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Exploring the educational experiences of children and young people with non-syndromic cleft lip and/or palate in the west of Scotland.

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A B S T R A C T

Historically, society has developed and presented the concept of 'disability' in negative terms. This in turn led to the identification of individuals/groups with some medical conditions as 'different' from the general population. However, this theory has more recently been challenged by the narrative of inclusion which has contributed to questioning the term 'difference' and has replaced it with 'diversity'.

Young people with cleft have previously been identified in society by their 'difference' due to speech and appearance issues. Existing literature, largely from medical professionals, suggested that young people with cleft underachieve. Studies to date have been mainly carried out using quantitative methods. These investigations suggested a number of areas of challenge – primarily linguistic, cognitive, self-concept and concerning the expectations of others. In contrast, this research set out to attempt to understand more deeply the reasons for the suggested underachievement using qualitative research methods to explore the social and educational lives of young people with cleft at three different stages in their development.

This research found that the narrative of underachievement among the young people with cleft involved in the study did not follow the pattern expected as it emerged from the medical literature. Overall individuality characterised the learning trajectory of the young people with cleft. All young people were making progress in their learning albeit at their own speed and as appropriate, with support. The experiences of learning at clubs/associations was more inclusive than those at school where no support was required and there were different expectations of adults supporting learning in clubs and schools. Labelling was a contentious issue but in individual cases this had negative consequences which were counterbalanced by friendship circles often formed at nursery school. This study highlighted teachers' lack of knowledge of this medical condition and its potential consequences for educational experiences in individual cases and a lack of interpersonal and inter-agency communication.

This study therefore challenges the deeply integrated societal stereotypes of young people with cleft. It highlights the importance of listening to children's voices and offers suggestions to both educational and medical professionals for improving the experiences of the young people concerned.

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Author's Declaration

I declare that, except where explicit reference is made to the contribution of others, that this thesis, *Exploring the educational experiences of children and young people with non syndromic cleft lip and/or palate in the west of Scotland* is the result of my own work and has not been submitted for any other degree at the University of Glasgow or any other institution.

Signature:

Printed Name: ALICIA MARION GIFFEN

ABBREVIATIONS

BB	Boys' Brigade
BBM	Blackberry Messenger Service
BCLP	Bilateral Cleft Lip and Palate
CAD	Compensatory Articulation Disorder
CfE	Curriculum for Excellence
CLAPA	Cleft Lip and Palate Association
Cleft	Generic term for cleft in general
Cleft Lip and/or palate	Cleft Lip and Palate and Cleft Palate Only
CLEFTSiS	National Managed Clinical Network for Cleft Service in Scotland
CLP	Cleft Lip and Palate
CPD	Continuing Professional Development
CPO	Cleft Palate Only
ENT	Ear Nose and Throat
ICT	Information and Communications Technology
IQ	Intelligence Quotient
NHS	National Health Service
PE	Physical Education
RCSLT	Royal College of Speech and Language Therapists
SCQF	Scottish Credit and Qualifications Framework
SIMD	Scottish Index of Multiple Deprivation
SQA	Scottish Qualifications Authority
UCLP	Unilateral Cleft Lip and Palate
UNCRC	United Nations Convention on the Rights of the Child
UNESCO	United Nations Educational, Scientific and Cultural Organisation

Cleft lip and palate, cleft palate only, child-centred, inter-agency working, progress in learning.

C H A P T E R   O N E
The Introduction to the Study

1.1   Background to the Study

1.1.1   The Introduction

This is a study exploring the educational experiences of young people who have been perceived to have shared a similar journey - one where they have had cleft lip and/or palate. This introductory chapter is divided into four sections. The first section provides a background to the study, covering the origins of how I first became interested in the subject area and how my motivation to undertake the study developed. Secondly, there is a discussion of the area this study will address. Thirdly, the chapter identifies the research questions that underpin the study.   The final section of this chapter provides an overview of the thesis structure.

1.1.2   The origins of the study

I had the privilege of teaching pupils, aged between twelve and eighteen years of age, with various physical disabilities, for two years. During this time, I had the pleasure of seeing young people achieving success in their studies. Their standards of attainment were often high and their resilience when faced with learning challenges was impressive to everyone who worked with them, but at the same time humbling for me. I wished to understand more about how young people managed to achieve so much whilst at the same time dealing with what could be a significant disability. I elected to undertake a study for my Master of Education degree working with three pupils with severe communication disorders.

At the same time as working towards my Master's degree, I was attending the hospital as a patient because I had to undergo an operation to remove a pleomorphic adenoma in my cheek. The operation held a risk that my speech nerve could be damaged and this made me reflect on how important communication was in everyday life. When I returned to my studies I chose a course in communication difficulties which included the topic of cleft.

The term 'cleft' (NHS, 2014 a) is a generic term that includes different cleft conditions. At a subsequent check-up at the hospital for my own medical condition I noticed the surgeon was wearing a badge indicating he was a cleft palate surgeon and we began to discuss the issue of cleft. Realising I was interested in the subject area and working on a study about communication at the university he invited me to attend his clinic to extend my knowledge of cleft. Such was my interest that I made four subsequent visits and when I completed my degree of MEd I decided to offer to undertake a study in cleft lip and/or palate for the degree of Doctor of Philosophy, working at the interface of education and medicine.

After permission was granted for me to undertake this study in cleft lip and/or palate I arranged a meeting with the supervisors and the surgeon and speech therapist. We discussed my experiences in teaching, especially those experiences where young people, even when facing profound challenges, achieved so much in the school where I worked. He reflected on the relationship between cleft and achievement and described a perception that young people with cleft were underachieving although the reasons for this were unclear. The discussion stayed with me. Having previously taught pupils with physical disabilities who were simultaneously undergoing medical treatment, knowing their success in their studies raised questions about cleft in my mind. What was the reality of attempting to learn whilst dealing with cleft lip and/or palate? This was the catalyst for my study.

1.1.3 The issue of cleft

> A cleft is a gap or split in either the upper lip or the roof of the mouth (palate) or sometimes both. It occurs when separate areas of the face do not join together properly when a baby is developing during pregnancy (NHS, 2014b).

"Around one in seven hundred babies are born with a cleft around the world. That's over a thousand babies born with a cleft each year in the UK…. A cleft lip and/or palate is the most common craniofacial anomaly" (CLAPA, 2015a). The number of young people with cleft has been increasing because of the lower neonatal mortality rate, a rise in environmental teratogens, and increased marriage and childbearing amongst patients with cleft because of better care and outcomes (Watson, 2005). It is therefore increasingly possible that those who are involved in providing learning experiences, will encounter young people with cleft in their class or group.

Clefts can vary in severity, and each case may be placed somewhere on a wide continuum stretching from the least severe, a tiny notch on the lip (called a forme fruste or microform cleft) through to clefts that extend from the lip through the alveolar region and right across the palate. The cleft of the lip can be one-sided (usually on the left) called a unilateral cleft and two-sided, termed bilateral. The latter variation of the condition is more severe. Figure 1.1 below offers a pictorial comparison of the three biological structures which are relevant to this study:
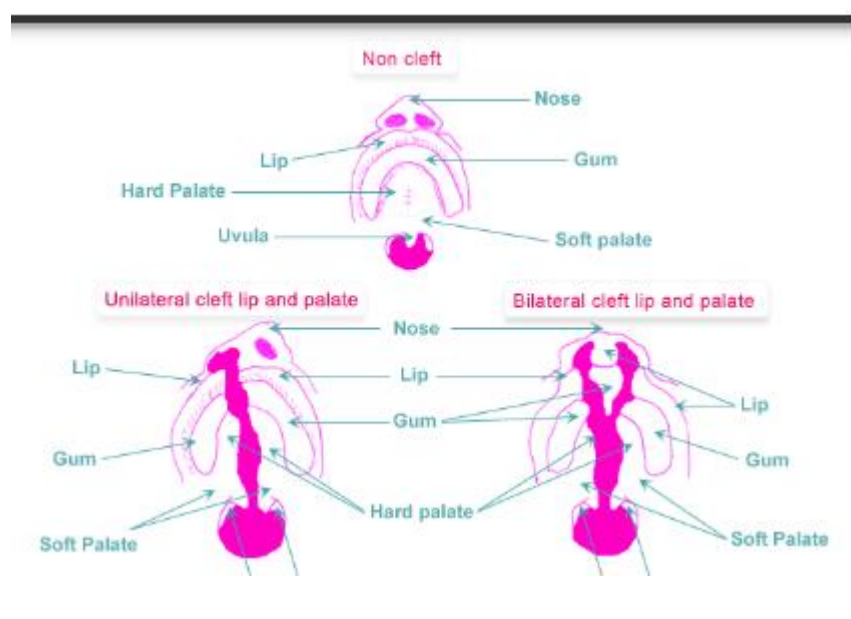
Figure 1.1: A comparison of the oral biological structures for non-cleft, unilateral, and bilateral cleft lip and/or palate cases (Spirecentre, NHS, 2014).

This study explores two variations of cleft which have different aetiologies (Fraser, 1955) – cleft lip and palate (CLP) and cleft palate only (CPO). Both medical conditions occur in utero and are present at birth. In this investigation the conditions are not associated with syndromes such as Stickler Syndrome or Van Der Woude Syndrome (Peterson-Falzone, Hardin-Jones, and Karnell, 2010). Similarly, those with cleft of the lip only are excluded due to lack of patient contact with the hospital beyond the initial lip repair at around three months of age. It is also acknowledged that some patients can present at hospital later in life with problems due to "severe injuries to the oral structures or from ablative surgery, usually for the treatment of malignant tumours" (McWilliams, Morris and Shelton, 1984, p.1). Such young people are also not participants in this study.

Cleft (CLAPA, 2015b) is sometimes but not always discovered by ultrasound during pregnancy and although abnormalities in the outline of the foetal face can be identified as early as twelve to fourteen weeks, identification is more usual at eighteen to twenty-two weeks (Chitty and Griffin, 2005). In Scotland, the policy recommended by National Health Service Quality Improvement Scotland is to check the foetus during the ultrasound at around twenty weeks. A study of the incidence of prenatal diagnosis was carried out in Glasgow over the period 1999 to 2008 (Paterson, Sher, Wylie, Wallace, Crawford, Sood, Gilgrass, Ray, and Devlin, 2011). These researchers found the percentage of all cleft cases diagnosed prenatally to be twenty-eight percent (2008) raising the possibility of heightened reactions of unprepared parents at the time of birth.

The effects on young people of orofacial cleft can be far reaching. Cleft can affect the physical growth and development of the teeth, speech, hearing, feeding capabilities and psychomotor and cognitive skills, creating both physical and psychological challenges (Strauss and Cassell, 2009). With clefts of the lip and alveolar region the frontal section of the face can be misshapen (the maxilla) and there can be a hole in the floor of the nose. Ross (1970, p.37) argued that "the major growth problem is maxillary retrusion." This means that due to abnormal growth in the mid-face region, teeth in the upper jaw lie behind those in the lower jaw when the person closes their mouth.

"The earliest documented history of cleft lip is based on a combination of religion, superstition, invention and charlatanism" (Bhattacharya, Khanna, and Kohli, 2009, p.54). Yet as far back as 390 BCE when the first recorded cleft lip repair was performed the patient went on to become Governor General of several regions of China (Miloro, Ghali, Larsen, and Waite, 2012). It was a dentist, Le Monnier, in 1766 in Paris who performed the first cleft palate repair and the advanced surgical procedures that are utilised by surgeons today have evolved from his straight-line repair to the use of cutbacks, triangles and Z-plasties. (Miloro, et al., 2012).   Figure 1.2 below offers a diagrammatical representation of the medical treatments provided for cleft and approximate age ranges for receiving such treatments:
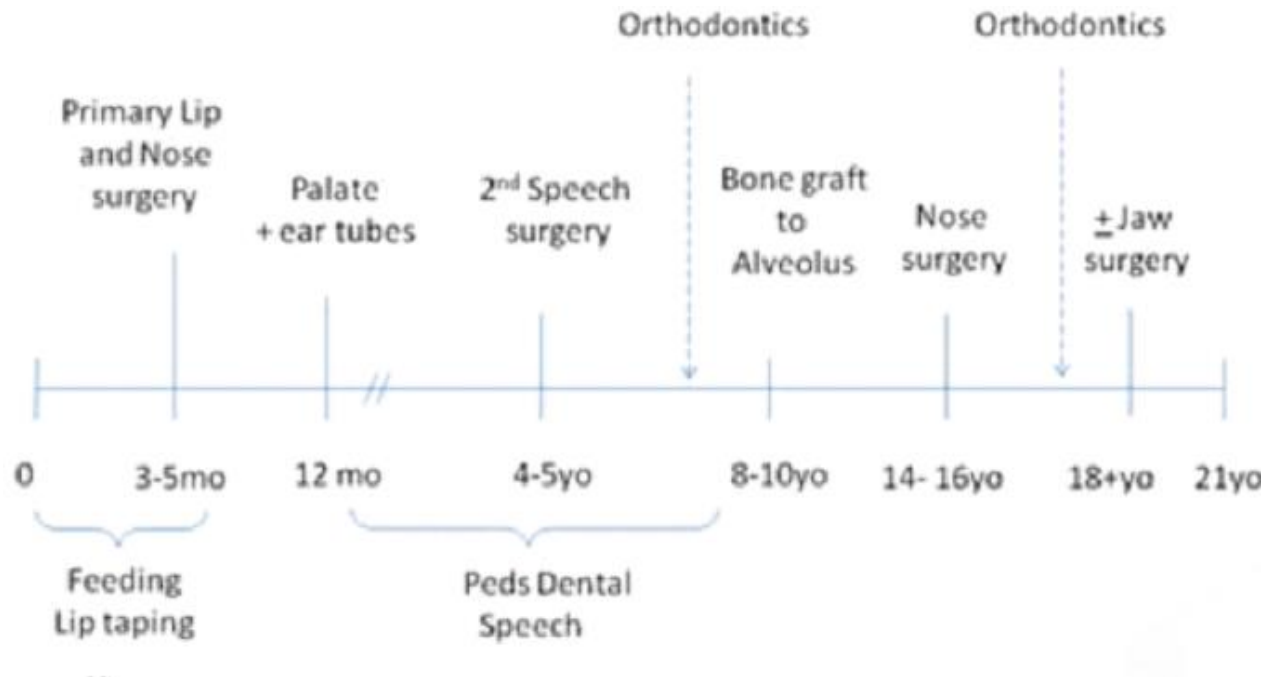
Figure 1.2: Timeline for the various medical treatments provided for cleft patients
(Oregon Health Science University Education, 2016)

Care for the child with cleft is undertaken by a multidisciplinary cleft palate/craniofacial
team who become involved as soon as the cleft is diagnosed, either before (through
ultrasound scan) or after the baby arrives. The team in the west of Scotland includes
specialists in the following disciplines: surgery, speech and language therapy, orthodontics,
dentistry, genetics, audiology, and psychology.

The visits to the cleft clinic alerted me to possible issues with speech, appearance and the
apparent importance of the role of others supporting the young people with cleft. This was
supplemented by the reading of relevant medical and educational texts. In the section that
follows, I discuss the medical and educational approaches to 'difference' and then consider
the areas this investigation will explore from an educational perspective.

1.2   A Discussion of Disability

In this section I endeavour to explore the evolution of approaches to disability and relate
these to different models of research. I continue by considering how 'difference' is
portrayed and how this may affect the concept of inclusion in education.

1.2.1 Approaches to disability

> While all societies have faced the fact of individuals who differed physically, intellectually or socially, how these differences have been addressed mirrors the vibrant and shifting gestalt of societal dynamics and forms one critical indicator of a society's humanity. (Winzer, 2007, p.21).

Two key perspectives are commonly adopted in relation to social science research – positivism and constructivism, (Denzin and Lincoln, 2011). This theorisation has also been reflected in medicine, although, medical professionals have traditionally embraced the positivist approach to knowledge creation. They have adopted a dualist view of a world outside to be discovered, an environment separate from the human being. Whereas, educationalists have more recently been moving towards a constructivist position – knowledge is created by interpretations of experiences of the people concerned. These experiences have been formed by interaction with the social and physical environment. The majority of studies about cleft and educational achievement have been carried out by medical professionals of different genres, based on a positivist perspective, using quantitative methodology (Richman, 1976; Richman and Eliason, 1982, 1984; Richman and Nopoulos, 2008 and Persson, Becker and Svensson 2012). However, there is evidence of change and more recent research studies carried out by medical professionals on cleft such as those of Moran and Pentz, (1995), Marshman, Baker, Bradbury, Hall and Rodd, (2009) and Tierney, O'Brien, Harman, Sharma, Madden, and Callery, (2015) evidence a change in approach towards researching within a constructivist perspective, using qualitative methodology. After an extensive search of the literature about cleft, I found that this was an area that had received little attention by educational researchers. I discovered only one study carried out by an educational professional (Gibbons, 2006) using a constructivist approach.

Within society, disability has been viewed from various perspectives. Based on previous work by Fulcher (1989) and Riddell (1996), Slee (1998, p.128) frames these perspectives as a five stage model of disability: medical perspectives/model, (for example, Laing, 1971), social constructionist perspectives (for example, Barton, 1997, 2003; Slee, 1998; Dyson and Milward, 2000; Allan, 2008; Riddell, 2009), material perspectives, (for example, Abberley, 1987; Oliver, 1990), postmodern perspectives (for example, Derrida,

1967; Foucault, 1977; Corker and Shakespeare, 2002; Young, 2011) and disability movement perspectives (for example, Oliver, 1990; Finkelstein, 1996). The medical model is differentiated from the other four perspectives as these four approaches come under an umbrella title of 'social models of disability' (Oliver, 1990). The medical model of disability focuses on the individual's "personal disease, pathology, disorder or deficit" (Christensen, 1996, p.64) and links this to their medical condition whereas the many variations of the social model agree "the inhospitable physical environment, in concert with the negative social attitudes that disabled people encounter result in the systematic oppression, exclusion and discrimination of disabled people" (Lang, 2001, p.2). For example, people with disabilities were historically portrayed in the media as "objects of entertainment, pity, fear, horror, humour and pathos" (Meekosha and Jakubowicz, 1996). However, with the establishment of the Union of the Physically Impaired Against Segregation (1976) groups of disabled peoples came together to seek their own empowerment and representation in society. This was the origin of the social model of disability (Barnes and Mercer, 2004). Variations of the social model include: social constructivism (knowledge built from experiences of people with disabilities), materialist perspectives (based on the capitalist system's oppression of people with disabilities because they are perceived as less economically productive), and postmodern perspectives (which rejects the notion of one collective group of people in society entitled 'the disabled' and instead emphasises complexity, and fluidity of the experiences of those with disabilities).

Theories of disability can be linked to epistemological stances. The medical model evolved from the positivist stance on knowledge creation with disability being viewed through a biological lens, focussing on the pathology within the child. Medical professionals measured information from the child's case against a standard which was fixed objectively, and then documented their results in statistical terms (Laing, 1971, Oswell, 2013). Sociologists like Oswell (2013, p.191) challenge this view by contending that all the individual statistics accumulated over the years "don't produce a single adequate image." In addition, some medical researchers (Wilson, 2000; Walsh and Gillett, 2011) although agreeing evidence based methods were positivist, contend that this does not reflect fully doctors' practices.

Until the middle of the twentieth century, educational professionals concerned with young people with disabilities also embraced the positivist approach and used the medical model to categorise the young people by their medical condition, emphasising their personal and functional limitations (Farrell, 2004). But, within society attitudes towards disability were evolving during the second half of the last century, and this was reflected in education as a transition to constructivist thinking linked to the social model (Winzer, 2007). Attention turned to the unique interpretations of the experiences of the young people and the importance of context (Dewey, 1938). The more holistic view of each young person meant that an analysis of disability had to look beyond the person and include wider factors in the person's relationship with the environment, both social and physical, (Montessori, 1946 Bruner, 1961, Vygotsky, 1978).

In this investigation, my interest moves beyond the narrow constrictions of disability that has emerged from the medical literature towards the social model, and more specifically, social constructivist perspectives where the testimony of the young people occupies a central role and provides a structure for the design of the study.

1.2.2 'Difference' and 'diversity'

'Difference' is portrayed in the literature in different ways. Hevey, (2004) describes the major distinction as being between those who see 'difference' as a source of division and those who embrace 'difference' as a source of new energy, of 'diversity' and variety. When 'difference' is associated with unequal or inferior status or to a position of subordination (Williams, 1992) this could have negative consequences for the learning of young people identified as 'different'.

Foucault, (1991, p.308) highlighted the use by institutions of "banal sets of practices" which afforded the institutional officials control of population groups. An example of this was that 'difference' could be facilitated and reinforced by institutional officials attaching labels to young people for separation purposes. Medical professionals were officials - adhering to the principles of the medical model - utilising diagnostic labelling for separating patients according to their medical condition. In a positivist manner, treatment plans were drawn up to offer remedies to cure or at least ameliorate the condition which resided in the patient. In the past, educationalists have also utilised diagnostic labelling,

this time as a means of separating learners into groups according to their pathology, giving legitimacy to the placement of some young people with disabilities into special schools. The educationalist's professional status also offered them specialised knowledge and status (Tomlinson, 2017).

The use of labelling and its consequences could extend beyond the level of the institution. For young people the construction of the self-concept is influenced by interactions with others – parents, teachers, club leaders, peers (Bronfenbrenner, 1979). For young people with disabilities, if any or a combination of the latter groups utilised labels to emphasise 'difference' this could have a negative effect on the self-concept of the young people leading to possible negative impact on their educational achievement through social rejection (Lindsay, Dockrell, and Mackie, 2008). A central premise of a socially constructivist view of knowledge creation is that equal respect is given to all contributors. But, labels could facilitate unequal power relations between labelled and labeller (Thomas and Loxley, 2001) reducing the value of collaborative practices in knowledge creation. If young people are medically labelled, educational professionals may assume that issues occurring in school relate to the medical label, dissuading educational professionals from further investigations and action (Bailey and Barton, 1999). Further difficulties of using labels can be listed as follows: they are self-fulfilling, difficult to shift and the individual negatively labelled may submerge under this status (Thomas and Loxley, 2001).

'Difference' is a common theme emerging from literature on young people with cleft. Any child with nonsyndromic cleft could have speech (Peterson-Falzone, Hardin-Jones and Karnell, 2010) and appearance issues (Rumsay and Harcourt, 2007). This perception of 'difference' could be exacerbated due to the ongoing, long-term specialised medical treatment that is sometimes involved with the conditions of CLP and CPO, resulting in an increased susceptibility to absence issues (Moran and Pentz, 1995). There is also a greater chance of sleep apnoea (MacLean, Hayward, Fitzgerald, and Waters, 2009) causing tiredness during school activities and when participating in interests outside of school. In education, both the national and international policy are that young people with cleft should not be separated from other young people, solely on the criterion of a medical label (Salamanca Statement, UNESCO, 1994; Standards in Scotland's Schools Act, 2000, Section 15). Nevertheless, as described above, the literature suggests that this does not necessarily mean that labelling is not happening in schools in other, unforeseen ways.

It was better Williams (1992, p.70) suggested to move from 'difference' towards 'diversity' which he defined as "a shared collective experience which is specific and not necessarily associated with a subordinated or unequal subject position."

1.2.3 Inclusion in Education

I have spoken of the way society has socially constructed 'difference' and the associated issues of labelling and I will now discuss how 'diversity' is currently perceived and interpreted within education through theories of inclusion.

From the nineteenth century young people with disabilities were considered "different, deviant and charity recipients" (Winzer, 2007, p.25). In 1858, as part of an agreement with the government to grant medical practitioners professional status, "it served state interests that the confinement and subsequent education of defective (sic) children should be overseen by medical men" Tomlinson (2017, p.33). By the close of the nineteenth century they were educated separately in institutions, giving birth to the dual system of special and general education. This segregated provision was "destined to become both the backbone and the chief bone of contention in special education for all of the next century" (Winzer, 2007, p.27). The system of special education, although reduced in prevalence, is still in existence today - with the creation of groups requiring both special treatment and special educators (Copeland, 2003). The current Scottish schools data are shown in the table below (Scottish Government, 2016a). These statistics present a picture illustrating the continued existence of special schools although their numbers are falling against a backdrop of a lower overall number of schools. They also illustrate across both years, a lower pupil/teacher ratio in special schools compared to the overall pupil/teacher ratio offering more individual attention to pupils in special schools.

Item of Interest	Year: 2010	Year: 2016
Number of Schools (primary and secondary)	2,692	2,390
Number of Special Schools	163	141
Pupil/Teacher Ratio	13.3	13.7
Special School Pupil/Teacher Ratio	3.6	3.6

Table 2.1: A comparison of data from schools in Scotland with special school data (Scottish Government, 2016a)

The concept of inclusion heralded a change in approach. With its roots within the human rights movement approach to social relations and conditions in society (Barton, 2003) that was prevalent particularly from the 1960s onwards, these humanitarian and egalitarian principles influenced educational thought. This resulted in a movement away from the separation of some young people with disabilities, replaced by an expectation that wherever possible they were to be educated in neighbourhood schools. Yet, Slee (2014, p.222) criticised the emphasis on locality,

> Inclusive education is not about relocation of people in the mainstream. Inclusive education presses us to consider the ontology of special and regular; presses us to resist such a bifurcation as redundant in democratic education.

He advocates a wider cultural shift in community attitudes towards inclusion such that this approach would permeate thinking more generally and live in the day to day practices of teachers.

Nevertheless, despite the initial focus on locality of educational provision, inclusive education offered young people the opportunity to learn through sharing their individual experiences and that this should better reflect, more fully, the reality of society. In support of this view, Oliver (1992, p.25) contended "that difference not merely be tolerated and accepted but that it is positively valued and celebrated." Reinforcing this view, Melero, Mancila and Garcia (2016, p.204) declared "Differences, far from being an obstacle, are considered a learning opportunity".

In policy terms, inclusion meant that all young people were to be accommodated in their local school (Salamanca Statement, UNESCO, 1994; Education for All, UNESCO, 2002) where all pupils are valued, included in studying all areas of the curricula, participating in classroom lessons and school community - where the attitude was to make the environment for learning welcoming to all (Dyson and Milward, 2000).   Yet, issues remain in the enactment of inclusive policies. Melero, Mancila and Garcia (2016, p.204) describe a situation as "educational apartheid" whereby diverse learners within classrooms do not receive the same learning opportunities. They recommend not an "identical curriculum" (Melero, Mancila and Garcia 2016, p.204) but rather a common curriculum where young people have access to the same curriculum content but pedagogical strategies vary to take account of the individuality of the learners. Slee (2007, p.165) criticises the superficiality of the approach interpreted as pedagogical strategies, "Placing kids with *appropriate support* in schools and classrooms that retain all the cultural hallmarks of exclusion ought not to be described as inclusive education". He continued by saying "(it) is not simply a matter of matching children with support to legitimize their seat at a desk." (Slee, 2007, p.165).

Ainscow (2007) highlighted the important work of teachers in bringing about an inclusive school ethos. He advocated encouraging teachers to challenge their own thinking even about long held views on certain groups of young people and collaboration amongst teachers and between teachers and adults in the wider community to enhance inclusion. However, Allan (2013) whilst accepting inclusion as increasing participation and removing barriers to participation suggested that confusion remained for teachers as to what inclusion is really supposed to do and for whom. Ferguson (2008, p.111) observed "Students can be 'in' but not 'of' the class in terms of social and learning membership".

Educationally there is a dearth of information as to the academic and social experiences of young people with cleft. However, Tomlinson (2017) contended that a medical superintendent at one of the first asylums for idiots (sic) devised a test for feeble-mindedness that included checking for an abnormal looking palatal structure. Medical literature on cleft identified areas of 'deficit' which medical researchers alleged might contribute to underachievement of children with cleft. For example, Richman and Eliason (1982) raised two hypotheses to explain this underachievement. They contended that, firstly issues of speech and language delays preclude the acquisition of reading and

academic skills and secondly that parents and teachers (and consequently the child) develop lower expectations of the child with cleft. Children are therefore not encouraged to excel at academic work and their perceived inhibition may compromise achievement (Richman and Eliason, 1982). Conrad, Dailey, Richman, Canady, Karnell, Axelson, and Nopoulos (2010) contended their study linked structural abnormalities in the brain with speech and cognitive domains of functional deficit.

Evidence suggests that medical professionals have engaged in research mainly of a quantitative nature, often by carrying out tests, such as intelligence testing, on the young people with cleft. A search of literature in this area revealed no research undertaken by an educational professional into how young people perceived their educational experiences expressed in their own words. In addition, medical studies have generally been conducted with little or no reference to the school curriculum being experienced by the young people. Neither have they sought to explore the young person's academic performance in a wide range of subject areas, nor have they sought to link test results to interviews with their teachers/tutors. Gathering information beyond test scores may have led to a deeper understanding of the issues raised in the academic articles. Finally, Allan (2013) highlighted an ongoing, strong and rigid special education paradigm which is driven by a deficit model. She said that "one effect of this … is the silencing of the pupils and their parents, making them mere recipients of provision" (Allan, 2013, p.791). Listening to the opinions of pupils and their parents would be an essential part of a study designed to challenge this paradigm. It is through listening to what young people with disabilities have to say that our understanding is deepened, particularly in areas causing them concern (Oliver, 1996; Tangen, 2008).

Set against a background of inclusion, this study, based on qualitative methodology, will explore the progress being made by young people with cleft in academic and social learning taking account of the role of these factors raised by medical literature – language and communication, cognition, self-concept and the role of others in supporting their learning.

1.3 The research questions

This study therefore sets out to explore how young people with cleft lip and/or palate go about making progress in learning whilst dealing with the medical conditions CLP or CPO. It traces their learning trajectory from dependence in childhood to independence at school leaving age. As such the study is entitled: *Exploring the educational experiences of children and young people with non-syndromic cleft lip and/or palate in the west of Scotland.*

This study will address the following five procedural questions:

Question one: In what ways, if any, does having cleft lip and/or palate impact on young people's experiences in school?

Question two: In what ways, if any, does cleft lip and/or palate impact on educational experiences which young people have outside school?

Question three: In what ways, if any, does cleft lip and/or palate impact on young people's perceptions of themselves as learners?

Question four: In what ways, if any, does cleft lip and/or palate impact on relationships with significant others who are working directly or indirectly to enhance the educational achievement of the pupils?

Question five: To what extent does cleft lip and/or palate impact on attainment in school?

1.4 The thesis summary

This thesis is divided into nine chapters.

- Chapter one outlines the background and demonstrates the significance of the study.
- Chapter two provides an extensive review of the relevant educational and medical literature already available in this area.
- Chapter three outlines and justifies the research design including the choice of the qualitative paradigm, research instruments chosen, data collection methods and analysis.

- Chapter four offers an analysis of findings emerging from the first set of interviews – undertaken with the young people.

- Chapters five to seven analyse findings emerging from the case studies which have involved interviewing parents, teachers, and organisational/club leaders.

- Chapter eight presents a discussion of the major findings of the study, and compares the theoretical models with the datasets.

- Chapter nine documents the conclusions of the study, analyses the strengths and weaknesses of the study, suggests recommendations for both the educational and medical communities and includes suggestions for further research.

