provides a review of pertinent literature regarding the possible impact of stammering on the educational outcomes and experiences of YPWS which highlights the rationale for the investigation and leads to the development of the research questions to be addressed by the two studies.

Chapter three describes the theoretical framework, the research design and methods that underpin the investigation. The theoretical framework took a pragmatist approach and used a mixed method sequential explanatory research design, comprising two studies, to explore the educational outcomes and experiences of YPWS. A sequential design involves one episode of data collection occurring before the next episode and for this thesis a quantitative study was followed by a qualitative study. A visual model is used to outline the relationship between these two episodes of the mixed methods design and how this approach addressed the research questions. This chapter also details the participants, recruitment procedures and sample sizes and also the data collection and analysis used in both studies.

Chapter four presents the quantitative results from the study one: a survey with YPWS which describes the participants' demographics, their perceptions of their stammer, their educational choices and achievement in secondary school and continuing education and their plans for the future. The chapter outlines the survey findings about the educational

choices and outcomes of YPWS which were then used to direct the development of the interview questions for the second study.

Chapters five to seven present mainly the qualitative findings from study two: an interpretative phenomenological analysis of interviews undertaken with YPWS which explored their educational experiences. Three major themes and sub-themes arising from their accounts describe their individual and shared experiences of stammering in the educational environment. Chapter five outlines the three overarching themes and then focusses on describing the first theme. It includes participants' self-reported measures about their stammering severity, the impact of their stammer on life in education and at work and levels of self-esteem. Chapter six presents the second theme and chapter seven describes the third.

The final chapter discusses the findings from the two studies in relation to each study's research question and sub-questions. A model derived from the data collected on the educational experiences of YPWS is presented and illustrated through three cases studies. Practice implications for SLTs and teachers are explored and possible future research is considered. The strengths and limitations of the study are then outlined followed by a conclusion summarising principal findings.

# CHAPTER 2. ADOLESCENTS, YOUNG PEOPLE WHO STAMMER AND THEIR EDUCATIONAL OUTCOMES AND EXPERIENCES

## 2.1 Overview

This chapter reviews the research that informed the design of the current project and is divided into two parts to reflect the development of the two studies. First, a review of the literature describes typical adolescent development, including the important changes that occur during this life stage, relationships, mental health and expected educational outcomes. This leads onto an appraisal of past research concerning the educational outcomes of PWS which highlights the gap in the literature and supports the rationale for the first research question and sub-questions for study one. The second part of the chapter reviews literature relating to the education experiences of PWS including their classroom participation, relationships, perceptions and mental health. This identifies the need for researching the views of YPWS in education and to the development of the second research question and sub-questions for study two.

## 2.2 Adolescence during secondary education

It is important to recognise the role of adolescence as a developmental stage in the experiences of YPWS while in secondary education. Adolescence may be defined as “the developmental period of transition from childhood to early adulthood, entered at approximately 10-12 years of age and ending at 18-22 years of age” (Santrock, 2008, p.18). It is a critical period of transition in the life-span of individuals being a time of rapid growth and change (WHO, 2016), particularly in the areas of biological, cognitive and socio-emotional development (Santrock, 2008).

**2.2.1 Adolescent development.** Adolescence is marked by physical maturation with the onset of puberty which is characterised by increased production of particular hormones. During puberty there is noticeable sexual maturation, voice change in males and the inception of menstruation in females. Adolescents also experience physical growth in terms of body size and shape, for example, increased height and weight as well as hair growth and muscle development. Alongside these physical changes there are transformations occurring in the brain, particularly in the pre-frontal cortex and limbic areas including the amygdala, which may influence the behaviours of young people. For example, heightened activity in the amygdala when processing emotional information has been

reported, which could be responsible for the impulsive emotional reactions of young people (Spear 2000).

Adolescents go through a period of cognitive development in relation to their intellectual ability and thought processing which Piaget termed as formal operational thought (Piaget, 1959). During this stage thought becomes more abstract and logical with adolescents developing the ability to reason, find solutions to problems and hone their decision making skills (Atwater 1992; Steinberg, 2005).

Adolescence is a crucial time for the development of self-concept. Rogers (1959) outlined three components to self-concept: self-image or identity (the individual's sense of self), self-esteem (the value the individual places on self) and ideal self (the individual's view of how they would like to be). Possessing a positive self-concept is considered important for contributing to an individual's sense of wellbeing (Santrock, 2008).

Erikson (1968) suggested identity development is a lifelong process but has a particular importance during adolescence, as individuals encounter a normative crisis that involves a struggle to achieve a true identity. According to Erikson, adolescents experiment and test different roles to help them decide who they are and the direction they will follow in life. He called this stage "identity versus identity confusion" with individuals seeking a positive identity which they can believe in. Santrock (2008) also suggested that adolescents start to consider the ideal standards to which they aspire and compare themselves with others in relation to these standards.

During adolescence the development of emotional autonomy may accompany identity achievement whereby the adolescent learns to cope with conflicts, set-backs and criticism in a constructive way (Atwater, 1992). Achieving emotional autonomy and a sense of identity may lead the adolescent to become less dependent upon parental and peer support and may reinforce feelings of positive self-esteem and self-efficacy (Atwater, 1992), which refers to the extent to which an individual feels confident of learning or performing behaviours and capable of managing a situation (Bandura, 1986). Self-efficacy reflects the self-belief of the individual which can impact the individual's choice of activity, motivation, persistence and achievement (Schunk & Miller, 2002). For adolescents there is typically a growth in self-efficacy as they learn to cope with physical, educational and social role adjustments, for example, they learn to navigate environmental changes, such as the transition from primary to secondary school and from secondary school to college or work and take increasing responsibility for making life decisions (Bandura, 2002). Consequently, adolescents' development of self-efficacy can be influenced by their participation in activities in their environment which can affect the direction of their future life choices (Bandura, 2002).

Studies examining changes to self-esteem during adolescence show varying results. Some suggested self-esteem decreases during early adolescence, particularly for females which may be related to females experiencing a negative body-image during puberty (Robins, Trzesniewski, Tracy, Gosling & Potter, 2002; Kling, Hyde, Showers, & Buswell, 1999). However, Baldwin and Hoffman (2002) found an increase in the self-esteem of adolescent boys which they suggested was linked to supportive family relationships.

Others have also suggested that an adolescent's self-evaluation may not necessarily reflect reality and if the evaluation is negative this can result in low self-esteem (Baumeister & Bushman, 2008). A negative self-evaluation usually occurs when an individual makes a comparison with others who possess perceived ideal standards, in terms of physical and academic characteristics. Failing to meet this high standard results in the adolescent feeling dissatisfied and can lead to lower levels of self-esteem (Santrock, 2008).

**2.2.2 Relationships and the communication context.** The self-concept beliefs of adolescents are not developed in isolation but through individuals' experiences with the environment and can be affected by observing the reactions of important others towards them (Shavelson & Bolus, 1982). Bronfenbrenner (1989) proposed an ecological framework which reflects the possible effect of a number of environmental systems on the development of the adolescent. At the centre of this framework is the young person who is surrounded by microsystems comprising of their home and school settings. Within these environmental contexts are people they interact with, such as parents, siblings, peers, teachers, and the social community who hold significance for adolescents.

***2.2.2.1 Parents.*** Research has suggested that parents continue to be important for young people during adolescence offering support and protection against stressful events (Schaffer, 1996). Close attachment with one or both parents during this time is believed to play a valuable role in trusting and promoting social relationships with others (Santrock, 2008).

Although relationships with parents remain key for many adolescents due to the support and guidance parents typically provide, this is a period of change when adolescents seek increased autonomy with a decline in parental involvement in their activities (Steinberg, 1993). At this time, adolescents frequently become more assertive, stating their opinions and become more private about personal matters, distancing themselves from their parents (Santrock, 2008). This period of change is commonly accompanied by parent-child conflict (Collins & Steinberg, 2006). Adolescents also make comparisons of their family with their ideal model of a family and can find fault with their parents, referred to as the de-idealisation

of parents (Atwater, 1992). As adolescents mature, parent-child relationships improve and become more positive, particularly when adolescents leave home to attend university (Sullivan & Sullivan, 1980).

***2.2.2.2 Siblings.*** The role of sibling relationships during adolescence has not been widely studied (Steinberg, 1993), but it is recognised that the relationship between siblings differs from those with parents and friends and is a fundamental part of an adolescent's upbringing (Furman & Buhrmester, 1985). Most children grow up with siblings in their family environment and the sibling relationship develops over time and is usually the longest relationship in the life of an individual (Cicirelli, 1994).

The amount of time spent together provides the opportunity for siblings to influence one another in relation to their behaviour and social and cognitive development (McHale, Updegraff & Whiteman, 2012). This can include copying sibling behaviour, teaching one another and developing cognitive skills such as problem solving, negotiating and constructing arguments (Dunn, 2007). Cicirelli (1994) suggested that siblings often play a greater role in the process of socialisation during adolescence than parents, perhaps because siblings are closer in age, have a better understanding of adolescent problems and can more readily communicate and disclose feelings and situations with each other.

Sibling relationships can vary in terms of the degree of closeness, support, conflict and competitiveness (Furman & Buhrmester, 1985). During adolescence research suggests sibling relationships can become more peer-like, being friendlier and closer through their shared family and school experiences (McHale et al., 2012; Buist, Dekovic, Meeus & van Aken, 2002). Kramer (2014) suggested that communicating with siblings offers a safe context for individuals to develop their interaction skills and learn to manage their emotions appropriately. Supportive sibling relationships have been linked to adolescent adjustment and positive patterns of behaviour (Branje, van Lieshout, van Aken, & Haselager, 2004; Daniels et al., 1985).

Studies investigating sibling relationships in which one sibling had a disability have found warmer relationships, more positive experiences and positive adjustment than between typical siblings (Stoneman, 2001). Research examining the sibling relationship between neurotypical children and children with autism and Down syndrome have found the typical sibling undertook a more responsible parental role (Knott, Lewis, & Williams, 2007).

***2.2.2.3 Peers.*** Studies have suggested that peer relationships become increasingly important and influential during adolescence with more time being spent interacting with friends rather than parents or other adults (Buhrmester & Carbery, 1992; Furman &

Buhrmester, 1985; Hussain et al., 2013). The young person has a desire to be liked, to fit in and be part of the group and gain acceptance from peers (Spear, 2000).

Researchers have suggested that friends help with shaping an adolescent's social development and support the transition to independence and adulthood (Collins & Laursen, 2004; Larson & Richards, 1994). Santrock (2001) proposed that friends provide reciprocal support in building self-identity and he described six functions of friendship: companionship (a familiar partner to spend time with and participate in joint activities), stimulation (information, excitement and amusement), physical support (time, resources and assistance), ego support (encouragement and feedback), social comparison (how they appear in relation to others) and intimacy/affection (a close and trusting relationship which involves self-disclosure).

Creating friendships and being part of a friendship group during adolescence provides social support and a sense of well-being (Rutter 1985). Peer support offers the opportunity for sharing of information and can heighten motivation and social activity, which can contribute towards building resilient behaviour (Bloom, 1990). Sullivan (1953) suggested that the adolescent's well-being is determined by whether the individual's social needs are met through friendships. He suggested that friends provide vital mutual support and promote feelings of self-worth. Hussain et al. (2013) also stated that peers provide mutual support regarding future educational decisions including subject choices.

In contrast, failure to make close friendships is believed to result in loneliness and loss of self-worth (Parker & Asher 1987; Sullivan, 1953). Buhrmester (1990) reported that teenagers who lacked friends experienced increased feelings of loneliness, depression and anxiety as well as reduced levels self-esteem compared to teenagers who had close friends. Some adolescents may find it challenging to form peer relationships because of personal factors they believe are viewed negatively by others, (e.g., being seen as unattractive) (Sexson, 2005). Peer relationships have also been found to contribute to negative outcomes for adolescents in relation to academic adjustment (Buhs, Ladd, & Herald, 2006), delinquency (Ellis & Zarbatany, 2007; Moffitt, 1993), aggression (Espelage, Holt, & Henkel, 2003), depression (Landman-Peters et al., 2005; Shahar & Priel, 2002), or social anxiety (Elizabeth, King, & Ollendick, 2004).

**2.2.3 Mental health.** The majority of young people manage the period of adolescence successfully, without developing serious psychological or emotional difficulties (Powers, Hauser, & Kilner, 1989; Spear, 2000). However, adolescents are at a higher risk of death and disability compared to children and older adults (Larsson & Melin, 1990; Petersen,

Compas, Brooks-Gunn, Ey & Grant, 1993; Rutter, 1986). This is reported to be due to avoidable events involving reckless behaviour resulting in accidents and to mental health issues (Wasserman, Cheng & Jiang, 2005). In the UK in 2013 the main cause of death for both males and females aged 15-19 years old was land transport accidents with suicide being the second main cause of death for males and the sixth cause for females (Office for National statistics, 2015). Similarly, WHO (2014) found suicide to be the second leading cause of death globally for young people aged 15-29 years old. A depressive disorder is the most common factor leading to suicide which typically begins during adolescence (Merry & Stasiak, 2011; Pelkonen & Marttunen, 2003).

Risk factors leading to mental health problems (such as depression) in adolescence include: a family history of depression, biological changes (e.g., puberty resulting in a negative view of self), psychosocial stress, illness, bullying, family problems, poverty, and the transition from primary to secondary school which can disturb friendship groups (Petersen et al., 1993; Thapar, Collishaw, Pine, & Thapar, 2012). Poor or limited peer relationships as well as being rejected by peers has been linked to the onset of depression in young people (Bearman & Moody, 2004; Kistner, 2006). Romantic relationship difficulties have also been associated with evoking depression, particularly in females (La Greca & Moore Harrison, 2005). In contrast, positive relationships with parents and with peers during late adolescence appear to counteract the adverse effects of stressful life events, as does support from mentors and having a sense of self-efficacy (O'Connell, Boat & Warner, 2009; Petersen et al., 1993).

## 2.3 Educational outcomes

**2.3.1 Measures of educational outcomes.** In the UK, educational achievement is assessed and measured throughout full-time schooling, but there are variations in timing and assessment between countries within the UK (Tassoni, 2007). In England, Education Reform Act (1988) introduced four main stages of learning, referred to as Key Stages 1-4 (Legislation.gov.uk, 1988), during which students study a national curriculum in state schools (DfE, 2014b). Student achievement is usually recognised by the passing of national statutory tests at the end of each stage of learning; Key Stage 1 at age 6-7 years, Key Stage 2 at age 10-11 years, Key Stage 3 at age 13-14 years and Key Stage 4 at age 15-16 years (DfE, 2014b).

At the end of Key Stage 4, General Certificate of Secondary Education (GCSE) and equivalent level 2 qualifications are used as the marker of achievement. Each student usually studies a number of GCSEs in a range of academic subjects, including Mathematics and English, and/or vocational subjects during a two-year period. Their knowledge and skills

relating to each subject are typically assessed at the end of their final year of study and grades are awarded, ranging from A-star (A*), the highest pass to grade G, the lowest pass. The pass grades from A* to C are recognised as level 2 qualifications and are required to go onto further level 3 study and they are often a requirement for many types of employment. The lower pass grades D to G are classified as level 1 qualifications. However, GCSE qualifications have recently been reformed and from September 2016 changes to the curriculum for core subjects will be made along with a new grading system which some argue will raise standards (DfE, 2013).

On completion of full-time compulsory schooling, students' attainment of GCSEs and equivalent qualifications can lead them to further full-time or part-time study, employment, volunteer work or an apprenticeship (Jin, Muriel and Sibieta, 2010). Students who decide to continue in full-time education at school or college will usually study Advanced Subsidiary (AS) and Advanced (A) Level qualifications over two years. The first part of the qualification is referred to as the AS Level and the second part as the A2 Level, with the two qualifications constituting the complete A Level qualification. Similar to GCSE qualifications there are a variety of subject choices with the majority of students opting to study three to four subjects and these are assessed at the end of each level of study (DfE, 2015). Following the attainment of A Levels many young people decide to attend University to follow a programme of study which involves an in-depth understanding of a subject and leads to an undergraduate Bachelor's degree qualification. This usually entails three or four years of study and is typically assessed through examinations and course work.

**2.3.2 Factors influencing educational outcomes.** Many factors have been reported as contributing to a young person's level of academic achievement (Abbott, 2012) including: socio-demographic factors, the family, teachers and individual factors.

***2.3.2.1 Socio-economic.*** Previous research has identified a strong relationship between socio-economic status (SES) and the academic achievement of children and young people (Ahmar & Anwar, 2013; Andreias et al., 2010; Caro, McDonald & Willms, 2009; Gutman & Vorhaus, 2012). Studies have found that children from an area of socio-economic disadvantage performed less well in terms of their academic achievement than peers from affluent areas (Andreias et al., 2010; Caro et al., 2009). Researchers have shown this difference in academic achievement between children from low SES and high SES backgrounds increases for adolescents (Andreias et al., 2010; Barreau et al., 2008; Goodman & Gregg, 2010) with students from high SES backgrounds achieving higher marks and examination grades compared to students from low SES backgrounds (The Royal Society, 2008). Furthermore, adolescents from low SES backgrounds complete fewer years

in education and are less likely to pursue further education at college (Alexander, Entwisle & Olson, 2007; Demi & Lewis. 2011).

Researchers have inferred that these differences in academic achievement are a result of children from high SES backgrounds being exposed to a better learning environment at home due to the accessibility of superior learning facilities compared to children from low SES families (Sirin, 2005). Similarly for adolescents Ahmar and Anwar (2013) suggested that parents with high SES are able to provide the education and health needs of the young people and to appreciate their difficulties during this period of development.

Studies examining the association between SES and academic achievement have used different variables to measure SES including traditional measures such as parental education, occupation and income or alternative proxy measures such as the young person's entitlement to free school meals and the deprivation in the local neighbourhood in which they reside (Crawford & Greaves, 2013; Oakes & Rossi, 2003; White, 1982). White (1982) argued that there is a wide variation in the strength of relationship between SES and academic achievement of young people which is due to the different measures of SES employed. He found that when traditional measures of SES are used there is a much weaker relationship between SES and academic achievement and suggested that alternative measures such as a family's stability, provision of academic guidance and attitude towards education are more strongly correlated to a young person's academic achievement. Further research has supported this suggestion, indicating that a positive home environment rather than parents' income or occupational status is a more accurate predictor of children and young people's educational achievement (Sanders & Epstein, 1998; van Steensel, 2006).

***2.3.2.2 Family.*** As discussed, parents' involvement with their children's learning has been associated with academic success (Ballantine, 1999; Miedel & Reynolds, 2000; Sumari, Hussin, & Siraj, 2010). Results from a meta-analysis of 52 studies involving over 3000 secondary school students concluded that parental involvement has a positive influence on young people's academic achievement (Jeynes, 2007). Two particular aspects of parental involvement were found to have the greatest impact on a young person's performance; parental style, which involves parents being supportive and caring yet maintaining a sufficient level of discipline within the home, and parental expectations, the extent to which parents maintain high but reasonable expectations of the young person's ability to attain a high level both academically and in terms of a future career. In particular, parental involvement was found to produce statistically significant results for grade achievement of young people (Jeynes, 2007). Jeynes (2007) also suggested that many

parents with a high SES level are also likely to recognise the value of a successful education and the benefits for career opportunities.

***2.3.2.3 Teachers.*** Smith et al. (2004) suggested that teachers' expectations of students directly affect their academic outcomes, with students doing less well academically if the teacher has negative academic expectations of them compared to when the teacher projects positive hopes for them. Furthermore, it is suggested that teachers who provide a supportive relationship enhance adolescents' learning and increase their academic self-efficacy and feelings of competence (Baker, Grant, & Morlock, 2008; Smith et al., 2004) as well as developing their sense of identity (Sexson, 2005). Similarly, Turner and Helms (1995) identified the behaviour of teachers as playing an important role in the development of students' self-concept and peer acceptance. They believed that to some degree teachers are accountable for the psychological well-being of pupils, stating, "teachers appear to be in a prime position to serve as a role model, as well as a reinforcer of children's social interaction" (Turner & Helms, 1995, p.343). Research has also found that teachers who adopt interactive teaching strategies, provide a consistent and rational approach to teaching and feedback, and strong classroom management skills improve students' behaviour, academic performance and attitudes towards school (Good & Brophy, 2002).

***2.3.2.4 Individual factors.*** An individual's intelligence and personality features, such as openness and conscientiousness, are associated with academic achievement, with intelligence being one of the most accurate predictors of academic achievement and school failure (Hernstein & Murray, 1994; Laidra, Pullman & Allik, 2007).

A high level of self-esteem has also been linked to positive educational outcomes for young people (Marsh, Byrne & Yeung, 1999), and some have suggested that this relationship is reciprocal (Marsh & Craven, 2006). However, others have shown there to be no difference between the self-esteem levels of gifted and non-gifted secondary school students (Vialle, Heaven & Ciarrochi, 2005). Baumeister, Campbell, Krueger and Vohs (2003) proposed that high self-esteem was not a predictor for successful educational performance but instead suggested academic achievement enhances the self-esteem level of individuals. Similarly, they suggested occupational success may increase self-esteem rather than the reverse being true. However, high self-esteem has been shown to influence an individual's persistence to keep trying despite initial failure (Baumeister & Bushman, 2008).

Ou and Reynolds (2008) suggested the educational achievement of young people can be informed by resilience theory, which has been defined as a dynamic process in which individuals adapt and manage when faced with adversity (Masten, 2014). Ou and Reynolds (2008) proposed a model of educational achievement to promote educational resilience in

young people which is based on a framework of risk and protective factors. This type of resilience framework was also adopted by Murray (2003) to understand factors influencing young people with disabilities. These models not only consider an individual's vulnerability or risk of negative educational outcomes but also assess the factors in the individual's life which protect or support them in achieving positive school outcomes and foster resilience. This evaluation of key risk and protective factors can then inform and support the outcomes of young people in education (Murray, 2003; Ou & Reynolds, 2008). Werner and Smith (1989) described children and young people who achieve positive outcomes despite negative risk factors as resilient. In relation to young people and educational outcomes, an individual's risk factors such as low intelligence and poor self-esteem need to be considered as well as their environmental context, for example, peer rejection as well as possible protective factors such as family and teacher support (Ou & Reynolds, 2008).

## 2.4 Educational outcomes of people who stammer.

Stammering has been associated with the educational performance of YPWS in a number of ways, such as PWS achieving lower grades in examinations, experiencing difficulties with language orientated tasks and verbal participation in classroom and extracurricular activities (Bennett, 2006).

Bloodstein and Ratner (2008) reviewed thirteen studies which examined intelligence levels of PWS. Ten of these studies claimed there was not a difference in the intelligence level of stammering versus non-stammering individuals but for nine of these studies a control group was not used. However, three studies, each involving a control group of non-stammering individuals, found a significant difference in the mean IQ in PWS from the mean scores of the non-stammering group (Schindler, 1955; Andrews & Harris, 1964). Whilst this review suggested some disagreement between researchers regarding the intelligence levels of PWS, it indicated that the verbal and non-verbal intelligence to be slightly lower in PWS. Bloodstein and Ratner (2008) suggested if stammering is more prevalent in the lower intellectual level of the typical population, as the research indicated, then the disorder of stammering would be expected to be more common in people with learning disabilities. They suggested that evidence exists to support this suggestion, in particular amongst people with Down Syndrome (Devenny & Silverman, 1990; Van Riper, 1982).

If there is a difference in intelligence levels and standardised attainment tests in schoolchildren who stammer compared to their peers, then it could be expected that YPWS complete their compulsory education with different educational qualifications and poorer examination results in comparison to the typical population of young people. In such cases it

could be the individual's learning difficulty rather than the stammering difficulty which affects educational progress. Bloodstein and Ratner (2008) also reviewed studies that explored the educational attainment of stammerers compared to non-stammerers on standardized achievement tests. These studies had mixed findings with some reporting no difference in the educational achievement of the two groups (McDowell, 1928; Schindler, 1955) whilst others found a delay in the performance of stammerers compared to non-stammerers. However, this review lacked detail concerning the methodology of the studies such as sample size and the age and gender of participants plus there was a lack of clarity as to how participants' stammering was defined and confirmed. Furthermore, given the age of these studies and that they were mostly based on American populations they appear to have limited relevancy to YPWS in the current UK educational system.

From reviewing the literature, a relatively small number of studies have reported empirical data detailing the educational achievement of YPWS in terms of school examinations or tests passed. Furthermore, the studies have measured different aspects of a child's learning at different ages and using different assessments which makes it difficult to compare the results. There is also a paucity of research concerning the qualifications studied and the grades achieved by YPWS at the age of 16 years. Only two recent studies shed light on this area.

Firstly, an investigation by O'Brian et al. in Australia (2011) surveyed 147 adults between 18-73 years old, with a confirmed diagnosis of stammering. Participants reported their highest educational level attained on a scale from 1 (did not finish high school) to 7 (doctoral degree). Participants were also asked to self-rate the severity of their stammer on a scale from 1 (no stammering) to 9 (extreme stammering) in relation to eight different situations. Participants provided two ratings for each situation; a typical stammering severity rating which reflected their average severity of stammering for a given speaking situation and their mean worst severity rating for the situation. Mean typical and mean worst severity of stammering scores were then calculated for each participant by averaging their individual scores across the speaking situations. Results indicated a significant inverse relationship between stammering severity and educational achievement. The authors suggested this finding supported the view that stammering has a negative influence on school experiences and choices throughout life, but questioned whether other reasons could account for the findings.

O'Brian et al. (2011) recognised that one limitation to their study was that some participants (18%) were still in education so these individuals may not yet have attained their highest education level. A further point to acknowledge is the very wide age range of participants

who took part in this study. It is likely the participants had varied educational experiences during their school years according to their age and the educational system and context they have been exposed to. Factors such as educational environment and opportunities for higher education could be influential in terms of academic progression and need to be considered in addition to the severity of stammering.

A second study examined the educational outcomes of compulsory education of YPWS in a British birth cohort study (McAllister et al., 2012). This involved secondary analysis of a dataset of 217 individuals with parental reported stammering at the age of 16 years. The analysis examined school leaving age, highest qualification achieved by the age of 50 years, unemployment early in working life, job pay at the ages of 23 years and 50 years and the social class of job at age 23 years and 50 years. Of particular relevance to the current study was their finding that individuals who were reported as stammering at age 16 years in 1974 showed no difference in the highest qualification achieved by the age of 50 years compared to the control group, nor were they significantly more likely to leave school earlier than the controls. The authors found other predictors of educational outcomes to be influential such as socio-economic status, parental education, and reading comprehension at the age of 11 years. These predictors are consistent with literature outlined earlier describing factors that may influence educational outcomes of young people.

The research by McAllister and colleagues (2012) was the first large scale longitudinal study investigating the impact of adolescent stammering on educational and employment outcomes in the UK and it has provided a valuable insight into the future for YPWS. There is, however, a lack of clarity with regard to the nature of qualifications attained by individuals. McAllister et al. categorised these in terms of National Vocational Qualifications (NVQs) levels 1 to 6. NVQs are recognised UK qualifications which are usually related to a particular industry involving practical related tasks and these are often part of an apprenticeship, building on an individual's skills.

In their study, other qualifications were grouped with NVQs for each level and appear to be listed as equivalent qualifications; for example, NVQ level 2/GCSAWSE grades A-C; NVQ3 level 3/ 'A' levels. It is questionable whether NVQs have an equivalency with these other qualifications. For example, it was not until 2007 that the first NVQ level 3 qualification, Accounting for technicians, was awarded UCAS tariff points and could contribute towards entry into a university programme of study. Despite this particular NVQ qualification attracting UCAS points, Kingston (2007) questioned whether universities would accept this vocational award as equivalent to 'A' levels and whether it was a relevant qualification for progression into Higher Education. This all-encompassing approach which is taken to

categorising qualifications makes it impossible to know whether PWS achieve the same academic profile as people who do not stammer. It does not provide any detail concerning the types of subjects studied at the different NVQ levels and whether PWS have a preference for certain subjects. Using a purely quantitative dataset also limits the understanding of why young people make particular educational choices.

The findings from the study by McAllister et al. (2012) conflict with other data which has provided insight into the self-perceptions and self-beliefs of PWS in regard to their educational achievement and employment experiences. For instance, Klompas and Ross (2004) conducted individual interviews with 16 adults who stammered (AWS) in South Africa, and reported that most participants believed that stammering had affected their academic performance. Similarly, Crichton-Smith (2002) interviewed 14 adults from the UK who stammered and found they all shared the belief that the act of stammering had restricted their lives in terms of their education and employment. These findings are supported by Hayhow, Cray and Enderby (2002), who surveyed 332 adults from the UK who stammered and revealed that stammering had the greatest effect on their school life (n=268, 81%) and choice of occupation (n=173, 52%), compared to their leisure activities (n=98, 30%), friendships (n=79, 24%) and relationships (n=62, 19%). Similarly, Klein and Hood (2004) found that 70% of 232 AWS in the USA thought stammering reduced their chances of getting a job or being promoted. They reported that 36% of the adults believed that stammering interfered with their work performance and 20% were refused a job or promotion because of their stammering. Furthermore, participants with further or higher education experience reported their stammering to be less of a hindrance in their life. However, all participants involved in these studies were recruited through self-selection processes which could have resulted in the sample of participants being unrepresentative of the stammering population and therefore bias research findings. Furthermore, Klein and Hood's (2004) sample of participants all had involvement with the National Stuttering Association support groups in the USA and this support network may have positively influenced their life experiences and views.

## 2.5 Summary of literature, rationale and research questions for study one

Adolescence is a time of change for young people with the environment and others, such as family and peers, being of particular importance. The educational outcomes achieved by young people in the UK are a key milestone during this life stage and the context of their background, individual characteristics and other people in their environment are potential

factors contributing to their successful educational achievement. However, little is known about the educational choices and outcomes or impacting factors for YPWS and this has led to the development of the current study and the following research question and sub-questions:

**Research question 1:** What are the educational choices and outcomes of YPWS in secondary school and continuing education?

Sub-questions:

i. Is there a difference in the educational qualifications of YWPS compared to national attainment levels for young people in the UK?
ii. What subjects are chosen for study by YPWS and why?
iii. What are the post 16 education and employment choices of YPWS?

## 2.6 Educational experiences of people who stammer

The earlier review of research concerning adolescent development has shown that although most young people successfully navigate the period of adolescence (Powers, Hauser, & Kilner, 1989; Spear, 2000) for some this is a vulnerable time in their lives (WHO, 2014). Furthermore, some suggest that for YPWS "the challenges of adolescence can be magnified by stuttering—a social communication disorder that may disrupt typical patterns of interpersonal relationships" (Blood, Blood, Dorward, Boyle & Tramontana, 2011, p. 69). This next section focuses on the reported educational experiences of PWS during the period of adolescent development.

**2.6.1 Classroom activities.** Previous research has described past negative classroom experiences reported by AWS (Butler, 2013, Crichton-Smith, 2002; Daniels et al., 2012; Hayhow, Cray & Enderby, 2002; Klompas & Ross, 2004). Oral communication within the classroom was recalled by AWS as a main area of difficulty with tasks such as reading aloud, delivering oral presentations and answering questions in class having been particularly challenging. Butler's (2013) study, involving individual interviews and focus groups with 38 AWS aged 19-89 years old, reported participants' memories of being pre-occupied with whether they would be chosen to speak in class by their teacher and the fearful anticipation accompanying these thoughts: "the impact of the fear of speaking aloud meant that participants excluded themselves physically, emotionally or cognitively" (p.59). Some participants also mentioned positioning themselves at the back of the class in an attempt to be overlooked by teachers. Consequently, participants described how they

perceived their attention and concentration for class activities to be poor which impacted their engagement with learning.

Similarly, Daniels et al.'s (2012) thematic analysis of individual and group interviews with 21 AWS, who were an average age of 47 years old, described the belief of 19 participants that stammering had negatively impacted their learning experience and academic performance. They perceived that their stuttering had affected their academic grades, particularly for oral assessments. Crichton-Smith (2002) also reported findings from the accounts of individual interviews with 14 AWS aged 26-86 years old. One participant described feeling the need to work harder to obtain high academic grades, two described leaving school early and others perceived that they had not achieved their academic potential. Arnold, Li and Goltl (2015) commented on the increasing demands of the school curriculum requiring oral communication in the USA and the importance of ensuring students who stammer receive the appropriate support to enable their participation. Similarly, in the UK, oral communication is key for some academic subjects such as English or foreign languages and resources are available to support YPWS with these often challenging assessments (BSA, 2014).

Blood, Blood, Tellis and Gabel (2001) indicated that adolescents who stammer are more likely to describe communication apprehension than their peers. Past research by McCrosky and Daly (1976) suggested teachers link the communication apprehension of students with reduced competence, and such views may then cause increased levels of communication apprehension and avoidance behaviour in students (Arnold et al., 2015).

Some research has described the difficulties experienced by YPWS in participating in other school activities (e.g., school plays), and the exclusion they felt as a result (Butler, 2013; Crichton-Smith, 2002). At times, the students chose not to take part, but sometimes teachers advised this, perceiving this would be helpful to the student. However, other participants in the study by Butler (2013) felt extra-curricular activities beyond the classroom provided them with more opportunities to participate and communicate their thoughts through other means such as art. Similarly, sport was viewed enthusiastically by a number of participants because they were able to excel at a non-speech orientated activity.

A limited amount of research has reported on how YPWS would like teachers to respond to their stammer within the classroom but one study found YPWS wished to be treated the same as their peers at school (Hearne et al., 2008). This study focused on the perceptions of 13 adolescents and YPWS regarding their experiences of stammering and their experiences of therapy. Similarly, Adriaensens and Struyf (2016) undertook a study with ten teachers to explore their views of adolescents who stammered in their class and reported teachers received few requests from these adolescents to be treated differently from their peers.

The findings of some studies have indicated that young people and AWS believe teachers should have increased understanding of stammering and be aware of how to support a student who stammers (Daniels et al., 2012; Hearne et al., 2008). However, Adriaensens and Struyf (2016) reported that teachers did not view the young person's stammer as a problem and they would not draw unnecessary attention to the difficulty, if the young person appeared to be coping in class and peers were not reacting negatively towards them. The teachers described rarely discussing the young person's stammer with them or the class but recognised openness about stammering could be helpful. Similarly, Daniels et al. (2012) reported how AWS believed the current school environment to be more supportive compared to their own previous school experiences, due to the recognition of people with disabilities and their needs within education and in relation to an improved awareness of SLTs in meeting the social and emotional needs of students who stammer.

### 2.6.2 Relationships and perceptions

***2.6.2.1 Peers.*** Klompas and Ross (2004) found that AWS described their stammering as having an impact on their peer relationships at school and recalled being teased by peers as a key problem. Butler (2013) reported male participants had difficulties forging close friendships at school and feelings of isolation, while females described close friendships with one or two other girls at school. However, the age at which these friendship experiences occurred was not clear and so may not reflect secondary school relationships. Other studies found the majority of adolescent participants did not believe their stammer would influence whether peers would like them or want to be friends with them, and did not view their stammer as a stigmatising disorder (Blood et al., 2003; Blood & Blood, 2004). In line with this Daniels et al. (2012) found only one participant out of 19 reporting past negative experiences with peers.

There is very little evidence examining how children and young people view peers who stammer, but research from Langevin, Packman and Onslow (2009) found that children in their pre-school years begin to develop negative reactions towards their peers who stammer. This research supported an earlier study by Griffin and Leahy (2006) which showed the perceptions held by young children (3-5 years of age) of a dysfluent speaker are generally negative in nature.

Franck, Jackson, Pimentel and Greenwood (2003) compared the attitudes of 75 children aged 9-11 years towards two video recordings of an adult reading a poem, with the first speech sample containing 3.2% of stammered syllables and the second sample 14% of stammered syllables The children rated the speaker on a bipolar adjective pair scale; six

pairs were related to personality traits, (e.g., shy/outgoing) and the other six pairs were intelligence related (e.g., sharp/dull). Results showed the school aged children gave significantly more negative ratings towards the speech sample with a higher level of percentage stammering compared to the more fluent sample. Franck et al. also observed the behaviour of the children whilst viewing the videos and noted that during the more fluent reading few comments to peers were made and fewer questions were asked about the speaker compared to when observing the more dysfluent speaker. In contrast the children frequently laughed, whispered comments to peers about the dysfluent speaker's reading and had many questions about the speaker following the viewing, such as "why is he doing that?" and "can't he get that fixed?" (p.10). Hartford and Leahy (2006) also found children aged 6-13 years, who listened to two audio recordings of fluent and dysfluent speech samples, perceived the speech of an adult who stammered more negatively than a speaker who was fluent. Their observations of the way children reacted to hearing the dysfluent speaker (e.g., giggling and whispering) were consistent with the work by Franck et al. (2003).

Ham (1990) suggested children become more aware of stammering as they get older. This study reported that 6-8 year old children had a less well developed stereotype for the speaker who stammered compared to older groups of children aged 8-10 and 11-13-year old. Franzoi (1996) suggested the process of forming stereotypes develops with age as the individual synthesises information. Similarly, Hartford and Leahy (2006) found that although the children aged 6-13 years old perceived the fluent speaker more favorably than the dysfluent speaker the younger children aged 6-8 years had less negative stereotyped views compared to the older children. They also found 81% (21) of the children aged 11-13 years old indicated a preference to be friends with the fluent speaker whereas equal numbers of the children aged 6-10 years chose to be friends with the fluent and dysfluent speaker. This may be accounted for by older children tending to choose friends who have similar traits to them who they can relate to rather than identifying with people who they view as different to themselves, such as YPWS (Shaffer, 1999).

However, Evans, Kawai, Healey and Rowland (2006) investigated peers' perceptions of a 16-year-old adolescent who stammered. In contrast to studies with children, the older adolescents viewing the videotape of the dysfluent speaker made few comments regarding the teenager's personality. Although they believed the speaker would experience teasing they did not feel the teenager would have difficulty making friends. The authors suggested that this difference in outlook is possibly due to an overall increased tolerance towards people with disabilities in society. These findings are supported by Evans, Healey, Kawai and Rowland (2008) who found that fluent adolescents aged 10-14 years old were happy to speak to peers who stammered and that the presence of stammering did not affect whether

the peer would be a personal friend or be part of their friendship group. Furthermore, the adolescent participants felt at ease when communicating, both listening and speaking, with the peer who stammered.

Mayo and Mayo (2013) studied college students' views regarding whether they would have a romantic relationship with a YPWS. They found less than one third of participants would have such a relationship and one half of participants were uncertain but reported they would use a combination of factors about the YPWS to support their decision making, such as the person's personality, severity of stammering, intellectual level and physical attractiveness. Van Borsel, Brepoels and De Coene (2011) also reported that adolescents and young people aged 16-23 years perceived peers who stammered as less attractive than non-stammering peers and were less inclined to become romantically involved with a peer who stammered. The authors acknowledged that these results should be seen in light of some design issues with their study, for example little information was provided to the participants about the stammering behaviour observed and the stammering viewed was of a severe nature. Further research is needed regarding the perceptions of adolescents and young people towards YPWS with varying degrees of stammering.

***2.6.2.2 Bullying.*** In the UK Davis, Howell and Cooke (2002) found CWS to be more at risk of being bullied than their peers and at risk of being rejected or ignored in a social context. Similarly, Blood et al. (2011) compared the self-reported experiences of bullying of 54 YPWS and 54 young people aged 13-18 years who did not stammer and found 44.4% of the adolescents who stammered were bullied in contrast to 9.2% of non-stammering young people. The results from this study cannot be generalised to the population of adolescents who stammer due to its sample size, the lack of representation from a range of ethnic groups and limited female participation, but the study does concur with outcomes from other studies concerning children and adolescents who stammer being at greater risk of bullying than their peers (Blood & Blood, 2004; Blood & Blood, 2007; Langevin, Bortnick, Hammer & Wiebe, 1998, Van Riper, 1973).

***2.6.2.3 Teachers.*** As children go through their school life they have to contend with new challenges, cognitively, socially and emotionally (Stewart & Turnbull, 2007). Each year they change classes, which will usually include forming a relationship with a new teacher, who "exerts a strong influence on children's behaviour and attitudes in all sorts of ways" (Stewart & Turnbull, 2007, p.108). The behaviour of teachers can impact student achievement and influence the acceptance of students by their peers (Turner & Helms, 1995). Teachers have a role in supporting students who stammer to help them manage

challenges they may face socially as a result of potential negative beliefs of peers (Franck et al., 2003).

Previous research investigating the relationships between CWS and their teachers shows mixed findings. In a study by Daniels et al. (2012) only one participant from 19 adults described previous negative experiences with teachers. In contrast, Butler (2013) reported many AWS recollected strong negative encounters with teachers during their school life. Although the sample consisted of a range of ages from 19-89 years, it was a recurrent theme “spanning six decades of educational practice” (p. 59). Butler (2013) stated how participants recalled that their requests to be excused from oral classroom activities were unhelpful, with some teachers questioning whether the student actually stammered and believing the student’s plan was to simply avoid class participation. Hearne et al. (2008) reported varied responses from adolescents who stammered with some describing how teachers associated their stammer with nervousness and ignored their stammer, seldom approaching the students about their stammer. However, the few participants who did describe intervention from teachers found this to be approached in an unhelpful way.

Lass et al. (1992) used a questionnaire which required teachers to list as many adjectives as they could think of which they felt described four hypothetical PWS, of which there were 2 children aged 8 years (one male, one female) and two adults, again one of each gender. The traits generated by the teachers fell into four main categories: personality, physical appearance, intelligence and speech behaviour. The large majority (67%) of traits were negative, and of these 71% were related to personality. A small proportion of positive traits (20%) and neutral traits (13%) were listed. This study also found there was a high degree of similarity in how all four subjects who stammered were viewed, regardless of age or gender, and the most frequently cited adjective was “shy” for all four subjects, although “insecure” and “nervous” were also common. These researchers concluded that teachers’ perceptions of PWS include a majority of negative personality stereotypes and they suggested that since teachers have a vital role in the educational process that their perceptions are important to the progress of children who stammer. Lass et al. (1992) recommended that teachers receive training prior to practice and as part of their continuing educational development to increase their awareness of stammering and in particular to see the child who stammers as a whole person and not just in terms of their stammering behaviour. This study was replicated by Silverman and Marik (1993) who reported similar findings to Lass et al. (1992). However, whilst Silverman and Marik (1993) acknowledged that teachers assigned negative adjectives to PWS in the study, they argued that this did not automatically infer that teachers viewed PWS unfavourably.

Dorsey and Guenther (2000) examined the attitudes of college professors toward college students who stammered compared to non-stammering college students. The professors were asked to rate either a hypothetical student described as stammering or a hypothetical student who did not stammer as to the degree to which the students possessed particular personality traits. The questionnaire was sent to 100 professors, 50 of whom were asked to rate the student who stammered with the other half completing it in relation to the student who did not stammer. For 15 out of 16 personality traits, the student who stammered was rated more negatively compared to the fluent student, for example they were rated lower on the personality traits connected to intelligence and competence in comparison to students who did not stammer. There was just one trait where the non-fluent student was rated more positively than the fluent student: being regarded as less aggressive. This finding suggested that college professors viewed the personality traits of college students who stammered more negatively than students who did not stammer. However, these findings are questionable as they are based on a small sample size of 34 returned questionnaires from professors and there was no clarification as to how many of these concerned ratings of the student who stammered versus the student who did not stammer. Furthermore, these findings appeared to relate to students in the American education system but the authors did not define the 'college' context, the age of the hypothetical college students or the status of the college professors. This lack of detail makes it difficult to relate these findings to the population of children and YPWS who are engaged in different educational contexts within other countries.

A recent study compared the beliefs of teachers with those of the general public about PWS. Participants' data were accessed through an international database which holds completed responses to The Public Opinion Survey of Human Attributes -Stuttering (POSHA-S) from over 9,000 people from 33 countries. For this study responses were gathered and analysed from 269 K-12 teachers (who taught children from kindergarten, 5-6 years to 12$^{th}$ grade, 17-18 years approximately) and from 1,388 non-teachers, which excluded SLTs, PWS, under 18s, those with a classroom role or any occupation which lacked clarity. The survey asked respondents to rate statements concerning four areas: personality traits, who should help stammering, causes of stammering and potential for social and professional success of PWS. Results showed there to be no difference between the two groups of participants in relation to the accuracy of their beliefs about PWS. Also for both groups female respondents had more accurate beliefs than male respondents and respondents' beliefs increased in accuracy with age, with more years of education and if acquainted with a PWS. (Arnold et al., 2015). This latter finding highlights how increasing people's awareness and understanding of stammering could effect change in people's beliefs about PWS.

A further study by Li and Arnold (2015) explored the reactions of K-12 teachers and non-teachers toward PWS. Similar to the previous study the researchers accessed replies to the POSHA-S from the same two groups of teachers and non-teachers. The survey asked respondents to self-report their reactions to PWS in relation to four areas: accommodating/helping, sympathy/social distance, knowledge/experience and source of knowledge about PWS. Results revealed that there was no significant difference in the reactions of teachers and non-teachers towards PWS on the individual components of the scale, apart from the component concerning knowledge of sources. This component showed that teachers accessed more knowledge sources about stammering than the general public. There are limitations with this study regarding the fact that respondents were not asked to rate statements in relation to children or YPWS at school but in general to PWS. Their responses could differ if they were instructed to think of or view a video-recording of a specific child or YPWS and potentially the results would be more applicable to the current study.

Arnold and Li (2016) used the POSHA-S database to investigate whether there was an association between the inaccurate beliefs of 2,206 adults in America, excluding SLTs and PWS, and their anticipated behaviour and affective reactions towards PWS. The beliefs scale described in the prior study by Arnold, Li and Goltl (2015) and two measures (accommodating/helpful and sympathy/social distancing) from the reactions scale used by Li and Arnold (2015) gathered responses regarding beliefs and anticipated reactions to PWS. The results showed people's beliefs significantly influenced their intended responses towards PWS, for example, respondents who held the accurate belief that stammering had a genetic cause indicated increased understanding and helpful reactions towards PWS. Also respondents who believed it was possible for PWS to have positive social and work opportunities, were more likely to interact with them in a positive supportive way. Although the study by Arnold and Li (2016) was not specifically focused on teachers it is important since teachers' inaccurate beliefs of PWS are likely to impact on their reactions towards students who stammer. Arnold et al. (2015) suggested if teachers' beliefs are more accurate and they have understanding of the ability of students who stammer then this may positively impact on the academic achievement of these students.

In contrast, Irani and Gabel (2008) asked K-12 teachers to assign traits, using a semantic-differential scale, in response to a written description of either a PWS or a fluent speaker and found teachers described both speakers positively. A total of 178 teachers took part in the study with 88 teachers completing the scale in relation to PWS and 90 responding to the description of the fluent speaker. The authors suggested that this finding indicated a change in the outlook of teachers towards PWS and an increase in their tolerance and acceptance of

PWS. Although these results represent a positive shift in teachers' attitudes towards PWS, the study did not identify the gender or age of the two speakers or the severity of stammer for the PWS. This detail would further inform the results of the study and possibly explain this change in teachers' perceptions of PWS. Other studies have also indicated an increase in the accuracy of teachers' knowledge about stammering and more positive views towards students (Irani, Abdalla & Gabel, 2012; Pachigar, Stansfield & Goldbart, 2011; Plexico, Plumb & Beacham, 2013).

Irani, Gabel, Hughes, Swartz and Palasik (2009) examined the views of 204 K-12 American teachers regarding the career advice they would offer PWS compared to fluent students. Participants self-completed a survey in response to a written description of either a PWS or a person who did not stammer. Results indicated that teachers did not view particular careers to be more suitable for PWS compared to fluent students but did judge 10 careers which they viewed to require frequent, extensive and strong communication skills (e.g., law) as being more difficult and possibly less advisable for PWS. This is an important finding since, as discussed earlier, previous studies have indicated that teachers' opinions can impact the decisions of students who stammer (Stewart & Turnbull, 2007; Turner & Helms, 1995).

**2.6.3 Mental health.** The act of stammering can result in a range of physiological and behavioural reactions and impact on an individual's thoughts and emotions (Beilby & Yaruss, 2012), resulting in a negative mood and social anxiety in YPWS (Tran, Blumgart & Craig, 2011). Previous research has shown that social anxiety, (fearing negative evaluation from others in social situations or performance orientated tasks), usually begins during adolescence at an average age of 13 years old (Kessler et al., 2005). Research has suggested that high anxiety levels are related to a decrease in self-esteem levels and quality of life, and can be associated with depression (Stevanovic, 2013).

A study by Blood and colleagues (2007) compared the self-reported anxiety and self-esteem scores of adolescents who stammered with non-stammering adolescents (aged 12-18 years) using the Revised Children's Manifest Anxiety Scale (Reynolds & Richmond, 2002) and The Rosenberg Self-Esteem Scale (Rosenberg, 1965). Although Blood et al. (2007) found that the group who stammered had higher levels of anxiety compared to their peers, these higher scores were still within the normal range and there was no significant difference between the two groups. A correlation was found between high anxiety and low levels of self-esteem for both the adolescents who stammered and the control group participants but no association was found between anxiety and stammering severity. These results contradicted previous research findings which reflected the view that YPWS are more anxious and nervous

compared to non-stammering peers (Crowe & Walton, 1981; Ham, 1990; Ruscello, Lass, Schmitt & Pannbacker, 1994). However, the group of adolescents who stammered were receiving therapy at the time of the study so their scores may over-estimate or under-estimate their anxiety level and bias the study's results.

Furthermore, research by Gunn et al. (2014) examined the anxiety of 37 adolescents who stammered aged 12-17 years and found 38% of the YPWS received at least one diagnosis of mental disorder with the most common diagnosis being anxiety. A comparison between younger (12-14 years) and older adolescents (15-17 years) found higher levels of anxiety, depressive mood, reactions to stammering and emotional and behavioural difficulties for the older age group (Gunn et al., 2014). This finding is supported by Smith, Iverach, O'Brian and Kefalianos (2014) who suggested that the negative self-perceptions of PWS increase over time. Iverach and Rapee (2014) also suggested that the persistence of stammering and the resulting adverse reactions are likely to contribute to a development of anxiety in PWS.

Other studies have focused on the self-perceived communication apprehension of YPWS and their peers. Blood, Blood, Tellis and Gabel (2001) found increased communication apprehension ratings for 39 YPWS associated with meetings, discussion groups, interactive communicative situations and public speaking compared to 39 adolescents who did not stammer. Similarly, Erickson and Block's (2013) study of YPWS aged 11-18 years found 64% (n=23) of participants rated high communication apprehension on the meetings sub-scale of the Personal Report of Communication Apprehension (McCrosky, 1984) and 81% (n=29) on the public speaking measure.

Smith et al. (2014) identified methodological flaws in a number of the studies reviewed here, such as small sample size reducing the statistical power of the study; samples taken from clinical populations of YPWS so study results only reflect YPWS who are either waiting for therapy or receiving therapy and do not include untreated YPWS; and many studies included a wide age range of participants so findings for specific ages cannot be identified. However, despite these limitations, Smith et al. (2014) acknowledged that the individual findings of these studies highlight important areas to consider in the assessment and treatment of YPWS, including the psychological challenges for YPWS, the elevated speech related anxiety in YPWS, and the need to address speech related anxiety at an early stage.

## 2.7 The voices of young people who stammer

The studies reviewed show there is a lack of prominence given to the voices of YPWS. The United Nations Convention on the Rights of the Child (1990) under Article 12, states that the views of children should be listened to and that they should be participate in any decision

making process in line with the age and maturity of the child. It adds that a child's capacity to voice their views develops as they mature and that the opinions of teenagers will hold greater credibility compared to a young child. This is supported by the UK Children's Act (2004) which states that children should have a voice and be involved with matters that may affect them. These views are aligned with the World Report on Disabilities (WHO, 2011) which values and recommends consulting with people with disabilities and gaining their perspectives on their lives in order to improve the awareness of others and foster a supportive environment for all.

Although recent research has made progress in listening to and taking account of children's views in relation to their speech and language needs and therapy provision (McCormack, McLeod, McAllister & Harrison, 2010; McLeod, Daniel & Barr, 2006; Owen, Hayett & Roulstone, 2004) there is little about the perspectives of YPWS in terms of their lived experiences of being an individual who stammers or about their opinions regarding school life and speech and language therapy provision. The current study therefore aimed to capture and understand the experiences of YPWS in education and of those who have recently completed their education. It is crucial to gather the accounts of this specific population so that their perceptions and views can be taken into account by professionals such as teachers and SLTs when working with this group of young people. Furthermore, the perspectives of YPWS are important to hear in the wider context of school provision as recent UK Government legislation was approved to ensure young people aged 18 years old will remain in education or recognised training.

## 2.8 Summary of literature, rationale and research questions for study two

Studies reviewed report the negative perceptions of PWS concerning the impact of stammering on their educational experiences of PWS. However the majority of findings were based on retrospective accounts of individuals' experiences of a particular education system, often experienced a long time ago or in another country. Participants' recollection of events could be distorted by the process of time and their reflection influenced by life events and they may therefore bear little relevance to YPWS in the current UK education. This review has highlighted the need to engage with YPWS and to listen to their voices about their perceptions of their educational experiences and outcomes. The meaningful involvement of YPWS is essential in order to identify and address the potential needs of this population and has led to the development of the following questions for study two:

**Research question 2:** How do young people who stammer perceive their educational experiences during secondary school and continuing education?

Sub-questions:

i. How do YPWS describe and manage their experiences of living with stammering as young people in education?
ii. How do YPWS describe the impact of stammering on their educational experiences?
iii. How do YPWS feel about their educational achievement and future prospects?

This thesis therefore sought to expand on the findings of educational outcomes and experiences, particularly those pertaining to the experiences of YPWS by providing a current and in-depth understanding of the phenomenon of stammering and how it is lived and experienced by young people and how it may influence their educational outcomes.

# CHAPTER 3. METHODOLOGY

## 3.1 Overview

This chapter is divided into two main sections. The first section discusses the theoretical framework and methodological choices made to address the research questions. The worldview perspective that has been adopted is described and justified with relevant literature. The second section describes the specific research design, including participant selection, research procedure, data collection and analysis methods.

## 3.2 Theoretical framework

The rationale for this study is based on the premise that YPWS do less well academically than their peers, an idea which has been proposed in some retrospective studies with adults, but which requires further exploration. There is a dearth of research concerning adolescents who stammer, particularly in relation to their educational performance, their views of their stammering behaviour and the impact this may have on their educational choices and progress in the UK education system.

It is important to listen to the views of YPWS to gain an insight into their perspectives of their academic performance, and to hear their voices describing their current or recent educational journey, in order to determine the best clinical and educational management for them, and to inform overarching government policy in regard to people with a disability.

The research questions guided the research philosophy and methodology chosen for this thesis. Traditionally social science research is viewed in relation to two main paradigms, namely positivist and constructivist, which are seen to hold opposing views (Saunders, Lewis & Thornhill, 2009). Positivists sit within a scientific structure and view reality as fixed and ordered, independent of the researcher. All phenomena or behaviour can be observed and rigorously measured to test hypotheses, and theory can then be built on observable credible facts (Bowling, 2009). In contrast, constructivists believe there are numerous interpretations of reality which are dependent on the interaction between human beings and their knowledge of their world. People will construe experiences and events in their consciousness and develop their understanding of the world in the context of their individual characteristics, their interactions with others and their social and cultural environment (Vygotsky, 1978). The researcher needs to understand the individual differences between people and make interpretations of individuals' experiences and views of their world (Saunders et al., 2009). Constructivism recognises that any interpretation of others is

influenced by the researcher's own experiences, set of meanings and values which impose subjectivity.

A further research paradigm or worldview is pragmatism (Creswell, 2009), which is the theoretical framework underpinning the research design for this study. Pragmatists are not committed to one philosophical approach but recognise the need to draw upon a combined research approach instead:

'It is more appropriate for the researcher in a particular study to think of the philosophy adopted as a continuum rather than opposite positions. At some points the knower and the known must be interactive, while at other, one may more easily stand apart from what one is studying' (Tashakkori & Teddlie, 1998, p.26).

The pragmatic tradition evolved in the late nineteenth century and early twentieth century through the work of American researchers Dewey and James (Reichardt & Rallis, 1994) and more recently the writers Patton (2002) and Cherryholmes (1992). Researchers in this paradigm believe the truth about the real world cannot be understood via a single scientific method and choose the methodology that is most appropriate for answering the research questions. In terms of epistemology, both observable phenomena and subjective meanings can provide acceptable knowledge to answer the investigation's research questions. Pragmatists focus on the research questions and utilise both quantitative and qualitative research designs in order to understand the phenomenon.

For the first study an objective and value-free stance was taken to investigate and gather evidence about the types of subjects and qualifications taken by YPWS and to make a comparison with peers. For the second study an interpretative phenomenological perspective was adopted to gain an in-depth understanding of the educational experiences of YPWS. This was underpinned by constructivist epistemology which suggests there are multiple views of reality which can be studied, but the social and cultural context plays a significant part in individuals' experiences, thoughts and feelings (Vygotsky, 1978). People cannot be understood without considering the characteristics of the individual, the interactions with others and the historical, social and cultural environment that frame the individual experiences (Vygotsky, 1978).

## 3.3 Methodology and methods

A pragmatic perspective aligns well with a mixed methods approach to data collection and analysis (Tashakkori & Teddlie, 1998). According to Creswell and colleagues (2004), "Mixed methods investigations involve integrating quantitative and qualitative data collection and

analysis in a single study or a program of inquiry'' (Creswell, Fetters, & Ivankova, 2004, p.7). This "toolkit approach" (Ritchie & Lewis, 2003, p.15) reflects the pragmatist worldview of selecting suitable methodologies for addressing the research questions instead of being tied to a single theoretical viewpoint. Mixed methods studies have been carried out in speech and language therapy since the late 1990s and are valuable in addressing the complex nature of studying human communication difficulties (Glosgowska, 2011).

Researchers may choose a combined research approach, such as mixed methods for a range of reasons (O'Cathain et al., 2007). These include:

- Comprehensiveness, so that a full picture of the phenomenon is explained using both quantitative and qualitative approaches
- Increasing validity, where two methods are used to support the study's outcomes
- Development, whereby one method facilitates and improves the use of another method
- Emancipation, whereby the marginalised groups are given a voice in research
- Practicality, when a single method may be impractical to implement
- Salvaging, whereby one method rescues another that has faltered

Comprehensiveness and development were the primary reasons why a combined research approach was used in the current study.

**3.3.1 Research design.** This thesis used a mixed methods design involving two consecutive studies in order to gain a comprehensive picture of the educational progression of YPWS in secondary school and continuing education. In planning a mixed methods study decisions need to be made in regard to timing, weighting, mixing and theorising (Creswell, 2009). One approach, described as a sequential explanatory strategy, enables quantitative results to be elaborated on by an analysis of qualitative data in a second study of data collection (Creswell, 2009). That was the approach used in the current mixed methods study: the quantitative study (study one) provided information about the educational choices and qualifications of YPWS followed by a qualitative study (study two) which gave insight into the perceptions, attitudes and beliefs of the participants in relation to their educational experiences. The procedure for this approach is illustrated in Figure 3.1.

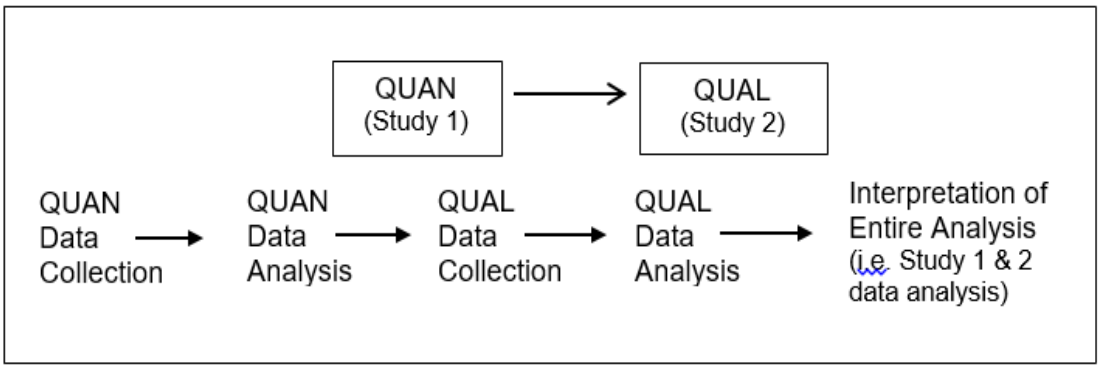



*Figure 3.1.* Sequential explanatory design (adapted from Creswell et al. 2003)

Proponents of mixed methods procedures usually consider that the quantitative phase in this model is given more weighting or priority than the qualitative phase (Creswell, 2009). However, for this study although the first priority is to carry out the quantitative aspect in this process, the qualitative study is just as valuable in helping to build a comprehensive picture of YPWS in relation to their academic progression and is essential in answering the research questions for this thesis.

Although the procedure appears to have two distinct stages, these are linked in two ways. The findings from the first study of the research inquiry influenced the focus of the second study in terms of specific areas to address in the next stage of the research process and the results of the second study expanded and supported the initial quantitative findings. This combined approach resulted in both quantitative and qualitative information to provide a deeper and richer description of the phenomenon. Figure 3.2 provides a flow diagram adapted from Yardley and Bishop (2008) which illustrates the mixed method design used to explore the research questions for both studies.

**3.3.2 Type of study.** The sequential mixed methods approach to this thesis included survey and interview data, involving the study of YPWS at a particular time. It included both current and recent retrospective reports from YPWS, that is, young people were asked about their current or recent decision making process regarding their educational choices, outcomes and experiences. The first study also followed up 15 participants to gather further information regarding their educational progression and employment choices.

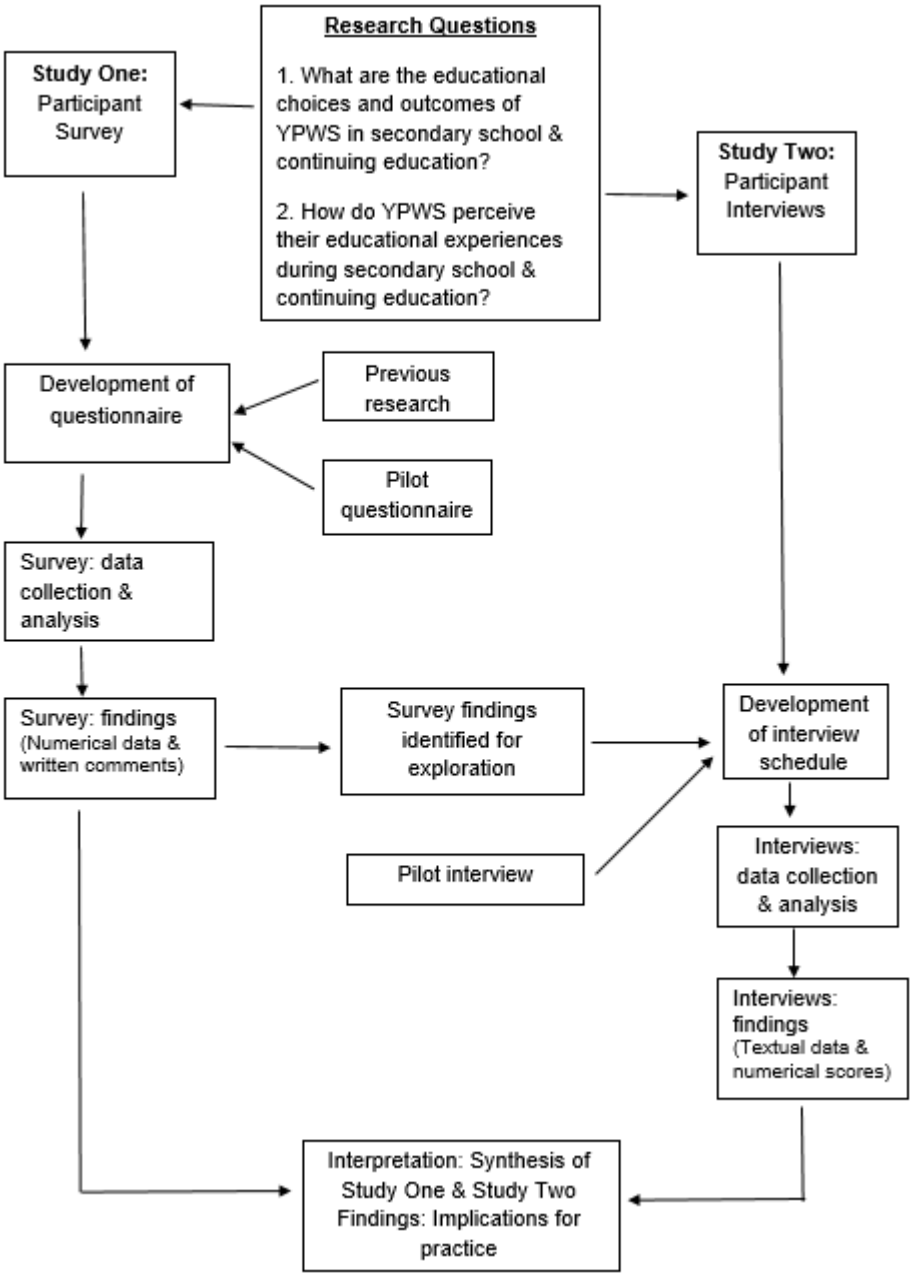



*Figure 3.2.* The relationship between the two studies within the mixed methods design

**3.3.3 Ethics.** For both studies the recruitment of participants via schools and the British Stammering Association (BSA) was approved by the University of Sheffield's ethics committee in the Department of Human Communication Sciences (see Appendix A.1). Ethical approval for recruitment via the National Health Service (NHS) was granted by the National Research Ethics Service (NRES) Committee South West and by Birmingham and Black Country Comprehensive Local Research Network (see Appendix A.1). In order for this study to receive ethical approval a number of considerations were taken into account in

accordance with the Royal College of Speech and Language Therapists' (RCSLT, 2006) code of ethics.

A participant information sheet was designed for each study which explained that ethical approval had been received from the appropriate ethics committee and included the purpose of the study and the possible risks and benefits of taking part. Details were given regarding the anticipated time required to take part to help participants to judge whether they had the time to commit to the study. As part of the consent procedure, agreement to audio-record the interview or for the researcher to take notes was explained. Contact details of the researcher and the supervisors of the project were included in case participants had questions or required a further explanation. The information sheet was piloted with young people aged 14 to 21 years of age and no issues were raised concerning the comprehension of the written material.

The information sheet explained that participants could be sensitive to some questions related to their stammering and their academic progress and sought to reassure them that there was no judgement being made about them in relation to their stammer or their academic ability. Potential participants were made aware that they did not have to answer every question and if any discomfort was expressed during the interview the interviewer would ask whether they wished to miss out the particular question or stop the interview and that the recording would be stopped immediately. They were informed they could withdraw from the study at any point. Contact details for the BSA were included to enable participants to receive telephone support from the Association if required. Participants recruited via the NHS had access to their speech and language therapist and to their local Patient Advice and Liaison service for additional support.

The information explained that there were no direct benefits to taking part in the investigation, but that their responses would provide valuable information about the educational outcomes and experiences of YPWS. A ten-pound online retailer voucher was offered to study one participants as a token of thanks for their time and effort taken in completing the questionnaire and study two interview participants were told they would be reimbursed for any travel expenses incurred.

To ensure the personal data of participants remained confidential the Confidentiality NHS Code of Practice (DoH, 2003) and the Data Protection Act (1998) was adhered to (Legislation.gov.uk, 1998). All participants' personal data was anonymised by allocating a number to each participant for the initial questionnaire study and using pseudonyms when reporting interview findings with participants in the second study. Participants were assured that they would not be identified in any results written up and possibly published. All

participant data was stored in a locked filing cabinet and the storing of electronic data, including audio-recordings, was password protected with researcher-only access to all data.

Participants gave consent to take part in the investigation prior to data collection commencing. Parental consent was also gathered for participants under the age of 18 years. Participants were reminded that their involvement was voluntary and they could decide to withdraw from the investigation at any time without there being negative consequences.

## 3.4 Study 1: A quantitative approach –survey design (Questionnaire)

**3.4.1 Overview.** In study one a survey was employed, a non-experimental quantitative approach, to shed light on the nature of the academic achievement of YPWS in terms of frequencies and comparisons with data from peers. Survey methodology is a commonly used quantitative research methodology which seeks to collect descriptive data regarding a particular population, in this case YPWS, through a questionnaire (Bowling, 2009). A non-experimental descriptive approach is used to gather evidence to develop and inform the clinical knowledge of practitioners and it can show the need for additional areas of study (Steen & Roberts, 2011).

### 3.4.2 Participant recruitment.

***3.4.2.1 Sample size.*** Power analyses are ideally used to determine sample sizes (Portney & Watkins, 2009) and are important in experimental research so that statistical significance can be reached at an appropriate alpha level. However, this was an exploratory study rather than an experimental one and was not seeking to test strictly defined and deductively derived hypotheses so power calculations were not necessary for this study.

This first stage of the research aimed to gather preliminary data from YPWS which was to be compared to national statistics data. Hall and Hall (1996) suggest that when research is of an exploratory nature where there is limited knowledge of the subject that a minimum sample size of 30 approximately should be considered. Thus, a sample size of between 30-50 participants was the aim for this first study. It was acknowledged that this sample size may be insufficient to permit valid generalisations to the population of YPWS, but it was intended to provide an initial consensus from the data. Further levels of evidence were gathered during study two.

***3.4.2.2 Participants.*** Purposive sampling was used to recruit participants who shared the key feature of stammering. Table 3.1 outlines the inclusion and exclusion criteria

that were used to reflect the population under study and to control for variables that could independently influence results of the investigation. Non-stammering peers: control participants were not recruited for this study but instead a comparison of data from YPWS was made by using statistics reporting pupils' achievement in England from the Department for Education - Data, Research and Statistics (DfE, 2014c). The attainment for level 2 and level 3 terms of qualifications achieved were accessed as well as some information regarding specific subject qualifications achieved.

***3.4.2.3 Recruitment process.*** Three stages of recruitment were necessary because the first two approaches yielded very few respondents.

Recruitment via secondary schools

Emails were sent to 52 schools requesting the head teacher to identify if there were any year 10 and 11 pupils, who had disclosed that they stammer to teaching staff, and who might be interested in participating in the study. Replies were received from just five, and only one of the schools was willing to be involved. As a result of this poor response, 15 schools were contacted by telephone and it was established that they had not received the email. They indicated that the email had not reached the intended recipient and that a hardcopy of the letter would be preferable. A hardcopy letter was posted to 370 schools in the West Midlands. A total of 49 replies (12%) were received from schools, and of these 12 schools identified 14 possible participants.

The 12 schools were sent the participant information sheet, consent form and questionnaire for participant completion. Four questionnaires were completed by YPWS, three males and one female and all participants self-reported having a stammer which was confirmed by their school teacher.

Recruitment via the National Health Service (NHS)

Due to the recruitment difficulties, a second phase of recruitment was undertaken via the NHS. Through the NHS ethics procedure, the researcher was allocated a local NHS collaborator who provided contact details of SLTs who had potential participants on their caseloads. The researcher sent SLTs information about the study and they were asked to approach students aged 15-18 years old who had a confirmed diagnosis of stammering. Potential participants were either receiving NHS speech and language therapy or were on review for their stammer in Birmingham Community Healthcare NHS Trust. This recruitment method did not generate any response from YPWS and no feedback was received from the lead SLT to account for this lack of response.

Table 3.1. *Participant inclusion and exclusion criteria*

| **Inclusion** | **Exclusion** |
|---|---|
| Confirmed diagnosis of stammering by a speech and language therapist or self-identification: Identification of participants with a common characteristic of stammering in order to be representative of the phenomenon being investigated. | Diagnosis of a moderate or severe language difficulty: This could impact on the individual's ability to understand and participate in the research study. It could also affect the educational progress of an individual and it would be difficult to determine the impact of this language need versus the stammering need on a young person's educational experience and outcomes. |
| Males and females: Stammering is prevalent in both males and females, although the gender ratio is 4:1 males to females. Both genders are important to include in the study in order to uncover data in relation to similarities and differences in their educational experience. | Diagnosis of a moderate or severe learning disability: If a participant had an additional learning need it would be difficult to determine the impact of this learning need versus the stammering need on the young person's educational experience and outcomes. |
| 15-18 year olds: This age range captures young people at time when they are making educational choices, taking examinations and making decisions regarding employment and careers. | Hearing or visual impairment: These could impact on the results of the study for the same reasons as stated above. |
| Bilingual: stammering is prevalent in monolingual and bilingual speakers. It is important to include both monolingual and bilingual YPWS to examine data in relation to similarities and differences in their educational experience. | |
| Attending mainstream school/college or employed full-time or part-time or unemployed: A wide sample of young people in different educational and work contexts will provide the opportunity to obtain data about the phenomenon under study and develop understanding. | |
| Living in the West Midlands region of the UK: This is a geographically diverse region with a wide variation in socio-economic status. The socio-economic differences and the rural vs. town locations could affect the educational experiences of YPWS. | |

Recruitment via the British Stammering Association (BSA)

A third approach to the recruitment of participants was necessary because of the lack of participants recruited through the previous approaches. A notice outlining details of the study was displayed on the website of the BSA and a voucher was offered to people willing to take part. Potential participants were asked to express their interest in participating by emailing the Chairperson of the BSA. The names of potential participants were then forwarded to the researcher. Additionally, the age range of participants for the study was raised, to include young adults up to the age of 25 years, in an attempt to increase the number of participants recruited.

The notice generated interest from 28 YPWS and 23 returned a completed questionnaire.

Recruitment via the Michael Palin Centre (MPC)

A notice outlining details of the first study was also displayed on the notice board at the MPC, a specialist support centre for PWS. Two YPWS responded to the notice and completed the questionnaire.

Table 3.2. *Summary of recruitment procedure and numbers of participants recruited*

| Recruitment procedure | Number of participants recruited |
|---|---|
| Secondary schools (via teachers) | 4 |
| National Health Service (via SLTs) | 0 |
| British Stammering Association | 23 |
| Michael Palin Centre (via SLTs) | 2 |
| Word of mouth | 6 |
| Total number of participants recruited | 35 |

### 3.4.3 Materials

***3.4.3.1 Development of the questionnaire.*** A self-administered questionnaire was designed comprising of a series of closed and open ended questions to appraise the educational progress and experiences of YPWS.

In reviewing relevant literature no existing survey was found to be appropriate for the aims of this first study. As a result, questions were developed by the researcher to address the aims of the study. These questions were based on current literature concerning the impact of stammering on educational experiences and career paths of adults who stammer (Daniels, 2012; Gabel, 2004) and literature regarding the educational outcomes of other speech and language populations (Palikara, Lindsay & Dockrell, 2009). In addition, the experiences of the researcher, as a SLT working with YPWS, influenced the questions asked.

The focus of the questionnaire was outlined at a regional meeting of specialist SLTs working with PWS, and a subsequent discussion was beneficial and confirmed the validity of the questions to be addressed. The questionnaire was also reviewed by two academics supervising the investigation.

It was not possible to confirm the reliability of the questionnaire due to this being a newly developed tool and time did not permit the re-testing of the tool for stability over time. However, the questions developed were based on empirical research, for example concerning the risk factors associated with stammering. Also by comparing the results from participants it could be seen that questionnaire items probed the same concept and yielded the same response categories which demonstrated a degree of internal consistency reliability.

The questionnaire was separated into three sections, commencing with general questions and proceeding to more specific questions regarding participants' stammering and educational choices and progress:

Section A: General Information

The first section gathered demographic information about the participant (e.g. gender, ethnicity, post code address, language(s) spoken, school year and place of study if applicable). All questions in section A of the questionnaire were closed questions.

Section B: Speech Details

The second section consisted of questions regarding the participant's view of their speech including a description of their stammering behaviours and patterns, feelings about stammering, support for stammering, other possible speech and language therapy needs and family history of stammering.

Section C: Educational Qualifications

The final section requested the participant to list educational qualifications being studied and/or achieved including GCSE or other level 2 qualifications plus level 3 qualifications and degree awards if applicable. It collected information regarding subject choices, reasons for choices including participants' perceived effect of their stammering on their choices and support received with choosing subjects. The last question concerned participants' plans for the future.

Sections B and C consisted of both closed and open questions. The closed questions involved participants choosing a category or indicating their answer from a choice of possible responses (e.g., how would you describe your stammer: mild/moderate/severe?) Open-ended questions were designed to collect initial qualitative data in regard to feelings about their stammering behaviour; reasons for their subject choices; support received in the decision making process and employment details, if applicable. Sufficient space was provided for participants' verbatim replies rather than participants choosing terms from a pre-determined list. If completed electronically the space for the response automatically expanded to accommodate any length of reply.

At the end of the questionnaire two points were made in relation to further contact with the participant. Firstly, the participant was reminded that the investigator would be in touch in the future to ask for the results of any outstanding examinations being taken and details of future plans such as further education or employment choices (this was detailed in the Information Sheet). Secondly the questionnaire asked each participant to indicate if they might be interested in being involved with the next stage of the study. This would involve a participant providing additional responses to questions during an interview. Potential participants would be sent further information about the second research study at a later point in the data collection process and be asked to re-consent for part two of the study.

***3.4.3.2 Pilot study.*** Pilot testing of the questionnaire was also undertaken with seven YPWS to guide the development of the final version. Participants were recruited via a notice about the pilot study posted on the website of the BSA, through word of mouth and via the City Lit stammering centre. Five males and two females aged 15-23 years who self-reported stammering were recruited (see Appendix A.2). These young people were asked to complete the pilot questionnaire (see Appendix A.3) and a feedback form concerning the questionnaire (Bell, 2005) (see Appendix A.4). Involving participants who were similar to the target population (e.g. in terms of gender and age range and administering the questionnaire

in the same way as was planned for the study) increased the internal validity of the questionnaire.

The benefits of conducting a pilot study were three-fold. Firstly, checking the participants' responses to each question helped to ensure there was a shared understanding of the meaning of the questions and that the questions were testing what was intended which supports the internal validity of the questionnaire. Secondly some initial data were produced for analysis which helped with the development of the coding frame for study one data analysis, enhancing content validity. Finally, the feedback form gathered information from participants regarding the comprehensiveness and appearance of the questionnaire.

The individual responses to question items and the feedback forms were reviewed in order to evaluate the pilot questions. This process highlighted questions needing change and these were addressed by making amendments to the study questionnaire (see Table 3.3). However, the findings from the pilot study showed that the questionnaire appeared to reasonably examine the scope of the phenomenon and measured what it intended to measure. Also the results provided an adequate range of responses from the participants which could be interpreted and measured, demonstrating good content validity.

Participant feedback from the pilot testing of the questionnaire was received from five out of the seven participants. This indicated that the instructions were clear and all questions were relevant and acceptable, with only minor changes in the wording of two of the questions suggested by participants, which supported the face validity of the questionnaire. Useful comments were received in regard to the layout of the questionnaire, such as providing more room for responses and IT issues concerning the availability of the form electronically and the necessary formatting required. Time to complete the questionnaire varied with some participants needing longer than the ten minutes advised in the participant information sheet. To address the feedback amendments were made to the questionnaire and participant information sheet, enhancing the internal validity of the questionnaire (See Appendix A.5).

Results from the pilot study were not included in the study analysis because the questionnaire was revised following the findings of the pilot phase and this could cause any results to be inaccurate. Also the participants from the pilot study were not included in the study as they had already been exposed to the pilot questionnaire and they may respond differently to those participants completing the questionnaire for the first time.

Table 3.3. *Question development*

| Questionnaire section | Issues identified | Amendments |
|---|---|---|
| Section A | 1. Participants were asked to express whether they would be interested in taking part in the second study, but their contact details were not requested. | 1. Added question requesting participant's email address. |
| | 2. The question asking participants' school year assumes participants are in school, but some were attending college or university and others were in employment. | 2. Replaced asking a participant's school year with a box to complete 'if studying' and asked attendance to be recorded in terms of school, college, university as well as their year group.<br>Inclusion of question re: participants' employment experiences. |
| Section B | 1. Some open ended questions generated a range of responses which needed to be read and initially recorded in a computer word document. . | 1. Some re-coding of categories in SPSS was required to enable all responses to be represented. |
| | 2. The question concerning the age when participants became aware of their speech difficulty, produced varied answers (e.g. their age, age band, stage of education and always having stammered). | 2. Coding of replies about awareness of stammering changed from coding participant's age to stage of education (i.e. pre-school, primary, secondary, post 16). |
| | 3. Participants' responses regarding what they do when they stammer were extensive. | 3. Coding was developed to cover the two types of reported behaviour; type of stammering and presence of avoidance behaviour. |
| | 4. Participants reported more than one response to questions. This meant the percentages and numbers presented were not always consistent with the total number of respondents. | 4. This was explained in the analysis of the study. |
| Section C | 1. Unnecessary replication of participant information concerning educational qualifications. | 1. Development of a simple table with headings asking participants' subjects studied and qualifications. |
| | 2. Some responses lacked clarity due to the wording and sequencing of questions. | 2. Re-wording of a question and use of table to record qualifications. |
| | 3. Information was lacking about participants' future study or employment plans which identified a gap in the questionnaire. | 3. Inclusion of question asking participants about their future plans. |

***3.4.3.3 Examination record form.*** 15 Participants who were awaiting results of examinations were contacted later to request their results. A form detailing the examinations they had recently taken with a space for results to be recorded was designed and participants were emailed or posted this form for completion (see Appendix A.6).

**3.4.4 Procedure.** All potential participants for the first study were initially sent a participant information sheet about the study (see Appendix A.7). Participants interested in being involved in study one were asked for their consent to participate by completing a consent form. Informed consent was gathered from all participants and from the parents of participants aged less than 18 years (See Appendix A.8).

On receipt of the consent form, each participant was emailed or posted the questionnaire for completion (depending on their preference) (see Appendix A.9). Participants were invited to indicate if they were interested in being involved in the second part of the research by ticking a box at the end of the questionnaire. Participants with outstanding examination results were contacted at the relevant time point in the future and asked to list the outcomes from these and state their future educational or employment intentions.

### 3.4.5 Questionnaire Data analysis

***3.4.5.1 Quantitative data***. On completion of the data collection process a coding frame (Bowling, 2009) was used to organise and categorise the data. The responses to closed questions, including demographic information from section A of the questionnaire and rating questions in section B, were assigned numbers within a category, for example, for the gender variable, male = code 1 and female = code 2. This coded data was then manually entered into a Statistical Package for the Social Sciences version 22 database (IBM Corporation, 2013) (SPSS), together with population data from schools and statistics reporting pupils' academic attainment in England. A frequency analysis of participants' responses was generated and descriptive statistics were used where relevant to report key data.

***3.4.5.2 Qualitative data.*** Each questionnaire was read and re-read to enable the responses to be understood and organised in a systematic manner. Participants' responses to each open-ended question were recorded manually on a word document.

Participants' responses to open ended questions were also coded using labels generated after the responses to the questions had been analysed. This coding framework was therefore not predefined, but was developed by firstly creating a table of all participants' responses to each open ended question and then grouping common responses. A tally of

the number of responses to each code was recorded as a frequency count and then converted to percentages in order to illustrate similarities and differences in participants' responses. In addition, participants' responses were referenced with their participant identification number and relevant quotes from participants were identified to support the reporting of key views emerging from the data.

The results from this first study were interpreted and used in the development of the interview protocol for study 2. In this thesis, the results from each study are reported and discussed independently but then integrated in discussing the implications for practice and the conclusion to produce a holistic reflection of YPWS in education (Glogowska, 2011).

## 3.5 Study 2: A qualitative approach- interpretative Phenomenological analysis framework (Interviews)

**3.5.1. Overview.** In order to gain a deeper level of understanding of the educational experiences of YPWS in secondary school and continuing education, an interpretative phenomenological perspective guided the research design for the second study.

**3.5.2 Methodology.** Qualitative research is concerned with revealing and understanding the unique personal experiences of participants and how they make sense of their world. It seeks to produce a full and detailed verbatim account of participants' narratives to generate a useful understanding of the phenomenon (Smith, 2008). A qualitative approach involves the use of open ended questions, which allow participants to talk about the aspects of their experiences that they view as important to them. In this second study, the questions required a detailed description of their educational experiences from the personal perspective of a person living with stammering. These questions were also designed to probe and explain some of the quantitative findings in more depth. Using a purely quantitative approach, involving measurement scales, would not ensure that all areas relevant and meaningful to the individual are explored and would not necessarily provide a true insight into the lived experiences of YPWS.

*"Qualitative data collection techniques need to be participant-led, or bottom-up, in the sense that they allow participant-generated meanings to be heard. They need to be open-ended and flexible enough to facilitate the emergence of new, and unanticipated, categories of meaning and experience"* (Willig, 2013, p.23).

There are a number of different qualitative approaches that can be used in qualitative research which include for example, grounded theory, discourse analysis and phenomenology. Each of these have a different theoretical stance and may draw on different methodological emphasis. The chosen approach should be linked to the purpose of the research and underpinned by the theoretical viewpoint taken. It will then drive the research process including the choice and design of the data collection method and the analysis of data. This second study has adopted an interpretative phenomenological analysis approach as this subscribes to the social constructivist viewpoint which underpins the study and it focuses on interpreting the detail of individual experiences and their meanings in a particular context (Smith, Flowers & Larkin, 2009).

***3.5.2.1 Interpretative Phenomenological Approach (IPA).*** Phenomenology evolved through the work of Husserl in the 1930s and later by Heidegger in the 1960s. This approach is interested in studying human experience and places importance on understanding people's lived experiences of their circumstances. Researchers seek to gain knowledge of what it is like being a person in his or her everyday life and tries to understand and describe how the person makes sense of their personal and social world. Most phenomenological researchers aim to "bracket out" their own preconceptions in relation to the experience of the particular phenomenon under study, taking a neutral approach and remaining focused on the content of the person's experience. However, Heidegger (1962) developed hermeneutic enquiry which is a theory of interpretation which is at the core of humanity. This suggested as human beings we cannot help but bring our own view of the world to the research process and recognised that the researcher will have a perception of their relationship with a research participant and these may influence and be part of the interpretative process (Willig, 2013). This approach to interpretation helps the researcher to be aware of what they are doing when they are interpreting data (Smith et al., 2009).

IPA has its origins in phenomenology and is commonly used in health sciences research (Smith, 2011). It is interested in the lived experiences of individuals, what is important to them and how the individual understands and gives meaning to their experiences. With its distinctive focus on the lived experiences of the individual this approach emerged as the most suitable methodology to use for the current study. Furthermore, IPA acknowledges the impossible task of gaining direct access to a participant's perspective and accepts the researcher will have a history of presuppositions, a belief system based upon for example the researcher's gender, age, class and previous experiences and will draw upon their own experiences when making sense of participants' views of their experiences (Smith et al., 2009) which is in line with Heidegger's theory of interpretation. Smith et al. (2009) suggested

the researcher should keep a diary of their assumptions, expectations and thoughts prior to and following interviews with participants to aid their reflexivity (i.e. the researcher's awareness and honesty about one's thoughts and feelings in relation to the research (Shaw, 2010).

IPA provides a framework for idiographic exploration of individual cases and of what matters to the individual. Analysis occurs at the individual level so that an in-depth examination of the descriptions and claims made by the individual from their perspective can be gained. Interpretation of participants' individual stories is a cyclical process involving a double hermeneutic cycle, that is, the researcher makes sense of the participant who is making sense of his individual experience (Smith et al., 2009). First of all, the participant finds words to describe his experience and what this means to them and secondly the researcher sees this account through his "own experientially-informed lens" (Smith et al., 2009, p.36). IPA acknowledges the significance of the researcher's views which can both hamper and enhance the interpretation of another person's lived experience (Shaw, 2010). The researcher tailors the interview to the individual to gather an account of what is important to the person and seeks the individual's meaning filled reflections on his experiences.

The phenomenological approach aims for the researcher to be as close as possible to participants' personal experiences of the phenomenon; in the current study this concerns their educational experiences. Although researchers can get close to these described experiences they are one step removed from the story. Through the hermeneutic phenomenological process, researchers attempt to close this gap and for a fusion of horizons to occur between the participant and researcher (Shaw, 2010).

Following the analysis of the first case the process of phenomenological analysis then moves to the next participant's account until all individual cases have been analysed. An integrative analysis is then undertaken, to identify common themes and differences shared by participants. This step by step process is fully described in the later data analysis section of this chapter based on the procedure outlined by Smith et al. (2009). IPA typically advocates a small sample size but it can be used for larger studies as is the case for the present study. Smith et al. (2009) have suggested that with a larger sample the analysis may be focused more at the group level but with examples from individual cases.

**3.5.3 Participants.** The sample for this second study was drawn from the larger group of YPWS who had participated in study one. They were asked to indicate if they would be willing to take part in the second part of the research, involving an interview. Those who expressed an interest in taking part were emailed details (n=23). This included a participant

information sheet and a consent form. Participants under the age of 18 years were sent an additional consent form for parents to complete. On receipt of the signed consent forms participants were emailed to arrange a convenient date and venue to meet for the face to face interview. Nineteen of the 23 participants initially responded but two dropped out due to other commitments. Interviews were arranged with 16 of these participants and a further interview was arranged via Skype, but due to technology issues the interview data were unable to be transcribed and analysed so were not included in this study.

Final participants for the second study were 11 males and 5 females aged between 16 to 25 years old who experienced stammering. The sample varied in terms of age, educational level and/or employment, and speech and language therapy support. This diversity is important for an IPA study in order to be able to describe what can be shared between participants and what is different. The potential range of participants' views and experiences are essential to fully understand the phenomenon of stammering. Table 3.4 provides participant information.

Table 3.4 *Participant details* (all names are fictitious)

| **Participant name** | **Age at interview** | **Gender** | **Current Qualifications & grades** | **Currently in education/employment/ apprenticeship** | **SLT** |
|---|---|---|---|---|---|
| **Adam** | 18 | M | A levels: BBC | Education: College – re-sitting A levels to improve grades | Past |
| **Ben** | 18 | M | 9 GCSEs: A-C | Education: School – studying 3 A levels | Past |
| **Callum** | 19 | M | A levels: BCC | Apprenticeship in Facilities and management | Past |
| **Darren** | 21 | M | Level 3 Extended diploma | Education: University– degree in Business | Past |
| **Ed** | 25 | M | Masters | Employed - HR assistant | Current |
| **Floyd** | 22 | M | BSc (Hons) | Employed - Insurance | Past |
| **Gary** | 23 | M | Level 3 NVQ | Apprenticeship in Electrical engineering | Past |
| **Harry** | 22 | M | BSc (Hons) | Education: University- Master's degree in Transport planning | Past |
| **Isla** | 19 | F | Level 3 extended diploma | Education: University – degree in Nursing | Past |
| **Jess** | 18 | F | 8 GCSEs: A-C | Education: College - Level 3 extended diploma: Animal management | Past |
| **Kyle** | 25 | M | Masters | Employment - Disability Rights organisation | Past |

| | | | | | |
|---|---|---|---|---|---|
| **Liam** | 23 | M | GCSEs: Cx3; Dx3 | Employment - IT for solicitors | Past |
| **Mia** | 25 | F | Level 3 National Diploma & 2 A levels: DD | Education: University-degree in Radiography | Current |
| **Nikki** | 20 | F | A levels: BBB | Education: University-degree in Fashion | Past |
| **Owen** | 16 | M | 6 GCSEs: A- C & 3 Ds | Education: College - Level 3 extended diploma in Uniformed Public Services | Current |
| **Pippa** | 16 | F | 8 GCSEs: A-C | Education: School - studying 3 A levels | Current |

### 3.5.4 Materials

***3.5.4.1 Development of the interview schedule.*** A semi-structured interview schedule was developed with the main aim of exploring and understanding the individual participant's lived experiences of stammering in the educational environment. The interview structure was created by the researcher using the guidelines recommended for an IPA research design by Smith et al. (2009). As recommended by these guidelines, different question types were planned to allow participants to give detailed responses from their point of view in their own words.

In developing the interview schedule, proposed interview topics were initially discussed with the researcher's academic supervisors and subsequently amendments were made. The main change involved re- phrasing some questions to be more neutral and less leading. This would allow the participant to tell his story of his experiences in his personal world and not constrain his possible thoughts to those of the researcher. A pilot interview (see Appendix B.1) was then conducted with a male participant aged 25 years who had been involved with piloting the study 1 questionnaire. This process led to a revised interview schedule which included the following amendments:

- Reduction of broad topic areas from 12 to 8 to ensure interview focuses on the research questions and the interview time is reduced from 2 hours to 1 hour approximately
- Refocusing of open ended questions to be more specific in order to allow the participant to fully tell his story and ensure research questions are addressed
- Development of prompting and probing questions for each key question as necessary to gain participant's full story
- Re-structuring of the formatting for the interview schedule to be easier to follow

- Venue – ensure quiet library room (or a participant's home on request) to reduce external noise for the purpose of audio-recording

In addition to informing these changes the pilot interview gave the researcher practice in carrying out an in-depth interview as a researcher. As a speech and language therapist the researcher was familiar with gathering information from clients in the therapeutic context but this differed considerably from the experience of collecting data as a researcher. The pilot interview highlighted the need for the researcher to set aside her usual professional role as a therapist and to hold back from supporting clients to resolve their particular problems. Instead a more passive approach was adopted, giving the participant more time to tell their story, whilst continuing to monitor and facilitate the interview and respond sensitively to the participant.

Piloting of the proposed quantitative measures was also undertaken with the participant. This included the Rosenberg Self-Esteem Scale (Rosenberg, 1965) and the Wright and Ayre Stuttering Self-Rating profile (WASSP) (1999). The main purpose of carrying out the WASSP was to gain insight into the participants' feelings of 'disadvantage' educationally and at work and also their perception of stammering frequency. However, the test includes a number of other sections which were not required for the study so it seemed inappropriate for the participant to be asked complete the whole assessment. Administering the entire test would have also added time to the already long interview procedure. As a result, new shorter self-report measures were developed by the researcher to gather participants' perceptions of stammering severity and impact of stammering on life in education and at work.

The revised interview schedule included eight broad questions followed by prompting questions (Table 3.5). To put the participant at ease the interview schedule started with a straightforward question which asked participants to describe their current activity at school or at work. Questions two to four were phrased to elicit a narrative response from participants regarding their experiences. Questions five and seven in the schedule required participants to take a more evaluative approach in order to answer the question. Question types were avoided that were closed, leading or assumed that stammering did impact their lives within the educational context.

A semi-structured interview format allowed some control over the content and progression of the interview, but it was used as a guide rather than a fixed schedule. This flexible approach enabled the researcher to follow and respond to participants' particular interests or concerns. Prompting questions were also developed and used to ask participants to expand upon their replies and help the researcher's understanding of the individual's conscious experience of

an event. All participants were asked about the same topic areas and given similar prompts if needed. Probing questions were also prepared which asked participants to further explain a response and provide a deeper account when necessary, for example, “Can you tell me more about that?” and “How did that make you feel?”.

Table 3.5. *Interview schedule with key questions and prompts*

1. Can you tell me what you are doing now either in terms of being in education or at work?
   *Possible prompts:* What year are you in? What are you studying? Are you working part-time/full-time?

2. Can you tell me about your experiences at school? (and if appropriate at college and university)
   *Possible prompts*: How would you describe your academic activity*?* How did you get on with different classroom activities?

3. Can you describe your relationships with other people while you were at school?
   *Possible prompts:* teachers, friends, parents, speech and language therapist, differences compared to peers?

4. Can you describe your involvement in extra-curricular activity?
   *Possible prompts:* hobbies, interest, teams, clubs, societies? (in and outside of school)

5. What do you think influenced your school/career choices? How did you decide what to do?
   *Possible prompts:* role of stammering, own ability, other people, support?

6. What views/plans do you have about your future education and/or work choices?
   *Possible prompts:* What are you thinking of doing next? Do you have a long term plan for the future?

7. Do you think your life would be different if you didn’t stammer?
   *Possible prompts:* What do you think the education experiences are like for people who do not stammer? What would you be doing now that would be different?

8. What support do you think has or would have helped you during your life at school?
   *Possible prompts:* teachers, classroom participation, peers, family? What has helped you?

***3.5.4.2 Self-report measures***. In addition to the interview, participants completed 3 self-report measures to provide further information about their perceptions of their stammering and the impact of the stammering on their daily lives. These measures were: stammering severity, stammering impact on life at school/work and self-esteem. Each is outlined briefly below.

Stammering severity measure

A speech rating scale was constructed to ask participants to provide a personal judgement regarding the severity of their stammering during the one to one interview with the researcher. A nine-point numerical scale was adopted from O'Brian, Packman and Onslow (2004) which took the form of a horizontal line marked with points at regular intervals numbered from 1 to 9. Point 1 was labelled as "none" and point 9 as "extremely severe" (see Figure 3.3) This scale was presented on an A4 sheet of paper with written instructions at the top of the page, requesting participants to rate their frequency of stammering and to circle the number which they felt best described their speech during the interview (see Appendix B.2). This scale was chosen as it has previously demonstrated validity for asking adults who stammer about their severity of stammering (O'Brian et al., 2004).

*Figure 3.3.* Self-report stammering severity rating scale

Speech Rating

Please rate below the frequency of your stammering using the scale below.

1= no stammering; 9= extremely severe stammering.

Put a circle around the number which you feel best describes your speech.

none extremely severe

| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|---|---|---|---|---|---|---|---|---|

A verbal explanation (Table 3.6) was also developed to accompany the written instructions which were adapted from the guidelines used in the study by O'Brian et al. (2004).

Table 3.6. *Stammering severity rating scale: Verbal instructions*

| |
|---|
| Using the scale on this sheet of paper please can you think about your talking just now during the interview with me and rate your speech in terms of how much you were stammering. When thinking about your speech you need to base it on this scale: 1 = no stammering and 9 = extremely severe stammering. So if you felt you didn't stammer at all then you need to circle number 1, whereas if you felt it was extremely difficult/severe then circle number 9. If you felt your stammering was somewhere between no stammering and severe stammering, then put a circle around the number you feel best describes your speech.<br><br>There is no wrong or right answer this is just your view of your speech today with me so please feel free to use any number from the scale. |

Stammering impact on life at school and work

To examine the possible consequences of stammering on the lives of the participants in education and at work, a self-report measure was developed for use during the one to one interview. A numerical scale was created using a scale with nine numbered points (1-9) marked at regular intervals along a horizontal line (similar to the stammering severity rating scale) (see Figure 3.4). Participants were asked to indicate the extent to which their stammer impacted on their lives in education and at work. Each end of the horizontal scale was anchored by a phrase representing the extremes of possible impact on life. Point 1 of the scale was labelled as “not at all” and point 9 as “extremely severe”. Two separate scales were presented, one to measure participants’ perceptions of the impact on life at school and the other to measure the impact on life at work. Participants were asked to circle the number which best described the degree of this impact.

*Figure 3.4.* Self-report stammering impact on life rating scales

Stammering Impact on life rating

Please rate below the possible impact your stammer has or had on the following aspects of your life.

1= not at all; 9= extremely severe

Put a circle around the number which you feel best describes the impact.

At school/college

not at all extremely severe

| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|---|---|---|---|---|---|---|---|---|

At work (if applicable)

not at all extremely severe

| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|---|---|---|---|---|---|---|---|---|

These ratings added to the questionnaire data and the qualitative accounts from participants enabling a holistic picture to be gained regarding their lived experiences of stammering in education and at work.

Self-esteem measure

Participants’ feelings of self-worth were measured using the Rosenberg Self-Esteem Scale (Rosenberg, 1965) (see Appendix B.3). This is a standardised scale which consists of 10

statements, five of which are positively worded (e.g., “I am able to do things as well as most other people”) and five that are negatively worded (e.g., “I wish I could have more respect for myself”). Participants were asked to rate each statement on a 4-point scale from strongly agree to strongly disagree. All statements receive a score from 0 to 3 depending on the participant’s degree of agreement or disagreement to the positive or negative statements (see Appendix B.4 for scoring system and Appendix B.5 for a worked example).

***3.5.4.3 Researcher measures.*** The researcher also used the Stammering severity rating scale (described in section 3.5.4.2) to confirm the participant stammered and to identify their stammering severity following their individual interviews. The ratings from the participant and the researcher were compared to see if there was a difference in participants’ perceived stammering severity compared to the researcher’s scores. Research has shown that adults who stammer mostly agree with the severity ratings of their clinicians to within one scale value (O’Brian et al., 2004).

**3.5.5 Procedure.** Interviews were arranged at a convenient time and venue for each participant and lasted one hour approximately. To ensure the safety of both the participants and the researcher the majority of interviews took place in a room booked through a local library which provided a quiet place where the interviews could not be overheard. There were two exceptions where participants requested for the interview to take place within their homes. Participants were emailed in advance details of the venue for the interview and directions if required. Appropriate precautions were taken by the researcher to ensure personal safety, such as carrying a charged mobile phone, informing a contact person of the interview time and venue and being aware of safety issues during the interview.

At the beginning of each interview, time was taken to build a rapport with the participant and put them at ease by briefly referring to the questionnaire they had previously completed and explaining the purpose of the current study. Participants were reminded of the information sheet they had read and were then given the opportunity to ask further questions about the study. Following any questions, their consent was discussed again including agreement for the interview to be audio-recorded.

The interview schedule was introduced to the participants by explaining that there were some questions they would be asked and that there were no wrong or right answers to these questions. The researcher mentioned that participants would probably be doing most of the talking as the researcher was interested in discovering what is important to the individual

and what they wish to share about their education experiences. The semi-structured interview then proceeded with the researcher using the interview schedule as a guide.

To conclude the interview, the final question moved away from the participants describing their past lived experiences and asked them to consider future ways YPWS could be supported at school. At the end of the interview participants were thanked for their time in answering the questions and asked if there was anything else they wished to mention. The recording device was stopped which signalled the end of the interview. Occasionally participants unexpectedly spoke of additional points of interest so, with their permission, the audio recording was re-started.

Participants were then asked to complete the stammering severity rating scale, the speech impact on life scales and the self-esteem measure. Finally, the researcher summarised the participants' experiences at the end of each interview and time was allowed for participants to ask any questions they might have about the research study and their involvement.

Participants were thanked and their travel expenses were agreed and paid by the researcher. Participants were reminded that a summary of the outcomes of the investigation would be posted on the BSA website in the future, but they were welcome to email the researcher if they wished to receive a full report of the findings or if they had any queries. Following the interviews each participant was sent an email to thank them for taking the time to participate in the study.

On completion of each interview, the researcher reflected on the interview process by making written notes in relation to her role within the interview and her reactions to the participant and also how the participant had responded to the interview questions and process as a whole.

**3.5.6 Transcription.** Once all interviews had been completed the interview data were transcribed by the researcher with some support from an academic transcription service during a sixth month period. IPA transcription is described as being at the semantic level as it is interested in the content of a participant's account and its meaning that can then be interpreted. This process entailed noting all words spoken by both the participant and the researcher in order to capture the dialogue and the interactional context. Other features were also recorded such as pauses and laughter, which can provide further meaning to the participant's words. Prosodic features are not usually considered in IPA transcription and were not recorded during this transcription process. However, at a later stage of analysis some paralinguistic characteristics were found to be worthy of note when interpreting the

meaning assigned to participants' comments, for example the use of stress to give emphasis to their response.

Participants' moments of stammering were not transcribed as the researcher was only interested in the content of their response and not the nature or frequency of stammering. Occasional words that were unclear, which were possibly due to stammering, were noted as inaudible in brackets. Some researchers (e.g., Poland, 2002; Willig et al., 2008) refer to 'tidying up' the transcript by correcting errors in language and pronunciation or by guessing an unclear word, but the purpose of this transcription was to provide an accurate reflection of the participant's account so unintelligible words were noted as such.

Following transcription each script was transferred to a double spaced, line-numbered document with wide margins set on both sides of every page. This allowed space for written comments and coding for the stages of analysis. A copy of each transcript with the wide margins was printed for documenting comments (see Appendix B.6 for example).

**3.5.7 Qualitative data analysis.** The conversation from each interview was analysed by the researcher following the IPA recommended 6 steps (Smith et al., 2009). The initial analysis took an idiographic approach and focused on understanding the voice of the individual by describing and then interpreting each interview script. The analysis then identified the recurring themes across all interview transcripts and resulted in the development of a framework of significant themes that captures the shared educational experiences of YPWS. The steps are outlined below.

**Step 1: Reading and re-reading the case**

To familiarise the researcher with the participant's narrative the transcript was read whilst listening to the audio-recording of the interview. Time was then taken to re-read the transcript to become immersed in the participant's world and to gain an overview of the interview structure.

Following the readings, the researcher began to make notes in her reflective journal regarding her initial thoughts and feelings from listening to and reading the participant's account. This reflexive practice was a continuous process which informed the research.

**Step 2: Initial noting: exploratory comments**

During the process of reading the transcript, comments were noted by the researcher in the right hand margin of the transcript. These included *describing* what the participant had said;

commenting on *linguistic* features in terms of the participant's use of language and *conceptual* comments in regard to gaining an idea of the person.

A small section or sentence of the script was taken at a time and comments were noted. This involved the researcher summarising, paraphrasing and making connections between what the participant had said as well as similarities, differences, repetitions and contradictions in their accounts. Words or phrases stressed by the participant were underlined and words perceived as significant were noted. Emotions reflected by participants through their tone of voice or the language used were highlighted. Questioning and reflecting on the text initiated the process of the researcher gaining a more abstract understanding of the participant's experiences and adopting an interpretative approach.

**Step 3: Developing emergent themes**

This step involved transforming the researcher's initial notes into emergent themes that captured the core meaning of the script. These themes emerged through the researcher reading through the initial notes, reflecting the participant's own words, and then producing a succinct phrase to express the theme. Emergent themes were generated throughout the transcript and were noted in the left hand margin of the transcript. These themes aimed to reflect the participant's thoughts but they also conveyed the researcher's understanding or interpretation of the participant's lived experiences.

**Step 4: Searching for connections across emergent themes**

The next step was to explore the emergent themes and to bring together associated themes to produce a framework of the interesting and significant features of the participant's narrative. This was achieved by firstly writing a chronological list of the emergent themes on a word document with illustrative quotes from the participant and then taking an analytical approach to understand possible associations between themes. Related themes were then brought together to form a summary of clustered themes. Frequent referral to the participant's quotes helped to ensure the cluster themes reflected the participant's account and helped the researcher to monitor the continual process of interpretation.

Super-ordinate themes evolved from examining the associations within each cluster theme and then developing a new name to encompass these connections. This re-naming became the title for each super-ordinate theme for each participant.

**Step 5: Moving to the next case**

The remaining transcripts were analysed, one at a time, taking the same IPA approach. The researcher was required to bracket, as much as possible, the initial ideas generated by the analysis of the previous transcripts to ensure each individual's particular point of view was described and understood.

**Step 6: Looking for patterns across cases**

Once all transcripts were analysed comparisons were made between them to establish group level themes. A hardcopy list of each participant's super-ordinate themes on separate sheets of paper were laid out on a table and these were scrutinised for key and recurrent themes. To be recognised as a recurrent theme the super-ordinate theme needed to be present in most of the participants' accounts. This second study involved a large sample of participants so it was essential to refer to the specific words of individuals to confirm each group theme.

The researcher's analysis and interpretation of participants' experiences was not discussed with the participants to gain their feedback about themes emerging from their interviews. This is not a necessary requirement of the IPA approach because the findings were the researcher's subjective interpretation of their experiences which evolved through the researcher's engagement in a double hermeneutic cycle (Smith et al., 2009). There was an extended period of time between carrying out the 16 interviews and transcribing and analysing the interview data and the YPWS would not have necessarily remember exactly what they conveyed to the researcher and the participant may not feel in a position to participate in this process. Member checking would have been an additional demand placed on the YPWS which would be time-consuming and possibly upsetting.

### 3.5.8 Quantitative data analysis - self-reported measures

#### *3.5.8.1 Stammering severity rating and stammering impact on life rating scales.*

Participants' self-reported numerical ratings were categorised using descriptors to reflect their perceptions regarding their stammering severity and the impact of their stammer on their lives at school and work (Figure 3.5). Participants' responses were presented individually in a table for each of the 16 participants and these data were used, together with the qualitative data, to create a profile of each participant.

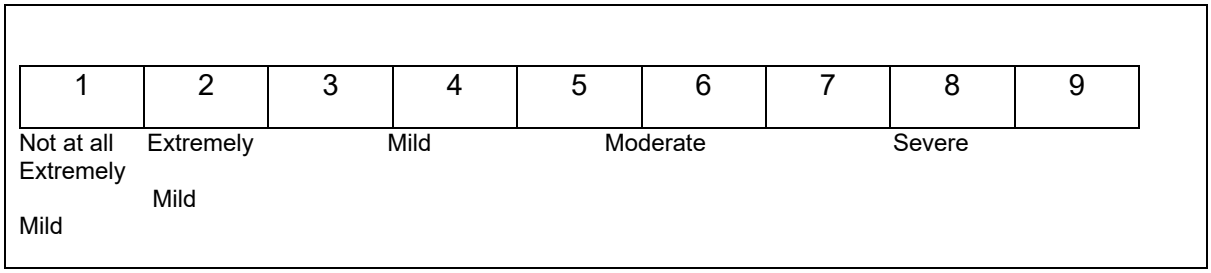



*Figure 3.5.* Numerical rating scale with descriptors

The researcher's stammering severity measure for each participant was also recorded and compared with the participant's self-report rating. Agreement between the two sets of ratings was judged as being within one scale point. A difference was noted if the ratings differed by more than one scale point (O'Brian et al., 2004). Any difference between the participant's and researcher's rating was described in the participant's profile.

***3.5.8.2 Self-esteem measure.*** Participants' scores on the Rosenberg Self-Esteem Scale (Rosenberg, 1965) were analysed according to the scale protocol. Participants' responses to specific self-esteem statements were examined to see if there were statements describing particular features of self-worth which participants reacted to more negatively. Findings were described for each individual participant contributing to their participant profile and included in the participant's table of results.

The self-report measures from each participant were also collated in terms of frequency of response and used to provide a general overview of results for the group. However, due to the small number of participants there is no attempt to perform statistical testing.

## 3.6 Reflection

IPA research recognises that although the findings of a study are driven by participants' lived experiences the researcher is involved with interpreting their stories, and the researcher's own background, experiences and thoughts may influence the conclusions reached (Smith et al., 2008). In light of this it is important for the researcher to take a reflective approach to the research process and to keep a record of their own experiences in relation to the different stages of the research study (Smith, 2009). Yardley (2008) also suggested that this reflective process adds to the transparency of the findings.

For the second study a reflective diary was kept during the recruitment of participants and throughout the data collection and analysis process. Diary entries were handwritten and dated on A4 paper in chronological order for all participants after their interview and again following the analysis of each interview. The diary detailed the researcher's interpretation of her interview experience including her emotional reaction to each participant and their

narrative as well as her interpretation of their words. This personal reflection involved the researcher asking herself questions about her practice and insights following each interview (e.g., what do I understand from X's account?; did I stay focused and keep to my protocol – if not why not?; what did I find difficult and why?). The diary also recorded the researcher's preliminary thoughts about the messages that the participants were sharing which increased the researcher's understanding of the phenomenon being explored.

In line with the IPA approach the researcher initially reflected on each individual participant's story, attempting to bracket her thoughts concerning the other participants' interviews and to allow new thoughts to arise. This reflective analysis along with the coded extracts emerging from the participant's account was used to describe and aid the understanding of a participant's lived experiences. Later in the process of group data analysis the researcher reflected on the links between participants' accounts and used single sheets of A3 paper to group together the different issues and the broader themes. This reflective activity involved the researcher asking herself a number of questions (e.g., what are the salient points arising?; what are the similarities and differences across participants?; why do I think this extract is important?; how often was a particular experience reported?; how are my thoughts connected to previous theory?; how are my thoughts linked to my experiences as a therapist?).

The diary described the types of challenges encountered during the data collection and analysis phases including; the frustration and anxiety caused by the difficulties faced during the recruitment process and the need to be resourceful in finding solutions to these problems; coping with the emotional suffering of some participants and in one case the extreme distress of a participant and the need to put aside the therapeutic role in naturally trying to help the young person with their stammer and instead maintain the role of a researcher. The diary was useful for recording thoughts and feelings about the interaction and the process and facilitated the development of research themes. It also helped to support the researcher's learning and development as a researcher.

Extracts from the reflective diary are presented below. They have been chosen to illustrate the researcher's reactions and initial interpretation following the data collection stage and how the process of reflection and interpretation following data analysis helped to inform the study's findings.

**Reflections following interview with Darren:** *Darren was easy to listen to and very happy to chat to me and share his experiences. He often repeated a word to stress the importance of something to him. He had made a choice to go to college and leave school because of his stammer and the "terrible times" there. He would have stayed with his friends at school if he*

*didn't stammer but the negative experiences at school made him want to leave and have a fresh start at college. Here he could be the person he wanted to be, have a new identity and be a respected Darren. He described the positive changes he had experienced since leaving school, which included attending group speech therapy and how he liked his new world. He had established a new life, independence and self-control. He felt in control of his life and responsible for his future direction. Darren has a positive outlook on life now but he clearly suffered during his school years which made me feel sad but also cross that he had not received speech and language therapy sooner or consistent and appropriate support from his teachers. I felt I wanted to apologise to him for the lack of help he had from my profession. I wished I could have said that SLT provision had improved – but I knew from my knowledge as a SLT that this was untrue. I feel I'm attributing blame to my own profession and to politicians and I want to be able to put this right.*

**Reflections following analysis of interview with Darren – my interpretation:** *The seemingly past negative experiences identified by Darren appeared to be attributed to his experiences at school but learning in a new environment at college was viewed by Darren as a fresh start in a more adult environment. This new environment seemed to support personal positive change. He had developed self-respect, self-control and this positive transformation was on-going for him in his current life at university. It appeared the changes experienced during his education years, as he lived with his stammer, impacted his behaviour and attitude towards himself. Personal growth occurred as he started to value himself and his life. An important theme emerging is how Darren's educational environment and the reactions of those within it seemed to have impacted on his ability to change and cope with stammering as a young person.*

**Reflections following interview with Floyd:** *Floyd appeared confident and successful. He came across as academically able and sporty. From his account he has achieved well, has good friends and support from family and from some teachers. He had just left education and started a job in London. He was very focused on his career plan, achievement and managing his stammer. He talked about how he was always willing to have a go in life although recognised how it can be tough, particularly now he is in a corporate work environment. However* during *the interview he talked nonstop and quickly and I found it difficult to keep track of what he said. I felt unsettled and not in control of the interview. I found it was difficult to move the conversation forward as he discussed at great length specific experiences so I felt he was choosing the direction of the interview and I was more of a passive listener. This concerned me as I worried that I would have incomplete data which would have implications for my findings. He thanked me at the end of the interview and offered to have further contact with me if I needed more information from him. He was*

*clearly grateful for being listened to which made me feel guilty that I had been impatient and too concerned about my own agenda. On reflection I realise that these events were clearly important to him and on reading back my reflection on his account I can see that I have captured much of his lived experience of being a YPWS. I do have an understanding of his story so perhaps this interview went better than I thought.*

***Reflections following analysis of interview with Floyd - my interpretation:*** *It was apparent from Floyd's experiences that there were a range of influences that impacted on his ability to adapt to living with his stammer. He was coming to terms with his stammer and learning to be less sensitive, having a positive outlook and being accepting of others' reactions. As well as his self-agency he seemed well supported by others in his environment to effect change. The combination of these factors seemed to have helped him cope with his stammer and build his resilience, 'enabling' him to live (comfortably?) as a YPWS. Being enabled (by own strengths and supportive others) evolved as an emergent theme for Floyd.*

**Reflections following interview with participant Nikki:** *I found Nikki hard to listen to and to follow her narrative because of her frequent use of the word 'like' as well as her severe blocks and that she didn't seem to re-start her narrative where she had left off. What added to this difficulty was the extreme distress she clearly experienced when talking to me which made me feel sad and concerned for her well-being. Her resentment as to why she should be the one who stammered was evident. She also resented others who would tell her to have a go at speaking when she knew she couldn't speak and disliked how others wanted to fix her. What came across was her immense anger towards herself and others. This anger was particularly intense towards the teacher who made her feel like a leper. Listening to her suffering at the hands of other professionals concerned me and exasperated me. Although I was in the researcher role I found I drew upon my skills as a therapist to support her through the interview. I offered her the opportunity to stop the interview but she wished to continue with this and seemed to value being listened to. Later she talked about her stammer being less of a nightmare than it had been and this made me question whether I should explore the nightmare further with her but through reflecting in action (Schon, 1983) I decided not to, I think because I feared it may have increased her emotional distress. I think this decision reflected my emotional intelligence I have as a therapist. Instead I focused on her perception of her stammer being 'less' of a problem and by pursuing this she described ways she was learning to manage it. Also reflected were signs of contentment and self-recognition of her academic ability and writing skills. This was a powerful story and one that will stay with me.*

**Reflections following analysis of interview with Nikki - my interpretation:** *The interview seemed to reflect Nikki's difficult journey in managing her stammer and finding self-*

*acceptance. It became clear that a key factor to support Nikki's participation in education was the need for increased awareness and understanding of stammering by others, particularly teaching staff. Recent attendance at a SLT support group had given her the opportunity to meet others who stammered and make friends and provided her with a space where she could be herself. The emotional distress in coping as a young person who stammers, recognising her abilities and the need for understanding and support from others seemed to be themes emerging from Nikki's account.*

## 3.7 Validity

Yardley (2000; 2008) developed four key criteria for appraising the validity and quality of qualitative research, but recommends a flexible approach is taken in applying these criteria as individual studies will address aspects in different ways. Table 3.7 summarises Yardley's criteria and how these criteria have been addressed in the current study.