The next chapter, chapter two, will begin to explore the research questions through a review of both the educational and medical literature available.

C H A P T E R   T W O
The Literature Review

Chapter one identified the importance for all young people of making progress in social and academic learning. However, young people with cleft have been portrayed, mainly in the medical literature, as potentially underachieving in these areas. In this chapter, I explore the medical literature and more generally the educational literature, relating to the areas attributed by medical professionals as possibly compromising learning. Set within the background of disability to inclusion, as discussed in chapter one, the following areas of literature are considered: issues of language and communication, cognition, the self-concept and the role of others in supporting learning. The aim is to move beyond a reductionist model, simply identifying possible causes of underachievement, to building a strong knowledge base from which to introduce and explore the datasets in chapter eight.

The literature reviewed in this chapter was identified from searches using keywords, from relevant electronic journals and hand searches of hard copy journals, bibliographies from articles and books, and from conversations with knowledgeable others who recommended key texts. This chapter acts as a backdrop to the research and salient points emerging here thread through the fabric of this study.

2.1   Language and Communication

This section examines the role of language and communication in learning. Three theories of language acquisition are explored and the possible implications of cleft are considered. The section ends by extending the consideration of speaking and listening skills to that of written language.

2.1.1 The importance of language and communication in learning

Hill and Kuczaj (2011, p.322) suggest that human language is "a symbolic, rule-governed system that is both abstract and productive, characteristics that enable its speakers to produce and comprehend a wide range of utterances." Language involves the use of words as symbols, rules such as forming grammatical structures and abstract thinking since a "finite number of linguistic units (sounds, words, and the abstract classes that contain these

units) and a finite number of rules are capable of yielding an infinite number of grammatical utterances" (Hill and Kuczai, 2011, p.323). These researchers contend that language development involves acquiring knowledge of the following systems: pragmatic (cognitive and social skills such as turn taking), phonological (perception and production of sounds), syntactic (grammatical structures and rules) and semantic (word-meaning). Speech is the oral representation of language but there is also the written form and hand signals. Each method relies on sequences of muscle movements (Drake, Vogl and Mitchell, 2010).

Communication skills are important for both academic and social learning. Bryce (2013, p.66) explained "Working alongside others means that clarification, influence and stimulation arises from shared activity, the interpersonal context drives the learning." Different types of communication are prevalent in modern classrooms. Verbal communication and listening skills are required in classroom settings for "commenting, questioning, protesting or rejecting, requesting, commanding" (Dell, Norton and Petroff, 2007, p.265). In addition, the increasing prevalence and usage of digital technology in learning environments requires a competency in language (oral and written) to optimise online learning opportunities (Mills and Unsworth, 2016). As children mature, their texts become more subject specialist. Unsworth (1997, p.30) suggests that "Texts used in each curriculum area differ in their structure and features" and that children should be prepared to handle these differences or it will be detrimental to their literacy use across the curriculum.

Language is also recognised to be a facilitator of cognition (Luria, 1973; Vygotsky, 1978). Speech is "a mechanism of intellectual activity – a method for use in operations of *abstraction* and *generalization* and a basis for *categorical thinking"* (Luria, 1973, p.307).

The ways in which children learn language and communication have been understood over time using different models of language acquisition. These models, which are discussed below, are not mutually exclusive but practice is informed by examining the various models.

2.1.2 Three theories of language acquisition

Three major theories of language acquisition have dominated thinking since the 1930s. In this section I will interrogate developments in these theoretical positions and relate this to the development of language learning in children with cleft. These theories have generally been known as behaviourism, nativism and social interactionism, advanced respectively by B F Skinner (1904-90), Noam Chomsky (1928-) and Jerome Bruner (1915-2016).

Behaviourism

Skinner's (1938) theory, named radical behaviourism, emerged from the principles of general behaviouristic theory and not from research into language. Behaviourism evolved from the philosophical perspective of empiricism, that knowledge is primarily based on experiences which are derived from the senses (Locke, 1689). "There are no innate ideas implanted in the human mind" (Locke and Spencer, 2014, p.xviii). Behaviourists recognise "the covert and essentially private world of mental life" but their preference was to study observable behaviour as this offered an opportunity for objective study (Blackman, 1984, p.4). Language was considered a form of behaviour and could be explained as another set of responses. This approach is based on the belief that infants start with a mind that is blank (tabula rasa) and can be trained to imitate sounds/words that are modelled by more advanced communicative partners. Skinner's view of language acquisition was based on 'finite' single word processing. For this to occur what is required is adequate listening ability and sufficient memory, the development of the physical ability to make the sounds/words. However, there was no underlying mental processing necessary, the focus instead was on the observable, materialistic nature of behaviour.

When the infant/child correctly repeats the required utterances he/she is offered a reward which could be as simple as a smile or words of praise. When he/she is not successful the infant/child has to repeat the behaviour. Rewards can also be utilised to reduce/remove undesirable behaviour until this reaches extinction.

Nativism

Critics of the behaviourist theory of language acquisition, such as Chomsky (1957) and Bruner (1983), contended that with behaviourism the emphasis was on the child learning grammar through reinforcement. Yet, this theory appeared to lack the ability to explain generative syntax, grammar constructions. It also did not offer a plausible explanation of how the child can combine words in sentences when the words had not previously been heard together in the form of the same sentences before. So although this explains the child's production of language it does not account for the speed or complexity of comprehension of language acquisition.

As an alternative to behaviourism, Noam Chomsky (1965) proposed the theory called nativism which asserted that grammar is innate.

> To say language is innate is to express the belief that some crucial and relevant internal nature differentiates my granddaughter from rocks, bees, cats and chimpanzees…On current understanding, (this internal nature) is an expression of genes, which somehow yields a language faculty"(Chomsky, 2000, p.51).

He theorised that an innate language acquisition device (LAD) enabled the infant/child to be able to use transformational grammar to change sentences into other states. This device should explain the speed at which the infant learns language. Chomsky's view was that syntax develops on two levels: the 's structure', surface meaning and the 'd structure' a deeper meaning, which is more abstract, not related to the environment. Therefore, it is this 'd structure' that is innate.

However, from the 1990s Chomsky was developing the 'minimilist program' which focused attention away from grammar and towards the brain of the hearer-speaker which proceeds to associate sound and meaning (Chomsky, 2000).

Social Interactionism

Bruner rejected behaviourism in favour of social interactionism. "The only way language can be learned is by *using* it communicatively" (Bruner, 1983, p.119). Starting from the perspective of the infant, the driver of communication is the satisfaction of their needs, the infant's approach is not random but surprisingly abstract, involving their cognitive

endowment. Central to this theory is meaning making related to the context and dependent on the conditions at the time of the communication (Bruner, 1983). Yet, Bruner did not completely reject Chomsky's innate grammar theory.

> Perhaps the best claim can be made for a case grammar. It is based on the reasonable claim that the concepts of action are innate and primitive. The aspiring language learner already knows the so called arguments of action; who performed the action, on what object, towards whom, where, by what instrument, and so on. (Bruner, 1983, p.34).

Bruner (1983) argued that the three facets of language acquisition – syntax, semantics and pragmatics – could not be learned independently of each other but rather are learned interdependently. Bruner said (1983, p.18) "language acquisition "begins" before the child utters his first lexico-grammatical speech". He continued (1983, p.18) by further explanation. "It begins when mother and infant create a predictable format of interaction that can serve as a microcosm for communicating and for constituting a shared reality." With use of what he called the Language Acquisition Support System (LASS) Bruner described 'formats' which he defined as "standardized initially microcosmic patterns between an adult and an infant that contains demarcated roles that eventually become reversible" (Bruner, 1983, p.120). Bruner accepts Chomsky's LAD but he concentrated on the meaning making within the communication rather than perfection, "Well-formedness does not make utterances either effective or appropriate or felicitous (Bruner, 1983, p.119). Bruner (1983, pp.119-120) reflected that "infants learning language are *not* academic grammarians inferring rules abstractly and independently of use". It is the interaction between LAD and LASS that makes it possible for the infant to enter the linguistic community and at the same time, the culture (Bruner, 1983). With this system there is participation by an active child in language exchanges to make meaning in context.

Although these models are presented separately as historical developments in thinking, in practice the distinction is less clear: all three models could be perceived as interlinking and overlapping as we try to understand the developmental experiences of young people as they learn language.

2.1.3 Cleft and the theories of language acquisition

For young people with cleft communication can present particular challenges. Peterson-Falzone, Hardin-Jones and Karnell (2010) contended that at least twenty-five percent of children with cleft can be expected to experience normal speech development without any intervention yet for the remaining seventy-five percent issues can occur. Experiencing difficulties with early speech development can affect a child's self-confidence resulting in reluctance to engage in conversation (Chapman and Hardin, 1990; Frederickson, Chapman and Hardin-Jones, 2006). In more severe cleft cases this can result in selective mutism and reduced communicative confidence (Royal College of Speech and Language Therapists, 2009).

Current thinking (Vygotsky, 1978; Bruner, 1983) commonly argues that children learn to communicate most effectively through social interaction. However, because of the specific physical difficulties that young people with cleft have to face, practices they encounter may relate more closely to behaviourism than to social interactionism. Whilst these practices are evident to some extent in all young people's experiences, the balance may be different for young people with cleft.

Behaviourism and cleft

Parents may model the sound which the infant/child then imitates. However, from a listening perspective, young people with cleft can be susceptible to otitis media (Paradise, Bluestone, and Felder, 1969; Viswanathan, Vidler, and Richard, 2008) which causes mild to moderate deafness (20-60 dB) in the affected ear due to excess fluid in the Eustachian tube and possible inadequate muscle movement in the hearing apparatus (National Deaf Children's Society, 2016). Peterson-Falzone, Hardin-Jones and Karnell (2010, p.214) reported that "Clinicians have speculated that … otitis media may be associated with delays in cognitive and language development and delays in later academic performance".

Infants with cleft lip and/or palate may have early feeding difficulties that may interrupt the opportunities for infant participation in preintentional communication such as body posture, facial expression, limb extension, hand gestures, directed gaze and gaze aversion, crying, cooing and delays in babbling (Neiman and Savage, 1997). Pillemer and Kaye

(1989, p.201)) suggest from the infant's point of view "structural abnormalities of the mouth could interfere with recognisable smile responses or distort the vocalizations necessary for triggering attachment responses." Field and Vega-Lehr (1984) found infants with cleft spend less time looking at their mothers, vocalizing and smiling which suggests delay in the child's acquisition of early social, communicative and/or cognitive skills.

Challenges may arise due to the inadequacy of the speech apparatus of young people with cleft including lip, palate, dental and occlusal deviations (Kuehn and Moller, 2000). This can result in inaccurate articulation, affecting their pronunciation and consonant-vowel inventory and syllable shape (Peterson-Falzone, Hardin-Jones and Karnell, 2010). Difficulties can also emerge because of reduced sensation from the cleft repair (Morris and Ozanne, 2003). Children with cleft can experience "delayed or disordered acquisition of phonological processes with abnormal development of the sound system of language and the rules that govern sound combinations" (Royal College of Speech and Language Therapists, 2009). The research of Field and Vega-Lehr (1984) also highlighted conversational devices, brief utterances such as 'yea' and 'aha' were used more frequently by mothers of children with cleft lip and palate to indicate to the child that he/she should continue the conversation. The researchers speculated this could be due to the repetition requests made to the child as the latter exhibited more speech sound errors and this rendered their speech more difficult to understand. Mothers also used more utterances in the form of teaching/modelling. They labelled objects, attempted to elicit the names of the objects or corrected the child's labelling more frequently.

Some young people with cleft are susceptible to velopharyngeal inefficiency (breathing difficulties) which increases occurrence of hypernasality "a resonance alteration primarily of vowels (and sometimes voiced consonants) that occurs when the oral and nasal cavities are abnormally coupled" (Peterson-Falzone, Hardin-Jones and Karnell, 2010, p.225). Sounds such as /b/, /s/, /k/ can be affected. The sounds /k/ and /g/ are plosives, consonants produced by the stoppage of the airflow using the lips, teeth or palate, followed by a sudden release of air. The consonants /s/ and /f/ are fricatives, made by forcing breath through a narrow opening made by the lips and teeth. There can also be issues with hyponasality which is a reduction in nasal resonance due to too little air escaping through the nose because of a partial blockage of the nasal airway (for example, sounds /m/ and /n/). Research by Patel and Ross (2003) highlighted ten of the twenty adults (aged

between eighteen and fifty years) found /s/, /k/, /g/ challenging, they had been aware of substituting one sound for another in the pronunciation of /f/ and had to manage hypernasality.

In keeping with behaviourist theory, (operant conditioning), reinforcement is given by the interactive partner to indicate if pronunciations of sounds/words are correct or incorrect (Skinner, 1938). This could be physical reinforcement such as the receiving of an object or social reinforcement, as simple as a smile or words of praise. If the child with cleft cannot make the correct sound due to physical impairment no matter how much effort they will not receive the reward. Even after surgery this issue may not be completely solved. Marsh (2006, p.122) observed "Surgeons sometimes say that they will 'correct' or 'reconstruct' differences without the use of the modifier *partially*." This indicates that the repaired cleft will not restore the child's oral organs to what it would have been if the child had been born without a cleft and improvements to speech may be limited. In addition, the child with cleft has increased susceptibility to develop compensatory articulation disorder (CAD) whereby the child inappropriately physically moves their speech articulators because they are unable to correctly do so, an issue which could become habitual. For example, misplacing sounds by anterior tongue placements being shifted backwards (to velum/soft palate) so 'table' becomes 'cable'. Pamplona, Ysunza and Jimenez-Murat (2001) found none of their twenty-nine patients (aged three to eight years) who presented with CAD showed an adequate level of language development. The degree of language delay was greater in the situational context as compared to the semantic and discourse contexts.

Nativism and cleft

When considering the theory of nativism in relation to cleft, some research suggests that infants/children with cleft can construct sentences but these are less complex in terms of syntax (Kommers and Sullivan, 1979). If there is an innate component to grammar then this could be less well developed because of the pronunciation issues, previously documented, including delayed language development - confusion could be caused by failure to recognise syntax errors. For example, failing to add the 's' sound to indicate plurals. 'S' is one of the sounds with which it is recognised that young people with cleft may have difficulty. The issue of hearing may also affect syntax (Schonweiler, Lisson,

Schonweiler and Hausamen, 1999). These researchers found whilst researching with four to five year old children that children with cleft who had conductive hearing issues had severely affected morphology, phonology, syntax, vocabulary, language comprehension and auditory perception. The issue of the deeper 'd' structure could be affected by the cognitive issues (thinking ability) that young people with cleft have been documented as experiencing (Nopoulous, Berg, Canady, Richman, Van Demark, and Andreasen, 2002; Conrad, et al., 2010).

For young people with cleft Chomsky's minimalist project (1990s) still raises the issues of listening skills being affected due to hearing loss, and of speaking and cognition issues.

Social Interactionism and cleft

In the conceptualisation of language acquisition as defined in the theory of social interactionism, speech is aided by context/environment then there is no need for precision and the articulation and phonological issues with cleft may present less of a challenge. This would lessen the need for repetition and help bolster self-confidence. Although listening could still be an issue the active child could use other senses to help comprehend what is required. Bruner's 'formats' being built up slowly allows the child to develop at their own pace which reduces the opportunities for CAD to develop as the child is more relaxed. This encourages a good relationship to be built between child and communicative partner and reduces the probability of behavioural issues.   However, the child must make sense of what is going on, a deeper level of thinking is required and this could be more challenging for a child with cleft but this could be aided by learning in context. The lack of precision may have more consequences for written communication than behaviourism which is focused on precision.

From a medical point of view, research into speech development appears to offer a mixed picture of models of language acquisition to be adopted. For example, Stoel-Gammon (1992) contended that the more children see, hear and feel particular sounds which are repeatedly modelled in specific ways the more likely they are to produce the sounds themselves. Yet, Albery and Russell (1994) encouraged parents to take advantage of what the child is doing naturally to encourage appropriate speech development. This latter might suggest a more social interactionist approach. However, the majority of the research

literature from speech therapists identifies and explores the deficits in language of children with cleft and attempts to offer solutions to these issues often by intensive practice of set exercises.

2.1.4 Written communication

Today's learners need to become proficient at reading of written text and in reading within the online environment. Mills and Unsworth (2016) concluded that complicated hyperlinked reading required "careful planning, monitoring, predicting and questioning and involves moving speedily and efficiently by skimming and summarising valid findings". Moran and Pentz (1995, p.47) warned "Delayed language development may be reflected in difficulty with language-related academic tasks," thus highlighting the potential academic scope of the effects of language difficulties because young people may struggle with literacy across the curricula as is explained in Curriculum for Excellence documentation (Scottish Government, 2009b).

Smith (2000, p.11) commented that "the greater the child's flexibility in using spoken language, the easier it will be to draw on spoken language skills to support written language." Berninger and Gans (1986, p.57) contended that "reading is parasitic on speech". Referring back to language acquisition theories, behaviourism encourages concentration on single word speech whilst social interactionism on meaning making. This may have implications for written language. When developing reading skills, Smith (2000) highlighted the issue of delay at single word decoding leading to slowness to move to more holistic processing necessary for deriving meaning from larger sections of text. Ellis (2015) cautioned against over reliance on sounding out individual words when learning to read as many high frequency words did not conform to phonic rules. Ellis contended that children should be encouraged to use the overall meaning of the sentence rather than focussing on single words. She also stressed the importance of good general knowledge to aid text comprehension. Yet, children in poorer socio economic backgrounds tend to achieve less and may have less access to a wide range of experiences from which to build good general knowledge (Hirsch, 2007; Goodman and Gregg, 2010). In addition, children have different experiences "no one would question that a child in a slum tenement has a different experience from the city boy, or a boy on the seashore one different from the lad who is brought up on inland prairies" (Dewey, 1938, p.40).

The situation with reading and spelling is complicated by the prevalence within the general population of dyslexia. This is a contested concept but is commonly described as "a continuum of difficulties in learning to read, write and/or spell which persist despite the provision of appropriate learning opportunities" (Dyslexia Scotland, 2015, p.1). At present in Scotland, ten percent of the population are claimed by some to experience dyslexia (Dyslexia Scotland, 2015, p.2). It has been suggested that dyslexia may be linked to cleft (see section 2.1.5).

2.1.5 Cleft and written communication

The speech issues that can occur for young people with cleft may have consequences for their development of other language areas. During a study of the reading of young people with cleft, researchers Richman, Eliason and Lindgren, (1988) found thirty-five percent had an overall rate of moderate reading disability whilst the rate for severe reading disability was seventeen percent. The rates were "considerably higher for the youngest (ages six to seven years) with clefts. At this stage of reading the child is learning sound-symbol relationships and syllable blends" reflected Richman, Eliason and Lindgren (1988, p.24). Collett, Stott-Miller, Kapp-Simon, Cunningham, and Speltz (2009) found children with cleft performed lower on basic reading, phonological memory and reading fluency than controls. However, outcomes in a subsequent study by Collett, Leroux and Speltz (2010) highlighted no significant differences in the reading of children with cleft at ages five and seven years but outcomes instead were predicted by other factors including demographic variations. They accepted that this may have been due to cohort population disparities.

Richman and Ryan (2003) contended that there may be a difference between children with CLP and children with CPO. In their study, the former were more likely to have a verbal expressive disorder as their articulators primarily were affected and so made more phonetic errors whereas the latter were more likely to have a general language disability and made more gestalt reading mistakes.

There could be difficulties linking the grapho-phonic elements of print because of the need for memory skills. Richman and Ryan (2003, p.157) reflected "It is well known that efficient verbal labelling, storage, and recall are important aspects of learning to read".

Richman, Wilgenbusch, and Hall (2005) researched different types of short-term memory deficits (visual versus verbal) in children aged seven to nine years and concluded that visual memory was significantly correlated with reading ability.

Accepting the term 'dyslexia' Richman and Ryan (2003) proposed reading disabilities of children with cleft lip and/or palate showed many similarities to those children without cleft who had developmental dyslexia. Children showed symptoms similar to a naming-memory deficit model of developmental dyslexia. The researchers advocated reading assistance should avoid sight word approaches and focus on oral phonics treatment. Goldsberry, O'Leary, Hichwa, and Nopoulos, (2006) found that individuals with cleft exhibited neural inefficiency during reading and language tasks that was comparable with that observed in adults with dyslexia. This loosely suggested there may be a link between cleft and dyslexia.

Concern has been expressed about writing with some young people with cleft. Kommers and Sullivan, (1979) investigated the writing progress of seventeen children with cleft palate. The children, aged eight to thirteen years, all ranked below the fiftieth percentile in total words used, words per sentence and syntax scores. Apart from being less productive in writing, spoken language skills could be linked to spelling. Hart, Scherz, Apel, and Hodson, (2007) contended that those without disabilities learned how to spell words by breaking them down, phonically, into segments, and writing the segments, repeating the sounds to make sure all the sounds were represented. Those with communication and physical impairments were unable to engage in rehearsal due to articulation issues. Lacking phonological and phonetic awareness, they could only perform logographic knowledge (ability to reproduce whole words) in spelling. Researchers Lee, Young, Liow, and Purcell, (2015) compared fifteen children with non-syndromic cleft lip and/or palate with fifteen controls and conducted a comparison of cognitive-linguistic processes underlying the spelling performance of children with cleft. The conclusion was that the children with cleft lip and/or palate underachieve in phonological awareness and spelling skills. An issue worthy of notice was that they were significantly poorer on phoneme deletion and nonword spelling.

Research by Conrad, et al., (2010) into aspects of the cerebellum in relation to cleft led these academics to recommend further exploration of the issue of manual dexterity and this

could have educational consequences for physical movements needed for writing. Anatomically, "while frontal lobe controls movement, the cerebellum "fine tunes" movement. This area of the brain controls fine motor movement, balance and the brain's ability to determine limb position" (SSM Health Care, 2015).

2.2   Cognitive Issues

Exploring the learning of young people with cleft is a central theme of this thesis. This section begins by defining and critically reflecting on key terms that influence our understanding of learning: cognition, memory, metacognition and intelligence. Each sub section offers insights into issues emerging from the literature that relates cognitive issues to the experiences of young people with cleft.

2.2.1 Memory

Cognition can be defined as "mental activity such as attention, memory, problem-solving, thinking, intelligence" (Esposito, Grigorenko, and Sternberg, 2011, p.85). All of these are important when making progress in learning and this section discusses aspects of memory including its relationship to attention and problem-solving. Finally, this section explores the impact of cleft on aspects of memory.

Working and Long-term Memory

Sprengler (1999, p.46) contended that "the only evidence we have of learning is memory". Of particular interest to this research are aspects of working memory and long term memory. Working memory is defined by Baddeley, Eysenck and Anderson (2009, p.19) as "a system that not only temporarily stores information but also manipulates it so as to allow people to perform such complex activities as reasoning, learning and comprehension". However, Kirschner, Sweller and Clark (2006, p.75) highlighted that "long-term memory is now viewed as the central dominant structure of human cognition. Everything we see, hear and think about is critically dependent on and influenced by our long-term memory."

In the case of working memory, Baddeley and Hitch, (1974) proposed a model comprising of a phonological/sound element and a visual element controlled by a central executive. Information enters the cognitive chain through perception from the senses, (visual, auditory, tactile, olfactory, gustatory, and kinaesthetic). From the stage of perception, information from the senses is added to the knowledge base. This comes about with the aid of a phonological loop which has two subcomponents, a short-term phonological store, with auditory memory traces and an articulatory rehearsal process which revive the memory traces. The store is assumed to have a limited capacity and memory traces decay quickly, within seconds. But, by using subvocal rehearsal, they can be refreshed but this depends on a vocal or subvocal articulatory process. The phonological loop is also involved in language acquisition, and probably in both the acquisition of grammar and of reading skills (Baddeley, Gathercole and Papagno, 1998). In earlier cognitive research, Conrad, (1964) had suggested there exists a phonological similarity effect by which remembering a series of words which are phonologically similar is much harder than those that are dissimilar. Another issue is that of word length whereby as the word length increases it takes longer to remember the word. Several suggestions have been put forward to explain the word length effect and this has not yet been resolved. Within the phonological loop model, longer words take longer to rehearse and more decay takes place (Baddeley, Thomson and Buchanan, 1975). However, it can also be argued longer words are more complex and are open to more interference (Caplan, Rochon and Waters, 1992).

The visual element is termed the visuo-spatial sketchpad which stores visual information that can be manipulated. This can work in tandem with the phonological loop to process information concurrently from auditory and visual sources.

In 1995, Logie built on Baddeley and Hitch's (1974) model of working memory by including within working memory a visual cache which stores information about form and colour and an inner scribe which deals with visual and spatial movement and is employed as an active rehearsal process in the visual cache, like a counterpoint to the inner speech linked to the phonological store.

The phonological and visuo-spatial sketchpad are controlled by a central executive. Baddeley, Eysenck and Anderson, (2009, p.53) contended that "A major function of the central executive (area of working memory) is that of attentional focus, the capacity to direct attention to the task at hand". Any issue that interferes with aspects of the working

memory could affect the attention capability of the learner and reduce their concentration on the learning experiences.

Long-term memory is of paramount importance for the lasting retention of information and skills because working memory, particularly for unfamiliar information, is seriously limited. Kirschner, Sweller and Clark (2006) contended that an individual became skilled in a subject area because of the amount of information stored in long-term memory about that speciality. For example, in the case of problem-solving, experts using this approach draw on their experience stored in long-term memory and select and apply the best procedures for solving the problem and problem solving makes heavy demands on working memory.

Tulving (1972) contended that long-term memory was comprised of three parts – procedural which involved unconscious thought, such as performing skills, semantic which involved conscious thought such as storing general knowledge about the world and episodic which involved conscious thought storing memories of specific events within an individual's life. Squire's (1992) model of long-term memory endorsed multiple forms of memory. He highlighted two separate pathways – non-declarative and declarative memory. The former is concerned with "highly specific perceptual skill learning, win-stay habit learning, artificial grammar learning and priming of novel material" (Squire, 1992, p.240). In contrast, the latter involves conscious recall and recognition (for example, knowing facts). Declarative memory improves markedly during infancy but this is not the case for non-declarative memory which improves little with age.

Proactive interference is defined as the tendency for earlier items to compete at the stage of retrieval with the items to be recalled. Also, when trying to remember information individuals may find they experience competing memories which divert their thinking to some other, related experience. This is called the competition assumption (Anderson, Bjork and Bjork, 1994). Any experiences they have, positive or negative, may result in these memories being regularly reinforced by environmental cues.

Working and Long-term Memory and cleft

There are a number of possible implications of the above points for learners with cleft. Relating to working memory, information enters through perception originating in the senses (Bremner, 2011). In the case of attention, for young people with cleft, the issue of

impaired hearing "could result in "tuning out" information as the child loses attention" (Cleft Palate Foundation, 2008, p.7).

With Logie's model of the phonological and visuo spatial areas, young people with cleft can find hearing, articulation and phonology challenging (see section 2.1) with possible consequences for the inner speech/rehearsal/phonological loop and recall of words that are similar sounding and longer in length. Ceponiene, Hukki, Cheour, Haapanen, Ranta, and Naatanen's, (1999) study on cortical auditory dysfunction in children with oral cleft found children with cleft lip and palate as having increased susceptibility to deficiency in auditory short term memory trace maintenance which these researchers deduced could contribute to language and learning disabilities. The storage and retrieval of visual information could affect the reading of young people with cleft. In their quantitative study, Richman, Wilgenbusch and Hall (2005) found visual memory significantly related to issues in the reading ability of children with cleft.

Since explicit memory develops rapidly in infancy, it is interesting to speculate if surgery to address the fistula in the palate which occurs at around nine months old (Peterson-Falzone, Hardin-Jones and Karnell, 2010) interacts with explicit memory development.

For young people with cleft, previous negative experiences such as being labelled, (see chapter one) may compete for attention and interfere with retrieval of present experiences. These negative experiences could further be reinforced by environmental cues because the young people are mixing with the same peers regularly at school.

2.2.2 Metacognition

Guskey (2007, p.12) said successful learners try to understand their mistakes. "They ask the teacher about the items they missed, look up the answer in the textbook or other resources, or rework the problem so they do not repeat those errors." To help with this they make sense of their experiences of the world – cognitive development - through an internalization of language (Vygotsky, 1978, Bruner, 1983). This inner speech is the tool whereby the child reflects on the learning experiences they have engaged in to get to the vantage point of this new knowledge.

Biesta (2016) contended that there needs to be a combination of thinking, action and reflection to achieve progress in acquiring knowledge. The reflection is needed because it

is not sufficient to acquire the skills necessary for a task but learners need to develop a critical capacity to decide which skills to use. Memory and thinking skills are needed to identify possible strategies to accomplish a task and reflection to decide on which strategy to follow. This reflection makes use of knowledge built from past experiences to project thinking forward. However, there is a higher level of thinking which goes beyond this. It involves reflection on the thinking that led to the choice of strategy, was that thinking robust? Using a filing cabinet analogy, can that thinking be filed for future use? This higher level thinking is termed metacognition (Flavell, 1979), and young learners increasingly use metamemory (Baddeley, Eysenck, and Anderson, 2009), the knowledge we develop about our own memory, to help them build successful strategies for future use. This is important in this thesis because of possible relationships between cleft and language learning. Metacognition involves the development of a new language of learning, which may have implications for language learning and cleft. I found no literature linking metacognition with cleft.

2.2.3 Intelligence/s

Intelligence (g) and Multiple Intelligences

The concept of intelligence is deeply contested. With the prevalence of scientific measurement in the late nineteenth century and early twentieth century the Stanford-Binet intelligence scales (1916) became a popular way of assessing the child's academic potential. Although Binet himself did not propose that intelligence should be viewed as one entity that was inherited. This concept developed as work on the test evolved in the United States of America. In Britain, interest in intelligence was supported by many research papers and books written by Francis Galton (1822-1911) on eugenics and inheritance and later, by the work of Cyril Burt (1883-1971). Intelligence testing was underpinned by the premise that it is possible to arrive at one score to denote the intelligence of a human being and this was fixed at birth. Intelligence as a general factor, termed 'g', is intellectual rather than emotional, and it is innate (genetic). The belief that intelligence was fixed was challenged by Flynn (1987) who found that there was an increase in the intelligence test scores of all levels in society. Gardner (1983) criticised the narrowness of intelligence testing, and advances in neuroscience, for example, studies of plasticity of the brain and speed and efficiency of neural signalling, have cast doubt on the theory (Deary, Penke, and

Johnson, 2010). Interestingly, it is now believed that the brain creates new pathways and alters existing pathways depending on experiences when learning new information and creating new memories. There is also a role for the environment and for genetics in shaping the brain (Eposito, Grigorenko and Sternberg, 2016).

Gardner challenged the rigidity of intelligence test theory. Instead Gardner presented a wider, kaleidoscope view of multiple intelligences (MI). "MI theory illuminates the fact that humans exist in a multitude of contexts and that these contexts both call for and nourish different arrays and assemblies of intelligence" (Gardner, 1993). Gardner's model (1983) suggests that there were at least seven intelligences – linguistic, logical-mathematical, visual-spatial, body-kinaesthetic, musical-rhythmic, interpersonal (how the individual relates to other people) and interpersonal (self-reflective) and another two intelligences, existential and naturalist, were later added in his book 'Intelligence Reframed' (1999). Gardner (1999, p.87) argued that

> MI theory questions not the existence but the province and explanatory power of g. By the same token, MI theory is neutral on the question of heritability of specific intelligences, instead underscoring the centrality of genetic and environmental interactions.

Gardner therefore highlighted the fact that when someone goes to attempt a task they often use a combination of various intelligences within a certain environment - to perform at a music concert a musician would need proficiency in using the instrument, but also the ability to communicate with the audience, language skills to read music and so on. This model implies that children can combine their intelligences in unique configurations and this individuality has implications for learning regarding adopting a child-centred approach.

Having a particular aptitude in one area of intelligence would not predict the child was necessarily gifted in another area or all areas as Gardner contended (1999, p.31) "strengths are distributed in a skewed fashion". Gardner (1999) said there is a need for those engaged in teaching the young person to learn about the student's strengths, interests, preferences, anxieties, experiences and goals. He therefore advocated periods of observation of

children as being more conducive to assessing the abilities of young people in different areas of the curriculum than one-score intelligence tests.

Gardner further developed his theory in 1999 redefining his meaning of intelligence. He conceived of (1999, p.33) an intelligence as "a *biopsychological potential to process information that can be activated in a cultural setting to solve problems or create products that are of value in a culture".* He continued by suggesting that intelligences are 'potentials' which introduced a role for those around the young person such as parents, siblings, teachers to help the young learner to activate these potentials and access opportunities available set within the cultural environment in which the learner inhabited.

Intelligence Testing and Cleft

There has been a predisposition amongst medical professionals when considering the intellectual potential of young people with cleft to use the positivist approach, with quantitative studies based on intelligence testing. The IQ scores were illustrated in terms of the Bell curve showing graphical representation of the normal distribution (Fendler and Muzaffar, 2008). For example, Nopoulous, et al. (2002) suggested that children with non-syndromic cleft experienced significant alterations in brain morphology which affected cognitive function and this manifested in a lower IQ (Intelligence Quotient) and abnormalities in language function.

In relation to cleft there are at least three issues of concern when using intelligence testing. Firstly, if the learner is being judged on the basis of one intelligence score then this could prevent the full potentials of the young person from being recognised and developed in line with the theory of MI. Secondly, IQ testing is framed with a heavy emphasis on linguistic and mathematical skills - a criticism that Burt accepted - and these are the skills which young people with cleft may have difficulty with. The score itself would not comprehensively reflect their true potential. Thirdly, if young people with cleft are presumed have low IQ scores they could be adversely labelled, and educational professionals, parents and some peers may develop lower expectations of their academic ability (Moran and Pentz, 1995). These issues may also affect the general population of learners but in this study I am particularly interested in their application in relation to cleft,

especially since this has been (to date) the major basis of projecting the likely academic performance of the young people with cleft.

2.3   Self-Concept and Learning

To make progress in learning, it is important for young people to develop the confidence to engage in academic and social learning experiences. Such confidence also enables them to realise their rights as a learner in the context of UN legislation (UNCRC, United Nations, 1989) as having voice, audience and impact (Lundy and Cook-Sather, 2016). For young people with cleft, self-concept is an issue of particular importance. In this section I explore developments in thinking about self-concept since the middle of the twentieth century. I start by critically examining Maslow's motivational theory, and tracing the possible effects of cleft on the journey the young learners take in attempting to fulfil their potential. This section will then explore the literature on the relationship between esteem and progress in academic learning, and will reflect critically on how these ideas emerge in the literature on cleft.

2.3.1 Maslow's pyramid of needs

Maslow and the Self-concept

The humanist psychologist, Maslow, published in 1943, the document entitled 'A Theory of Human Motivation' whereby he developed a hierarchical model of human needs represented in the form of a five layered pyramid. The young person ascends the pyramid in a series of steps with the goal of fulfilling their potential (self-actualization). The steps, in ascending order are: level one, 'physiological', level two, 'safety', level three, 'love/belonging', level four, 'esteem' and finally, at the top of the pyramid, 'self-actualisation'. Maslow singled out the first two years of life as extremely important because he contended that if individuals have achieved gratification of their needs during these early stages they tended to remain secure and strong throughout their life no matter what challenges they might face.

Level one is physiological in nature and includes the necessities of eating and drinking. Maslow (1943, p.12) said "If hunger is satisfied, it becomes unimportant in the current

dynamics of the individual." Level two concerns the security of body and health, Level three is important in the sense particularly of social development – family, friendship and membership of social organisations. Level four, entitled 'esteem' concerns confidence, achievement, respect for others and respect from others. Maslow (1943, p.18) stated there were two aspects to this. Firstly, "the desire for strength, for achievement, for adequacy, for confidence in the face of the world and for independence and freedom". Secondly, "the desire for reputation or prestige (defining it as respect or esteem from other people), recognition, attention, importance or appreciation." In other words, developing esteem within oneself and developing the concept when engaging with others. If these needs are not met Maslow said this may result in feelings of inferiority, of weakness and of helplessness. This could then develop into what Maslow referred to as feelings of discouragement, or developing some kind of compensatory or neurotic tendencies. If a young person finds that their needs are not fulfilled at a particular level then they may be unable to progress to the next level and the educational potential (academic and social) of the young learner could be compromised.

Maslow's pyramid was criticised for being reductionist (Geller, 1982) in reducing human behaviour to a set of needs and for its presentation of needs in the form of a hierarchical ascendency. In fact, Maslow does accept most people are only partially satisfied in most or all levels of the pyramid at any time in their lives but he argued that "The organism is dominated and its behaviour organized only by unsatisfied needs." (Maslow, 1943, p.12). These unsatisfied needs then become the motivator. Geller (1982) contended that Maslow in presenting an inadequate theory of evil, ignored a spiritual dimension and Maslow ignored the role of collective needs as a focus of improving the self (Lewis, 2011). Carl Rogers (1980), also a humanistic psychologist and influenced by Maslow's writings, believed rather than focussing solely on individual introspection and self-actualization, the model should be extended to include the importance of the environment in which the young person inhabited, especially the attitudes of those who developed interrelationships with the young person. This will be further discussed in Section 2.4 (The Role of Others in Supporting Learning).

Maslow's Pyramid and Cleft

Despite the criticisms of Maslow's theory, the importance of key life experiences on the development of a positive self-concept remains a powerful idea. The literature on cleft points to ways in which the development of young people with cleft may be interrupted by their medical experiences. For example, some infants with cleft experience feeding difficulties which can hamper their development. (Bannister, 2005). They also have increased contact with the hospital personnel and the physical aspects of surgery, much of this taking place during what Maslow termed the critical first two years of life. Pope's (1999) research suggested that having ongoing medical attention might give the toddler the message he/she is not competent and for him/her the world is a dangerous place (Level two).

Level three of Maslow's pyramid is concerned with the individual's desire for developing relationships with family, friendships and socialising more generally, for example, attending clubs and organisations. Pillemer and Kaye (1989), in a study of children with craniofacial conditions, including cleft, suggest a profile of a passive, socially withdrawn, family-dependent child. However, "Relationships are critical for individuals with craniofacial conditions, who experience social rejection because of the fundamental importance of face in human interactions." (Mouradian, 2001, p.255). The benefits of participation in outside activities have been highlighted by Mouradian (2001) who said that instead of concentrating only on improving their facial appearance, young people with cleft would benefit from taking part in sports and recreational and artistic activities. Yet, in an earlier study, Peter, Chinsky and Fisher (1975) found that adults with cleft tended to rely on extended family for social activities and participated less frequently in voluntary associations. Social activities tended to be that of informal visiting patterns and a few one-to-one friendships.

Young people with cleft can experience difficulty with self-concept. This may be related to a visible differences (for example, scarring from surgery, difference in facial shape, and malocclusion), and/or invisible differences such as speech, and possibly cognition issues. However, there can be variation in individual reaction to physical differences. Surgeon Jeffrey Marsh (2006, p.118) contended, "a minor blemish for some children may cause more psychological impairment than major deformity." In addition, the research of

Rumsay and Harcourt (2007, p.113) shows that although "those living with visible difference face a host of additional challenges … others (the majority) adjust well." Bull and Rumsay (1988, p.103) found that older children may be more influenced by facial features than younger children due to their greater ability to form abstractions. They concluded "improved visual-spatial abstract ability of adolescents may result in awareness of even minor facial changes."

Previous research has suggested that young people with cleft are commonly described as shy (Tobiasen and Hiebert, 1984, Turner, Rumsay and Sandy, 1998) and viewed as observers, who lack leadership skills (Van Demark and Van Demark, 1970). This inhibition led Richman and Eliason (1982, p.249) to contend "that in the classroom where some degree of competitiveness and independence is necessary for success, inhibition may result in underachievement". Although, Richman (1983, p.111) suggests that there was no significant psychopathology identified in groups of adolescents with cleft and no specific 'cleft palate personality'.

Self-concept can be affected by the reaction of others. Aspinall (2006) highlights that it was only in the eyes of others that she was 'different'. Research by Schneiderman and Harding (1984) explores peer reaction to facial 'difference'. Young people were given colour slides of children with/without cleft to see their reactions. The participants with cleft were labelled as "boring, stupid, sad, dirty, mean and bad". Tobiasen's research (1987) supports this result. Her study consisted of showing pictures of a child with cleft and then the same child with the cleft removed to participants aged eight to sixteen years of age. Children with facial issues were considered "significantly less friendly, less popular, less likely as choices as friends, and less smart" (Tobiasen, 1987, p.378).

The relationship between social acceptance and achievement was developed by Lindsay, Dockrell and Mackie (2008, p.2) who argue that "being a victim of bullying or social rejection has been linked to lower intelligence and academic achievement". Gibbons (2006) suggests that typical adolescent insecurity was often intensified for young people with cleft. She contended (2006, p.56) "I would caution that although anxieties are indeed usual in adolescence, young people with cleft may feel their experience is magnified by earlier negative interactions with peers." An earlier study by Patel and Ross (2003) supports this finding. Their research documented that eight out of twenty subjects reported

name calling and teasing by their peers. Interestingly, Hunt, Burden, Hepper, Stevenson, and Johnston, (2007), found that instead of the cleft lip and palate itself being the prominent significant predictor of psychosocial impairment, it was the associated teasing that caused concern. This issue has been recognised and there are examples in medical literature of ways in which attempts have been made to lessen the impact of peer reactions through, for example, support (physical and psychological) for young people with cleft. Support is provided by the multidisciplinary cleft teams (Peterson-Falzone, Hardin-Jones, and Karnell, 2010).

From the research discussed in this section it appears that there may be a relationship between cleft and the self-perception of the learner which could affect learning.

2.3.2 Self-esteem, the self-concept and multidimensional perspectives in academic learning

Despite the elevated role accorded to self-esteem as a contributor to making progress in academic learning, some researchers have different views about the relationship between self-esteem and academic achievement. Self-enhancement theorists argue that self-concept variables are primarily causes of academic achievement whereas skills development theorists advanced the theory that self-concept variables are primarily consequences of academic achievement (Calsyn and Kenny, 1977). They argue that these different perspectives have implications for the nature of interventions to help the learner. Self-enhancement theorists believe the best way forward is to bolster the self-concept of the learner whereas the skills development theorists would take the view it was best to concentrate efforts on working towards an improved performance, for example, reviewing the curriculum (Calsyn and Kenny, 1977).

There are two important questions emanating from this debate that are of concern to this study: how important is self-esteem and what is the direction of the causality between the self-concept and academic achievement? The relationship between self-esteem, self-concept and achievement is a contentious area. Baumeister, Campbell, Krueger, and Vohs, (2003) claimed that self-esteem had no benefits and in fact may be detrimental to subsequent performance. However, in a later study Valentine, DuBois, and Cooper, (2004) found a complex interaction between self-concept and achievement, where academic self-

concept had a positive effect on subsequent performance and academic achievement had a positive effect on subsequent academic self-concept. These researchers continued by suggesting that stronger effects of self-beliefs were specific to the academic domain and stronger when measures of self-beliefs and achievement are matched by domain (same subject area). Marsh and Craven (2006) found that academic achievement had little relationship to self-esteem but argued the former was significantly related to the academic self-concept. They theorised their research in their Reciprocal Effects Model (REM) which illustrated that self-concept and performance were reciprocally related and mutually reinforcing constructs (Marsh and Craven, 2006). But the most powerful effects of self-concept, these researchers contended, are based on the specific components of the self-concept most logically related to specific outcomes (a multidimensional perspective) rather than on the global component of self-concept represented in global measures of self-esteem which they viewed as a unidimensional perspective. For example, when considering trying to improve the performance outcomes in mathematics, it was the relationship between maths self-concept and maths achievement that was of primary concern.

In conclusion, in answer to the questions posed at the beginning of this section, the literature suggests that self-esteem is not considered a major factor in academic achievement, rather it is the specific self-concept related to the specific achievement outcome that is important. The direction of causality between the specific self-concept and the specific academic achievement is reciprocal.

These conclusions have important implications for parents/teachers/lecturers who seek to support learners. Marsh and Craven (2006) argue that if those providing learning experiences aim at raising the self-concept without dealing with performance then any improvement will be unlikely to last. They view the situation is even less valuable if they target aspects of the self-concept unrelated to the area of intended performance gain. For example, introducing a strategy which raises maths self-concept if the young person is struggling in English classes. Similarly if teacher/lecturers introduce interventions to enhance performance and do nothing to enhance the participant's self-belief then benefits are unlikely to last.

Marsh and Craven (2006) recommend that any interventions and support given should be incorporated into ordinary class activities and should not be viewed as a separate endeavour with young people removed from the general classroom as this may limit the

chances of the learner receiving the support to access resources and will be unlikely to increase academic achievement. They also stressed, from a different perspective, the importance of the work of Sommer and Baumeister (2002) because the latter contended that high self-esteem could offer a buffer against any negative impact of failure on persistence and performance.

There is no information documented in the cleft literature about the multidimensional aspects of the self-concept specifically in relation to academic achievement in school based subject areas. However, in the case of interventions, Moran and Pentz (1995) recommended that learners with cleft should not be removed from classes they enjoyed for learning support reasons as this may be counterproductive.

2.4   The Role of Others in Supporting Learning

Young people do not live their lives in isolation, and there is an understanding that their environment and the role of context play an important part in their learning. Those who inhabit their worlds and interact with them are therefore integral players in their environment and play a pivotal role in their learning experiences (Vygotsky, 1978). This section will explore the role of other parties who may make a contribution directly or indirectly to the learning of young people with cleft. I use Bronfenbrenner's (1979) concentric model of individual development as a lens through which to explore the environment of young people with cleft. In particular, I explore the roles played by the key individuals, in a direct relationship with the child. Then, I consider the interrelationship between different groups of adults helping the child. The section ends by reflecting on how cultural developments and recent evolution in international law have perhaps altered relationships within Bronfenbrenner's original theory with particular reference to young people with cleft.

2.4.1 Bronfenbrenner's ecological, concentric model of human development
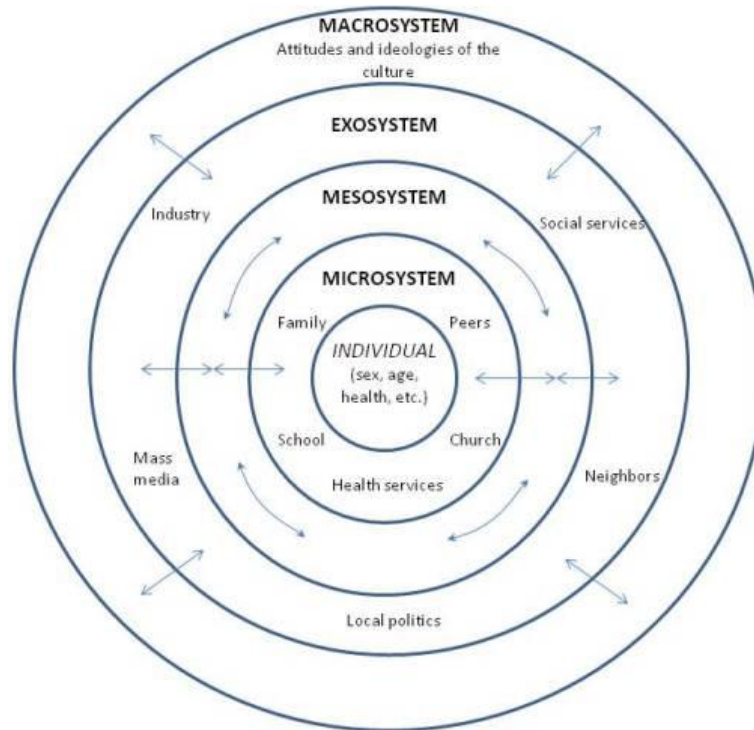
Figure 2.1 Bronfenbrenner's ecological model of development (Hchokr, 2017)

In his model Bronfenbrenner (1979) proposes five layers of factors that could affect a child's learning, directly or indirectly. These circular layers are nested within one another, placing the child at the centre. Each layer is depicted in order of immediacy in relation to the child. Nearest to the child is the microsystem, containing, for example, the child's interactions with parents/carer, friends, family and grandparents. The next circle is the mesosystem which depicts the interrelationships between groups within the microsystem as they affect the child, for example, the relationship between parents and teachers. This element also depicts the relationship between the micro and the exosystem. Beyond this circle is the exosystem, for example, neighbours, Social Services, parents' work, and the next circle is the macrosystem, for example, the child's culture, legal system and social institutions, and finally the chronosystem which explores changes over time. Since the child's learning is influenced by each of these forces and most directly by the culture and actions of other parties operating within the child's microsystem and mesosystem, this study was designed to concentrate mainly on these influences. However, consistent with

Bronfenbrenner's theory the study will also explore how changes in the macrosystem have affected the relationships within and between the micro and mesosystems.

2.4.2 The microsystem

Bronfenbrenner's (1979) model describes the microsystem as the relationship between various parties in a direct relationship with the child. Until this point the focus of this study has been learning: the development of interactive language and communication skills, accessing and utilising cognitive skills to facilitate thinking and metacognition, the development of the self-concept as a requirement for active participation in learning. In all of these areas the role of others directly engaging with the young person in learning experiences has been emphasised. In this section, using Bronfenbrenner's model I focus on the microsystem from the perspective of the young person with cleft where three worlds intersect, the family (the relationship between the young learner and the parent) education (those offering learning experiences, teacher/lecturer/instructor), and medicine (the surgeon, the speech and language therapist and the orthodontist).

Within the family, the parents' role has been highlighted as central in the education of children (Bastiani, 1997; Prior, 2013). Prior (2013) contended that this goes far beyond ensuring the child's attendance at school. In Scotland, this role is considered to be so important that it is enshrined in law. The Scottish Parental Involvement Act (2006) defined the role of parents as within three areas of influence: learning at home and in the community, being involved in home/school partnerships and by voicing the parental view by way of membership of the Parents' Councils whereby parents can be involved in the activities of their local school.

In education, traditionally, the teacher/lecturer/instructor's role involves planning what is to be taught (the curriculum) how to go about this, (pedagogical considerations) and assessing how successful the process has been (progress and attainment). From a constructivist perspective (see section 2.5), Bruner (1996, p.4) viewed the teacher's role as "a guide to understanding, someone who helps you discover on your own". Yet, learning theory has evolved to view the teacher's role as reaching beyond facilitator to co-constructor of knowledge (Ang, 2016). This is achieved through dialogue (Vygotsky, 1978; Bruner, 1983, 1996). Carnell and Lodge, (2002, p. 16) contended "Dialogue is

grounded in the assumption that learners are teachers and teachers are learners. Hierarchies are broken down and boundaries less evident". Making progress in learning occurs when learners are dissatisfied with their present level of knowledge and so they strive to enhance their understanding by engaging in more challenging experiences. Teachers can work with learners to develop their self-efficacy which will facilitate future learning (Bandura, 1977).

Young learners who experience issues with their learning over and above the usual classroom challenges may be allocated additional support. In Scotland, this is documented in the Education (Additional Support for Learning) (Scotland) Act, 2004, amended by the Education (Additional Support for Learning (Scotland) Act, 2009). In 2015, twenty-two percent of all Scottish pupils were identified as having additional support needs (Scottish Government, 2015a). The situation can be fluid, determined by the individual learning needs of the child or young person and therefore could be of a short-term nature, whilst in other cases, additional support may be provided throughout their school career (Scottish Government, 2013a). However, with additional support there have been areas of contention for some time. Educationalists such as Barton (1997) have criticised the concept of having specially trained teachers linked to certain pupils as this could enhance 'difference' and lead to labelling of the young people concerned.

Cleft may pose additional complications for the microsystem. Peterson-Falzone, Harden-Jones and Karnell (2010, p.372) listed the early reactions that parents may experience on discovering their child has a cleft: "disbelief, shock, guilt, depression, resentment, grief, rage, frustration, fear, anxiety, protectiveness and stigmatization." They state that perhaps the greatest fear is embedded in the question "Is he going to be retarded? (sic)". Marsh, a cleft surgeon, questioned how parents view cleft. He reflected (2006, p.116) "That many parents use the verb *to fix* during the initial surgical consultation reflects back on the tension between surgical normalization and diversity affirmation." A significant question for this study is to consider the extent to which this attitude influences the relationship between child and parent as regards learning, academically and socially? Endriga and Kapp-Simon (1999) found that parents described their children as less socially apt and more withdrawn than their peers without cleft. In research by Patel and Ross (2003, p.478) one participant complained "(my parents) cocooned me, protected me, in many ways restricted me from doing things and my brother felt I got more attention." The relationship

between expectation and achievement is a consistent theme in the literature. Moran and Pentz (1995, p.45) encapsulate the essence of the argument arguing that "It is extremely difficult for students to develop positive self-images and achieve their potential when parents and teachers expect less of them." Any external challenges such as teasing/bullying can interfere with cognitive processes (see section 2.2). Communication between child and parent is important in solving such issues. Hunt et al., (2007) found children generally do tell their parents they have been teased but it was not clear parents knew how to handle this teasing.

The context within which the child with cleft is situated is important and contexts can be constructed. Moran and Pentz (1995, p.47) reflected "the knowledgeable teacher can do a lot to promote an environment in which such a child can earn appropriate attention and respect from both classmates and school personnel". There is evidence, however, that the context in school did not always enable the child with cleft to thrive. Richman (1978a) reported that teachers found children with cleft significantly more inhibited in the classroom than parents did at home. Richman (1978b) also analysed the potential impact of incorrect assumptions some teachers made about children with more noticeable facial disfigurement. Teachers tended to underestimate the ability of the more able learners and overestimate the ability of the children who found learning more challenging. The implications of this latter finding is that the former group may not be presented with work which presents the correct level of academic challenge whilst the latter group may be at risk of not receiving additional support.

Additional support may play a role in the experiences of young people with cleft. Yazdy, Autry, Honein and Frias, (2008) researched the use of special education by children with orofacial cleft in Atlanta. Their study of seven hundred and seventy-seven children found twenty-six percent were in special education for at least one year compared to eight percent of the general population who had no major birth issue. They reported that the most common type of support was from speech and language services where participants were four times as likely to be receiving support as people without cleft.

Groups such as health professionals may play an enhanced role in the lives of young people with cleft compared to the experiences of young people without cleft. The role of the interdisciplinary cleft team based at the hospital is to provide integrated medical care

for the child (CLEFTSiS Standard Statement 6). In this investigation, consideration is given to the role of the surgeon, speech therapist and orthodontist.

From the time of their birth all children with cleft will come under the care of a cleft surgeon. Strauss and Cassell (2009, p.427) contended "the pressures for conformity to a common societal standard of appearance or function are evident in advertising and media images." This is related to what Foucault (1977) referred to as the subjectivation of human beings into 'normal' and 'deviant' and has become embedded in the 'normalisation' debate. The surgical role encompasses both reconstructive surgery which attempts to restore abnormalities due to birth defects and cosmetic surgery which is carried out to please the patient or her/his parents (Marsh, 2006). Cleft surgery encompasses elements of both reconstructive and cosmetic surgery because it is carried out to improve the physical functioning and appearance of the mouth which in turn should also help speech intelligibility and psychosocial functioning (Watson, 2005).

Yet, research suggests that patients may have unrealistic expectations of surgery. Bjornsson and Agustsdottir (1987) found the anticipated results from surgery exceeded the actual outcomes. Whilst Mouradian (2001, p.255) viewed the relationship between patient and surgeon as "an important source of support, information, hope and advice for patients," she also reflected that although the lives of some patients could be dramatically improved by surgery, others are still unhappy even with good surgical outcomes. Marsh (2006) also cautioned that ideally proportioned faces do not necessarily produce psychosocial benefits for those who have or acquire them. Strauss and Cassell (2009) highlighted that some social scientists are now suggesting alternative choices to surgery, emphasising the role of: family life, culture, myth, education, courage, faith and/or humour. Aspinall (2006, p.16) reflected that despite being called "big nose, snot face, flat face" she developed sources of resilience: her family support, secure friendships and joining groups that shared her interests.

Speech therapists specialising in cleft address the issues of speech and language development and feeding concerns. In a study by Patel and Ross (2003) all the participants who received speech therapy had a positive view of their sessions – benefits included raising self-esteem, self-confidence and giving them a more positive outlook on their lives. In terms of relating speech therapy to learning within the curriculum, Collett, Leroux and

Speltz, (2010) undertook a study exploring reading and cleft. They reflected that since one third to one half of the children received speech therapy this could have helped reading-related skills such as phonological processing and reduced disparities in basic reading. But these researchers acknowledged they did not have access to educational records to verify these reports which were based on parental views. .Despite the importance of speech therapy, the CLAPA News magazine (2015, Issue 26) reported that in a short study conducted for the magazine, only fifty-five percent of people questioned said they got all the specialist speech and language therapy they believed they needed.

2.4.3 The mesosystem

The mesosystem in Bronfenbrenner's model depicts the interrelationships between parties whose actions impact on the child. In this study I focus on interaction between the following groups: parents and teachers, different genres of teacher, the interrelationship between parents and the medical professionals. There is a lack of evidence documenting interaction between all parties and club/organisational officials and between teachers and medical professionals.

When exploring the link between parent and school, Prior, (2013, p.235) reflected that "The notion of parents as partners … is as yet in its infancy in many areas of Scotland." She considered that there is a long history of resistance to parental involvement in Scottish schools and the result at present is a "patchwork" where the parent is not always guaranteed a welcome when they visit. Some parents contended that teachers "failed to take account of parents' knowledge of their own children." (Crozier, 2000, p.46). Ferguson (2008, p.116) reflected that "Many schools struggle to get parents to come to meetings and events and are often dissatisfied with 'parental involvement'". She continued that family members might feel intimidated by the schools' expectations of them and in some cases parents viewed school work and homework as separate tasks. In addition, parents might be influenced by their own negative experiences of school life and reject participation (Prior, 2013). There has also been criticism of communication between the school and the parent. In her research, Crozier (2000) found some parents admitted they did not read all the information sent to them and they thought too much information was overwhelming.

Even within schools, tensions may emerge between different teaching contexts, for example, between class teacher and special educator. King-Sears (2008) reflected that each genre of teacher may be unsure of their roles, may be unsure of what instructional techniques to use and how to pace the learning.

In the case of cleft, medical professionals usually collaborate as members of an interdisciplinary team. Peterson-Falzone, Hardin-Jones and Karnell (2010, p.1) reflected "The primary advantage of team care is the opportunity that the professionals on the team have to consult with each other on-site and in real time *before* making treatment decisions."

Parents interviewed by Manchester researchers Nelson and Kirk, (2013) viewed cleft-care practitioners as competent and trustworthy, but identified areas for improvement which included information giving on aspects of the child's surgical procedures. Research suggests that when mothers of children with cleft have been encouraged by speech therapists to adopt an active role in speech therapy sessions there has been a significant improvement for the child (Pamplona, Ysunza and Jimenez-Murat, 2001). This is consistent with the broader educational claims of good home school relationships described earlier in this section (page 58).

However, the communication channel between speech therapists and teachers may not be altogether smooth. Hartas's study (2004), although not specifically focused on cleft, found specialist support teachers and speech and language therapists viewed collaborative opportunities were constrained by rigid organizational structures and both groups perceived collaboration as a distinct, formal activity which they engaged in within a pre-set time and place.

2.4.4 The Macrosystem: legal changes and cultural shifts in societal views

Within society past generations have assumed medical professionals would tell parents about the treatment they would suggest for the child and then liaise with the parents and then discuss the treatment with the child (Oswell, 2013). This meant collaboration first amongst elements of the mesosystem and then passing the decision through the microsystem. However, health professionals are subject to the requirements of the

UNCRC (United Nations, 1989). There may now be a movement of emphasis towards medical professionals interacting directly with the young person. This indicates a shift from elements of the mesosystem liaising (parent and medical professionals) to the medical professionals engaging directly with the child (within the microsystem). This has come about because of elements within the macrosystem (legal changes reflecting cultural evolution). Oswell (2013, p.242) explained this cultural shift, "Central to the liberationist discourse was an understanding of the child as an autonomous and rational agent able to freely make decisions about their life". Yet, the maturity of the child may pose a challenge as to final decision making and consent giving.   Aspinall (2006) reflected on the dilemma as to who was going to benefit from the surgery – the patient or others who were having difficulty coming to terms with the patient's 'difference' and this may affect the balance of decision making.

In education, changes coming from the aforementioned developments in the macrosystem may revolve around a movement from unidirectional flow of communication in the microsystem (teacher to child) to bi-directional (co-constructive interaction) between the teachers and learners. In educational circles this shift has emanated from the desire to take account of 'student voice', to both listen to and act on learners' views (Cook-Sather, 2006). Young learners, in this context, are involved not only in receiving the curriculum but collaborating with teachers in the design and implementation aspects of curriculum and pedagogy (Hulme, McKinney, Hall, and Cross, 2011). This respects the view that "young people have unique perspectives on learning, teaching and schooling, … and that they should be afforded opportunities to actively shape their education" (Cook-Sather, 2006, p.359). This is important for all young people including those with cleft (UNCRC, Article 12, 1989).

Section 2.5   Learning and Attainment

This section provides an overview of the ways in which the learning process can be understood, and considers implications for curriculum, learning and teaching and perspectives on attainment. First, three key theories are explored; behaviourism, constructivism, and social constructivism; second, consideration is given to the relevance of these models in understanding the learning of pupils with cleft. The section ends by

providing brief background information of the setting in which the study took place, particularly in relation to aspects of the models of learning discussed.

2.5.1 Three Theories of Learning

In this section I discuss three prominent theories of learning. These theories represent a historical trajectory of the development of our understanding and conceptualisation of knowledge acquisition. However, although considered individually in this chapter, the relationship between theory and practice is a more complicated business and aspects of different theoretical positions could be found in the same school or classroom. These theories, prevalent from the early twentieth century, are the substance of this section, and are listed in the table below along with some prominent proponents of each theory.