Table 3.7. *Application of validity criteria in the current study (Yardley, 2000, p.219)*

| **Features of validity** | **How the study demonstrated features of validity** |
|---|---|
| 1. Sensitivity to context<br><br>Theoretical; relevant literature; empirical data; sociocultural setting; participants' perspectives; ethical issues.<br><br>This can be demonstrated through: the reading of existing literature, the researcher's commitment to understanding participants' lived experiences, sensitivity to socio-cultural, and linguistic factors, awareness of the power imbalance between the researcher and how this can potentially influence the research. | Acknowledgement of previous research through extensive literature review which highlighted the gaps in the research and informed the planning of the investigation.<br><br>Appropriate awareness of philosophical principles underpinning the approach.<br><br>Use of an IPA method captured the experiences and meanings associated with being a YPWS in the education context.<br><br>Use of open-ended, non-directive questions allowed participants to talk about the aspects of their experiences that they viewed as important to them with the individual being seen as an active participant rather than a subject. The researcher was skilled in working and gathering information from PWS and actively prompted and responded to participants' replies as appropriate.<br><br>IPA was used as a sensitive method for in-depth data analysis and interpretation of data. Paralinguistic characteristics were noted when interpreting the meaning assigned to |

| | |
|---|---|
| | participants' comments, for example the use of stress to give emphasis to their response.<br><br>Bracketing, as much as possible, the initial ideas generated by the analysis of previous transcripts to ensure each individual's particular point of view was described and understood in its own right.<br><br>Information about the researcher was provided to participants prior to them giving their consent to take part in the first study. The context for the interview was a neutral setting, usually a public library or a setting of their choice.<br><br>Benefits of the investigation explained to participants as their responses provided useful information regarding the experiences of YPWS in education and employment. This information aimed to inform professionals such as teachers and SLTs working with YPWS.<br><br>Provision of written detailed information to participants for both studies so they could make an informed decision and give informed consent. Consent was gained separately for each study. Prior to gaining consent and at the start and the end of interviews participants were given the opportunity to ask questions and reminded of their right to withdraw from the study or abstain from answering any questions that wished to. |
| 2. Commitment and Rigour<br><br>In-depth engagement with topic; methodological competence/skill; thorough data collection; depth/breadth of analysis.<br><br>This can be demonstrated through: prolonged engagement with the phenomenon; the competence and skills in the methods used and immersion in the data, adequacy of the sample, thorough data collection, analysis and interpretation, triangulation of data. | The researcher had extensive knowledge of the phenomenon as an academic but also in working as a SLT, linking theory to practice within a clinical setting.<br><br>The researcher had extensive knowledge of the IPA approach underpinning the study.<br><br>Despite persistent problems in recruiting participants, a purposive sample of participants was recruited that met the study's inclusion and exclusion criteria. The sample included self-selected male and female volunteers who were mostly in education.<br><br>The interview was piloted with one participant which allowed the schedule to be tested and |

| | |
|---|---|
| | feedback to be gained from the participant leading to revision of its structure and questions.<br><br>The researcher became immersed in participants' transcripts and adopted an in-depth procedure for analysing each individual's data by describing and interpreting their experiences and then making comparisons between participants' data to establish group level themes.<br><br>Triangulation of data was achieved by gathering data using different methods (survey and interview data) to gain comprehensive in-depth understanding of the phenomenon.<br><br>A clear and detailed account of the data collection and analysis which led to the conclusions of the investigation was documented. This provided a paper-trail for auditing the credibility of the research and demonstrated the researcher's commitment to quality and validity.<br><br>A sample of interview transcripts was checked by a fellow researcher which provided an independent audit of the transcript. This led to constructive feedback and discussion and the re-framing of some emergent themes leading to the development of super-ordinate themes. Regular reviewing and discussion of the text took place with the researcher's supervisory team in regard to confirming and modifying the data analysis. This helped to guide and develop the researcher's knowledge and skills thus enhancing the credibility of the investigation.<br><br>The researcher kept a reflective journal during the second study's data collection process. Following each individual interview the researcher noted her reactions to each participant which included thoughts and emotional responses associated with carrying out the interview with the participant and the key message from the participant.<br><br>The researcher summarised the participant's narrative and the researcher's understanding of their experiences at the end of each interview. |

| | |
|---|---|
| | This enabled the participant to affirm, contradict, correct or change information gathered by the researcher. This also provided an opportunity for participants to add any other information they thought to be of importance to the researcher. |
| 3. Transparency and Coherence<br><br>Clarity and power of description/argument; transparent methods and data presentation; fit between theory and method; reflexivity.<br><br>This can be demonstrated through: providing a consistent and complete description of the research process in order to create a version of reality. | A detailed description of the stages of the research process was provided including details of the sample of individuals, and the steps used to collect and analyse data. Extracts of the textual data from the interviews were presented to illustrate each theme identified by the analysis.<br><br>The researcher openly reflected on and discussed her personal assumptions and beliefs concerning her methodological perspective through discussion with supervisors and a reflective log. The IPA approach recognises that a researcher is not unbiased and brings to the research process their own views and expectations that could influence the interpretation of how participants' describe their experiences. |
| 4. Impact and Importance<br><br>Theoretical (enriching understanding); sociocultural; practical (for community, policy makers, health workers).<br><br>This can be demonstrated through: the conclusions drawn from the study and its usefulness and value in SLT and educational practice. | Listening to the voices of YPWS and using an IPA approach provided a focus on the individual and their lived experiences of being a YPWS in education. The findings highlighted their activity and participation within the educational context and shed light on factors influencing their educational experiences and outcomes.<br><br>Novel findings providing implications for practice have been considered in chapter 8. A tentative model was developed to describe the lived experiences of YPWS in education which may be drawn upon by SLTs when appraising the strengths and needs of YPWS in the educational setting which illustrated the contribution to practice.<br><br>A mixed methods approach was used to provide a comprehensive perspective of the educational experiences and outcomes for YPWS who were currently or recently in education, which was in line with the theoretical perspective underlying the investigation. |

# CHAPTER 4. STUDY ONE FINDINGS (QUESTIONNAIRE)

## 4.1 Overview

In this chapter, in keeping with the sequential design of the study, the survey findings from study one are firstly reported followed by an outline of the key findings identified for further exploration in study two. The analysis of the interview data from the second study is presented in chapters 5-7 and subsequently a summary is provided integrating both quantitative and qualitative findings.

The survey was completed by 35 participants who stammer. In this chapter, both numerical survey data and the textual data from the survey's open-ended questions are reported. Examples of participants' qualitative responses to the open ended questions are provided to illustrate themes emerging from the data. The contents of this chapter mirror the questions asked in each section of the questionnaire.

## 4.2 Questionnaire Section 1: Demographic profile of participants

The survey respondents were mainly white (n=29, 82.9%), English-speaking (n=32, 91.4%) young adults. They ranged in age from 15-25 (mean 20 years) and represented a range of educational levels and/or employment states. Two-thirds of the group were male (n=24, 68.6%) (see table 4.1 for main demographic features of the participants).

## 4.3 Questionnaire Section 2: Details about participants' stammering

Table 4.2 provides details of participants' stammering history including the age at which they first became aware of the stammer, the type and severity of stammering experienced, family history, help received for stammering, and any other speech and language needs. Examples of participants' written responses to open-ended questions are also listed in the table and referenced with their participant identification number in brackets.

**4.3.1 Awareness of stammering.** Most of the participants reported becoming aware of their stammering in either pre-school (n=12, 34.3%) or primary school (n=15, 42.9%), Six (17.1%) participants reported becoming aware whilst at secondary school, and two (5.7%) became aware of their stammer post 16 years, one of whom appeared to be describing a late onset of stammering known as acquired stammering. Many of the participants reported feeling that they had always stammered which was reflected in their additional comments. The majority of participants perceived the severity of their stammering

Table 4.1. *Demographic profile of participants (n=35)*

| Demographic feature | Sub-group | Number |
|---|---|---|
| Age (years) | 15-17<br>18-21<br>22-25 | 8<br>14<br>13 |
| Gender | Male<br>Female | 24 (68.6%)<br>11 (31.4%) |
| Ethnic group | White<br>Asian<br>Black | 29 (82.9%)<br>3 (8.6%)<br>3 (8.6%) |
| Language(s) spoken | Monolingual (English)<br>Bilingual | 32 (91.4%)<br>3 (8.6%) |
| Education level/Employment status | Full-time study<br>Full-time work<br>Apprenticeship<br>Voluntary work<br>Out of work (seeking employment) | 24 (68.6%)<br>4 (11.4%)<br>4 (11.4%)<br>1 (2.9%)<br>2 (5.7%) |
| Education environment | School<br>College<br>University<br>Not applicable | 6 (17.1%)<br>7 (20.0%)<br>13 (37.1%)<br>9 (25.7%) |

to be “moderate” (n=26, 74.3%) or “mild” (n=7, 20.0%). Participants reported different types of stammering and all had received speech and language therapy.

**4.3.2 Stammering features and avoidance behaviours.** The majority of participants (n=29, 82.9%) reported experiencing blocks; just over half (n=19, 54.3%) experienced repetitions of speech sounds and words and 14 (46.7%) participants reported prolongations of speech sounds. The majority of participants described their stammer as consisting of more than one characteristic and were able to provide precise details. Almost three-quarters (n=25, 71.4%) of participants described using avoidance behaviours (see Appendix C.1).

**4.3.3 Family history of stammering.** Twenty (57.1%) participants cited a family history of stammering, with almost equal numbers reporting stammering on their father’s or mother’s side of the family. One participant reported stammering on both sides of her family.

**4.3.4 Help for stammering.** The majority of participants (n=31, 88.6%) reported that they had attended speech and language therapy in the past and 12 (34.3%) currently do so. One participant had not received therapy in the past but had started to receive therapy recently, at the age of 22 years old.

Four (11.4%) participants reported receiving support from others such as a parent or teacher and just one attended a local support group for people who stammer. A further four

Table 4.2. *Participants' details about stammering (participant identification number in brackets)*

| Details about stammering | | Number of participants | Examples of participants' comments |
|---|---|---|---|
| When first aware of stammering | Pre-school (up to 4 yrs)<br>Primary school (5-10 yrs)<br>Secondary school (11-16 yrs)<br>Post 16 years | 12 (34.3%)<br>15 (42.9%)<br>6 (17.1%)<br>2 (5.7%) | *Always. Since I can remember speaking (6)*<br>*Had slight stammer since the age of 3, but never really an issue. Became more apparent around the age of 16, which is when I started to really become aware of it (29)*<br>*My stammer became apparent shortly after I began studying my MSc in Autumn 2011. Previously I have had no speech difficulties (32)* |
| Severity of stammering | Mild<br>Moderate<br>Severe | 7 (20.0%)<br>26 (74.3%)<br>2 (5.7%) | *Moderate – I stammer a lot but can go through various short bouts of fluency at times (10)* |
| Types of stammering | Repetitions<br>Prolongations<br>Blocking | 19 (54.3%)<br>14 (40.0%)<br>29 (82.9%) | *A mixture of stretching out sounds and having complete blocks where I can't say the first syllable. (35)* |
| Avoidance behaviour | Avoidance behaviours reported<br>None reported | 25 (71.4%)<br>10 (28.6%) | *My head is like a thesaurus I substitute words all the time (12)* |
| Family history of stammering | Father's side<br>Mother's side<br>Both sides of family<br>No family history | 10 (25.7%)<br>9 (26.7%)<br>1 (2.9%)<br>15 (42.9%) | N/A |
| Help with stammer | SLT in the past<br>SLT currently<br>No SLT<br>McGuire Programme<br>Specialist Centre (MPC)<br>From others (teacher/parent)<br>Local support group | 31 (88.6%)<br>12 (34.3%)<br>2 (5.7%)<br>4 (11.4%)<br>3 (8.6%)<br>4 (11.4%)<br>1 (2.9%) | N/A |
| Other speech & language need | Dyslexia<br>Dyspraxia<br>None identified | 2 (5.7%)<br>1 (2.9%)<br>32 (91.4%) | N/A |

participants (11.4%) reported attendance at a McGuire Programme (2003). Three participants received speech and language therapy from MPC.

For 32 (91.4%) of participants stammering was their only speech and language need. The three (8%) participants experiencing an additional difficulty included two with dyslexia and one with dyspraxia.

**4.3.5 Participants' perspectives about stammering.** When asked "How does your speech difficulty make you feel?" all participants described negative feelings evoked by their stammer. This was an open-ended question which allowed participants to describe their own feelings rather than choosing from a pre-determined list. Table 4.3 shows the frequency of words used by participants to reflect their feelings and thoughts and examples of participants' written comments. The most common feelings reported in response to stammering were frustration and anger. Participants also expressed how having a stammer made them feel different to other people. There were 7 (20%) participants who despite experiencing some negative feelings also described how they were gradually coming to terms with their stammer.

**4.3.6 Situations perceived by participants that make stammering worse.** When asked "When do you stammer the most?" all participants reported specific situations which they believed had a negative impact on their stammering as shown in Table 4.4. This was an open-ended question which asked participants to identify situations when they stammered the most rather than selecting possible situations from a given list. The number of times participants mentioned each situation were tallied up and these are presented in Table 4.4.

Almost half of the group (n=17, 48.6%) mentioned presentations, reading aloud and talking in front of a group of people as situations when they would stammer more. Other specific situations included speaking to new people, parents and teachers, speaking on the telephone, during interviews, when put on the spot, a new situation, drinking alcohol and when rushing.

**4.3.7 Situations perceived by participants when they stammer least.** In response to the question, "when do you stammer the least?", the majority of participants (n=33, 94.3%) reported at least one situation when they stammered the least (see Table 4.5) but there were two (5.7%) participants who stated "I'm not really sure" and "I don't know". Almost one-third of the group (n=11, 31.4%) described stammering less with both family and friends. A smaller number mentioned other situations including: when not at school (n=5; 14.3%), when alone (n=4, 11.5%) and when performing (n=4, 11.5%).

Table 4.3. *Participants' feelings and thoughts associated with stammering*

| Participants' reported feelings and thoughts | Number of participants | Participants' comments |
|---|---|---|
| Frustrated | 19 | *Frustrated and angry when I need to get my point across or can't do normal things (37)*<br>*Frustrated and annoyed that I can't say what I want to say. (29)* |
| Angry/annoyed | 14 | |
| Feel different/lack confidence/ self-conscious/worthless/afraid | 15 | *It makes me feel the odd one out and afraid to talk (1)*<br>*Feel like an idiot (20)* |
| Sad/depressed | 10 | *On the verge of tears sometimes (8)*<br>*At school it used to be very depressing as I'd get reports of attitude problems and lack of effort in discussion work when in reality I wasn't putting my hand up or responding in as few words as possible due to the stammer (10)* |
| Embarrassed | 10 | *It makes me feel embarrassed and not at the same standard as other people of my age (4*) |
| Worried/anxious/nervous/agitated /stressed | 7 | *My speech difficulty can leave me frustrated and agitated at times – sometimes because my drama teachers have to have a second thought before casting me in school productions (2)*<br>*Worried that people don't listen to what I have to say (23)* |
| Coming to terms with stammer | 7 | *I do get slightly embarrassed when I stammer in a big group; however, I have come to terms with my stammer and am happy to let other people know (15)* |
| Limited by stammer | 6 | *I feel I could do much more with my life and feel at times that my stammer hinders my choices in life (36)* |
| Terrible/awful/horrible | 3 | *Terrible at times because I can't say what I want (7)*<br>*It makes me feel awful (22)* |
| Tired/exhausted | 2 | *Tiring, mentally tiring to have to put up with it most days (17)* |

Table 4.4. *Situations in which participants identified they stammer most*

| Situations reported by participants | Number of participants |
|---|---|
| Reading/Presenting/Talking in front of group | 17 |
| With new people | 7 |
| Phone calls | 6 |
| Saying own name | 5 |
| With parents | 5 |
| Interviews | 4 |
| Put on the spot | 3 |
| With teachers | 2 |
| New situation | 2 |
| Drinking alcohol | 1 |
| When rushing | 1 |
| Talking to important people | 1 |
| When there is something important to say | 1 |

Table 4.5. *Situations in which participants identified they stammer least*

| Situations reported by participants | Number of participants (n=35) |
|---|---|
| With family | 11 |
| With friends | 11 |
| When not at school | 5 |
| When alone | 4 |
| Performing e.g. singing | 4 |
| Avoiding/ Saying a few words/short sentences | 3 |
| At work: serving customers/teaching | 3 |
| When not thinking about it | 2 |
| Alcohol | 2 |
| Playing sport & adrenaline increasing | 2 |
| When feeling comfortable | 2 |
| Don't know | 2 |
| When no repercussions | 1 |
| When shouting | 1 |
| Talking on the phone | 1 |

## 4.4 Questionnaire Section 3: Education

### 4.4.1 Educational achievement of GCSEs at the end of compulsory education.

Table 4.6 displays participants' academic performance at the end of compulsory education, aged 16 years, compared with pupils' attainment in England. Participants' attainment of 5+ GCSE grades A*- C (91.2%) and 5+ GCSE grades A*-C, including English and Maths (91.2%) was above the average for pupils in England (82.9% and 60.6% respectively).

Analyses comparing the academic results in all categories for male and female participants showed the trend towards females achieving superior results to males. This reflects the data for pupils in England.

Table 4.6. *Participant (n=34) GCSE achievement (or equivalent) compared with pupils in England*

| | 5+ A*- C grades | 5+ A*- C grades including English & Maths | 5+ A*- G grades | 5+ A*- G including English & Maths |
|---|---|---|---|---|
| Study participants: | | | | |
| Male (n=24) | 87.5% | 87.5% | 95.8% | 95.8% |
| Female (n=10) | 100% | 100% | 100% | 100% |
| Total (n=34) | 91.2% | 91.2% | 94.1% | 94.1% |
| Pupils in England (2012/13) * | | | | |
| Male | 79.6% | 55.6% | 94.8% | 93.0% |
| Female | 86.5% | 65.7% | 96.9% | 95.4% |
| Total | 82.9% | 60.6% | 95.8% | 94.2% |

*Source: National data from Department for Education - Data, Research and Statistics 2012-13 (DfE, 2014c)

**4.4.2 Educational achievement at 'A' level.** Two-thirds (n=22, 64.7%) of participants had achieved 'A' level qualifications or equivalent level 3 qualifications and eleven (32.4%) participants were currently studying 'A' levels or equivalent qualifications at the time of the study. There was one (2.9%) participant who had not gained a level 3 qualification. Participants' level 3 achievement was slightly above pupils in England (95.6% and 92.3% respectively). The attainment of 2 'A' level passes grades A* to E (or equivalent) for male participants was 93.3% compared to 92.1% of male pupils in England and 100% for female participants versus 92.4% for female pupils in England. However, due to the small sample size these differences cannot be seen as significant.

**4.4.3 Progression to University Education.** Out of 27 participants aged 18 years and over, nine participants (33.3%) had achieved undergraduate degrees (level 4-6 qualifications) which was above the average (27.2%) for young people in England and Wales (Office for National Statistics, 2011 Census). In addition, the data showed that one (3.7%) participant had a foundation degree (a level 5 qualification), ten (37.0%) participants were currently studying an undergraduate degree, four (14.8%) graduates were undertaking a Master's degree and six (22.2%) participants were studying a level 3 qualification.

**4.4.4 Subjects studied at GCSE and 'A' level.** At GCSE level (or equivalent) participants studied an average of nine subjects (range 5-13) which is comparable with pupils in England. All participants reported studying English and Maths but a variety of other GCSE qualifications were also taken (see Table 4.7). The majority of participants (n=31, 88.6%) took science, which is compulsory in the majority of secondary schools, and over half of the participants studied a foreign language which is also compulsory in some schools. Participants studied a vast range of subjects at 'A' level or equivalent. The most popular subject choice for 'A' level was English (n=6, 27.3%) followed by Information Technology (n=5, 22.7%). There were 5 (22.7%) participants who had chosen to study BTEC qualifications (see table 4.7).

Table 4.7. *GCSE and 'A' level subjects studied by participants*

| GSCE level | | A level | |
|---|---|---|---|
| Subjects | Participants (n=35) | Subjects | Participants (n=22) |
| Science | 31 | English | 6 (27.3%) |
| Foreign Language | 19 | Information Technology | 5 (22.7%) |
| History | 17 | Business/Maths/Psychology | 4 (18.2%) |
| Religious Education | 16 | Physics/Geography/ Philosophy & Ethics | 3 (13.6%) |
| Information Technology | 15 | Biology | 3 (13.6%) |
| Geography | 14 | Art/Economics/History/Music | 2 (9.1%) |
| Business | 8 | Media/Film studies/Modern studies/Product design/ German/Latin/Chemistry/ Photography/ Further Maths/ Sociology | 1 (4.5%) |
| Drama | 6 | BTEC Diploma in Health & Social Care | 4 (18.2%) |
| Media | 5 | BTEC Diploma in Business | 2 (9.1%) |
| Music | 5 | BTEC Animal Biology | 1 (4.5%) |
| Physical Education | 4 | | |
| Food Technology | 2 | | |
| Resistant materials technology | 1 | | |

**4.4.5 Reasons for subject choices.** Participants were asked to provide their own reasons to the open-ended question "Why did you choose these subjects?". As Table 4.8 shows, the majority of participants (n=28, 80.0%) stated that their choice was guided by what they found enjoyable and interesting. However, nearly two-thirds (n=20, 57.1%) of participants' selections were influenced by their speech difficulty.

Table 4.8. *Participants' reasons for subject choices*

| Reason for choice of subject | Number of participants (n=35) |
|---|---|
| Enjoyable/interesting | 28 (80.0%) |
| Related to speech difficulty e.g. involved few presentations | 20 (57.1%) |
| Good at the subject | 9 (26.5%) |
| Relevant/important for future career | 9 (26.5%) |
| Creative subject | 4 (11.4%) |
| On teacher's advice | 4 (11.4%) |

**4.4.6 Most enjoyed subjects.** When participants were asked to identify the subjects that they most enjoyed and why, they stated a variety of subjects with a wide range of reasons and some commented on their enjoyment of more than one subject. Some reported subject enjoyment due to the opportunity for non-verbal expression, but most reported enjoyment based on subject content (see Table 4.9 for most enjoyed subjects and participants' supporting comments).

Table 4.9. *Subjects most enjoyed*

| Most enjoyed subject | Number of participants (n=35) | Examples of participants' comments |
|---|---|---|
| English | 9 (25.7%) | *I think I enjoyed English the most as it involves writing. It is easy to express myself, difficult when speaking. I think word substitution has increased my vocabulary and this really helped me when writing essays (12)* |
| History | 7 (20%) | *History is one of my favourite subjects because learning about the history of the earth has been amazing (7)* |
| Business | 6 (17.1) | *I see a potential career path in this subject because I find it captivating (7)* |
| Drama | 5 (14.3%) | *Drama because I just love acting (1)* |
| Maths/Sciences/Information technology/Art | 4 (11.4%) | *Maths and physics because I didn't have to talk very much (38)* |
| German/Media/Geography | 3 (8.6%) | *Geography and media, I found it something I was good at (25)* |
| Design & technology/ Textiles | 2 (5.7%) | *Freedom to express what I'm thinking in terms of drawing and models (18)* |
| Physical education/ Beauty therapy/Health & social care/ /Sociology/ Philosophy/Engineering/Music | 1 (2.9%) | *Engineering, I just found it relaxing and it's something I enjoy making things out of pieces of material and how everything is put together (39)* |

**4.4.7 Subjects least enjoyed.** When participants were asked to specify the subjects that they least enjoyed and why, they generated a range of subjects with a variety

of reasons why (see Table 4.10). The responses to this question also linked back to the earlier question regarding “reasons for subject choices”. The analysis showed that as many participants disliked English as those that liked it. A total of nine (25.7%) participants named English as their least liked subject. This dislike was reflected in some of their responses and suggested a link to their speech. There were 3 participants who stated no dislike of any subject and 1 participant did not respond to the question.

Table 4.10. *Subjects least enjoyed*

| Least liked subject | Number of participants (n=34) | Examples of participants’ comments |
|---|---|---|
| English | 9 (26.5%) | *I didn’t enjoy English in the early years of secondary school when a lot of the lesson was spent reading out loud, around the class. I found this very stressful* (21) |
| Maths | 7 (20.6%) | Maths, because I wasn’t very good at it (22) |
| Foreign languages/Sciences | 4 (11.8%) | *GCSE English and French were horrible, especially oral exams and class discussions (23)*<br>*Chemistry -it was very hard (42)* |
| Physical education | 3 (8.9%) | *P.E because I don’t like sport in general (5)* |
| Drama/Humanities/Fine art/ Resistant materials/ Electronics/ Information technology/Functional skills/Accounting | 1 (2.9%) | *Humanities based subjects -find them quite boring (15)* |
| No dislike of a subject | 3 (8.9%) | *I just found them all really interesting. (19)* |

### 4.4.8 Perceived effect of stammering on participants’ choice of subjects.

In response to participants being asked whether their stammer had influenced their choice of subjects, 20 (57.1%) believed stammering had affected their choice. The majority of these participants (n=18, 51.4 %) reported their stammer had a negative effect on their choices but two (5.7%) perceived their stammer as having a more positive influence on subject choice. The following quotes reflect the participants’ differing views:

*In terms of which modules I chose at University it did. The first thing I would look for is whether the assessment involved a presentation! If it did I would avoid the module (12)*

*I picked drama and my drama teacher had a stammer and he said he got out of stammering through acting plus every time I act I don’t stammer (1*)

**4.4.9 Advice from others.** Almost half of the participants (n=17, 48.6%) reported that no advice had been given to them in choosing their subjects; however, five (14.3%) received advice from a parent, three (8.6%) had guidance from a teacher, two (5.7%) had assistance from careers adviser and one (2.9%) received advice from a relative.

### 4.4.10 Plans for future: Further study and Employment.

Table 4.11 provides details of participants' future plans for study and employment. The majority of participants (n=24, 68.6%) were currently in education but were at different levels of study (i.e. GCSEs, 'A' Levels; under-graduate degrees; master's degrees) and most of these participants (n=18, 75%) cited specific plans for the future including continuing in education or aiming for a particular career. Other participants (n=8, 22.9%) were employed either full-time or as an apprentice and all planned to continue with their current employment. There were five (14.3%) participants who were uncertain about their future careers and a further two (5.7%) who did not provide this information.

Table 4.11. *Participants' current and future education/employment plans*

| Age range (years) | Number of participants (n=35) | Participants' current education/employment | Participants' future education/employment plans (n=35) |
|---|---|---|---|
| 15-16 | 4 (11.4%) | Level 2 study (e.g., GCSEs) | 2 (5.7%) to go to College & University<br>2 (5.7%) plans not stated |
| 17-21 | 6 (17.1%) | Level 3 study (e.g., 'A' Levels/BTEC) | 4 (11.4%) to go to University<br>2 (5.7%) to seek employment |
| 19-22 | 10 (25.7%) | Undergraduate degree | 6 (17.1%) to seek employment (e.g., Healthcare, Fashion, Business, IT, Media)<br>4 (11.4%) plans uncertain |
| | 4 (11.4%) | Master's degree | 3 (8.6%) to start a PhD<br>1 (2.9%) to seek employment |
| | 4 (11.4%) | Apprenticeship | 4 (11.4%) Continue with chosen trade |
| | 1 (2.9%) | Voluntary work | 1 (2.9%) plans uncertain |
| 23-25 | 4 (11.4%) | Employed | 4 (11.4%) Continue with current employment |
| | 2 (5.7%) | Seeking employment | 2 (5.7%) Continue to seek employment |

A range of potential careers were mentioned by participants with a variety of reasons as reflected in participants' comments below:

*4.1*
*My career aim is to be a University Lecturer. Therefore, after my MA I am looking to embark on a PhD. One of the reasons for this career choice is because I want a job that involves having to speak on a daily basis. I want to prove to myself and others that just because I stammer, it has not held me back in any way. And the times when I have been called 'unemployable' or offered an interview and then had this withdrawn when they heard me stammer, I guess I want to prove a point (12)*

*My ambition is to be successful in my band, but if that doesn't work out I think I would like to stay in my line of work (electrical engineering) as I am not under any pressure to talk to many people and the work is fairly well paid (24)*

*I genuinely find it* [pianist] *interesting and I don't see the performance side of music as work, it's more of a hobby (35)*

Two participants also mentioned issues with gaining employment due to their stammer:

*4.2*
*I had applied for a job and she* [employer] *called up to arrange an interview but as soon as I started talking she said, you would have problems working here as it is quite a fast paced environment, and after that she hung up (12)*

*I was never able to get a job, I had the grades but no one would hire me. But then I became a breastfeeding peer supporter after having my daughter (25)*

## 4.5 Study One findings identified for further exploration

This first study provided some preliminary findings about young people's experiences of stammering and their educational choices and outcomes. These findings were used as a platform to inform the second study involving interviews with 16 participants. Table 4.12 shows the study one findings that were identified for further exploration in order to explain the survey findings and provide a deeper understanding of the lived experiences of young people who stammer during their years in education.

Table 4.12. *Study One survey findings identified for further exploration.*

| |
|---|
| 1. Participants' academic achievement was found to be comparable to pupils in England, but academic choices and activity appear to be impacted by stammering.<br>*How do YPWS describe their activity and outcomes at school?* |
| 2. Negative thoughts and feelings associated with stammering are expressed by participants.<br>*How do young people perceive their experiences of being a person who stammers?* |
| 3. Participants report stammering less when with family and friends.<br>*How do YPWS describe their experiences of interacting with others, including family, friends and teachers?* |
| 4. The majority of participants had received speech and language therapy.<br>*What are their experiences of SLT?* |
| 5. Some participants expressed their lack of control over stammering whilst others reported learning to cope.<br>*What are their experiences of managing their stammer?* |

# CHAPTER 5. STUDY TWO FINDINGS (INTERVIEWS) – THEME 1

## 5.1 Overview

This chapter is the first of three that present the analysis of data collected during the interviews with young people who stammer. In this chapter, the interview participants are described, and information provided about their self-reported perceptions of stammering, based on measures obtained during the interviews. An in-depth analysis of the group's core experiences is then given. Although the analysis focuses on group experiences, the resulting themes are explained using extracts from the individual participants. This is in keeping with idiographic approach of IPA which emphasises the importance of giving participants a voice. This chapter describes the first theme and the next two chapters will describe themes two and three.

## 5.2 The participants

Table 3.4 in Chapter 3 gave initial demographic details of each participant. Here further information about the individuals taking part in study two of the thesis is given. Firstly, the quantitative data collected from participants during the interviews is summarised at a group level and then combined with qualitative information to build a holistic description of each individual. Although the participant profiles included here are not part of the interpretative phenomenological analysis, content (including direct quotes) taken from the participants during their interviews is provided. These profiles aim to characterise each individual and offer the reader clarity and context in understanding his or her story.

**5.2.1 Participants' stammering severity.** When participants were asked to rate their stammer during the interview on a scale from 1-9 with 1 being "no stammering" and 9 being "extremely severe stammering", there were no participants who rated themselves as "1" or as "9". The majority (*n*=13) of participants self-reported a severity rating within the extremely mild to mild category. Two participants rated their speech as moderate and one participant self-reported a score falling within the severe range (see Appendix C.1). The researcher's ratings of participants' speech confirmed that all participants stammered and participant and researcher ratings were in agreement for 11 out of the16 participants. For the remaining 5, the participants all rated their stammer as less severe than the rating given by the researcher (see Appendix C.1).

### 5.2.2 Participants' perceived impact of stammering on life in education.

In response to participants being asked whether their stammer had an impact on their life in education on a scale from 1-9 with 1 being "not at all" and 9 being "extremely severe", one participant reported that his stammer did not impact on his life in education and four believed their stammer had a mild effect. A further four participants rated their stammering as having a moderate influence on their lives in education and almost half of the sample reported that stammering had a severe impact (see Appendix C.2)

Three of the young people who stammered provided different impact ratings according to the educational context they experienced. Their scores showed a decrease in the severity of impact on their life at college and/or university compared to their experiences at school (see Appendix C.2).

### 5.2.3 Participants' perceived impact of stammering on work life.

Participants were asked to rate the possible impact their stammer had on their work life using the same numerical scale for impact on their life in education. Out of the 16 participants, the majority (*n*=11) reported their stammer had a mild effect on their lives in the work setting and a further participant stated that it had no effect on his work life. Ratings from two participants indicated their stammer had a moderate impact and a further two reported it had a severe effect on their lives in the workplace (see Appendix C.2)

**5.2.4 Participants' self-esteem.** The results of participants' self- completed Rosenberg self-esteem questionnaires found the scores for 15 out of the 16 participants were within or above the normal range of 15 to 25, indicating appropriate levels of self - esteem for these individuals at the time of their interview (see Appendix C.3). Five of these 15 participants achieved scores above 25, indicating high levels of self-esteem above the normal range. There was one participant whose self-esteem score of 12 fell below the normal range which suggested she had a poor level of self-esteem

The Rosenberg self-esteem scale also asked participants to respond to ten statements as to whether they strongly agreed, agreed, disagreed or strongly disagreed to statements of self-worth. One participant responded negatively to 7 out of the 10 statements which reflected her low self-esteem score described earlier. Some negative responses were also expressed by a further 8 participants, but it should be noted that the self-esteem level for these participants was within the normal range of 15- 25. Half (*n*=8) of the participants in the study agreed with the statement, "I certainly feel useless at times"; four of these participants also agreed to the statement, "I wish I could have more respect for myself". The sentiments of three other statements "All in all, I am inclined to feel that I am a failure"; "I am able to do

things as well as most other people"; and "On the whole I am satisfied with myself" generated negative responses from two participants. There were seven participants who responded positively to all ten statements which reflected their self-esteem scores of 23 and above (see Appendix C.4).

### 5.2.5 Participant profiles.

**Adam**

Adam was an 18-year-old young man who recalled stammering from the age of 3 years. At the time of the interview, he was at college re-taking 'A' levels to improve on his BBC grades in order to study drama at the university of his choice which required higher grades. He self-rated his stammer as mild and he saw his stammer as having no impact on his school life but a moderate impact on his work-life. He was motivated to do well and to not let his speech be a barrier to his life choices and his self-esteem score of 23 was within normal range. However, he talked about feeling ashamed and guilty about stammering and how he continually had to "beat his stammer down" to be on top of it. These feelings are reflected in his agreement with two self-esteem statements "I wish I could have more respect for myself" and "I certainly feel useless at times".

**Ben**

Ben was 18 years old and had stammered since the age of 4 years old. He was in the 6th form at school studying 3 'A' levels and hoped to go to University to study business management. Ben rated his stammering severity as extremely mild, compared to the researcher's moderate rating, but this matched his view of his stammer as having a mild effect on his experiences at school and at work life. He also responded positively to all of the self-esteem statements, achieving a high score of 27, reflecting his positivity. Ben disliked being made to feel different to others because of his speech and he believed he had developed a "thick skin" to cope with the "complete humiliation of stammering".

**Callum**

Callum was 19 years of age and felt he had always stammered. He passed 3 'A' levels at grades BCC at College last year and chose to do an apprenticeship in Facilities Management, rather than go to University. Callum described feelings of depression associated with his stammer whilst he was at school and he rated his stammer as having had a moderate effect on his school life which lessened to a mild effect at college. At interview he demonstrated a determined attitude towards life and rated his stammering

severity as extremely mild and described its impact on his work life as mild. His self-esteem score was 25, at the upper limit of the normal range.

**Darren**

Darren was 21 years of age and reported becoming aware of his stammer when giving a talk at school he was 14 years old. He was currently studying a degree in business at university having previously achieved a diploma in this subject at college. Although Darren rated his stammering severity as mild during the interview, compared to the researcher's rating of moderate, he described it as "terrible at times" during his secondary school years with it having a severe impact on his school life. He described leaving school to have a "fresh start" and that at college and university his stammer had only a mild impact on his life in these contexts. Darren responded positively to all self-esteem statements and his score of 24 was within the normal range which seemed to reflect the comment he made about himself "I like him".

**Ed**

Ed aged 25 years became aware of his stammer when he was about 7 years old. He had recently passed a master's degree which he had studied part time whilst working full-time and at the time of the interview Ed continued to work full-time in a Human Resources role. During his education years he perceived his stammer as having a severe impact on his life but rated his speech as having a mild impact on his work life. Ed's self-esteem level was above the normal range, scoring 28, although he saw himself as having a severe stammer. Ed was currently experiencing a lack of career progression but his outlook on life was optimistic and he had constructive plans for the future involving further study.

**Floyd**

At interview Floyd was 22 years old and he recalled realising his speech was different from others when he was 8 years old. At the time of the interview he worked full-time for a leading insurance business having achieved an undergraduate degree in statistics and economics during the last year. He rated his stammer as mild, compared to the researcher's rating of moderate, but his rating was in line with his view of his stammer as having exerted a mild influence over his previous years in education and on his current work life. Floyd recognised his academic strengths and sporting ability and he had a positive approach to life. Out of the participants, he recorded the highest level of self-esteem with a score of 29 out of 30 which reflected his self-confidence.

**Gary**

Gary was 22 years old and recalled stammering for as long as he could remember. After leaving college with 3 ‘A’ levels he completed an apprenticeship in electrical engineering and he was continuing to work in this trade at the time of the interview. He rated his severity of stammer and its impact on his life at school as moderate but now in full time employment he rated his stammer as having a mild effect on his work life. Outside of work, Gary wrote lyrics and played guitar in a band and the band had recently won a regional band competition. He expressed hope for further musical success in the future and saw a career in music as “definitely my dream”. Gary’s response to the self-esteem measure indicated a high level of self-esteem, with his score of 26 being above the normal range.

**Harry**

Harry was 22 years of age and reported having a slight stammer from the age of 3 years old but he became more aware of it when he was 16 years old. At the time of the interview he was studying a Master’s degree in transport planning at university having previously achieved 4 ‘A’ levels at school and an undergraduate degree which had included a one-year work placement. Harry rated his stammering severity as mild which had a mild impact on his life at university and his part-time job. However, in the past Harry saw his stammer as “shameful” and reported his stammer as having a severe impact on his school life. At interview Harry’s self-esteem score of 18 fell within the normal range but he strongly agreed with the self-esteem statement “I wish I could have more respect for myself” and he agreed with the statement “I certainly feel useless at times”.

**Isla**

Isla aged 19 years felt she had been aware of stammer since learning to talk and she remembered this becoming an issue for her when she was 5 years old. After passing her GCSEs she successfully completed a Level 3 diploma in Health and Social Care and was at University training to be a nurse. Isla rated her stammering severity as extremely mild and also the impact of her stammer as having a mild effect on her school and university life and her part-time work. Isla described how she had wanted to be a nurse since the age of 8 years old so believed her stammer had not interfered with her career choice. Isla indicated positive responses to all statements of self-worth and scored 23 which corresponded with her current outlook on living with a stammer “I’ll never let my speech get in the way of what I want to do”.

**Jess**

Jess was 19 years old and became aware of her stammer when she was 11 years of age, although she was told it started in primary school. After studying the first year of 'A' level subjects Jess left school and went to college where she was currently enjoying her studies in animal management. Her self-reported stammering severity rating was mild but she described her stammer as having a severe impact on both her life at school and at work. Out of the participants, she recorded the lowest level of self-esteem with a score of 12 which was below the normal range of 15-25. Jess responded negatively to 7 out of the 10 self-esteem statements and she strongly disagreed with statement number 6 "I take a positive attitude toward myself". Jess' low self-esteem was reflected in her comment "I'm not very confident".

**Kyle**

Kyle, 25 years old, had recently started to stammer, shortly after he began studying for his Master's degree. He had previously been a fluent speaker, being able to confidently give presentations and speak freely, so he found his stammer extremely frustrating. Kyle also had cerebral palsy diagnosed at the age of 2 years old which he positively managed. At the time of the interview Kyle had successfully completed his Master's degree in brand marketing and was working for a disability rights organisation but was also considering further study at doctoral level. Kyle currently saw his stammering as mild which had a mild effect on his work life. However, he perceived his stammer as having had a severe impact on life at university which reflects the shock and struggle he experienced in learning to cope with the sudden onset of his stammer. Kyle's self-esteem score of 23 was within the normal range and he only disagreed with one statement "On the whole I am satisfied with myself". This perhaps reflected his view that he always strived to develop himself and looked out for his next challenge.

**Liam**

Liam aged 23 years old became aware of his stammer at the age of 6 years old. Following his GCSEs, he left school and started a science course but due to a lack of financial support he had no choice but to leave college and start working. He had experienced frequent changes in employment but he was currently working in IT for a firm of solicitors. Liam reported his stammering severity to be mild but he felt his stammer had a severe impact on both his school life and current work life. Despite this Liam had a positive outlook to life reflected in his words "I just live life day-by-day, whatever comes, just take it". His overall self-esteem score of 19 fell within the normal range although he disagreed with the

statement “I am able to do things as well as other people” and agreed with the statement “I certainly feel useless at times”.

**Mia**

Mia who was 25 years old reported stammering since the age of 4 years old. She had successfully completed GCSEs and achieved 2 ‘A’ levels grades DD and following this she had an arranged marriage at the age of 18 years. Unfortunately, her marriage did not last and following her divorce she returned to live with her family and firstly studied a beauty course and then went to university where she was currently studying to become a radiotherapist.

Mia reported a moderate degree of stammering severity and rated her speech as having had a severe impact on her school life, which decreased to moderate at college and to mild at university. As part of her university course she also attended work placements and in this setting she rated her speech difficulty as having a moderate effect on her experiences. Mia’s positive responses to the self-esteem measure indicated a high level of self-esteem, with her score of 26 being above the normal range, which reflected her self-belief and self-determination.

**Nikki**

At interview Nikki was 20 years old and recalled stammering since the age of 7 or 8. She was at university studying a degree in fashion having previously passed her GCSEs and gained BBB grades at ‘A’ level. Nikki rated her stammer as mild, compared to the researcher’s rating of severe, but felt her stammer had a moderate impact on her life in education and a mild effect on her part-time work. Although Nikki felt her stammering severity was mild, she found it extremely distressing and was visibly upset throughout the interview. However, she was happy with her university course and she was applying for jobs she felt she would enjoy. Her self-esteem score of 21 was within the normal range, but she agreed with two self-esteem statements “I certainly feel useless at times” and “At times I think I am no good at all”.

**Owen**

Owen, aged 16 years old, said he had stammered since the he was 3 years old. He had just taken his GCSE examinations at school and was intending to go to college to study a level 3 Diploma in public services. His self-reported stammering severity was mild and he described

this as having a mild impact on both his school life and part time job. Although Owen's self-esteem score of 18 fell within the normal range, he responded negatively to four statements on the scale. He agreed with the statements "All in all I am inclined to feel that I am a failure", "I certainly feel useless at times" and "At times I think I am no good at all" and he disagreed with the statement "On the whole I am satisfied with myself". His mixed responses seemed to reflect the comment he made "Some days I'm really confident and some days I'm not confident at all".

**Pippa**

Although Pippa, aged 16 years old, was told she had stammered from a young age, she only began to be bothered by it when reading aloud in class at the age of 13 years old. At the time of the interview she was at school having recently taken her GCSE examinations and was planning to go to college to study 3 'A' levels. Pippa rated her stammer as mild but viewed it as having a moderate effect on her life at school and an extremely mild impact on her volunteer work. Pippa's self-esteem level was 18, within the normal range, but she strongly agreed with the statement "I wish I could have more respect for myself" and disagreed with the statement "I certainly feel useless at times". These negative responses seemed to reflect how Pippa was learning to understand and manage her stammer but she was optimistic about the future and was looking forward to college life.

## 5.3 Super-ordinate Themes

Nine sub-themes emerged from the analysis of the 16 interviews with young people who stammer. During the IPA analytic process these sub-themes were then organised into three super-ordinate themes:

1. Living with being a person who stammers in education: the struggle
2. Being a person who stammers in education: the impact
3. Learning to cope: the journey

These overarching themes aim to capture the key patterns and links between the emergent subthemes which detail the shared experiences of young people who stammer. The structure of the super-ordinate themes and sub-themes is presented in Figure 5.1.

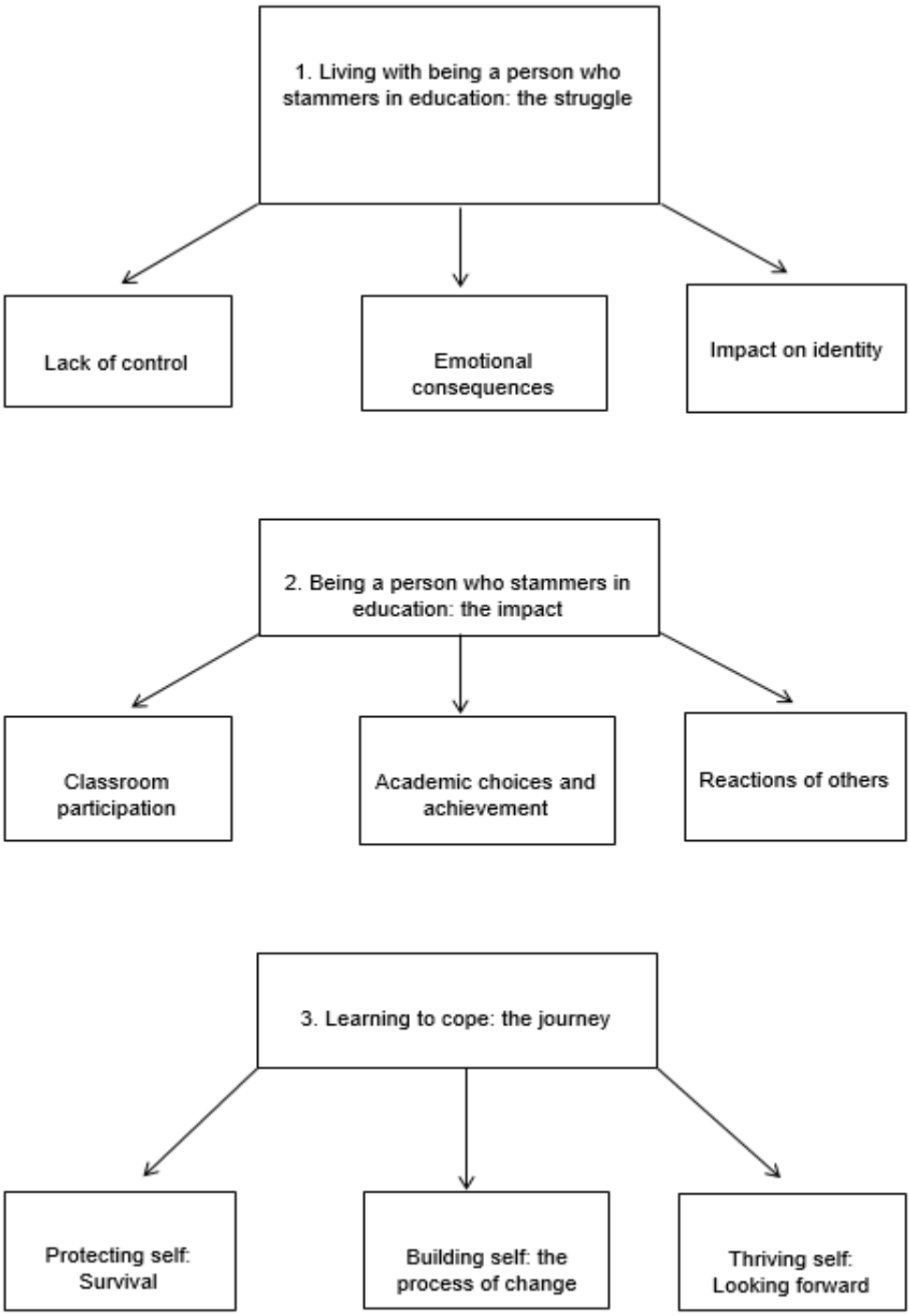



*Figure 5.1.* Summary of super-ordinate themes and sub-themes.

An overview of the first super-ordinate theme and sub-themes is provided in this chapter, the second theme is discussed in chapter 6 and the third theme in chapter 7. The themes are described using extracts from the interview transcripts to illustrate participants' experiences in their own words (which appear in italics in grey shaded sections) and to provide evidence for the themes. Each group of extracts that support participants' experiences is annotated with the chapter number followed by the extract number in chronological order. Chapter 8 provides a discussion of the findings and refers back to the numbered extracts in order to support the discussion.

The transcript notation applied to the individual extracts is indicated in Figure 5.2.

| |
|---|
| …. = text omitted because too long and/or omitted text did not add to the example. |
| [ ] = explanatory text added by the researcher when quote in not clear, e.g. use of "it" refers to e.g. [his talking] |
| The name of participant and line number from the transcript are cited following each participant's quote. |

*Figure 5.2.* Transcript notation used in quoted extracts from participants.

## 5.4 Super-ordinate Theme One: Living with being a person who stammers in education: the struggle

**5.4.1 Overview of super-ordinate theme one.** The participants in this study talked about their lived experiences of stammering during their years in education. This first super-ordinate theme illustrated how stammering was embedded in their daily lives, and depicted the struggle experienced through living as a young person who stammers. This super-ordinate theme embodied the sub-themes described by participants: their struggle to control stammering, the subsequent emotional consequences, and the personal impact on their identity.

The three sub-themes are discussed separately in the sections below, but they are connected by the overarching theme of how being a YPWS was a struggle during the participants' time in education.

| Super-ordinate Theme One | Sub-themes |
|---|---|
| 1. Living with being a person who stammers in education: the struggle | 1a: Lack of control |
| | 1b: Emotional consequences |
| | 1c: Impact on identity |

**5.4.2 Sub-theme 1a: Lack of Control.** For almost all participants the experience of stammering was overwhelming with participants describing their inability to control their stammer. Associated with this lack of control was a strong feeling of helplessness experienced by the young people. This was illustrated by Callum's account which described how his lack of control over his speech left him immobilised at school.

*5.1.*

*I sit in, kind of, like, terror, just frozen all the time. (Callum, 97-98)*

Kyle described how he was powerless to stop himself from stammering despite recognising when he was more susceptible to it. Furthermore, his account indicated his struggle to understand why he stammers.

*5.2*

*But when I'm tired or stressed it will then come out again. It's really, really weird because I can't control it. Once it starts coming out I can't then control it. (Kyle, 61-64)*

*Yeah and it just frightened me because everything else I've dealt with I could see, oh yeah, problem, I can fix that, I can do this, but with the stammer I was like, I don't even know why this is happening and I can't stop it and I can't get my words out either. (Kyle, 76-80)*

Like Kyle, other participants struggled to understand their stammering and its unpredictable nature. There was a sense from the interviews that the variability of their stammering behaviour created feelings of uncertainty which fuelled their lack of control. Darren described the variability of his speech and how this had ramifications for his activity at school. Emerging from Darren's account were his feelings of confusion, not knowing how to participate and his perception that he was not equipped to manage his speech.

*5.3*

*…and at school it varied so much, some days I would have a day when I could answer a question out loud, and some days I can't even speak a word. (Darren, 35-38)*

*…and because my speech would change every day, it made me really confused and stuff, and I just didn't know how to act. (Darren, 149-151)*

*Because I had so much I wanted to say, but I just couldn't because I didn't have that much learning in how to control your stammer, so it was really hard to deal with, in so many respects. (Darren, 295-298)*

Similarly, other participants, like Callum and Gary, felt their speech could not be relied upon when facing different challenges in the school environment. It appeared that that their stammering undermined their autonomy and impacted their decision making in terms of whether or not they engaged with an activity. The accounts from Nikki and Liam reflected their lack of control over their speech but also their feelings of resignation.

*5.4*

*I had no doubt in my abilities, I knew I was clever, I could write, I could speak, it's just whether or not I could do that, when I wanted to do that, that was the issue (Callum156-160)*

*But it became a problem when, like, you're put on the spot and that's when it just really becomes this massive thing that it really shouldn't be, because it just feels like it's so in control of you and you're not in control of it. And it's so…it just spontaneously happens. I mean, like, one minute, I'll be talking fine and then the next minute I can hardly talk. And then, like, you think to yourself, this is not worth the risk talking sometimes. (Gary, 143-152)*

*I was like, well, there's no point, I can't do it now because I'm just going to fail it. (Nikki, 61-62)*

*I thought oh okay, this is what I do, nobody else has it, I'll just live with it. (Liam, 280-281)*

Participants appeared to be acutely aware of their stammer in speaking situations and it seemed to be a constant part of their experiences in education. Pippa recognised how speaking at school was increasingly necessary as she progressed through school and important for progressing in life. The accounts from Pippa and Owen revealed their intense thinking about stammering and the self-talk they practiced in relation to their stammer.

*5.5*

*Basically my brain just like tells me this is really important, I have to get this done but then it* [her brain] *brings up that basically I've got my stammer and then of course because I'm telling myself about my stammer the stammer then comes out really badly just because I'm thinking about it so much. (Pippa, 358-362)*

*If anything I just think that like my stammer has got a bit more present, simply because I've been thinking about it more and it's just come on a bit from there. In Year 9 and the start of Year 10 I didn't really think about it that much but now it's kind of become a bit of a bigger thing because of course now you have to speak so much 'cause it's so important to get along in life. (Pippa, 432- 438)*

*Actually, if I'm talking to a high status person, let's say, they might be really important, and I might feel like, oh I can't stammer, I can't stammer, if I've got to talk to them, either way, I'm just thinking, don't stammer, don't stammer. And, it makes me tense inside; it will probably just make it worse. (Owen, 928-933)*

Callum also seemed engulfed by the constant thinking about speech difficulty. He described the questions he asked himself and his attempts to understand his stammer and the solutions to cope with it. However, his use of the word 'trapped' suggested he felt ambushed by his stammering, powerless and incapable of resolving his situation. This lack of control clearly resulted in him feeling afraid and anxious, exemplified by his repeated mention of feeling scared. He revealed the recurrent cycle he was immersed in and there was a sense that he lived an unrelenting 'Groundhog Day' of stammering: "you know when you go to sleep, the next morning you're going to be going back to the same place…and nothing is going to change". This was salient feature in his account. Callum also asked himself the question as to why he cannot be normal. Callum appeared to be searching for an answer to explain the cause of his stammer, which reflected his lack of understanding of the difficulty. This notion of normality was mentioned by further participants and described in the following sub-theme 1.2.

*5.6*

*Yeah, that's the thing, you're very aware of it, because you know, you're in a room with 30 people, you know that you're going to be under pressure to speak all the time and you're, kind of, in your own head, because you can't speak, you're always thinking and talking to yourself, like, how to get out of the situation. I'm scared and you're talking to yourself, so you're very, very aware, but I'd say, it was more around 13, 14, like, after the first year of high school, I'd realised, okay, this is when I'm always going to have these bad situations, how do I get out of it? How do I solve it? (Callum, 118-132)*

*It's, kind of, always in the back of your head, you can't really deceive yourself, you know what you're thinking, you know what you're scared of, you can't think, just, like, concentrate and you'll do fine, like, you're always going to be nervous, you're always going to be scared. (Callum, 1989-1995)*

*So you're always saying to yourself, like, why is it happening to me? I should have been fine, it shouldn't have happened, why can't I just be normal and not stutter? I shouldn't be in this situation in the first place and because you can't get out of it, it just makes it worse, because you feel, kind of, trapped as well, like I said, you know, you're going to be in the same school for the next four years and you can't get out of it and this experience is going to happen again. You know when you go to sleep, the next morning you're going to be going back to the same place and that makes it a lot worse, it makes things just a lot worse knowing that you can't get out of it and nothing is going to change. (Callum, 2074-2098)*

Liam also held the view that if he was communicating with others his day would certainly involve stammering. His stammer seemed to have a predictable presence in his daily life

with there being no relief from it. Liam implied his energy levels were depleted during the day because of the effort of facing the daily unrelenting nature of stammering.

*5.7*

*There's no break in it unless I'm spending a whole day inside on my own. Apart from that I've got loads of energy at night, but every day, because it is a thing which you have to do every day, you don't get a break from it. (Liam, 1539-1543)*

Other participants directly referred to the physical and mental effort experienced in relation to their thoughts and their attempts to communicate. Harry perceived his frequent thinking about his speech led to tiredness and this in turn had a negative impact on his learning at school.

*5.8*

*When I did go through a bad patch, it would seem to wear me down, as in it would tire me out as well, 'cause it's such a strain on the body as well. And there's the mind, because, like, you're trying to concentrate and you're tense, it's just a really tiring experience [laugh] basically. Yeah. (Gary, 156-161)*

*A lot of my thinking time would go on my stammer and that would make me tired, so therefore when it did come to work then I wasn't very successful because I was too tired to take anything in. (Harry, 411-415)*

*I know that I can't help it but of course other people don't know that, so they're just saying it jokingly but I take it really personally 'cause I know how much effort having to put in to say the stuff and then they're saying that and it just puts me off of it. (Pippa, 126-129)*

**5.4.3 Sub-theme 1b: Emotional consequences.** All participants expressed powerful emotions associated with stammering. Participants spoke about the emotional reactions they experienced during and after talking to others. Essentially three negative emotions emerged from their accounts: guilt, shame and unhappiness.

Many of the young people held the assumption that stammering was an unacceptable behaviour. Participants, such as Pippa, described the need to strive for fluency, and this seemed driven by the individual's own expectation and belief that it was wrong to stammer. Consequently, there was a sense that participants felt guilty for stammering. Other participants, such as Harry, expressed feelings of imperfection and Jess experienced physiological reactions and feeling at fault for stammering.

*5.9*

*It's been, for my speech, it's just been awful because of course I know how important it is to get stuff right (Pippa, 339-340)*

*Because I'm very much somebody who is a perfectionist, and the thought of me not being perfect is hard to deal with. But I have got better though at that. But certainly back then, it was very much like no, you're not allowed to have a flaw, I must be perfect. I must be this; I must be that. (Harry, 235-240)*

*I'd feel sick and my hands would sweat and shake and my heart would race. Yes, I'd just feel really bad about doing it. (Jess, 580-584)*

Extracts from a number of participants showed how the young people took responsibility for their stammering and blamed themselves for failing to be fluent. The individuals clearly placed the onus to be fluent on themselves and when unable to achieve this they appeared to become frustrated and angry with themselves. This misattribution of guilt suggests that the young people had a lack of understanding regarding the origins of their stammer.

*5.10*

*No matter how much you try to use techniques, you're going to trip up a bit and then it's going to be me pointing the finger at myself saying, oh, stupid me again. (Gary, 431-434)*

*You'll lash out at other people, but you're always…because of the stutter, it's no one else's fault, therefore you can't be angry at anyone else, it's your own fault. (Callum, 2074)*

Both Pippa and Owen also expressed how they felt guilty about their audience having to listen to their stammered speech. They seemed concerned that their listeners had to be patient and Pippa inferred that her verbal contribution would not be valued by the listener. This reflection suggests a possible lack of self-worth experienced by Pippa.

*5.11*

*then I get embarrassed for the people who are having to try and listen to it and I just feel like, I don't know, a bit embarrassed that they've got to sit through it and try and grin and bear it. (Pippa, 30-32)*

*…because they're waiting for me to either finish the sentence, or start the sentence in some cases, which is often the case for me. And, I just feel bad for them, because everyone is waiting to hear what you've got to say. (Owen, 209-213)*

As a result of their perception that they should be fluent, participants described feeling embarrassed or ashamed if they stammered when communicating with others at school. Adam described feeling acutely ashamed of himself when he "slipped up" on "something so easy". He also stressed how hard it was for him to articulate some words by his frequent use of the word 'very'. There is a sense that Adam saw his inability to speak fluently as a failure on his part and this adverse feeling lingered and appeared to exacerbate his negative self-perception. For Adam this seemingly painful experience fuelled his fear of future communication exchanges and subsequently acted as a catalyst for further instances of stammering.

Adam seemed to believe his stammer “feeds off” his feelings of fear, shame and guilt associated with his failure to communicate fluently. His account showed that he was developing an understanding of his speech behaviour, but despite this he seemed powerless to stop the growth of the apparent parasite (i.e. his stammer).

*5.12*

*If I have a moment, if I have, like, one moment and I'm speaking to someone and I can slip up, or I find a word very, very, very hard, and I just can't, you know, say it how I want to say it, then that moment can stay with me all day, which can lead to more hiccups later on. Because I suppose you have that notion of, like, not self-hatred, but more of, like, you feel - not self-hate, but, like, ashamed, kind of, you're putting all this work in then for this moment on something so easy, just a conversation from one to one, you can slip up on a word, you, kind of, feel ashamed, you know, I've gone through all this work and I slip up on a word like that. And then that, kind of, grows on you psychologically, which in a way, is what a stammer feeds off. (Adam, 433-454)*

*I think, deeper down, it's* [the stammer] *all fed off things like self-hatred or feeling ashamed, or feeling guilt from, like, past experiences of speaking. And I think that is what makes your fear of social interaction grow and grow. (Adam, 468-472)*

Harry also reflected on the intense feelings of shame and embarrassment that he felt would ensue if he was heard to stammer. These emotions appeared to be related to his fear of being negatively evaluated by others so he hid his stammer at school. However, he also felt guilty for not disclosing his stammer and for not being honest with others. Collectively these feelings associated with the fear of disclosure and non-disclosure of stammering seemed to become increasingly exacerbated over time for Harry living with his stammer.

*5.13*

*It’s just the shame, the fear of someone finding out, the embarrassment. I suppose the guilt as well with not going to school or not really telling someone, so you feel guilty and ashamed of yourself. Yeah, just all those feelings really and a spiral downwards, they get worse and worse. (Harry, 600-604)*

These extracts from Adam and Harry show their sensitivity to stammering but also their depth of thought in relation to their speech difficulty. This in turn appears to reflect the psychological struggle and mental effort experienced by these young people who stammer, as described in the previous sub-theme.

Others described the emotional distress related to their stammering which manifested as unhappiness. Two participants, Gary and Callum, referred to previous experiences of depression. During Gary’s narrative he used the word ‘really’ on several occasions which appears to affirm the impact of living with his stammer. He described a process of being weakened by his stammer which eventually overwhelmed him and resulted in him feeling

depressed. Callum commented on his negative outlook on life as a young teenager. At this stage he saw any attempts he might make to communicate with others as inevitably resulting in failure. He based this view on his past endeavours to participate and his subsequent defeats. Callum therefore perceived conversation as pointless and chose to withdraw from interacting with others. There is a sense that Callum felt that nothing was worth attempting in his life because he was helpless to deal with his stammer and this led to his depressive mood.