Theories and Theorists of Learning

THEORY	THEORIST	LIFESPAN
Behaviourism	B F Skinner	1904-1990
Cognitive Constructivism	Piaget	1896-1980
	Bruner (early)	1915-2016
Social Constructivism	Bruner (later)	1915-2016
	Vygotsky	1896-1934

Table: 2.2: Prominent theories of learning and some of their proponents

Behaviourism

The title 'behaviourism' has its origins in a publication by Watson (1913) entitled 'Psychology as the behaviourist views it' but the theory of radical behaviourism is generally attributed to the psychologist B F Skinner. In line with deterministic principles which postulate that an individual can be trained to behave in a certain way, teaching and learning occurs through the transmission of information from adult to child with the child adopting a passive role in the process. Based on operant conditioning (Skinner, 1938) the central tenet holds that all behaviour is learned and maintained by exerting control over aspects of the learner's environment. The principle (Skinner, 1974) is that behaviour is affected by prior learning experiences so behaviour that has resulted in positive experiences in the past is likely to be repeated (Thorndike, 1898) and undesirable

behaviour will be expected to result in unpleasant consequences. The emphasis then is on reinforcers rather than punishments and the need for these should fade as the required pattern of behaviour is established, finally reaching extinction when the behaviour is consistently observed. Learning comes about through changes in behaviour.

From the behaviourist viewpoint, the curriculum is based on the premise of logical positivism (Maag, 2014) as it is proposed that the only knowledge that is valid is that which is observed.   The curriculum is generally fixed in content with the child being viewed cognitively as a 'blank slate' (Locke, 1689). It is generally conceptualised as linear, with clear progression through levels. There is an interest in how to perform a certain behaviour, when and where to do so and what behaviours to learn. Decisions about what should be learned are normally taken by those providing the learning experiences.

In classrooms and at organisations, the teacher/club leader, is the dispenser of knowledge (Baird, Hopfenbeck, Newton, Stobart and Steen-Utheim, 2013). Strategies such as precision teaching, direct instruction, and methods of mastery learning (Bloom, 1968) are consistent with behaviourism. These teaching strategies often are implemented using standardised textbooks. Concepts can be taught out of context by manipulating features of the environment. Behaviourism is based on the 'banking system' of knowledge acquisition (Freire, 1970) which gives priority to the quantity of information stored rather than the quality or usefulness, ignoring the importance of looking for meaning and of observing patterns in the information.

In the behaviourist model, progress is made in learning/attainment when the learner demonstrates the desired behaviour (Skinner, 1938). Emphasis is on knowledge learned rather than on creativity and this is also apparent in the testing of knowledge which is based on finding the 'right' answers instead of an emphasis on meaning making which can involve different ways of arriving at solutions and different ways of viewing concepts. The stimulus for interest in future learning often comes from the short-term rewards received for successfully completing tasks. But, Baird (2013) contended that it was hard to categorise any assessments as behaviourist because that would infer the assessments were unconcerned with mental activity.

However, behaviourism as a way of understanding learning has been challenged for being reductionist in that "only observable, measurable, outward behaviour is worthy of scientific enquiry" (Bush, 2006, p.14). Behaviourism is based on a positivist approach, whereby "meanings exist in the world which are separate from experiences" (Weegar and Pacis, 2012). The theory is derived from evidence from experiments on animals (cats, rats, dogs, and pigeons), the results of which are reported in terms of statistical measurements (Weegar and Pacis, 2012). It is challenged by those who feel that it takes too limited a view of the factors involved in the learning process. Constructivists such as Piaget (developing his theories since the 1920s) proposed that learning comes about through child- centred activity, where knowledge is built by the child from life experiences such that the child is a knowledge creator rather than a knowledge recipient. It is also argued, for example, that breaking down tasks into smaller segments to allow the learning to be overtaken in sections does not allow the learner the opportunity to view the bigger picture or its ramifications (Krause, Borhner, Duchesne and McMaugh, 2010). Bandura (1986) criticised behaviourism because it failed to take account of the role of cognitive thinking that could occur between the stimulus and response. He also highlighted a lack of credit for displaying characteristics such as perseverance, and empathy because the attainment criteria were based solely on successful achievement of the behaviour observed.

Cognitive Constructivism

In comparison with behaviourism where knowledge is seen as being transmitted from adult to child, constructivism (Dewey, 1938; Piaget, 1960s) is based on the premise of children building their own knowledge, interpreted from their experiences. The emphasis is on meaning making as the child searches for patterns within her/his individual experiences and builds knowledge through interaction within her/his personal environment and therefore the 'knowledge' is unique to the child. It is also suggested that learning is more likely to be retained as it has meaning to the child and constructed in context (Dewey, 1938). This is a rejection of the Platonic, realist epistemology of knowledge creation because it espouses the view that knowledge is not there to be 'discovered' but is constructed through experiences (Denzin and Lincoln, 2011),

Piaget was an influential constructivist thinker. His theory of cognitive development has been influential in Western education systems since the 1960s and has significantly

affected aspects of curriculum development, pedagogy, and assessment. While his theory was based on the importance of biological maturation and genetic endowment, he also accepted the role of nurture, contending that children responded to their environment to meet their own goals. He considered that development preceded learning and divided the trajectory of learning into four stages with corresponding age groups: sensorimotor (birth to around two years old); preoperational (from two years to approximately seven years); concrete operational (from seven years to approximately eleven years) and formal operational (from eleven years to late teenage years). At sensorimotor stage the infant explores the world using her/his senses, can use reflexes and can co-ordinate these and object permanence has developed; at preoperational stage the child adopts a self-oriented and egocentric approach, he/she is developing proper syntax and grammar and the use of imaginary thought is strong and toward the end of this stage conservation is developing; at concrete operational stage the young person has overtaken the principle of reversibility of thinking, can understand more than one viewpoint, and consider some outcomes and concepts are attached to concrete situations; at formal operational stage the young learner may think abstractly, use hypothetical deduction and reason theoretically, concepts can be applied to different contexts. However, not all people reach this stage. This linear view fitted with the traditional organisation of schools into yearly age groups and, it could be argued, has underpinned many of the processes relating to progress and assessment.

Teaching and learning in this model is based on Piaget's (1985) view that learning comes about through cognitive conflict. Knowledge is stored in schemas and when the learner encounters new experiences, knowledge is either assimilated into existing schemas or the knowledge causes conflict with what is stored at present in the schemas and the learner must find a way of accommodating the new knowledge to bring their thinking back to a state of cognitive equilibrium. Consistent with the constructivist approach, teachers should provide learning experiences which cause cognitive conflict such as problem solving, and open ended questioning, give opportunities for personal research and encourage learners to demonstrate and present knowledge employing whatever means they feel most appropriate - oral, written, and kinaesthetic. Those providing the learning experiences are the facilitators of, or guides to, knowledge creation, setting problems that are personally meaningful and sufficiently challenging for the learner. This emphasis on problem solving has the facility to replicate situations in the real world and is therefore moving the learner towards independence. This then invokes a self-regulated learner focusing on criteria

referenced rather than norm based assessment (Gipps, 1994), motivated by intrinsic feelings of achievement on successfully accomplishing tasks rather than the extrinsic rewards available in the behaviourist model.

Piaget's theory has been the focus of critique. Bruner (1966) challenged Piaget's 'age and stage' model of cognitive development. Piaget's model is linear, whereas Bruner asserted that the individual could be operating at various levels at any time throughout life. He described three levels of cognitive state: enacted (up to one year, infant represents past events through motor responses), iconic (one to six years, information is stored visually in the form of images) and symbolic (seven years and above, information is stored in symbol form such as language and mathematical symbols). This means young learners in Piaget's model must reach one developmental level before moving on to the next, whereas Bruner (1966) identifies the child's dominant level of development then matching the subject matter to what the child has learned before and in context, and to offer experiences which present opportunities for the learner to extrapolate beyond their present level of learning to create new knowledge. Bruner contended that when faced with new material that caused cognitive conflict the individual (no matter what age) should move through his three stages (enacted, iconic, and symbolic) to gain an understanding. Bruner advocated the 'spiral curriculum' whereby knowledge is revisited in an increasingly more complex way as the child ages. Bruner (1960, p.33) contended "we begin with the hypothesis that any subject can be taught effectively in some intellectual honest form to any child at any stage of development". This is consistent with Neisser's view (1967) that memory is constructed from repeated experiences or events and does not resemble a snap shot. The spiral curriculum may also help young people with memory issues as knowledge is revisited each time in a more complex form.

Donaldson (1978) also questioned the reliability of Piaget's thinking. Criticising the age and stage aspects of Piaget's theory, she emphasised that the learning context is key and that given the correct support young children can become skilled in some areas before they reach the age and stage identified by Piaget. For example, in the Early Years, Donaldson (1978, p.17) considered Piaget's claim that the young child has difficulty 'de-centring' - a claim which he based on his 'three mountains' experiment. This is where a child is presented with three differentiated mountains and a doll placed in a different location to the child. The child is asked to identify from a series of ten cards what view the doll would

see. The child up to around six years will give their own perspective of the scene and not that which the doll would see (Piaget and Inhelder, 1956). Donaldson (1978) citing alternative experiments by Hughes, challenged Piaget's conclusions. She reasoned that because Piaget's task relied on abstract thinking, the child in Piaget's task failed to comprehend what he/she was supposed to do and could not understand the "motives and intentions of the characters" (Donaldson, 1978, p.24). She concludes that the gap between children and adults is not so great in this respect as Piaget's work would suggest. Piaget was also criticised for his views on object permanence and conservation, and it is suggested that his theory also failed to take account of the role of others in helping children overcome issues in learning and in emphasising the role of the culture in which they develop (Vygotsky, 1978). Donaldson (1978) emphasised the role of the parents in preparing the child for school and the teacher, for example, in the way they approached teaching reading. Piaget's theory involved measurement against 'norms' of development. The expectancy of reaching certain stages by certain ages gives rise to the possibility of labelling some children as less capable (Kugelmass, 2007) when there may be a range of reasons why development has been different.

Constructivism encourages the child to follow their interests in pursuit of learning. However, in practice, the amount of influence the child exerts on curriculum development can be limited because of restrictions caused by a range of pressures, for example, teachers' beliefs and expertise, curriculum models or external examination (Biesta, 2016). Researchers Bron and Veugelers, (2014, p.134) attempted to reconcile these different perspectives by viewing the curriculum "not as a product or a fixed set of requirements, but as a process wherein external aims give direction but also where teachers and students influence what is actually experienced in class." Haladyna and Rodriguez, (2013) contended that cognitive constructivism at present provides the prevailing theoretical structure employed when compiling assessments.

The theory of constructivism is closely connected with that of social constructivism which is addressed in the section below. I have outlined the two separately to highlight the potential differences in understanding the mechanics of learning. Some of the key critiques of Piaget's theory are addressed in social constructivist theory.

Social constructivism

Social constructivism is a stage further along the continuum of learning theory development, one that according to Shepard (2000) encompasses elements from cognitive, constructivist and sociocultural theory.   Highlighting that young learners construct their own knowledge through meaning making, social constructivists accept the socio-cultural aspects of learning (Vygotsky, 1978) emphasising the importance of historical cultural background and context and the role in learning of interaction with others (Sfard, 1998; Cobb, 1999). Bruner argues (1996, p.4) "(c)ulture then, though itself man-made, both forms and makes possible the workings of the distinctively human mind." He continued "(l)earning and thinking are always *situated* in a cultural setting and dependent upon the utilization of cultural processes." Learning is viewed as the result of a complex evolving active situation where the individual and environment are both constantly changing because of contact between these two variables (Bredo, 1997).

Stobart and Hopfenbeck (2013) contended there has been a shift in European thought towards socioculturalism which they define as "an umbrella term for approaches which root learning in social interaction".   Perhaps Vygotsky (1978) was the most eminent scholar of the socioculturalist theorists. He contended that meaning is negotiated by questioning and explaining through interaction with others within specific contexts and environments (interpsychological) and at the same time using inner speech for thinking purposes to internalise and reflect on the knowledge (intrapsychological). Therefore, there is a social aspect to learning which is operating in tandem with internal, cognitive activity using inner speech. Gray and MacBlain (2012, p.73) reflected that "(m)ediated, social, collaborative activity can be thought of as the bridge which brings a child from lower order concrete thinking to higher order abstract thinking." Language is pivotal for meaning making and engaging in higher order thinking in the social constructivist approach (Vygotsky, 1978; Bruner, 1983).

Pedagogically, there is an emphasis on meaning making through interaction of the learner with others.   Vygotsky (1978) suggested that learning takes place within the 'Zone of Proximal Development' (ZPD) which is the distance between the actual developmental level and the potential level which can be reached by interaction with advanced partners (Vygotsky, 1978). These individuals, groups, technologies, provide 'scaffolding' (Wood,

Bruner, and Ross, 1976) which facilitates thinking within the ZPD that leads the learner to the higher developmental level.

Social constructivism is closely related to the principles of discovery learning. Bruner (1996, pxii) suggested

> acquired knowledge is most useful to a learner, moreover, when it is 'discovered' through the learner's own cognitive efforts for it is then related to and used in reference to what one has known before.

Bruner, challenged Piaget's view of the role of language in cognitive development. Piaget contended that language was "a reflection or mirror of cognition and not a major influence on thinking itself" (Watson, 2000, p.135) whereas for Bruner (1983) language plays a pivotal role in the development of cognition. This has possible pedagogical ramifications for this study.

A socially constructivist perspective of attainment argues since no objective reality is uniformly interpretable by all learners, then assessing the acquisition of such reality is not possible (Jonassen, 1992). Yet, there must be an opportunity for young people to construct their learning in a way that reflects their unique perspectives of the world built from their unique experiences. Moss (1994) argues for more interpretive, classroom based approaches to assessment such as building of portfolios and assessment of coursework (Elwood, 2006) and giving credit for workings in problem solving (James, 2006). Research on Assessment for formative purposes (generally termed assessment for learning) over the last nineteen years has been embedded in sociocultural theory (Black and Wiliam, 1998; Hayward, 2012; Baird et al., 2013). This has emphasised the function of assessment as being an integral part of the learning process, raising understanding and attainment (Black and Wiliam, 1998; Hayward and Spencer, 2010). The focus then is on the process of knowledge construction in context and on regular metacognitive processing of information rather than 'one size fits all' summative assessment characterised by labelling pupils using letters, numbers, or statistical scores.

In a similar fashion to constructivism, tensions can arise between the rigidity of the examination syllabus set by external authorities and the notion of young people

personalising their learning through interaction with others and being involved in standard setting with teachers and those offering courses in schools (Sadler, 2010). Apart from possible argument as to the content of the learning between national curriculum authorities (what knowledge a young citizen is expected to have) and teachers and learners, there is also the spectre of validity of assessments constructed locally by teachers and learners. National comparisons become difficult to standardise and problems ensue in ranking young learners (Newton, 2013).

Tensions exist in the ways in which social constructivism is enacted. In her reflections on the changing role of the teacher and learner/s in assessment, Hayward (2012) contends that learners ultimately control motivation and engagement with their own learning and their views on assessment should thus be moved to centre stage. Given space and listener attention with a serious view to action (Lundy, 2007) young learners were capable of and even relished fulfilling the participatory role.   However, if those supporting learning are also viewed as having a pivotal role in assessment, this challenges the child-centred view of learning, and provides a reason for moving to a co-constructivist approach (Ang, 2016). The challenge will be to rebalance the roles of teacher and learners in assessment in a system where educational theorists move to champion sociocultural theories of learning, but the examination system remains firmly rooted in individualistic constructivist practices.

2.5.2 The impact of cleft on the models of learning

After an extensive search of the literature on cleft I was unable to find any previous research exploring theories of learning in the context of the education of young people with cleft. Yet, there are important issues to explore as previously identified from the literature on cleft – for example, aspects of inclusion, issues of language and communication, aspects of cognition, of self-concept and the role of others in the learning process. This is an issue to which I will return in Chapter eight (a discussion of findings incorporating evidence from the research datasets).

2.5.3 The Scottish education system: learning and attainment

The current educational context for all learners in Scotland (ages three to eighteen) is the national curriculum framework entitled Curriculum for Excellence (CfE) launched in 2004. It is intended that through these experiences young people will develop the knowledge, skills, attributes, and capacities required to demonstrate four key capacities – to become successful learners, confident individuals, responsible citizens, and effective contributors (Scottish Executive, 2004).

The curriculum was intended to encourage personal development alongside social responsibility (Priestley, 2013). Within this single coherent structure, CfE was intended to reduce the levels of centralised prescription associated with the previous curricula and develop a model focussing on child-centred learning set within contexts appropriate to different learners and different communities, therefore recognising specific cultural settings.

Consistent with this broader definition of learning and consistent with the definition offered by Scottish Government, (Scottish Executive, 2006) CfE includes learning experiences which occur both inside and outside schools and colleges. Indeed, as Macbeth (1989) reflected it is difficult to attribute learning specifically to one of the three main areas – school, home and community – as these three elements overlap. Learning experiences which occur outside school are included in the evidence and analysis within this study.

Adhering to the wider interpretation of the curriculum as culturally influenced, CfE is based on the principles of challenge and enjoyment, breadth, progression, depth, personalisation and choice, coherence, and relevance (Education Scotland, 2008). The inclusion of the principle of personalisation and choice enables learners to create new knowledge which is meaningful to them within their culture.

Making progress/attainment in learning within CfE (2013) is defined as the "measurable progress which children and young people make as they advance through and beyond school and the development of a range of skills, knowledge and attributes needed to succeed." Five stages through which young people will progress are identified. However,

tensions exist as this curriculum was established to provide learning experiences on a culturally situated and child-centred basis yet the stages which are broadly based on age espouse a linear progression suggesting lack of opportunities for individual pacing of learning.

Curriculum for Excellence Levels
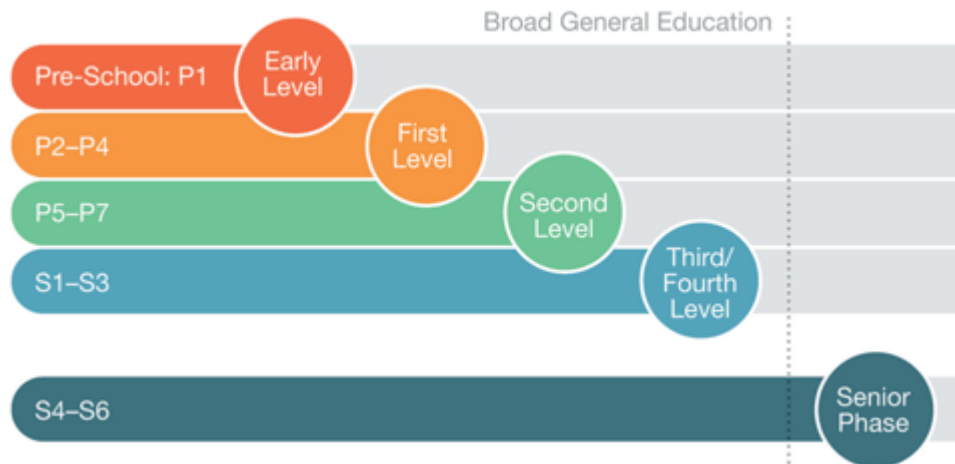
Figure 2.2: Education Scotland, 2014: Curriculum Levels

The curriculum in Scotland has eight subject areas – arranged in alphabetical order – Expressive arts, Health and wellbeing, Languages, Mathematics, Religious and moral education, Science, Social studies, and Technologies. There are three additional cross curriculum areas of study – Literacy, and Numeracy, and Health and Wellbeing (Scottish Government, 2009b). This encourages interdisciplinary thinking and skills development. However, Priestley and Humes (2010) argue that this curriculum has the limitations of a content model of curriculum development with education based on the transmission of knowledge rather than a process curriculum which is designed with a view of education as a process of development. Although the latter could be more unpredictable (Stenhouse, 1975) a process curriculum offers freedom to explore paths not foreseen at the start and this could lead to better outcomes and cater more for the individual learning interests of the young people thus raising motivation. There are tensions in reconciling these aspirations with society's need for formal national qualifications. This relationship is made more intense because educational assessment, designed to reinforce a society's culture, is a major influence on curricula (Baird, 2013).

It should be noted that attainment in this thesis is reported using a mixture of systems of assessment because of the time scale covered by the study. Pupils in the oldest group provided results based on the former assessment system, the Scottish Credit and Qualifications Framework (SCQF). Standard Grades were attempted by pupils in S3 and S4 and have three award levels, Foundation (SCQF 3), General (SCQF 4) and Credit (SCQF 5). Standard Grades have been supplemented in recent years with Intermediate 1 (SCQF 4) and Intermediate 2 (SCQF 5). Higher levels were generally attempted in S5 and S6 (SCQF 6) and Advanced Higher (SCQF 7) in S6. Standard Grades and Intermediates have now been replaced by National Levels which the two younger age groups in this research were working towards. The percentage of young people achieving SCQF grades in Scotland, using the former examination system, for year 2011/12 were

Scottish Examinations and the Percentage of Pupils Achieving these Results (in the year 2011/12)

Examination	Percentage achieving this grade
No passes	1.7
Standard Grade Foundation/Access/ SCQF 3	2.4
Standard Grade General/Intermediate 1/SCQF 4	14.4
Standard Grade Credit/Intermediate 2/SCQF 5	25.8
Higher/ SCQF 6	37.5
Advanced Higher/SCQF 7	18.2

Table 2.2: The percentage of pupils achieving different examination levels, 2011/12. (Scottish Government, 2013b)

A recent evaluation of the success of CfE was carried out by the OECD (Organisation for Economic Co-operation and Development, 2015). The remit of the document was to examine the 'broad general education' element of CfE which concerns young people up to the age of fifteen years. Whilst achievement is above international averages, and a formative emphasis was recognised in assessment, challenges remained in the performances of young people in certain areas, particularly in reading and mathematics. A cause for further concern was the increased achievement gap in literacy and numeracy between the least and most deprived areas.

Section 2.6   Conclusion on the Literature

Medical research based mainly on intelligence testing has highlighted that young people with cleft have a propensity to underachieve. The following issues are suggested by medical professionals from different genres as possible causes of this proposed underachievement: language and communication issues, cognitive issues, self-concept and the role of others in supporting learning.

From an educational perspective, based on the various literature identified, and explored in this chapter, there appears to be justification for placing these issues under the spotlight during this research study.

Given the issues raised by the previous literature, the next chapter will consider the methodology to be used to explore the experiences of young people with cleft who are learning in schools/colleges and at outside activities in the west of Scotland.

C H A P T E R   T H R E E
Research Methodology

This chapter outlines and justifies the research design adopted in this study including the sampling strategy, the choice of research instruments and any limitations therein.

3.1 Introduction to the Methodology

From an ontological point of view this study was set in the constructivist paradigm (Denzin and Lincoln, 2011). This paradigm suggests that there are no overall 'truths' as might be found within a positivist world view. Rather, I have taken a relativist approach. Pring (2004) contended that instead of searching for 'truth' we try to 'make sense' of our life experiences in a reality that is constantly changing. Pring (2004, p.62) reasoned "we do this through constructing connections, meanings, frameworks through which experience is sieved and made intelligible." This approach is concerned with human beings co-constructing realities which are in a constant state of change and development, where humans have agency and therefore have a choice in their actions.   Guba and Lincoln, (1985, p.39) contended "realities are wholes that cannot be understood in isolation from their contexts". Therefore constructivist researchers must consider participants and their natural environments as inextricably linked. This is in contrast to the approach called 'positivism' which adopts a kind of scientific or naïve realism (there is a social reality that exists independently of human conceptions and interpretation), where the humans are passive and are controlled by their environment. In this approach the researcher adopts an objective stance, aiming to create knowledge deductively, testing data successively to see if they match a hypothesis about what is being studied. Often a level of probability of certainty is associated with the result which is usually portrayed in statistical terms. A dilemma arises for positivists because they state that the truth about all empirical phenomena can be found through scientific and logical reasoning, and the purpose of research is to discover this truth, and researchers seek to 'discover' this. However, when they get their research results they have no accepted standard to measure it against because it is that reality they have been looking for in the first place (Guba and Lincoln, 1985).

So, this study, set within the constructivist paradigm, offers an interactive exploration of human experience where young people are dealing with the medical condition of 'cleft' whilst trying to make progress in learning in schools/college and in social spaces.

From a constructivist epistemological stance knowledge is seen as created inductively, based on human interaction and communicated by human beings. Substantive theory emerges from the data (Guba and Lincoln, 1985). These researchers contended that what is important is more than knowledge expressed in language form (propositional knowledge) but also includes tacit (intuitive, felt) knowledge as a source of data, "because often the nuances of the multiple realities can be appreciated this way; because much of the interaction between investigator and respondent or object occurs at this level" (Guba and Lincoln, 1985, p.40).

This study set out therefore to adopt a subjectivist viewpoint. There is an emphasis on myself as the researcher building knowledge about cleft through reaching a consensual narrative with the participants to represent their personal realities accurately. However, it is questionable whether the researcher can always remain 'inside' the inquiry: at times I move outside the narrative construction to adopt the role of an 'outsider' making judgements on the data, deciding on questions to ask and lines of inquiry to follow up. This insider/outsider perspective is examined more deeply in Section 3.2 of this chapter. Since each person comes to the research with their own set of values there could be conflict as the researcher attempts to move away from 'self' and present an approximation of the views of others. (Denzin and Lincoln, 2011). For example, the phrase 'understanding pupils better' might have different meanings for different people. A subjectivist stance is in contrast to that adopted by the positivist approach whereby the researcher adopts an objective, dualist stance, unconnected to the emerging data.

Positivist approaches look at empirical facts/events and seek to identify their causes. Knowledge is not a straightforward matter of interpreting phenomena using reason and logic and identifying the causes of effects as a positivist view would maintain. Rather, knowledge development can occur in a spiral where knowledge acquisition in one area may be a catalyst for the activation of knowledge in another. Knowledge, in socially constructivist terms, can be advanced by viewing situations from different angles and revisiting previously acquired knowledge to reassemble the pieces of a puzzle in a way that

moves understanding forward in new directions (Poplin, 1988). Different participants in this study constructed their knowledge of the world differently and this resulted in multiple realities. These multiple realities were not unconnected entities but rather offered the possibility of overlapping areas of understanding which could be termed objective idealism (Spencer, Ritchie, Lewis, and Dillon, 2003). Objective idealism offered the constructivist researcher the potential to go beyond descriptive interpretations and drawing from collectively shared understandings, to perhaps develop leads hitherto unforeseen, thus moving towards a deeper understanding of cleft as a phenomenon.

I viewed reality as sets of dynamic interactions in which young people played an active role in shaping their world and as they went about this, their reality was constantly changing. For example, educational experiences at school/home/clubs constituted one set of dynamic interactions and another set occurred where they interacted with medical experiences. This study was set at the interface of both these sets of experiences and it was the realities of the participants at this interface that I tried to reconstruct. In accordance with the study title, an exploratory approach was appropriate since there appeared to be very little research of this kind already undertaken, that is, grounded in the perspectives of the young people.

The role of the insider/outsider researcher is examined in more detail in the section that follows.

3.2 The insider/outsider debate

Constructivist epistemology involves the building of knowledge from shared experiences and through engagement with the world (Pring, 2004). To believe otherwise is to neglect external reality, replacing reality with idealism that is focused on the mind alone (Sikes and Potts, 2008). The insider/outsider debate concerns the methodological location from where the researcher attempts to build the data. Brannick and Coghlan (2007, p.60) define insider researchers, engaged in qualitative studies, as "native to the setting and so hav(ing) insights from the lived experience". This is in opposition to researchers who have allegedly had no previous cultural membership of the group (Denzin and Lincoln, 2011) and no embedded experience within the research area and are therefore termed outsider researchers.

The work of insiders has been accused of lacking objectivity due to them being too close to the issues and consequently their reports are seen to lack validity. However, Brannick and Coghlan (2007) contend that through a process of reflexive awareness researchers could rebut this challenge. Since the 1980s researchers have been encouraged to include autobiographical details to improve transparency for readers of their reports (Sikes and Potts, 2008). Nielsen and Repstad (1993) reflected that being an insider is useful in that these researchers know the terminology, can avoid any areas that may be considered off limits, understand the mind set of their colleagues and can utilise their experience to frame follow up questions which elicit richer data. On the other hand, being an insider may mean assuming too much and failing to probe enough, and/or substituting their own answers instead of employing critical thinking negotiated through bi-directional knowledge building (Grant, Nelson and Mitchell, 2008).

Although this study is concerned with a complex kaleidoscope of overlapping familial, educational and medical worlds it is only by having extensive experience as a teacher, including teaching young people with disabilities, that I could be considered an insider researcher. I have never taught pupils with cleft. I have previously entered into the culture of school life, been a member of the social group of teachers, have an awareness of shared values held by the teaching profession and speak the culture's language. For example, as a secondary school teacher my natural inclination when exploring progress in learning is to review teacher reports and reflect on examination results. I would contend that having a background knowledge in the educational environment was helpful while accepting that my thinking may have been coloured by past teaching experiences leading to hastily made assumptions. For example, at first I expected young people with speech issues to have the propensity to struggle academically but on reflection this was refuted by my previous more positive teaching experiences with young people with speech difficulties. It was important for me to actively search for any assumptions that I was making whilst analysing the data and drawing conclusions from the data.

In contrast, Grant, Nelson and Mitchell (2008) contend that the outsider researcher has to gain the trust of the community being researched and tensions can surface. They suggest that the group may historically have been oppressed or the researcher may be viewed as a representative of a service provider the participants have had negative dealings with in the

past. This involves the researcher having to build a relationship with the group, reassure them of having a respectful co-constructivist relationship with the researcher to enable the voice of the participants to be accurately portrayed. The researcher has to relinquish full control allowing power to pass to the researched. In this study, I would contend that participants were enthusiastic about telling their narratives but did not associate me with medical personnel. They were aware of my teaching background and there was one incidence of a parent hesitating before making adverse comments about her experiences with school staff.

However, where research concerns human behaviour it is unlikely to be classified as purely objective no matter whether the researcher is external to the area being researched or embedded within it (Smyth and Holian, 2008). This is because qualitative studies involving choices are interpretive and therefore influenced by the experiences and values of the researcher. In any case, objectivity is not the main focus of most qualitative research since the aim is to report co-constructed examples of practice which offer the reader knowledge that provokes further reflection.

Grant, Nelson and Mitchell (2008) reflected that what is important, whether from an insider or outsider perspective, is that the research is negotiated, transparent, credible, and accurately reflects the community it concerns.

The next section addresses the research approach as relevant to this study.

3.3 The Research Approach

Quantitative methodology was rejected in favour of qualitative methodology (Denzin and Lincoln, 2011). A major aim of the former is to provide generalisations. However, the aim of this study was to offer examples of experiences. Using the qualitative approach I accepted the fact that the knowledge of individuals was unique to their set of circumstances and the interactions with myself were also unique. Any shared understandings offered were individually located in space and time. As such they were specific to this period and could not be directly replicated to produce generalisations.