*5.14*

*And, like, it* [the stammer] *really did get me down in some points of my life, like when it's just really stressful anyway, and then that on top of it, it's just…it just really seems to wear you down, and then that becomes a bigger thing than what it actually is. I just get, like, really depressed. It's hard to describe depression, but, yeah, that's definitely the feeling I had. (Gary, 456-458)*

*Not to be too depressing about it, yeah, I thought about it the other day, maybe I had a little bit of depression when I was younger, because it really was a point where you don't see anything positive, so you don't want to talk to people, you don't see the point of doing things, there's no point in going to talk to that person, probably going to fail, there's no point, you don't see any positivity, you think, what if I try harder? I've tried hard before; it backfired against me, so therefore I have no grounds to think positively. (Callum, 2022-2034)*

Callum further described the perpetual stammering he experienced during his secondary schooling. He clearly recalled this unbearable period of his life when he stammered on a daily basis and loathed going to school. His feeling of misery was palpable and again he was at a loss as to why he stammered, adding to his negative emotions and view of himself.

*5.15*

*And so at the worst, I remember it was just, at its worst, every single day, a month of just solid…there's no point in going to school, I don't really want to and forced myself to go, if it wasn't illegal for me to bunk off school, I would be doing so quite frequently and I'm going to have to go into the same place every single day, like, the worst mindset I had was the next four years I'm going to have to go into the same place I hate and I'm scared to go into and I'm going to be miserable for four years and once I first had that thought, I was miserable for ages, because I thought to myself, I'm going to be angry and frustrated with myself, why do I stutter? (Callum, 2043-2058)*

Another participant, Nikki, cried throughout the interview when describing her experiences of stammering. She explained that whenever she talked about her speech she became acutely distressed. She was unable to suggest why this happens to her, but she longed to be able to speak about her speech without becoming upset. From listening to Nikki's account of being a person who stammers there was a sense in her tone of voice that she felt very angry about having a stammer. She seemed to struggle to articulate her thoughts about something that is

clearly emotive to her which she could not make sense of. Her emotional feelings of anger and frustration, heard in her tone of voice, seemed to trigger her sobbing.

*5.16*

*It's not fair. It's just a reaction. If I speak about it then I'm going to…I'm not even upset, I'm just sobbing. I'm like I'm not even upset. But it's just not fair. I wish I could speak about it and just not be upset. But I'm not even upset right now, it just happens…. It's just really emotional. I don't know why. It always is, so I don't know. (Nikki, 879-889)*

**5.4.4 Sub-theme 1c: Impact on identity.** Many of the participants described their speech as being different to others and they discussed their speech in terms of "normalcy". Participants viewed stammering as something that was wrong because no one else they knew spoke in this way. Some also expressed feelings of frustration associated with stammering and had a strong desire to speak "normally" (i.e. like their fluent peers). The following accounts from Jess, Mia and Pippa support the earlier extract from Callum regarding the social comparisons made by young people who stammer and their feelings of difference.

*5.17*

*I realised that something wasn't right, like I couldn't talk as fast as everyone else (Jess, 15-17)*
*All my friends, everyone else, like teachers and everyone didn't have it so I thought perhaps it was something that I shouldn't have (Jess, 34-35)*

*Because it's not normal, is it? It's not normal. (Jess, 129)*

*I just want to be able to like talk as normal people talk (Mia, 841)*

*I went through like a few months of just getting really angry at myself just because I so wanted to just like talk to people casually and just be like blah blah blah and not have to stop and go oh sorry guys, just wait a few minutes. (Pippa, 721-724)*

A feeling of isolation was described by both Harry and Darren because they saw themselves as different and they felt nobody could relate to them due to this difference. Harry also thought he was the only person who stammered. These narratives give a sense of their loneliness but also their lack of understanding about stammering during their lives at in education.

*5.18*

*Well, it made me feel very closed from the world I suppose. I thought I was the only one, and now of course I realise that I'm not, but sometimes it certainly feels like that. It feels like it's just you and I suppose back in sixth form it was a very lonely place. I know that sounds quite deep, but it was really. It was, it was quite a lonely place I suppose. It felt like no one really got me. (Harry, 357-363)*

*And it made me really feel isolated from everyone because I had something that they can't really relate to. (Darren, 172-174)*

The young people's awareness of their speech being different to others and their shared feelings of guilt, described in the previous sub-theme, appeared to affect their behaviour in the education context. The young people's accounts indicated that they changed the way they acted in particular situations by restricting what they said or taking on a particular persona to support their interaction.

*5.19*

*It's like there's times when I want to talk but like I'd rather not talk because I'd get stuck. (Mia, 458-450)*

*Because when you, like, put on a voice or where you change the way you talk, you can talk fine then, so it's, kind of, like an escape. So by being the class clown, I could talk fine (Gary, 24-28)*

These adaptive behaviours impacted on participants' participation in education and brought to the fore how stammering defined their education experiences and their identity. Extracts from Mia and Nikki described how stammering limited their expression and the feelings of frustration experienced as a result of not having control over what they wished to say. Subsequently this inability to have a voice meant they could not expose their true self which resulted in their true identity being hidden.

*5.20*

*It's kind of like I get a bit frustrated because there's so much inside but I can't get it out or show it, and so that can get a bit frustrating. (Mia, 830-832)*

*I can't show, I don't know, just me, just in a presentation or anything because it just shuts it off. And I'm like this is not me, it's not fair (Nikki, 867-869)*

Some participants described how the presence of stammering influenced the way they viewed themselves. In the interview with Harry, he talked about how his sense of self was flawed by his stammer. He seemed to indicate that there was a conflict between his self-identity and being a person who stammers. He saw the two as incompatible, inferring that his stammer was kept hidden to protect his identity. Owen described how his stammer defined him which seemed to imply he had accepted living as a person who stammers. His acknowledgement that his stammer had impacted his character suggests his identity was altered.

*5.21*

*I guess it was just being imperfect; it's that I couldn't be me and stammer. It just wasn't a thing…it just wouldn't work. (Harry, 247-249)*

*Yes, the stammer has changed it* [his personality]*, it's forged my personality, moulded it to what it is now, it's what makes me me, in other words, it makes me the person I am. (Owen, 395-398)*

For Nikki, saying her name was very hard and she described how she experienced negative reactions from others if she hesitated in saying her name. To avoid such responses, she replaced her real name with a name she could say at the particular time. This inability to say her name appeared to undermine her identity as she changed from being Nikki to being a person called either Michelle or Amy.

*5.22*

*They're like, oh, what's your name, and I'm like, oh, no. And everyone's like, oh, right, forgotten your own name and I'm like, yes, I've forgotten my name. Yes, of course I have. (Nikki, 394-397)*

*I don't know I used to work in a bar and if people are like, oh, what's your name I just used to lie every time …I don't know it's…it's just stupid how my name is Michelle, every time I was always…always be like Michelle or Amy because people just think my name's Amy a lot and I'm like it's not my name it's so weird. (Nikki, 406-413)*

Similarly, several participants expressed their concern regarding others' evaluations of their personality and ability due to their stammering behaviour or withdrawal from situations and lack of interaction. Harry described his anxiety in relation to how others may view him and some participants believed some teachers and peers formed invalid opinions of them, perceiving them to be a different person to whom they are. Liam, Callum and Nikki each talked about how they felt others developed inaccurate views of their personality, for example, seeing them as shy or nervous.

*5.23*

*The whole time I get so completely worried and consumed about what the other person might think of me (Harry, 168)*

*They saw me do it* [stammer] *and they just thought I was nervous. (Liam, 358)*

*Everyone in my school is just going to think I'm just weird, because no one is going to say, well, what's he got? And no one understands and people have an assumption about stuttering, thinking it means you're just nervous or scared all the time. (Callum, 2278-2283)*

*But I'm not a nervous person really. I'm really loud and everyone's like…I don't understand what happens to you, and I'm like me neither! Because I'm not like that, I'm not shy, I'm not like a wallflower or anything. I'm really not. So it's just so annoying. (Nikki, 861-866)*

Some participants, like Mia, expressed concern that their lack of participation might cause others to doubt their ability. Adam also seemed scared to reveal his stammer as he feared people would view him as inferior and similarly Kyle believed others may see him as less intelligent because he stammers. Nikki's extract described how she avoided stammering by pretending to be indecisive or to be thinking when ordering a drink which gave her time to utter a word. She believed this behaviour caused others to form negative views of her, seeing her as 'ditzy'.

*5.24*

*The person might think* [because she does not speak], *oh, she's just like…like she's quiet or she doesn't understand or she don't know anything but like I do. It's just I won't say it. (Mia, 458-462)*

*I don't want them to know that I stammer because then they might judge me as being less of a person than what I am, which is completely ridiculous really, but… (Adam, 62-65)*

*I don't know what they associate stammering with. It's just sometimes I think, particularly with that one individual who I had a problem with, is lack of intelligence through having a stammer, when in fact I feel I'm quite articulate but it stopped me from being what I was. (Kyle, 401-407)*

*I'm like can I have a latté, but I think I want in a shot, and I think… I mean yeah, I'm just like…think for ages but I'm not thinking. I'm like hmm, I don't know what I want. I do this thing where I'm like oh, I can't decide because I'm… so people just think you're ditzy and stuff and I never know what I want. I'm just filling in time until I can say what I want. (Nikki, 1042-1045)*

Finally, Ben described how people associated him with stammering and how he found this demeaning perhaps because he felt this didn't recognise or value his other attributes.

*5.25*

*It was just sort of something I was known to do…… it was completely humiliating (Ben, 55-56)*

The impact of stammering on self-identity was clearly important for the young people in the study. It seemed participants changed their behaviour in an attempt to manage their stammer. However, by adapting their verbal interaction in the education context there appeared to be a shift in their identity. For many, there was the sense that their identity was eroded and their true self could not emerge, rather it was oppressed (5.22) This then impacted self-worth and self-esteem for some.

# CHAPTER 6. STUDY TWO FINDINGS (INTERVIEWS) – THEME 2

## 6.1 Super-ordinate Theme Two: Being a person who stammers in education: the impact

**6.1.1 Overview of super-ordinate theme two.** This second super-ordinate theme describes participants' views of their experiences in their daily lives in education. It includes three sub-themes which reflect their participation in the classroom, their academic choices and achievement and the reactions from their teachers and peers.

| Super-ordinate Theme Two | Sub-themes |
|---|---|
| Theme Two: Being a person who stammers in education: the impact | 2a: Classroom participation |
| | 2b: Academic choices and achievement |
| | 2c: Reactions of others |

**6.1.2 Sub-theme 2a: Classroom participation.** Participants described how they believed their stammer impacted their ability to take part in daily classroom activities. All participants reported that their stammering had an adverse effect on their participation and they recalled several types of activity that proved difficult for them, resulting in a negative experience. They used a number of adjectives to describe the undesirable feelings they associated with classroom activity including, for example, 'hideous', 'scared', 'hurt', 'sad', 'panicky' and 'hate'.

***6.1.2.1 Reading aloud.*** Multiple participants mentioned their challenging experiences of reading aloud. Jess described her experience of reading in front of her peers as awful but it was also clear that the anticipation of reading aloud created great anxiety for her. This seemed to have been triggered by the uncertainty as to whether she would be chosen to read and by her prediction that she would stammer on words in the proceeding passage. There is a sense that Jess felt helpless in this situation knowing that she could not omit or substitute any of the words in the passage. Her fear and apprehension was emphasised by her repeated use of the phrase "please not me".

*6.1*

*Hideous…. I had to read out loud. That was awful. The teacher would read a bit of the book and then she would pick someone else to read the next paragraph and then they would pick someone else. I was like, please not me, please not me, please not me. It was so weird because I knew that I would have to scan. I didn't know when I was going to get picked so I had to scan through all the words to pick out the ones that I knew I was going to get stuck on. I was like I can't change the words because everyone else is reading off the same bit so it was like, no, help me. (Jess, 367-377)*

Similarly, Nikki expressed the panic and dread she felt whilst anticipating the possibility of being chosen to read and her negative feelings associated with the task.

*6.2*

*in English and stuff…just when you, sort of, just read a bit of the book out in class I would just…I'd just sit there and literally I would be so panicky. I'd be like…they'd come to me and like, no. It was so bad. (Nikki, p6. 225-229)*

For Liam, reading aloud was a laborious challenge which caused him much embarrassment. He remembered the process of standing up to read in class and the lengthy time it took him to read in comparison to his peers. He dwelled on the intense negative feelings of reading aloud which then affected his confidence when speaking to others. This experience would stay with him for the remainder of the day, making him feel awful. As a result of this repeated negative experience, he decided to take aversive action and from then on he refused to participate in class speaking activities such as reading aloud. Liam's narrative reflected the powerful and lasting impact caused by this activity which triggered high levels of anxiety manifested as panic attacks which he continues to suffer.

*6.3*

*I tried in my middle school a few times in English and it was just problems after problems when I did it. I used to stand up and where it would take one person five minutes to read two pages it would take me twenty minutes. And for the whole day after that I felt embarrassed when I talked to anybody, and it was just awful. I did that two or three times in my first year at that school and then it dawned on me for the rest of my time at school, for my whole school period just from that moment, just don't do it again. Because it was just right, I felt so bad for doing it at that period, every time I was going to do it, it's like oh, I remember that, I'm not doing that again. (Liam, 742-753)*

*It got so stressful of me doing it that I got panic attacks, and anxiety, which I've still got now because of that. So I do suffer a lot from them now. (Liam, 860-863)*

Other participants spoke about their feelings of nervousness and panic when reading aloud and how this prompted their stammer. Pippa used the metaphor of being frozen to describe her inability to speak when chosen to read. This depicted her lack of articulatory control

which impeded her speech and inability to take part in the class activity. This experience had emotional consequences causing her to feel sad and humiliated. The paralinguistic features of Pippa's communication emphasised her ordeal. In the transcript below, she stressed particular words (shown in bold) and also repeated words that highlight her distress.

*6.4*

*Yeah, in Year 8 so basically we had to read something in English. Basically the teacher chose me to read but I basically completely froze and I **tried** really, really hard to say it but I couldn't and it was just **so**, so hard. So basically that wasn't my fault and I was like embarrassed and upset because of course the whole class was waiting for me to speak but I just couldn't and I got really, really upset about it. So then in the end the teacher just told me not to worry about it and she'd ask someone else and I was like phew but it was **really**, really embarrassing basically. (Pippa, 265-272)*

Callum described his feelings of anxiety when reading aloud and his concern regarding the potential reactions of others. He talked about his feelings of nervousness and like Pippa he referred to the metaphor of feeling frozen but in relation to his fear of being nominated to read. He also remembered his experience of stammering when reading in a Latin class and recalled becoming stuck on a word and being unable to look at his peers for fear of their negative response. His accounts seem to illustrate the effort and distress he endured in trying to join in with this routine activity and the resulting anxiety he suffered.

*6.5*

*But let's say a situation where, I remember a lot of the time, because I did English literature in college and also English in high school, I was always more nervous in those lessons because there'd always be someone picked on to read, so I was, like, I can't do that, I can't do that for my life and so I'd just sit there in, kind of, like, terror, just frozen all the time. (Callum, 83-98)*

*Even though I'm really good at Latin I was still nervous, because speaking aloud I still couldn't do it, so when it came to it, there was, like, most Greek names have three bits to it and I couldn't get past the surname in a sentence, I was stuttering so much and getting more nervous. I couldn't look up, I was too scared to look up, I didn't want to see how other people were looking at me if I looked around all my other classmates, so I didn't want to see their reaction, didn't want to see their faces, so I kept looking down, but I still couldn't do it (Callum, 315-333)*

Mia reported avoiding reading aloud and other speaking activities because of the possible negative evaluations of others, even though she wanted to take part. Her account described the potential embarrassment she experienced by speaking out in class and it also showed her disappointment at not being able to join in because of her anxiety. Darren described his tactics to avoid reading, and while pleased if he could evade the task, he was also unhappy that his stammer constrained his participation. Darren recognised the positive and negative

consequences of not contributing in class and appeared to be frustrated by how his stammer limited his school life.

*6.6*

*I did want to like stand up and talk or…read out loud and stuff but I stopped myself because like I'm too scared to speak because it was like embarrassing or people would laugh at me. (Mia, 89-92)*

*I would sit at the back or right in the corner at the front, and I would literally hope that someone else would put up their hand, or she doesn't really ask me. And most of the time I wasn't really asked to read out from the book. But, how it made me feel, even though I was happy that I was not reading out, it made me sad that I can't do something that I really want to. So it has that dual effect in a way. (Darren, 190-193)*

Isla clearly described her dislike of reading aloud in class and how she would always try to avoid this. She explained that she would gain support from a friend who would read for her.

*6.7*

*I'd avoid reading things, in English and stuff like that, because I never enjoyed English anyway, but they'd always make you read a section from a book, like a page each, or you'd be the reader for the class, I'd always avoid doing that. (Isla, 286-90) You'd just; you'd try to get your friend to do it instead. I would go, you do it! (Isla, 294-295)*

From a young age Ed was able to avoid reading because his parents had asked his teachers to bypass him. Ed seemed pleased he could abstain from this activity. The choice to avoid speaking in class was one way participants managed their stammer. This strategy and others used to manage stammering are fully described in Super-ordinate Theme 3.

*6.8*

*At primary school, we had to sit in circles and read out to each other and the teacher used to skip me. (Ed, 230-2) My parents had told them to. I was happy with that. (Ed, 241-245)*

Two participants, Floyd and Owen, stated that stammering did not have any impact on their ability to read aloud. Both talked about coping well with reading in front of others despite their stammers. There is a sense of them being surprised at their ability to join in with this activity.

*6.9*

*Funnily enough, I was always very good at reading aloud, so much so I'd be fluent when I read aloud. That was in the first stages of secondary school. I think towards the end in the sixth form, I remember there were times when we had to read things, and then I got a bit stuck, I think when I became…I think when I started to think about it, that's when I got a bit more stuck. But yeah, reading I was fine. (Floyd, 360-367)*

*Reading out loud, I'm fine with that actually. Well, at the start I might stammer because I've had to go up and speak in front of everyone, and I realise it's me who has got to be talking. But, after that, all you've got to do is just read the words out, you know, and it's easy pretty much. (Owen, 125-130)*

***6.1.2.2 Presentations.*** Oral presentations were also a regular part of classroom life for many of the participants, with presentations being frequently used as a method of assessing their knowledge and skills either individually or as part of a group assessment. Participants described their struggle with delivering presentations, causing them similar negative experiences to those when reading aloud. They also highlight participants' concerns regarding the potential impact a poor oral performance may have on their academic achievement and the ways they tried to cope.

Floyd remembered being aware of the first occasion when his stammer was an issue for him; when he was giving a presentation. Similar to earlier recollections from Pippa and Callum, he related his inability to utter a word to the metaphor of becoming frozen. The distress caused by this event seemed to have affected his memory of whether he completed the presentation but he was able to recall the emotional upset he felt. This negative experience associated with presenting in class is in contrast to his earlier recollection of reading aloud. It might be that Floyd was supported by the written word when reading in front of others, but this was not clear from his account.

*6.10*

*However, the first real incident that I can remember about my speech was in year eight, was in an English class. I was giving a presentation, I think, in front of the class and I froze. (Floyd, 127-130) I just got up and I couldn't get a word out, I don't even think I finished the presentation either. It was the end of the day, so I remember after the class finished, I was walking back to my car and I was even crying too. Got in the car, I think I just broke out into tears. I mean, it was quite sad but, yeah, it was quite tough [laugh] I remember. (Floyd, 166-172)*

Callum explained his stammer could not be prevented in oral presentations, despite preparing well. He recalled the negative feelings associated with stammering in class and stressed how he was never able to forget these experiences. He repeated the word 'never' to accentuate his point.

*6.11*

*There were situations in high school and in college, where I couldn't get out of a bad situation, so if there was a presentation I had to do, no matter how much preparation there was, I did, I used to end up in a situation where I stuttered really badly and you* ***never*** *really forget those situations, you* ***never*** *forget. I can always remember a bad time I had in high*

*school that will never really go away from me, because it was so embarrassing and it made me so angry and frustrated, (Callum, 234-245)*

Darren and Pippa both described having to deal with the unpredictable nature of their stammer when giving a presentation. They mentioned how the fluency of their speech could suddenly be interrupted by a significant stammer which Darren described as a 'giant block'. It seemed that his inability to anticipate his stammer left Darren feeling uncertain as to how to cope. Pippa's account illustrated the effort she exerted in trying to speak and this was emphasised by her stressing and repeating the words 'really' and 'pushing'.

*6.12*

*The first slide I was completely fine, really fluent, but the next one, I had a giant block, and I didn't know what to do, because thirty seconds ago I was speaking fine, and now I have this really hard block. (Darren, 89-93)*

*So basically midway through this assessment so my speech went completely blocked for like 40 seconds or something like that and it was so hard 'cause I was like* ***really****,* ***really pushing, pushing*** *myself to say it but I couldn't. (Pippa, 370-375)*

Some participants also discussed their concern about the detrimental effect stammering might have on their assessment grades and influence whether they passed their assessments. Pippa's narrative showed her frustration about stammering during a presentation and she appeared worried that this might impact on the grade she will be awarded. Likewise, Nikki described the challenge of delivering presentations and the angst she experienced in relation to the possibility of failing her university degree due to her oral performance. She also spoke of her desire to be like her peers and to be treated the same, but she recognised this was not possible and that she required support with presentations.

*6.13*

*I knew how important it was to do this assessment to get my grade and now out of nowhere I was having a really bad stammer. (Pippa, 386-387)*

*Like single presentations and they're like really hard. That's like impossible pretty much (Nikki, 603-604). If I'm doing just I don't know just a presentation, then it's so much…I just feel so pressured. (Nikki, 848-9) This is my dissertation, this is my degree and I'm really like worrying that I'm going to fail because of this* [her speech] *and that sort of thing. It just gets really hard. (Nikki, 927-930)*

*Presentations…I'm there… and just I need some help but I don't want to be special. I just want to be like everyone else, but I'm…you know, I can't be. It's really hard. (Nikki, 123-126)*

Callum showed the immense worry he felt in the build up to a presentation which he believed would affect his educational achievement. His narrative indicated he was not concerned with preparation phase of the presentation but instead his mind was completely focused on

worrying about the delivery of the oral presentation in 6 weeks' time. Callum's negative feelings associated with presenting in front of others seemed to cause him high levels of anxiety and these thoughts appeared to consume him.

*6.14*

*One example is for business studies, GCSE, and this was towards the final grade, so my final overall grade and I had to do a presentation based on a business model, can't remember what, but the main thing is that you had to do a presentation in front of the whole class. So we had to prepare it for weeks, so making the presentation, doing all the research for it, but that was totally irrelevant to me, the main thing was that I knew that in six weeks' time, or whatever, I had to do a presentation and when you have time to think about it, you get more nervous, because in your head, you're thinking, six weeks' time, six weeks' time that's going to happen, I'm going to have to do that. (Callum, 251-266)*

For Ed, presentations were also a daunting experience which he said he loathed, but he recognised that his peers who did not stammer were likely to fear this type of activity too.

*6.15*

*I always used to hate to do. And that was always quite scary but scary for anyone, at the end of the day. (Ed, 309-313)*

Some participants described ways of coping with presentations. Jess spoke about several strategies she used which included asking her teacher if she could be the first to present in her class, choosing to present in front of a smaller group and delivering her presentation as quickly as she could. She expressed relief and contentment from completing the presentation and there was a sense of achievement.

*6.16*

*I did it in front of half the class and I made sure I went first. I told the teachers, please can I go first to get it done and out the way, and I remember that was okay. (Jess, 482-485)*

*Everyone else was doing theirs on a different day but I had asked to do it during that particular lesson because it's got the least amount of people in it (Jess, 490-493)*

*I got mine done in 11 minutes and I remember speeding through it and going as fast I could, trying to get it out. I did it and I was so pleased at the end. (Jess, 558-561)*

Kyle mentioned the planning he put into preparing for a presentation and the practice he undertook, which seemed to enable him to cope with this class activity. Adam talked about feeling more comfortable with carrying out presentations if he could do this as part of a small group. He found the group supportive and some of the pressure he experienced was alleviated.

*6.17*
*So the way I managed it that day was I knew exactly what bits were mine and I had everything planned out, it all had been practised (Kyle, 128-30)*

*Because we had them in English, that was when they used to worry me a bit. But usually it was a lot better if you did them in groups of, like, two or three, so you weren't…you know, so it wasn't completely down to you, you had people there supporting you as well and taking some of the weight of your shoulders really. (Adam, 377-85)*

Owen believed his ability to do presentations had improved over time and he now felt less anxious about them. He indicated clear aspirations for the future and saw the importance of being able to present information to others if he wants to become a fire fighter. He referred to his determination which he thought would help him to succeed. This is an attribute which Owen and other participants mentioned in relation to learning to cope with their stammer at school which emerged from their accounts and is described in Super-ordinate Theme 3.

*6.18*

*Over the years I have improved and I don't feel as much anxiety, and for my future job I might need to do more presentations in front of everyone, because I want to be a fire fighter. That means I would have to inform people, such as schools or workplaces, maybe about fire alarms or just general safety about fire. (98-104) I'm quite determined, as I mentioned before. (Owen, 108)*

Ben was the only participant who said he enjoyed class presentations despite his stammer. He appeared to relish the opportunity to put forward his ideas but also seemed supported by the written text which he could refer to during his oral presentation.

*6.19*

*Even though I have this stammer, I love talking in front of people, and giving presentations, which I did in my business studies. It was pitching ideas to people. (Ben, 206-209)*

*I like doing it. It's a set thing, it's a set script of which I almost memorise from, but not completely, and I can still go a bit freelance with it. (Ben, 222-224)*

***6.1.2.3 Answering questions/contributing in class.*** It was clear from the accounts of a number of participants that answering questions in class proved challenging. Several young people talked about their unwillingness to answer questions for fear of stammering and their use of strategies to help them avoid this class activity. Jess and Harry both recalled how they would pretend to not know the answer to a question despite being aware of it. Jess described feeling troubled by her evasive behaviour and there was a sense that she felt some guilt because of her deceit. Harry mentioned how one particular teacher seemed puzzled by his apparent inability to recall an answer to a question that he clearly should have

known. Like Jess, he preferred to not show his true ability and to keep up the pretence. The confused reaction from Harry's teacher seemed to suggest that she lacked an understanding of Harry's plight. As a result of these participants using strategies to cope with their stammering it appeared that their true identity remained hidden, as described in Super-ordinate Theme 1.

*6.20*

*Answering questions, I don't think I was that great, because I don't remember many questions I answered. So I guess that tells you I might have avoided a few. (Floyd, 360-69)*

*Like if the teacher asked a question and I knew the answer, I wouldn't say it. And it felt really bad, because I know the answer but I don't want to say it. (p6 246-8) … … but if I knew that I'd get stuck on it, I'd say I don't know then they would ask someone else (Jess, 253-254)*

*I just would simply pretend that I didn't know the answer. So if a teacher asked a question, even if it wasn't aimed just at me, I would never bother to put my hand up. So even if I knew the answer clearly, I just wouldn't bother to say. (Harry, 102-106) She* [his German teacher] *wouldn't get annoyed or cross, but she would say something like you must know the answer, or something, because we've done it before. And I would just be like oh, I'm sorry, but I don't know the answer. But then I did really know the answer, so yeah. (Harry, 121-126)*

Gary and Nikki were also reticent about answering questions in class and they adopted similar avoidance behaviour as previously described by other participants. However, they recognised that their lack of contribution in class had negative consequences for them. Gary admitted that the easier option was to avoid answering questions, but he was unhappy that his stammer restricted his class participation and his voice could not be heard. Nikki seemed to feel that her lack of class participation did not reflect her aptitude and impacted on her teachers' opinions of her.

*6.21*

*…but, like, the rest of my lessons, I think I didn't contribute as much as I think that I could have, because of my stammer. (Gary, 78-80) …. if I was, like, asked a question, I think I was more inclined to say, look, I don't know, and even if I did know the answer, I'd just…because it was easier. (Gary, 231-234) ……it's not nice because…yeah, like, it's hard because you want to think…like, you have a voice and when something like a stammer holds you back, it's not good, no. (Gary, 241-244)*

*If I was asked then I'd be like erm, I think it's this, or I could say it as I would. And then if I couldn't I'd be like I don't know.* [even when did know] *(Nikki, 1113-1115) …. I was like I do know, it's really annoying. But just on reports and stuff it was always like oh, she could participate more in class (Nikki, 1120-1122)*

Similarly, Callum recalled the effect he believed his stammer had on his school experiences and he believed it was essential to contribute to oral activities to show your ability and

engagement. However, Callum indicated his extreme dislike of school due to his stammer and described the impact it had on his life at school. He saw the ability to express himself competently as a vital measure of how others viewed him and of his success at school. He worried that his difficulty in speaking would cause others to question his ability and they would perceive him as less intelligent. He described the extra effort he made and actions he took to demonstrate his capability, through both his written work and attempts to answer questions in class. Although he referred to his feelings of self-doubt he was able to reassure himself of his academic ability through his achievement of good examination grades.

*6.22*

*So I think I pretty much hated high school, because of the stutter, because it just made it harder to do things in class, so high school is a lot about participation and speaking out as well to also demonstrate that you're doing well in class and when you can't do that, you can't speak out or show that you know the answer or things like that, it makes you, kind of, doubt yourself and I thought to myself, like, if I can't speak and show that I'm intelligent enough, I'll have to do the hard work, I'll have to study and then prove it in my written work. (Callum, 33-44) … So if I ever had to do homework or essays, things like that, I always made sure I studied, because I couldn't verbally show that I was smart enough, but I did know that I'm smart in my own right, because when it comes to tests I'm getting high grades (Callum, 46-51)*

Later in the interview Callum referred back to his experiences of answering questions in class and the effort he made to participate was clear from his account. His attempts to join in with oral activities clearly reflected his determination to show his teacher that he was engaged with learning in the classroom and that he wanted to be involved despite his continuing self-doubt.

*6.23*

*I always had to make the conscious effort that if I knew the answer I had to say it. So if I sat in the classroom, didn't say anything, was always quiet, then the teacher would be concerned and think I'm not trying or I'm not doing anything, so to make it easier for myself, I, kind of, made my own little rules with the teacher, but whenever I did know the answer, I put my hand and try and say it, because that way I showed I'm still demonstrating, I'm still trying, even though it's hard and I didn't want to speak, but if I did know the answer I would try and say it, even though it may make me look stupid after it. (Callum, 100-113)*

Owen talked about his current experiences of answering questions at school. He described the variability of both his stammer and his levels of anxiety and how these impacted on his ability to participate in class. He described the challenge of speaking in front of his peers and how on some days he would choose not to speak if his anxiety levels were raised but other times he would feel confident enough to take part. He mentioned his determination to be involved in class activities and the gratification he felt if he succeeded in being able to

express himself. There was a sense of real achievement if he was able to communicate exactly what he set out to say, similar to the self-satisfaction expressed by Callum.

*6.24*

*Well, asking questions is quite hard, you know, because you have to put your hand up and speak out in front of everyone and that's quite difficult sometimes. But, it depends really, sometimes I can be quite determined, you know I'm quite a determined person; I just put my hand up no matter what. And, I don't always stammer, it comes and goes, I have bad days and I have good days, it depends on confidence as well. Some days I might have anxiety, or I might feel tension in me, so I might not speak or speak quiet in general. Other days, I might have lots of energy, full of confidence, and I will just feel if I have got a question I will put my hand up and just ask it, and the chances are 90 per cent, or 80 per cent, I won't stammer at all. (Owen, 36-50) … It makes me feel great, you know, because I've asked the question I've wanted to say, and I've done it. (Owen, 54-56)*

Finally, Pippa spoke about her recent experiences of answering questions at school. She explained how teachers' responses to her speech had been upsetting and had discouraged her from responding to questions. She described how they lacked awareness of her stammer and as a result their responses were inappropriate. She believed that the teachers were not intentionally hurtful but that she still found their reactions distressing to deal with. Further analysis of teachers' behaviour is reported in sub-theme 2b.

*6.25*

*I've just had teachers basically just jokingly telling me to you know like hurry up and that. So basically they didn't know about my stammer but it still hurt me and it kind of like put me off asking questions in their class again (Pippa, 234-237)*

***6.1.2.4 Answering the register.*** Some participants described their daily classroom experience of answering the register which involved responding to the teacher when their name was called out. Mia explained how she was aware of where her name occurred in the register so in advance of her name being called out she would begin to articulate her name. This anticipation helped her to manage this mandatory activity. Owen also described his initial difficulty with this requirement but indicated that he learnt to cope with this over time. Their accounts indicated that they started to learn to manage their stammer during their time at secondary school. This process of learning to cope with their stammering is described in Super-ordinate Theme 3.

*6.26*

*Like at the start of a form they'd say the register, and I'd kind of like know my name, like at what point it was, and kind of like start to say it first – if that makes sense – so I've got enough time to say it. (Mia, 120-124)*

*Answering the register… I used to find that really hard at first, but you get over it. (Owen, 878-879)*

Floyd and Jess both mentioned an occasion when they needed to say their names in class and the impact of their stammer. Both described getting stuck with their speech and it was clear from their accounts the struggle they encountered. Floyd showed his perseverance and his eventual success in saying his name. In addition to the negative experience of being unable to utter her name Jess also had to contend with the reaction of a peer who laughed at her. Participants described other reactions of their peers in Sub-theme 2.3.

*6.27*

*Hi, my name is thingy, thingy, thingy, thingy, and literally repeated thingy a hell of a lot. And yeah, I got my name out in the end somehow. (Floyd, 911-914)*

*The whole class was sitting down and as you go in, the teacher's desk was there and the class is there so I walked in and walked up to the teacher and had to say my name. Oh, don't. I had to walk up to him and he asked me for my name, and obviously I got stuck, and I remember one of the guys at the back of the class was laughing at me. (Jess, 338-344)*

***6.1.2.5 Other school activities.*** Participants cited further activities that involved speaking in front of others which they described as problematic. These included taking part in assembly and talking in groups. Mia had a vivid memory of being assigned a role in a school assembly and the impact her stammer had on this activity. She recalled her emotions of being frightened and daunted by the task and the moment of being unable to speak because of her stammer. However, despite the demands of this activity Mia did take part in the assembly and this appeared to reflect her determination to engage with speaking activities. Although Mia's account was of an event that took place some time ago the distress it caused her was still evident during the interview and she said this negative experience remains with her.

*6.28*

*it was in assembly and they just told us what parts to do, and they were like, just go and get on stage and like do it. And I was so scared and like if I'm scared and nervous it's like I can't talk at all. I get stuck quite bad. And that has stayed with me because like I got stuck really bad, and it's still like…I can still think back to that and it's like, oh my God, scary. (Mia, 26-33) ... Like I just had to stand up and I had to like say…I can't remember exactly but I did get up and saying those couple of words was like so challenging for me personally, and that has stayed with me forever. (Mia, 37-42)*

Floyd described his experiences of talking to his peers and explained how talking to a group of people is difficult for him whereas interacting with someone on a one to one basis is not an issue. He accounted for this difference by describing how he finds a group situation

stressful because he is aware of others listening to him and he worries that he may say something inappropriate. In this social situation Floyd felt anxious and he described his behaviour as reclusive. It appears that he becomes self-conscious because he fears how others may judge him so this limits his contribution to the group conversation. Floyd admitted talking in a group remained a challenge for him.

*6.29*

*And when I used to talk to them individually, it was fine. When I was in a big group and people having jokes and things like that, I always remember I didn't add much to it, didn't say much. I think a group environment, definitely, is different to just talking to an individual. You've got more pressure there….because this is another problem I'm still having now is talking to people one on one, it's fine, it's in a group that still I'm quite reclusive as well (Floyd,796-798) …. when I'm in a group, I get quite nervous, especially if I'm saying something, I'm very aware that everyone is listening. I'm always conscious that I don't want to say anything stupid as well. I think that's a little bit of social anxiety, too. (Floyd, 812-816)*

Jess also spoke about her negative response to taking part in a group activity that teachers regularly used at the start of each academic year. This involved the class getting to know one another one by recalling the names and hobbies of peers. Like Mia she described getting stuck with her speech but persevering with the task. She appeared to cope by speaking as fast as she could and by focusing on an object rather than looking at her peers. She also recollected the same unpleasant physiological reactions evoked every time she was involved with this exercise.

*6.30*

*I know. I was like, not this again, please. So again I was three-quarters of the way round and I had to say everyone's names and hobbies and I felt the same ill and sweating and… I remember staring at the table just getting through it really quickly and then getting stuck on a name, as I do, and that was awful. (Jess, 744-749)*

Another participant, Nikki said her school reports, whilst acknowledging her effort and achievement, also commented on her lack of communication and participation in class and recommended she should start to join in. Nikki's frustration at not being able to take part and reveal her true self and ability was clear and links to participants' hiding their identity as described in Super-ordinate Theme 1.

*6.31*

*Yeah, just on all my reports, it was always like oh, tries really hard, achieves this, blah-blah-blah, but start speaking to your friends and participating more in class. And I'm like no! [laughs] I would but I can't do it. (Nikki, 1127-1130)*

### 6.1.3 Sub-theme 2b: Academic choices and achievement.

A finding emerging from the accounts of some participants was their perception that stammering hindered both their academic achievement in foreign language subjects and their choice of school subjects studied from the ages of 14-16 years old. Although this sub-theme has fewer accounts to draw upon, it is a distinct theme which reflected their views about their educational performance which was important to them.

***6.1.3.1 Examination grades.*** Three participants spoke about their GCSE examination results in foreign language subjects. Despite passing the examinations with high grades they described how they felt their speech difficulty prevented them from achieving a top mark. The participants acknowledged that even when they had attained a reasonable grade there was a sense of not achieving their full academic potential. Their perceived under-achievement consequently seemed to leave them with feelings of disappointment.

*6.32*

*…I think probably I could've done better. But I mean I say better, I mean I still got a B for German so it wasn't that bad. But I'm sure I could've got an A. (Harry, 419-423)*

*I did do an exam in that a talking one* [Urdu]*, and I got stuck quite bad, and I think that…that kept me a bit back because I would have got…I would have got an A star but like I didn't because I got A…like if they had told me write it down I would have wrote it down but as they said, speak it, say it, I just got stuck. (Mia, 415-420)*

*I did struggle a bit in GCSE doing French and German. I remember my oral exam wasn't the most fluent. I mean, it wasn't bad, I got a decent result in it* [grade A]. *But yeah, it could have been better, I think. (Floyd, 406-408)*

Mia and Floyd specifically referred to struggling with their speech during the oral component of their language examination and how this impeded their result. Mia's narrative also mentioned the presence of a recording device during her oral examination. She expressed some uncertainty as to the use of the recorder but assumed the device was specifically for her and was required to help the teachers decipher her speech. It seemed Mia's knowledge of the recorder's existence negatively impacted on her examination performance and she commented on feeling this restricted her presentation.

*6.33*

*And they had a recorder as well, so probably what I was trying to say they didn't understand it, maybe or…I don't know. So that kind of kept me back I think. (Mia, 420-423)*

***6.1.3.2 Choice of subjects.*** Many participants stated that their stammer had impacted their school subject choices. Mia and Nikki felt their speech difficulty played a part

in influencing which subjects they chose to study at school from the ages of 14-16 years old; for both stammering restricted the subjects they selected. Mia's account firstly described how her speech was an important variable impacting her decision making in life in general. She believed her options were limited because of her speech and she suggested that she would have made different choices if it was not for her stammer. Mia described how she would opt for subjects at school that required less speaking and avoid subjects such as drama that involved a strong oral aspect.

*6.34*

*I'd have more choices, like I'd be different to what I've chosen; like…because like…when I kind of choose something my speech is kind of a factor that makes me decide what I'm going to do, basically. (Mia, 10-13)*

*It's like at school as well the choices that I made were based on the subjects that had more talking to do or the ones that didn't involve as much talking. I wouldn't choose like drama and stuff, things that involved a lot of talking. (Mia, 83-86)*

Similarly, Nikki described how her choice of subjects was constrained by her stammer. She was deterred from choosing to study German at an advanced level despite her clear academic ability and her passion to study languages. She was resigned to the idea that she would not succeed at the subject because she felt incapable of the oral element of the subject as a result of her stammer. Nikki's disappointment was evident when she used the expression of feeling 'gutted'. She also commented on her inability to speak normally when she compared herself to others and there was a sense of her feeling dissatisfied with herself.

*6.35*

*And I was absolutely gutted. Yes, because I love German but I was like, well, there's no point, I can't do it now because I'm just going to fail it. (Nikki, 60-62)*

*Because I know I can do it just in my head I've got just all the knowledge but I can't say it. But I was really, really good at, yes, just foreign languages and stuff and I was going to do German at 'A' level but it was…it was just like, no, because it was so much like speaking tasks. It was half oral, half written and I was like, well, I can't do that can I? (Nikki, 50-56) So, I absolutely love German but I was like, well, I can't do it because I can't talk like a normal person. (Nikki, 86-87)*

Mia's stammer continued to influence her future subject and career choice at University. She described her interest in both radiography and radiotherapy but decided on a career in radiotherapy because she thought this would involve less interaction with others. However, in practice she found the reverse of this to be true. It seemed though that this was not an issue for her as she described how she enjoyed communicating with people.

*6.36*

*You know when I've chosen this course as well it's like there was a diagnostic, I think there was therapy and between them both I…I liked them both, like the field itself, but my choice was determined by which one like involved more talking, but at the time I didn't realise that therapy has got more contact with people. But like the thing is that I like talking to people quite a bit. It's just that I get stuck. (Mia, 51-58)*

Floyd described how his stammer did not deter him from choosing to study two languages for his GCSEs. It was clear from his account that he would not allow himself to hide behind his stammer and to use his speech difficulty as a reason to avoid these subjects. There was a sense of his determination to participate in the opportunities presented to him and to not let his stammer dictate his decision making.

*6.37*

*I chose to…I did French and German in year seven, eight and nine. Then for GCSEs, I had the choice to do either or to do both, and I chose to do both. (Floyd, 391-393) …but in school, I never let my stammer get in the way of making a decision like, okay, whether or not to do two languages. I was always very good at just chucking myself in there, not using my stammer as an excuse. (Floyd, 396-398*

**6.1.4 Sub-theme 2c: Reactions of others.** This sub-theme outlined participants' experiences of their encounters and relationships with teachers and their peers in the education environment including at school, college and university.

Participants spoke about teachers' reactions to their stammering and this included frequent reference to their teachers' levels of awareness of stammering. Some also suggested how teachers could support a young person who stammers in the classroom.

***6.1.4.1 Teachers' reactions to stammering.*** Participants' perceived experiences with teachers varied. Owen and Ed recognised their teachers' patience and support. Pippa, who was still at school, also described how most teachers were patient and gave her time to speak because she made them aware of her stammer.

*6.38*

*All teachers have been fairly patient I would say. (Owen, 218)*

*She* [Teacher] *was fantastic as she actually went out of her way to try and help me. (Ed, 290-291)*

*Most teachers are really patient and they just wait because most of them know 'cause in the past I've like said oh I have a bit of a stammer sometimes, so they're fine with it. (Pippa, 169-171)*

Jess talked about how her teachers adapted class activities to support her participation, once she made them aware of her stammer. This support involved teachers changing the type of questions they asked her, allowing her extra time for an oral presentation and to deliver the presentation in front of just the teacher and a friend, rather than the whole group.

*6.39*

*I remember I told my history teacher about it and when the teacher would ask people round the room stuff, he would ask me a different question, like a question you had to answer, with a yes or no answer, I had that instead so it was easier for me. (Jess, 418-424)*

*I said, no, I can't do it* [presentation] *in front of these people. I don't know them properly. So we arranged it so I would do it at a break and just in front of the teacher and a close friend instead, and that was easier. (Jess, 473-480)*

*I had to tell a teacher that I was worried that my stammer would cause me to lose time so the teacher said she would allow me an extra minute because of it, (Jess, 548-554)*

As a result of Pippa and Jess being open with their teachers about their stammering it appeared that their teachers adopted a positive attitude towards them and Jess' teacher implemented supportive strategies. The reassuring stance of their teachers towards them appeared to enable Pippa and Jess to feel accepted and in turn this seemed to enhance their well-being. Similarly, Darren reported how some of his teachers are aware of his stammer and regard him as a "normal student", despite his stammer, which subsequently makes him feel able to participate in class. Darren recognised the inclusive approach taken by his teachers and it appeared their behaviour provided Darren with a sense of acceptance and belonging within the class. He seemed to express gratitude for being treated as a typical student in spite of his speech difficulty.

*6.40*

*They still treat me like a normal student, and I'll happily answer any question, sort of thing, so they're kind of not trying to treat me differently because of my stammer, and they're trying to make me part of the class as well. (Darren, 544-548)*

Adam and Darren described how some of their teachers lacked knowledge about stammering, with Darren's teacher admitting that she had no experience of teaching someone who stammers. Both stated that once their teachers were aware of it they showed a willingness to learn how to help them. Darren described how his teacher told other staff about his speech which he viewed as helpful. Adam appreciated the open discussion he was able to have with teachers about his speech. He also valued the time they took to listen to him and their efforts to support him.

*6.41*

*And the following year I had changed my course, and the teacher I had said that, I've never had someone who's stammered before, and I don't know how to teach you. (Darren, 64-67) …and she also spread the word as well, to other teachers, and that was really, really good. (Darren, 77-78)*

*A lot of them didn't really know a lot about it, but they were always open to wanting to talk about it, if I had issues about it, of course. And they would understand and they would have time after lessons or after school to speak about it, and try and work on any issue I had. (Adam, 246-254) ……Yeah, a very, very open environment, yeah, which was great really. So that really helped me. (Adam, 259-260)*

Gary talked about how he felt the need to try to talk fluently at school because his teachers were unaware of his stammer. In hindsight he wished he had felt able to disclose this to them, as it may have eased the pressure on him to be fluent. He showed an understanding of why his teachers had limited knowledge of stammering and considered this to be due to its lack of prevalence. However, Gary also suggested that teachers' understanding of stammering might have recently improved because of film and media coverage about stammering.

*6.42*

*So I regret not having the confidence to tell the teachers, but I guess, like, because it's quite rare thing to have a stammer, I guess the teachers just…they didn't really know anything about stammers, I don't think. I think, like, it helps now with The King's Speech and stuff. I think that probably teachers are more aware and they can pick up on the students that might have a stammer, but I found it hard that they didn't know, so I felt like I was under more pressure to speak fluently. (Gary, 181-190)*

Ed sympathised with teachers because by hiding a stammer it made it very difficult for teachers to be aware and to be responsive to the difficulty. He suggested that teachers need to be supported to become mindful of stammering. Ed also felt that one of his teachers supported him by giving him less to say in a group oral presentation. However, he believed this was not because he stammered, but because the teacher thought he was shy, as he was always quiet.

*6.43*

*It is hard as teachers can only help if they are aware of it. I hid it, and people who stammer can become experts at hiding it. (Ed, 635-637). You can't blame teachers; you have to just encourage awareness of it. (Ed, 663-664)*

*So for our oral assessment* [in English] *he asked everyone to read out from a play, and the part that I had only had one sentence. I think that was on purpose, he purposely gave me*

*that part. He was aware that I was what he called shy, but he was not aware that I had a stammer. (Ed, 170-177)*

*People are not quiet because they are shy, often there are underlying reasons. (Ed, 181-182)*

Callum also recalled an occasion when one teacher, who was aware of his stammering, tried to help him in class. He described his experience of stammering in a lesson and being told to stop talking by the teacher. He showed his distress at her reaction, when he stated his annoyance with the teacher for not allowing him to express himself and for pitying him. This experience appeared to have had a lasting and significant impact on Callum, perhaps because despite his effort to take part in class he was humiliated and left feeling that his contribution was not valued. There was a sense that Callum felt rejected and incapable and subsequently it seemed he experienced a loss of self-worth.

Yet regardless of the impact this had on Callum's emotional state, he saw the teacher's response as an attempt to help him and he believed that she did not intentionally cause him harm. This demonstrated the mature attitude taken by Callum and also illustrated the reflection he did in relation to his stammer and others' reactions to it.

*6.44*

*So she stopped me actually, she just thought that I couldn't do it, I couldn't finish it and so she just stopped me and that made me even more annoyed the fact that I didn't actually finish, she just had to cut me off, not in a mean way, she didn't do it to embarrass me, she just thought she would give me a break, because she thought I couldn't do it and that made me more annoyed, she showed pity on me which made me more annoyed as well. That's always stuck with me and I was, like, it's just a bad experience, but I don't blame her for it, but that makes it worse for you, because then you feel like you can't do it and you've failed. (Callum, 293-313)*

Other participants also recalled how their teachers showed a lack of understanding about their stammering and how to react to them. In contrast to Callum, participants often viewed their teachers' responses as detrimental to them.

Ben talked about the lack of support he received from his teachers, even though he tried to explain to them about his stammer. He recalled one incident involving a temporary teacher who did not believe he had a stammer and accused him of lying. This showed the teacher did not trust Ben's report that he had a speech difficulty and also illustrated her lack of understanding about stammering. The teacher's reaction aggravated Ben causing him to leave the lesson and seek help from his Head teacher. Ben described a further encounter with another teacher who responded to him by repeatedly telling him to "shut up" whenever he spoke in class. He stated this was a regular occurrence which he experienced over a long

period of time. From Ben's account it appeared he was bullied by this teacher which he had no control over. As a result of the power relationship it seemed Ben had no option but to become resigned to it.

Ben's interactions in the classroom illustrated the impact his teachers' responses had on him which resulted in him loathing and disrespecting his teachers as well as feeling angry and dejected.

*6.45*

*I had a German teacher in Year 8 that because my normal German teacher had gone off for a knee operation, we had a substitute… that horrible woman. But she asked me to read something out of the book, and I went, I really don't want to, I've got a stammer, and I'd got her over to one side by this time, and I told her I'd got a stammer and I didn't want to because I wasn't the most friendly with the other students at that point. And she went; don't lie to me to get out of reading. So I picked up my stuff, walked off, and walked straight into the head's office. (Ben, 69-81)*

*Any time I was talking to her* [the teacher] *or to someone else, and she didn't like it, Ben, shut up. It was every…it was at least three times a lesson for two years. (Ben, 126-128) …. I hated the teachers, they were awful. (Ben, 130)*

Nikki also spoke about her experiences with teachers and in particular remembered the reaction from one of her teachers on disclosing that she stammered. She talked about setting up to do a presentation in class and how she made the teacher aware she stammered. The teacher responded by suggesting he would get a special bell and ring this when he needed to stop her talking, if she took too long. This was said to her in front of her peers. Nikki clearly found the teacher's remark offensive and she showed her distress by responding to him "I'm not a leper". Her teacher's comment both angered and upset Nikki, but the way she associated herself with a leper also suggests the teacher's reaction had a notable impact on her self-worth. The use of the word 'leper' conveyed her strong feeling of affliction and she appeared to be left feeling like an outcast with negligible self-respect.

*6.46*

*And I was like I'm not a leper. I don't need a bell for like when I like go around and I was just like what does that even mean. I was like you're so nasty. I just like thought he thought he was being like funny and I was like I'm sorry but that is just so disrespectful. (Nikki, 722-724)*

Pippa recalled the response of one of her teachers when she tried to speak during a class activity. She remembered getting stuck and being told by the teacher to "spit it out", a comment which she found both unhelpful and irritating. Pippa described the impatience of the teacher, who was not prepared to give her time to speak, and the associated frustration

she experienced when she was then unable to express herself following the teacher's remark.

*6.47*

*So basically my cookery teacher she asked me a question so I tried to like say it but I couldn't so basically she told me to spit it out but then of course after that I kind of like couldn't speak to her because I was just annoyed that she couldn't just wait a few minutes, a few seconds. Yeah, so like some teachers are really annoying. (Pippa, 183-189)*

Some participants commented on their teachers' apparent disinterest in their stammer and lack of support. Isla believed her teachers did not acknowledge her speech difficulty or show empathy, in spite of her teachers being aware of her stammer. It was clear to Isla that her speech difficulty was of no importance to her teachers and she showed her disappointment in their lack of regard and understanding of her stammer.

*6.48*

*Yes, they* [her teachers] *knew all about it* [her stammer]*, but they never once asked (Isla, 226-227)*

*I don't think schools acknowledged it really, like when you'd clearly have a problem with it, even though they knew about it, they knew you were accessing help for it, they wouldn't respect it and acknowledge the fact that it hurt; they didn't respect it really. (Isla, 1337-41)*

Like Isla, Nikki and Liam's stories reflected their teachers' lack of concern regarding their speech, even when their teachers were informed of it. However as well as the indifference shown by Isla's teachers, Nikki and Liam also recalled negative verbal responses from their teachers. Despite Nikki's attempt to try to explain her speech problem to her teacher, Nikki's teacher reacted with a dismissive comment, trivialising her speech problem. Liam's account reflected the humiliation he felt when his teacher spoke of Liam's inadequacy in front of his peers. This was just one incident reflecting the absence of support Liam experienced throughout his schooling.

*6.49*

*I'd be like you don't understand and like she'd* [the teacher] *be like, oh, yes, well, everyone's got problems (Nikki, 830-831)*

*I think in middle school I do remember my mum writing a note to the school saying can Liam be excused from any reading out loud. And the teachers looked down upon that. I remember this one guy, I think it was year eight it was, he got that letter as well and instead of supporting me in a way, he looked down and when it came to my turn he goes oh, just leave Liam, he can't do it, and then move onto the next guy, which obviously it was quite embarrassing. But no, at school I got no support at all. (Liam, 80-89)*

Liam explained that it was rare for a teacher to show any understanding about his stammer and to offer help. He could only remember two teachers offering support for his stammer.

*6.50*

*Is there anything I can help with? That was rare to hear, that was extremely rare. I think I've only heard that from two teachers at school my entire school period. (Liam, 450-452)*

Jess described how accessing any help with her speech within education had to be driven by her. She talked about the effort she made to see her tutor at particular times of the day so that she could speak to him privately about her speech and the support she required in class, without being overheard. This demonstrated Jess' proactivity but showed that the onus was on her to seek support.

*6.51*

*I think it was pretty much up to me, yes. I mean, when I was actually at school, in year nine and stuff, I would see my tutor at break or I would stay behind after form time in the mornings to speak to him on his own rather than having to speak out in front of everyone else (Jess, 170-175)*

***6.1.4.2 College and university support.*** The reactions to stammering that participants experienced from teachers at college and university seemed different compared to school. Some participants spoke of a more understanding and supportive relationship with their teachers in higher education environments.

For instance, Isla talked about her positive relationships with teaching staff at college in contrast to her earlier adverse experiences at school. At college, she was regarded as an adult with individual needs that teachers were interested in helping. In this new environment she experienced understanding and support from staff and the positive aspects of being a person who stammers were recognised. Compared to her past experiences at school it was evident that Isla felt valued and supported by her college teachers and this appeared to have had a positive influence on her self-respect and her life at college.

*6.52*

*So when I got to college, I loved it there, they were really good at college, and they were very supportive through everything (Isla, 171-173) …I think they treat you like an adult…they'd go round everyone individually, so you'd get asked something personally. And that was good. (Isla, 180-182)*

*They'd just see it as a weakness. But college, they'd see it as a strength. I remember when I went to the careers meeting at college, she said, it's a strength, because it shows you can…* [she hesitates], *you're above other people, rather than it being a weakness. (Isla, 195-201)*

Similarly, Mia described a more receptive and proactive approach taken by teachers at university towards supporting her with her stammer compared to her school experiences. Mia was training to become a radiotherapist at university and she spoke about both the support from her university personal tutor, who helped to refer her to speech and language therapy, and also how hospital teaching staff on her clinical work placement had an encouraging attitude towards her.

*6.53*

*Like in primary school and secondary school there wasn't as much support I'd say because they just kind of like accepted me the way I was and carried on with it; whereas in uni now they realised, she's got a stammer, and they kind of like attempted to support me with it like a bit more. (Mia, 629-636)*

*She realised that I've got a stammer, like it was quite bad, so they* [personal tutor] and *referred me to speech and language therapy. (Mia, 585-586)*

*Some staff, they'll let you go and do the patients' check-up and they'll say go for it (Mia, 1019-1020)*

Jess discussed how disclosing her stammer on her college application form triggered a programme of support from the college. This involved pre-course support sessions for Jess and other students with particular needs to help them prepare for college as well as a support mentor on starting her course. Jess particularly appreciated her mentor and reflected on how she was able to open up to her. At the time of the interview, Jess was at university but continued to have contact with her college mentor which indicated the value she continued to place on her support.

*6.54*

*I think, because I had made a note that I had a stammer, they invited me to do this two-week programme sort of thing, which I think is for people who have things like special needs and would find starting in September a lot more comfortable if they did this two-week period in the summer holidays before starting, so I was invited to go for that, and I think it was because of my speech. (Jess, 717-24)*

*I have a success mentor which I see once a week and I've seen her since starting in September. (Jess, 796-8) She came across as so caring and understanding that it felt like I could talk to her and just say what I wanted. So I still see her. (Jess, 839-841)*

***6.1.4.3 Communication between teachers.*** Some participants spoke of their frustration regarding the poor communication amongst their teachers at school in relation to their stammer. Liam and Callum reflected on the challenge they faced each year when starting a new class with a new teacher. It appeared from their accounts that information

about their stammering was not transferred between teaching colleagues which resulted in their new teachers being unaware of their speech difficulty. Both participants saw this as an annual event which placed an unnecessary demand on them. It was also clear from Callum's narrative that this had a negative effect on his confidence as he had to build a new rapport and understanding of his stammer with a new teacher each year. Nikki described similar problems with new or substitute teachers being unaware of her speech difficulty. She thought she was viewed by these teachers as awkward for refusing to take part in class.

*6.55*

*Well, when you go to your next year it just started again from fresh. I don't know if it was just my teachers but they didn't communicate with all the teachers who were lower years. When they got a new class our new teachers knew nothing about us, nothing at all. (Liam, 503-07)*

*I'd always find it hard every single year, because every year you get a new teacher, therefore I'd speak less, so let's say you spend a whole year trying to get to know your teacher and you're confident speaking to them and then by the end of the year you get a new teacher and you start again (Callum, 1289-1296)*

*Just if you have a new teacher or a supply teacher and they go, oh, you do it and I'm like, I'm not doing it. I reckon they just think I'm an arse-y kid. (Nikki, 281-286)*

***6.1.4.4 Educating teachers.*** A number of participants viewed the education of teachers about stammering as important. Floyd suggested this could be achieved by teachers listening to presentations about stammering from people who stammer or SLTs.

*6.56*

*However, first and foremost, I believe they need to be educated in stammering. (Floyd, 511)*

*Perhaps it could be as simple as doing presentations to teachers where people actually go and explain to them, you know. It can be one presentation a year perhaps to schools where people with stammers or who work with people who stammer can actually explain it. (Floyd, 523-529)*

Adam thought teachers should receive training perhaps as part of their initial teacher training to increase their understanding of stammering which he inferred would make them more approachable and easier to talk to. Liam believed there should be at least one teacher with knowledge of stammering. Many participants also talked about the interaction skills of teachers and how teachers should learn to be patient and listen to YPWS when communicating with them in the classroom.

*6.57*

*I think, whether in the training of becoming a teacher, whether they integrated, like, a little more knowledge into things such as stammering, because you speak to some teachers who*

*don't have any, like, knowledge of it, who haven't come across people who stammer. And then that can usually be a bit harder to talk with because they're completely new to it. (Adam, 943-951)*

*I definitely think there should've been at least one person out of the whole school that does have a brief knowledge or who can see that pupil who has got that problem. (Liam, 1347-1350)*

*I would say that if the child comes to you really be patient and listen to what they say. (Harry, 972-973)*

Others talked about the potential value of having an open discussion about their stammer with teachers. They believed this would enable teachers to understand their needs and support them in coping with classroom tasks. Nikki described how this would provide the opportunity to talk about less formal options for presenting in class. Similarly, others, like Callum, suggested negotiating with teachers regarding how individuals can contribute in class so that the young person can remain engaged with learning. A number of participants stated that they were not asking to be treated differently rather just requesting help to support their class participation.

*6.58*

*Just to have an actual, I don't know, in-depth discussion* [with her teacher] *and for her to understand and ask me what I want. Because I would rather do the presentation, just on my iPad and be this is it, this is just all the words I was going to say, just in a script and then speak about it. (Nikki, 922-927)*

*If they're having to read from a book, I should choose myself to speak rather than you making me, because that would make me more nervous, in a sense, but the teacher shouldn't let the child be lazy and complacent and not do anything in class and not contribute, but you can't force them, so you need to try and find that balance with the child, because you don't know what that is. (Callum, 514-522)*

*There's no need to give them any special extra treatment, because that's not what they/we want. It singles us out and makes us look worse. (Ben, 789-791)*

Some suggested teachers should be more proactive in talking to YPWS in order to support them. This would enable teachers to find out what the problem is, to discuss ways to help and provide reassurance to YPWS. Harry recognised that initially some YPWS may not want to speak about their stammer to a teacher but that they should be encouraged to do so.

*6.59*

*But if they could talk to the people who don't interact with the class that much, or if they could ask something like why can I not do the group presentation, then find out why, and how they can help them, it would really help the student. (Darren, 472-476)*

*Maybe if they had like sat you down, talked to you more, like supported you emotionally, gave you a bit more confidence, because if someone says, it's okay. You're normal. Like you've got a stammer, just get you to like accept it a bit more maybe, because then you have a bit more confidence to be able to go for it that bit more. (Mia, 986-992)*

*I think it would be a good idea to go up to the child and ask to speak to them, and the child might not want that, and I can totally get why the child wouldn't want that. But I think sometimes you have to force them to talk about it. (Harry, 974-977)*

***6.1.4.5 Reactions of peers to stammering.*** Some of the participants mentioned experiencing negative responses from peers at school. For a few young people this chiefly involved mimicking of their stammer.

*6.60*

*They just tried to mimic me. (Ed, 261) Well, at that age* [primary school age] *I found it quite hurtful. (Ed, 265)*

*They used to say stuff like they used to pretend to stutter, saying my name is Liam but they would do it in a stutter. (Liam, 162-164)*

*They'd go, right, A-A-A-Adam [laugh]. (Adam, 1051-1052)*

Others also remembered being laughed at by peers. Jess described earlier how stammering on her name during class registration caused peers to laugh at her. Ben, Owen and Pippa recalled similar occurrences at school and for Owen and Pippa these unhelpful reactions appeared to perpetuate their stammering behaviour and feelings of anxiety.

*6.61*

*A girl I'd known in primary school called me over to come and talk to her and her friends. And when I started talking to them, they just started laughing at me because I'd stammered. (Ben, 47-51)*

*But as I started secondary school, well everyone wasn't as mature as you are now, and you had some people who used to laugh at it, I'm aware I do stammer more then. (Owen, 229-232)*

*They'll like jokingly say spit it out but then of course if someone says that to you then basically you feel panicked and like you have to rush (Pippa, 74-77)*

Floyd clearly remembered a time and place when a peer accused him of not being to speak properly. Although Floyd initially appeared to play down the comment in terms of its impact he recognised that he still has a vivid memory of the experience.

*6.62*

*Yeah, I can, I can tell you about that incident very well, actually. It was a person called Eric, I think I had said something to him and he didn't like it. And then he said, oh, well, at least I*

*can talk properly or something like that. And as I'm sure you know, I can remember a lot about it, I can remember exactly where it happened. But yeah, it didn't affect me that much, maybe a day or two. But it's quite funny how it is engrained into my mind. (Floyd, 95-106)*

Mia also described similar comments from peers telling her she could not talk, but she stated these remarks were from her younger days at school. She appeared to think these unhelpful responses were due to the immaturity of her peers at that time and now at university she described peers as more accepting. Other participants, like Liam and Adam, also reported these type of peer responses occurring up to the age of 12 -13 years and, like Mia, Adam thought this was due to the immaturity of his peers.

*6.63*

*Uni is not too bad because people aren't that young. They kind of accept it a bit more, but school was like because they're only young, oh, she can't talk, kind of thing. She can't talk. (Mia, 328-332)*

*But yeah, it was difficult. It didn't happen as much in high school but in middle and lower school it happened a lot. (Liam, 126-128)*

*I found years seven and eight, you know, a lot of people are growing up then, I was bullied a lot more then about it than I was in any other year really. (Adam, 1043-1047)*

***6.1.4.6 Family reactions to stammering during school years.*** The majority of participants talked about positive relationships with their families as described in theme three. However, Ed, Gary and Callum mentioned unsupportive responses from their families. Ed described a less communicative relationship with his parents which appeared to lack trust. This was the only reference he made to his parents.

*6.64*

*I'm not really that close to them, and they only found out I was planning to attend the therapy centre after opening my post. (Ed, 364-366)*

Gary and Callum also described past reactions from their parents towards their speech which they viewed as unhelpful. However, both of them appreciated that their parents did not realise the impact their response had on them and that harm was not intended.

*6.65*

*My family, like, I remember, for example, if I got stuck on a word, my parents would say, no, don't do that, just start again, or something, they said it with the best intentions, not in a nasty way but, no it was more of them trying to help me, even though it didn't help me at the time. (Gary, 373-379)*

*The only thing that made me feel bad when I was younger was if I was stuttering, they, my parents, didn't realise the effect, always saying, slow down, try again, stop, had on me, but then I told them one day, stop saying that, I hate that and they stopped doing it and therefore I was fine. (Callum, 841-844)*

Callum also described the comments his parents made to him which they thought should help him, but he came to disbelieve them after trying and failing. As Callum continued to tell his account it seemed this experience of trying to heed his parents' advice and then failing caused him not only distress but also anger and resentment towards his parents. He seemed angry at his parents' and others' lack of understanding about stammering.

*6.66*

*I tried hard, they told me if I just stay positive I wouldn't do it and I did, therefore they lied to me or they're just stupid, they don't know anything, my parents don't know anything, they never tried to help me, they don't know anything and that's just, like, everyone else (Callum, 2058-2064)*

# CHAPTER 7. STUDY TWO FINDINGS (INTERVIEWS) – THEME 3

## 7.1 Super-ordinate Theme Three: Learning to cope: the journey

**7.1.1 Overview of super-ordinate theme three.** This super-ordinate theme describes how the participants learnt to cope with their stammer in order to gain control over their lives. To achieve this control, they appeared to undertake a journey of recovery involving adaptation and change, which was described in their narratives and explained through the sub-themes.

| Super-ordinate Theme Three | Sub-themes |
|---|---|
| Theme Three: Learning to cope: the journey | 3a: Protecting self: Survival |
| | 3b: Building self: The process of change and enabling factors |
| | 3c: Thriving self: Looking forward |

**7.1.2 Sub-theme 3a: Protecting self: Survival.** The accounts from all participants described various coping behaviours they adopted in order to manage their stammering within the educational environment. A number of them spoke of hiding their stammer because of the fear, embarrassment, and other emotions associated with revealing their stammer. These protective behaviours included four main types of strategies which participants employed to keep their stammer hidden from others. These included being quiet, avoiding situations, changing communication and pretence. These strategies appeared to divert attention away from themselves and shield the individuals from the possible negative responses of others perceived by the YPWS.

***7.1.2.1 Keeping quiet.*** Ed described how he hid his severe stammer at school by not engaging in conversation. He reduced the amount he spoke and this lack of talking became typical for him. Ed's account showed how he learned to live with his stammer by adapting his social behaviour for the whole period of his school life. It was not until he started speech and language therapy at the age of 18 years old that a change to his behaviour became an option for him. His need to bury his stammer and avoid the risk of it being identified appeared to indicate his intense fear of others' reactions at school towards him being a person who stammers.

*7.1*

*So when I was at school, I always used to hide my stammer, to the point where I only spoke when I was spoken to. (Ed, 9-11) … And, it stayed that way up until I went to speech and language therapy when I was around 18. (Ed, 16)*

*I could easily go through a whole day and only speaking, say, 100 words (Ed, 135-136) … Well, after a time it became normal* [not to speak] *(Ed,142)*

Like Ed, Darren talked about speaking less and keeping to himself at school. He described feelings of being scared and confused which seemed to reflect his lack of understanding of his speech and resulted in a cognitive state of turmoil. Darren's decision to restrict his communication to cope with his stammer clearly limited his social interaction at school causing him to feel disconnected from others. His narrative portrayed the sense of loneliness he experienced.

*7.2*

*And for that whole year it was really negative. I spoke less, I acted more isolated, and the reason why, was because I was really confused, sort of scared in a way, and had all this uncertainty. (Darren, 23-27) …. It made me quite detached from everyone, because I was avoiding (Darren, 210-211)*

Jess remembered starting to hide her stammer after moving house and going to a new school. This episode of change resulted in Jess being exposed to a new setting where she did not want others to find out about her speech, so she began to conceal her stammer. She viewed her stammering to be unacceptable so avoided speaking situations and asked friends to help her. Later during the interview Jess identified herself as a perfectionist and judged her speech to be flawed. She seemed to question but then confirmed her belief that stammering was not normal behaviour. Although she saw her stammer as not being a severe problem its mere presence resulted in her needing to keep this imperfection hidden.

*7.3*

*It wasn't until we moved that it became an issue, like starting my new school and having to meet new people and just the whole environment was different and yes, that's when it became an issue. I started to hide it and didn't want people to know. I think I was older so I was a bit more aware of it and, you know, all my friends, everyone else, like teachers and everyone didn't have it so I thought perhaps it was something that I shouldn't have so I would cover it up and avoid situations and get my friends to do things for me, which I still do even now. (Jess, 24-40)*

*but I still hide it because I'm a bit of a perfectionist, and I don't know if that's linked to stammering or not but I know that my stammer isn't that bad anyway, but because for me it's not completely fluent I would still hide it. (Jess, 120-5) …. Because it's not normal, is it? It's not normal. (Jess, 129)*

Ben mentioned he did not experience difficulty speaking to people apart from when ordering food from a waiter. He described how his speech impeded him but seemed baffled as to why this happened. Like Jess he avoided talking and enlisted the help of others to speak for him.

*7.4*

*It's really strange, because I can talk to anybody except a waiter myself. So I always get somebody else to order my food for me, because I get physically choked up, I get stuck. I've no idea why, but I just sort of [noise] yeah. (Ben, 1069-1073)*

Isla described how she coped with her speech during the daily routine of travelling to college on the bus. She reduced the amount she spoke by purchasing a bus pass which she could show the driver rather than asking for a daily ticket. According to Isla, this avoidance strategy eased the potential effort and angst she would experience in this situation.

*7.5*

*I went through a phase though, when it was applying for university time, which was when my speech was worse. I bought a bus pass, it was valid, and it only saved me about £2, but I bought it for the sake of you wouldn't have to say anything, you can just show it. And I did that for eight weeks, I think it was. But I did that just to avoid it. I wanted to focus on college, and I knew that if I did that it would make it easier. (Isla, 663-670)*

Liam also recalled how he avoided speaking as much as possible at school and that he would refuse to speak in class. His skill in hiding his stammer meant that his teachers were unaware of his speech difficulty. However, Liam's non-participation in class was viewed by teachers as uncooperative behaviour and often resulted in him being in trouble with teachers and excluded from classes.

*7.6*

*Oh, at school I avoided any speaking as much as possible, literally everything. If it involved talking out loud I would refuse. It was point blank refuse, which was hard because obviously the teachers in upper school didn't know I had a stammer, so I got in trouble a lot, they thought oh, he's refusing, get out my class. That happened a lot. (Liam, 325-331)*

***7.1.2.2 Avoiding situations.*** Like Liam, Harry withdrew from speaking when at school but he would also avoid going to school on some days if he could. His truant behaviour was kept a secret from his family and possibly unnoticed by his school.

*7.7*

*Well, it gradually got worse and worse, and then I started to hide it more until I didn't really speak so much, and then I sometimes couldn't be bothered to go to school. (Harry, 40-42) … there were certain times when I just chose to stay at home or something. If my parents*

*weren't at home, so they were both out, then I thought well, they won't know. So I just would stay at home. (Harry, 73-78)*

Isla mentioned her uneasiness with ordering food at a counter in a café. She believed this communication situation accentuated her stammering behaviour as it required her to speak up using a louder voice. This showed her fear of others hearing and being aware of her stammer.

*7.8*

*I'd avoid, when you go to a café, the ones where you have to order over the counter, I like the ones where you can just sit and order from the table. I never liked ordering over the counter, because they could never hear you, so you'd have to speak really loud, and I never liked that, I used to avoid going into places like that. (Isla, 1185-1191)*

Nikki and Liam also described the protection their parents offered. This involved their parents writing a note to excuse them from a school activity. This was viewed by Nikki and Liam as a successful outcome because they were able to avoid a speech focused task.

*7.9*

*If I needed a note and stuff, because I didn't want to do anything, then they'd write one for me and that sort of thing, fine. (Nikki, 977-979)*

*So when presentations did come, obviously in middle school I've got a way to fix it, my mum wrote to the school. (Liam, 427-429)*

Similarly, Jess described how her brother helped her so that she could avoid asking for entry to the swimming pool, although this enabled Jess to avoid the feared situation, she expressed her unease with requesting her brother's support. Her negative feelings seemed to be underpinned by a feeling of guilt that she as his older sister should be capable of managing the situation and not need to rely upon his help.

*7.10*
*Like when me and my brother go swimming, rather than me paying because I'm older than him, rather than me asking for the wristband before we get in and paying, I will get him to do it instead, which I know is bad because he shouldn't have to do it, but, you know, he gets on with it. He doesn't try to encourage me to say it. He will just get on with it. I do feel bad that I get him to do it. (Jess, 235-242)*

***7.1.2.3 Changing communication.*** Instead of limiting the amount they spoke or avoiding situations some participants persisted in finding a way to communicate without stammering. Strategies involved participants changing the way they spoke by replacing feared words or using pauses with the goal of their stammer remaining a secret. Ed described his skilful ability to avoid stammering by constantly replacing feared words with

words he could say. Kyle talked about changing his communication through the use of pausing rather than stammering and, like Ed, he also recognised his proficiency in masking his stammer. By hiding his stammer in this way Kyle gained control over his speech and reduced his feelings of anxiety.

*7.11*

*Most of them didn't realise that I had a stammer as I had become an expert at hiding it, substituting words. My head is like a thesaurus I substitute words all the time (Ed 118-119)*

*Well I would say more I use the word disguise but I mean manage it. So I suppose when it first happened I would panic and I would try to force my words to come out, which makes it worse, whereas now I just pause. If I'm clever enough I can sort of pause halfway through and people don't even notice that pause, unless you're actually looking for it, and I thought, okay, I can kind of give the impression [laughs] that nothing's happened there, you know. I suppose, yeah… yeah, I have disguised it as such but I've also managed it because I think well if I don't get stressed out about it. (Kyle, 592-603)*

Similarly, Nikki averted stammering by circumventing words. Although she recognised that this practice was not ideal she saw it as necessary because she believed listeners would not wait for her response. This indicated the lack of value Nikki placed on her verbal contribution and her overall feeling of negative self-worth.

*7.12*

*I don't know I just…yes, avoid words. It's not the way to do it. I know it's not the way to do it but sometimes you've just got to do it. (Nikki, 478-80) I'm like, nobody got time to wait for me to talk. So, there's just no point is there really so I just like…I skirt around it. (Nikki, 494-496)*

Mia described difficulty with expressing what she would like to eat in the university canteen because of her stammer. She recalled that rather than naming the food she wanted she would use the phrase 'I want that' and this was accompanied by her pointing at the particular food.

*7.13*

*Like if I was to go to the canteen just like…it wasn't too bad, because I'd say, like, I want that. I want that, instead of saying, can I have let's say pizza, I'd say that and point. (Mia, 113-116)*

Harry described a number of tactics to help him keep up the pretence of being a fluent speaker. Similar to Jess and Ben, Harry explained how he would attempt to get another person to speak when in difficulty with his speech. He described other ways he coped with his stammer as 'tricks' which included using the word 'like' to hide a moment of stammering and pretending not to know the answer. Like Nikki, Harry seemed to resort to these strategies in order to hide his stammer despite seeing these behaviours as a negative ploy.

These adaptive behaviours described by Harry seemed to illustrate his motivation to find a solution to help manage his stammering.

*7.14*

*I would just try and act and I would try and find some way to get around it. So like for example, if I was trying to say something then I would try and get the other person to say it*. (Harry, 91-92)

*Or I do tricks. So what I do quite often is I say the word 'like'…which I know is quite a common thing for young people, but especially with me it's like a trick that I do. And I shouldn't be doing that, but it's one of those things, it's something I can't help. So I just find ways of getting around things, or I just would simply pretend that I didn't know the answer. (Harry,* 96-103)

***7.1.2.4 Pretence.*** Nikki and Jess described masking their stammer by pretending to be indecisive or incompetent. They seemed to prefer to use this coping strategy, even though others may make a judgement about their ability, rather than risk being seen as a person who stammers. These behaviours illustrated the cognitive effort experienced by some participants in order to disguise their stammer.

*7.15*

*I'm like can I have a latté, but I think I want in a shot, and I think… I mean yeah, I'm just like…think for ages but I'm not thinking. I'm like hmm, I don't know what I want. I do this thing where I'm like oh, I can't decide. (Nikki, 1034-1038)*

*So I was looking down at my notes, pretending to read along. That's what I do as well. I also pretend that I can't read my handwriting. (Jess, 289-291)*

### 7.1.3 Sub-theme 3b: Building self: The process of change and enabling factors.

This sub-theme described how participants begin to gain control over their speech by developing their confidence and competence in managing their stammer and their interactions with others in the education environment. It describes the participant's journey through this process of development and identifies factors during their lives in education which appear to support this process of change.

#### *7.1.3.1 The process of change*

*Realisation.* Some participants recalled making a decision to confront their stammer, which in turn evoked a change in the way they learned to cope with their speech. Their readiness for change seemed prompted by their prior experiences of stammering and accrued negatives feelings. For Ed, Pippa and Callum this process of change was facilitated by seeking support from speech and language therapy. They took responsibility for their

speech and consequently the initiative to access therapy as young adults between the ages of 16 to 18 years old. This action appeared to demonstrate how these young people re-appraised their experiences of living with their stammer and decided to exert some control over their lives. Participants' experiences of speech and language therapy are reported later in a different sub-theme.

*7.16*

*I actually realised that I had to do something about it. I then went to speech therapy. After that, that is when I came out, did not hide it anymore. After that point everything changed. (Ed, 300-307)*

*So I got really like frustrated with myself and I thought I need to do something just something if anything can be done so then went to the doctor and he said I'll refer you* [to SLT] *and then, yay. I'd say I'm really glad I've had it because it's really given me some techniques (Pippa, 724-727)*

*And so after high school, it was, like, my stutter was annoying me, so I thought I want to try and do something about it now and see if I can improve it and, so, yeah, I put myself forward, I asked my GP, can you refer me to this person and he referred me to that person and I finally got referred (Callum, 687-694).... it wasn't my parents getting me the referral, I did it myself, I thought I have to find a solution to this, I did it all myself on my own drive. (Callum, 2297-2300)*

*Becoming less sensitive.* For some participants learning to adjust to stammering involved becoming less sensitive about it. Pippa and Floyd both talked about stammering in front of others and being able to take a more relaxed approach to it. This showed a reduction in their fear of stammering and seemed to indicate a positive change in their thinking and feelings about their speech.

*7.17*

*So usually so I'll laugh and I'll try and finish what I want to say…So basically so I kind of like laugh it off a bit and then of course because the people usually laugh it off too and know me so well and all that so basically they just laugh with me 'cause they know it's going to make me feel better (Pippa, 45-48)*

*Since going to university, I worked out that, do you know what, being light hearted about your speech is probably the best way to go. If you make it too much of an issue, then it is going to be too much of an issue. So yeah, that was good. (Floyd, 997-1001)*

Other participants described how they had become less sensitive about their stammering behaviour by developing a "thick skin". Ben and Adam appeared to have needed this defensive layer to protect them from the negative effects of adverse experiences. Adam also mentioned his acceptance of his stammer which reflected his positive adjustment to his speech and a sense of him developing resilience.

*7.18*

*But as I've grown up, I've learnt to have a thick skin because it's necessary. (Ben, 24-25)*

*So I just got to the point where I just accepted it and it didn't really used to affect me really, you just get a thick skin for it. (Adam, 1062-1072)*

*Developing a comfort zone.* Some participants spoke about feeling more at ease with their speech as they gradually developed a comfort zone at school or college. Floyd talked about feeling comfortable in the company of his friends and Adam mentioned becoming familiar with both the daily school routine and the people within his environment. Adam acknowledged that securing his comfort zone at school took time and there was a sense of the effort this involved when he pointed out the need to re-establish his comfort zone on going to college.

*7.19*

*But as the years passed, because I was in secondary school for a good seven years, it usually got better as you get more used to the regime of it really. You're going into the same classes, the same…you're socialising with the same people, doing work with the same teachers, that you basically get quite comfortable with that surrounding and it starts to become quite a comfort zone, which is fine. (Adam, 44-52)*

*So yeah, I was very comfortable in their* [his friends] *company, so that was good. (Floyd, 987)*

*Then, of course, after the seven years, you've got college which means you start again because you're in a new place with new people and new teachers, so you've got that. So you have to basically start again and try and make that comfort zone as well. I've got a good support system at school, so that really helps in making college a comfort zone for speaking really (Adam,1112-1114)*

Mia explained how she contemplated going to college or to a mixed school for sixth form study, but this prospect evoked speech related anxiety. It seemed too risky for her to leave the safety of her school so she decided to remain there to study her 'A' levels.

7.20

*And I was probably a bit more like scared to go to college because like because it was girls and boys so I'd be like a bit more nervous and like more conscious of it…I had the choice to stay on at sixth form because it was just a girls' school, so like I chose to stay there rather than go to a mixed school or sixth form college (Mia, 132-142)*

Jess also recalled how she opted to study for 'A' level subjects so she could stay in her familiar school environment. This showed how Jess' stammer had an impact on her educational decisions which resulted in her initially studying for 'A' levels rather than

pursuing her qualification of choice. In retrospect she believed it would have been better to have gone to college in the first place to have studied her current course.

*7.21*

*I think I should have started straightaway* [at college] *rather than going to do my ASs* [at school] *but I think the reason I did my ASs there was partly because it would have been the same journey on the bus and same people and it's the same environment and the same teachers and it just would have been easier for just to go into that, rather than start a completely new place and new people, which is what in the end I had to do. (Jess, 615-22)*

*Developing acceptance and openness.* Most participants recognised reaching a point, usually in their late teenage years, when they began to accept their stammer. This process of acceptance was recognised by some participants as a key and important step in helping them to cope with stammering. The acceptance of their stammer appeared to enable them to manage their speech through disclosure of stammering to others. Admitting they stammered became a new coping strategy and seemed to be part of their recovery process.

*7.22*

*I think one of the major steps is actually accepting you are a stammerer, accepting you always will be. (Adam, 490-492)*

*The best bit for me about it, was just coming to terms about it and telling people about it and talking to people about it and then just having to admit to myself that I have a stammer and I can…like, that's not a problem. I can't help it. (Gary, 115-119) .....It was a liberating experience* [laugh], *because now, like, it's not really a problem. (Gary, 124-25)*

Both Adam and Gary recognised their stammer as a problem which would not disappear and they described the need to admit their speech difficulty to themselves and to others. Gary's comment also relayed how his acceptance of his stammering brought with it relief and a sense of freedom and this feeling was similarly expressed by a number of other participants. Ed had a severe stammer which he had successfully hidden by keeping quiet or by avoiding feared words as previously described. He likened his disclosure of his stammer to that of a gay person revealing their sexuality to others and he acknowledged the relief associated with this self-disclosure.

*7.23*

*Well, I stopped hiding it and for the first time I could just be myself. (Ed, 311-312) ...It was like a whole load had been lifted (Ed, 316) …. I compare it to someone coming out as homosexual, that's a big relief. (Ed, 320-321)*

Harry also described the sense of relief he felt after telling people of his stammer because he was no longer burdened with the negative thoughts of how people might view him.

*7.24*

*Yeah, well, because it just got to a point where it was like I couldn't hide it away because it was gradually getting worse, and my tricks that I had weren't…some of my tricks weren't working. So I just had to really because I just couldn't not. (Harry, 141-145)*

*Well, it made me feel slightly better* [having told people] *because the whole time I get so completely worried and consumed about what the other person might think of me. (168-170) .... I could talk about it and it felt like a weight was lifted. (Harry, 189-90)*

Some participants talked about choosing to move from school to college at the age of 16 for their further education and how this transition helped them develop increased self-acceptance and openness about their speech. For Darren, despite recognising that he had a good friendship group at school, he talked about how he felt going to college would offer him the opportunity of a new beginning. He described the different mix of people he encountered at college and it seemed this environment fostered an acceptance of differences in both culture and verbal expression. This more inclusive context appeared to have made Darren feel more comfortable and integrated in the educational setting.

Later he spoke about the conscious decision he made to implement changes to his attitude and appearance when starting university, by leaving his old self behind and developing a new self-image. There was a sense that Darren was liberated and consequently felt capable of self-change. Darren's account showed the determination he had to become the person he wanted to be and there was a sense of self-satisfaction ensuing from his new persona. These extracts reflected Darren's college and university experiences and showed the growth in his self-acceptance and self-worth.

*7.25*

*Because all my friends were there, and I wanted to be with them, but when my stammer came along, I wanted just something different, in a sort of way, so I thought, let's get out of there, and have a fresh start. And I thought, go to college. (Darren, 833-837). My stammer was so different at school; it was really negative. I think that's the environment to be honest. (Darren, 904-906)*

*Because everyone was from different areas around the region and they would just talk differently, like how they would describe something, or how they would say something, and and it was like all these cultures had been brought into college, into the same one, and it was just really different. (Darren, 935-941)*

*I sort of tried to press the reset button for university, and be someone who I want to be. I just do the things that I want to do. I kind of forced myself into it because it will be a positive thing in the long run, and I just like re-inventing myself or just inventing myself? Who knows! But, I just became a new respected Darren so it's been quite a lot of fun. (Darren, 946-973)*

*I want to be that Darren, so I thought, okay let's do it. (Darren, 981-982) .....I like him (Darren, 988) …More outgoing, I'm more positive, dress differently that sort of stuff. (Darren, 1012-1013)*

Similarly, Pippa spoke about her plan to leave school this year and go to college and, like Darren, she saw this as a chance to have a fresh start. The idea of going to college seemed to motivate her to take a new approach to managing her speech when she stammered. This involved her adopting a more relaxed and open attitude towards her speech. This willingness to be more open with others about her stammer seemed to indicate that she had become more accepting of her stammer. She was looking forward to talking to new people at college and believed the people she would meet would be unperturbed by her speech. She had planned how she would manage any moments of stammering and was hopeful that her speech would be less of a problem for her in this new environment.

*7.26*

*...so I'm kind of going to college to meet new people so basically if my stammer does start just like say oh, oh sometimes I stammer, don't worry about it, you know what I mean, that sort of thing and then just because it [college] looked really cool.... the people who are going there haven't really heard me have any speech times. So they're not gonna care and I'm not gonna care, I'm gonna make the most of it. Just get on with it. (Pippa, 623-636)*

*I'm hoping to just meet new people and just to...I don't know, just start afresh really. I just think it would be quite nice to talk to new people and of course if I do stammer just like casually tell them oh sometimes this happens and just like smile about it and then that's that basically yeah and then they know so it's out there and then hopefully it won't be such a big deal. (Pippa, 704-712)*

Callum described the process of change he experienced to help him cope with his speech. He explained how previously he put all his effort into trying to be 'normal', which meant not stammering, and managing the constant thoughts and fears he had regarding what others would be thinking about him if he stammered. Through support from speech and language therapy, he altered his behaviour by disclosing his stammer to others and taking a positive attitude towards his stammer. He reported that he was no longer reticent in speaking to people and he had a more relaxed view of his stammer should it occur. This appeared to have given him a sense of freedom which resulted in reducing his anxiety and increasing his contentment and social participation. During the interview Callum also exuded a feeling of calmness at achieving his acceptance of his stammer.

*7.27*

*Like, when I was younger, I said I never wanted to mention it, I never wanted anyone to know, I wanted to see if I could get through a conversation without stuttering, so everyone thought I was normal, but if you say from the start, I've got a stutter, that's it out on the table,*

*there's nothing more to say, they know it. So if I find myself stuttering now with someone I don't know, I'll just say, sorry, I have a stutter and then can you understand what I'm saying? …because if they don't know that, I'm thinking to myself that they think I'm weird, whereas, if I just say I've got a stutter, then that's why he's stuttering, therefore I feel less nervous. (Callum, 600-616)*

*It's changed from going to…I cannot stutter in any situation, I will try and avoid it at every single cost, whereas, now, I will go and talk to that person, if I do I do, if I don't I don't and that's pretty much it…. if you say, I've got a stutter, you don't care, you're free about it, it doesn't really matter. (Callum, 1946-1956)*

*I have a stutter and that was the best thing I learnt from speech therapy it was just, yeah, I've got a stutter, this will probably happen, I probably accept it and move on with it, because if I accept it, I'll be a lot happier. (Callum, 1974-1979)*

Like Callum, Gary also mentioned that he preferred to admit he stammers rather than keeping up the pretence of being a fluent speaker and he inferred that this is because it is less effortful for him. His comment also illustrated his sense of humour that he seemed to use to help him when communicating with others about his stammer.

*7.28*

*Like, now I've accepted it, it's easier if I need to talk to someone and they ask me for my address, I would say that I've got a stammer and we can be here all day or I can just write it down for you [laugh], because that'll be a lot quicker. I prefer that than having to go through the process of having to pretend I don't have one, and then trying to say it. (Gary, 625-632)*

Harry had a similar story of learning to accept his stammer through attending the McGuire private treatment programme, but he described the struggle he experienced to deliberately stammer openly. Harry spoke about the physical effort it entailed but also how admitting he stammered had revealed his imperfection to others. However, this disclosure, although challenging, appeared to have been a positive turning point for him. Harry talked about being able to participate in conversations more and this has improved his well-being.

*7.29*

*And when I joined the programme and they tell you to stammer on purpose sometimes because it helps, and I find that incredibly hard to do. It takes every fibre of my body to try and do that. But it does work and it makes me feel a trillion times better. But it's just doing it. It's so hard to do (Harry, 539-544) …. Because you're telling someone that you stammer and you're showing it and it's just… It goes back to being a perfectionist I think and it's about…it's basically about allowing someone to know that you're not perfect. It seems quite silly, but that's what it comes down to really. (Harry, 550-555)*

*I just said then that by the way, I do have a stammer so just bear with me. And then since then, I don't know, it's not really been too bad really. (Harry, 689-691) …But I talk more, so*

*then there's more chance of me stammering, but in proportion to the amount that I speak, then I'm better. (Harry, 697-699)*

#### *7.1.3.2 Enabling factors*

*Individual factors.* A number of the participants described particular abilities and qualities they possessed which they felt supported them in coping with their stammer in the educational context. Floyd referred to both his academic and sporting aptitude a number of times during the interview and believed these strengths helped him cope with his stammer in his life at school. He also mentioned the positive academic support he received as part of his private education. The last extract summed up his view that having a good friendship group, being academic and also sporty had supported him through school. There was a sense of him feeling that these strengths had compensated him for having to live as a person who stammers.

*7.30*

*Without being too big headed, I was quite clever during school and that, I think, was a big reason why I also wasn't picked on either because I was doing well academically. (Floyd, 10-13)*

*So yeah, another thing from when I was young, I started off in private school. And I think that's where…that obviously helped me to be quite academically strong. (Floyd, 69-71)*

*I mean, I was also quite strong at sports, I played football and cricket ever since…well, I've played football ever since I could remember too, and yeah, big on cricket at that point too. So again, I was part of the football team and the cricket team. (Floyd,113-118)*

*But again, I had a good group of mates up until sixth form, fortunate enough to be academically strong, good at sports. So I think that helped me through school, definitely. (Floyd, 438-51)*

Others also spoke about their ability to take part in extra-curricular and volunteering activities during their school lives. Participating in group activities seemed to give them a strong sense of belonging. During these activities their speech was not a focus and they seemed to have positive control over their lives.

Darren talked about how his involvement with sport gave him a feeling of normality and this appeared to give him a positive sense of well-being. Similarly, Owen saw exercising as a time when he felt released from thinking about his stammer as well viewing it as beneficial to his speech. Jess thought her volunteer work was helpful for her speech because it involved her interacting with others. Jess' account also reflected the possible benefit of forging friendships through being part of volunteer network. In a number of Jess' narratives her

mother appeared to feature as a strong support for Jess. The role of family is described later in this sub-theme.

*7.31*

*I did the football, mainly the sport ones (Darren, 226) … It was fine, it was normal, it was really good. (Darren, 234)*

*Being more physical helps me to forget. It's like exercise, it just helps my breathing in general. (Owen, 955-956)..... I'm moving about, being more physical, and that improves it. (Owen, 326-327)*

*I volunteered for St John's Ambulance, so I worked with them for quite a while. And that was also good for my speech, because it was every Wednesday night and there'd be a group of us, and we'd all do group activities, and my mum said that would be good for communication and getting close with each other, and it was, it was very good (Isla, 1130-1136)*

The accounts from Gary, Kyle and Liam described their sense of achievement at being involved in a sporting activity. For Gary there was a feeling of pride associated with his success and for being known by others for his sporting skills rather than for his stammer. This recognition of his physical ability by others perhaps helped to alleviate the negative effects of being a person who stammers and promoted his confidence and self-esteem. Similarly, Liam confirmed his success at playing chess by participating in a National competition, which seemed to strengthen his self-belief. Kyle voiced how his physical difficulty and stammer did not deter him from joining in with sport. He sounded both confident and proud of his ability.

*7.32*

*I used to go to the skate park, 'cause, like, I used to skate every spare minute I had, really. So I was always there and I was always pretty confident, and a lot of people, they knew me, just because I was pretty good at skating.... which was good [laugh]. (Gary, 361-368)*

*I did in middle school get into a chess club, which I excelled at a lot. I got into the National British Tournament. (Liam, 532-537)*

*I mean I play wheelchair basketball in my spare time (Kyle, 541-542)*

Some participants described their effort to become more socially active with the aim of communicating more. The accounts from Ben, Darren and Mia showed their motivation to deal with their speech difficulty by improving their social participation with the intention of increasing the amount they spoke to others. Darren's determination and his pro-active manner were reflected in his account and showed his capacity to create change in his life. Mia also talked about her deliberate choice to interact more through getting involved in different activities and Ben clearly increased his communication with others by taking part in

a range of events. Ben's account illustrated a can-do attitude and a belief that his increased interaction and participation with others positively influenced others' attitudes towards him.

*7.33*

*And I thought to myself, right, I'm going to force myself to socialise and be in the kitchen where everybody is and stuff, talk to them, and tell them about me, instead of staying in my room for the whole year and not really socialising. (Darren, 268-273)*

*And I've chosen things that involved a lot of talking and talking to people. (Mia, 374-376)*

*I have taken part in school handball, basketball, ultimate Frisbee, Danish longball is another. (649-50) …. I've been head of my house council for three years now. (700-701) …. I've found the best way to almost be more accepted is to do more things, to talk to more people, to just get myself out there. (Ben, 754-756)*

*Friendship support.* Although some participants experienced being teased at some point during their education as described in Super-ordinate Theme Two, most participants, including Adam and Ben, spoke of being part of a friendship group which they believed helped them in managing their stammer in the educational environment. This inclusion also seemed to give them a feeling of acceptance. Ben specifically mentioned the constant supportive relationship provided by his girlfriend and also how he felt he could completely depend on his other friends. He described the friendly banter he experienced with his friends which he was clearly comfortable with.

*7.34*

*I usually find my philosophy is, if you're nice to someone, well, then there's no reason why they shouldn't be nice back and be a friend. So I can't…so I've never really had issues with making friends really because of it. I was usually fine with most people really; I was a fairly popular person at school. (Adam, 223-229).... I've got a good support system at school, so that really helps in making college a comfort zone for speaking really. (Adam, 1112-1114)*

[Describing his feelings of being accepted] …. *this is an understatement, but through the hardships I've been through, it just feels like the world. I mean, my girlfriend that I've had for coming up to three years, and she's wonderful, because she's always there, always supports me. My friends are just incredible. As much as they take the Mick, I could ask them for anything and they'd do it. (Ben, 761-768)*

Both Darren and Gary similarly described how friends supported them with their speech and how they valued this support. Both perceived that their friends helped them to feel more at ease which in turn aided their speech.

*7.35*

*They're my really close friends and I've known them for the best part of my life. And because of my relationships being positive and all that sort of stuff, it helps me to basically*

*speak.... I'm surrounded by that support, the understanding, and it helps me to relax. And it really, really helps. (Darren, 425-461)*

*I just felt having my other friend with me just made things more relaxed for me, and my speech was pretty good. (Gary, 260-263)*

Friends at university were also appreciated by Floyd, but he appeared to show a sense of surprise that these friends would want to live with him and that they seemed to care about him. Harry expressed similar surprise about his friends being patient at university. This perhaps reveals a lack of self-worth for Floyd and Harry at this time.

*7.36*

*Fortunately, my mates were more than accommodating, too. I was comfortable in their presence as well, it wasn't just a case of me being there so I had some mates, I actually enjoyed being in their presence, too. So that was obviously great. (Floyd, 1009-13).... And yeah, these three guys actually asked me to live with them, so, you know, that was a very nice thing, too. So that was good (Floyd, 1023-25)*

*But I was very pleasantly surprised at just how nice they were about it all, so then it was me and seven others and not one of them cared at all, the fact that I stammered. So they were very patient and they just waited and that was really quite nice because it's not that I wasn't expecting that or that I was expecting to be teased or anything like that, but I certainly wasn't expecting somebody to be so nice about it all. So that was really nice. (Harry, 374-383)*

Isla began university with feelings of apprehension, but she soon found her peers to be relaxed, communicative and helpful which she felt benefitted her speech. She had not expected to experience this supportive environment where, despite large numbers of students, she felt relaxed and at ease with interacting with her peers.

*7.37*

*he first term, was all in university, so it was quite daunting at first, (Isla,393-394) .....But with speech, I was a bit on edge at first, the first two weeks, but everyone gets along with each other, and I didn't think it would be like that. Everyone, there's 400 of us, and if you see anyone from the course, they'll just talk to you. So you talk to anyone, everyone talks to each other, everyone helps each other. Everyone's very supportive. We have our little home groups as well where there's 20 of us, so you always feel comfortable, so that's helped my speech a lot. (Isla, 403-406)*

A few participants stated other benefits from being part of a friendship group. Both Gary and Callum thought their friends helped to protect them from being bullied or teased by others at school. Callum also described the importance of his friends in motivating him to go to school as well as their support in counteracting potential bullying.

*7.38*

*Like, to be fair, I've always been friends with the majority of people I meet, so I've never been picked on because of it, like, never really. (Gary 99-101)*

*I'm lucky, because I know people can be bullied, but I was never bullied myself, because, like I said, I had no issue making friends, because I've got friends, no one is going to pick on and I'm also I'm quite tall and no one is going to pick on me anyway. (Callum, 2421-2427)*

*I always say that I never went to high school for education, just to go and see my friends and that made things a lot better, the only reason to go, if I had extra hassle of people picking on me, I probably wouldn't have gone to high school, probably wouldn't have bothered. (Callum, 2441-2449)*

However, Ed disclosed how his speech was a barrier to him forging friendships because he remained quiet. Participating in sport helped him to gain some friends, but what really made a difference to him was when he disclosed to his stammer.

*7.39*

*I had very few friends (Ed, 58).... Because, in order to make friends you had to speak, and of course I was really, really quiet. However, I was able to make some friends through sport. (Ed, 64-66)*

[Since coming out].... *Much happier, I have more friends and I could not care less what people think. (Ed, 676-676)*

Nikki described the acceptance of her boyfriend towards her speech which appeared to be helpful but she also reported that others showed interest in her stammer and wanted to engage with her about her speech and resolve it. Nikki was clearly not interested in this sort of discussion and her comments seemed to reflect how she had to endure her stammer and wished for some sort of normality.

*7.40*

*It doesn't really bother him, he's like whatever.....if I'm having a bad day with it I'd be like I can't talk today. He'd be like okay. (Nikki, 1198-119)*

S*ome people always just want to speak about it, and I'm like you don't need to talk to me about it, it's not an issue. I saw this lad once and he was always on about that; how can we fix this? I was like Ted, just leave it out, I don't care! Can we not just be normal? And he'd be like I'm so interested in it. And I'm like I'm not! I've had it all my life; I'm so bored of it right now. (Nikki, 1216-1223)*

*Family support.* The majority of participants stated their parents or a sibling provided them with positive support during their education. This could be in relation to them being an

empathetic listener, offering emotional support, providing protection from bullying at school and liaising with teachers over speech focused activities.

Participants' accounts illustrated the comforting and reassuring responses and in some instances the constancy of the parent as someone who could be depended upon. Liam mentioned the support his mother gave him in relation to his stammer but he also recognised how the lack of knowledge she had about stammering made it difficult for her to help him.

*7.41*

*My dad has been the main one I think. He's always been almost an enforcer, to make sure things go well, and I'm like almost bullied for it. (Ben, 836-838)*

[Dad says] ... *just says to me like, don't get nervous and try and stay calm. (Mia, 234-235)*

*She* [Mum] *goes, don't worry you'll be fine, and all that sort of stuff. And I was like, okay. (Darren, 265-268)*

*Mum has been very supportive with this a lot, very supportive. She's tried to help me a lot, she'd try and control it, and she knows when to just leave it and let's not talk about this. But yeah, she's been helpful. (Liam, 286-290) .... She struggled a lot though, because she didn't know anything about it.... So yeah, so it's been a learning curve for her as well. (Liam, 293-5)*

Several participants stated that their speech was not an issue at home so it was not particularly mentioned or discussed. Isla described not stammering with her family which she felt was due to her close relationships with her parents. Callum also indicated that he did not stammer with his family which, like Isla, seemed linked to his close family relationships and the way his family reacted to his stammer. There was a sense of participants feeling relaxed and comfortable with their speech in the home context.

*7.42*

*Like it's not an issue at home at all, it's not a problem and we don't really like speak about it a lot. (Nikki,1004-1005)*

*I did speak about it quite a bit to him, but now I just don't talk about it. Not because I don't feel like I can, it's just because we've got more important things to talk about, so…it's great (Gary, 502-506)*

*I've never stammered with them, ever, because obviously I'm very close to them anyway, (Isla, 827-828)*

*Yeah, my family, it's interesting, they always said, because obviously with knowing me they never noticed it and therefore them saying they don't notice it or they don't pick up on it made me feel less nervous, therefore I don't stutter with them. (Callum, 829-831)*

*Mentoring support.* There were two participants who mentioned the support they had gained through a mentor and a key worker during their education. Jess described how she

had regular contact with a mentor since starting college last year. This was as a result of her disclosing her stammer during the admissions process. It was clear from Jess' account that she appreciates the interaction and social support she gains from seeing her mentor. She described how she was able to be herself in her presence, did not need permission to stammer and felt accepted. Jess expressed how she valued both her mentor's understanding and her assistance with activities. It also seemed that her mentor initially supported Jess by acting as a conduit between Jess and her lecturers which eased Jess' angst. However, Jess commented on how she was now able to manage liaising with lecturers herself indicating a growth in her self- confidence.

*7.43*

*So I feel like when I'm with her I'm allowed…at the beginning of the first year I felt like she was the only person I was allowed to stammer in front of because I knew that she wouldn't react to it or anything. She came across as so caring and understanding that it felt like I could talk to her and just say what I wanted. So I still see her. (831-41) .... I like seeing her. She's helped me with issues that I've had, not assignment wise, so things like when I've had to go down to the student services and talk to them about my bus pass, she will come with me and will speak for me and things like that, and she'll email lecturers and tell them that I'm worried because I'm too embarrassed and scared to go up to them, but I can do that pretty much all the time now so… (Jess, 862-874)*

Adam also talked of the support he received from a key worker at school when starting secondary school. He explained the key worker's supportive role and how she recognised the potential issues associated with his stammer. His support seemed similar to Jess' mentor, but he also commented on the key worker's limited understanding of stammering.

*7.44*

*I used to have a key worker who I used to be quite open about it with. But again, they didn't have much knowledge about it at all really. But they were always there, just to help and be supportive emotionally really. (963-967)*

*I spoke a lot with my key worker. Usually, she would ask about it* [his stammer] *or say, how was your speech today and is it fine, have you had any issues, has anyone been bullying you, have you had any issues with your work at all, has it held you back at all. Yeah, it was, yeah* [helpful]*. Definitely around years seven and eight, yeah. (Adam, 1038-1039)*

*Speech and Language Therapy support.* All participants except for Jess talked about their experiences of SLT. Jess referred to the difficulty she had experienced in accessing the service where she used to live, but she had seen a SLT when she moved house. However, she did not make any further comment about her SLT experiences. Ed described a similar struggle to see a SLT through the NHS but also how the SLT admitted her lack of

stammering expertise which led her to recommend private SLT. However, through Ed's persistence he was referred to a specialist centre for therapy.

*7.45*

*We tried to get speech therapy but there wasn't any in our catchment area at the time (Jess, 19-21)*

*Well, I had very little. For example, I had an appointment at X Hospital with a speech therapist, and in that she told me what options I had, all of them private, and that she couldn't help me as it was not her specialism. (Ed, 48-51) I had to look for treatment privately, as there weren't any speech or language therapists in the area which specialised in stammering. (Ed, 28-31) So, after years of trying I contacted the Centre directly, and I was very lucky that a charity in the USA funded for me to attend a two-week course (Ed, 36-38)*

Many participants recalled experiences of therapy as a child or young adolescent as unhelpful. Some felt the therapy did not make a difference to them and for Harry sessions revolved around talking to the SLT which seemed to lack purpose or therapy was viewed to be of poor quality. Nikki associated her unsuccessful therapy with a challenging phase of her life when she was a young teenager experiencing difficulty with understanding and accepting her stammer. She also felt the therapy was poor and it seemed that it did not focus on the issues she was faced with at the time. However, she expressed positive experiences of therapy in later adolescence and appreciated the one to one intervention. She seemed to indicate a preference for the individual therapy she recently received rather than the previous group therapy.

*7.46*

*As a child they started it but I think I just stopped because it didn't really work for me. (Mia, 164-165)*

*And I had a few years of speech therapy when 13, 14, it was just me going and spending an hour with this guy, where you're just reading out of a book and him just saying right, when you feel you're going to stutter just take a deep breath and start again, and you won't do it.....That didn't really help. (Liam, 27-32)*

*When I was a young child then I did. It wasn't very much. And then I remember having some again in year ten I think but it didn't really make a difference to… Well, the first person it was a weekly thing and it was about trying to concentrate on breathing or something, but it was a bit useless really. And then another person I saw was much better, it was just talking. Yeah, it didn't really do much but it was nice just to go and talk to someone really. I think that's what I got out from it, just simply talking, just talking to a neutral person. (Harry, 483-521)*

*Well, I had just a session, just a one day thing when I was about 13. And I hated the whole world when I was 13; I was like this is not fair; I don't like this. This is so shit; it's not helping me, like rar-rar-rar, attitude the whole time. But it wasn't actually very good therapy. They gave us loads of sheets and we're like oh, do the slide technique and all. (Nikki,1463-69) …*

*But then I had some more when I was 16, 17, just in sixth form, and that was really, really good… It was one-on-one, once a week, and that was really good. (Nikki, 1478-1482)*

Most participants had recently received therapy or were continuing with therapy and others were involved with the McGuire Programme. Some participants spoke of their positive SLT experience and its benefits with Darren describing it as life changing. Also for Callum SLT had evoked great change. He talked about his increased ability to communicate with others, including being able to use the telephone, and how this was noticed by family and friends. Callum's account illuminated the way therapy had empowered him with the ability to communicate readily with others giving him a feeling of freedom and self-control. Others like Pippa spoke of specific therapy approaches that were useful and Ben described how he continued to draw upon his previous therapy resources when needed.

*7.47*

*Then I went to the therapy centre and that actually changed my life. (Darren, 30-32) ...the centre really helped, my speech therapist helped (Darren, 304-305)*

*I did notice a massive improvement from before I went to now and so do my family and so do my friends and, yeah, because I can tell, in a sense, I talk to my family more, so I never used to call my grandma, because I just [sighs], you know, I couldn't call her, couldn't use the phone and she's in Barbados, whereas, now, I can do so freely, because I really don't care. (Callum, 703-712)*

*I'd say I'm really glad I've had it because it's really given me some techniques that really helps me, yeah which is what she [SLT] taught me and it's really helped. (Pippa, 726)*

*They taught me new techniques that I've used throughout the last five/six years now. (Ben,157-160) I mean, I've still got the fluency booklet in my wardrobe, and whenever I'm having a bad day I go back through it. I go and use the techniques again. And just refresh myself a bit. (Ben, 1013-1016)*

Others spoke of their experiences of learning useful techniques to support their stammer, but also of their original hope of being cured. For Gary and Liam there was a sense of disappointment that they would never be free of their stammer but they showed a positive outlook towards managing their stammer indicating their recognition of it and a degree of acceptance.

*7.48*

*My intentions were that I'd go there and they'd cure it… (Gary, 418-420) …I kept going, and we didn't even work on techniques for quite a while, and I'm like, oh, this is so annoying, but now in hindsight, I can see why she got me to come to terms with it and just talk about it first, before we went in to techniques and I think that was definitely the best thing for me to do. (Gary, 418-430)*

*But it didn't get rid of it. You can't really get rid of it really. It's always there and it will always be there and I do it nearly every day still, but I have definitely learnt how to control it. (Liam, 40-41)*

Positive experiences of group therapy were mentioned by a few participants. For some it was the first opportunity to meet others who stammered and to realise they were not the only one who stammered. Callum described his previous feeling of being alone with his stammer but how contact with others reassured him and helped him put his stammer in context.

*7.49*

*And so I never really met someone who was in my situation and therefore I felt more on my own and so going to the centre made me think that it's more of a common thing and people have the situation too and they put things into a…can't say it... perspective for me, yeah. (Callum, 668-673)*

Nikki also spoke about the mutual support and friendships gained from attending a support group. Here people shared a common problem and their experiences in a forum that she likened to Alcoholics Anonymous. It was clear from her description the comfort and enjoyment she experienced from being part of this group. It was an environment where she felt at ease with her stammer and felt valued for who she was. It also gave her the opportunity to develop a close relationship with another YPWS.

*7.50*

*And then just in* [X place] *there was a meeting group and just a support group, and that was like so good just because I was there…yeah. There were loads of people that have it as well and now I'm best friends with someone that I met there and we're so close and it's really, really nice. (1482-87) ...We don't notice each other are stammering because we don't really do it that much. And with other people it's worse, but with him I'm like yeah, whatever. Because you've got one, we're both… It's fine. (Nikki, 1488-1491)*

*It's basically like alcoholics anonymous but for stammering.....And it is really because in the first sessions you have to be like hi, my name's Nikki and I've been stammering since I was seven, and I've been stammering because of this, and I just…and that sort of thing. (Nikki, 1513-1521)*

Four participants who had attended the McGuire Programme reported positive experiences. Similar to Callum's experience of group SLT, Harry described the relief from being able to discuss his speech with other PWS and how it helped put his stammer in perspective, lessening its importance. Adam also appreciated the programme being delivered by PWS since they had first-hand knowledge and experience of both stammering and the McGuire course so were seen as being able to offer credible support.

*7.51*

*But when I joined the programme then I could tell people about it and I could talk about it and it felt like a weight was lifted. And then because although I still stammered it wasn't such a big thing. (Harry, 188-191)*

*…it's run by stammerers, so people who have been on the course who are there to help other people who stammer. So there's that connection, you know, they understand (Adam, 509-513).*

**7.1.4 Sub-theme 3c. Thriving self: Looking forward.** The final sub-theme, emerging from the participants' narratives, referred to their view of their current life as young people who stammer. They described their experiences of how they managed their stammer and the continuing challenges, their outlook on life and their plans for the future. Emanating from the accounts of their current experiences was the participants' positive and active voice. This was in contrast to the negative and resigned mood they conveyed when describing their earlier days of stammering. This shift in attitude seemed to signify a growth in their self-identity and self-esteem and reflect a degree of recovery.

***7.1.4.1 Gaining control.*** Most participants' accounts compared their previous management of their stammer with their current approach towards it. Their stories reflected a positive change in how they now coped with being a person who stammers. Many, like Mia acknowledged the continuing presence of her stammer but described a feeling of control over it. Both Callum and Liam felt this ability to manage their stammer had come with age or from tackling previous stammering experiences. Others also expressed gaining confidence in managing themselves and having developed an understanding of stammering.

*7.52*

*Because from what I was to what I am now, at this point in my life, I just like accept it and I kind of just deal with it, and cope as I go along. (Mia, 380-382)*

*Yeah, as you get older you realise, I can do these things, you get experiences where you do speak and you've done it before, it makes it easier. (Callum, 178-181)*

*But now I look at it, because I'm a lot older and my life has changed loads now. I will stick up for myself a lot now. (Liam, 150-153)*

*It's improved a lot; it improves as my confidence increases. (Owen, 898-899)*

*I know what it is now, I know when it's happening, I know what I can do to kind of try and disguise it, even though, you know, I'm really not that bothered anymore. (Kyle, 642-644)*

A number of participants recognised their own ability to manage their stammering. They described taking responsibility for their communication using different strategies. The following participants' extracts demonstrate the development of their self-reliance by using

self-help behaviours and taking a solution focused attitude towards their speech. There was a distinct sense of their self-agency and resourcefulness which helped them successfully manage their speech. Ben mentioned how he referred to his previous speech and language therapy for guidance and Darren described how he remained positive and spoke to others about his stammer rather than suffer alone.

7.53

[I say to myself] *Don't worry about it. Just talk. The way you are is fine. (Mia, 531-532)*

*I've learnt my own technique by trying to control it in my head. (Liam, 1625-1627)*

*I don't know I always find a way to work my way around stuff. (Nikki, 469-470)*

*So if I find myself stuttering now with someone I don't know, I'll just say, sorry, I have a stutter and then can you understand what I'm saying? (Callum, 606-607)*

*If I was having a bad phase, then I would look at the positives, speak to someone or try to help myself rather than not telling anyone, doing it by myself and really worrying. (Darren, 317-321)*

***7.1.4.2 Positivity.*** The majority of participants conveyed an optimistic and determined outlook in regard to managing their stammer. This appeared to show the positive adjustment they made in regard to their thinking about their speech and view of themselves. There was a strong feeling that they continued to 'tackle' their stammer and not be defeated by it.

*7.54*

*Rather than have a chip on my shoulder I have just learned to persevere. (Ed, 518-519)*

*I'm always going to think, you know, there's always an option. (Kyle, 1 523-4) .... because I've got this thing, you see, when someone says I can't I then have to do it [laughs]. (Kyle, 801-802)*

*I don't change words all the time and I don't order things that I don't want. I will say what I want to say rather than changing them just because they're easier to say. I will say it even if I get stuck. (Jess, 211-216)*

*You have to think quite positively about it, because any negativity about it, you know, that can build and then feed in, and then it can just get worse and worse then. So it's just trying to think I'm tackling it well and I'm doing very, very, very well right now in overcoming it, and I'm doing what I want to do, without it holding me back. (Adam, 1237-1243)*

As described in the previous sub-theme most participants had fostered a more accepting attitude towards their stammering. Gary, Harry and Callum show their acceptance which in turn has led to self-forgiveness. Their previous feelings of self-hate, shame and feeling bad

were replaced with a more positive emotional state which appeared to contribute to an improved self-identity.

*7.55*

*Whereas now, I dealt with coming to terms with it first, like, I accept it, and I don't hate myself for it. (Gary, 434-436)*

*But now I'm not so bad. So I don't think it's shameful now (Harry, 240-241)*

*I've got a stutter, therefore there's nothing to hide, I'm not going to feel bad about it. (Callum, 633-637)*

***7.1.4.3 Continuing challenges in managing stammering***. Although all participants recalled a positive change in their ability to cope with their speech, a few participants described how their stammer persisted and remained a part of their lives. The experience of living with stammering was described by Nikki as less of an ordeal for her, but its continued presence and variation in severity still troubled her, as indicated by her emotional distress during the interview. Harry and Mia also described their ability to manage their stammer whilst both acknowledged that their stammer persisted.

*7.56*

*I don't want to say happier, but a bit less of a nightmare all the time. So it's still hard. It's still something that's there all the time, like the severity, it fluctuates a lot. (Nikki, 1250-55)*

*I still know in parts sometimes when I've been talking to you I do hide it a bit. I'm not being completely fine about it. But certainly a lot better than I would be, (Harry, 722- 724)*

*But like there's certain times that I'm not too bad and there's times that I'm quite bad. So I don't know. It's just like I take it as it comes. (Mia, 60-63)*

***7.1.4.4 Sense of achievement.*** There was a feeling of success expressed in the extract by Mia regarding her academic progress. She showed pride in being the first person from her family to go to university, and perhaps more importantly, for being female. It seemed that education was not especially valued by her family and for her to attend higher education was not a family expectation. Although Mia acknowledged the encouragement and support from her mother she clearly stated how she herself was the driving force behind this accomplishment. A sense of triumph was voiced by Mia.

7.57

[I'm the first to have] ...*Gone to university, from my whole family, so it's like a big thing in our family because our family is not too much like on education. They go to school and to college and that's kind of about it, but in my family I'm the first woman to actually go past it*

*so it's a big thing for us, and I kind of did it…my mum kind of…like she pushed me along and she said like go for it, but I kind of like did it for myself. (Mia, 930-938)*

Similarly, Ed commented on being the only person to reach university from his family. He attributed this achievement to his stammer because it made him devote his time to studying rather than going out and mixing with friends.

*7.58*

*If I hadn't of had a stammer I might not have gone to Uni, as I am the only person in my family who has. (Ed, 716-718) …. as I always had my head stuck in books, rather than out socialising. (Ed, 727-728)*

Others also reflected their feelings of success regarding their educational progress and believed their stammer had not affected their outcomes. Their accounts reflected a sense of purpose and success and revealed a feeling of satisfaction with their lives despite living with a stammer.

*7.59*

*I feel like I've still come out with my full potential, even with it. (Adam, 691)*

*To get a distinction, you had to show that you were confident, and I was like, I'm not going to get a distinction, I'm not a confident person at all. So I knew I would get at least a merit but I didn't think I would get a distinction and I did in the end and I was like, oh my God. (Isla, 561-666)*

*So I chose radiotherapy and that course has got me into it…like I weren't too sure that I'd get in, so when they accepted me I was like, oh my God. It was like I've got in and I've got a place and I'm going to start. (Mia, 512-515)*

*But yeah, so then I went through my final year of university, got the grades I wanted, fortunately, so couldn't have asked for anything more, actually. (Floyd, 1141-1144)*

*I'm happy just with what I'm doing now, because…yeah, it's good and I really, really like what I'm doing and I don't think I would've wanted anything else. (Nikki, 1159-1161)*

*I'm always up to doing lots of things. So I don't think I've missed out on anything at all. (Adam, 691-698)*

***7.1.4.5 Contentment.*** Many participants described increased satisfaction with their current lives despite a continuing need to manage their stammer. Ed expressed his increased happiness with life particularly now he has friends. He saw his stammer as 'stable' and he was less concerned about others' opinions of him. Darren's extract clearly demonstrated his enjoyment of his course despite coping with a demanding workload. Both Nikki and Gary described feelings of satisfaction at being able to express themselves well in writing. This seemed important to them and reflected their development of self-competence.

*7.60*

*It's not really improved, it's just stable. (Ed, 600) Much happier, I have more friends and I could not care less what people think. (Ed, 675-676)*

*So it's a really, really good course, lots of fun, and also work! I hadn't anticipated how much work there'd be but I'm getting through it! (Darren, 610- 616)*

*Now I do a lot more than just I ever have done with my blog and I write and stuff and I go to Uni. I'm really, really busy actually. (Nikki, 1377-1379)*

*So I write a lot of the lyrics. Me and the singer, like, do about half and half, so…and I write a lot of poetry and stuff. I just feel like it's a good way to say some of the more complex words, it's actually harder to speak, like, I can still get them out by putting them on a piece of paper, which is nice. (Gary, 808-814)*

***7.1.4.6 Aspirations.*** The positive and determined approach taken by many of the young people in relation to coping with their stammer was often extended to their current and future plans. The accounts from Darren and Mia demonstrated how they had taken responsibility for managing their future. They appeared proud of their success in terms of the specific outcomes being achieved but also their ability to take and maintain control over their decision making and future life events.