A further reason for deciding against the use of a quantitative approach was because it had already been used extensively by medical staff, particularly in the form of IQ tests of the young people. Medical staff used this test results evidence to make predictions of future academic performance of the children. For this study, it was felt that intelligence testing was too narrow in its focus, because it did not consider the social side of learning, nor look below the surface to explore a framework of links to explain what was happening over time, why it occurred and what were the consequences for those involved. Previous studies, mainly based on quantitative data, raised professional and medical issues but did not attempt to understand issues from the perspectives of the young people.

The search for meaning was undertaken using mimesis. This approach, with traditions stretching as far back as the ancient Greek philosophers, viewed participants as actors, reconstructing the experiences that had unfolded in their world. Evidence was interpreted from data coming from the dialectical process (Gadamer, 1960) but with "an agenda for negotiation of those claims, concerns and issues that have not been resolved in the hermeneutic dialectic exchanges" (Pring, 2004, p.62). The hermeneutical process here implies acceptance of a multiplicity of meanings in a text and the interpreter using their knowledge of the subject area. (Kvale, 2007). However, Gadamer (1960) viewed the interpreter as not simply decoding the interactions but rather bringing to the interpretive process their own history and culture and anticipated explanations. So this should offer new and perhaps deeper perspectives on the data. However, to increase the credibility of the study it is important for the researcher to make appropriate elements of their own history known.

By concentrating on their own words, the study aimed to offer deeper insights into the world of young people with cleft. As Reason and Bradbury (2008, p.571) argued, collaborative inquiry has "the potential to shift the broader social context from one where the silencing of children is unremarked, to one where their voice and competence may eventually be credited – and celebrated."   The decision was taken to make the young people the focus of the exploration because they were the only ones who really understood what it felt like to have this medical condition whilst trying to engage in social and academic learning.

It was recognised that what was being explored was the participants' interpretations of their experiences. Connelly and Clandinin (1990, p.2) argued for the efficacy of using narrative as a means of understanding real experiences "education is the construction and reconstruction of personal and social stories; teachers and learners are storytellers and characters in their own and other's stories." Exploring real experiences was lacking in previous cleft research especially in the educational field. Listening to the voice of the child is an important part of this study and is further discussed in the section that follows (Section 3.4) in relation to the changing conceptualisation of 'childhood' and the 'child'.

Even if oral sources might not always seem fully reliable, Portelli (1991, p.2) argued that: "Rather than being a weakness, this is however, their strength: errors, inventions and myths lead us through and beyond facts to their meanings."

The narrative of the study moves from the voices of the young people to a kaleidoscope of views from adults engaged directly or indirectly in their learning.

Following the constructivist approach the collection and analysis processes were undertaken side by side. This took into account the complexity of life because, as data were collected and analysed the meanings interpreted could inform the next stage of data collection. As interactions produce unforeseen challenges it was possible for me to return and adapt the study as it progressed. Data were analysed, synthesised and categorised into patterns from which developed the narrative. Therefore, this is a data driven study which arises from and is documented in narrative.

Qualitative research offered the possibility of focusing on the experiences of a small number of participants with the purpose of examining these in-depth. Crabtree and Miller (1992) suggested that qualitative studies were suitable for research where the sample size was in the region of six to twenty. This small number of participants was ideal for a subject area which was complex as there was a diversity of aspects within the medical condition. Such individuality manifested itself for example in the two medical conditions (cleft lip and palate and cleft palate only), in the extent of the cleft, in the medical treatment plan provided for each patient/pupil, and in the possible psychosocial reactions to the cleft.

3.4 The Conceptualisation of the Child and Childhood before and after the UNCRC (1989).

The way in which childhood and the child have been conceptualised within society has been a deeply contested area (James, Jenks and Prout, 1998). Historically, five models of the child were portrayed in literature (James, Jenks and Prout, 1998): the evil child (conceived with original sin and therefore in need of discipline and protection, having no rights), the innocent child (born naturally good, valued for their individuality, but open to corruption by society) the immanent child (children develop a reasoning capability by interacting with adults), the naturally developing child (natural growth measured against 'norms' set by timeframes) and the unconscious child (concerned with drives and instincts - the child in a state of 'becoming'). These five models have been influenced by the works of five eminent scholars respectively: Hobbes (1588-1679), Rousseau (1712-1778), Locke (1632-1704), Piaget (1896-1980), and Freud (1856-1939). However, the historian Aries (1962) suggested that instead of one concept entitled 'childhood', this term might have varied in meaning and this relativity opened the possibility of analysing the term from different perspectives leading to a new sociological model of childhood.

James, Jenks and Prout (1998) suggested this new sociological model of the child has four forms which they entitled: the social structural child, the tribal child, the minority group child, the socially constructed child, but these forms may not be mutually exclusive. This study, set within the constructivist paradigm, adheres most closely to a socially constructed view of the child. This means rather than a universal concepts entitled 'childhood' and the 'child', this offers the prospect of multiple forms of childhood and is in opposition to the biologically deterministic, material view of the 'child'. The socially constructed child has agency to build their own world through meaning making, originating from personal experiences (Bruner, 1961) and interaction with others (Vygotsky, 1978), and is situated locally, within time and space. However, James, Jenks and Prout (1998) accepted that the presence of the material child in biological terms imposes limits on this sociological model of the child.

Historically, the views of children have not been heard because they occupied an inferior status within society, a 'becoming' rather than a 'being' (Tangen, 2008). Their decision making ability was questioned because of their age and experience. They were often

considered the property of their parents and in working class homes deemed an economic resource, employed for long hours in factories and mills (Oswell, 2013). As the value of an educated workforce became recognised, reinforced by philanthropic influence (Tomlinson, 2017) children began to be educated by the state. The Education (Scotland) Act 1872 introduced a compulsory national system of elementary education in Scotland for young people aged five to thirteen (Anderson, 2013). Childhood progressively became viewed as a separate time in the lifecycle where children were to be nurtured within a protective family environment and be developed within cultural 'norms' reinforcing existing social structures (Foucault, 1977). Increasingly, there was a predisposition to use statistics for measurement, to distinguish between the 'normal' child and those labelled 'different'. This was reflected in education by Piaget's (1960s) developmental model. Children who were labelled 'different' could be removed from others of their age group as a form of further disempowerment.

However, in the later decades of the twentieth century as part of the Rights Movement (see chapter one) the child was progressively being viewed more as a 'being' rather than a 'becoming' (Tangen, 2008). Gillett-Swan and Coppock (2016) highlighted the conceptual shift in the view of childhood within sociology, underpinned by three assumptions: firstly that the child was a social rather than biological construction; they were social actors worthy of being the subject of research and; capable of receiving and giving knowledge. Oswell reflected (2013, p.241) "Central to the liberationist discourse was an understanding of the child as an autonomous and rational agent able to freely make decisions about their own life." This highlighted that young people are the experts on their own lives (Oliver, 1992).

The UNCRC (United Nations, 1989) came from a move to champion the rights of a section of the population that had hitherto been silenced, viewing the child as a responsible player who could make a difference in the world we live in (Oswell, 2013). James, Jenks and Prout, (1998, p.68) reflected that the Act "in principle, sets out to restore the balance between children's rights and those of their adult carers such as parents, teachers, social workers and medical practitioners." Previously, adult interference has been legitimized through ideologies of care, protection and privacy (James, Jenks and Prout, 1998).

However, the UNCRC (1989) was not a panacea and has been challenged on various accounts. For example, McDowall Clark (2013, p.7) contended that "there is no meaningful definition of childhood that could hold true for all societies and cultures; it will always vary according to cultural norms and expectations" but Boyden (1991) contended that the UNCRC (1989) tended to conceptualise childhood in terms of its Western representation.

 L'Anson (2016, p.26) reflected that this document "was itself produced through a process in which children were conspicuous by their absence" despite advocating greater children's participation and expression. Also, Article forty-two states that the principles and provisions of the convention should be widely known to adults and children. However, Phillips (2016, p.40) reflected that a child "cannot be a rights holder if they know not what rights they hold" and she continued by suggesting that the number of children who know their rights is minimal.

Article twelve (UNCRC, 1989) involves the right of children to express their views. However, Lundy (2007) contended that 'voice' was not enough. For a successful implementation of Article twelve it was important to focus on four factors: voice (children must be encouraged to express their views), space (children must be given the opportunity to express a view), audience (the views should be listened to by all relevant parties) and influence (the views should be acted upon as appropriate). Lundy's model argues that these elements are inter-related and are not static so once the child is informed of the results of her/his influence, the process may begin again. Robinson and Taylor (2007) contended in the case of 'voice' there are four core values – a conception of communication as dialogue (each party respect other parties), the requirement for participation and democratic inclusivity (all young people have the right to voice their opinion), the recognition that power relations are unequal and problematic, and the possibility for change and transformation. It was not enough simply to listen respectfully, action must be seen to follow.

Adults (particularly parents) may be reluctant to relinquish power over children and listen to them and act on what they say (Foucault, 1977). There is a question of age and maturity and young people mature at different rates. However, Oswell (2013) suggested replacing

adult rights by adult responsibilities - allowing social structural changes in the ways in which children are treated by parents, educationalists and health and welfare workers.

Discussing inclusivity, McDowall Clark (2013, p.33) reflected that "because ideas about the 'typical' child have such a strong hold on perceptions of childhood, children with disabilities challenge popular ideals of the perfect family". Lundy and Cook-Sather, (2016) reported that it was important for children with disabilities to be accorded equal rights within the UNCRC (Article two) to ensure they do not experience a 'double denial' of their rights because of questioning of their competence. Lundy and Cook-Sather (2016) emphasised adults must look for non-verbal cues especially for younger children and enable the communication of children with disabilities to be understood.

This study is consistent with the ideals of the UNCRC in that it moves to include all young peoples' voices (Article two), with a view to action being taken by appropriate familial and professional groups. In an area where children's voices have on the whole remained silent (Article twelve) this study challenges this view by empowering the young people to express themselves (Article forty-two) and through dialogue, attempts to restore the balance of power between the children and adults involved.

The methods employed in this research will be discussed in the section that follows in chronological order of their utilisation.

3.5 Specific research instruments

In accordance with qualitative methodology the research instruments chosen were semi-structured interviews, a selection of case studies and finally interviews with professionals engaged in the medical treatment of the pupils. These methods would facilitate an interactive, in-depth exploration of issues from the point of view of the young people as well as seeking the views of those actively involved in their learning and treatment to reach shared understandings from their various worlds.

The questions for the semi-structured interviews were based on themes that emerged from the literature and clinical visits: literacy issues, cognitive issues, the psychological effects of hospital attendance, participation in social life experiences, self-esteem, and attitudes of

parents, teachers and peers, medical treatment, and the potential effects of cleft on attainment. The questions for the three schedules varied for each age group in terms of language and length. (see Appendix one). A selection of puppets and toys were used during the interviews with the youngest group of participants. The purpose of the puppets and toys (see Appendix two) was to engage the youngest group either by my using the puppet or toy character to take the role of a conversation partner speaking directly with the child or by using two puppets – I would manipulate one puppet and the child the other to externalise the experience for the child. Some children preferred a straightforward interview choosing the toys that represented their hobbies as a focus to begin discussions on their social interests. A selection of pictures showed examples of playground activities and in class activities and organisations which started a conversation (Adamson and Adamson, 2010; Civardi, 2010; Hunt and Brychta, 2008).

The responses which came from the interviews with the young people provided the themes that were the basis for this study. These were classified under the following headings: curriculum, teaching and learning, additional support, social learning, medical treatment and progress in learning. These then were used to form the questions for the case studies (see Appendix four).

3.5.1 The Semi-structured Interview

The interview approach allowed me to reach areas of reality that I would not normally have been able to explore, such as young people's subjective experiences and attitudes. The young people could express their responses in their own words. I encouraged the interviewee to reflect on certain themes but did not offer any personal opinions about them. The interview also offered the possibility of using "naturally occurring" empirical materials since issues of speech, hearing and memory could be informally assessed throughout the interview by the researcher. Both during the interactions with participants and on examining the transcripts from the voice recordings I was aware of forming impressions. The issue of considering interview experiences as a specimen of interaction rather than supplying answers about the topic was considered by Perakyla and Ruusuvuori (2011, p.529) in a positive manner, "it should be understood as a continuum rather than a dichotomy…. the researcher is in more direct touch with the very object that he or she is investigating."

Greig, Taylor and Mackay (2013, p.155) contended that as they attempt to make sense of their experience

> research participants consciously and unconsciously tailor their responses to fit that context, knowing that they are presenting themselves to a particular audience. Thus, stories are created and recreated in the midst of the shifting connections individuals forge among past, present and future.

This could raise suspicion about information offered but if stories were inconsistent I was present to clarify if there had been a misunderstanding of the question, to reflect if this was due to the interviewee's personality or if/why the response had been deliberately misleading. During the interview participants sometimes discovered new aspects of themes, resulting in them changing their evidence. Kvale (2007, p.13) viewed the interview as "a learning process for the interviewee, as well as for the interviewer." However, he continued that it was, "outside the scope of research interviews for the interviewer to argue the strength of his or her own conception of the topic investigated".

Throughout the interview salient points could be developed. However, this could engender an asymmetrical power relationship. The research interview is not an open everyday conversation between equal partners (Kvale, 2007). Kvale contended the researcher defines the interview situation, determines the topic, poses questions and chooses what themes to follow up. But, the interviewee can decide not to respond to the questions or talk around them, or if they feel uncomfortable with the direction of the interview, they can end it. To lessen power asymmetry this study adopted a post-modern, socially constructive approach to knowledge creation (Denzin and Lincoln, 2011). Using collaborative interviewing the participants and myself contributed input on a more equal footing. For example, if a young person chose to follow a particular line of response, they could continue to develop their evidence. For example, this occurred in the case of speech, which led on to a discussion on teasing or bullying.

In this study interviews were conducted with the aid of an interview framework based on areas from the literature. The broad schedule encouraged a consistent line of questioning across interviews which facilitated ongoing comparative analysis. Areas were explored

orally by using a combination of open and closed questions. Open questions allowed me to probe experiences to a deeper level and the interviewees to elaborate on their responses as they chose fit, with the hope that this would result in rich data. In contrast, closed questions encouraged the younger and less verbally expressive participants to respond, building their confidence. Telephone interviewing was rejected for several reasons: a lack of opportunity to view body language, the difficulty of confirmation of the identity of respondents, the possibility that parents might attempt to manipulate answers, the possible hesitancy of young children about answering questions over a telephone and my inability to use puppets/toys and pictures to elicit responses.

Focus groups were also rejected as it might be unclear who was speaking when tapes from these natural conversations were transcribed. Focus groups would also necessitate the participants speaking about their medical condition in front of strangers. As patients tended to receive medical treatment on an individual basis this did not encourage fraternization amongst those with this medical condition. The phenomenon under investigation was a sensitive area, where emotions might be displayed and I needed to adopt a sensitive approach, allowing the participants to have time to explore the issues for themselves. "They will also need continuing help in moving below initial or stylised response to reach inner knowledge that has either been suppressed, or has remained largely unconscious" (Ritchie, Lewis, McNaughton, Nicholls and Ormston, 2013, p.38). I believed the appropriate approach would be a one-to-one interview carried out in a natural environment where the interviewee was likely to feel most comfortable.

A range of other potential approaches to data collection was considered. I decided against recording events in real time, for example, by using a diary, for a number of reasons. First, it would be easy for young people to forget to write up the diary. Second, the writing up of a diary might have been difficult for five year old pupils, and risked parental influence. Similarly, recording life events around cleft using a time line was rejected because this might have disadvantaged the five year olds who lacked writing skills. At the CLAPA conference in Glasgow (October 2013) the psychologist Nicola Stock speaking of cleft histories argued that, "Memories are for families" highlighting the point that very young children often have little memory of their early years and the focus on cleft at that time. To ask them to record such early life events might have confused and upset them. As they

could all describe academic, social and emotional aspects of their current life, I decided to co-construct their realities in this way.

A questionnaire was also rejected. This would have offered more privacy because with interviews the anonymity of the participant could be compromised as the researcher is able to link a name and personal details to the interviewee. However, this would not have offered an interactive approach to clear up misunderstandings or develop important points. The danger of compromising anonymity was deemed less of a problem than losing the interactivity.

Flick (1998) highlighted some of the practical difficulties of using interview as a research instrument: mediating between the interview schedule based on the research question and the interviewee's style of presentation. The issue of the sequencing of the questions was important. In this study some participants gave more developed answers which covered later issues and I concentrated hard to ensure that all areas were covered whilst avoiding repetition of data exchanged. At times, particularly when interviewing parents, it was difficult to judge when to support interviewees because their evidence strayed into what might be territory which did not constitute the focus of the study yet might contribute to overall understanding of issues.

It was sometimes difficult to arrange interviews to fit into a busy timetable of household commitments. But interviewing young people in their natural, home environment reduced the time and stress for participating in comparison with travelling to a central Glasgow location such as the university.

Overall, interviews provide narrative and this was a good way of building an understanding of the realities under investigation. Elliott (2005, p.26) reasoned

> A narrative will not capture a simple record of the past in the way that we hope that a video camera might. However, if the research focus is more on the meanings attached to individuals' experiences and/or on the way that those experiences are communicated to others then narratives provide an ideal medium for researching and understanding individuals' lives in social context.

Population and sampling

Around sixty new cases of cleft are recorded in Scotland each year, predominantly in the west of the country. This offered an ample population base from which to draw voluntary participants. The decision on the nature of the sample was taken following consultation with the medical team. The sample did not include young people with syndromes or other additional medical complications (as defined in the introductory section), as the medical team envisaged the study to be a bridge between the quantitative studies in the area of medical research and a qualitative study from an educational perspective. Those with cleft lip were also excluded because following the cosmetic operation to close the cleft at three months, there is little contact with the hospital.

A letter of invitation with a tear-off slip inviting participation in the study was sent out via the dental hospital to patients in three age groups. Due to insufficient interest from the first round of letters, a second set was sent out to the older two age groups after widening the age parameters. The pattern of responses is shown below in Table 3.1

Results after the first 44 letters were sent out	
5 years	7 responses
10 years	1 response
15 years	2 responses

Results from another 90 letters sent out to the 2 older groups	
5-6 years	No letters required
9-11 years	9 responses
15-18 years	6 responses

Table 3.1: Responses from mail shots advertising the study

After receiving an explanatory telephone call about the aims and requirements of the study, the participants who volunteered are shown in Table 3.2 below:

AGE	NUMBER OF PARTICIPANTS	GENDER (M or F)	MEDICAL CONDITION CLP or CPO
5 years	7 participants	3 males 4 females	4 CLP (3 males, 1 female) 3 CPO (3 females)
9-11 years	9 participants	5 males 4 females	4 CLP (3 males, one female) 5 CPO (2 males, 3 females)
15-18 years	8 participants	4 males 4 females	4 CLP (3 males, one female) 4 CPO (one male, 3 females)
TOTALS	24 participants	12 males 12 females	12 CLP (9 males, 3 females) 12 CPO (3 males, 9 females)

Table 3.2: Pupil participants in this study

Use of the Scottish Index of Multiple Deprivation (SIMD)

A key theme emerging from educational literature on academic performance was the impact of social and economic status on the achievement of pupils. (Raffo, Dyson, Gunter, Hall, Jones and Kalambouka, 2009). The surgeon believed that young people with cleft who live in low socio-economic areas perform more poorly across all medical outcomes. This offered a competing theory to explain progress in learning rather than attributing such progress simply to cleft.

It should be noted, however, that there appears to be no Scottish statistics available linking poverty, this medical condition and educational attainment. I decided nonetheless to consider the possibility of such a linkage and gathered relevant data using the SIMD to categorise the pupils' addresses.

The SIMD 2012 identifies small area concentrations of multiple deprivation across all of Scotland (6505 data zones). It provides a relative measure of deprivation, comparing data zones by ranking them from the most to the least deprived. In this study, I chose to use the quintile categorisation such that the dataset had been split into five groups each containing twenty percent of the data zones (ranked one to five, most to least deprived) (Scottish Government, 2015b).

The overall index is a weighted sum of the seven domain scores. The weighting for each sum is based on how important the domain is in measuring multiple deprivation, how robust are the data and the time lag between collecting data and producing the SIMD. The domain weightings used in the SIMD 2012, which were expressed as a percentage of the overall weight were: current income (twenty-eight percent), employment (twenty-eight percent), health (fourteen percent), education (fourteen percent), geographic access (nine percent), crime (five percent), and housing (two percent).

Whilst this index provides a broad basis on which to make comparisons, it is not without difficulties. Fischbacher (SCOTPHO, 2013) criticised the Index as unreliable for classifying individuals because there could be variation within a zone. Some pupils lived and attended schools in catchment areas which were similar, so they did not mix with pupils from areas with a different SIMD indicator. Others did attend school in a catchment area with a different SIMD indicator and this may have affected their educational experiences including peer interaction.

The numbers of pupils residing in the different SIMD categories, arranged by age groups, is shown on the next page in Table 3.3. In interpreting the possible impact of SIMD categorisation on the findings, I kept in mind the possible inaccuracies of the categorisation referred to in the preceding paragraphs.

AGE GROUP	SIMD CATEGORY	
5-6 Year Olds	**Number 1**	**2**
	Number 2	**0**
	Number 3	**2**
	Number 4	**1**
	Number 5	**2**
9-11 Year Olds	**Number 1**	**2**
	Number 2	**4**
	Number 3	**0**
	Number 4	**2**
	Number 5	**1**
15-18 Year Olds	**Number 1**	**2**
	Number 2	**2**
	Number 3	**2**
	Number 4	**2**
	Number 5	**0**

Table 3.3: Age groups and socio-economic areas

Selection of the Interview Items

The selection of the interview items came from an exploration of general educational literature and research of the literature on cleft and clinical visits. Most books and journal articles written about cleft had come from the medical field with little from previous educational research. The items arising were embedded in the loose interview schedule that formed the core of the interview. The ordering of the items corresponded to that of the five questions.

Methods of Collecting Data (including those for the case studies)

Generally permission was given to record the interviews on a digital voice recorder. The recording included time lapses and meaningful participant sounds, which enriched the data. The recordings were transcribed verbatim in order to capture precisely what the participants were saying and offer the reader the opportunity to form a good understanding of experiences.   In several cases a pre-prepared worksheet (Kvale, 2007) was used for manual recording because the participant felt stressed by the prospect of voice recording and chose this method. On one occasion unforeseen equipment failure forced me to record

responses manually into the worksheet. Field notes were added when necessary. Usually this was to record information from parents – elaborations or clarifications of points made by children during their interviews. I believed that the use of video recording could be too invasive, particularly when young children were involved and since some of the participants had a visible difference.

Pilot Study of the Interview schedules

The purpose of the pilot study was to have individual interviews with members of three groups of young people whose age, gender and social class grouping matched that of the anticipated participants in the actual research study. Three local schools with different types of catchment areas agreed to pilot one of the three interview schedules with four of their pupils. The basis of this design of the pilot came from a combination of factors from research literature (as documented in the Literature Review) and information from the medical personnel along with the strong link to poorer outcomes for lower social classes. It was intended to focus on three different stages of the pupils' schooling which coincided with three important points in the medical treatment of some of the young people – secondary surgery in the early years, alveolar bone grafting at later primary school stage and jaw surgery at the end of their secondary schooling. A mix of the gender of participants was appropriate because some of the literature emphasised gender difference (as documented in the Literature Review) and because there is a general but not exclusive link between gender and condition - girls have a tendency to have CPO and boys CLP.

Three sets of questions were composed, one for each age group. The interview questions for the youngest group were piloted by two Primary One pupils (one boy and one girl) and two Primary Two pupils (one boy and one girl). These young people resided in a socio-economic Class Five area and attended a local suburban primary school. The interview schedule for the middle age group was piloted by four Primary Five pupils (two boys and two girls) in a rural primary school in a social and economic Class Four area. The school was of a small size and pupils of Primary Five, Six and Seven were being taught in a composite class. The interview questions for the oldest age group were piloted by four pupils (two boys and two girls) in an inner city comprehensive secondary school in a socio-economic Class One area. I taught at this school during the time of the pilot study. Two of the pupils who were asked to participate were making good academic progress, the

other two pupils were chosen at random from lower level ability sections in English and mathematics. Permissions were obtained from the pupils and where they were under sixteen years of age, from their parents. Relevant parties signed a consent form which was a replica of that used generally in the study.

The interview schedules were tested to ensure that they were age appropriate by way of language and timing and that the puppets, toys, pictures and model skull which the researcher intended to use were suitable. In order to encourage the participation of the youngest group puppets/soft toys such as 'Bumble the Snow Monster' and 'Magic the Dragon' were used and Surgeon Bear and Teacher Bear helped comprehension of the questions. These were also trialled along with realia to represent a selection of hobbies and pastimes. For example, a toy ipod and a small guitar linked with the characters were used to represent their interest in music, a small ball and small replica Scotland T shirt represented football. Pictures of members of organisations such as the Rainbows and Brownies were shown to aid discussion (see Appendix two). These interested the five year olds, encouraged them to respond and aided comprehension of the questions. A self-portrait drawing activity was included for the two younger age groups to see if pupils included any visible difference. This idea came from an article on pupils at transition from primary to secondary school (Marshman, et al., 2009). A separate Plain Language Statement (see Appendix three) was composed for the youngest participants to be read to them prior to them taking part in the interview. This was also piloted. This proved successful and the wording raised the self-esteem of the pupils as they were informed their opinions mattered to educational and medical personnel. The evidence for this came from the fact they nodded or smiled and looked pleased.

As a consequence of the pilot study the following adaptations were introduced to the original plan. Some questions were re-phrased to take account of ambiguity. The drawing activity, the self-portrait, was removed because it was deemed an unreliable tool, as there was no guarantee it would highlight any points participants were unhappy about in relation to their appearance and it could be labelled insensitive. An illustrated sheet was prepared to remind participants of the areas within the school curriculum in Scotland (see Appendix five). The pupils were offered a choice of having their interviews recorded manually, in a computer file or using a digital voice recorder. The results of the pilot study illustrated the method of recording responses orally via the digital voice recorder was superior to the

other two methods. It was therefore decided to discuss the possibilities for recording responses with the pupils but explaining to them that the voice recorder was my preferred option. The interactions were more natural and I could keep eye contact with participants, which was more difficult with manual recording or keying in information to a file. It was also faster and allowed more reflection time for both myself and the interviewee. I could later replay the interview as many times as I wished to identify hesitations and non-verbal sounds such as sighs. This method also allowed me to have two hands free to operate the puppets which enriched the responses of the youngest group. It became apparent that one of the two boys felt he was too mature for this type of approach and I reverted to a more direct approach – without the realia. This adaptation of the approach to eliciting responses was used in the actual interviewing for the study, as I found the seven pupils interviewed were at different stages of maturity. During the pilot study, when 'Magic the Dragon' first appeared he startled the youngest participant because of his size. She soon got over this and became intrigued by him. However, when asked at the end to rate the toys she said she preferred 'Bumble'. Although 'Magic' was used in the final interviews, he was increasingly replaced by 'Bumble'.

Conduct of Interviews

Parents and pupils were offered a choice of locations for the interview – at home, at the university or at a place of their choosing. In practice, all interviews were carried out in the homes of the pupils. This was due to the distance some of the parents and children would have had to travel to get to the dental hospital or the university and/or the difficulty of finding childcare for siblings. During the study I travelled from the Western Isles to the Solway Firth to interview the pupils. All the pupils from the youngest age group were interviewed with their parent/s present. Generally within the two older groups the parent and child had made the decision as to whether the parent/s were to be present at the interview before I arrived. I said to parents they were welcome to sit in but they were asked not to influence their child's answer and generally any information given by them was considered supplementary and added clearly as given by the parent either verbatim or in field notes made after the taped interview was concluded. Interviews were limited to forty minutes' duration. No reward was offered for participation in the study.

The categories the young people perceived as important formed the basis for the interview schedules for the case studies.

3.5.2 The Case Study

Exploratory case studies (Yin, 2009) were chosen because this approach offered the opportunity to provide deeper explanations of the concepts involved in areas where the effects of cleft might intersect with learning.

> The case was the design frame for understanding the details of what was happening … The key is to draw rich, interconnected information from this singular focus (the case) and derive unique insights from the analysis that follows. (Thomas, 2011, pp.43-44).

Within the case the method of exploration was multiple interviews. It was also a collective case study (Stake, 1995) as the research involved six cases. Boundaries were set for the case studies to explore how cleft affects progress in learning. This was achieved by choosing six cases based on two medical conditions and three age groups. The six cases were located across various socio-economic classes. In each case, at least two adults concerned with the learning of the young people were interviewed.

This was an instrumental case study (Stake, 1995) as it was undertaken with the purpose of making educational experiences better for the young people with cleft as they attempt to progress with their learning. This case study is based on real life experiences and it is hoped the recommendations will give a cause for reflection and action.

Case study could be considered intrusive as a means of collecting data, even allowing for informed consent. However, sensitively handled, collecting primary data, constructed through interviewing individuals from different participant groups appeared to offer the best way of covering the wide range of issues coming from the first interview sets. Observation might have been more haphazard being less focused on the issues.

Triangulation was used as a means of understanding the phenomenon of cleft through the eyes of the various parties involved. I searched individual cases for patterns within the

data which were interpreted from the 'data up' and across cases to reach common findings and identify anomalies (Flick, 1998). The tension between what was consistent across cases and what occurred only in individual cases could have led to a reinterpretation which might encourage a better understanding of the phenomenon.

However, differences in the meaning of language may be problematic because, we have what Bassey (1999, p.43) termed "a *more or less* agreed symbolic system, in which different people may have some differences in their meanings", these nuances of meaning may be important when constructing shared understandings. For example, the word 'Inclusion' means different things to different people.

The question of the extent to which generalisations can be made on the basis of case studies was an issue to be considered. Denzin (1984) highlighted the dilemma – the greater the emphasis on a reality constructed from unique interactions, the less generalisation through triangulation is possible. Simons (1996, p.225) defended this paradox as nevertheless valuable. She contended "the tension between the study of the unique and the need to generalise is necessary to reveal both the *unique* and the *universal* and the *unity* of that understanding".

Stenhouse (1985, p.49) contended that

> generalisation and application are matters of judgement rather than calculation, and the task of case study is to produce ordered reports of experience which invite judgement and offer evidence to which judgements can appeal.

In this study generalisations were made from within the data in each case study and across case studies and these were compared externally with patterns that appeared to emerge from previous literature to try to offer fresh thinking on the topic. Generalisations were of an analytical form (Yin, 2009) and did not rely on statistical generalisations tested against a broader theory.

Population and Sampling

The decision as to which young people should form the focus of a case study was deferred

until after the first interviews were completed. The population from which they were selected was necessarily from the original group of participants. The young people were selected using the following criteria: age, medical condition, social and economic class and how they thought they were progressing at school. The participants selected are shown below in Table 3.4 along with their salient details:

NAME AND AGE	MEDICALCONDITION	SIMD	PROGRESS IN LEARNING
Tulisa, age 16	**CPO**	**two**	**Reservations with progress**
Jessica, age 13	**CPO**	**five**	**Progressing well**
Sally, age 11	**CPO**	**one**	**Reservations with progress**
Lauren, age 18	**CLP**	**four**	**Progressing well**
Liam, age 13	**CLP**	**one**	**Reservations with progress**
Sam, age 7	**CLP**	**one**	**Progressing well**
The age differences reflect the time lapse between the original interviews and the case studies. The information on progress in learning was taken from the pupil's views.			