*7.61*

*I told myself that…not how can someone know what's best for you, but it's your future, and it has to be your choice in a sort of way, so I made it myself. (Darren, 789-792)*

*So then I thought like I'm going to go back and achieve something better, because like at this time you can't not have a job and you can't not be educated, so it's got to be done. One more year. One more year and then I'll be done hopefully. (Mia, 947-952)*

Pippa and Owen described their plans to go to college and then university. They both indicated specific careers they were currently aiming for and there was a sense that they did not view their speech as a potential barrier to their decision making or future progression. Pippa mentioned her goal to study speech and language therapy and seemed to view her stammer as a positive attribute which would enhance her understanding when working with clients.

*7.62*

*I'm going to College to do three 'A' Levels. Because right now I'm quite hoping to go into speech and language therapy just because I know a bit about it now and I feel that I could, what's the word, empathise in a way with people. Yeah, yeah I'd like to think it would be a good idea. Right now that's still my main goal or choice. (Pippa, 534-541)*

*The plan is, for now, I might do this course and then go to university. It depends if I like it though, I've still got two years to decide whether I still want to continue in public services.*

*Or, I might do another course, such as business, you know, I still want to do business, I like business, and it means I've got more qualifications. (Owen, 646-55)*

Other participants spoke of their plans to go onto Higher Education, with Jess and Ben hoping to go to university and Adam aiming to go to university or to drama school. All three participants seemed focused on their target and like Pippa and Owen their speech did not seem to be a factor influencing their educational choices.

*7.63*

*So yeah, I'm working hard and doing lots of theatre groups outside of school as well, so I can get more experienced for drama school as well. Because I want to either do that at uni or go start acting through drama school. (Adam, 191-195)*

*I hope to go to university, I hope so, to do marine biology or palaeontology. (Jess, 999-1000))*

*I've applied to business management, and I've been accepted by four or five universities. (Ben, 428-434)*

Harry and Ed described their thoughts about pursuing a higher degree such as a doctorate. It was clear that their experience of stammering had not undermined their academic achievement or future scholarly plans.

*7.64*

*So I'm doing my master's which is in transport planning and I'm keen to do a PhD. So I've spoken to my tutor about it and explained all about my topic and she thinks it's a good idea. (Harry, 746-751)*

*I am contemplating going into law, either that* [law conversion] *or study a PhD, which is crazy. [Laughs] (Ed, 529-534)*

Other participants demonstrated a clear ambition in regard to their prospective employment, which illustrated the pro-active nature of the individuals and their sense of self-direction. Adam recounted his determination to become an actor and his commitment to this career was supported by his current hard work at college. Similarly, Owen identified a future career as a firefighter and had taken steps towards realising this by enrolling in a Public Services course. He also mentioned his ambition of setting up his own business which reflected his positive attitude towards his future personal development. At the time of the interviews, Isla was a student nurse and described how she was considering her job preferences post qualification. Her narrative showed her positive outlook in relation to securing a nursing job in the future. Nikki, who was due to complete University shortly after the interviews, outlined several areas of work in which she was interested and described how she had begun to

apply for positions. Nikki's account showed she had given thought to her different options and was motivated to aspire to a job she believed she would enjoy.

*7.65*

*Well, at the end of it, I know that I definitely want to become an actor. So that's what I really want to do. I want to become a classical theatre actor and do Shakespeare. (Adam, 812-815)*

*Later in life, I might be a fire fighter part time and start my own business as well. (Owen, 660-661)*

*I'd like to go straight into a ward job, I'm not sure what in yet, maybe surgical or something like that. (Isla 1215-1219) Yes, so I should be alright for a job at the end. (Isla, 1234)*

*I've applied for just a buyer job with X company in Leicester, so that's one thing I'd like to do, or I don't know, like social media and stuff, marketing and that sort of thing. Online marketing, I've had experience in that and that sort of thing. (Nikki, 1302-1307)*

In contrast Gary described how he did not have a clear view of his future when he was 18 years old but after achieving his 'A' levels he undertook an apprenticeship. From his account it was clear he was happy to be in a job which entailed little speaking but at the same time he stated that this career choice was not ideal. His laughter accompanying this extract seemed to accentuate the point that his current job was not what he had imagined doing. Gary seemed torn between his desire to be in a role involving more communication and a job which was less demanding on his speech.

*7.66*

*After I left college with my A Levels, I largely didn't know what to do and I went to Connexions and they said that maybe learning a trade might be good. And I thought, well, I don't have a job and I don't want to do anything, and I need to do something, so I thought, yeah, alright. And then they referred me to the electrical course, because that's the one I wanted to do out of all of them. It wasn't a career that I dreamed of doing [laugh], no. (Gary, 705-717)*

*And there's a lot of people around me, but it's quite a relaxed atmosphere. So there's no pressures there which is nice. (Gary, 306-8) But, like, job wise, I would rather be more interactive with people, but it's just not worth the stress it would put on me, in my opinion. (Gary, 327-329)*

Later during the interview Gary explained how he perceived some types of employment, involving significant verbal interaction, as less suitable for PWS. He suggested that rather than pursuing jobs involving the pressure of speaking it may be preferable for people who stammer to explore jobs more suited to their other strengths. Although he highlighted that

being a PWS need not necessarily hamper career choices, he believed jobs requiring strong communication were likely to result in persistent anxiety for an individual.

*7.67*

*I think that certain jobs for people that stammer aren't…they're just not really for them. Like, it's…I think that just because you stammer, you're going to be good at other things, so you shouldn't feel like you have to do a job where you talk on the phone, but at the same time, if you feel like that's your passion, I mean, like, you should go for it. But it's probably best not to go down that route if you don't want constant stress. (Gary, 782-791)*

Like Gary, Callum was also an apprentice. Callum's account described his uncertainty regarding his future employment but he was clearly keen to set himself achievable targets and remained optimistic. He acknowledged that his current job was not outstanding but stated he was content with aspiring to a 'B' grade status in life. Callum seemed satisfied with his work choice, being happy to settle for a job which afforded him stability and he conveyed a positive outlook for his future. However, there was a sense of both Gary and Callum feeling they were in jobs which appeared below their potential. They seemed to have chosen to accept less challenging roles which they could manage rather than adding stress to their lives and risking failure.

*7.68*

*You just want to go far no matter how far it is, I just want to do well and I think having that mentality makes it easier for me, like, I can't fail if I have a real target in a sense, so, yeah, that makes things a lot easier. (Callum, 1808-1812)*

*I guess, it's like…it's not amazing, it's not CEO of a company, just want to be clever enough and do well and be a manager and that's fair enough for me. I guess I, kind of, show a lack of drive, not really, I don't see it that way in a sense, like, it's more being just content I suppose. (Callum, 1846-1852) …Yeah, that's one way of thinking of it, yeah, just B, I just want to be a B pretty much, yeah, nothing special but good enough, yeah. (Callum, 1861-1864)*

*I don't know where it's going to lead, like I said, the apprenticeship is 12-month employment so they can either keep you on or help you find a job somewhere else, so hopefully I should do fine after that or do well, but I don't know where I'll be in a years' time, in two years' time, like I say, stable working somewhere, but I can't guarantee for now. (Callum, 1878-1885)*

Ed also cited his primary goal was to find a career with no demands on his speech but he appreciated few such jobs exist. He expressed his prior uncertainty as to his future career choice and the lack of support from a career advisor but his narrative reflected his sense of satisfaction in securing a job in Human Resources (HR).

*7.69*

*I didn't ever speak to a careers advisor, the plan that I had was just to find a career that didn't require speaking. [Laughs] And there aren't a lot of careers like that, lorry driving perhaps, but I can't think of anything else. (Ed, 277-280)*

*I had not chosen HR, when I graduated I wasn't sure of exactly what I wanted to do, but after I started working in HR I really enjoyed it and have stayed in HR ever since. (Ed, 434-436)*

Ed had continued to work in HR whilst completing a Master's degree. In the following extract Ed explained he was told he needed a higher degree to be considered for promotion. However, he was subsequently clearly exasperated and disappointed that despite achieving his Master's degree he had not been supported by his Manager to pursue a higher grade post advertised in the department. It appeared that Ed believed his stammer had compromised his prospects of furthering his HR career.

*7.70*

*Even though they had said in order to progress you have to have it* [a Master's degree]*, we are advertising for an HR Advisor, which is one up from administrator, I have not been encouraged to apply. So, I'm not very happy here right now. (Ed, 570-5s74)*

Ed also referred to the many job interviews he had experienced and one particular instance of being rejected because of his stammer. These experiences of rejection appeared to have fuelled his negative opinion of employers and may have contributed to his thoughts and low mood in relation to his current employment.

*7.71*

*I had attended lots of interviews, and of course there are some people who won't employ somebody who stammers. (Ed, 444-46)*

*I had applied, she called up to arrange an interview and as soon as I started talking she said, you would have problems working here as it is quite a fast paced environment, and after that she hung up. (Ed, 459-62)*

## 7.2 Summary of qualitative analysis

Through a process of firstly listening to the voices of the young people and then reading and re-reading each individual transcript, it became apparent that the YPWS felt their stammer constrained their lives at school. The analysis describes the young people's responses to stammering during their years in education which are individual, unpredictable and intricate. Their descriptions provide an understanding of their meaningful responses to their experiences with a common theme of adaptive behaviours being developed to hide stammering and protect the self from the feared reactions of others.

Themes are inter-related by the way they show how managing stammering for the young people involves on-going change and transformation and also by the range of influences that impact their choices and decisions in living and coping with stammering as a young person in education. In particular the analysis focuses on their engagement with teachers and class activities which typically delimited their school participation. The themes trace the changes they experience over time and for most the positive process of transformation, involving gradual acceptance of stammering and building of self. The young people's unique personal characteristics supported their journey of learning to cope with stammering which recognises their resourcefulness and development of self-agency. They also made use of their interactions with significant others, such as family, peers, mentors and SLTs to facilitate their development of self which the young people acknowledged and valued.

Although the pattern of each individual account reflects the different manifestations of stammering and their personal and idiosyncratic reactions to living as a YPWS, collectively they demonstrate a similarity. Their narratives indicate a shift in perception of identity from a self which was depleted and eroded to the development of gaining a sense of true self. The analysis shows the importance of the development and change of others' understanding about stammering in order to influence the negative opinions of significant others and to support YPWS in their lives at school.

# CHAPTER 8. DISCUSSION AND CONCLUSION

## 8.1 Overview

The purpose of this thesis was to explore the current educational outcomes and experiences of YPWS in the UK education system using a mixed methods approach, which comprised a quantitative study, followed by a qualitative study. In this final chapter the quantitative and qualitative findings are discussed in relation to each of the study's overriding research questions and existing literature, with the aim of enhancing the understanding of the educational outcomes and experiences of YPWS in secondary and continuing education (i.e. college/university) and contributing to the current research in this field. Following this, recommendations are suggested for future clinical practice and research. The chapter concludes with a discussion focused on the strengths and limitations of the thesis from both a quantitative and qualitative perspective followed by the principal conclusions of the thesis.

## 8.2 Study One: Research question 1: What are the educational choices and outcomes of YPWS in secondary school and continuing education?

This section discusses the key survey findings from the 35 YPWS (aged 15-25 years) who participated in study one. The quantitative analysis is discussed according to each of the three sub-questions for study one. The findings provide insights into the current qualifications achieved by 35 YPWS, their choice of and rationale for subjects studied and their decisions about post 16 education and employment.

### 8.2.1 Sub-question i: Is there a difference in the educational qualifications of YWPS compared to national attainment levels for young people in the UK?

Results of the survey showed that the participants' academic achievement, in terms of level 2 and level 3 qualifications, was commensurate with pupils in England. The number of subjects studied at level 2 by participants was also equal to the national average taken by pupils. This study complements the findings by McAllister et al. (2013) who found no difference in the highest qualification achieved by people who stammer by the age of 50 years. These research findings are important to convey to YPWS particularly as it is contrary to the bulk of previous research which associates stammering with negative outcomes in education (Butler, 2013; Daniels, 2007; Klompas and Ross, 2004). These differences in findings are likely to be due to methodological differences with some studies adopting a qualitative approach which reflected participants' perspectives of

their past educational experiences and outcomes rather than measuring qualifications achieved. The advantage of the current study is that it included current quantitative measures of young people's achievement in the UK education system. Additionally, the second study of this thesis involved qualitative interviews with YPWS thus providing an in-depth and comprehensive understanding of YPWS in education.

### 8.2.2 Sub-question ii: What subjects are chosen for study by YPWS and why?

A range of subjects at level 2 and level 3 were studied by participants. Although most reported their primary reason for their choice of subjects studied was based on their interest and enjoyment of content, some participants chose not to study subjects with a strong oral component, such as languages and drama, due to their stammer. Indeed, the subject choices of over half of participants were influenced by their stammer. Despite an individual's desire and academic capacity to study some subjects, stammering appeared to be a barrier to their subject choices. Although previous studies have referred to the communication apprehension of PWS in relation to classroom activities such as oral presentations (Daniels, 2012; Klompas & Ross, 2004), earlier research has not reported on how a young person's subject choices can be affected by their stammer and how YPWS often avoid subjects involving an oral element. Currently there is an awareness that students who stammer can find oral work challenging and recommendations to support them are provided through online resources (from organisations such as BSA) and via a young person's SLT.

However, the survey results from the present study also found many participants did not receive any help with their academic choices and very few gained advice from teachers or careers advisers. This finding suggests the academic and career guidance for YPWS in education is limited but reflects recent findings from the Office for Standards in Education (Ofsted) that reported that "only one in five schools were effective in ensuring that all its students in Years 9, 10 and 11 were receiving the level of information, advice and guidance they needed to support decision-making" (Ofsted, 2013, p.5) and this suggests a need for improved provision. Despite the limited academic advice received by the YPWS in the current study their educational achievement was in line with student national averages suggesting equivalent academic ability and positive self-agency.

### 8.2.3 Sub-question iii: What are the post 16 education and employment choices of YPWS?

The first study showed that all participants, aged 16 years and over, had been or were engaged with post 16 education either at school, college or through an apprenticeship. This contrasts with previous research by Butler (2013) who described how the perceived negative school experiences of AWS deterred them from choosing further

study, with only five out of 38 participants interviewed reporting positive engagement with Higher Education. One explanation for this difference is the current expectation for young people to continue with further education beyond the compulsory school age. During the last few years UK Government policy has implemented changes to increase education and training opportunities for young people and in 2015 the compulsory education leaving age was increased from 16 to 18 years old (DfE, 2014a).

The results of this study also identified participants' future plans. The young people expressed individual plans which ranged from continuing in education, pursuing specific careers or remaining in their current employment role. A variety of career choices were mentioned by the young people with different reasons supporting their choice (4.1). Few cited their stammering as having influenced their choice of current or future employment (4.2).

Although there is a paucity of recent research regarding the influence of stammering on employment outcomes, the current findings are supported by McAllister et al. (2013) who found stammering did not impact the job prospects of PWS and by Klompas and Ross (2004) who reported the majority of participants felt their stammer had not affected their choice of occupation. In the current study, the young people seemed to recognise that they were not constrained in their careers by their stammer and that they could pursue and see themselves in control of their future goals. Similarly, Palikara et al. (2009) found young people with SLI also held positive views in relation to their future education or employment, although not all studies have found this (e.g. Clegg, Hollis, Mawhood & Rutter, 2005; Howlin, Mawhood & Rutter, 2000). Palikara et al. (2009) suggested this change in perspective may be accounted for by the passage of time during which participants were exposed to differing education systems and experiences. A further explanation could be that participants in the current study were self-selecting and may have been more positive about their stammer and future life choices, while other YPWS who had a less positive outlook may have chosen not to take part in the study.

## 8.3 Study Two: Research question 2: How do YPWS perceive their educational experiences in secondary school and continuing education?

The second study explored the educational experiences of 16 YPWS between the ages of 16 and 25 years and drew upon the IPA method and analysis to capture their understanding of their experiences. The next part of this chapter discusses the qualitative findings from

participants' interviews in relation to the three sub-questions identified for study two. It provides new evidence concerning young people's perceptions of their lived experiences of being a YPWS in education.

### 8.3.1 Sub-question 1: How do YPWS describe and manage their experiences of living with stammering as a young person in education?

The narratives of the YPWS revealed the profound daily struggle they experienced in living with stammering during their years in education. (5.1, 5.7, 5.8). Their accounts reflected their acute awareness of, and unrelenting thoughts about, stammering (5.5, 5.6). The unpredictable nature of stammering and their lack of understanding about it was a core problem for them, causing confusion and feelings of helplessness, and impacted on their participation (5.2, 5.3, 5.4, 5.5, 6.24). This finding supports previous qualitative studies involving interviews with young people and adults who stammered which reported their lack of insight about stammering and the suffering experienced (Corcoran & Stewart, 1998; Hearne et al., 2008) The current study's findings also confirm and highlight the continued need to support young people to gain knowledge and understanding about their stammer and their associated thoughts and feelings.

During the conversations with participants, there was an overwhelming sense of how their experience of stammering challenged their view of normality. It was apparent that many young people compared their speech with others and reported feeling different to their peers. They viewed their speech as not normal and believed it was wrong to stammer (5.6, 5.17). The absence of a valid reason to explain their stammer led to feelings of self-blame and evoked the emotion of guilt (5.9, 5.10. 5.11, 5.13). This emotion was recognised in the work by Corcoran and Stewart (1998) from interviews with eight AWS. They described some participants feeling at fault and consequently guilty because they were unable to justify the cause of their stammer. Other participants in this second study experienced shame because of their inability to speak to others without stammering (5.12, 5.13, 5.25). According to Lewis (1992) their shame can be explained by their experiences of inadequacy within a social context causing them to develop a negative self-evaluation.

Furthermore, many young people in the study described their experiences of loneliness and isolation associated with their stammer (5.18). For some this was accompanied by feelings of sadness, despair, depression and anxiety (5.14, 5.15). For one participant, Nikki, the emotional sadness of stammering was clearly evident throughout the interview, when she cried whilst describing her lived experiences of stammering (5.16). These findings from young people mirror the work by Iverach et al. (2011) with adults who stammer. They found

two-thirds of those seeking therapy were diagnosed with one or more mental health conditions, chiefly with anxiety.

For some participants, their attempts to cope with stammering in order to appear “normal” impacted on their personal behaviours, for example, speaking less and withdrawing from activities (5.19, 5.20). The young people described how these changes in their behaviour sometimes resulted in the formation of inaccurate perceptions by others (5.22). A few felt they were seen as shy by teachers and peers, whilst some believed others doubted their competence because they stammered (5.23, 5.24). These beliefs have been recounted by others who stammer and are consistent with previous accounts of the negative perceptions of educators and fluent peers towards people who stammer (Crowe & Walton, 1981; Dorsey & Guenther, 2000; Evans et al., 2007; Lass et al., 1992).

Participants’ self-concept appeared negatively affected as a result of comparing themselves with others and feeling others viewed them negatively (5.23, 5.24). For some this impacted their self-esteem and participation in education (5.19, 6.21). Okun (1997) defined self-concept as “the perception we have of ourselves based on information from significant others and from our experiences” (p.291). The narratives of some of the young people reflected a process of self-stigmatisation which can be explained by Corrigan and Rao’s (2012) four stage model of self-stigmatisation and mental illness. Firstly, the YPWS became aware of public negative stereotyping related to stammering and secondly they agreed with the stigma others associated with PWS. They then applied these views to themselves (stage 3) resulting in psychological harm (e.g. reduced participation and self-esteem) characteristic of stage 4.

In response to their fear of stammering or their previous negative experience of stammering, participants described behaviours they used to cope with their daily activity as a person who stammers. Two main approaches emerged from their accounts involving their development of personal behaviours: protecting the self; and developing self-acceptance and openness about stammering. Petrunik and Shearing (1983) also recognised the use of these approaches among people who stammer, and suggested another approach may be disavowal, whereby both the person who stammers and the listener overlook the occurrence of stammering. However, this was not found in the accounts of the young people in this study.

For many of the participants their approaches to coping were sequential and appeared part of a journey for the individuals. Initially participants made the choice of protecting themselves from the potential negative consequences of stammering by hiding it. This was achieved by speaking less or keeping quiet, getting others to speak for them, disguising it and avoiding

words and situations (7.1- 7.6, 7.10 -7.15).This approach aimed to keep stammering a secret so that their identity as a fluent speaker was maintained and they passed for “normal”. However, for some this seemed to be at the cost of adding to their feelings of inadequacy and restricting their educational achievement and participation (7.7, 7.8, 7.9, 7.15). Crichton-Smith (2002) also noted participants who concealed their stammering experienced subsequent personal gains and losses (e.g. successful hiding of stammering from listeners was viewed as a gain by participants but negative perceptions of self and lack of progression in life were experienced as internal and external losses respectively). Some young people in the current study chose to continue using this avoidance approach to manage their stammering in some social situations (7.8). This finding is in keeping with work by Bandura (1989) who found people will tend to avoid situations which they consider are beyond their ability and will restrict themselves to those they feel able to manage.

Following this period of self-protection, some participants recalled their decision, usually in their late teens, to learn to confront and accept their stammer (7.16). This was a gradual process which usually involved disclosing their stammer to other people which in turn brought them relief and increased their social and educational activity (7.17, 7.22, 7.27). One participant likened the experience to the disclosure of being an alcoholic and another to “coming out” as gay (7.50, 7.23). This phase of openness described by the present study’s participants seemed prompted by their previous adverse experiences of stammering and subsequent accrued negative feelings (7.16, 7.24). In disclosing their stammer, the young people gained control over communication situations in their lives (7.26, 7.27, 7.28, 7.29). Boyle (2015) suggested that disclosure of stammering reduces worry and shame and instead brings relief to PWS. Similarly, for people with mental illness Rusch et al. (2014) proposed that “disclosure or coming out can reduce self-stigma” (p.391).

An important finding from this second study is the description of personal characteristics and abilities which appear to support YPWS on their journey to accept their stammer. Although participants described negative experiences of living with a stammer, there was a strong sense of positivity and self-determination underpinning their journey (7.25, 7.26). Participants adopted a balanced outlook by acknowledging their stammer and taking control of it (7.27, 7.28). They all showed a quality of perseverance to ensure their speech was no longer a barrier in their lives (7.33). This positive attitude pervaded their current thinking and also their plans for the future. The ability of young people in the study to actively gain control in managing their stammering may be considered self-efficacy (Bandura, 1977). Self-efficacy has been found to protect against stressful life experiences and sustain wellbeing (Maciejewski, Prigerson, & Mazure, 2000; Plexico et al., 2005) and to be a significant factor in developing resilience in PWS (Craig et al., 2011; Cummins, 2010). In gaining control over

their stammer many of the participants involved themselves in extra-curricular and social activities which they believed promoted a feeling of belonging and increased both their confidence and positive thinking (7.30, 7.31. 7.32, 7.33). This echoes the work of Craig, Blumgart and Tran (2011) who found being more socially active enhanced the quality of life of people who stammer and was a key influence in protecting against mental health issues.

The capacity of participants to cope with their stammer was also reflected in their self-reported ratings in relation to the impact their stammer had on their current life at work, with the majority reporting no effect or a mild impact. In addition, all but one of the participants' measures of self-esteem were positive. Self-esteem, comprises a person's feelings of self-worth and self-competence, including self-efficacy, which is necessary for a person to hold a positive sense of self (Mruk, 1999). The participants' ability to manage their stammer (7.53, 7.54) appeared to have contributed to increased self-competence which in turn had improved their self-regard and enhanced their overall view of themselves evidenced by their healthy self-esteem scores. In this study, the one participant who recorded negative responses to a number of the self-esteem statements regarded herself as a perfectionist and saw her stammer as a barrier to her reaching her full academic potential and self-expectations, despite her academic success to date (7.3). She was continuing to learn to manage her stammer.

In addition to their personal strengths in coping with stammering, the young people perceived the support from their friends and family as an important factor contributing to their ability to cope with their stammer, which may have also contributed to their enhanced levels of self-esteem (7.34, 7.35). Plummer (2001) stated that quality support from family and friends was significant in developing children's self-esteem as children need to feel valued and approved of by others in order to develop acceptance of themselves. Despite some participants recalling instances of teasing by peers (6.60, 6.61, 6.62, 6.63), all participants spoke of being part of a friendship group which gave them a feeling of acceptance and happiness (7.36, 7.37, 7.39). They felt friends responded to their speech positively and some perceived them as protecting them from bullying during their education years. (7.38). The friendship and protection afforded by peers is a finding supported by an earlier qualitative study by Hearne et al. (2008) which found very few instances of adolescents experiencing teasing by peers about their stammer and described how some adolescents felt their friends safeguarded them. The sense of social belonging and the support provided by the social network described by YPWS in the current study is also in line with the research of Craig et al. (2011). This earlier study, involving 200 AWS, found protective factors such as positive social support had a valuable protective function against the negative impact of stammering and facilitated positive adjustment to stammering.

Most participants believed family members offered protection and support with their lives at school and at home (7.41, 7.42). This outcome is consistent with other studies involving AWS which found supportive family relationships provided a buffer against distressful events associated with stammering (Craig et al., 2011) and predicted increased quality of life for AWS (Boyle, 2014). However, a few young people viewed relationships with their family as unhelpful. It seemed these negative views were linked to adverse experiences when they were younger which revolved around parents' handling of their stammer (6.64, 6.65, 6.66). This supports the need for parents to be involved early on in the therapy process so they can learn about stammering and how to help their child (Millard, Nicholas & Cook, 2008; Yaruss & Coleman, 2006).

Aside from support from friends and family, one young person in the study, Jess, described benefiting from the regular support of a mentor at college (6.54). Jess' college recognised the importance of supporting the needs of students by identifying them early on through their admissions process. Jess described disclosing her speech difficulty on her college application form which triggered the implementation of support mechanisms. Jess was offered the chance to meet with a mentor when she first started college and one to one meetings continued on a weekly basis. This provided her with the opportunity to talk about her experiences of stammering and gather help with managing her participation at college (7.43). Similarly, Plexico, Manning & DiLollo (2005) analysed interview data from seven AWS aged 38-59 years old and reported that two participants experienced positive mentoring in the past. However, there is no detail provided as to whether the mentors were peers or the context in which this support was provided.

Learning to confront and accept their speech difficulty was sometimes facilitated by seeking help from a SLT. Of those participants who had engaged with SLT, the majority described negative experiences as a child or young adolescent, with most questioning the focus of therapy and its value (7.46). However, a number of them spoke more positively about recent experiences of SLT and the benefits (7.47). These differing experiences may be linked to individuals' readiness to change, the experience of the SLT in working with PWS or the focus of the therapy may not have been helpful to the young person earlier in their life. It is therefore vital for SLTs to consider an individual's motivation for intervention (Floyd, Zebrowski & Flamme, 2007) and to possess evidence based knowledge and suitable skills for managing PWS.

Currently in the UK a range of therapy options to support YPWS are suggested by RCSLT (2015), including fluency enhancing and psychological strategies. However, the current study found variation in the reported speech and language therapy experiences of the young

people. These differences appeared to be due to limited service provision, difficulties in accessing specialist therapy (including a lack of SLTs' training and experience in stammering) or due to participants' lack of motivation to seek therapy (7.45, 7.46). This variation in provision and experience of SLT is in line with previous findings by Davidson, Thompson, McAllister, Adams and Horton (2009) and Crichton-Smith, Wright and Stackhouse (2003) and remains a concern.

A few participants experienced group therapy offered by SLTs which they perceived as useful because it gave the opportunity to meet others experiencing life with a stammer (7.49). Nikki's attendance at a stammering self-help support group provided her with a safe environment where she could openly talk with others without feeling she would be negatively judged. In addition to this mutual support, Nikki found that she was able to increase her social activity and developed new friendships (7.50). The support offered by both types of groups can help PWS with building resilience and lessen the negative impact of stammering on the individual (Boyle, 2013). Other studies have reported that supporting one another in a group increases an individual's self-esteem, self-efficacy and results in enhanced wellbeing (Craig et al., 2011; McNeil, 2013; Murgallis, Vitale & Tellis, 2014; Russell & Topham, 2012). In the UK there are a number of self-help groups for people who stammer but these have variable attendance and the organisation and maintenance of these groups can be challenging (BSA, 2016). The BSA encourages its members to set up such groups, and the increasing use of social media offers an alternative social and supportive network for people who stammer (https://www.facebook.com/stammeringbsa).

The McGuire Programme was mentioned by four participants as a source of support for their stammer in relation to helping them confront and accept their stammer. Participants viewed the programme as helpful because it promoted self- acceptance of their stammer by advocating openness of their speech difficulty (7.51). The programme being delivered by PWS was seen as a further strength by one participant as the trainers had personal understanding and experiences of the challenges encountered by PWS (7.51). This approach had supported the YPWS on their journey to coping with their stammer by encouraging them to talk about their speech to others such as family and friends. This openness resulted in feelings of relief for the YPWS and promoted others' understanding.

**8.3.2 Sub-question ii: How do YPWS describe the impact of stammering on their educational experiences?** In this second study, the young people reflected on the way their life as a PWS impacted their ability to cope with functioning within the education environment. All described how their stammer and potential responses to their stammer restricted their participation in classroom tasks involving communication, including

reading aloud, oral presentations, answering questions, responding at registration and contributing to group discussions and assemblies. This is supported by retrospective accounts from AWS regarding the limiting effect of stammering on their lived experiences at school, described by Crichton-Smith (2002). Other qualitative studies by Butler (2013), Daniels et al. (2012) and Klompas and Ross (2004) similarly reported the negative perceptions of classroom difficulties with reading aloud and oral presentations of AWS. Although these previous studies revealed the retrospective school experiences of older adults who stammered and the current study focused on individuals' current or very recent educational experiences, the findings are consistent and confirm a lack of change in the classroom experiences and responses of YPWS within the education context.

Participants in the current study expressed the negative feelings they associated with being asked to take part in class (6.1, 6.2, 6.3, 6.11). In particular, constant feelings of anxiety were voiced which seemed to be attributed to the uncertainty as to whether they would be chosen to perform; lack of control to anticipate and manage moments of stammering; concern regarding the negative reactions of peers and worry that their performance may impact their academic achievement (6.3, 6.4, 6.5, 6.12, 6.13, 6.14). This continual anxiety affecting their participation and subsequent learning was in line with findings by Butler (2013) who described participants' fear associated with speaking which they perceived as adversely impacting their involvement with learning at school.

In particular, participants in the current study continually worried as to whether a teacher would call upon them to read aloud or respond to a question (6.1, 6.2) and some used the metaphor of feeling 'frozen' to describe their inability to read (6.4, 6.5). A few expressed the relief felt when a teacher bypassed them, but others had mixed emotions; feeling relief but also disappointment that their stammer inhibited their ability to join in with peers in class activities and as a result their voice could not be heard (6.6, 6.21). Further anxiety was described when reading aloud in class because participants knew deviations from the written text could not be made so they would need to confront feared words (6.1). For one participant this resulted in time being spent scanning the words in the text to pick out the potentially difficult words, which they then worried about (6.1). However, two participants felt comfortable to read in front of others perhaps because, as suggested by Pinto, Schiefer and Ávila (2013), the written script provided support by reducing the linguistic load (6.8, 6.9).

Participants also described how stammering interfered with their class performance in regard to oral presentations. In some cases, this resulted in participants abstaining from future oral

work by trying to appear inconspicuous, refusing to take part or by asking a friend to take their turn (6.3, 6.6, 6.7). One participant mentioned feeling 'frozen' at the prospect of speaking and although he would try to participate, attempts were usually disrupted by his stammer and the task abandoned (6.10). These reactions appeared to reflect their struggle to understand their stammering and its unpredictable nature which fuelled their lack of control and anxiety. Similar behaviour has been found with students experiencing social anxiety in Higher Education from a survey carried out by Russell and Topham (2012). Three-quarters of 787 self-selecting university students with self-assessed social anxiety reported they used strategies in managing their learning activity such as attempting to be inconspicuous by sitting at the back of the class or when doing group work asking friends to feedback to the whole class. Some students also described feeling sick, dizzy and afraid prior to giving an oral presentation. Findings from both studies highlight how the experience of anxiety impacts a young person's engagement with learning, unbeknown to teachers.

A number of participants had independently adopted self-help strategies to support spoken activities in the classroom, for example, asking to be first to read rather than waiting to be chosen or asking to present in front of a smaller group of people and using written text to support an oral presentation (6.16, 6.17, 6.19). These types of strategies and others are mentioned in a number of resources for YPWS (Action for Stammering Children, 2016; The British Stammering Association, 2014) although none of the participants mentioned accessing these support services.

Some participants worried about the possible reactions from peers if they did speak up in class, fearing being laughed at and seen as less intelligent than others (5.24, 6.6, 6.22). Despite this, most experienced positive relationships with peers (7.34, 7.35, 7.36, 7.37, 7.39). Some instances of teasing were described during their early school years (6.60, 6.61, 6.63), but only one participant referred to their experience as being bullied (6.63). This is consistent with Butler (2013) who found that peers were not a particular problem for PWS, but is contrary to past research which found teasing and bullying to be a common occurrence during adolescent school years for PWS (Blood & Blood, 2004; Davis et al., 2002; Erickson & Block, 2013; Hugh-Jones & Smith, 1999; Langevin et al., 1998; Mooney & Smith, 1995). Anti-bullying policies in schools introduced in the UK in the late 1990s/early 2000s and the start of the current century may have contributed to the contrasting findings from these studies.

Despite participants experiencing some negative responses from peers regarding their stammer, none suggested that their peers' understanding of stammering and behaviour

towards them needed addressing. During their secondary school years, the participants seemed to be more passive in accepting their peers' reactions to their stammering behaviour and took a more mature approach to coping with teasing (6.63). This finding is supported by Keltner et al. (2001) who reported that by the age of 12-13 years young people found teasing by others to be less upsetting and suggested this decline may be the result of developmental changes in young people's understanding of teasing. Furthermore, other studies investigating bullying have stated that there is a reduction in the reported instances of bullying from the age of 12 years (Erickson & Block, 2013; Hoover, Oliver & Hazler, 1992; Whitney & Smith, 1993). This apparent decline may not reflect a reduction in the frequency of teasing occurring in secondary school, but rather changes in how young people perceive and react to teasing (Keltner et al., 2001).

Several young people compared themselves to their peers and described how they would like to speak similarly to peers (5.17). Some felt it was unfair not being able to speak like others and to be able to show their true self (5.20). They talked about the physical and mental effort involved in speaking in front of others and how stammering in class situations generated feelings of embarrassment, frustration and anger (6.11, 6.12, 6.13). Some worried about the length of time it would take them to perform a verbal task and were concerned about their peers needing to be patient (6.3). They were worried peers would feel awkward or annoyed at having to listen to their stammered speech (5.11). This finding is consistent with Plexico, Manning and Levitt (2009) who described how PWS avoided situations to shield the listener from feelings of awkwardness in hearing the person stammer. Participants' interpretation of this situation reflected their cognitive anxiety and the lack of self-worth felt the participants during their lives in education. This in turn impacted their level of self-esteem and well-being.

Participants reported varying reactions from teachers towards their stammering behaviour. Some participants described negative and unhelpful responses from teachers. These included young people being made to feel pitied, humiliated, rejected; being accused of lying about being a person who stammers; being forced to take part, and being told to 'shut up' or to 'spit it out' (6.45, 6.47). One participant reported experiencing a bell being rung by a teacher to stop her speaking (6.46). Others commented on their teachers' disinterest and lack of support even when the teachers were aware of their speech difficulty (6.48, 6.49). These findings are in line with Butler (2013) who reported accounts of PWS describing teachers who would "purposefully taunt them" and that the "actions of teachers" were the chief reason for their difficult experiences at school (p. 62). Similarly, Klompas and Ross (2004) conveyed accounts from PWS who recalled experiencing negative reactions from

teachers and a lack of support from them. Many of these reactions amount to bullying by teachers which is concerning, but these findings from the current investigation seem to be consistent with the qualitative accounts from Hearne et al. (2008) and Butler (2013) who found teachers to lack awareness and to be unsupportive of students who stammer. Furthermore, two recent studies found teachers' beliefs about PWS to be similar to those of people in non-teaching professions, with no difference in accuracy of beliefs (Arnold & Goltl, 2015) and no significant difference between teachers' and the general public's levels of knowledge, experience, accommodation and sympathy (Arnold, Li & Goltl, 2015). Thus, the findings from both the current and earlier studies confirm the need to develop teachers' knowledge about stammering and how to support YPWS in education.

In contrast to these previous findings however there were also reports from the current study's participants of more positive reactions from teachers. Some talked about their teachers' patience and willingness to adapt class activities to support their participation, making them feel part of the class (6.38, 6.39, 6.40). This support appeared to rely on the young people disclosing their stammer so that the teachers were aware of their speech difficulty (6.49). Some also described how teachers spoke of their lack of knowledge of stammering, but they were usually keen to learn how to help and support the young person in the classroom (6.41, 6.42, 6.44). A number of areas of good practice were highlighted by the young people, such as teachers waiting, giving them time to speak, providing extra time for oral presentations and being asked closed questions (6.38, 6.39). Some teachers were seen to be helpful by sharing information with their colleagues about the stammering support required for individuals (6.41).

This finding is supported by other studies which have noted a positive change in teachers' attitudes towards PWS (Daniels, 2012; Irani & Gabel, 2008). The study by Daniels et al. (2012) using individual and group interviews with 19 AWS found only one participant reported negative experiences with teachers and the others indicated that teachers held neutral to positive attitudes towards them. However, the analysis did not provide extracts from participants' accounts to confirm their experiences or explain how their responses were coded. Irani and Gabel (2008) surveyed the views of 178 teachers in relation to either a description of a PWS or a fluent speaker using a semantic differential questionnaire. Positive characteristics were attributed to both speakers in regard to every item on the scale which suggested a shift in the outlook of teachers towards PWS. However, these views were based on teachers having read a description about a PWS rather than audio-visual recordings of PWS and furthermore teachers' responses to the questionnaire may have reflected more politically correct views expected of teachers.

The differences in findings from these studies, reporting both positive and negative reactions of teachers towards PWS, may be explained by the different research designs employed. Also, the opinions of different populations have been gathered (e.g. views of teachers and those of adults and young people who experience stammering) which therefore offer different perspectives and some accounts from older AWS whose recollections could be distorted through the prism of time. Participants mixed experiences in the present study also reflect the differences in teachers' behaviour in the current education system which may be attributed to differences in teachers' educational experiences but this finding clearly indicates the support teachers need in managing YPWS in education.

Many participants suggested ideas for teachers to support young people who stammer, in addition to specific training about stammering (6.56, 6.57). These included an open discussion between the young person and teacher about stammering and their needs, teachers being proactive in approaching the young person and negotiating suitable support, improving teachers' interaction skills and adapting class activities to facilitate their participation (6.58, 6.59). These kind of suggestions are acknowledged in various resources for teachers (e.g. Action for Stammering Children, 2016; BSA 2016; Kelman & Whyte, 2012), but the way in which this information is disseminated to teachers needs to be addressed. For example, Jenkins (2010) surveyed 72 teachers in the UK and found two-thirds favoured face to face training or discussion about stammering with a SLT. Participants also recommended specific ideas for improving support with presentations such as teachers creating a less formal environment involving smaller groups and making available technology resources such as iPads (6.16, 6.58). In previous research, Russell and Topham (2012) investigated the impact of social anxiety on students' learning and well-being in Higher Education and advised that teachers should consider "how general pedagogic approaches may be employed in the classroom to reduce potential performance anxiety and embarrassment for *all* students" (p.383), then recommended a number of similar supportive activities.

For some participants' their school experiences relating to their stammering had a bearing on their post-16 destinations. Those disaffected by their school life experiences chose to leave school and go to college which they viewed as a fresh start in a more adult environment and a place where they could meet new people (7.25, 7.26). Others preferred to continue with further study and remained at school. This offered them a more predictable and safe environment where they were already part of a friendship group and an existing awareness of the academic and classroom expectations (7.19, 7.20, 7.21).

Participants who attended college and university believed their stammer had less of an influence on their life in these settings compared to their life at school, indicating they experienced increased understanding and support from teaching staff in FE/HE compared to their previous school experiences (6.52, 6.53, 6.54). One participant talked of a more accepting and inclusive culture in an adult environment that fostered positive student-teacher relationships and encouraged students' personal development (6.52). Similarly, Palikara et al. (2009) found young people with a history of specific language impairment attending college appreciated the support system, increased autonomy and being spoken to as an adult. The study by Palikara et al. (2009) also reported that participants saw their transition from school to college as a positive experience which the authors suggested may be the result of colleges adopting a more flexible approach to address students' needs. It may be that these positive experiences are a consequence of actions taken by the young people to disclose their stammer, manage their speech difficulties, and accept support. However, it may also be that colleges and universities have greater capacity and resources to support the student learning experience as required.

### 8.3.3 Sub-question iii: How do YPWS feel about their educational achievement and future prospects?

Whilst the quantitative data from the first study did not find a difference in participants' educational qualifications and grades compared to national norms, results from the qualitative analysis provide additional insight into the educational performance of YPWS. Despite achieving high grades, some YPWS felt they could have attained higher grades if they did not stammer (6.32, 6.33). This suggests some YPWS sense they are underachieving and not meeting their full academic potential. This is consistent with the work by Daniels et al. (2012), who interviewed 21 adults who stammered aged 29 to 69 years, who reported they experienced academic costs to stammering which included reduced learning opportunities and achievement of lower grades.

A number of the young people in the second study talked about the importance of participating in class, in order to show engagement with learning, and to positively influence the opinion of teachers (6.22, 6.23). Some participants believed their stammer had a negative effect on their academic success; for instance, worrying that stammering in an oral examination might affect whether they passed the assessment (6.13). This is a finding matched by Weingarten (2012) who found most women who stammered, although seeming to achieve well academically, reported feeling their academic potential had not been fully met because of their lack of participation. Crichton-Smith (2002) also provided accounts from adults who felt they had not reached their full potential because their stammer had restricted their educational experience.

The effort and fatigue associated with controlling their stammer including the avoidance of participating in class tasks seemed to impact young people's learning and outcomes (5.8, 6.21). For example, the pre-occupation with thinking about the delivery of a presentation was at the expense of planning and researching the content which took them away from the purpose of the activity and could have impacted their academic outcomes (6.14). This hypothesis is supported by Butler (2013) who reported that all 38 adults who stammered, aged 19 to 89 years, taking part in individual and group interviews believed that the distracting negative thoughts arising from their constant worry about speaking in class affected their learning activity. However, other participants in the current study were keen to demonstrate their capability and compensate for their stammering and lack of contribution by putting more effort into their written work (6.22). Crichton-Smith (2002) and Daniels et al. (2012) also reported that some participants described studying hard to achieve higher grades in written work to compensate for their stammering.

A further important finding to emerge from the analysis concerned participants' future aspirations which they spoke about with optimism and enthusiasm (7.61). The young people seemed focused on what they hoped to become in the future and their stammer was not cited as a barrier to their ambitions (7.65, 7.68). Their positive outlook may reflect their current ability to manage their stammer (7.53, 7.54). This echoes the theme identified by Plexico et al. (2005), who carried out qualitative interviews with seven professionals who stammered aged 38-59 years, that individuals who were successfully managing their stammer adopted a positive approach to situations and their stammering behaviour ceased to negatively impact their future options and direction in life. However, Plexico et al. (2005) did not shed light on the current activity and participation that individuals pursued.

There was one participant in the present study who appeared to have gravitated towards a less challenging job in terms of its speech demands which reflected his belief that such careers were less suitable for PWS (7.66, 7.67). A further participant had also sought employment involving minimal speaking but he recognised there were few such opportunities and had taken a job in Human Resources. (7.69). However, prior to gaining this position he had experienced many unsuccessful interviews with one employer citing his stammer as a barrier to the job (7.71). Also he believed his stammer compromised his career prospects in his current employment despite achieving a higher qualification to support his progression (7.70). Although these reports were from two participants out of 16 it firstly indicates the need for individualised advice and counselling which encourages a YPWS to aim for careers they are interested in rather than pursuing those which require less

speaking. To meet this need, it is also essential for professionals providing young people support with career choices, such as career advisors and teachers, to have an understanding of stammering. A recent survey analysing responses from 21 career counsellors in the USA showed less than two-thirds believed PWS could pursue any job of their choice, suggesting a need for SLTs to provide to support and work with career advisors (Walker, Mayo & St. Louis, 2016). Secondly there is a need for employers to gain information and advice about stammering and how to support the recruitment process for PWS. Recently the Employers Stammering Network has been founded to address this need (British Stammering Association, 2016).

Despite some participants describing their stammer as impacting their educational choices and participation in oral activities in class, the majority of participants in the present study indicated satisfaction with their academic outcomes (6.36, 6.37, 7.59). Many of the participants were continuing in education to increase their level of qualifications with many aiming to start degree level courses whilst others were employed. These positive findings are important to highlight to YPWS and to the people in their environment, as they challenge much of the earlier research in this area which focuses on the negative outcomes for YPWS. These differences in findings may be explained by the over reliance of previous studies on the recollections of school experiences and achievements from older adults, which may be impacted on by their later life experiences. The comprehensive approach taken to this thesis demonstrates the advantages of using a mixed methods design, drawing upon quantitative and qualitative data to uncover and describe the current educational experiences and outcomes of YPWS.

## 8.4 Contribution to knowledge

The analysis of the educational outcomes and experiences of YPWS in this thesis showed that YPWS achieved similar educational outcomes as other pupils in England, but that their stammering impacted their lived experiences in education. The findings suggest that young people undertake a journey through educational settings and into adulthood as they learn to cope with stammering in their lives. A model is proposed to synthesise these findings and illustrate the experiences of the YPWS (Figure 8.1). The model has three main journey stages and it shows how YPWS may be enabled in terms of their sense of self and daily activity in their environment. Thus, their journey towards coping with stammering may be shaped by both the internal personal characteristics of the individual and positive external environmental influences.

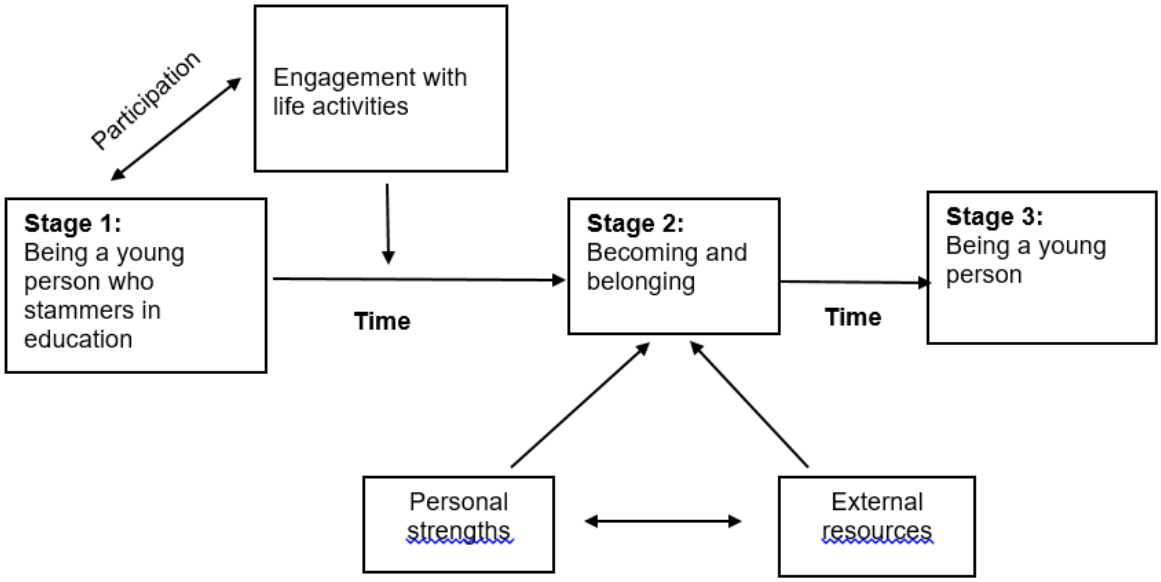



*Figure 8.1*. Model for learning to cope with life as a young person who stammers.

**Stage 1. Being a young person who stammers in education.** All the participants described the struggles they experienced as YPWS and their narratives revealed these struggles equally caused, and were caused by, difficulties with daily life activities in education. That is, being YPWS not only affected their participation and relationships, but also their understanding of themselves was influenced by the way they viewed their participation and choices, compared themselves with others and interpreted the reactions of others towards them in the education environment.

An individual's negative feelings and thoughts arising from these activities could confirm a negative view of self. However, these experiences could also strengthen the resolve of the individual and exert a positive effect on the process of learning to manage life as a young person who stammers in education.

**Stage 2. Becoming and belonging.** As individuals progressed through educational settings and participated in a range of life activities, their sense of 'self' continued to develop. Two inter-related sets of factors (personal strengths and external resources) appeared to contribute to their building of self. An individual's strengths comprised a number of qualities, such as, determination, adjustment and involving themselves in social or sporting activities. External resources include positive relationships with family and friends, having understanding teachers and, for some, involvement with speech and language therapy or the McGuire Programme. These internal and external factors appeared to interact to influence the individual's journey, giving them a sense of

becoming and belonging as a young person where their identity is less defined by their stammer. The model shows this process of movement and the importance of support in enabling this change.

**Stage 3. Being a young person.** Individuals who built a positive sense of self during their educational journey perceived their future life as a young person who stammers in a more positive light in comparison to their earlier years. This final part of the model reflects participants' positive evaluation of how they now manage stammering in their lives in education or at work and their psychological well-being, which is dependent upon a blend of their personal strengths and their external support. This part of their journey reflects their ability to cope with stammering, their feeling of satisfaction with their life and their aspirations for the future. The model illustrates a shift in their identity from being a 'stammering young person' to being 'a young person (who stammers)'. Although this appears as a positive end point in the model, the process of maintaining the individual's sense of control and self-satisfaction is an ongoing one.

The use of this model can be demonstrated by applying it to YPWS in this second study. Three examples of this application are presented here which illustrate the different personal journeys. The participants chosen for these examples differed both in age and current educational experience.

**Example 1: Owen**

Owen was 16 years old had just completed his GCSE examinations at school and was planning to go to college full-time to study a level 3 diploma in Public Services. Figure 8.2 illustrates Owen's journey in learning to cope as a young person with a stammer in education. It reflects his beliefs and emotions related to **being a YPWS in education** e.g. he saw his stammer as an ever present burden that he carried around with him which needed constant attention. It made him feel tense and reduced his feelings of self-worth. He described how stammering negatively affected his **engagement with school life** including his subject choices, his ability to join in with activities and express his ideas and it limited his interactions with others. Owen was quiet for fear of stammering and making a fool of himself and felt like he did not fit in. However, his account revealed a number of **personal strengths** which reflected his determination to take responsibility for himself and his life. These included his strong work ethic, his sporting ability and his motivation to succeed in life. He also recognised the benefits of **external resources** such as SLT, friends and patient teachers. Together these personal and external factors seem to have enabled Owen to

move towards **becoming an independent young person** with emerging self-belief and confidence in living with his stammer and developing positive plans for his future.

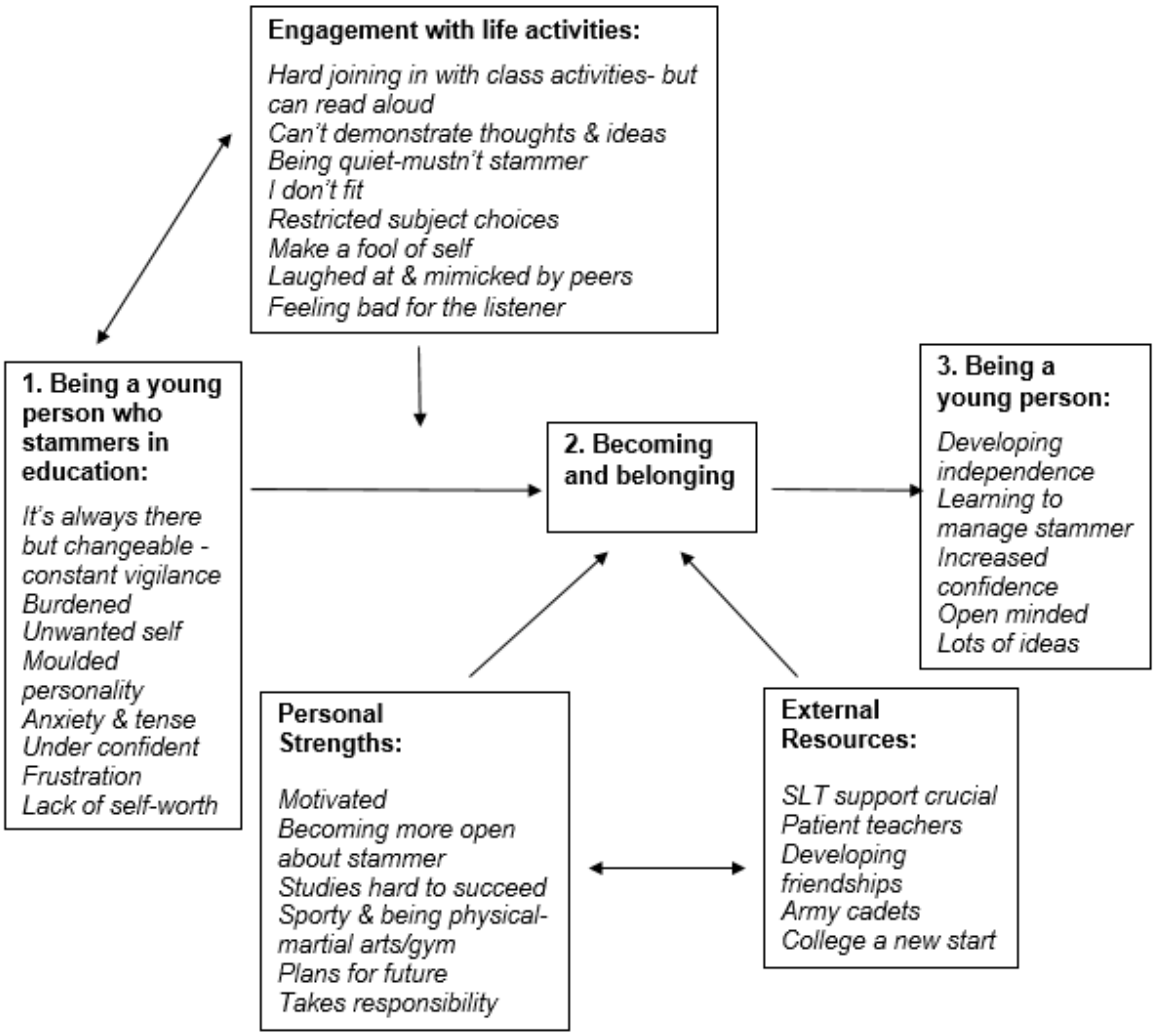



*Figure 8.2.* Owen's journey: his process of learning to cope with living as a YPWS.

**Example 2: Callum**

Callum aged 19 years old was undertaking an apprenticeship in Facilities Management so was working and attending college part-time. Figure 8.3 encapsulates Callum's thoughts and feelings associated with **being a YPWS in education**, such as the constant thinking about his stammer, its unpredictability and his feelings of anxiety and depression. He provided insight into how his stammer impacted his **engagement within the education environment**, e.g. the lack of others' understanding and the negative reactions from teachers; comparing himself to others; feeling different and worrying about his performance in class activities. However, his narrative reflected a number of **personal factors** which illustrated his self-determination and self-efficacy to improve his self-satisfaction with his life.

These included being aware of the need to show his capability by trying to participate in class, studying hard to achieve high marks, disclosure and acceptance of his stammer and seeking support. In addition, he described the **external resources** he drew upon to support his self-growth, such as SLT and belonging to a friendship group. These combined factors appear to have helped reduce the adverse impact of his stammering and led to Callum perceiving he had a sense of stability in his life with increased self-control, the ability to participate as a **young person in his environment** and a positive outlook towards his future life.

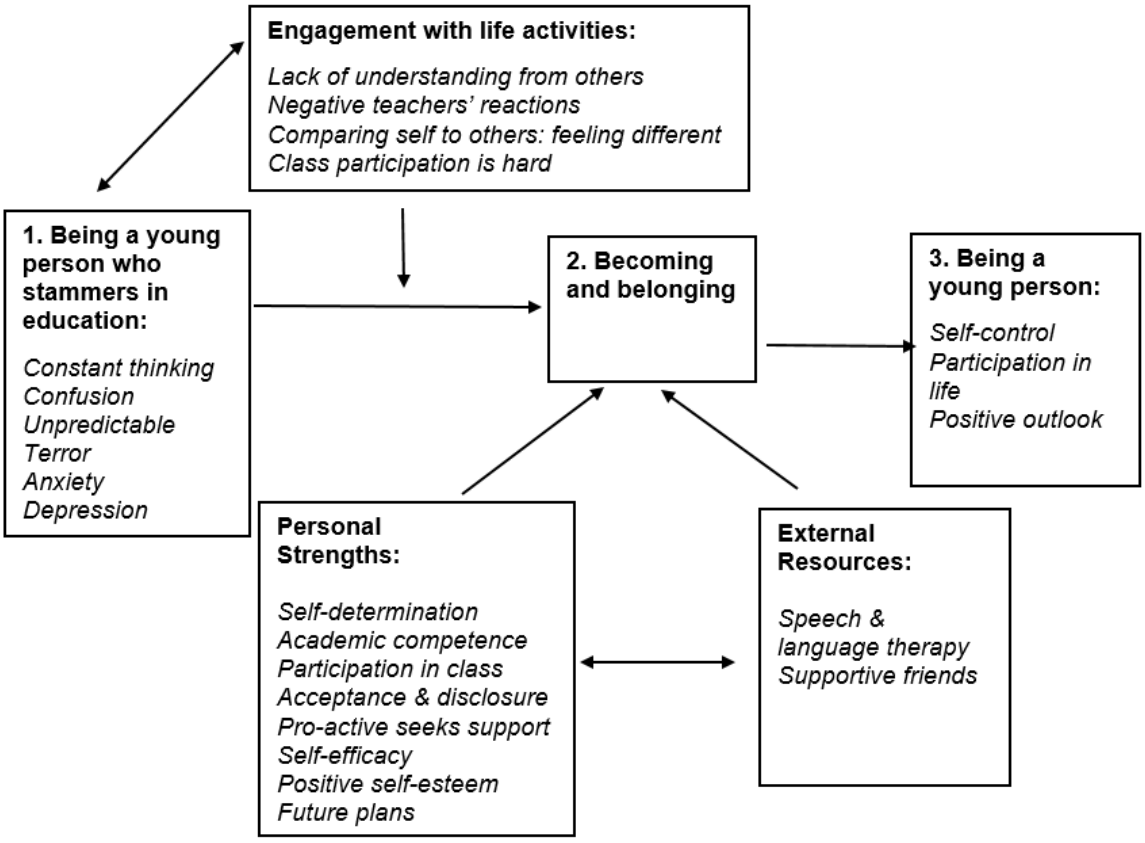



*Figure 8.3.* Callum's journey: his process of learning to cope with living as a YPWS.

### Example 3: Mia

Mia aged 25 years old was studying to be a Radiotherapist at University. Figure 8.4 reflects Mia's negative thoughts and emotions caused by **being a YPWS in education** including her struggle for self-control and self-acceptance and her feelings of distress. Mia perceived her stammer to have restricted her **engagement with education activities**, such as participation in class and extra-curricular activities and to have limited her relationships with others within education. However Mia's story revealed her **personal strengths** of resilience and positivity which together with her pro-active behaviour in seeking **external resources**,

e.g. help and encouragement from university teachers, SLT, family and friends, supported her to address personal challenges including her stammer. These factors underpinned her success in managing her **life as a young person** in education and led to her developing a sense of worthiness and enablement with clear aspirations for her future.