Table 3.4: Participants chosen to be the focus of a case study

One pupil with CLP, from the youngest group, was approached but declined to take part because she did not wish to highlight her medical condition to her teacher. Her mother reasoned that at seven years old her daughter was of an age to be able to determine her own feelings and this was respected by all concerned. Two further pupils, one from the original five year olds and one from the nine to eleven age group, could not be contacted.

Since an eighteen month time period had elapsed between the initial interviews and the case studies this had repercussions for the nine to eleven age group, as some of them had moved to secondary school.

It was decided to interview a parent, teacher/s/college tutor and an organisational/club leader for each case. This would allow me to access and compare the views of various adults about the same participant and thus enter more fully the child's various worlds.

Selection of Interview Items

The interview schedules for the case studies were based on the themes which emerged from the interviews with the young people. As there were some areas of the research which were particular to each group, a decision was taken to construct three interview schedules – one for the parent, one for the teachers, and one for the organisational/club leaders of the young person.

Pilot of the Case Study Interview schedules

The case study interview schedules were piloted individually by the parent and teacher of one pupil selected from the original group of five year olds. At the end of the interview with the child, both the child and his parent indicated their enthusiasm to participate further. Contact was made by telephone with the parent and child.   Both gave permission for the child to become the focus of the pilot case study. Permission was sought to interview the teacher both from senior local authority educational personnel and from the teacher. The interview schedule was also piloted by an additional support needs teacher who had not had any previous contact with any pupil selected. It had been established during the initial interviews that some of the pupils had additional support needs and such a teacher might volunteer for the study. A local retired Brownie/Guide leader piloted the organisational interview schedule.

Piloting of the case study interviews revealed that the proposed time allocation was too short. Interview times were extended to one hour. The balance of the form of questions was adapted to include more open ended questions. Some questions found to be leading were re-phrased. For example, for teachers, "Eight out of nine pupils said they had never had an issue with hearing. Do you think hearing may be an issue for young people with cleft?"

The study had been piloted by a primary school teacher who was responsible for teaching most curricular areas to her pupils. However, it was a different situation in secondary schools where teachers generally specialise in teaching one curricular area and not all teachers could be interviewed. English teachers and mathematics teachers were approached, along with one teacher from a practical subject, because some pupils stated a

preference for practical subjects over language learning during the first round of interviews
and also because this would add breadth to the curricular areas sampled.

Conduct of the Case Studies

In practice the following nineteen adult participants volunteered: six parents (five mothers
and one father), two primary school teachers, six secondary school teachers, one college
tutor and four organisational leaders. The last group included a Boys' Brigade (BB)
leader, an after school tutor, a theatre director and a karate instructor. This is illustrated in
Table 3.5 below:

NAME AGE/CONDITION	PARENT	TEACHER	CLUB LEADER
Tulisa (16 years, CPO)	Mother	College Tutor Course: Getting Ready for Work	No organised activities
Jessica (13 years, CPO)	Father	English Teacher Mathematics Teacher	Guide Captain unavailable to give comment
Sally (11 years, CPO)	Mother	Primary Class Teacher	After School Tutor
Lauren (18 years, CLP)	Mother	English Teacher Mathematics Teacher Art Teacher	Theatre Director
Liam (13 years, CLP)	Mother	Home Economics Teacher	Boys' Brigade Leader
Sam (7 years, CLP)	Mother	Primary Class Teacher	Karate Instructor

Table 3.5: Adult participant volunteers for the case studies

Six parents were interviewed at home. Interviews with teachers/college tutor were carried
out in school or college in a private room. Organisational/club leaders, were interviewed

in a variety of locations generally suggested by club leaders. At no time during interviews were the young people present. No reward was offered for participation.

3.5.3 Interviews with Medical Professionals

Interviews were carried out with a surgeon and a speech therapist because their involvement was critical to the medical progress of the young people through their professional interventions. According to Reason and Bradbury (2008, p.381), "We cannot frame the health professional, the intervention and the client as independent and separate entities. They are mutually interdependent and participating actors in a larger system." This is important because this study seeks to reach a shared understanding of areas where medicine interfaced with the educational realities of the pupils' lives.

The interviews with the medical professionals were carried out at the university. The topics discussed had emerged from the results of the interviews and case studies. Some questions specific to the medical specialty of the professional concerned were included.

The next section looks at the timeline that was adhered to whilst undertaking the study. It is presented in diagrammatical format.

3.6 Timeline of the study

Figure 3.1 below charts the progression of the study in terms of timescale:
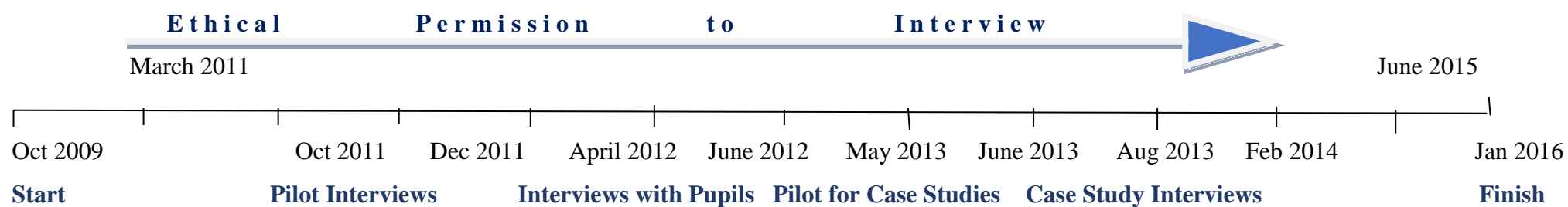
Figure 3.1: Timeline of the study

The section that follows will explore how the data were analysed, tensions within the data and how they were addressed.

3.7 Data Analysis - Strategies for ensuring trustworthiness

In terms of trustworthiness in qualitative research, Guba (1981) based his constructs for analysis on 4 criteria: credibility, transferability, dependability and confirmability. These, he argues, correspond to internal validity, external validity, reliability and objectivity respectively in quantitative research.

Credibility

This is concerned with presenting a true picture of the phenomenon to the reader. In this study I used interviews and case studies which are well established methods for researching qualitative data and all who volunteered were taken as part of the sample. To become knowledgeable in the subject area - prior to starting the study – I visited the clinic at the hospital where the medical treatment for cleft was carried out and studied the biological aspects behind cleft.

I was aware of and tried to guard against biases which could result in my misrepresenting what the participants said. Charmaz (2011, p.366) argued that in quantitative methodology "in the objectivist's logic the number of cases corrects the researcher's possible biases". This is less appropriate in qualitative studies because participant numbers are small. Instead triangulation was employed to find areas of shared understandings and areas of difference by having a sample that included a range of young people and adults.   Their individual viewpoints and experiences can be checked against others as the picture of cleft and progress in learning is constructed (Shenton, 2004).

Where there might be inconsistencies in the information given to me by the participant, I probed from a different angle or asked for clarification of aspects of the answer given.   For example a mother said that before one operation when her daughter was less than two years old, she was able to tie her shoes laces, write her name and read simple words. After the operation the mother alleged the girl was unable to do so.   I believed this to be unrealistic progress for the child's age so I asked the mother again to confirm the age of the child. The mother changed her story to attributing this to another operation at around five years of age.

The interviews, particularly those with the adults, contained thick description of experiences, events and opinions and the contexts that surrounded them. This offers the readers a better opportunity to assess the credibility for themselves.

Transferability

Shenton (2004) highlighted the tensions that exist in qualitative studies with the concept of transferability from a single study to other studies where a key factor is the importance of context. On the extent of transferability, Elliott (2005, p.26) argued:

> Qualitative research therefore adopts what we might call a 'common-sense' view of generalizability such that the reader is left to make up his or her own mind as to how far the evidence collected in a specific study can be transferred to offer information about the same topic in similar settings.

The aim of this study was to offer examples of experiences. Themes can be traced by readers who have a specific interest in what happens by way of that theme. For example, those concerned with absence can follow examples of when this issue affected the young people. I have supplied detailed information about the interviewees and the organisations taking part, details about methods employed, and the time period over which the study was carried out. This should help the reader decide on the extent of transferability to their own future studies.

Dependability

Shenton (2004, p.71) contended that "the processes within the study should be reported in detail, thereby enabling a future researcher to repeat the work, if not necessarily to gain the same results."   By its very nature qualitative research is about changing realities thus this is incompatible with the quantitative aim to replicate the methods to obtain the same outcome.   Nevertheless, in future other researchers may find it useful to follow a similar research path to see where it takes them. To take this into account an audit trail (see diagram, page 106) and detailed procedures have been documented.

Confirmability

This is concerned with the study being true to the data from the participants and not embedded in the history or culture of the researcher. I have described my possible areas of weakness with regard to objectivity in the section below on 'Reflexivity'. An attempt has been made to justify why decisions and methods were adopted throughout the study and the weaknesses of the methods employed have been discussed.

Open ended questioning allowed participants more flexibility to move away from the question which I posed and therefore influence the direction of their interview.

The study was loosely analysed using grounded theory in the sense that the data emerged from the views of the participants (Glaser and Strauss, 1967). Although confirmability is embedded in the way the theory is constructed as data comes from the participants, interpretations still remain to an extent the prerogative of the researcher.

The study was self-funded by the student so no outside agency or authority attempted to influence the results, the conclusions or the recommendations.

The 'Audit' Process

To ascertain how far the data and constructs emerging can be accepted the reader should be provided with an 'audit trail'. Shenton (2004) suggested two diagrams, one being data-centred, showing how the data were gathered and processed and the other a more theoretical trail whereby the concepts inherent in the research question could be tracked.

Figure 3.2 on the following page illustrates two approaches to constructing an audit trail for this study.

The Data-Centred Approach:

Interview Schedule   Case Study Schedule

| Interview Text | → | Coding | → | Emergent Themes | → | Interview Text | → | Coding | → | Emergent Themes | → | Triangulation | → | Results |
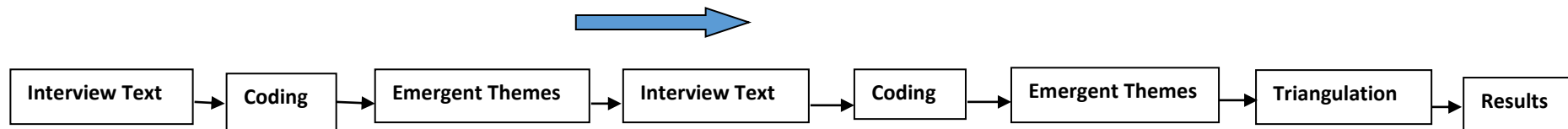
The 'Theoretical Audit Trail':

Issues from Clinical visits and Literature

5 Research Questions

Interview Protocol for the Pupils

Issues for the Case Studies

Case Study Protocol for adult participants

Findings and Recommendations from the data
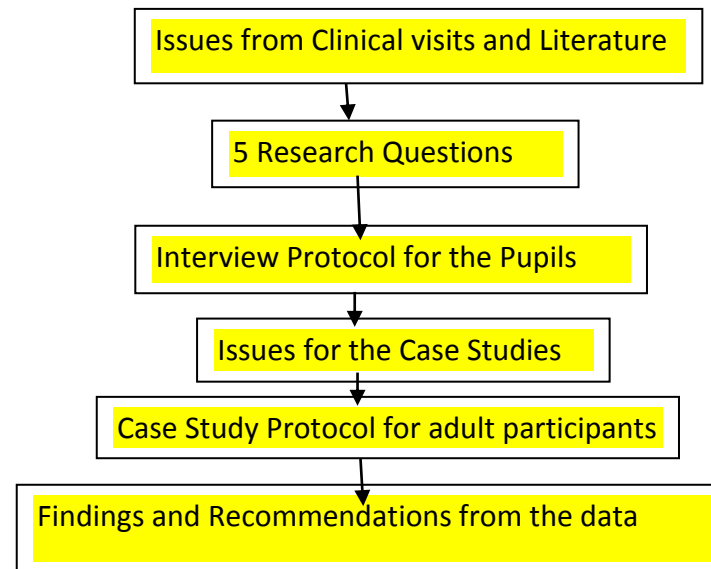
Figure 3.2: Two approaches to constructing an audit trail for this study

Reflexivity

There is a tension between the role of the researcher in co-constructing the data with the interviewee and the role of reflecting the world of the interviewee without personal influence intruding. I chose the area of study and developed the research questions. As Flick (1998, p.49) stated:

> Research questions do not come from nowhere. In many cases, their origin lies in the researcher's personal biography and his or her social context. The decision about a specific question mostly depends on the researcher's practical interests and his or her involvement in certain social and historical contexts.

To reflect on possible bias it is important to know something of my background - their gender, social class, race, and personal history.

I am female, white British and now living in an area termed socio-economic Class Four. I originally grew up in a tenement flat situated in a socio-economic Class One area of Glasgow.

I have been employed as a teacher in an inner city comprehensive secondary school for fifteen years. I have also been engaged for three years in working with young people aged twelve to eighteen years based in an integration centre which formed part of a city comprehensive secondary school. These young people had various additional support needs. For a period of four years I was employed as a teacher in a special school for physically disabled young people. These young people had a variety of physical disabilities including severe speech difficulties and all were of secondary school age.

I had never dealt with the education of children in early years. Before going out to conduct the research amongst this section of the population, I undertook a placement of one day a week, for four weeks, at a local primary school to familiarise myself with the language and idiosyncrasies of interactive engagement with Primary One pupils.

From a personal point of view I come from a background where both my parents are hearing impaired. My mother was both deaf and mute and my father lost his hearing at the

age of three years. Their marriage broke down when I was one year old. From early infancy I have been aware of some of the difficulties surrounding means of communication and these issues played a part in the break-down in my relationship with my mother at the age of eleven years.

Throughout the study I reflected upon my presuppositions about the progression in learning of young people with cleft and was aware these were sometimes being challenged by the data I collected and analysed.

Ethical considerations

Throughout the study the interests of the young people were always put first. The subject matter of the study was of a sensitive nature and this consideration was at the forefront of any decision taken in the design or implementation of this study. I found every interview emotionally moving and for some parents they had rarely if ever spoken to anyone outside the family about their feelings regarding 'cleft'.

Throughout this study all participants were known by a pseudonym. Twenty-two of the twenty-four young people have chosen their own assumed name and I allocated a name to two participants. To protect the identity of the young people the tear-off slips were returned to the university rather than the dental hospital so the medical team did not know which patients volunteered.

It was important, particularly with very young participants, not to overemphasise the 'cleft' issue to prevent creating within the child a feeling of 'difference'. Therefore, when questions were composed no mention was made of the word 'cleft'. During the interviews the principle of confidentiality was upheld. For example, one parent tried to engage me in discussion about her friend's child who had also volunteered to give an interview. I stated clearly I would not confirm or discuss the participation of other young people. Several comments made by parents were inappropriate to include because the evidence was unsubstantiated and concerned a purely medical issue.

The study was approved by the Ethics committee of the College of Social Sciences, School of Education at the University of Glasgow.

The section that follows describes and evaluates the data analysis procedures adopted in this study.

3.8 Data Analysis

Grounded theory, developed by Glaser and Strauss (1967), was formed with the intention of answering the critics of qualitative data analysis processes who maintained that the latter was not as rigorous as those developed for quantitative research. Theory emerges from the data, constructed from the exact words used by the participants and this may offer a more accurate representation of the real worlds that the research participants inhabited. Glaser and Strauss, (1967, p.1) advanced the following rationale for employing grounded theory. "Such a theory fits empirical situations, and is understandable to sociologists and laymen alike. Most important, it works – provides us with relevant predictions, explanations, interpretations and applications." They believed that a theory so linked to the data from which it was constructed would stand the test of time but should be flexible enough to be adapted when new material came to light challenging the theory in its original state. This is important in the case of 'cleft' where research is still ongoing.

Charmaz (2011, p.364) reflected that grounded theory "has become an evolving general qualitative method with three versions: constructivist, objectivist and postmodern." This study adheres to the principles of constructivist grounded theory. The tenets of constructivist grounded theory include accepting multiple social realities, and building knowledge which is temporally and culturally situated, therefore accepting that the researchers' perspectives affect the interpretations of data throughout the study. Generalisations remain partial, conditional and situated with an important role given to nuances of meaning which can be overlooked by an objectivist approach (Charmaz, 2006). This contrasts with objectivist grounded theory which adheres more towards scientific methodology, searching to discover a reality and construct a verifiable theory, from qualitative data, without due regard for time, space and situation, and favouring abstract generalisation (Corbin and Strauss, 1990). In contrast with constructivist and objectivist versions of grounded theories, post positivist grounded theorists view reality as fluid, complex and evolving.

Charmaz (2011, p.361) contended that "the strength of grounded theory not only resides in its comparative methodology, but, moreover, in its *interactive* essence." Data collection informs analysis and analysis informs data collection. Constructivist grounded theory offers a sequential, patterned way of handling the data to construct meaning from in-depth experiences. This is particularly useful in areas where there has been little prior knowledge (Grbich, 2013) such as in the case of cleft and progress in learning.

However, Guba and Lincoln (1985) reflected that grounded theory was challenged on account of its basis on multiple interpretations and therefore the inability to form a theory due to insufficient evidence (underdetermination). They (1985, p.207) counterbalanced this "every act of theory development, whether grounded or a priori, is creative in nature, going beyond empirical data or conceptual imaginings that suggested it." Guba and Lincoln (1985) also contended that facts are theory laden but by admitting tacit knowledge not only widens the investigator's ability to apprehend and adjust to phenomena in context it also enables the emergence of theory that could not otherwise have been articulated.

Grounded theory procedures as described by Barnett-Page and Thomas (2009) - an inductive approach to analysis, use of the constant comparison method, theoretical sampling to reach saturation - could offer a useful way forward to create new thinking about cleft and educational experiences by synthesis of data which went beyond mere description and was in line with the original intention of 'listening to children's voices'. But each of these three procedures has been challenged as discussed in the following paragraphs.

Firstly, the inductive approach to analysis, along with the situated and conditional aspects of constructivist grounded theory, give rise to the researcher's role being integrated into the research. Alvesson and Skoldberg, (2000) highlighted the difficulty of underplaying the researcher's own frame of reference and the influence this might have on generating categories. Therefore, the voice of the participants may be suppressed to give more weight to the views of the researcher (see Section 3.2: insider/outsider debate). In contrast, Corbin and Strauss's version of grounded theory drew nearer to positivism, because the role of the researcher was external to the research and they adopted vocabulary which was associated with positivism, for example, hypothesis, variables and reliability but this

focuses more attention on applying theoretical rules than representing the views of the participants.

Secondly, the use of the constant comparison method has fostered a debate on the positioning of the literature review. Glaser advocated conducting an initial analysis from preliminary data before carrying out a literature review. The purpose of this was to refrain from forcing the data collected into pre-conceived categories which may emanate from firstly consulting literature. Yet, any researcher coming into a field will wish to know what has gone before and it is unlikely that the researcher could begin their study without having an existing theoretical perspective (Grbich, 2013). From the perspective of this study, I started from observations from clinical visits and began to develop an understanding of the area being researched from these early observations. After listening to the young people discussing their educational experiences, I proceeded to consult educational and medical texts so data informed my reading which in turn informed further data collection and this led to the thesis questions.

Thirdly, there is debate as to what point 'saturation' is reached and this judgement is generally made by researchers, exposing them to accusations of bias or making mistakes. As the study develops tensions could result between the numbers of participants the researcher wishes to involve compared to the initial number of participants recorded in ethics forms at the start of the study. Strauss and Corbin (1998) contended that there had to be at least ten interviews for building a grounded theory and this study comprised individual interviews with twenty-four young people, nineteen case study participants and two medical professionals. Therefore, as far as possible, given the constraints of having ethical permission for twenty-four interviews and six case studies and given the time frame allowed, adherence to the principle of 'saturation' was carried out.

In addition, Alvesson and Skoldberg (2000) criticised the manipulation of data into coding which had echoes of the statistical method, more in line with the quantitative approach. So in this study, the data were analysed using coding to elicit themes but in line with qualitative research, I engaged with the data rather than standing apart from it.

In practice, although grounded techniques were loosely adhered to they were not followed stringently because this risked fracturing the data in such a way that findings and

subsequent conclusions and recommendations might be misleading. It was also believed unsuitable to force data into categories and account had to be taken of tension between categories as they emerged. Although line-by-line coding was undertaken, an attempt was made to refrain from over fragmentation of the data, which might have resulted in nuances of meaning being missed. Open coding, axial coding and finally selective coding were used to create original thinking on cleft and how it related to progress in learning. Open coding on a word-by-word, line-by-line, incident-by-incident basis moves the researcher's understanding forward and contributes to fulfilling two of the grounded theory criteria. These are fit and relevance (Charmaz, 2006).

> Line-by-line coding is a heuristic device to bring the researcher into the data, interact with it and study each fragment. This type of coding helps to define implicit meanings and actions, gives researchers directions to explore, spurs making comparisons between data, and suggests emergent links between processes in the data to pursue and check. (Charmaz, 2006, p368).

Strauss and Corbin, (1998) said axial coding helps with this reassembling of the data that have originally been fractured during open coding (Charmaz, 2006). Selective coding according to Saldana (2009, p163):

> Functions like an umbrella that covers and accounts for all other codes and categories… Integration begins by finding the primary theme of the research – what is called in grounded theory the *central* or *core category.*

The case study interviews were analysed using NVivo (Version 9, 2013). This was because NVivo offered a systematic, overarching framework from which to view and interpret the data. This was helpful because there was so much data involved. Yet it proved flexible enough to adapt as the analysis developed. It also facilitated the searching and grouping of items by way of categories. However, I acknowledge that computer programmes such as NVivo, whilst useful, are not a replacement for the human interpretation of nuanced data nor can they incorporate context specific elements (Guba and Lincoln, 1985).

The final section offers reflections back on the methodology adopted and offers suggestions as to alternative lines of approach.

3.9 Reflections on the Research Methodology

Speculative elements

Reflecting back on aspects of the methodology, there may have been different ways of approaching the preparation, design and implementation of the study. These possibilities are discussed in the paragraphs that follow.

Although previously a teacher, I was not experienced in teaching the Primary One age group. Nor was I known to the children in the study and familiarity with them and a better knowledge of how to elicit information from them might have produced more developed responses.

Different participants might have yielded a different result as there is no way of knowing for sure that those who volunteered were representative of the general population with cleft but this is not so important as generalisation is not a key element in a qualitative study which set out to explore examples of practice. The parents who volunteered were motivated to do everything in their power to help their child. They hoped the study would highlight areas of importance to all concerned and perhaps help them in their quest to do the best to support their child, for example providing useful teaching and learning strategies. The case study participants were inextricably linked to a sample of the pupils who volunteered to participate and several originally selected could not be contacted.

Although teachers were protected by a pseudonym it is important to keep in mind in interpreting qualitative data the extent to which the views of participants such as teachers might consciously or unconsciously reflect local authority or government policies, rather than actual experiences.

It is difficult to judge the power dynamics between the different parties that took part in the research. It is not known how young people viewed me, as perhaps their parents might

have informed them that I was also a teacher. This might have affected the way they responded.

The inclusion of a period/s of observation might have been useful to enhance the credibility of the study. An alternative approach to questioning within the schedules, specifically in respect of one question, might have given more control to the participants. This might have been difficult for the youngest group of participants to respond to extensively, but could have been used for the senior learners.

No application was made to the local Medical Ethics Committee to view the medical records of the young people and medical information documented and referred to in this study was supplied by the parents and young people themselves. Further information could have led to more detailed and richer information from discussions with the medical personnel involved, as they could have directly referred to individual cases. For example, where there were different possible explanations for an issue, medical records may have offered the definitive answer.

The interview arrangements offered another area for reflection. If the interviews had taken place at a different time or the pupils had been able to pre-prepare their answers, the responses to interview questions might have been different. For example, the interviews of some of the youngest group of pupils were sometimes undertaken after their school day was ended, when they were more prone to tiredness.

3.10 In Conclusion

Although this was a small study it may highlight areas for future larger scale research studies and can offer an audit trail for other qualitative researchers to follow. As far as I am aware this was the first in-depth study by an educational professional within this population group on the subject of making progress in learning. A strength of this study is that a variety of age groups and two medical conditions formed part of the sample selection and that the study was based on evidence that is relatively current since the young people were either at school or had just moved into further education. However, it was only one researcher's interpretation of the reality that the young person described. The young person's description was itself an interpretation of their life experiences. This does not

matter because the aim of the constructivist approach is not to discover universal 'truths' but rather to reflect the complex world in which we live where feelings and actions of one human being affect many others in different ways creating intersecting webs of reality.

C H A P T E R   F O U R

The Results of the Interviews with the Young People

The purpose of this chapter is to report the results of the research data that were collected from the twenty-four young people involved in the study.

Table 4.1 below shows the breakdown of the sample of young people interviewed. The table is organised in descending order of the age of the participants within each of the three age groups interviewed. Where there were several participants with the same age the order is alphabetical by participant's name. The table is intended for reference purposes for the reader to provide a context for the results that follow.

NAME	AGE	MEDICAL CONDITION	SIMD INDEX
Katy	18 years	CPO	4
Mack	18 years	CLP	1
Bruce	17 years	CPO	3
Kieran	17 years	CLP	3
Lauren	17 years	CLP	4
John	16 years	CLP	1
Rihanna	16 years	CPO	2
Tulisa	15 years	CPO	2

Jessica	11 years	CPO	5
Liam	11 years	CLP	1
Timmy	11 years	CPO	2
Lucy	10 years	CLP	2
Sally	10 years	CPO	1
Alex	9 years	CLP	4
Andy	9 years	CPO	4
Bella	9 years	CPO	2
Wayne	9 years	CLP	2
Sam	6 years	CLP	1
Aaron	5 years	CLP	5
Emily	5 years	CPO	3
Lois	5 years	CPO	1
Nina	5 years	CPO	3
Sarah	5 years	CLP	4
Scott	5 years	CLP	5

Table 4.1: Details of the twenty-four young people interviewed for the study

Nineteen themes emerged from the data analysis as described in the methodology. The nineteen themes are presented under one of five category headings, which correspond to/answer the five original questions for this study. Each section begins with a brief introduction to the theme and then the analysis of the views of the young people from each age group is presented chronologically. The quotations have been chosen by myself because they appear to illustrate best the major arguments presented by the young people interviewed. According to the evidence given by the young people some themes appeared

to warrant further investigation by way of case study evidence. Of these fourteen emerged as major themes, as listed in the summary at the end.

Question One: The ways in which cleft lip and/or palate may impact on young people's educational experiences in schools

4.1 Curriculum

4.1.1 Literacy Issues

Although literacy is a deeply contested term (Ellis, 2015), this study does not engage in this debate. This study focuses on the educational and social experiences of a number of young people in Scotland whose literacy experiences in schools are set within the context of the national curriculum framework, Curriculum for Excellence, where literacy is defined as:

> the set of skills which allows an individual to engage fully in society and in learning, through the different forms of language, and the range of texts, which society values and finds useful. (Scottish Government, 2009b p.10).

Therefore this definition is used within this study. Within CfE,

> Literacy is fundamental to all areas of learning, as it unlocks access to the wider curriculum. Being literate increases opportunities for the individual in all aspects of life, lays the foundations for lifelong learning and work, and contributes strongly to the development of all four capacities of *Curriculum for Excellence.* (Scottish Government, 2009b p.32)

The literacy framework in *Curriculum for Excellence* has the following elements: listening and talking, reading and writing. (Scottish Executive, 2006, p.17).

Listening

Nineteen of the young people did not have any issues with listening. Five pupils did find listening challenging.

The 5-6 age group

Aaron was the only one to have a problem with hearing. He had grommets inserted. He said he could always hear what the teacher was saying. He gave no indication he did not pay attention. Aaron always tried to respond to the teacher and to engage in group work and gave no indication he did not listen to others.

The 9-11 age group

In this group only Liam had hearing issues. When asked if he could always hear what the teacher was saying he replied, "Not really." He had to move his seat to hear but after he had grommets fitted the situation improved. Liam gave no indication he did not pay attention and always tried to respond to the teacher and participated in group work.

The 15-18 age group

Of the senior pupils, Tulisa, Rihanna and Mack raised the issue of hearing. Tulisa had fluctuating hearing loss and asked to move to the front of the class. Rihanna described her experience, "Sometimes when I was a bit younger, when I was at the back … when I couldn't hear them … I would always ask to move." Her grommets had been replaced by a hearing aid. Mack reflected, "Sometimes my hearing can be quite bad. I've been a few times to get my hearing tested but it's not too bad… it wasn't something I looked into really." If he missed something he "just asked them to repeat it or something thought through." Tulisa, Rihanna and Mack gave no indication that they had attention issues, although Mack said if something interested him this increased his enthusiasm to learn.

Talking

All of the young people had been assessed by speech therapists and had received varying levels of support ranging from five receiving no support to multiple sessions at the dental hospital, local health clinic and in school.

The 5-6 age group

Nina and Lois were still receiving speech therapy by the third term of Primary One. Nina had been attending every two weeks but this had been reduced to every three months. Lois was receiving regular blocks of therapy. Emily had originally had an issue with the /s/ sound, Lois with /s/ plus other letter combinations. All the young people said they had no difficulty communicating orally with class teachers/assistants, class peers, family and friends.

The 9-11 age group

Six of the pupils had received speech therapy. Sally was still attending every three months. She had difficulty with the /ch/ and /sh/ sounds. All the pupils indicated they communicated orally with class teachers/assistants, class peers, family and friends but Sally appeared reluctant to converse. She thought other people could not understand her and her responses at interview were short. Bella said she sometimes got answers wrong because of the way she said them but she kept trying.

The 15-18 age group

Six of the pupils had received speech therapy. Tulisa had attended sessions at varying times at the dental hospital, the local health centre and at school. She completed her speech therapy at the age of twelve years. She had difficulty with the /t/ sound. Tulisa said that after her operation she had to relearn all her sounds. Mack reflected that the teacher sometimes could not understand what he said although his family and friends understood him perfectly well, "The majority of pupils, I know them, and since they've been there for a while they know what I'm trying to say so it's not too bad but someone else will not know what I say"(Mack, age eighteen). Mack and Katy (age eighteen) were still unhappy about their speech. Katy said she should return to speech therapy for further sessions. Mack had agreed to have further surgery partly to improve his speech. Mack had been born with a bilateral cleft lip and palate.

Some pupils, particularly those with speech issues, found performance an unpleasant experience, for example giving presentations or singing. During the interviews some

pupils responded to questions by using sentences with complex constructions and more advanced vocabulary, whereas others offered responses which were often monosyllabic and at times communication was reduced to non-verbal means. Those who responded in this way included Lois, Scott, Sally, and Liam.

The 5-6 age group

None of the pupils introduced aspects of performance as an issue. Aaron sang a line and acted as one of the 'Innkeepers' at the school nativity play. During his interview he offered opinions, explanations and examples. However, Lois, who was receiving regular speech therapy, at times resorted to non-verbal communication during her interview.