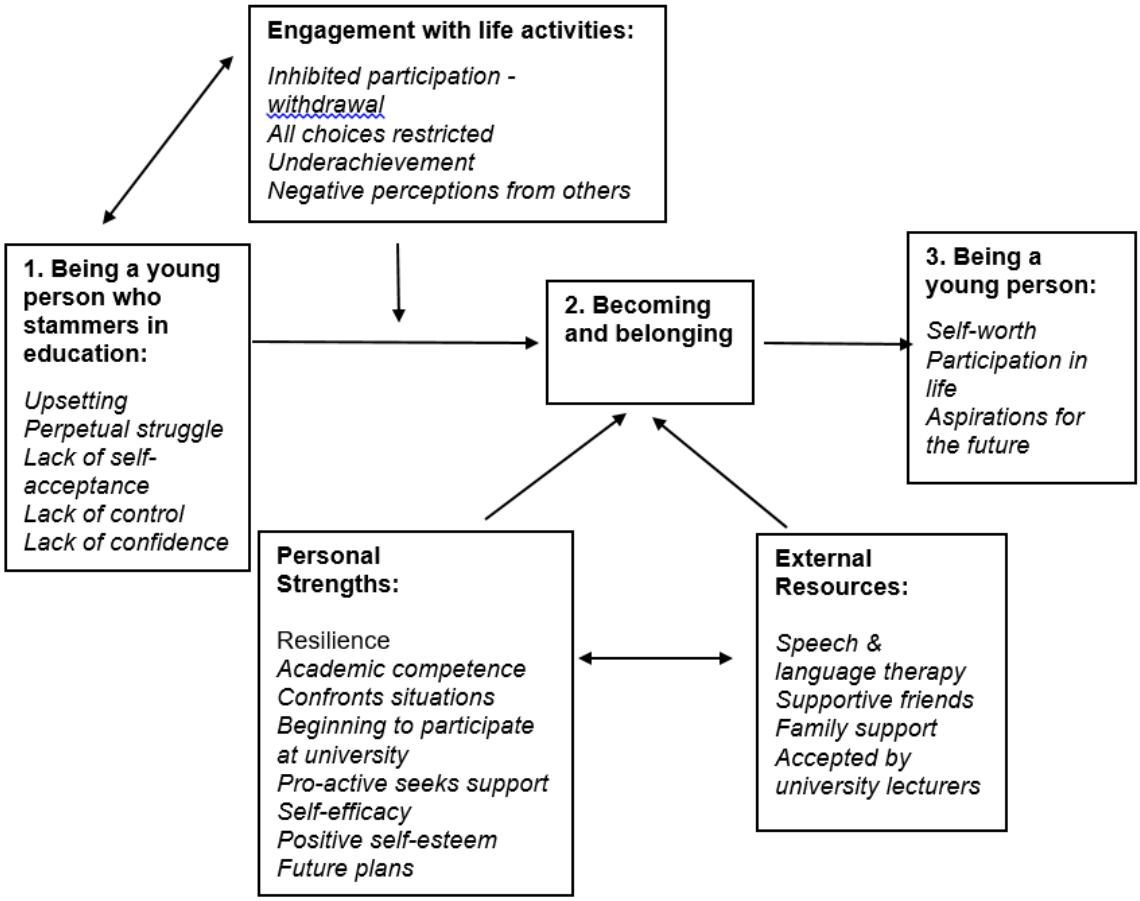



*Figure 8.4* Mia's journey: her process of learning to cope with living as a YPWS.

Although Owen, Callum and Mia differed in age and their current educational experience their journeys all show the importance of personal strengths and external resources for helping them to move on to stage 3 where they are managing as a young person (who stammers) in education. Indeed all participants in study two appeared to have developed positive outcomes in coping with living as a YPWS which may reflect the self-selection bias of the investigation (i.e., perhaps only young people with positive outlooks took part). However, the three examples indicate that participants reached stage 3 of their journey (i.e. positive outcomes) at different points during their education and the model illustrates the individual nature of how YPWS learn to manage their stammer in their lives.

## 8.5 Implications for practice

Explaining the journey of YPWS in learning to cope with their stammer in education, can also be used to inform the provision of SLT services. Thus, listening to the voices of the participants involved with this thesis has led to the following suggestions for SLTs and for others who support YPWS during the education years.

**8.5.1 Holistic appraisal of the strengths and needs of YPWS.** The model proposed in this thesis could be useful to SLTs in working with YPWS. It provides a systematic way of collating case information about YPWS, guiding the appraisal process and supporting the development of a holistic profile of the young person. Individual profiles can be achieved by undertaking a comprehensive appraisal procedure with the young people which examines the individuals' thoughts about stammering, their development of self-esteem, self-stigma and self-agency, as well as their overt features of stammering. Information needs to be gathered from YPWS about their daily activity and participation in education as well as personal individual strengths. It is also essential to identify the young person's stage of readiness for change in order for the SLT to facilitate their journey in managing their stammer. By using the model to complete individual profiles it should be possible to identify YPWS who have negative thoughts, feelings and experiences in education and to highlight personal areas for development in order to support their journey in coping with being YPWS in education.

As part of the holistic assessment Boyle's (2015) recently developed Self-Stigma of Stuttering Scale (4S) tool could be helpful to SLTs for examining the self-stigma of PWS. In addition, the external support available to the YPWS such as peers, family and mentoring schemes is a vital aspect of the assessment process in terms of gathering young people's views of their possible support network, as highlighted in the model. This holistic appraisal will then contribute to the planning and development of the individualised management strategy for the YPWS. Adopting the proposed model is in keeping with other researchers who recommend SLTs to take a holistic approach to working with YPWS which includes listening to their perspectives in order to understand the impact their communication need has on their lives (Boylan & Dalrymple, 2009) and to promote the preferred outcomes for young people (Lindsay et al., 2010).

**8.5.2 Bespoke management plans for YPWS.** Therapy approaches should be tailored to meet the individual needs of YPWS and incorporate what is important to them in terms of managing their stammer which to ensure treatment is worthwhile for the individual.

As mentioned earlier there are different UK therapy options for YPWS including fluency enhancing and psychological strategies (RCSLT, 2015). This present investigation asserts the need to support YPWS to gain an understanding of their stammer in order to prevent the development of potentially unhelpful thoughts and escalating mental health issues. This preventative recommendation is in line with the recent Government initiative 'Future in mind' (Department of Health, 2015) which recognises the limited resourcing for young people's mental health and wellbeing in the UK and seeks to improve support. This is a five year plan by the Department of Health and NHS England which details their vision for improving and maintaining children and young people's mental health. It includes targeting the prevention of mental health conditions and promoting resilience of individuals and support systems. PWS are not specifically mentioned in the plan but in light of the findings from this thesis there is a need for SLT intervention to focus on strategies which will promote the psychosocial adjustment of YPWS and thereby address their feelings and thoughts associated with living with stammering. This may involve therapy aiming to reduce the negative views of self, for example using acceptance and commitment therapy (Beilby, Byrnes & Yaruss, 2012), and improve the daily participation of young people who stammer, for example through cognitive behaviour therapy (Menzies et al., 2008). However, many SLTs working with YPWS may not feel comfortable or qualified in supporting YPWS in this way which suggests a clinical need for closer working between clinical psychologists and SLTs.

SLTs need to assist YPWS to identify and enhance their own ways of building coping skills and encourage self-efficacy as part of the therapy process. This could be addressed through group therapy approaches which would also offer beneficial peer support to the YPWS, viewed as a positive experience by participants in the second study. SLTs should encourage the social activity of YPWS within and beyond the group therapy in order to ameliorate possible feelings of social anxiety and increase social support networks. Whilst recognising the boundaries of the SLT's role, creating friendships through engagement with social, extra-curricular and leisure activities should be promoted to reduce potential feelings of loneliness and contribute to the YPWS' building of self. They should also be encouraged to become involved in stammering self-help groups where they can share experiences, forge friendships and benefit from mutual support, helping one another. Older group members may also be able to act as role models, providing additional support for younger members of the group.

The findings of this investigation also emphasise the importance of positive family relationships and the emotional support the family, particularly parents, can offer YPWS in

coping with stammering. Intervention should develop parents' understanding of stammering to support them in discussions with their child and ensure they provide helpful advice to the YPWS. Parents should also be engaged in the therapy process as early as possible so that an open forum is created for talking about stammering within the family. Their involvement should continue as the child progresses into adolescence in order to maintain an effective channel of communication between the parents and the YPWS. Parental participation in the therapy process will help them recognise the valuable role they can play in supporting their YPWS.

**8.5.3 Addressing SLT service provision for YPWS.** There is a need for ongoing SLT intervention to be available to YPWS and for SLTs to be aware of the range of ways in which stammering can impact on young people. Improved access to SLT services is necessary, as accessibility was an issue for some participants. Presently the availability and quality of SLT service seems dependent upon where the young person and family live in the UK. Specialist SLT centres providing quality provision for children and adults who stammer are established in a few regions of the country but these settings can only be accessed by a minority of the population. In other parts of the country there are reports of no services or limited provision being delivered by generalist and specialist SLTs. The Chairman of the BSA, N. Lieckfeldt (personal communication, March 21, 2016) stated "the increasing lack of NHS speech therapy, especially for adults, is becoming endemic".

This situation has perhaps been caused by the relatively low incidence of stammering with other client groups having a higher profile need, insufficient measures monitoring therapy outcomes and standards for PWS and the limited resourcing of services at both a national and regional level. It may also be due to recognition of the long term impact of other speech and language difficulties, resulting in prioritisation of those diagnoses. The long-term impact may have been less apparent for YPWS, but is clearly identified within the current investigation. Previous studies have reported on the general lack of SLT support for young people with speech and language difficulties in secondary school, with younger students being prioritised (Hollands, van Kraayenoord & McMahon, 2005; Lindsay et al., 2002).

The resourcing of current services to YPWS needs to be reviewed because of the possible emotional consequences and risk of mental health problems associated with stammering (Iverach et al., 2011). The provision of joint training for SLTs and clinical psychologists regarding the mental health of young people and stammering could be beneficial in promoting their understanding of these difficulties as well as fostering inter-professional working. The apparent disparity in SLT services for this population also needs to be

addressed by the SLT profession at a regional and national level. Regional specialists in disorders of fluency could be appointed as coordinators to liaise with service providers and commissioners to examine the current state of SLT services across all regions of the UK. Discussion regarding the availability of resources needs to take place with those commissioning SLT services which should include the evidence from the current and past studies concerning the well-being of YPWS and concomitant risk factors.

Regional group therapy programmes led by specialist SLTs may be a useful model of provision to consider due to the potential benefit this could provide YPWS and their families. This method of service delivery could also be a training opportunity for generalist SLTs which would increase their experience and competence in working with this client group. A further strategy would be to offer therapy for YPWS via telehealth. During the last ten years there has been rapid growth in digital health care in the NHS, with information technology providing professionals with alternative ways of managing caseloads and client need. There has also been an increase in internet use, with 80 per cent of the population currently accessing the internet at home and 30 per cent doing so via a smart phone, with young people showing a particular preference for this alternative form of communication (Office of Communications, 2012). Telehealth delivery for YPWS could prove more cost effective for commissioners by centralising services, reducing the need for clinical accommodation and decreasing SLTs' travel costs. It could enable YPWS to receive intervention from a specialist SLT in dysfluency and provide the opportunity for contact with other YPWS through group forums on Skype. However, it would be useful for further research to investigate the effectiveness of different models of service delivery that might be more accessible for this population.

In reviewing current SLT provision it is essential for SLTs to listen to the views of YPWS in order to identify and address the potential needs of this population. The meaningful involvement of YPWS in decisions regarding services that may affect them is important for the future development of educational policies, procedures and support mechanisms and for potentially shaping the speech and language therapy service and the views of SLTs. This is in line with Sackett, Rosenberg, Gray, Haynes and Richardson (1996) who suggested the evidence base for practice should be contributed to by both clinicians' and service users' perspectives regarding their experiences.

**8.5.4 Training needs of teachers.** In view of the current findings from this investigation and other recent literature, there is a need for teachers to engage with professional development opportunities to enhance their knowledge of stammering and their

perceptions of YPWS. It is important for them to understand the experiences of young people coping with stammering in education and for them to appreciate the possible constraints stammering can have on a young person's engagement with learning. In addition, it would be beneficial for teachers to gain knowledge and specific skills in how to support YPWS with oral language activities within the academic curriculum. This need could be addressed by enhancing the education of teachers which in turn should improve teachers' reactions and the support they offer their students within the classroom. Jenkins (2010) reported how teachers' viewed their training in stammering as minimal during their initial teacher training and since becoming a teacher. This might be expected because the prevalence of stammering is lower in comparison to prevalence rates for other speech, language and communication difficulties. However, teachers generally report limited training in working with children and young people with a range of communication need, not just stammering (Dockrell & Lindsay, 2001; Marshall, Ralph & Palmer, 2002; McLeod & McKinnon, 2007; Sadler, 2005).

Whilst Jenkins (2010) found that teachers had limited training opportunities and knowledge of resources, she also found they expressed a strong interest in receiving stammering information. This study highlighted teachers' preference for direct contact with a specialist speech and language therapist in dysfluency to develop their learning, rather than being sent information to read. Similarly, Abdalla and St. Louis (2014) found current methods, (providing written information and videos about stammering to teachers), seem to have little impact on teachers' learning about students who stammer. Since 2010 there has been no further reporting of UK teacher training developments in stammering. Resources are available, but often focus on the younger child who stammers and they rely on teachers' interest and time to access them.

Simulated practice activities (such as those offered to SLT students) could be extended to trainee teachers as well as to qualified teachers. This could involve supporting teachers to learn about children and YPWS as well as pupils with other speech, language and communication needs. Abdalla, Li and Arnold (2015), suggested teachers may learn more effectively about stammering through live contact with a PWS, although to date there is no evidence to support this as a method of learning for teachers. Similarly, a participant from the current investigation suggested service users could be involved in talking to teachers about stammering. Future developments in simulation could include joint inter-professional learning experiences to enhance the knowledge and skills of both trainee teachers and SLTs in regard to working with people who stammer. This type of learning opportunity would also

support placement provision for students at a time when securing adequate placements in practice settings is an issue (Hill, Davidson & Theodoros, 2010).

Opportunities for joint and reciprocal teaching of students on education and SLT programmes regarding stammering and other speech and language needs should be encouraged by Higher Education Institutions. This teaching should facilitate students sharing information regarding their roles and practice in supporting young people with speech and language needs which will help to promote collaborative working and in turn support the needs of YPWS in education.

**8.5.5 Pedagogy in the classroom.** The struggle experienced by YPWS to participate in class activities suggests the need to review practices in education and to promote pedagogic approaches which can support YPWS as well as other students who experience anxiety associated with oral participation in the classroom. For example, teachers could enable students to develop their ability to give oral presentations through a graded approach that modifies how the task is carried out to make it more manageable and successful for the student. Support strategies and skills to develop to help foster students' abilities to communicate in class are suggested in Table 8.1. These suggestions are based on the positive influencing factors that arose from the participants' narratives described in step two of the model "becoming and belonging".

This pedagogical recommendation is also supported by Russell and Topham (2012) who suggested teachers should advocate classroom practices "to reduce potential performance anxiety and embarrassment for *all* students" (p. 383).

Table 8.1 *Strategies and skills to aid oral communication*

| Strategies | Skills |
|---|---|
| Use of visual resources and technology aids e.g. prompt cards, PowerPoint, iPads<br>Preparation & contingency planning<br>Rehearsal<br>Goal setting to promote self-agency<br>Hierarchical exposure to activities (e.g. present to one person, to a small group)<br>Secure support mechanisms<br>Small group work/group presentations<br>Seek and build support mechanisms | Communication skills (eye contact, listening)<br>Self-monitoring (pausing, monitoring/timing speech)<br>Problem-solving<br>Balanced reflection<br>Confidence building (positive thinking)<br>Negotiating skills<br>Presentation skills |

**8.5.6 Mentoring programmes.** One participant in the current investigation experienced mentoring from an assistant at college which she reported as beneficial. Mentoring systems, in particular peer mentoring, are a growing provision within schools and are positively evaluated by young people who have been involved as mentees and a mentors (Philip & Spratt, 2007). Previous studies with the general school population have found peer mentoring for young people to promote confidence and self-esteem (Gulati & King, 2009) so it is likely that such schemes would be a useful support mechanism for YPWS. Peer mentoring could be offered face to face, via Skype or via email and would offer the opportunity for YPWS to talk about their speech and any possible experiences they find challenging within the educational context and/or at home. Mentoring of YPWS might also enable them to have the opportunity to learn about potential coping strategies which they can then implement to manage any challenging situations they arise.

**8.5.7 Academic and career guidance.** Findings from the thesis highlight the need for parents, SLTs, teachers and career advisors to be mindful of the support and advice YPWS typically need when making decisions about their academic and career choices. Previous research has shown how support from others is important for developing a young person's self-efficacy, as the beliefs and perceptions about the self can influence the future development and progress of individuals (Bandura, 1997). YPWS should be made aware that their speech difficulty need not be a barrier to their academic success, in terms of qualifications achieved, and to their future aspirations. Those involved with YPWS during their schooling should be proactive in supporting them to aim for their preferred options for GCSE qualifications as well as their choices for post 16 study.

YPWS need to be offered professional guidance about career choices as well as having informal discussions about their future options with family and friends, but the lack of support at school with these decisions is not restricted to just YPWS. In 2015 the UK Department for Education updated its statutory careers guidance for all schools which requires schools to ensure all students from the age of 12 years receive independent careers information regarding education and training choices that is aligned with each individual's potential (Department for Education, 2015). Therefore, it should now be the case that all students in the UK including YPWS benefit from comprehensive career guidance to support their decision making process at this critical time.

## 8.6 Implications for further research

A number of avenues for future research regarding YPWS have evolved from the thesis. There is a need to investigate the SLT provision for young people and adults who stammer in the UK. SLT services for YPWS at secondary school seem sparse and anecdotal accounts suggest NHS therapy provision for PWS, particularly adults, is being reduced or withdrawn in many areas. A BSA led initiative with the NHS Service Watch campaign is gathering some information about services for stammering, but a nationwide survey would also be useful to fully evaluate the SLT provision for stammering. The outcomes from this review could then inform research into service development involving service users and their families, SLTs and teachers resulting in recommendations for future need and delivery.

A commitment to developing SLTs knowledge, skills and confidence in working with PWS is proposed in the UK. To achieve this goal a review of student SLTs' education in stammering is required which will potentially lead to clearer curriculum guidelines being developed and adopted by Higher Education Institutes. Similarly, the content of initial teacher training programmes and CPD courses for teachers should be appraised with the view to incorporating suggestions to increase teachers' abilities to understand and support YPWS in the classroom. Future developments in simulation activities involving student SLTs, teachers and clinical psychologists in working with YPWS could also lead to further areas of research (e.g. an evaluation of cross-disciplinary education).

In view of the restricted SLT services for YPWS it is important to explore individuals' readiness for speech and language therapy. This research needs to investigate whether there are specific times or stages of readiness for change for YPWS. Results from this research will subsequently inform SLTs and help services with planning intervention for YPWS which should in turn enhance therapy provision.

A theme emerging from the participants' narratives was the active role they took in adapting and learning to cope in managing their stammer. Future research could examine this process of gradual acceptance and adaptation experienced by YPWS. For example, exploration of their experiences of disclosure and the decision making process and outcomes associated with disclosure of stammering. This research would provide YPWS with insight, from the perspective of a person who stammers, as to what it is like to disclose stammering, the changes occurring as a result and the difficulties and benefits. This would help YPWS with evaluating and deciding if this approach to managing stammering was an option for them. The process involved in young people choosing to disclose stammering and

the timing to do so would also be of interest to SLTs in their discussions of therapy intervention with YPWS.

Participants' perceptions of family support from parents and siblings were apparent from the accounts of a number of the YPWS in the thesis. Some reported the protective function parents are perceived to offer the young person against negative educational experiences but for a few their parents' management of their stammer had been an issue. Previous research has focused on the role of parents in supporting pre-school children who stammer in SLT but there is a dearth of research concerning the involvement of parents in SLT with older children, and in particular with adolescents and young adults. Future research could examine and describe parents' participation in the SLT process and identify the SLT support they may need as well as the support that can be given to help the YPWS.

Further research is needed to explore the current educational experiences of YPWS attending college and university. A few participants in the current investigation expressed positive views associated with being a student at college so further investigations (e.g. surveying staff involved in supporting young people with communication needs in Colleges and Universities) could be fruitful in identifying possible factors that enhance the learning environment and experience for YPWS in continuing education so that this good practice can be translated to secondary schools.

## 8.7 Strengths and limitations of the thesis

This is the first investigation of its kind to examine the current experiences of YPWS in the UK education system and to adopt a mixed methods approach with this population. This design has allowed a full exploration of the educational experiences and outcomes of YPWS which is a unique strength of the thesis compared to other research in this field. The review of literature revealed a paucity of research in relation to the current qualifications studied and attained by YPWS. To address this gap the first study provided initial survey findings giving some quantitative data in relation to the academic performance and progression of YPWS and it also informed the qualitative design of the second study.

The second study took an IPA approach to focus on developing an in-depth understanding of the lived experiences of YPWS in education. This method was particularly suitable for this study as the idiographic nature of IPA allows a case by case analysis enabling the voices of YPWS to be heard, described and interpreted. Consequently, using both quantitative and qualitative methods led to a more comprehensive understanding of how stammering impacts educational performance and how stammering is lived by young people in education which

can be used to inform future support for this population. Furthermore, results from previous qualitative studies reporting the impact of stammering on individuals' school experiences were based on older adults recalling their life at school. The present investigation has made an original contribution as it reports findings from young people aged 15-25 years old.

Providing the young people in this investigation with the opportunity for their views to be listened to may have enhanced their sense of self-worth and increased their confidence. In addition, having the young person's voice at the centre of this investigation means that any future SLT or education plans devised as a result would be informed by their perspectives of stammering on their lives. Three super-ordinate themes emerged from the narratives of the young people reflecting the group's shared experiences and these were explained and confirmed using extracts from the individual participants. Although the key themes reflect the core group experiences this study also recognises individual differences. Divergent views are described and interpreted to capture the meaning of their individual stories and are similarly viewed as important.

A major issue in first study was the difficulty in recruiting participants. The majority of young people were recruited through the BSA and all participants were self-selecting which may have introduced a sampling bias. The limited numbers recruited meant that it was not possible to use a sampling frame to allocate participants to the study as all volunteers were needed. This resulted in the sample comprising of participants from a limited range of socio-economic backgrounds and diverse cultures. Although the sample was made up of individuals of different ages they were chiefly White English and due to the small sample size the findings from study one cannot be generalised beyond this group to the wider population of YPWS. However, a strength of the second study was the successful recruitment procedure which engaged 16 young people to take part in one to one interviews. This sample was appropriate size for an IPA study which aimed to produce an in-depth analysis of the educational experiences and outcomes of YPWS. Also the same participants were involved with both of the studies which enabled findings identified in study one to be further explained in study two as required.

A further limitation was the varying ages of participants recruited to the two studies. This meant that the young people were at different points reporting different time periods in the education system. The potential implication is that survey data collected for a particular year in education may have been influenced by other factors operating at that time. However, the differing ages of participants was beneficial in terms of tracking their journey in learning to cope with their stammer and leading to a model to explain their journey.

The IPA approach entailed an explicit interpretation of participants' experiences by the researcher. This process of analysis naturally involved the researcher's own view of the world which made bracketing knowledge about stammering impossible. Furthermore, although measures were taken to address the power imbalance between the researcher and the participants, my role as a SLT and researcher was obvious to participants and could have influenced their responses.

A final limitation is that although the researcher summarised the participant's narrative at the end of each interview, the researcher's analysis and interpretation of participants' experiences was not discussed with the participants in enable them to check and provide feedback about the themes emerging from their interviews. This is not however a necessary requirement of the IPA approach because the findings are the researcher's subjective interpretation of their experiences which evolves through the researcher's engagement in a double hermeneutic cycle (Smith et al, 2009). There was an extended period of time between carrying out the 16 interviews and transcribing and analysing the interview data and the YPWS would not have necessarily remember exactly what they conveyed to the researcher and the participant may not feel in a position to participate in this process. Also, member checking would have been an additional demand placed on the YPWS which would be time-consuming and could possibly have been upsetting to them.

## 8.8 Conclusion

This mixed methods thesis has shown the value of research exploring the educational experiences and outcomes of young people who stammer. By focussing on and listening to the voices of young people about their lived experiences of being a YPWS in education the two studies captured their daily struggle and the impact their stammer had on their activity and participation. Their narratives also illuminated their journey in learning to cope with being a YPWS in education. Of particular interest is the value of their individual strengths and the importance of external support as factors that enable a process of self-development which helps the young person to cope and live with stammering more successfully. The model, developed from the data collected from YPWS, encapsulates these findings and shows the shift in the individual's sense of identity from being a stammering young person to being a young person who stammers but who is a young person first and foremost.

The findings of the thesis demonstrate the need for SLTs and teachers working with YPWS in education to promote the psychosocial adjustment of YPWS. In achieving this, professionals need to support the young people in developing their knowledge of

stammering, awareness of their own strengths and supportive networks and their capacity to cope with stammering by building and maintaining an identity which is less defined by stammering. For SLTs and teachers to successfully support YPWS in education their personal and professional development needs must be identified and met to ensure they are both confident and competent in their role. Teaching practice should be reviewed and adapted to create opportunities for YPWS and their peers to enhance their oral participation in the classroom in a way which reduces performance anxiety and embarrassment. In addition, the development of mentoring programmes for YPWS to become mentors and mentees at school would promote self-confidence and self-esteem.

Speech and language therapy services for YPWS require a nationwide review in order for matters concerning funding, coordination and integration of provision to be identified and addressed. Adapting and coordinating existing limited resources is recommended to optimise current therapy services and to create a cohesive support network which is beneficial in meeting the needs of YPWS.

It is proposed that these findings will be of particular importance to YPWS and encourage them to see themselves as capable of achievement that is comparable to others; also that their academic choices and career aspirations do not need to be constrained by their stammer but instead should be influenced by their interests. Furthermore, the development of the model detailing the journey of participants in this thesis will hopefully provide other YPWS with an awareness of how they might positively manage their stammer in their lives and be useful to the professionals supporting YPWS in education.

# REFERENCES


Abbott, K. P. (2012). *The influence of the family on adolescent academic achievement.* Unpublished graduate thesis, Iowa State University, Iowa, USA.

Abdalla, F., & St. Louis, K. O. (2014). Modifying attitudes of Arab school teachers toward stuttering. *Language Speech and Hearing Services in Schools*, *45*(1), 14–25.

Action for stammering children. (2016). *Teenagers information.* Retrieved September 2, 2016 from http://www.stammeringcentre.org/teenagers-who-stammer.

Adriaensens, S., & Struyf, E. (2016). Secondary School Teachers' Beliefs, Attitudes, and Reactions to Stuttering. *Language, Speech, and Hearing Services in Schools*, *47*(2), 135-147.

Ahmar, F., & Anwar, E. (2013). Socio economic status and its relation to academic achievement of higher secondary school students. *Journal of Humanities and Social Science, 13*(6), 13-20.

Alexander, K. L., Entwisle, D. R., & Olson, L. S. (2007). Lasting consequences of the summer learning gap. *American Sociological Review*,*72*(2), 167-180.

Andreias, L., Borawski, E., Schluchter, M., Taylor, G., Klein, N., & Hack, M. (2010). Neighborhood influences on the academic achievement of extremely low birth weight children. *Journal of Pediatric Psychology, 35*(3), 275-283.

Andrews, G., & Harris, M. (1964). *The syndrome of stuttering.* London: Heinemann Medical Books.

Arnold, H. S., & Li, J. (2016). Associations between beliefs about and reactions toward people who stutter. *Journal of Fluency Disorders*, *47*, 27-37. No issue

Arnold, H., Li, J., & Goltl, K. (2015). Beliefs of teachers versus non-teachers about people who stutter. *Journal of Fluency Disorders*, 43, 28–39.

Atwater, E. (1992). *Adolescence.* 3rd edition. New Jersey: Prentice Hall.

Baker, J.A., Grant, S., & Morlock, L. (2008). The teacher-student relationship as a developmental context for children with internalizing or externalizing behavior problems. *School Psychology Quarterly*, *23*(1), 3–15.

Baldwin, S. A., & Hoffmann, J. P. (2002). The dynamics of self-esteem: A growth-curve analysis. *Journal of Youth and Adolescence, 31*(2), 101-113.

Ballantine, J. H. (1999). Getting involved in our children's education. *Childhood Education*, *75*, 170-171.

Bandura, A. (1977). Self-efficacy: toward a unifying theory of behavioral change. *Psychological review*, *84*(2), 191.

Bandura, A. (1986). *Social foundations of thought and action: A social cognitive theory*. New Jersey: Prentice-Hall.

Bandura, A. (1989). Regulation of cognitive processes through perceived self-efficacy. *Developmental psychology*, *25*(5), 729.

Bandura, A. (2002). Social cognitive theory in cultural context. *Applied Psychology, 51*(2), 269-290.

Barreau, S., Carneiro, P., Chowdry, H., Crawford, C., Dearden, L., Goodman, A., Gregg, P.,Macmillan, L., Sibieta, L., Sylva, K., & L. Washbrook, L. (2008). The socio-economic gradient in child outcomes: the role of attitudes, behaviours and beliefs. Interim Report for the Joseph Rowntree Foundation: York, UK.

Baumeister, R. F., & Bushman, B. J. (2008). *Social psychology and human nature.* (1st ed.). Belmont, CA: Thomson Wadsworth.

Baumeister, Campbell, Krueger & Vohs (2003). Does High Self-Esteem Cause Better Performance, Interpersonal Success, Happiness, or Healthier Lifestyles? *Psychological Science in the Public Interest*, *4*(1), 1-44.

Baxter, S., Johnson, M., Blank, L., Cantrell, A., Brumfitt, S., Enderby, P., & Goyder, E. (2015). The state of the art in non-pharmacological interventions for developmental stuttering. Part 1: a systematic review of effectiveness. *International Journal of Language & Communication Disorders, 50(5),* 676-718.

Bearman, P. S., & Moody, J. (2004). Suicide and friendships among American adolescents. *American journal of public health, 94*(1), 89-95.

Beilby, J. M., Byrnes, M. L., & Yaruss, J. S. (2012). Acceptance and Commitment Therapy for adults who stutter: Psychosocial adjustment and speech fluency. *Journal of Fluency Disorders*, *37*(4), 289-299.

Bell, J., (2005). *Doing your Research Project.* (4th ed.). Berkshire, England: Open University Press.

Bennett, E. M. (2006). *Working with people who stutter: A lifespan approach.* Columbus, OH: Merrill Prentice Hall.

Blood, G. W., & Blood, I. M. (2004). Bullying in adolescents who stutter: Communicative competence and self-esteem. *Contemporary Issues in Communication Science and Disorders*, *31*, 69–79.

Blood, G. W., & Blood, I. M. (2007). Preliminary study of self-reported experience of physical aggression and bullying of boys who stutter: Relation to increased anxiety. *Perceptual and motor skills*, *104*(3), 1060-1066.

Blood, G. W., Blood, I. M., Dorward, S., Boyle, M. P., & Tramontana, G. M. (2011). Coping strategies and adolescents: Learning to take care of self and stuttering during treatment. *SIG 4 Perspectives on Fluency and Fluency Disorders, 21(3),* 68-77.

Blood, G. W., Blood, I. M., Maloney, K., Meyer, C., & Qualls, C. D. (2007). Anxiety levels in adolescents who stutter. *Journal of Communication Disorders, 40*(6)*,* 452-469.

Blood, G. W., Blood, I. M., Tellis, G.M., & Gabel, R. M. (2001). Communication apprehension and self-perceived communication competence in adolescents who stammer. *Journal of Fluency Disorders*, *26*(3), 161-178.

Blood, G. W., Blood, I. M., Tellis, G. M., & Gabel, R. M. (2003). A preliminary study of self-esteem, stigma, and disclosure in adolescents who stutter. *Journal of Fluency Disorders*, *28*(2), 143-159.

Blood, G. W., Blood, I. M., Tramontana, G. M., Sylvia, A. J., Boyle, M. P., & Motzko, G. R. (2011). Self-reported experience of bullying of students who stutter: Relations with life satisfaction, life orientation, and self-esteem. *Perceptual and motor skills*, *113*(2), 353-364.

Bloodstein, O. (1993). *Stuttering: The search for a cause and cure.* Boston: Allyn & Bacon.

Bloodstein, O. (1995). *A Handbook on Stuttering*. (5th ed.). San Diego, CA: Singular Press.

Bloodstein, O., & Ratner, N. B. (2008). *A handbook on stuttering*. New York: Thomson Delmar Learning.

Bloom, M. V. (1980). *Adolescent-Parental Separation.* New York: Gardner Press.

Bowling, A. (2009). *Research methods in health.* (3rd ed.). England: Open University Press.

Boylan, J., & Dalrymple, J. (2009). *Understanding advocacy for children and young people*. Columbus, OH: McGraw-Hill Education.

Boyle, M. P. (2013). Psychological characteristics and perceptions of stuttering of adults who stutter with and without support group experience. *Journal of Fluency Disorders, 38*(4)*,* 368-381.

Boyle, M. P. (2015). Relationships between psychosocial factors and quality of life for adults who stutter. *American Journal of Speech-Language Pathology*, *24*(1), 1-12.

Boyle, M. P., Daniels, D. E., Hughes, C. D., & Buhr, A. P. (2016). Considering disability culture for culturally competent interactions with individuals who stutter. *Contemporary Issues in Communication Science and Disorders, 43,* 11.

Branje, S. J., 1. van Lieshout,C.F., van Aken, M.A., & Haselager, G.J. (2004). Perceived support in sibling relationships and adolescent adjustment. *Journal of Child Psychology and Psychiatry, 45*(8),1385–1396.

British Stammering Association (2014). *School/Education.* Retrieved September 18, 2015 from https://www.stammering.org/help-information/topics/school-education

Bronfenbrenner, U. (1989, April). The developing ecology of human development: Paradigm lost or paradigm regained. In biennial meeting of the Society for Research in Child Development, Kansas City, MO.

Buhrmester, D. (1990). Intimacy of friendship, interpersonal competence, and adjustment during preadolescence and adolescence. Child development, 61(4), 1101-1111.

Buhrmester, D., & Carbery, J. (1992, March). Daily patterns of self-disclosure and adolescent adjustment. In *biennial meeting of the Society for Research on Adolescence, Washington, DC.*

Buhs, E. S., Ladd, G. W., & Herald, S. L. (2006). Peer exclusion and victimization: Processes that mediate the relation between peer group rejection and children's classroom engagement and achievement. *Journal of Educational Psychology*, *98*(1)*, 1*-13.

Buist, K. L., Dekovic, M., Meeus, W., van Aken, M. A. G. (2002). Developmental patterns in adolescent attachment to mother, father, and sibling. *Journal of Youth and Adolescence, 31*(3),167–176.

Butler, C. (2013). *'*University?… hell no!': Stammering through education. *International Journal of Educational Research, 59, 57-65.*

Caro, D. H., McDonald, J. T., & Willms, J. D. (2009). Socio-economic status and academic achievement trajectories from childhood to adolescence. *Canadian Journal of Education*, *32*(3), 558-590.

Cherryholmes, C. H. (1992). Notes on pragmatism and scientific realism. *Educational researcher*, *21*(6), 13-17.

Cicirelli, V. G. (1994). The longest bond: The sibling life cycle. In L. L'Abate, (Ed.), *Handbook of developmental family psychology and psychopathology.* (pp. 44-59). Oxford, UK: John Wiley & Sons.

Clegg, J., Hollis, C., Mawhood, L., & Rutter, M. (2005). Developmental language disorders–a follow-up in later adult life. Cognitive, language and psychosocial outcomes. *Journal of Child Psychology and Psychiatry*, *46*(2), 128-149.

Collins, W., & Laursen, B. (2004). Changing relationships, changing youth: Interpersonal contexts of adolescent development. *Journal of Early Adolescence, 24*(1)*,* 55-62.

Collins, W. A., & Steinberg, L. (2006). Adolescent development in interpersonal context. *Handbook of child psychology.* New York, Wiley.

Corcoran, J. A., & Stewart, M. (1998). Stories of stuttering: A qualitative analysis of interview narratives. *Journal of Fluency Disorders*, *23*(4), 247–264.

Corrigan, P. W., & Rao, D. (2012). On the self-stigma of mental illness: Stages, disclosure, and strategies for change. *The Canadian Journal of Psychiatry*, *57*(8), 464-469.

Craig, A., Blumgart, E., & Tran, Y. (2011). Resilience and stuttering: Factors that protect people from the adversity of chronic stuttering. *Journal of speech, language, and hearing research*, *54*(6), 1485-1496.

Craig, A., Hancock, K., Tran, Y., Craig, M., & Peters, K. (2002). Epidemiology of stuttering in the community across the entire life span. *Journal of Speech, Language, and Hearing Research, 45*(6)*,* 1097-1105.

Craig, A., & Tran, Y. (2005). The epidemiology of stuttering: The need for reliable estimates of prevalence and anxiety levels over the lifespan. *Advances in Speech Language Pathology, 7*(1), 41-46.

Crawford, C., & Greaves, E. (2013). A comparison of commonly used socio-economic indicators: their relationship to educational disadvantage and relevance to Teach First. *Institute for Fiscal Studies: London, UK*.

Creswell, J. W. (2003). Research design: Qualitative, Quantitative, and Mixed Methods Approaches. London, Sage Publications.

Creswell, J. W. (2009). Research design: Qualitative, Quantitative, and Mixed Methods Approaches. (3rd ed.). London, Sage Publications.

Creswell, J., Fetters, M., & Ivankova, N. (2004). Designing a mixed methods study in primary care. *Annals of Family Medicine, 2*(1), 7-12.

Crichton-Smith, I. (2002). Communicating in the real world: Accounts from people who stammer. *Journal of Fluency Disorders*, *27*(4), 333–353.

Crichton-Smith, I., Wright., J & Stackhouse, J. (2003) Attitudes of speech and language therapists towards stammering: 1985 and 2000, *International Journal for Language and Communication Disorders*, *38*(3), 213-234.

Crowe, T., & Walton, J. (1981). Teacher Attitudes Toward Stammering. *Journal of Fluency Disorders, 6*(2), 163-174.

Cummins, R. A. (2010). Fluency disorders and life quality: Subjective wellbeing vs. health-related quality of life. *Journal of Fluency Disorders, 35*(3), 161-172.

Daniels, D., Gabel, R. M., & Hughes, S. (2012). Recounting the K-12 school experiences of adults who stutter: A qualitative analysis. *Journal of Fluency Disorders*, *37(2)*, 71–82.

Davidson Thompson, T. C., McAllister, J., Adams, M., & Horton, S. (2009). Evaluation and discharge criteria in therapy with adults who stutter: A survey of speech and language therapists. *International Journal of Speech-Language Pathology*, *11*(1), 45-53.

Davis, S., Howell, P., & Cooke, F. (2002). Sociodynamic relationships between children who stutter and their non-stuttering classmates. *Journal of Child Psychology and Psychiatry, 43*(7), 939-947.

Demi, F., & Lewis, K. (2010) White working class achievement: An ethnographic study of barriers to learning in schools. *Educational Studies, 37*(3), 245-264

Department for Education (2013). *GCSE reform from 2015.* Retrieved June 3, 2016 from http://webarchive.nationalarchives.gov.uk/20130401151655/http://education.gov.uk/schools/teachingandlearning/qualifications/gcses/a00221366/gcse-reform.

Department for Education (2014a). *Participation of young people in education, employment or training*. Retrieved June 3, 2016 from https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/349300/Participation_of_Young_People_Statutory_Guidance.pdf

Department for Education (2014b). *National curriculum in England: framework for key stages 1 to 4.* Retrieved June, 3, 2016 from https://www.gov.uk/government/publications/national-curriculum-in-england-framework-for-key-stages-1-to-4.

Department for Education (2014c). Statistics at DfE. Retrieved December 12, 2014 from https://www.gov.uk/government/organisations/department-for-education/about/statistics

Department for Education (2015). *Careers guidance and inspiration in schools*. Retrieved September 10, 2016 from https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/440795/Careers_Guidance_Schools_Guidance.pdf.

Department for Education and Skills (2006). *Further education: Raising skills, improving life chances.* Retrieved September 10, 2016 from https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/272259/6768.pdf.

Department of Health (2003). *Confidentiality NHS Code of Practice.* Retrieved January 10, 2011 from https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/200146/Confidentiality_-_NHS_Code_of_Practice.pdf

Department of Health (2015). *Future in mind: Promoting, protecting and improving our children and young people's mental health and wellbeing.* Retrieved September 10, 2016 from https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/414024/Childrens_Mental_Health.pdf

Devenny, D. A., & Silverman, W. P. (1990). Speech dysfluency and manual specialization in Down's syndrome. *Journal of Intellectual Disability Research*, *34*(3), 253-260.

Dockrell, J. E., & Lindsay, G. (2001). Children with specific speech and language difficulties-the teachers' perspective. *Oxford Review of Education*, *27*(3), 369-394.

Dorsey, M., & Guenther, R. K. (2000). Attitudes of professors and students toward college students who stutter. *Journal of Fluency Disorders*, *25*(1), 77-83.

Dunn J. Siblings and socialization. In: Grusec JE, Hastings PD, editors. Handbook of socialization: Theory and research. New York: Guilford Press; 2007. pp. 309–327.

DuPont, M. K. (1946). *A comparative study of educational adjustment among stuttering and non-stuttering children. M.A. thesis, University of Iowa.*

Elizabeth, J., King, N., & Ollendick, T. H. (2004). Etiology of Social Anxiety Disorder in Children and Youth. *Behaviour Change, 21*(03), 162-172.

Ellis, W. R., & Zarbatany, L. (2007). Peer group status as a moderator of group influence on children's deviant, aggressive, and prosocial behavior, *Child Development, 78*(4)*,* 1240-1254.

Erikson, E. H. (1968). *Identity Youth and Crisis*. New York: W. W. Norton.

Erickson, S., & Block, S. (2013) The social and communication impact of stuttering on adolescents and their families. *Journal of Fluency Disorders, 38*(4), 311-324.

Espelage, D. L., Holt, M. K., & Henkel, R. R. (2003). Examination of peer-group contextual effects on aggression during early adolescence. *Child Development, 74*(1), 205-220.

Evans, D., Healey, E. C., Kawai, N., & Rowland, S. (2008). Middle school students' perceptions of a peer who stutters. *Journal of Fluency Disorders*, *33*(3), 203-219.

Evans, D., Kawai, N., Healey, E. C., & Rowland, S. (2007). Middle school students' perceptions of stuttering. In J. Au-Yeung & M. Leahy (Eds.), *Research, treatment, and self-help in fluency disorders: New horizons, Proceedings of the Fifth World Congress on Fluency Disorders* (pp. 230-235). Dublin, Ireland: International Fluency Association.

Floyd, J., Zebrowski, P. M., & Flamme, G. A. (2007). Stages of change and stuttering: A preliminary view. *Journal of Fluency Disorders*, *32*(2), 95-120.

Franck, A. L., Jackson, R. A., Pimentel, J. T., & Greenwood, G. S. (2003). School-age children's perceptions of a person who stutters. *Journal of Fluency Disorders*, *28*(1), 1-15.

Franzoi, S. L. (2012). *Social psychology.* (6th ed.). Redding, CA: BVT Publishing.

Fry, J. P., Botterill, W. M., & Pring, T. R. (2009). The effect of an intensive group therapy program for young adults who stutter: A single subject study. *International Journal of Speech-Language Pathology, 11*(1), 12-19.

Fry, J., Millard, S., & Botterill, W. (2014). Effectiveness of intensive, group therapy for teenagers who stutter. *International Journal of Language & Communication Disorders, 49*(1), 113-126.

Furman, W., & Buhrmester, D. (1985). Children's perceptions of the qualities of sibling relationships. *Child development, 56*, 448-461.

Glogowska, M. (2015). Paradigms, pragmatism and possibilities: mixed-methods research in speech and language therapy. *International Journal of Language & Communication Disorders*, 1-10.

Good, T. L., & Brophy, J. E. (2002). *Looking in classrooms.* (9th ed.). Boston: Allyn & Bacon.

Goodman, A. & Gregg, P. (2010). Poorer children's educational attainment: How important are attitudes and behaviour? Joseph Rowntree Foundation: York, UK. http://www.jrf.org.uk/publications/educational-attainment-poor-children

Griffin, M., & Leahy. (2006). Young Children's Perceptions of a Dysfluent Speaker. In J. Au-Yeung & M. Leahy (Ed.), *Research, treatment, and self-help in fluency disorders: New horizons*, *Proceedings of the Fifth World Congress on Fluency Disorders* (pp. 217-222*).* Dublin, Ireland: The International Fluency Association.

Guitar, B. (2014). *Stuttering: An integrated approach to its nature and treatment.* (4th ed.). Baltimore: Lippincott Williams & Wilkins.

Gulati, A., & King, A. (2009) Supporting Vulnerable young people in transition Addressing poverty of wellbeing. *In Perspective, October 2009.*

Gunn, A., Menzies, R. G., O'Brian, S., Onslow, M., Packman, A., Lowe, R., ... & Block, S. (2014). Axis I anxiety and mental health disorders among stuttering adolescents. *Journal of Fluency Disorders, 40,* 58-68.

Gutman, L. M., & Vorhaus, J. (2012). The impact of pupil behaviour and wellbeing on educational outcomes. Retrieved September 10, 2016 from http://dera.ioe.ac.uk/16093/1/DFE-RR253.pdf

Hall, D., & Hall, I. (1996). From agreement to research brief. In D. Hall & I. Hall (Eds.), *Practical social research: Project work in the community* (pp.76–94). London: Macmillan.

Ham, R. (1990). What is Stuttering: Variations and stereotypes. *Journal of Fluency Disorders, 15*(5-6)*,* 259-273.

Hancock, K., & Craig, A. (1998). Predictors of stuttering relapse one year following treatment for children aged 9 to 14 years. *Journal of Fluency Disorders, 23*(1), 31-48.

Hancock, K., Craig, A., McCready, C., McCaul, A., Costello, D., Campbell, K., & Gilmore, G. (1998). Two-to six-year controlled-trial stuttering outcomes for children and adolescents. *Journal of Speech, Language, and Hearing Research, 41*(6), 1242-1252.

Hartford, E., & Leahy, M, (2006) The Perceptions of Primary School Children of a person who Stutters. In J. Au-Yeung & M. Leahy (Ed.), *Research, treatment, and self-help in fluency disorders: New horizons*, *Proceedings of the Fifth World Congress on Fluency Disorders* (pp. 217-222*).* Dublin, Ireland: The International Fluency Association.

Hayhow, R., Cray, A. M., & Enderby, P. (2002). Stammering and therapy views of people who stammer. *Journal of fluency disorders*, *27*(1), 1-17.

Hearne, A., Packman, A., Onslow, M., & Quine, S. (2008). Stuttering and its treatment in adolescence: The perceptions of people who stutter. *Journal of Fluency Disorders, 33*(2), 81-98.

Heidegger, M. (1962). *Being and Time*. Oxford: Blackwell.

Herrnstein, R. J., & Murray, C. (1994). *The bell curve: Intelligence and class structure in American life.* New York: Simon & Schuster.

Hill, A., Davidson, B.J., & Theodoros, D.G. (2010). A review of standardized patients in clinical education: Implications for speech-language pathology programs. *International Journal of Speech-Language Pathology, 12*(3), 259-270.

Hollands, K., van Kraayenoord, C. E., & McMahon, S. (2005). Support to adolescents experiencing language difficulties: A survey of speech-language pathologists. *Advances in Speech Language Pathology*, *7*(3), 113-129.

Holmbeck, G. N., Colder, C., Shapera, W., Westhoven, V., Kenealy, L., & Updegrove, A. (2000). *Working with adolescents: Guides from developmental psychology.* New York: Guildford Press.

Hoover, J. H., Oliver, R., & Hazler, R. J. (1992). Bullying: Perceptions of adolescent victims in the Midwestern USA. *School Psychology International*,*13*(1), 5-16.

Howlin, P., Mawhood, L., & Rutter, M. (2000). Autism and developmental receptive language disorder—A follow-up comparison in early adult life. II: Social, behavioural, and psychiatric outcomes. *Journal of Child Psychology and Psychiatry*, *41*(05), 561-578.

Hugh-Jones, S., & Smith, P. K. (1999). Self-reports of short- and long-term effects of bullying on children who stammer. *British Journal of Educational Psychology*, *69*(2)*,* 141–158.

Hussain, S., Ali, R., Zaman, A., Ghaffar, A., Aamir, S. M., & Minaz, M. (2013). The impact of peer groups on the academic achievements of secondary school students. *Journal of American Science, 9*, 13-16.

Irani, F., Abdalla, F., & Gabel, R. (2012). Arab and American teachers' attitudes toward people who stutter: A comparative study. *Contemporary Issues in Communication Science and Disorders*, *39*(39), 12-20.

Irani, F., & Gabel, R. M. (2008). Schoolteachers' attitudes towards people who stutter: Results of a mail survey. *Canadian Journal of Speech-Language Pathology and Audiology*, *32*(3)*,* 129–134.

Irani, F., Gabel, R. M., Hughes, S., Swartz, E. R., & Palasik, S. T. (2009). Role entrapment of people who stutter reported by K-12 teachers. *Contemporary Issues in Communication Science and Disorders*, *36,* 48–56.

Iverach, L., Menzies, R. G., O'Brian, S., Packman, A., & Onslow, M. (2011). Anxiety and stuttering: Continuing to explore a complex relationship. *American Journal of Speech-Language Pathology*, *20*(3), 221-232.

Iverach, L., & Rapee, R. M. (2014). Social anxiety disorder and stuttering: Current status and future directions. *Journal of Fluency Disorders*, *40*, 69-82.

Jenkins, H. (2010). Attitudes of teachers towards dysfluency training and resources. *International Journal of Speech-Language Pathology, 12*(3), 253-258.

Jeynes, W. H. (2007). The relationship between parental involvement and urban secondary school student academic achievement: A meta-analysis. *Urban Education*, *42*(1)*,* 82 - 110.

Jin, W., Muriel, A., & Sibieta, L. (2010). *Subject and course choices at age 14 and 16 amongst young people in England: insights from behavioural economics.* Retrieved June 11, 2016 from

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/182677/DFE-RR160.pdf

Kaur (1971). A study of relationship of socio-economic status with the achievement of students in secondary school. PhD thesis in education pan university.

Kelman, E., & Nicholas, A. (2008). *Practical intervention for early childhood stammering: Palin PCI approach*. UK: Speechmark Publishing Ltd.

Kelman, E., & Whyte, A. (2012). *Understanding stammering or stuttering: A guide for parents, teachers and other professionals.* London: Jessica Kingsley Publishers.

Keltner, D., Capps, L., Kring, A. M., Young, R. C., & Heerey, E. A. (2001). Just teasing: A conceptual analysis and empirical review. *Psychological Bulletin, 127*(2), 229-248.

Kessler, R. C., Adler, L. A., Barkley, R., Biederman, J., Conners, C. K., Faraone, S. V., et al. (2005). Patterns and predictors of attention-deficit/hyperactivity disorder persistence into adulthood: results from the national comorbidity survey replication. *Biological Psychiatry, 57*(11), 1442-1451.

Kingston, P. (2007, March 06). No Accounting for Taste. Guardian, Retrieved September 2, 2012 from http://www.guardian.co.uk/education/2007/mar/06/furthereducation.uk2.

Kistner, J. (2006). Children's peer acceptance, perceived acceptance, and risk for depression. *The interpersonal, cognitive, and social nature of depression*, 1-21.

Klein, J. F., & Hood, S. B. (2004). The impact of stuttering on employment opportunities and job performance. *Journal of Fluency Disorders*, *29*(4), 255-273.

Kling, K. C., Hyde, J. S., Showers, C. J., & Buswell, B. N. (1999). Gender differences in self-esteem: a meta-analysis. *Psychological Bulletin, 125*(4), 470.

Klompas, M., & Ross, E. (2004). Life experiences of people who stutter, and the perceived impact of stuttering on quality of life: Personal accounts from South African individuals. *Journal of Fluency Disorders*, *29*(4), 275–305.

Kloth, S. A. M., Kraaimaat, F. W., Janssen, P., & Brutten, G. J. (2000). Persistence and remission of incipient stuttering among high-risk children. *Journal of Fluency Disorders, 24(*4), 253-265.

Knott, F., Lewis, C., & Williams, T. (2007). Sibling interaction of children with autism: Development over 12 months. *Journal of Autism and Developmental Disorders, 37*(10), 1987-1995.

Kramer, L. (2014). Learning emotional understanding and emotion regulation through sibling interaction. *Early Education and Development, 25*(2),160-184.

La Greca, A. M., & Harrison, H. M. (2005). Adolescent peer relations, friendships, and romantic relationships: Do they predict social anxiety and depression? *Journal of Clinical Child and Adolescent Psychology, 34*(1), 49-61.

Laidra, K., Pullmann, H., & Allik, J. (2007). Personality and intelligence as predictors of academic achievement: A cross-sectional study from elementary to secondary school. *Personality and Individual Differences, 42*(3), 441-451.

Landman-Peeters, K. M., Hartman, C.A., van der Pompe, G., den Boer, J. A., Minderaa, R. B., & Ormel, J. (2005). Gender differences in the relation between social support, problems in parent-offspring communication, and depression and anxiety. *Social Science & Medicine, 60,* 2549-2559.

Langevin, M., Bortnick, K., Hammer, T., & Wiebe, E. (1998). Teasing/bullying experienced by children who stutter: Toward development of a questionnaire. *Contemporary Issues in Communication Science and Disorders*, *25*, 12-24.

Langevin, M., Packman, A., & Onslow, M. (2009). Peer responses to stuttering in the preschool setting. *American Journal of Speech-Language Pathology*, *18*(3), 264-276.

Larsson, B., & Melin, L. (1990). Depressive symptoms in Swedish adolescents. *Journal of Abnormal Child Psychology, 18*(1), 91-103.

Larson, R. W., & Richards, M. H. (1994). Family emotions: Do young adolescents and their parents experience the same states? *Journal of Research on Adolescence, 4*(4), 567-583.

Lass, N. J., Ruscello, D. M., Schmitt, J. F., Pannbacker, M. D., Orlando, M. B., Dean, K. A., ... & Bradshaw, K. H. (1992). Teachers' perceptions of stutterers. *Language, Speech, and Hearing Services in Schools*, *23*(1), 78-81.

Legislation.gov.uk, (1988). *Education Reform Act, ch.40. (1988).* Retrieved from http://www.legislation.gov.uk/ukpga/1988/40/contents

Legislation.gov.uk, (1998). *Data Protection Act, ch.29. (1998).* Retrieved from http://www.legislation.gov.uk/ukpga/1998/29

Legislation.gov.uk, (2010). *Equality Act, ch.15. (2010).* Retrieved from http://www.legislation.gov.uk/ukpga/2010/15/contents

Lemert, E. M. (1962). Stuttering and social structure in two Pacific societies. *Journal of Speech and Hearing Disorders, 27*(1), 3-10.

Lewis M. (1992). *Shame: The exposed self.* New York: The Free Press.

Li, J., & Arnold, H. S. (2015). Reactions of teachers versus non-teachers toward people who stutter. *Journal of communication disorders*, *56*, 8-18. No issue

Liddle, H., James, S., & Hardman, M. (2011). Group therapy for school-aged children who stutter: A survey of current practices. *Journal of fluency disorders, 36*(4), 274-279.

Lincoln, M. A., & Onslow, M. (1997). Long-term outcome of early intervention for stuttering. *American Journal of Speech-Language Pathology, 6*(1), 51-58.

Lindsay, G., Dockrell, J., Law. J., Roulstone, S., & Vignoles, A. (2010). *Better communication research programme: 1st interim report.* Warwick: Department for Children, Schools and Families.

Lindsay, G., Soloff, N., Law, J., Band, S., Peacey, N., Gascoigne, M., & Radford, J. (2002). Speech and language therapy services to education in England and Wales. *International Journal of Language & Communication Disorders*, *37*(3), 273-288.

Maciejewski, P. K., Prigerson, H. G., & Mazure, C. M. (2000). Self-efficacy as a mediator between stressful life events and depressive symptoms. *The British Journal of Psychiatry*, *176*(4), 373-378.

Marsh, H. W., Byrne, B. M., & Yeung, A. S. (1999). Causal ordering of academic self-concept and achievement: Reanalysis of a pioneering study and... *Educational Psychologist*, *34*(3), 155-167.

Marshall, J., Ralph, S., & Palmer, S. (2002). 'I wasn't trained to work with them': mainstream teachers' attitudes to children with speech and language difficulties. *International Journal of Inclusive Education*, *6*(3), 199-215.

Masten, A. (2014). *Ordinary magic.* New York: The Guildford Press.

Mayo, R., & Mayo, C. (2013). College students' perspectives on dating a person who stutters. *College Student Journal*, *47*(1), 169-177.

McAllister, J., Collier, J., & Shepstone, L. (2012). The impact of adolescent stuttering on educational and employment outcomes: Evidence from a birth cohort study. *Journal of Fluency Disorders, 37*(2)*,*106-121.

McCormack, J., McLeod, S., McAllister, L., & Harrison, L. J. (2010). My speech problem, your listening problem, and my frustration: The experience of living with childhood speech impairment. *Language, Speech, and Hearing Services in Schools*, *41*(4), 379-392.

McCroskey, J. C. (1984). The communication apprehension perspective. Avoiding communication: Shyness, reticence, and communication apprehension, 13-38.

McCroskey, J. C., & Daly, J. A. (1976). Teachers' expectations of the communication apprehensive child in the elementary school. *Human Communication Research*, *3*(1), 67-72.

McDowell, E. D. (1928). Educational and emotional adjustment of stuttering children. *Columbia University Contributions to Education, 314*, 57.

McGuire, D. (2016). *The McGuire Programme Beyond Stuttering.* Retrieved May 30, 2016, from http://www.mcguireprogramme.com/sites/default/files/2014-international-evaluation-audit-final.pdf

McHale, S. M., Updegraff, K. A., & Whiteman, S. D. (2012). Sibling relationships and influences in childhood and adolescence. *Journal of Marriage and Family, 74*(5)*,* 913–930.

McLeod, S., Daniel, G., & Barr, J. (2006). Using children's drawings to listen to how children feel about their speech. In *Speech Pathology Australia National Conference, May. Perth, WA, Australia*.

McLeod, S., & McKinnon, D. H. (2007). Prevalence of communication disorders compared with other learning needs in 14500 primary and secondary school students. *International Journal of Language and Communication Disorders, 42*(sup1)*,* 37-59.

McNeil, C. (2013). In C. Cheasman, R. Everard, & S. Simpson, S. (Eds.). *Stammering therapy from the Inside. New perspectives on working with young people and adults.* Guildford, UK: J & R Press Ltd.

Menzies, R. G., O'Brian, S., Onslow, M., Packman, A., St Clare, T., & Block, S. (2008). An experimental clinical trial of a cognitive-behavior therapy package for chronic stuttering. *Journal of Speech, Language, and Hearing Research, 51*(6), 1451-1464.

Meredith, G., & Harrison, T. (2014). *Acceptance and the rise of pride.* Retrieved September 20, 2016, from http://isad.isastutter.org/isad-2014/papers-presented-by/perceptions-and-interpretations/acceptance-and-the-rise-of-pride/

Merry, S., & Stasiak, K. (2011). Depression in young people. *Improving the Transition*, 191.

Miedel, W. T., & Reynolds, A. J. (2000). Parent involvement in early intervention for disadvantaged children: Does it matter? *Journal of School Psychology*, *37*(4), 379-402.

Millard, S. K., Nicholas, A., & Cook, F. M. (2008). Is parent–child interaction therapy effective in reducing stuttering? *Journal of Speech, Language, and Hearing Research*, *51*(3), 636-650.

Moffitt, T. E. (1993). Adolescence-limited and life-course-persistent antisocial behavior: A developmental taxonomy. *Psychological Review*, *100*(4)*,* 674-701.

Mooney, S., & Smith, P. (1995). Bullying and the child who stammers. *British Journal of Special Education, 22*(1)*,* 24-27.

Morgenstern, J.J. (1953). *Psychological and social factors in children's stammering.* Unpublished PhD thesis, University of Edinburgh, United Kingdom.

Mruk, C. J. (1999). *Self-esteem research theory and practice.* (2nd ed.). London: Free Association.

Murgallis, T., Vitale, C., & Tellis, G. M. (2015). Perceptions of Persons who Stutter before and after Attending Support Group Meetings. *Procedia-Social and Behavioral Sciences*, *193*, 202-208.

Murray, C. (2003). Risk factors, protective factors, vulnerability, and resilience a framework for understanding and supporting the adult Transitions of youth with high-incidence disabilities. *Remedial and Special Education*, *24*(1), 16-26.