The 9-11 age group

Three pupils out of nine disliked performance based activities. Jessica said, "Well … I'm not particularly fond of reading out loud in front of the class." She continued by saying she felt she was more affected than her friends.   Yet, at school, she had played a courtier in the school play 'Beauty and the Beast'. Wayne was unwilling to give his solo talk in class and only the encouragement of the teacher helped him overcome this. He added, "I don't like singing because you have to stand and sing out." Sally disliked drama and she concluded this was because she was shy. During her interview Sally occasionally resorted to non-verbal communication. Wayne was reluctant to record his interview on the voice data recorder which could be played back. He chose to have me note his responses manually because he was uncomfortable with other people listening to him even though his mother explained it would only be the researcher and possibly university staff who would hear him.

The 15-18 age group

Lauren chose to join a performing arts group which included acting and singing.   In contrast, Katy, who had speech issues, reflected, "I don't like reading out, I feel quite self-conscious about it." Kieran said, "Stand out in front of people … just get nervous."

Reading

In school, reading begins as a distinct area of learning where children first build skills involved in becoming a reader, and by developing a positive attitude to reading, they can decode and understand a range of texts of increasing difficulty and in different subject areas.

In this study there was an interesting pattern in the attitudes of young people to reading. From enthusiasm for reading in the early years, their levels of eagerness declined progressively through the age groups.

The 5-6 age group

These children were in the early stages of acquiring literacy skills. With only one exception, all of the young people interviewed enjoyed reading in class. Lois did not consider reading as one of the activities she enjoyed in class largely because of the associated homework, although she said she did not have any particular difficulty with this homework.

The 9-11 age group

By the time the children were nine to eleven years only two pupils out of nine named reading as an activity they enjoyed. The remaining seven pupils variously preferred creative and/or problem-solving, technological and/or physically active pursuits. One child indicated that she had found reading difficult when younger. Bella said, "Reading is useful for you when you're older and for your future. I do have problems sometimes with it because I have trouble pronouncing some words." Bella suggested that pronunciation had caused her problems in understanding the meaning of the text. She continued, "This has got much better since I've got older and I'm now in a higher level than I should be." Bella had attended speech therapy from early infancy until age five. "The speech therapist had picture cards and I said the words with those sounds. I also practised the sounds I had trouble saying with my Mum." (Bella, age nine).

Sally enjoyed reading but found it challenging and opted to attend an after school club for extra support. She said that having an issue with memory had affected her in tests, and

particularly in language work. She was attending speech therapy once every three months. Liam also received additional support to help him improve his skills. He worked on the 'Toe-by-Toe' programme (Toe-by-Toe, 2015) reading letter combinations by sounding them out and reinforcing the learning by having him say each combination correctly three times. He said he had been identified as having dyslexia, but found 'Toe-by-Toe' helpful.

The 15-18 age group

None of this group listed reading as an activity they particularly enjoyed. They preferred creative and/or problem-solving and/or physical pursuits. Tulisa struggled with reading for understanding and reading aloud. She spoke of having a secondary surgery on her palate during the first weeks of her primary education. She had to wait for this operation. She reflected, "My speech was really bad … I had trouble with sounds such as /t/ … after my operation I had to learn the sounds again." Tulisa had speech therapy until she was twelve years old and had also been identified as having dyslexia. She reported she had been identified as having short-term memory problems. Tulisa had the support of a reader for her examinations, at age sixteen. Although Katy had been very successful in her examinations, she too had an issue with reading, "… in my English exam I had a reader for my exam …. But like I've always struggled with it." This referred to reading out the words not the understanding of the text.

Writing

For the majority of young people in this study spelling and the physical act of writing did not present any issues. For some spelling and writing were of concern.

Spelling - The number of pupils affected by spelling issues had increased by the end of primary schooling and decreased during secondary schooling.

The 5-6 age group

Amongst this group only one child had an issue with spelling. Sarah found sounds sometimes caused her difficulty. She explained, "I learnt a word today and it's 'there' and

it sounded like, 't', 'h' and then an 'a' and 'r' but it's 't h e r e'." In contrast, Nina had no difficulties, "I'm on word wall three – sixteen new words to learn."

The 9-11 age group

Six out of nine pupils found spelling an issue. Bella was in Primary Five. She reflected, "I've got good ideas but I can't spell the words … For spelling I'm still on the orange card but the P3 boy is on the green and that's higher than orange." Some pupils attributed poor spelling to being unable to remember the letters. Others contended that they had issues with the sound of the words leading to writing it down wrongly. Bella, Liam and Sally had difficulties with reading and also stated they had issues with spelling. Liam was identified as having dyslexia.

The 15-18 age group

Three out of the eight pupils in this group raised spelling as an issue. Katy reflected, "Ever since I started, I was able to write… it's always been noticed I can't spell". She denied this was connected to her speech issue - the sounding out of words - but could not provide an alternative reason, "I think I'm just an awful speller" (Katy, aged eighteen). Lauren offered a solution, "I'm not that fond of reading very much so I think if I read more it would improve it." Tulisa and Katy, who received reading support in examinations, stated they had issues with spelling. Tulisa had dyslexia and this could have contributed to the spelling issue. She had a scribe in examinations to ensure the examiner could comprehend her answers.

Handwriting - The majority of the young people reported no issues with the physical act of writing. Four young people raised this as an area of concern. This appeared to occur randomly across the three age groups.

The 5-6 age group

Lois won the prize for 'Star Writer' and Scott thought writing was "really fun." In contrast, Nina said, "Sometimes I find writing hard. My teacher says my letters are too big." Aaron had difficulty copying out in the time allotted, with further consequences. He

said, "When I don't get it done on the first day, the next day it's all rubbed out so I can't really remember."

The 9-11 age group

Within this group only Liam said he had difficulty "making the letters". He was using a special pencil to help him. He had to use paper with wider line spacing, sometimes drawing wider lines on blank paper. This all led to him disliking writing.

The 15-18 age group

Only Tulisa raised this issue, "I write the exam and the reader checks it". It could be rewritten if necessary by the scribe.

4.1.2 Numeracy Issues

Numeracy is defined in this study as:

> the confidence and competence in using number which will allow individuals to solve problems, analyse information and make informed decisions based on calculations. (Scottish Government, 2009b, p.37)

For seventeen of the twenty-four pupils, the learning of mathematics was not an issue of concern. The seven remaining pupils did have an issue with mathematics. Although concern was randomly spread across the age groups, interestingly six out of seven of the pupils who were experiencing difficulties with mathematics were girls.

The 5-6 age group

Of the five year olds Sarah reflected, "Sometimes when I come home from school with my maths homework I find it difficult to remember what to do." When discussing sums she was of the opinion, "Sometimes they're really hard and I don't know them." She preferred reading and writing to mathematics.

The 9-11 age group

Four pupils raised this issue. Jessica enjoyed mathematics but she found she was slower to complete the work than she was with other curricular areas. Timmy singled out problem-solving in mathematics as his greatest difficulty and this was an area where he specifically wanted to work in a group to seek support. Bella reflected, "I don't like mathematics. I find it a wee bit difficult. I don't know if that's because I'm in one big class… The teacher has eleven pupils and I'm the only one in P5." Sometimes Lucy also did not like mathematics. She found difficulty with some areas of mathematics such as reading temperature scales.

The 15-18 age group

Two pupils raised mathematics as an area of concern. Tulisa listed memory issues and dyslexia as impeding her progress in learning mathematics along with absence early in her education. She felt she had missed important building blocks of knowledge in mathematics. These issues led to her disliking this curricular area. Lauren also found mathematics challenging and highlighted the area of problem-solving as difficult.

4.1.3 Metacognition

Reflection on learning and building of learning strategies are important for making progress in learning.

The 9-11 age group

Seven out of nine young people said they reflected on their learning. Jessica said, "Well, in the classroom if I've just learned something I know it. If it's playtime I go outside, em, I usually think about it in my head." However, two young people did not engage in reflection. Timmy said, "I just think about my X box here and that's it."

The 15-18 age group

Six out of eight young people said they reflected on their learning but this usually occurred in connection with attempting homework tasks rather than an on-going process. Mack and John said they did reflect on their learning if they were interested in the content. Lauren said, "Yeah, uhu … probably like when I'm home and doing homework and stuff." Two pupils said they did not usually engage in reflection. Kieran said, "No, not really, not enough."

4.1.4 The Preference for Practical Subject Areas

In Scotland, the study of English, mathematics, physical education (PE) and religious and moral studies is compulsory until sixteen years of age. Apart from these curricular areas young people are involved in making choices of subject areas to study from the age of thirteen to fourteen years old. This specialisation increases as they progress through secondary schooling. Younger children study a broad curriculum covering the areas documented in 'Curriculum for Excellence'. As pupils progressed from early years to final examinations, many appeared to develop a preference for the practical subjects. This may have been linked to a decreasing desire to engage in reading and writing.

The 5-6 age group

This group appeared to enjoy a wide range of activities across the curriculum, with exceptions noted in the sections that follow. Emily said there was nothing that she didn't like and Scott said the only thing he didn't like was being "grumpy … or naughty".

The 9-11 age group

At this stage in their learning the young people began to highlight their preference for practical areas such as art (six out of nine liked this). Lucy liked art because she liked to create things, Bella because it was "easy and fun." Jessica said art was her best subject, "I'm quite good at drawing," Sally particularly liked painting. Otherwise pupils said they enjoyed a variety of activities, with the exceptions discussed in the Literacy section. Timmy said he liked "mathematics because I find it a little bit easy and PE because it's really fun." Andy also enjoyed mathematics and PE and Lucy described PE as "fun".

The 15-18 age group

Despite some pupils experiencing difficulties with English and mathematics, all eight senior pupils stated they agreed with the mandatory approach to these four subject areas (English, mathematics, PE and religious and moral studies) because they provided valuable life skills and knowledge. However, when given a choice most senior pupils preferred to study subjects such as art which involved an emphasis on practical activities. Lauren reflected, "I like doing practical things instead of written ones." None of the senior pupils chose to study a modern foreign language beyond Standard Grade level and some stopped studying the foreign language at the end of Second Year. Some senior pupils such as Kieran stated they preferred science subjects or practical subjects to languages (including aspects of English). Rihanna, Mack and John specifically said they did not like writing although they were able to attempt the writing. Tulisa was encouraged by teachers to replace English classes with making benches for charity and her curriculum also included home economics, (health and food technology and fashion and textile technology), music, and art.

4.1.5 Exploring Social Activities Inside School

Some young people engaged in a variety of social activities outside of the classroom. The participation depended on the opportunities offered at the school and the interests of the young people.

The 5-6 age group

This group indicated there were fewer opportunities for attending school based clubs during Primary One. Sarah did attend a lunchtime club with her friends, playing 'Tig' and 'Parachute' in the gym. Younger pupils engaged in the variety of traditional playground activities involving social interaction with peers such as 'Tig', and 'Hide and Seek.' Sam contended, "We play 'Army' or we play 'Doggie games' ... or we play 'Spies'… Sometimes I play football… I don't like doing 'Hide and Seek'." All the boys played football. Girls preferred skipping and Emily reflected, "I like playing the obstacle course and I like doing hopscotch."

The 9-11 age group

The young people generally spent their time in the playground talking with friends but Andy, Timmy, Liam and Wayne also enjoyed playing team games such as football. Jessica liked skipping whereas Bella and Alex played 'Tig'.

Jessica participated in 'Run for Malawi' and the 'Chess club'. Andy lived in a rural area and took part in cross country running. Bella attended the after school Christmas club which took place in the period before the festival. Lucy enjoyed the Science club because she liked experiments and solving problems. She had been a member of the choir, attending with friends, but she gave this up because they weren't doing much singing. Alex attended a Street Dance group at school and had performed with the group in front of large audiences.

The 15-18 age group

Older pupils preferred to chat to their friends in the playground or in a social area of the school. However, Lauren attended 'Amnesty International' meetings. She explained this was about helping people round the world and human rights and this interested her. Mack was the captain of the school football team.

Question Two: The ways in which cleft lip and/or palate may impact on young people's educational experiences outside of school

4.2 Exploring social activities outside of school

When young people were able to choose activities outside of school, many chose practical activities with potentially less language involved. However, when the young people were interviewed none of them gave the impression this was the reason they chose particular activities. They chose them "for fun/enjoyment" and to relax. At no time was the cleft raised as an issue interfering with any of these activities or with membership of these organisations.

The 5-6 age group

All the five to six year olds were engaged in a range of pastimes – usually several activities each. Particular favourites included swimming, cycling, dancing, gymnastics and the martial arts. Emily and Sarah were members of the 'Rainbows'. Emily especially liked wearing the uniform and learning her promise. Sarah went cheerleading and hip hop dancing. Sometimes activities were easier to access due to the young person's home location. For example, Scott, who liked sailing, lived near the banks of the river Clyde. Nina was talented at running and she ran the 3K marathon in aid of the charity Cleft Lip and Palate Association. Aaron had grommets so he used ear plugs when he went swimming as a precaution.

The 9-11 age group

Seven out of nine young people were involved in a wide range of activities including sports, dance, music, martial arts and youth organisations. Sally was a member of the 'Brownies', Jessica was in the 'Guides' and Liam had been a member of the 'Boys' Brigade' since he was five years old. Andy, Timmy and Wayne were interested in team games as well as individual pursuits. In contrast, Bella lived in a remote rural area where she had little chance of joining organisations. Lucy did not participate in activities outside of school.

The 15-18 age group

The senior pupils tended to be less involved in outside clubs and activities. They were preoccupied with preparing for SQA examinations. Some spent their spare time relaxing with groups of friends. However, Lauren was a member of a theatre group and Kieran was interested in the martial arts. Katy played the oboe in the local authority council band. Rihanna danced in tap and freestyle competitions. Mack was a member of both a fishing club and a football team. The football team won the local league and he had his picture featured in a local newspaper.

Question Three: In what ways do cleft lip and/or palate impact on young people's perceptions of themselves as learners.

4.3 Exploring the perceptions of themselves as learners

One of the four capacities (Scottish Executive, 2006, p.1) is to become a successful learner. What follows is this researcher's own interpretation of what the young people thought of themselves as learners, based on what they said and based on interpretations of the actions they described.

All the pupils attended their local primary or secondary school in accordance with statutory law (Standards in Scotland's Schools Act, 2000, The Education (Additional Support for Learning) (Scotland) Act, 2004).

4.3.1 Learning through Interaction with Others

All pupils believed they were making progress in their learning. They said that they participated in lessons, interacting with teachers, classroom assistants and some peers. This may suggest their communication skills were satisfactory. At times interaction between study participants and some of their peers was problematic due to the attitude of the latter.

The 5-6 age group

Each pupil said they tried to answer the teacher's questions during lessons if they were able to. Aaron said, "Well sometimes when no one else knows I just put my hand straight up when I know". In return they all received praise from the teacher at appropriate times. Emily said, "Mrs X put a wee sticker on my bunny book … my wee notebook." Only Sam said it did upset him if he gave a wrong answer. None of this group was receiving additional support at school.

All the five year olds enjoyed working in groups. Emily expressed her view "I like to work together … because I can have some friends beside me." Although the five to six year olds

were not asked about taking a leadership role, Aaron and Lois said they did not take the lead in their group.

Two of this age group were teased at school. In Sarah's case it was directly due to a visible difference. A small boy asked Sarah about the shape of her nose when they were in the playground. In Sam's case it may have been due to the remaining visual element of the cleft repair. Sam was aware he was being blamed for the misdemeanours of other pupils, "Well, I always get teased by one of my friends… they say I done it … When I actually see them do it." The fact that Sam introduced this into the conversation showed his possible sensitivity to their actions. However, he said when he was unsure of the work in class, "Well, sometimes one of my friends helps me." There were no serious behavioural issues raised by this group.

The 9-11 age group

Each pupil said they tried to answer the teacher's questions during lessons if they were able to. They sought help for their work from a variety of sources. Bella reflected, "If the helper or the teacher are free then I'll ask one of them. If they are busy then I will ask one of my friends… I pick one I think will get it right." They received praise from the teacher when they merited it. Jessica reflected, "All my teachers, every single teacher I've ever had has praised me for my work because I'm so good … I'm so good my teachers say." Wayne recalled: "I got praise for my private talk. I didn't want to do it but my teacher said I could do it." When they made mistakes, only Alex said he felt "quite bad … because you got it wrong" but he continued that he felt sad but not too upset. At this stage Liam was receiving additional support in school but outside the class for one hour a day and Sally was attending an after school club once a week.

Five of the pupils of this age preferred working in groups. Lucy contended "If I'm stuck or anything I can ask them for help and if they're stuck they can ask me for help." Four pupils wanted to work alone, but for different reasons. Sally gave as her reason, "because everybody else is noisy". Andy did not wish to get distracted by others, Jessica wanted to personalise her responses and Timmy wanted to challenge himself, especially in mathematics but he might prefer group support if he was doing difficult problem-solving.

Five pupils, including Sally and Liam, did not usually adopt a leadership role. Jessica said, "I would volunteer to take charge but I wouldn't want to as much as other people because I feel that everybody has their own opinion and you don't just rush into things … and don't let anybody say anything." Lucy said she did not really take charge of a group but that was because the class was not organised in groups for learning. Timmy's response was, "Try to, but always there's someone who's a little step ahead of me… guess someone wants to be em leader, more than me."

There was one behavioural incident of note which was a reaction to persistent bullying. Bella had regularly been called a 'Vampire' during the first two years of primary school. This was because her teeth looked out of place. In response she bit one of the group who taunted her. She said "It has stopped now as they're afraid of me hitting them. We're all friends now." In contrast, some peers provided positive support. Lucy reflected that after her bone graft operation, "My friend, she brought me my homework so I could do it at home so I could catch up on it."

The 15-18 age group

All pupils said they engaged in responding to teachers' questions. They sought help from various sources when they needed it. Bruce said, "I'd probably ask a friend who was sitting next to me and if they can't help out I'd ask the teacher." On teacher praise the response was more varied. Six out of eight pupils said they regularly received praise. In contrast, Katy contended, "They don't usually praise people, just if you get into trouble… you'll only get attention if you're bad… if you are good, never, which most people are. You never get any kind of attention because that's kind of expected of you." Bruce said it was expected of Higher pupils to do well. Although, Tulisa said she did receive praise at secondary school Tulisa complained that at primary school, "they said I wasn't as good as my big brother." When they gave a wrong answer six out of eight adopted a resilient attitude. Lauren said, "I'm OK because I know that I'll learn from it." However, Tulisa reflected that it had taken her a long time to learn to laugh about it and move on but in Katy's case the effects were enduring, "A wrong answer in class, I take it personally – it's probably in the past, like bullying and stuff" and she spoke of always feeling judged and judging herself. Two pupils, Tulisa and Katy, were receiving additional support but only for examinations.

Five of the pupils preferred to work in groups. Rihanna reflected, "It's a bit more interesting. You can get a lot more done." Kieran and Tulisa said it depended on the activity they were engaged in. Katy preferred to work alone, "I don't really like relying on other people. I'd rather just do it myself."

In Tulisa's case she felt she had to adopt a leadership role at times because in the XL class Tulisa said that she was the only one that was motivated to do the work of the class. Two pupils seemed unenthusiastic about adopting a leadership role. Lauren reflected, "I don't know. I'm not as strong as like I don't like to take charge, and that I feel that's kind of a bit too bossy." As Lauren enjoyed an interest in playing roles at her theatre group this was surprising. Kieran also did not adopt a leadership role.

For four of the eight pupils teasing or bullying was a concern. Katy reflected that she was bullied throughout her school career. Her exasperation can be felt in her words. "It's one of the most common birth defects yet people still act like you're some kind of freak." Katy doubted the effectiveness of the school discipline policy to deal with the situation "All the teachers do is, oh if you like tell them like if it's not taking their attention or … they're doing nothing … oh well, or giving them into trouble, that doesn't stop them." John was open minded, "Some people might tease you … No, not in a bad way. They don't mean to be harsh." Kieran was bullied when he was younger and linked this to joining the cadets and Tae Kwon Do classes. Tulisa was teased during her early school career because of her speech. This abated after she gave a presentation to her class on the topic of cleft. However, at secondary school Tulisa's interaction with her peers was not always positive since Tulisa was suspended twice, once for fighting and once for being drunk at school.

4.3.2 Attitude to Learning

The pupils were enthusiastic to learn but to different degrees. As the pupils became older they moved from valuing the enjoyment of the learning experiences to valuing learning in terms of enhancement of future employment prospects.

The 5-6 age group

Amongst this group Aaron reflected, "I just love to learn" whilst Emily offered a similar opinion, "I like to learn lots more and lots more." Scott agreed. When asked how they felt when they learned something new, Emily and Sarah independently used the adjective "happy". Aaron, Nina, Lois and Sam all felt "excited".

The 9-11 age group

In this age group, all were enthusiastic but some with caveats. Bella felt she "wanted to learn more for the future" and Jessica contended that as she learned something new that was taking her further towards high school. For some pupils such as Timmy their level of enthusiasm depended on their interest in the topic and if the new learning was easy. Lucy said, "If I'm learning new things in art I would be excited about it but if I was learning new things in mathematics I would be a bit nervous because I wouldn't know anything about it."

The 15-18 age group

Senior pupils adopted a positive attitude to new learning but two expressed limitations. Katy advised "Go for it!" and was busy planning her university course. But for Mack and Bruce enthusiasm varied with interest. Bruce reflected, "Graphics and things where they teach us new things it's interesting but most other subjects I'm not really so bothered." He aimed to be an architect and enjoyed and valued Graphics.

4.3.3 The Effects of Attending the Hospital

Having to attend the hospital might have engendered emotions in the pupils which could have led to them feeling 'different' to their peers. This appeared to lessen with age.

The 5-6 age group

Sarah said she felt "sad" when she had to travel there, Nina didn't like going and Sam said he felt he was missing out on school. None of the pupils were scared of the hospital. Scott

said he wasn't scared of the hospital but "Sometimes I'm scared of sharks and …
crocodiles."

The 9-11 age group

Timmy and Bella said they were not afraid of going to the hospital. Timmy, who travelled
from the Western Isles said, "I just think of it as a holiday." The other pupils did not raise
any issues.

The 15-18 age group

Rihanna reflected, "I've always been kind of nervous about it but when I had got the tube
up my nose I didn't like it." The latter event had happened when she was younger.
Otherwise no pupils raised this issue.

4.3.4 Elective surgeries

Senior pupils were asked if they had ever requested surgery and for what purposes. Six out
of eight had not asked for any surgical procedure. Two pupils had been offered further
surgery and turned it down. One pupil had been considered for surgery but after
investigations the surgery did not take place.

15-18 age group

Mack praised the orthodontic work. "Facially... I'm happy with my teeth… I just take the
view that my speech hasn't really changed… I feel a difference in my confidence." After
discussions with the cleft team Mack made a decision, "My nose, that's what I've asked
for and eh … I don't like my speech. My speech is the other thing I've asked about. The
surgeon says that's why I'm getting these operations – to try to make my speech clearer,
and my nose, it would reduce the bulk." Bruce (then nine years old) asked for surgery to
correct a small residual hole in his palate. This was because it was big enough for little
pieces of food to catch in. The reason was not speech related.

Katy said, "I didn't ask for it, but my speech isn't great and they had some investigation and they said I might have this surgery and it will help and then they said you don't actually need it… I was like agreeing - this wasn't me asking but an option. They kind of got my hopes up and then they said actually no, you're not a candidate for it."

Tulisa indicated, "No, I didn't have the operation here." (Pointing to her jaw). After discussions between Tulisa, her mother and the surgeon she decided it was not necessary. Rihanna also rejected jaw surgery after similar discussions.

4.3.5 Setting Goals for their Future

All young people in the two older age groups had an idea of what they wanted to pursue as a career.

9-11 age group

The selection of careers being considered was wide – policeman, teacher, working with computers, artist, vet, footballer, lawyer. Alex said, "I think I would go to college or university first then … a fashion designer or own a boutique or a shop."

15-18 age group

Again the selection of careers was wide - nurse, primary teacher, architect, mechanic. John intended to go to college or university. At the time of interview Mack had just left school and accepted an apprenticeship in horticulture.

Question Four: The impact of cleft on relationships with others offering support in the learning process

4.4 Cleft and the relationship with others

4.4.1 The Parental Role

Young people all reported that their parents provided support for them. The support

tended to lessen as the young people got older and was frequently replaced by peer support.

The 5-6 age group

All members of this age group said they always did their homework and that their parent/s helped them if they were not sure what to do. Parents encouraged their children to enrol in clubs and took them along to participate.

When a small boy asked Sarah why she had a funny nose, it was her mother who defended her, asking the boy "Why do you have such an ugly face?" So sometimes parents dealt with the issue themselves rather than involve the school.

The 9-11 age group

Seven out of nine young people did their homework and where necessary they received help from their parent. Lucy reflected, "If I'm in class I would ask my teacher but if I'm at home and I'm stuck at a question I would ask my Mum and Dad … Well, if it's maths homework my Dad, if it's my spelling, usually my Mum." In contrast, Jessica explained, "I don't usually need any help because homework is quite easy."

Although Sally and Timmy said their parent offered them help they both had not handed the homework in at some stage. Sally was once put on a 'hot spot' losing her 'Happy Half Hour' because she forgot her homework and Timmy had spent his morning interval completing his homework.

Lucy's parents discouraged her from playing outside or riding a bicycle around her area in case she injured herself. The child spoke of this situation at interview with parental agreement.

The 15-18 age group

During the senior stages parents encouraged their child to do their homework. Parents helped when they could and parents of four pupils regularly reviewed their homework. At

times, Tulisa did not tell her mother she had homework. Tulisa said, "We get a letter home or get shouted at by the teacher …. I've had a letter home."

Tulisa's mother was unhappy about the Primary One teacher's attitude to Tulisa - particularly concerning Tulisa's speech and absences. The parent complained to the Head teacher about the teacher's comment that Tulisa should not be starting school because her speech was not up to the standard expected of pupils beginning Primary One. She also complained that the teacher made the remarks in front of another prospective Primary One pupil who repeated her allegations to Tulisa.

4.4.2 The Benefits of Medical Treatment

During their school career, young people received a variety of medical treatment related to their cleft to alleviate various concerns. Each person was working with a treatment plan tailored to their own needs.

In this study young people attended for medical treatment for speech therapy, operations and orthodontic treatment.

The 9-11 age group

Six out of nine pupils had benefited from speech therapy at some point. Bella reflected, "The speech therapist helped me a lot. The exercises I did helped with my school work. I had bother with the letters /r/ and /s/. The speech therapist had picture cards and I said the words with those sounds."

Seven out of nine pupils did not see any link between their surgery, orthodontic treatment and their learning. In contrast, Liam felt his treatment had enabled him to cope better in class and Alex thought his bone graft had given him more confidence.

The 15-18 age group

Six of the eight pupils said their medical treatment had been beneficial to them in class. On the subject of speech therapy Rihanna said, "I can never remember not being able to

say things… I daresay speech therapy would have helped increase confidence, yes." Bruce and Tulisa agreed. Mack said "Speech therapy probably did help me." John believed his speech therapy had helped him at primary school but he had always been shy and this remained as this was just his personality.

Rihanna had orthodontic treatment to correct an overbite and she felt it helped her appearance. Mack, who spoke of the benefits of his orthodontic treatment was still unhappy about his speech and aspects of his appearance. He had asked for more surgery. Kieran said his operations had resulted in less bullying which allowed him to concentrate more on his class work. Two pupils did not see a link. When asked if her medical treatment had improved her confidence, Lauren reflected, "I wouldn't say they have helped any, just part of the routine… I've not noticed anything but they could have, but I've not noticed it." (This was before Lauren's jaw surgery). On speech therapy, Katy contended, "I know I should go back but em …. I mean she gave me some techniques but they weren't practical." When asked if her medical treatment had given her more confidence for example to give presentations at school, Katy replied it had not.

4.4.3 Absence

Given the individuality of the treatment plan the majority of the young people were absent for anything from a half day for check-up audits up to blocks of six weeks for operations which included recovery time. The timing for operations can be viewed in the table in Appendix six. Speech therapy was carried out in a variety of locations – in school, at a local Health centre and at the Dental hospital. Each young person would have had different time requirements.

The 5-6 year group

The absence rate of the pupils varied. Emily contended, "I'm only off school on Saturday and Sunday." But Nina had been absent for two weeks for a secondary surgery within the early months of starting school. Nina's mother had contacted the school and received support to make up the work.

All pupils had been assessed by speech therapy. At some point all seven had received sessions with a speech therapist. By Primary One, three out of the seven pupils were still receiving support. They were Emily (who originally had an issue with the /s/ sound but by the middle of Primary One was judged fine), Nina who attended for sessions every three months and Lois who had issues with /s/ plus other letter combinations. The latter was receiving regular blocks of support. These were daily appointments and the pupils received help from the school to make up the work missed.

The 9-11 year group

Six out of nine pupils had received speech therapy but most had finished this by the age of eight years. Lucy contended, "We go away for maybe ten minutes or so – You don't really miss much because you're still doing the same subject when you come back." She was now assessed not to need help. However, Sally's speech was being assessed every three months at the dental hospital.

When Liam attended the dental hospital for daily appointments the hospital personnel offered him a time at the end of the day so he only missed around an hour of schooling. Wayne had an operation in Primary One and he said it had not affected his class work. Liam had an operation three years before (age eight) but he felt this did not affect his class work. However, he was receiving an hour a day additional support outside the class. Lucy and Alex had alveolar bone graft surgery. Lucy was absent for around two and a half weeks. She said, "I never really lost that much because I got some homework home." When she returned to school she was working outside the class for a short period of time to catch up on work missed. She was allowed to leave the class five to ten minutes early at break, lunchtimes and at the end of the day for approximately six weeks. Alex recalled, "When I got my bone graft we had a week left of school then we had a big break." He used the holiday period to recuperate. He felt his absence for medical treatment had not affected his class work but he was absent from PE for six months.

Lucy had braces and had to attend appointments with the orthodontist. She broke two sets of braces and was eventually fitted with a different type of brace.

The 15-18 year group

In terms of speech therapy, all pupils had received this except Lauren and Kieran. In Tulisa's case this extended until she was twelve years old.

Katy said, "Teachers gave me work and I wouldn't be able to do it till I had recovered from the operation." Katy continued, "When I got older it was more kind of my responsibility to catch up but when I was younger I'm guessing I wouldn't have missed as much." Lauren and John were both absent for operations during the first two years of secondary schooling. Lauren said, "In Second year I was off for a few weeks but it wasn't affecting me that badly because I wasn't doing anything incredibly important then." She felt absence became more of a factor as the pupil entered the senior/final years of their education. Lauren continued "I'd normally go to my Guidance teacher and she would speak to all the other teachers." John said "I've not been absent very hard, only in First and Second year. I don't think it affected me, not really… I didn't need any extra support in the school." In contrast, Tulisa did feel that missing lessons at primary school had affected her education. She was absent for six weeks during the first months of primary schooling. Her mother received work from the school.

Katy reflected "Hospital appointments, they weren't frequent enough to interrupt school really but orthodontist, they're regular and I'd miss like an afternoon class every couple of weeks so the orthodontist, yeah a wee bit." Lauren also mentioned "I've got a few for the orthodontist quite recently."