Oakes, J. M., & Rossi, P. H. (2003). The measurement of SES in health research: current practice and steps toward a new approach. *Social science & medicine*, *56*(4), 769-784.

O'Brian, S., Jones, M., Packman, A., Menzies, R., & Onslow, M. (2011). Stuttering severity and educational attainment. *Journal of Fluency Disorders*, *36*(2)*,* 86–92.

O'Brian, S., Packman, A., & Onslow, M. (2004). Self-rating of stuttering severity as a clinical tool. *American Journal of Speech-Language Pathology*,*13*(3), 219-226.

O'Cathain, A., Murphy, E., & Nicholl, J. (2007). Integration and publications as indicators of “yield" from mixed methods studies. *Journal of Mixed Methods Research*, *1*(2), 147-163.

O'Connell, M. E., Boat, T., & Warner, K. E. (Eds.). (2009). *Preventing mental, emotional, and behavioral disorders among young people: Progress and possibilities*. Washington: National Academies Press.

Office for National Statistics. (2011) *Census: Aggregate data (England and Wales)*. UK Data Service Census Support. Retrieved January, 26, 2013 from http://infuse.ukdataservice.ac.uk

Office for National Statistics. (2015). *What are the top causes of death by age and gender?* London: ONS Digital. Retrieved May 30, 2016 from http://visual.ons.gov.uk/what-are-the-top-causes-of-death-by-age-and-gender/

Office of Communications (2012). *Report. Adults media use and attitudes report*. Retrieved September 10, 2016 from http://stakeholders.ofcom.org.uk/binaries/research/media-literacy/media-use-attitudes/adults-media-use-2012.pdf

Ofsted. (2013). *Going in the right direction.* Retrieved September 2, 2016 from https://www.gov.uk/government/publications/careers-guidance-in-schools-going-in-the-right-direction.

Okun, B. F. (1997). *Effective helping: Interviewing and counselling techniques*. (5th ed.). Pacific Grove: Brooks/Cole.

Oliver, M. (1983). *Social Work with Disabled People*. Basingstoke, UK: Macmillan.

Ou, S. R., & Reynolds, A. J. (2008). Predictors of educational attainment in the Chicago Longitudinal Study. *School Psychology Quarterly*, *23*(2), 199.

Owen, R., Hayett, L., & Roulstone, S. (2004). Children's views of speech and language therapy in school: Consulting children with communication difficulties. *Child Language Teaching and Therapy*, *20*(1), 55-73.

Pachigar, V., Stansfield, J., & Goldbart, J. (2011). Beliefs and attitudes of primary school teachers in Mumbai, India towards children who stutter. *International Journal of Disability, Development and Education*, *58*(3), 287-302.

Palikara, O., Lindsay, G. & Dockrell, J.E. (2009). The voices of young people with a history of specific language impairment (SLI) in the first year of post-16 education. *International Journal of Language and Communication Disorders, 44*(1), 56-78.

Parker, J. G., & Asher, S. R. (1987). Peer relations and later personal adjustment: Are low-accepted children at risk? *Psychological bulletin, 102*(3), 357.

Patton, M. Q. (2002). *Qualitative research and evaluation methods.* (3rd ed.). London: Sage Publications.

Pelkonen, M., & Marttunen, M. (2003). Child and adolescent suicide. *Pediatric Drugs, 5*(4), 243-265.

Petersen, A. C., Compas, B. E., Brooks-Gunn, J., Ey, S., & Grant, K. E. (1993). Depression in adolescence. *American Psychologist*, *48*(2)*,* 155-168.

Petrunik, M., & Shearing, C. D. (1983). Fragile facades: stuttering and the strategic manipulation of awareness. *Social Problems*, *31*(2), 125-138.

Philip, K., & Spratt, J. (2007). A synthesis of published research on mentoring and befriending. *Manchester, UK: The Mentoring and Befriending Foundation.*

Piaget, J. (1959). *The language and thought of the child* (Vol. 5). London: Psychology Press.

Pierre, J. S. (2012). The construction of the disabled speaker: Locating stuttering in disability studies. *Canadian Journal of Disability Studies, 1*(3), 1-21.

Pinto, J. C. B. R., Schiefer, A. M., & Ávila, C. R. B. D. (2013). Disfluencies and speech rate in spontaneous production and in oral reading in people who stutter and who do not stutter. *Audiology-Communication Research, 18*(2)*,* 63-70.

Plexico, L., Manning, W. H., & DiLollo, A. (2005). A phenomenological understanding of successful stuttering management. *Journal of fluency disorders*, *30*(1), 1-22.

Plexico, L., Manning, W. H., Levitt, H. (2009). Coping responses by adults who stutter: Part II. Approaching the problem and achieving agency. *Journal of Fluency Disorders, 34*(2), 108-126.

Plexico, L. W., Plumb, A. M., & Beacham, J. (2013). Teacher Knowledge and Perceptions of Stuttering and Bullying in School-Age Children. *SIG 4 Perspectives on Fluency and Fluency Disorders*, *23*(2), 39-53.

Plummer, D. (2001). *Helping children to build self-esteem.* London: Jessica Kingsley Publishers.

Poland, B. D. (2002). Transcription quality. In N. King, & C. Horrocks (Eds.), *Interviews in qualitative research* (P. 144). London: Sage Publications.

Portney, L. G., & Watkins, M. P. (2009). *Foundations of clinical research: applications to practice*. England: Pearson Education Limited.

Powers, S. I., Hauser, S. T., & Kilner, L. A. (1989). Adolescent mental health. *American Psychologist, 44(*2), 200.

Proctor, A., Yairi, E., Duff, M. C., & Zhang, J. (2008). Prevalence of stuttering in African American pre-schoolers. *Journal of Speech, Language, and Hearing Research, 51*(6), 1465-1479.

Reichardt, C. S., & Rallis, S. F. (1994). Qualitative and quantitative inquiries are not incompatible: A call for a new partnership. *New directions for program evaluation*, *1994*(61), 85-91.

Reynolds, C. R., & Richmond, B. O. (2002). *Revised children's manifest anxiety scale.* Los Angeles: Western Psychological Services.

Ritchie, J., & Lewis, J. (2003). *Qualitative research practice.* London: Sage Publications.

Robins, R. W., Trzesniewski, K. H., Tracy, J. L., Gosling, S. D., & Potter, J. (2002). Global self-esteem across the life span. *Psychology and aging, 17*(3), 423.

Rogers, C. (1959). A theory of therapy, personality relationships as developed in the client-centred framework. In S. Koch (Ed.), *Psychology: A study of a science. Vol. 3: Formulations of the person and the social context*. New York: McGraw Hill.

Rosenberg, M. (1965). *Society and the adolescent self-image*. Princeton, NJ: Princeton University Press.

Royal College of Speech & Language Therapists. (2006). *Communicating Quality 3: RCSLT's Guidance on Best Practice in Service Organisation and Provision.* London: Royal College of Speech & Language Therapists.

Royal College of Speech & Language Therapists. (2016). *Role of speech and language therapy in dysfluency.* Retrieved March 12, 2016 from https://www.rcslt.org/clinical_resources/dysfluency/role

Ruscello, D. M., Lass, N. J., Schmitt, J. F., & Pannbacker, M. D. (1994). Special educators' perceptions of stutterers. *Journal of Fluency Disorders, 19*(2), 125-132.

Rüsch, N., Abbruzzese, E., Hagedorn, E., Hartenhauer, D., Kaufmann, I., Curschellas, J., ... & Kawohl, W. (2014). Efficacy of Coming Out Proud to reduce stigma's impact among

people with mental illness: pilot randomised controlled trial. *The British journal of psychiatry*, *204*(5), 391-397.

Russell, G. and Topham, P. (2012). The impact of social anxiety on student learning and well-being in higher education. *Journal of Mental Health, 21*(4), 375-385.

Rutter, M. (1985). Resilience in the face of adversity. Protective factors and resistance to psychiatric disorder. *The British Journal of Psychiatry, 147*(6), 598-611.

Rutter, M. (1986). The developmental psychopathology of depression: Issues and perspectives. *Depression in young people: Developmental and clinical perspectives,* 3-30.

Sackett, D. L., Rosenberg, W. M., Gray, J. M., Haynes, R. B., & Richardson, W. S. (1996). Evidence based medicine: what it is and what it isn't. *British Medical Journal. 312* (*7023),* 71-72.

Sadler, J. (2005). Knowledge, attitudes and beliefs of the mainstream teachers of children with a preschool diagnosis of speech/language impairment. *Child Language Teaching and Therapy, 21*(2)*,* 147-163.

Sanders, M. G., & Epstein, J. L. (1998). School-family-community partnerships and educational change: International perspectives. In A. Hargreaves, A. Lieberman, M. Fullan, and D. Hopkins (Eds.), *International Handbook of Educational Change*. Hingham MA: Kluwer.

Santrock, J. W. (2001). Adolescence. (8th ed.). New York: McGraw-Hill.

Santrock, J. W. (2008). *Life-span development.* (11th ed.). New York: McGraw-Hill.

Saunders. M., Lewis, P., & Thornhill, A. (2009). *Research methods for business students.* (5th ed.). England: Pearson Education Limited.

Schaffer, H. R. (1996). *Social development.* Oxford, UK: Blackwell Publishing.

Schindler, M. D. (1955). A study of educational adjustments of stuttering and nonstuttering children. In W. Johnson, & R. R. Leutenegger (Eds.), Stuttering *in children and adults* (pp. 348-357). Minneapolis: University of Minnesota press.

Schunk, D. H., & Miller, S. D. (2002). Self-efficacy and adolescents' motivation. *Academic motivation of adolescents, 2*, 29-52.

Schwartz, H. D. (1993). Adolescents who stutter. *Journal of Fluency Disorders, 18*(2)*,* 289-302.

Sexson, S. B. (2005). *Child and adolescent psychiatry.* (2nd ed.). Oxford: Blackwell Publishing.

Shaffer, D. (1999). *Developmental psychology – childhood and adolescence*. London: Brooks/Cole publishers.

Shahar, G., & Priel, B. (2002). Positive life events and adolescent emotional distress: In search of protective-interactive processes. *Journal of Social & Clinical Psychology, 21*(6), 645-668.

Shavelson, R. J., and Bolus, R. (1982). Self-concept: The interplay of theory and methods. *Journal of Educational Psychology*, *74*(1)*,* 2-17.

Shaw, R. L. (2010). Embedding reflexivity within experiential qualitative psychology. *Qualitative Research in Psychology, 7*(3)*,* 233-243.

Sheehan, J. G. (1975). Conflict theory and avoidance-reduction therapy. In J. Eisenson, (Ed.), *Stuttering: A Second Symposium*. New York: Harper and Row.

Silverman, F. H., & Marik, J. H. (1993). Teachers' Perceptions of StutterersA Replication. *Language, Speech, and Hearing Services in Schools*, *24*(2), 108-108.

Sirin, S. R. (2005). Socioeconomic status and academic achievement: A meta-analytic review of research. *Review of educational research*, *75*(3), 417-453.

Smith, J. A. (Ed.) (2008). *Qualitative psychology: A practical guide for research methods.* (2nd ed.). London: Sage Publications.

Smith, J.A. (2011). Evaluating the contribution of interpretative phenomenological analysis. *Health Psychology Review, 5*(1), 9–27.

Smith*,* E. P., Boutte, G. S., Zigler, E. & Finn-Stevenson, M. (2004). Opportunities for schools to promote resilience in children and youth. In K. Maton, C. Schellenbach, B. Leadbetter, & A. Solarz (Eds.), *Investing in Children, Youth, Families, and Communities: Strengths-Based Research and Policy.* New England: American Psychological Association.

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. London: Sage Publications.

Smith, K. A., Iverach, L., O'Brian, S., Kefalianos, E., & Reilly, S. (2014). Anxiety of children and adolescents who stutter: A review. *Journal of Fluency Disorders, 40,* 22-34.

Snidecor, J. C. (1955). Tension and facial appearance in stuttering. In W. Johnson, & R. R. Leutenegger (Eds.), Stuttering in children and adults (pp. 377- 80). Minneapolis: University of Minnesota Press.

Spear, L. P. (2000). Neurobehavioral changes in adolescence. *Current Directions in Psychological Science,* 9(4)*,* 111-114.

Statistical Package for the Social Sciences. IBM Corp. Released 2013. IBM SPSS Statistics for Windows, Version 22.0. Armonk, NY: IBM Corp.

Steinberg, L. (1993). *Adolescence*. (3rd ed.). New York: McGraw Hill.

Stevanovic, D. (2013). Anxiety Sensitivity in Relation to Anxiety Symptoms Among Serbian Youth. *International Journal of Clinical Psychiatry and Mental Health, 1*(1)*,* 25-32.

Steen, M., & Roberts, T. (2011). *The handbook of midwifery research.* New Jersey: Wiley Blackwell.

Stewart, J. L. (1960). The problem of stuttering in certain North American Indian societies. *Journal of Speech and Hearing Disorders, Monograph Supplement 6.*

Stewart, T., and Turnbull, J. (2007). *Working with Dysfluent Children*. UK: Speechmark Publishing Ltd.

Stoneman, Z. (2001). Supporting positive sibling relationships during childhood. *Mental Retardation and Developmental Disabilities Research Reviews, 7*(2), 134-142.

Sullivan, H. S. (1953). *The interpersonal theory of psychiatry*. New York: Norton, 1953.

Sullivan, K., & Sullivan, A. (1980). Adolescent–parent separation. *Developmental Psychology, 16*(2), 93.

Sumari, M., Hussin, Z., & Siraj, S. (2010). Factors contributing to academic achievement and moral development: A qualitative study. *The International Journal of Research and Review*, *5*(2)*,* 18-24.

Tashakkori, A., & Teddlie, C. (1998). *Mixed methodology: Combining qualitative and quantitative approaches*. Thousand Oaks, Calif: Sage Publications.

Tassoni, P. (2007). *Child development 6 to 16 years.* Oxford: Heinemann.

Thapar, A., Collishaw, S., Pine, D. S., & Thapar, A. K. (2012). *Depression in adolescence. The Lancet, 379*(9820), 1056-1067.

Threats, T.T. (2006) Towards an international framework for communication disorders: use of the ICF. *Journal of Communication Disorders*, *39*(4), 251-65.

Tran, Y., Blumgart, E., & Craig, A. (2011). Subjective distress associated with chronic stuttering. *Journal of Fluency Disorders, 36*(1), 17-26.

Turner, J. S., & Helms, D. B. (1995). *Lifespan development*. (5th ed.). Orlando: Harcourt Brace & Company.

Tyrer, A. (2013). *Is the stammer a disability?* Retrieved September 20, 2016, from http://www.stammeringlaw.org.uk/disability/disab.htm

United Nations Convention on the Rights of the Child, September 2, 1990. Retrieved from http://www.unicef.org.uk/Documents/Publication-pdfs/UNCRC_PRESS200910web.pdf

Van Borsel, J., Brepoels, M., & De Coene, J. (2011). Stuttering, attractiveness and romantic relationships: The perception of adolescents and young adults. *Journal of Fluency Disorders*, *36*(1), 41-50.

Van Riper, C. (1973). *The treatment of stuttering*. New Jersey: Prentice Hall.

Van Riper, C. (1975). The stutterer's clinician. In J. Eisenson (Ed.). Stuttering: A second symposium (pp. 453-492). New York: Harper & Row.

Van Riper, C. (1982). The nature of stuttering. New Jersey: Prentice Hall.

Van Steensel, R. (2006). Relations between socio-cultural factors, the home literacy environment and children's literacy development in the first years of primary education. *Journal of Research in Reading*, *29*(4), 367–382.

Vialle, W. J., Heaven, P. C. L., & Ciarrochi, J. V. (2005). The relationship between self-esteem and academic achievement in high ability students: Evidence from the Wollongong Youth Study. *Australasian Journal of Gifted Education, 24*(2), 17.

Vygotsky, L. S. (1978). Mind in society: The development of higher mental process. (M. Cole, V. John-Steiner, S. Scribner & E. Souverman, Eds.). London: Harvard University Press.

Walker, R., Mayo, R., & Louis, K. O. S. (2016). Attitudes of College Career Counselors Towards Stuttering and People Who Stutter. *Perspectives of the ASHA Special Interest Groups*, *1*(4), 44-53.

Ward, D. (2008). Stuttering and cluttering: Frameworks for understanding and treatment. UK: Psychology Press.

Wasserman, D., Cheng, Q., & Jiang, G.X. (2005). Global suicide rates among young people aged 15-19. World Psychiatry, 4(2), 114-120.

Weingarten, L.B. (2012). *An exploration of the experiences of women who stammer. Professional doctorate thesis, University of East London.*

Weisz, J. R., & Hawley, K. M. (2002). Developmental factors in the treatment on adolescents. *Journal of Consulting and Clinical Psychology, 70*(1), 21.

Werner, E. and R. Smith (1989). *Vulnerable But Invincible: A Longitudinal Study of Resilient Children and Youth.* New York: Adams, Bannister, and Cox.

White, K. R. (1982). The relation between socioeconomic status and academic achievement. *Psychological Bulletin, 91*(3)*,* 461-481.

Whitney, I., & Smith, P. K. (1993). A survey of the nature and extent of bullying in junior/middle and secondary schools. *Educational research*, *35*(1), 3-25.

Williams, D. E., Melrose, B. M., & Woods, C. L. (1969). The relationship between stuttering and academic achievement in children. *Journal of Communication Disorders, 2*(2), 87-98.

Willig, C. (2013). *Introducing qualitative research in psychology.* (3rd ed.). Berkshire, England: Open University Press.

Willig, C., & Stainton-Rogers, E. (Eds.) (2008). *The sage handbook of qualitative research in psychology.* London: Sage Publications.

Wolf, A. (2011). *Review of vocational education: The Wolf Report.* Retrieved September 10, 2016 from https://www.gov.uk/government/publications/review-of-vocational-education-the-wolf-report.

World Health Organization (2001). *International Classification of Functioning, Disability and Health*. Geneva: World Health Organization.

World Health Organization (2011). *World Report on Disability.* Retrieved May 30, 2016 from http://www.who.int/disabilities/world_report/2011/report.pdf.

World Health Organization. (2014). *Preventing suicide: A global imperative.* Retrieved May 30, 2016 from: http://www.who.int/mental_health/suicide-prevention/key_messages.pdf.

World Health Organization. (2016). *Maternal, newborn, child and adolescent health* [online]. Geneva: World Health Organization. Retrieved May 20, 2016 from http://www.who.int/maternal_child_adolescent/topics/adolescence/dev/en

Wright, L., & Ayre, A. (1999). Wright and Ayre Stuttering Self-Rating Profile (1999). UK: Speechmark Publishing Ltd.

Yairi, E. (1997). Early stuttering. In R. F. Curlee, & G. M.Siegel, (Eds.), *Nature and treatment of Stuttering: New Directions* (2nd ed.). Boston: Allyn & Bacon.

Yairi, E., & Ambrose, N. (1992). A longitudinal Study of stuttering in children: A preliminary report. *Journal of Speech, Language, and Hearing Research*, *35*(4), 755-760.

Yairi, E., & Ambrose, N. G. (2005). *Early childhood stuttering for clinicians by clinicians.* Texas: Pro Ed.

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health, 15*(2), 215-228.

Yardley, L. (2008). Demonstrating validity in qualitative psychology. In J. A. Smith (Ed,), Qualitative *Psychology: A practical guide to research methods.* (2nd ed., pp. 235-251). London: Sage publications.

Yardley, L, & Bishop, F. (2008). In C. Willig, & W. Stainton-Rogers (Eds.), *The sage handbook of qualitative research in psychology.* (pp. 352-369). *London*: Sage Publications

Yaruss, J. S., & Coleman, C. (2006). Treating preschool children who stutter: Description and preliminary evaluation of a family-focused treatment approach. *Language, Speech, and Hearing Services in Schools*, *37*(2), 118-136.

Yaruss, J. S., Quesal, R. W., & Murphy, B. (2002). National Stuttering Association members' opinions about stuttering treatment. *Journal of Fluency Disorders, 27*(3), 227-242.

Yaruss, J. S. (2007). Application of the ICF in fluency disorders. *Seminars in Speech and Language*, *28*(4)*,* 312-322.

Yaruss, J. S., & Quesal, R. W. (2004). Stuttering and the International Classification of Functioning, Disability, and Health (ICF): An update. *Journal of Communication Disorders, 37*(1)*,* 35-52.

# APPENDIX A. Study ONE (Questionnaire)

# Appendix A.1: Ethical approval letters

The University Of Sheffield.

**Department of Human Communication Sciences**
31 Claremont Crescent
Sheffield S10 2TA UK

**Head of Department**
**Professor Joy Stackhouse**, PhD., F.R.C.S.L.T., C.Psychol., A.F.B.Ps.

**Telephone: +44 (0) 114 222 2418/ 2402/ 240**
**International: +44 (0) 114 222 241**
**Fax: +44 (0) 114 273 054**
**Email: hcs-support@sheffield.ac.u**
**http://www.shef.ac.uk/hc**

7th June 2011

Dear Helen

Title: To investigate the educational achievement of young people who stammer (2)

Thank you for your submission to the HCS Research Ethics Committee. The committee has reviewed your submission and supporting documents and grants you approval to commence the research.

We hope your project proceeds smoothly

Yours sincerely

[redacted]

Prof R Varley
Chair of HCS Ethics Committee

# ETHICS REVIEWER'S COMMENTS FORM

This form is for use when ethically reviewing a research ethics application form.

| | |
|---|---|
| **1. Name of Ethics Reviewer:** | Richard Body<br>Ben Rutter<br>Sarah Spencer |
| **2. Research Project Title:** | The role of stammering in the educational progression and career decision making of young people who stammer. |
| **3. Principal Investigator (or Supervisor):** | Helen Jenkins |
| **4. Academic Department / School:** | HCS |

**5. I confirm that I do not have a conflict of interest with the project application**

**6. I confirm that, in my judgment, the application should:**

| Be approved: | Be approved with *suggested* amendments in '7' below: | and/or | Be approved providing *requirements* specified in '8' below are met: | NOT be approved for the reason(s) given in '9' below: |
|---|---|---|---|---|
| X | | | | |

**7. Approved with the following suggested, optional amendments (i.e. it is left to the discretion of the applicant whether or not to accept the amendments and, if accepted, the ethics reviewers do not need to see the amendments):**

**8. Approved providing the following, compulsory requirements are met (i.e. the ethics reviewers need to see the required changes):**

•

**9. Not approved for the following reason(s):**

**10. Date of Ethics Review:** 01/10/13 [redacted]

NHS
Health Research Authority

**NRES Committee South West - Frenchay**
Bristol Research Ethics Centre
Level 3, Block B
Whitefriars
Lewins Mead,
Bristol
BS1 2NT

Telephone: 0117 342 1334
Facsimile: 0117 342 0445

09 March 2012

Mrs Helen Jenkins
Senior Lecturer
Birmingham City University
Department of Speech & Language Therapy,
Seacole West,
Westbourne Road, Edgbaston,
Birmingham
B15 3TN

Dear Mrs Jenkins

| | |
|---|---|
| **Study title:** | **A mixed methods study to investigate the educational achievement and educational experiences of young people who stammer compared to young people who do not stammer.** |
| **REC reference:** | **12/SW/0081** |
| **Protocol number:** | **URMS 131840** |

Thank you for your letter of 04 March 2012, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

**Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

**Ethical review of research sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

**Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

**You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Confirmation should also be provided to host organisations together with relevant documentation.**

**Approved documents**

The documents reviewed and approved by the Committee are:

| *Document* | *Version* | *Date* |
|---|---|---|
| Covering Letter | | 04 March 2012 |
| Evidence of insurance or indemnity | | 15 February 2012 |
| Interview Schedules/Topic Guides | 1 | 25 January 2012 |
| Investigator CV | HJ | 15 February 2012 |
| Letter from Statistician | | 14 November 2011 |
| Letter of invitation to participant | 2 | 04 March 2012 |
| Other: CV S Brumfitt | | 04 November 2011 |
| Other: CV J Stackhouse | | 14 February 2012 |
| Other: Notification to SLT | 1 | 15 February 2012 |
| Other: Introductory letter to SLT | 1 | 15 February 2012 |
| Other: Mutual confidentiality agreement form | 1 | 14 November 2011 |
| Other: Letter to schools | 1 | 15 February 2012 |
| Participant Consent Form: Dual - young person/parent | 2 | 04 March 2012 |
| Participant Consent Form | 2 | 04 March 2012 |
| Participant Information Sheet | 2 | 04 March 2012 |
| Protocol | 1 | 10 February 2012 |
| Questionnaire | 2 | 04 March 2012 |
| REC application | | 15 February 2012 |
| Referees or other scientific critique report | | 14 September 2011 |
| Response to Request for Further Information | | 04 March 2012 |
| Summary/Synopsis | 1 | 15 February 2012 |

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

**After ethical review**

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

**12/SW/0081** **Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

[redacted]

pp **Dr Mike Shere**
**Chair**

Email: ubh-tr.SouthWest5@nhs.net

*Copy to:* *Nicola Donkin, University of Sheffield*
*RM&G Consortium Office, Birmingham & Black Country Comprehensive Local Research Network*

# Appendix A.2: Demographic profiles of pilot study participants

| Participant | Recruited by | Age | Gender | Ethnic Group | Education /Employment status | Education environment |
|---|---|---|---|---|---|---|
| 1 | BSA | 15 | M | White | Full time study/year 10 | School |
| 2 | Known to researcher | 17 | F | White | Full time study/year 12 | School |
| 3 | Known to researcher | 22 | M | Asian | Full time study | University |
| 4 | Known to researcher | 25 | M | Asian | Full time work | Not applicable |
| 5 | Independent SLT | 23 | F | White | Part time study/work | College |
| 6 | Independent SLT | 21 | M | Asian | Full time study/part time work | University |
| 7 | Known to researcher | 21 | M | White | Full time work | Not applicable |

# Appendix A.3: Pilot questionnaire

Pilot Questionnaire schedule

Re: Project to investigate the educational progress of young people who stammer

Thank you for agreeing to answer these questions. This questionnaire is part of a research project looking at the educational progress of young people who have difficulty with the flow of their speech, which we refer to as non-fluency or stammering (or the term stuttering is used in some countries such as America and Australia).

The questionnaire has three sections. Please complete each section by either ticking the relevant box(es) or by writing your answer on the lines provided.

Section A: General Information

Your name: .....

Date of birth: ☐☐/☐☐/☐☐

Gender: Male ☐ Female ☐

Post code of where you live: ☐☐☐☐ ☐☐☐

How would you best describe your ethnic background?

African ☐ American/Black ☐ Caucasian ☐ Asian ☐ Other ☐

What is the main language you speak? .....

Do you speak any other languages e.g. with family or friends? Yes ☐ No ☐

If your answer is 'Yes' please specify the language(s): .....

School Year Group: Year 10 ☐ Year 11☐ or other.....

Where are you studying? (Name of school, college or university).....

.....

If you are working please list type of work.....

.....

Section B: Speech details

Do you have difficulty with the flow of your speech which you may describe as non-fluency or stammering? Yes ☐ No ☐

When did you first become aware of your non-fluency/stammering?

.....
.....

Would you describe your non- fluency difficulty/stammering as:

mild ☐ moderate ☐ severe ☐

Can you describe what you do when you are non-fluent/stammering? For example, do you repeat parts of words (m-m-m-money); do you stretch out speech sounds (sssssun); do you get completely stuck and say nothing; do you hide it by saying instead another word that is easier to say?

.....
.....
.....
.....

How does your speech difficulty make you feel?

.....
.....
.....

When does it happen the most?

.....
.....

When does it happen the least?

.....
.....

Are you receiving help from a Speech and Language Therapist for your non-fluency/stammering? Yes ☐ No ☐

Have you had Speech and Language Therapy in the past for your non-fluency/stammering? Yes ☐ No ☐

Are you receiving help from anyone else for your non- fluency/stammering?

Yes ☐ No ☐ If your answer is 'yes' please tick the relevant box(es):

Teacher ☐ Parent ☐ Other☐ Please state.....

Do you know if anyone in your family has ever been non-fluent/stammered?

Yes ☐ No ☐

If your answer is 'Yes' please state who, e.g. father, uncle, grandmother

.....

Do you have any other speech and language difficulties, such as, dyspraxia, dyslexia? If so, please list below

.....
.....

Section C: Educational qualifications

What qualifications are you currently studying or have previously studied?

GCSEs ☐ 14-18 Diploma ☐ AS levels☐ A levels☐ Degree☐ Other☐

Please list the subjects you are studying or have studied:

.....
.....
.....
.....
.....
.....
.....

Why did you choose these subjects?

.....
.....
.....
.....

Did anyone help or advise you with choosing your subjects? Yes ☐ No ☐

If your answer is 'Yes' please tick one of the following:

Teacher ☐ Careers advisor ☐ Parent ☐ Friend ☐ Other ☐ please specify:
.....

Which subject(s) do/did you enjoy the most? Why?

.....
.....
.....
.....

Which subject(s) do/did you least enjoy? Why?

.....
.....

.....
.....

Do you feel your non-fluency or stammer has influenced the choice of subjects you are studying or have studied? Yes ☐ No ☐

If your answer is yes, please briefly describe how:

.....
.....
.....
.....

Please list the results (grades) of any qualifications you may have already taken:

.....
.....
.....
.....
.....
.....
.....

If you have left formal education, please list date of leaving and reason for doing so.

.....
.....
.....

Please describe any employment positions you have held since leaving education.

.....
.....
.....
.....

Thank you for taking the time to answer these questions. Please email or post this completed questionnaire to Helen Jenkins: Helen.jenkins@bcu.ac.uk or post to Helen Jenkins, Department of Speech & Language Therapy, Birmingham City University, Cox Building, Perry Barr, Birmingham B42 2SU.

Future contact: (This does not apply to participants involved in the pilot study)

1. I will contact you again in August 2011, via email, to ask you to email me your examination results and for information regarding your future educational choices and results post 16 years.

2. As mentioned in the information sheet the second part of the project will follow up some participants from part one of the study. This second phase will aim to find out further information about the educational choices participants have made. This phase will involve participants providing additional answers to questions either via email or during an informal discussion.

I am inviting you to take part in the second phase of this research project. Please could you indicate whether you would be willing to be involved in this further project?

Yes ☐ No ☐

If you answered 'Yes' then I will send you, at a later date, information about this further study and the necessary consent forms.

Thank you for taking the time to answer these questions. Please email or post this completed questionnaire to Helen Jenkins: Helen.jenkins@bcu.ac.uk or post to Helen Jenkins, Department of Speech & Language Therapy, Birmingham City University, Cox Building, Perry Barr, Birmingham B42 2SU.

# Appendix A.4: Feedback form

**Feedback Form re: Pilot Questionnaire**

Thank you for taking part in the pilot study for my research project regarding the educational progress of young people who stammer. I should be very grateful if you could answer the questions below which will provide me with valuable feedback regarding the questionnaire and guide me in preparing the final version for the main study.

1. How long did it take you to complete the questionnaire?

2. Did you find the instructions clear to follow?

3. Did you find any of the questions unclear or ambiguous? If so please identify which ones and state why.

4. Did you object to answering any of the questions?

5. Did you feel any questions on a particular area were omitted?

6. Did you find the design of the questionnaire comprehensible and attractive?

7. Any other comments?

Thank you for completing this form. Please email to Helen.jenkins@bcu.ac.uk

# Appendix A.5: Summary of feedback

Summary of Feedback forms re: Pilot Questionnaire

| Question | Response (n=5) | Amendments |
|---|---|---|
| 1. How long did it take you to complete the questionnaire? | 5-10 minutes (n=2)<br>15 minutes (n=1)<br>20 minutes (n=1)<br>30 minutes (n=1) | Completion time for questionnaire changed from 10 minutes to 20-30 minutes in participant information sheet. |
| 2. Did you find the instructions clear to follow? | All replied 'Yes' | |
| 3. Did you find any of the questions unclear or ambiguous? If so, please identify which ones and state why. | All replied No, except for one:<br>"When did you leave formal education? Was unsure what formal education meant." | Re-wording of a question and use of table to record qualifications. |
| 4. Did you object to answering any of the questions? | All replied 'No' | |
| 5. Did you feel any questions on a particular area were omitted? | All replied 'No' except for one:<br>"It doesn't ask about when I may have started speech therapy and whether this had an impact on educational development choices (not that it would have changed my answers, but perhaps someone else's)." | Explored during the interview phase of the study. |
| 6. Did you find the design of the questionnaire comprehensible and attractive? | 'Yes' (3 participants). Two others commented:<br>"I believe the questionnaire should have been like this, so people could type what they think rather than what I had to do, which was print it off, handwrite it, scan it and then send it, rather than the simple way of just typing and sending it through an email."<br>"Bit technical (sorry) but the lines move around as you fill in the answers. It would be easier if the file was in Rich Text Format." | Re-formatting of questionnaire changing script to Rich Text Format.<br><br>The dotted lines for responses replaced with boxes to complete which provide more space for answers if hand written and the boxes enlarge if the form is completed electronically. |
| 7. Any other comments? | 'None' (3 participants). Two others commented:<br>"Not enough space to write all my qualifications and grades."<br>"For one of the questions about advice when selecting courses, had several people help, including parents, teachers, career advisers, however question states to pick only one option." | Inclusion of table with headings asking for participants' subjects studied and qualifications.<br><br>Question re-worded to allow more than one option to be selected. |

# Appendix A.6: Follow up questions

Follow up Questions for Year 10 -13 pupils

Re: Project to investigate the educational progress of young people who stammer

Thank you for completing my original questionnaire. As mentioned previously I would now be grateful if you could list your examination results in the table below. Please could you also tell me what you are currently doing e.g. further study/working.

Your name:

Your email address or other contact details:

Exam subjects & results

| Subjects taken (e.g. GCSE, BTech, NVQ) | Results: grades | Date passed (e.g. August 2012) |
|---|---|---|
| | | |

Please list the qualifications and subjects you are planning to study next:

Why have you chosen these subjects?

If you have left school/college please list date of leaving and reason for doing so.

Please describe any employment positions you have held since leaving school or any jobs you are doing whilst you are also studying.

What are your plans for the future e.g. further study or career?

Thank you for taking the time to answer these questions.

Please email or post this completed questionnaire to Helen Jenkins:

Helen.jenkins@bcu.ac.uk or post to me using the stamped addressed envelope.

# APPENDIX A.7: Participant sheet



**Participant Information Sheet**

**Research Project Title**: Educational outcomes and experiences of young people who stammer.

This project is about young people who have difficulty with the flow of their speech which we refer to as non-fluency or stammering. Stammering is a speech difficulty and is known as stuttering in some countries such as America and Australia. Non-fluency or stammering is when a person has difficulty with the flow of their speech despite knowing exactly what they want to say. People have different types of stammering which can include repeating part of a word and/or a speech sound, stretching out speech sounds and/or getting completely stuck on a word. Non-fluency or stammering can be noticeable to other people but some people can hide their stammer so that no one knows about it.

You are being invited to take part in this educational research project. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others (parents/carers) if you wish. Please ask me if there is anything that is not clear or if you would like further information. Take time to decide whether or not you wish to take part. Thank you for reading this.

**What is the project's purpose?**

The purpose of this study is to find out about the school (or college) and career choices and progress of young people who stammer.

This information will be gathered by using a questionnaire which will be emailed or posted to 15-25 year olds who volunteer to take part in the study. There is a second part of the study which will follow up some participants from part one of the study and ask for their views about the educational choices they have made.

**Why have I been invited to take part?**

You are being asked to be involved with this project because you are a young person who has identified yourself as someone who stammers. There will be other young people taking part in this study who have contacted me via the British Stammering Association.

**Do I have to take part?**

It is up to you to decide whether to join in with the project. It is entirely voluntary and no-one will tell your school or employer if you have taken part. If you decide to take part you will be

given this information sheet to keep and be asked to sign a consent form and you can still decide to withdraw from the study at any time without there being negative consequences. You do not have to give a reason.

**What will happen to me if I take part?**

You will be asked to sign a consent form agreeing to take part. If you are under 18 years of age you will also need to tell your parents or carers about the project and ask them to complete a consent form too. You will then need to send these consent forms back to me. Once I have received these forms from you I will email or post you a questionnaire to fill in.

**What do I have to do?**

The questionnaire is a list of short questions which will mainly involve you giving a short answer or brief description and this should take you about 20-30 minutes to do. You will then email (or post) your completed questionnaire to me. If you are currently studying for an exam(s) I will ask you to email or post me your exam results at a later date. At the end of the questionnaire participants will be asked to indicate if they are interested in taking part in the second part of the study. This second phase will take place between November and December 2012 and involve volunteers providing additional answers to questions about their education and job choices during an individual (informal) interview with the researcher which should take up to an hour maximum. Volunteers will be seen for the interview at either the University or at their home (whichever is most convenient) and the interview will be audio taped.

**What are the disadvantages or risks of taking part?**

There are no expected disadvantages or risks in taking part in this study.

**What are the advantages of taking part?**

Although there are no direct benefits for you taking part in the study, you may find through answering questions related to your stammering that you would like some support with your speech. If this happens then I can put you in touch with the British Stammering Association who will be able to advise you. It is also hoped that the responses from you and others taking part will provide valuable information about the educational choices and progress of young people who stammer.

**What happens if the research study stops earlier than expected?**

You will be notified that the research has stopped and the reason for this.

**What if something goes wrong?**

If you are unhappy and wish to complain about any event occurring during or following your participation in the study then you should contact Professor Shelagh Brumfitt, Project Supervisor: s.m.brumfitt@sheffield.ac.uk . If you are dissatisfied with how your complaint is handled then you can contact the University's Registrar and Secretary: Dr. P. Harvey, Registrar & Secretary's Office, The University of Sheffield, Firth Court, Western Bank, Sheffield S10 2TN.

**Will my taking part in this project be kept confidential?**

All the information you give me during the research study will be kept strictly confidential. Your name will not be used in any reports or publications so you cannot be identified. Please see the following website for further information regarding ethical advice on anonymity, confidentiality and data protection:

www.shef.ac.uk/researchoffice/gov_ethics_grp/ethics/factsheets.html

**What type of information will you ask me and why is it important for the research project?**

- The questionnaire will ask you: general information about yourself, details about your stammering and questions about the qualifications and subjects you are studying or have studied at school.

**What will happen to the results of the research project?**

The results of the project will be written up and may be published. However participants will not be identified in these write ups; no participant will be referred to by name. You can ask to see the full report by emailing the researcher and a summary of the research will be available on the British Stammering Association website.

**Who is organising and funding the research?**

Project supervisors: Professor Shelagh Brumfitt & Professor Joy Stackhouse, Department of Human Communication Sciences, University of Sheffield.

**Who has ethically approved the project?**

This project has been ethically approved via the Human Communication Sciences Department's ethics review procedure. The University's Research Ethics Committee monitors the application and delivery of the University's Ethics Review Procedure across the University.

**Contact for further information**

Postgraduate researcher: Helen Jenkins email: helen.jenkins@bcu.ac.uk

Project Supervisor: Professor Shelagh Brumfitt email: s.m.brumfitt@sheffield.ac.uk

# APPENDIX A.8: Consent forms

## Participant Consent Form

Title of Research Project: Educational outcomes and experiences of young people who stammer.

Name of Researcher: Helen Jenkins

Supervisor: Professor Shelagh Brumfitt

**Participant Identification Number for this project:** **Please tick box**

1. I confirm that I have read and understand the information sheet explaining the above research project and I have had the opportunity to ask questions about the project. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline. ☐

3. I understand that my responses will be kept strictly confidential. I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research. ☐

4. I agree to take part in the above research project. ☐

5. I agree for the data collected from me to be used in planning part two of the project. ☐

| _____ | _____ | _____ |
|---|---|---|
| Name of Participant | Date | Signature |

## Parent/Carer Consent Form

Title of Research Project: Educational outcomes and experiences of young people who stammer.

Name of Researcher: Helen Jenkins

Supervisor: Professor Shelagh Brumfitt

**Participant Identification Number for this project:** **Please tick box**

1. I confirm that I have read and understand the information sheet explaining the above research project and I have had the opportunity to ask questions about the project. ☐

2. I understand that my child's participation is voluntary and that he/she is free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should my child not wish to answer any particular question or questions, he/she is free to decline. ☐

3. I understand that my child's responses will be kept strictly confidential. I give permission for members of the research team to have access to my child's anonymised responses. I understand that my child's name will not be linked with the research materials, and will not be identified or identifiable in the report or reports that result from the research. ☐

4. I agree to my child taking part in the above research project. ☐

5. I agree for the data collected from my child to be used in planning part two of the project. ☐

_____ _____ _____

Name of Parent Date Signature

(*or legal representative*)

## APPENDIX A.9: Study One questionnaire

Questionnaire re: study to investigate the educational outcomes and experiences of young people who stammer

Thank you for agreeing to answer these questions. This questionnaire is part of a research project looking at the choices and progress made at school and at work by young people who stammer.

The questionnaire has three sections. Please complete each section by writing or typing your answer in the boxes provided.

Section A: General Information

Your name:

Your email address:

Date of birth:

Gender: e.g. Male  Female

Post code of where you live:

How would you best describe your ethnic background?

E.g. African  American/Black  Caucasian  Asian  Other

What is the main language you speak?

Do you speak any other languages e.g. with family or friends? If your answer is 'Yes' please specify the language(s):

If studying: school/college year group: e.g. year 11

If studying, where are you studying? (Name/address of School/College)

Section B: Speech Details

Do you have difficulty with the flow of your speech which you may describe as non- fluency or stammering? Yes or No

When did you first become aware of your stammering?

How would you describe your stammering?

mild moderate severe

Can you describe what you do when you are stammering? For example, do you repeat parts of words (m-m-m-money); do you stretch out speech sounds (sssssun); do you get completely stuck and say nothing; do you hide it by saying instead another word that is easier to say?

How does your speech difficulty make you feel?

When does it happen the most?

When does it happen the least?

Are you receiving help from a Speech and Language Therapist for your stammering? Yes or No. If yes, please give name of your speech & language therapist.

Have you had Speech and Language Therapy in the past for your stammering? Yes or No

Are you receiving help from anyone else for your stammering?

If your answer is ‘yes’ please say below the person who helps you e.g. teacher, parents

Do you know if anyone in your family has ever stammered?

Yes No

If your answer is ‘Yes’ please list who, e.g. father, uncle, grandmother

Do you have any other speech and language difficulties, such as, dyspraxia, dyslexia? If so please list below

Section C: Educational Qualifications

What qualifications and subjects are you currently studying or have studied in the past? E.g. GCSEs, 14-18 Diploma, AS levels, A levels, BTech certificate/diploma or any other qualifications

Please list the qualifications, subjects and any grades achieved in the table below:

| Subjects taken (e.g. GCSE, BTech, NVQ, A levels) | Results: grades | Date passed (e.g. August 2012) |
|---|---|---|
| | | |

Why did you choose these subjects?

Did anyone help or advise you with choosing your subjects? Yes No

If your answer is 'Yes' please indicate the person(s) below:

Teacher Careers advisor Parent Friend Other (please say who):

Which subject(s) do you enjoy the most? Why?

Which subject(s) do you least enjoy? Why?

Do you feel your stammer has influenced the choice of subjects you are studying? Yes No

If your answer is yes please briefly describe how:

If you have left school/college please list date of leaving and reason for doing so.

Please describe any employment positions you have held since leaving school or any jobs you are doing whilst you are also studying.

What are your plans for the future e.g. further study or career?

Future contact:

1. I will contact you again, via email, to ask you to send me any outstanding examination results and for information regarding your future educational choices (if applicable).

2. As mentioned in the information sheet the second part of the project will follow up some participants from this first study. This second study will aim to find out further information about the educational and employment choices participants have made. This further study will involve participants providing additional answers to questions during an informal discussion/interview.

I am inviting you to take part in the second phase of this research project. Please could you indicate whether you would be willing to be involved in this further project?

Yes /No

If you answer 'Yes' then I will send you, at a later date, information about this further study.

Thank you for taking the time to answer these questions.

Please return this completed questionnaire to Helen Jenkins either by: Email to: Helen.Jenkins@bcu.ac.uk or Post to: Helen Jenkins, Birmingham City University, Department of Speech & Language Therapy, Seacole West, Westbourne Road, Edgbaston, Birmingham B15 3TN

# APPENDIX B. Study Two (Interviews)

## Appendix B.1: Pilot interview schedule/topic guidelines

Interview schedule:

Introduction/ Confidentiality

Participant's name: ……..

Date: ……. Code: ……..

Thank you for agreeing to come and talk to me today. This interview is part of the research study that you have been participating in over the last few months. You have already completed a questionnaire and you have sent me your recent exam results. The interview today is the next part of the study will focus on asking you more detail about your school/college/university progress, your experience of stammering and your future plans. Before we start, I want you to know that what we discuss today is completely private and confidential. I will not be telling anyone (parents/teachers/speech & language therapist) about what you say to me.

Interview topics

1. Description of present/previous school/college e.g. type, size, location

2. General/overall educational experience

3. Description of academic progress, including discussion of exam results and perceived impact of stammering

4. Participation at school e.g. in lessons, extra-curricular activities and perceived impact of stammering

5. Experiences with others e.g. teachers, peers and family and perceived impact of stammering

6. Help and support at school for educational progress e.g. from teachers, peers and family; what helped most/least; help you may have liked to have received/possible changes or improvements to support

7. Speech and language therapy experiences e.g. support for stammering/school progress

8. Perceived differences in school experiences for people who do not stammer

9. Current study/employment e.g. what subjects/qualifications/course are now being studied; why these subjects/course chosen OR work e.g. full/part time job; out of work OR Gap year/other activity

10. Future plans e.g. further academic study, career preferences

## Appendix B.2: Stammering severity rating scale

Speech Rating

Please rate below the frequency of your stammering using the scale below.

1= no stammering, 2= extremely mild stammering, 9= extremely severe stammering.

Put a circle round the number which you feel best describes your speech.

none extremely severe

| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|---|---|---|---|---|---|---|---|---|

Speech Impact on life rating

Please rate below the possible impact your speech has or had on the flowing aspects of your life.

Put a circle round the number which you feel best describes the impact.

At school/college

not at all extremely severe

| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|---|---|---|---|---|---|---|---|---|

At work (if applicable)

not at all extremely severe

| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|---|---|---|---|---|---|---|---|---|

Participant Number:

Date:

## Appendix B.3: Rosenberg's self-esteem scale (1969)

The questions below ask about your current feelings about yourself. For each of the following, please circle the answer that best describes how strongly you agree or disagree with the statement about yourself.

| Statement | Strongly agree | Agree | Disagree | Strongly disagree |
|---|---|---|---|---|
| 1. I feel that I'm a person of worth, at least on an equal plane with others. | SA | A | D | SD |
| 2. I feel that I have a number of good qualities. | SA | A | D | SD |
| 3. All in all, I am inclined to feel that I am a failure. | SA | A | D | SD |
| 4. I am able to do things as well as most other people. | SA | A | D | SD |
| 5. I feel I do not have much to be proud of. | SA | A | D | SD |
| 6. I take a positive attitude toward myself. | SA | A | D | SD |
| 7. On the whole, I am satisfied with myself. | SA | A | D | SD |
| 8. I wish I could have more respect for myself. | SA | A | D | SD |
| 9. I certainly feel useless at times. | SA | A | D | SD |
| 10. At times I think I am no good at all. | SA | A | D | SD |

Participant Number:

Date:

## Appendix B.4: Rosenberg's self-esteem scale – scoring

Scores are calculated as follows:

- *For items 1, 2, 4, 6,* and *7:*

  Strongly agree = 3
  Agree = 2
  Disagree = 1
  Strongly disagree = 0

- *For items 3, 5, 8, 9,* and *10* (which are reversed in valence):

  Strongly agree = 0
  Agree = 1
  Disagree = 2
  Strongly disagree = 3

The scale ranges from 0-30. Scores between 15 and 25 are within normal range; scores below 15 suggest low self-esteem.

## Appendix B.5: Participant's completed Rosenberg's self-esteem scale

The questions below ask about your current feelings about yourself. For each of the following, please circle the answer that best describes how strongly you agree or disagree with the statement about yourself.

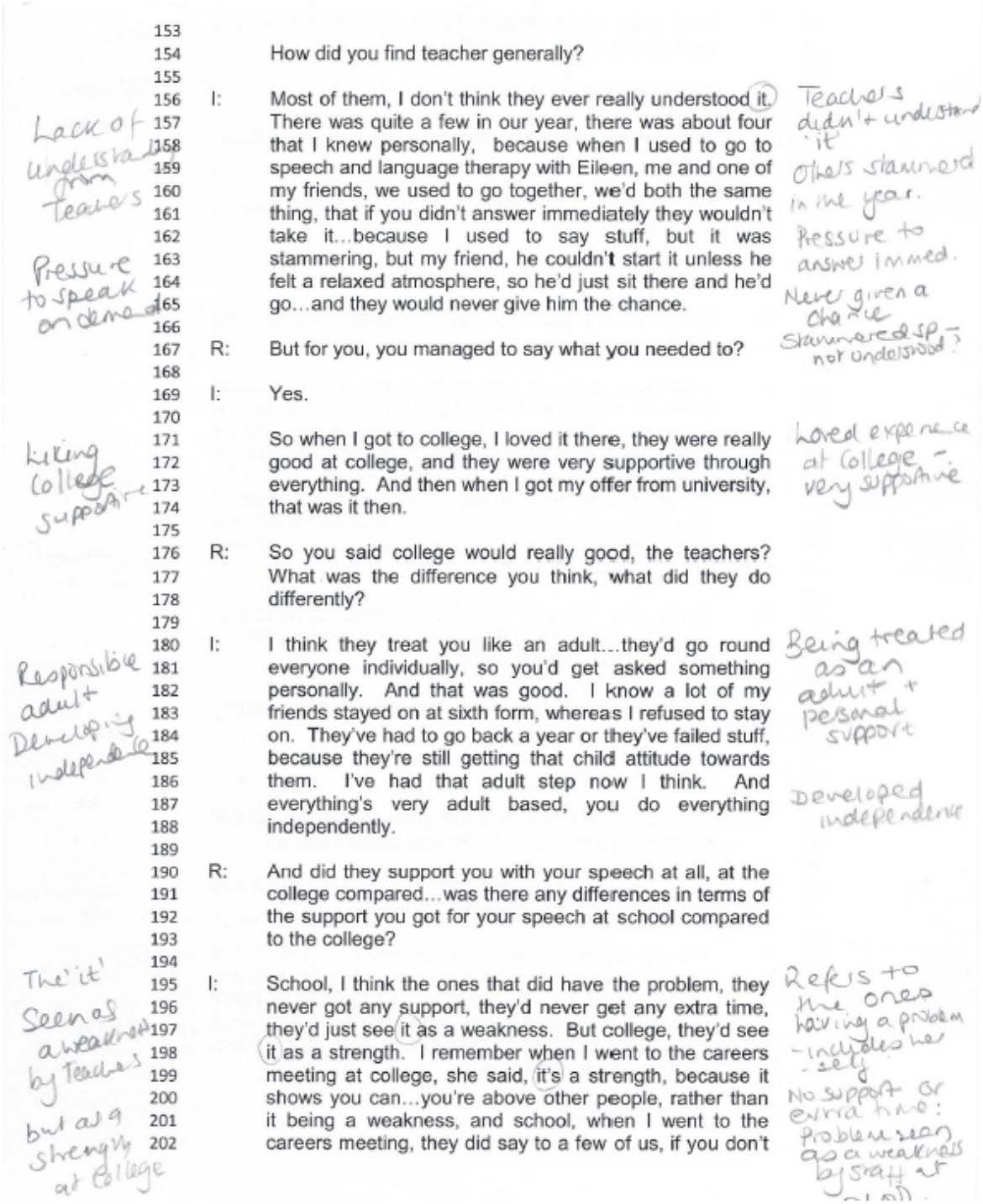
| Statement | Strongly agree | Agree | Disagree | Strongly disagree | Score |
|---|---|---|---|---|---|
| 1. I feel that I'm a person of worth, at least on an equal plane with others. | SA | (A) | D | SD | 2 |
| 2. I feel that I have a number of good qualities. | SA | (A) | D | SD | 2 |
| 3. All in all, I am inclined to feel that I am a failure. | SA | A | (D) | SD | 2 |
| 4. I am able to do things as well as most other people. | (SA) | A | D | SD | 3 |
| 5. I feel I do not have much to be proud of. | SA | A | D | (SD) | 3 |
| 6. I take a positive attitude toward myself. | SA | (A) | D | SD | 2 |
| 7. On the whole, I am satisfied with myself. | SA | (A) | D | SD | 2 |
| 8. I wish I could have more respect for myself. | SA | A | (D) | SD | 2 |
| 9. I certainly feel useless at times. | SA | A | (D) | SD | 2 |
| 10. At times I think I am no good at all. | SA | A | D | (SD) | 3 |

Participant Number: 30

Date: 24/04/2014

Self-esteem Score = 2.

## Appendix B.6: Example of a participant's transcript



How did you find teacher generally?

I: Most of them, I don't think they ever really understood it. There was quite a few in our year, there was about four that I knew personally, because when I used to go to speech and language therapy with Eileen, me and one of my friends, we used to go together, we'd both the same thing, that if you didn't answer immediately they wouldn't take it...because I used to say stuff, but it was stammering, but my friend, he couldn't start it unless he felt a relaxed atmosphere, so he'd just sit there and he'd go...and they would never give him the chance.

R: But for you, you managed to say what you needed to?

I: Yes.

So when I got to college, I loved it there, they were really good at college, and they were very supportive through everything. And then when I got my offer from university, that was it then.

R: So you said college would really good, the teachers? What was the difference you think, what did they do differently?

I: I think they treat you like an adult...they'd go round everyone individually, so you'd get asked something personally. And that was good. I know a lot of my friends stayed on at sixth form, whereas I refused to stay on. They've had to go back a year or they've failed stuff, because they're still getting that child attitude towards them. I've had that adult step now I think. And everything's very adult based, you do everything independently.

R: And did they support you with your speech at all, at the college compared...was there any differences in terms of the support you got for your speech at school compared to the college?

I: School, I think the ones that did have the problem, they never got any support, they'd never get any extra time, they'd just see it as a weakness. But college, they'd see it as a strength. I remember when I went to the careers meeting at college, she said, it's a strength, because it shows you can...you're above other people, rather than it being a weakness, and school, when I went to the careers meeting, they did say to a few of us, if you don't

# APPENDIX C. Participants' quantitative data collected during the interviews

# Appendix C.1: Participants' and researcher's stammering severity scores

Participants' perceived stammering severity

| **Self –reported stammering severity** | **Participants** |
|---|---|
| Not at all (score of1) | None |
| Extremely mild (score of 2) | Ben, Callum, Isla |
| Mild (score of 3-4) | Adam, Darren, Floyd, Harry, Jess, Kyle, Liam, Nikki, Owen, Piippa |
| Moderate (score of 5-6 | Gary, Mia |
| Severe (score of 7-8) | Ed |
| Extremely severe (score of 9) | None |

Differences between participant self-reported and researcher reported stammering severity scores (Scale: (scale1-9; 1=no stammering; 9=extremely severe stammering)

| **Participant** | **Self –reported stammering severity** | **Researcher reported stammering severity** | **Difference in rating** |
|---|---|---|---|
| Adam (2) | 4 | 5 | +1 |
| Ben (4) | 2 | 5 | +3 |
| Callum (6) | 2 | 2 | 0 |
| Darren (7) | 4 | 6 | +2 |
| Ed (12) | 8 | 8 | 0 |
| Floyd (15) | 3 | 6 | +3 |
| Gary (24) | 6 | 5 | -1 |
| Harry (29) | 3 | 3 | 0 |
| Isla (30) | 2 | 3 | +1 |
| Jess (31) | 4 | 4 | 0 |
| Kyle (32) | 4 | 3 | -1 |
| Liam (34) | 4 | 3 | -1 |
| Mia (36) | 6 | 7 | +1 |
| Nikki (37) | 4 | 7 | +3 |
| Owen (40) | 4 | 5 | +1 |
| Pippa (41) | 4 | 6 | +2 |

## Appendix C.2: Participants' impact on life scores

Participants' perceived impact of stammering on school life

| Impact of stammering on life at school | Participants |
|---|---|
| Not at all (score of 1) | Adam |
| Extremely mild (score of 2) | None |
| Mild (score of 2-4) | Ben, Floyd, Isla, Owen |
| Moderate (score of 5-6) | Callum, Gary, Nikki, Pippa |
| Severe (score of 7-9) | Darren, Ed, Harry, Jess, Kyle, Liam, Mia |
| Extremely severe (score of 8) | None |

Participants' perceived impact of stammering on their lives in different educational contexts

| Participants | Impact of stammering on life in education (Scale:1-9; 1=not at all; 9=extremely severe) | | |
|---|---|---|---|
| | School | College | University |
| Callum | 6 | 4 | Not applicable |
| Darren | 7 | 4 | 2 |
| Mia | 7 | 6 | 4 |

Participants' perceived impact of stammering on work life (Scale:1-9; 1=not at all; 9=extremely severe)

| Impact of stammering on work life | Participants |
|---|---|
| Not at all (score of 1) | Darren |
| Extremely mild (score of 2) | Callum, Ed, Gary, Pippa |
| Mild (score of 2-4) | Ben, Floyd, Harry, Isla, Kyle, Nikki, Owen |
| Moderate (score of 5-6) | Adam, Mia |
| Severe (score of 7-9) | Jess, Liam |
| Extremely severe (score of 8) | None |

## Appendix C.3: Participants' self-esteem scores

## (Rosenberg's self-esteem scale, 1965)

Participants' self-esteem scores (Scale 0-30; scores between 15-25= within normal range; scores below 15 = low self-esteem)

| Participant | Self-esteem score |
|---|---|
| Adam (2) | 23 |
| Ben (4) | 27 |
| Callum (6) | 25 |
| Darren (7) | 24 |
| Ed (12) | 28 |
| Floyd (15) | 29 |
| Gary (24) | 26 |
| Harry (29) | 18 |
| Isla (30) | 23 |
| Jess (31) | 12 |
| Kyle (32) | 23 |
| Liam (34) | 19 |
| Mia (36) | 26 |
| Nikki (37) | 21 |
| Owen (40) | 18 |
| Pippa (41) | 18 |

## Appendix C.4: Participants' responses to Rosenberg's

## self-esteem statements

| Statement | Positive responses | Negative responses |
|---|---|---|
| 1. I feel that I'm a person of worth, at least on an equal plane with others. | All participants | None |
| 2. I feel that I have a number of good qualities. | Adam, Ben, Callum, Darren, Ed, Floyd, Gary, Harry, Isla, Kyle, Liam, Mia, Nikki, Owen, Pippa | Jess |
| 3. All in all, I am inclined to feel that I am a failure. | Adam, Ben, Callum, Darren, Ed, Floyd, Gary, Harry, Isla, Kyle, Liam, Mia, Nikki, Pippa | Jess<br>Owen |
| 4. I am able to do things as well as most other people. | Adam, Ben, Callum, Darren, Ed, Floyd, Gary, Harry, Isla, Kyle, Mia, Nikki, Owen, Pippa | Jess<br>Liam |
| 5. I feel I do not have much to be proud of. | All participants | |
| 6. I take a positive attitude toward myself. | Adam, Ben, Callum, Darren, Ed, Floyd, Gary, Harry, Isla, Kyle, Liam, Mia, Nikki, Owen, Pippa | Jess |
| 7. On the whole, I am satisfied with myself. | Adam, Ben, Callum, Darren, Ed, Floyd, Gary, Harry, Isla, Jess, Liam, Mia, Nikki, Pippa | Kyle<br>Owen |
| 8. I wish I could have more respect for myself. | Ben, Callum, Darren, Ed, Floyd, Gary, Isla, Kyle, Liam, Mia, Nikki, Owen | Adam<br>Harry<br>Jess<br>Pippa |
| 9. I certainly feel useless at times. | Ben, Darren, Ed, Floyd, Gary, Isla, Kyle, Mia, | Adam, Callum, Harry, Jess, Liam, Nikki, Owen, Pippa |
| 10. At times I think I am no good at all. | Adam, Ben, Callum, Darren, Ed, Floyd, Gary, Harry, Isla, Kyle, Liam, Mia, Pippa | Jess<br>Nikki<br>Owen |