Rihanna used a video contact with the surgeon to minimise travel time from a remote area to the hospital and this also reduced the stress experienced by the patient. Mack reflected, "The times off were mostly in the holidays. So the summer holidays or before I went back to school."

4.4.4 Pain

The majority of pupils did not raise the issue of pain. Three young people said they had experienced pain and this occurred across a variety of age groups.

The 5-6 age group

Aaron complained of pain "see when I had the ear infection, when I was still in the school". His mother immediately denied the ear infection had anything to do with the cleft. However, medical research has found cleft to be connected to increased risk of ear infections. When asked if he thought pain from the infection had affected his work at school Aaron replied, "Hmm … well not really."

The 9-11 age group

There were no reports of pain in this group.

The 15-18 age group

Tulisa complained of her orthodontic treatment, "It's painful when they tighten the braces up. Last week I didn't go to school. I was off a day." However, Tulisa's mother disputed this, saying her daughter missed school because she was unwell, not because of the braces. When asked about experiencing pain due to her braces, Katy replied, "A wee bit, but nothing" and when asked if this had affected her concentration she responded "No, not at all."

Question Five: The extent to which cleft lip and/or palate impacts on attainment in schools?

4.5 Attainment

4.5.1 Academic Attainment

All of the pupils said they were making progress in their learning. Those at the beginning of their school career were very positive whilst this varied more by the middle age group and at the end of their schooling they measured their success by their final examination results. (These examination results can be viewed in Appendix seven).

The 5-6 age group

All pupils said they were doing well at school except Scott who did not answer this question clearly. Emily said she did not find anything hard. The young people were eager to describe and/or show the fruits of their labour – certificates, awards, trophies, golden tickets, stickers, samples of their work. Aaron had a certificate which said, "My teacher thinks I'm magic." He received this at assembly for having his work displayed on the 'Wall of Excellence' at the entrance to the school. Each of the pupils could explain to the researcher what evidence they based their opinion on – teacher reports, parents' nights. In class, for formative assessment, some were tracking their progress on charts.

The 9-11 age group

All of the young people in this group said they were doing well in class. This opinion was based on school reports, understanding of day-to-day classwork, and test marks. Bella contended, "I think I'm doing well because I don't have problems with the work I'm given. I can self-check my work to the answers at the back of the book and I get them right." Bella was motivated to succeed, "Sometimes I make mistakes because of the way I say it. But I keep trying to get it right." Two pupils raised the issue of pacing. Wayne reflected "I'm quite slow" to finish and Sally "Sometimes I fall behind in my work." Sally received additional support at the after school club.

The 15-18 age group

The eight senior pupils were the only group to offer comparable data since their results were achieved at national examination level. All the pupils were motivated to do well in these examinations but to varying degrees. Kieran said, "The SQA exams can set the course and tone for the rest of your life." Although she said she was motivated to succeed, when Tulisa was asked how important she felt the final examinations were for her future she shrugged her shoulders.

Pupils were sitting a wide variety of examinations: Access, Standard Grades, Intermediates, Highers and Tulisa was taking a Duke of Edinburgh award. English and mathematics are mandatory in Scottish schools until the end of Fourth year (around age

sixteen). The reasons for choosing the other examination subjects were that they enjoyed these subjects but as they progressed to higher level/Fifth year the choices became more career-orientated.

All of the pupils were setting career goals for themselves, which included college and university courses or future jobs. Katy contended "obviously university is not the be all and end all but for me like that was the way I wanted to go There is so much competition to get into university that you need to do well." Tulisa started with the intention of being a vet but found she had to change to working towards becoming a mechanic. When interviewed Lauren said, "I want to be a primary teacher …. I really like working with children and I just think it would be fun to teach." Mack had just started an apprenticeship in horticulture. He reflected, "I've got a job just now, I'm quite rich and I'm doing well."

4.5.2 Memory and Language Issues in Testing

The 9-11 age group

When taking tests, four pupils preferred to take tests orally and four by writing answers. Lucy said she preferred to speak answers into an Icam for language work and in mathematics she would write.

Jessica reflected, "I prefer tests when I write the answer because then I can put more detail into it because I don't like speaking a lot because I get out of breath sometimes." Sally also had issues with speech. Alex and Wayne found it easier to write. In contrast, Andy and Timmy found answering orally quicker and Timmy remarked, "Less boring". Bella found writing confusing and Liam did not like writing.

Wayne, Alex, Andy, Liam, and Jessica said they had no issues with their memory. Lucy and Timmy said they were more likely to remember if they were interested in the work or it meant something to them. In contrast, Sally and Bella said they had problems remembering work. Bella said, "I can't do it unless the page is in front of me." Both these pupils preferred problem-solving tests. However, Jessica, Andy, Alex, Wayne and Liam also preferred problem-solving tests because they enjoyed these or found them easier.

Timmy disliked problem-solving and Lucy said it depended because sometimes problem-solving could be difficult.

15-18 age group

Six out of the eight senior pupils preferred to write their answers to tests rather than answer orally. Kieran gave no particular reason for this, John said it was what he was used to, Bruce and Rihanna thought it gave more time to think about the answer. But Katy and Tulisa gave speech related reasons. Any issue Tulisa had with writing comprehensibility was overcome by having a scribe. In contrast, Lauren found it difficult to discipline herself to move through the paper systematically so preferred to answer orally. Mack said he had no preference.

When offered the choice of one large test covering all the topics versus short-term targeted tests, Katy, Kieran, Rihanna and John chose one end of year examination. This was because they thought it got it over with, it was easier, it required less detailed answers and for no apparent reason respectively. The others chose formative, end of unit testing. Only Tulisa linked this to memory issues and said there was less stress involved.

When asked if they preferred problem-solving testing as opposed to recall of information, Katy, Lauren, Kieran, Rihanna and John preferred to recall information. Bruce, Mack and Tulisa liked problem-solving. Only Tulisa gave the reason that her opinion came from her memory issue.

4.5.3 The Role of Additional Support

In the final examinations two seniors received additional support. The support was given for literacy reasons. Katy had a reader and Tulisa a reader/scribe and her booklets printed on coloured paper because of dyslexia. Katy reflected, "It was only … assessed when I was in Fifth year. But like, I have, I've always struggled with it."

4.5.4 Attainment in Social Activities

All the young people considered school subject examinations as more important than tests

for hobbies because of the effect of their grades on their future career prospects. However, at social clubs/organisations some did take tests and sit level examinations.

5-6 age group

This was the group who engaged in the most outside activities. Some were placed in groups according to their skill in the activity. Nina went swimming. She reflected, "I'm in the Seahorse group." Emily said, "I like doing gymnastics … We do splits and we do handstands and gymkhanas … we have badges and I'm on Seven."

9-11 age group

Jessica reflected, "I've got my confectioner badge where you can make sweets and test them out and see if they actually tasted nice and I got a Royal Wedding Badge – it was a special edition badge. You had to compete in races and make paper aeroplanes designed in the Royal Wedding design." Liam had achieved five badges at the Boys' Brigade. Andy, Wayne and Timmy competed at football tournaments.

15-18 age group

Kieran had achieved a Black Belt in his Tae Kwon Do classes. Lauren performed regularly in theatre shows. Rhianna competed in dance championships. When she took her teaching certificate in dance Rihanna explained, "There is a theory side to things where you have to talk about it as well… you have to explain movements."

Reflections on the data

4.1 Curriculum

The seven children in the youngest cohort were enjoying the broad range of school subjects but for some issues were emerging, for example in literacy. Young people in the nine to eleven age group linked practical subjects such as art and physical education with enjoyment and ability to cope with the subject area. For some pupils this was not the case

with literacy skills. If pupils were doing well in a subject area there might arise the perception they had natural ability in this and felt motivated to develop this further. Tulisa enjoyed making benches and said art was her favourite subject. She won an award for her work in the XL class making benches, and her photo was featured in the local paper. Otherwise, she simply accepted her subject choice and focussed on getting on with life. Tulisa was working towards becoming a mechanic, which was an occupation of a practical nature.

Most of the children and young people did not have an issue with hearing. For those that did there were two types of issue - a consistent hearing loss confirmed by hospital testing and fluctuating hearing loss which was sporadic but after testing was not considered severe enough to warrant treatment. Pupils dealt with their own problems in very practical ways, for example, by moving to the front of the class or requesting that teachers repeat their statements. Pupils often had to be proactive in asking to be moved, but after this they simply got on with their work. The exception was Liam who had difficulty with his grommets and said he didn't always hear. Mistakes could have been made by pupils if they misinterpreted or guessed what teachers were saying but teachers could use visual as well as oral methods to teach the material.

Out of twenty-four children and young people nineteen had had more extensive support for speech development although speech therapy had ended for the majority by the age of eight years and for Tulisa by twelve years. Mack and Katy were still unhappy with their speech. Mack had a bilateral cleft lip and palate which meant he had two clefts, one each side of his mouth. However, although speech was still an issue with some of the senior pupils, none of the young people were using any forms of speech aid, for example, Makaton, British Sign Language or an Augmentative and Additional Communication device.

Oral presentation of material is important for learning. During language classes pupils are awarded grades for presentations. Giving a presentation is a potential learning strategy for sharing and checking knowledge in any subject area. Some pupils seemed to experience a lack of confidence to present material orally. The lack of confidence could have been part of their personality rather than being cleft related. For example, Sally described herself as shy. During her interview Tulisa deferred to her mother to explain an incident. However,

this was because she experienced emotional distress at the memory of the incident rather than this being speech/cleft related.

Children learning to read will sound words out or say them internally. If they have a speech issue this may cause difficulties including misinterpreting words and their meanings. As Bella's speech improved, so did her reading. In contrast, Sally was continuing to attend speech therapy and her reading was still an issue. Sounds specifically related to cleft were causing issues.

Tulisa and Liam were identified as having dyslexia and it is difficult to speculate what part cleft played in their reading issue. Sam was in the process of being assessed for dyslexia at the time of the case study interviews. His teacher did not appear to consider the possibility of 'cleft sounds' where there is a possibility the child's speech apparatus makes pronunciation difficult or impossible. The rate of prevalence of dyslexia amongst the general population is ten percent (Dyslexia UK, 2015).   In this study of twenty-four young participants, that would be equivalent to around two to three young people being identified as dyslexic. This is approximately in line with the general statistic of ten percent.   The speech therapist raised the danger of young people being labelled as 'cleft' and other conditions being missed as everything was attributed to the cleft. Certainly, Tulisa was ten years before she was identified as dyslexic and had a package of learning support put in place.

Apart from speech, other factors could have been involved. Those with memory issues such as Tulisa and Bella might have been slower to remember sounds and required more reinforcement when learning using phonics and recalling sight words. The issue of recall of sounds and whole words was also prevalent in their spelling. Bella reported difficulty remembering work for tests and Tulisa preferred a short test at the end of a unit of work because she had memory issues.

Almost half the young people had spelling issues. The later palatal surgeries may have encouraged compensatory articulation to develop and children developed patterns of speech which could be difficult to correct. The surgeon said that the child had to have a vocabulary developed enough for speech therapists to make a recommendation for surgery so those who had later surgeries could well be children who had the greatest delay in

communication skills to begin with. However, Timmy's mother contended he began speaking at ten months and his vocabulary had always been ahead of his age. His secondary surgery was at two and a half years and he had spelling issues. His mother said she recognised the spellings as resembling the way he used to speak before the secondary surgery.

Five years of age may be too early to identify issues with spelling and Sarah's comments about the word "there" illustrate that English is a challenging language to learn rather than her issue being related to cleft sounds.

Experiencing poor auditory short-term memory can affect spelling and this might have been a contributory factor in the cases of Tulisa and Bella. In conjunction with this Tulisa appeared to have a borderline fluctuating hearing disorder.

In class work teachers could have asked for clarification of the misspelt words but misinterpretations in examinations could have affected final grades. However, at the senior stages, Tulisa, was receiving additional support in the form of a scribe.

Nina, Aaron and Liam could have been experiencing difficulty with physical control of the pencil, suggesting possible lack of dexterity perhaps leading to slower progress. Tulisa's requirement for a scribe could have been due to issues with spelling or expression rather than illegible writing.

In experiencing difficulties in mathematics they may have been no different from others in their class who did not have medical conditions, especially at the senior stages of the curriculum, where the work was challenging. Lucy was in the top section for mathematics so the content of the course would be more difficult. Problem-solving was mentioned as an area of difficulty and this may be linked to reading and understanding of questions. Unlike language where answers can be expressed in different ways, in mathematics teachers are generally looking for the utilisation of one method to solve a problem and missing the teaching of the method may have consequences especially in the early stages of schooling. In later stages pupils might experience more difficulties at home making up more difficult work and parents may not be able to help. There was a link again to memory issues. In Bella's case there was a reference to school organisation in respect of

composite classes rather than cleft but she also mentioned having memory issues earlier in her interview.

Generally pupils engaged in reflection on their learning but it was linked to completing homework tasks; and not an on-going activity. This raised questions as to whether it was ever cross curricular in nature. Some reflected only if they were interested in the subject.

4.2 Exploring social activities outside of school

None of the pupils mentioned their medical condition as raising any issues with social mixing and all reported that they were participating in social interaction.

Where there might have been an issue with cleft Aaron adapted his situation as a precaution. Although none of the young people in practice found the cleft interfered with participation in outside activities, Lucy was not encouraged at home to try outside activities because she had ongoing treatment. She did participate in school clubs. Kieran chose martial arts and the cadets at least in the first instance as an antidote to bullying.

4.3 Exploring their perceptions of themselves as learners

Generally the young people were working interactively with teachers treating pupils in a similar manner to other pupils in the class. Tulisa was the exception and this was speech-related. Reasons for not liking group work did not appear cleft related except in Katy's case - she seemed to lack trust in others. She linked her attitude to being bullied, and the bullying to her speech issue. Some pupils displayed a more resilient attitude to bullying, possibly linked to their personality and to the way comments were interpreted. What could have been interpreted as bullying because of malicious intent might have actually been due to curiosity, particularly among inquisitive younger children.

When discussing taking the lead in the group the response was mixed. Some reasons given were not cleft related, such as classroom organisational strategy or a misunderstanding of the leadership role. However, Timmy's response highlighted a possible lack of self-confidence in being slow to volunteer. Others such as Kieran, Liam and Sally portrayed

themselves as quiet pupils. Kieran had been bullied and Sally thought people could not understand her speech. This may have highlighted a lack of confidence to speak out.

Tulisa had been bullied at school but by secondary school the bullying had stopped due to her giving a presentation about cleft.   Yet, her early experiences regarding bullying may have increased the pressure to 'fit in' as she progressed through her school career. She got into trouble for drinking and fighting. In Bella's case the long term nature of the teasing could have pushed her patience too far. By acting like a vampire and punishing the other child, she had restored the power dynamic to a more equal balance, but, some might argue, by using the wrong means.

The young people approached learning in a similar way as those without this medical condition. As they got older and the work progressively more difficult they had decided what their aptitudes were and developed a liking for those as their successes gave them more confidence to continue learning in this area. For some they had to adapt to having additional support but this should have eased issues that had arisen.

There seemed to be few reactions to hospital attendance, even with pupils who faced operations. The treatment plan for cleft tended to be a long term one so the pupils were accustomed to hospital attendance.   Any emotional reactions could have been temporary since attendance for treatment was of short duration and sporadic.

Only two pupils actively requested more surgery. This might suggest that the majority of pupils had reached a level of confidence whereby more surgery was not considered a priority, leaving them better able to concentrate on their studies. In Katy's case she was still looking for solutions. The surgeon contended, "People have appropriate procedures carried out where the benefits outweigh the risks … How people feel about that is different." In this case the pupil, although disappointed, accepted the medical opinion and continued on, performing well in her examinations.

The pupils set career goals without considering the cleft as a major factor. With regard to senior pupils, this is further discussed in the section on 'Attainment'.

4.4 The impact of cleft on relationships with others

The young people follow a medical treatment plan from birth. Many saw benefits of the treatment in improving their speech and appearance and therefore giving them more confidence and raising their self-esteem. Others had little contact with the hospital and could not remember their operations because they happened in early infancy. This may have been the explanation for the reluctance of some to discuss the benefits – they didn't remember a before and after scenario and in some cases the pupils appeared quite surprised to be asked about the benefits of their treatment. Some operations provide fast and obvious benefits such as jaw surgery which reshapes the face but others such as some orthodontic procedures appear to take longer for their effects to be obvious. It may be considered a success of the original treatment that they were not pointing to aspects of the cleft seriously holding them back and pushing for more treatment. Or it could have been because of the nature of the operations and orthodontic treatment, that there were no immediately obvious results - for example, to help teeth come through in the correct place. Contact with the surgeon and orthodontist was more infrequent. There tended to be a greater number of visits to the speech therapist and pupils built up a relationship with her and sometimes discussed educational progress with her. They could see benefits quite quickly with speech therapy as their sounds improved.

Absence could have affected the relationship with both medical staff and teachers. Young people did not find short absences an issue and said they made up the work either by themselves, by help from peers or by receiving advice from the teacher as to how to overtake the learning they had missed. However, Rihanna reflected, "The most they will say is to copy out of somebody else's jotter… the teacher probably wouldn't notice you weren't there." Recurring blocks of absence, even if short term such as one day at a time, often for orthodontic treatment, could be more disruptive, particularly at the senior stages where older pupils believed the stakes were higher. For those who experienced a single block of absence for an operation there was more reliance on class teachers interacting with the Guidance department to offer support. The actual time spent in hospital for the operation and recuperation time was not worthy of contact with the Hospital school. Absence at the start of primary school was also an issue in some cases where the absence was prolonged such as that of Tulisa. Additional support was given to some pupils to keep

them up-to-date with the work of the class but it sometimes meant removal from the main classroom.

Certain elements of hospital policy were welcomed by pupils. The hospital policy regarding scheduling of appointments and operations, including usage of new technology, helped to reduce the time and stress of daily visits and this aided continuity of learning in school. However, the recommended time for recuperation, by medical personnel, was four weeks for the alveolar bone graft yet that was not always adhered to by some pupils in physical education or attending physical outside activities.

From this data it seemed any pain young people experienced had minimal or no effect on learning so there was little need for contact with the hospital regarding this matter. There were different reactions to the orthodontic treatment which might be related to the personal resilience of the pupil and their motivation to attend school.

The parental role appeared to be the central influence on the young person's life. No young person suggested that their parent had acted in a manner that displeased them with regard to school or that their parent ignored them when they requested help. One child perceived her parents were anxious about her engaging in social activities locally. All parents except Jessica's helped with homework but pupils admitted to sometimes not telling their parents they had homework.   Timmy and Sally failed to attempt homework but they managed it later, so this did not appear to be because they were not coping due to some cleft related issue. At the later stages some parents may have lacked the knowledge to help. Sometimes the parent had to act as intermediary to deal with teasing or bullying issues especially when this happened to young children.

4.5 Progress in Learning

From the table (see Appendix seven) all senior pupils were making progress in learning at different levels just as any group of pupils chosen at random would be expected to do. They had all achieved a group of Standard grades/Intermediate passes by the end of their Fourth year. The overall level of grades was relatively good with most passes at or above Four at Standard Grade and most Intermediates at A-C. However, Tulisa had failed to achieve her Access Three award in mathematics and this was internally assessed, based on

a series of end of unit tests. At Higher level, as the level of difficulty increased, there was a consequential fall in the grades achieved. In subjects such as Art and Design the written component of the examination played a larger role. This could have been a factor in Bruce's case where his grade dropped dramatically but when he was interviewed, only weeks before the examination, he did not say he was finding difficulty with written work. It could simply be attributed to a wide variation in level of difficulty between the two examination levels. In Intermediate One Art there was no written component, the subject being entirely practical. At Standard grade level, half of the pupils were studying a modern foreign language and although the grades they achieved were in line with their other grades, they declined to pursue this further. This meant none of the senior pupils studied a foreign language beyond Standard grade.

The literacy issues previously discussed – speech and writing – and memory issues were reflected in some pupils' assessment preferences. Therefore, in some cases preferences could have been cleft related.

From the early stages of secondary education, school policy was to use setting, such that most young people were placed in classes commensurate with the level of study their teachers believed they could cope with. As such they were confident of achieving passes in their selected subjects. Other than Katy and Tulisa, they needed no additional support. Interestingly, Katy was not assessed as needing support until Higher, nor for the other higher examinations, some of which required extensive reading.

With social activities there appeared to be less reliance on literacy skills and more emphasis on oral and practical skills. At no time did any young person indicate they required and/or received additional support at their chosen club/organisation.

In Conclusion

The young people interviewed were just like young people in general – the number of issues each person had seemed to be somewhere on a continuum starting from one and stretching to many. Some of the issues were short-term issues and others were longer term. Each young person's experiences were woven together to form a unique patchwork yet this does not detract from the issues that thread through the lives of some learners.

The most important themes raised in this study, which might be connected to cleft were:

- literacy issues

- numeracy

- metacognition

- additional support for learning

- preference for the practical subjects

- issues with social activities

- teasing or bullying

- behaviour

- parental role

- parents and inter-agency relationships

- absence

- pain

- attainment

- memory and language issues in assessment

Young people introduced themes on a wide variety of topics which is why the list for further exploration is so broad. It was also important to take the themes raised and triangulate them with the views of the adult participants. The fact that individual experiences were so varied was accommodated by the choice of individual case studies to further explore the themes more deeply and across a kaleidoscope of views.

The following chapter will explore the themes identified by triangulating the views of a selection of parents, teachers and organisational/club leaders associated with six of the aforementioned young people.

C H A P T E R F I V E

The Results of the Six Case Studies
Primary school stage

Introduction to the Case Studies

Chapter Four explored the analysis of the data provided by the twenty-four young people during individual interviews identifying themes of importance to the young people about their learning. This chapter presents findings from the case studies where the themes identified in chapter four are explored in greater depth with parents, teachers, and organisational/club leaders of six of the twenty-four young people interviewed - triangulating the views of the young people with a broader range of people who played a range of roles in different aspects of their lives.

The criteria for selection of case study participants has already been discussed in more detail in Chapter Three (Methodology). In summary, the choice was based primarily on age and whether the young person required additional support. An attempt was also made to select a mixture of young people with CLP and CPO and who lived in a variety of socio-economic areas, as noted by the SIMD.   There was a gap of approximately eighteen months between the twenty-four interviews and the six case studies.

The results of the case studies are presented in chapters five, six and seven. Each chapter is concerned with two pupils from one age group: chapter five with primary school pupils, chapter six with pupils in the earlier stages of secondary schooling and chapter seven with senior pupils approaching the end of their secondary education/at college. Themes are presented in the case studies in a similar order to the presentation of themes identified at the end of chapter four. The focus now is to seek to add to the understanding of situations where young people with cleft do experience difficulties. The views of the surgeon and speech therapist interviewed for this study are included where appropriate. A pen portrait of the young person is presented at the beginning of each case study to introduce him/her.

5.1　　　　　　　　　S A M

Pen portrait of Sam

Sam was seven years old and lived with his parents and his baby sister in a flat near the sea front on an island off the Clyde coast. (SIMD One). The school that he attended was situated locally in a small seaside town. This school provided education for pupils aged from five to twelve years and had a capacity for seventy-eight pupils. Sam was in his third year of primary schooling and he was in a composite Primary Three/Primary Four class. During his interview Sam reflected that he was progressing well at school and said that he was frequently "on the green" using the class traffic lights method of formative assessment.

Sam had been born with CLP. This medical condition resulted in a cleft of the lip which was closed during an operation at around three months and another operation was required when he was nine months to close a fistula in the palate. At the time of this last operation the surgeon also operated to alter the shape of his nose. His mother said that a small hole remained in his palate.

In Sam's case study, data was collected from interviews with his mother, his primary teacher and his karate instructor.

Introduction

Sam was invited to become the focus of a case study because his responses indicated that he was progressing well in his school work and in his social activities. However, when the three adults were interviewed it became clear that Sam's perceptions were not always consistent with others' views. From Sam's point of view he may have mistaken progress in learning with good behaviour and since he was keeping "on the green" in the latter this would not necessarily mean that he was progressing in the former. However, he may not have experienced any major issues in the first two years of his schooling. This is less likely as his teacher said he had not been progressing at the rate that you would expect for his age during Primary One and Primary Two. Sam's mother indicated during her

interview that there had been poor communication between the school and the home particularly during the first year of Sam's primary school education. Was Sam now progressing well in his learning?

Literacy Issues

Listening

Sam: *Mhm, [he always hears what the teacher is saying].*

Sam's mother said that his listening skills were good. She reported, "The school has now got a rating system for listening and Sam very recently was awarded a score of ten out of ten for his listening." Interestingly, later in her interview she said that Sam was undergoing tests for his hearing at the hospital. Sam's primary teacher reflected that Sam had definitely no hearing issues and described his listening as "usually very good." She continued by saying, "Within his own literacy he has other difficulties which aren't specifically, they are more of reading, rather than listening and talking which you would associate with the cleft, if it's speaking." This shows confusion as to the possible effects of the cleft and this view changed as the interview progressed - when she linked the way Sam spoke to his reading ability.

Sam's primary teacher and karate instructor both reported that Sam's attention fluctuated depending on whether he was interested in an activity and this could lead to him failing to listen properly to teaching. His teacher said that he was placed in a group who "just need to be kept on task, to be encouraged ... they kind of go off in a day dream so quite often they've got another adult working with them … a kind of focusing role."   The karate instructor agreed. When asked if Sam had an attention issue he reflected, "Yes, I would say so. Whether that's got anything to do with the cleft or not I do not know because I'm not totally up on the info on how kids behave with cleft." Later in the interview the karate instructor said, "apart from the attention sort of thing I'm not aware that he's any different to any of the rest of them to be honest… But a lot of kids are similar at that age." The instructor contended, "a lot of times, not paying attention when he should during the class, obviously when it comes to the point of having to go out there and doing that on your own that's where the ones that have listened a wee bit more know a wee bit more." The

instructor continued "But he gets there. He has the ability to do it. It's just the attention thing that tends to be holding him back slightly."

Talking

Sam: *I like to work together … because, eh, I don't know*

Sam's mother said that his speech was good and that he had attended speech therapy sessions for six months while at nursery and was then discharged. The speech sounds that he had trouble with were those documented as generally giving a problem for children with cleft including 't', 'sh', 'f'. Sam's mother said that Sam was fine about speaking out if he has practised it beforehand. He could be very shy about speaking out and would then tend to keep his head down, but he would do it.

His teacher held a similar view, "When he speaks he's very clear. He's able to make most words and signs with his mouth and form them correctly. There are a few he struggles with." The teacher thought that a little bit of reinforcement of sounds might have helped Sam's work but there had been a cut in the speech therapy input on the island. His mother also commented that a young speech therapist had visited their house to help Sam when he was around three years of age but when he would not engage with her she had left without giving any advice or strategies to help Sam. The karate instructor reflected on Sam's speech, "Not bad now. Initially he was a wee bit nasally… but now not much but there again I'm used to him. The other youngsters don't have trouble understanding him either… There's never been a problem understanding him if that's the point." Sam's mother said that he had a small hole remaining in his palate. However, the speech therapist said that it may seem as if there was a hole remaining on the surface, but the underlying structures could be intact. She also contended that surgeons sometimes did not wish to operate unless there were functional issues such as food was coming down his nose.

Sam's mother thought working as part of a group was good for Sam because his speaking was good and that he did not face any specific challenges. At the karate club he was working in a group of six learners and she said, "It is a smaller group and working in this way suits Sam." At school his teacher said that he was a confident participant within his own group of three. These three children all received additional support for aspects of

literacy. The teacher had noticed, "Sam can sometimes sit back and allow other children to do the work for him but I think that's related to his confidence, especially in a written task … it's a composite class and he's in the younger stage so I think that sometimes can kind of knock children's confidence a bit."

The karate instructor contended, "Pairs, we do a lot of things in groups. A good bit of the karate is partner work. One of the three main sort of disciplines in karate to pass a belt is basics, kata, which is set moves in a routine, and then your partner work when you'll do your moves with another person." Sam would take part, the instructor said, "It's not something he would shy away from… If they're doing something that either doesn't understand then the other one will always help … but that's just across the board. That's nothing specific to him."

Sam appeared to take a leadership role when he was confident within the group. His mother said that at the karate club he was a leader socially amongst his friends. The karate instructor felt that this group were not at a stage where one would take the lead but that he could be at the front to do the kata. The teacher said, "I have never seen him take on that role within a mixed ability group but within his own ability group he quite often takes the lead and directs other children in the learning."

Reading

Sam: *No [he doesn't have trouble reading]. Mhm [he likes it].*

Sam's mother said, "His weakness is his reading especially the sounds that go together. He also tends to look at the pictures in a book and makes up the story based on the pictures rather than actually reading the book. He is at Stage Three using the 'Biff and Chips, Kipper and Floppy' series of books". His mother reflected that he had a lack of self-confidence. She continued, "He shuts down if he doesn't get it quickly and makes it up. He had a one-to-one for reading twice a week." Sam was also working on reading with a "quiet partner" and Sam's parents felt that the fact Sam was in a composite class seemed good for him as he was mixing with and learning from pupils from P3 and P4. His mother said that how information was presented to Sam made a difference. It was better for Sam

to listen to the questions and answer orally. Reading the information and then processing it was more difficult for him.

Sam's teacher said that he had difficulty with his reading. He was being tested for dyslexia. However, the teacher raised a possible link to the cleft, "that could also be linked to the fact, to the way that he speaks and the way his sounds come across can link to what he is seeing on the page as he is saying them so em I suppose in that respect it could impact on his literacy which then obviously is going to impact across the whole curriculum". She added that this year she had really seen a progression in his work and that his reading improved when he was enthusiastic about the material he was reading. "I think it is the level of challenge that he is receiving against the level of success he is able to achieve. I think as long as you get that balance right they are able to access it, so you become more engaged in it and motivated to do it.   Sam is interested in war and battles and things so I'm looking at information books about big pieces of machinery."

The teacher reflected that Sam struggled with the written text, "it is general retention, of remembering what sound, what letters go together to make which sounds, so blending them together. He can see letters and he can tell me individual initial sounds, what they are. He sometimes gets confused between the names of letters and their sound but that can be the input he's had previously – how much, it's really getting the balance right, so reinforcement of that". The teacher added, "He has the additional support teacher come in and works with him on a Tuesday morning within his group for literacy, for reinforcement of sounds, blends, word building, writing, about an hour a week…. Reading, writing, a combination where they are learning through each other so if they are doing reading they'd be writing the sounds as well as reading."

Sam also had difficulty with general retention of key words. The teacher called key words those that are look and say words rather than sounding out words. She said that the way to deal with this was through reinforcement.

Her teaching strategy for reading was to have pupils read individually, as a pair and as a group. During whole class teaching the teacher sometimes had to reword questions for Sam and the others in his group because lessons such as on newspaper articles on 'Glow' network were "too strongly worded for him" (Sam's teacher).

The karate instructor said, "for kids of that age it is verbal and visual because I'll say, "This is what I want you to do," (instructor demonstrates the move with his body). He continued by saying that the moves were repeated again and again and that "Man, woman, dog and child, they all get the same."

Writing

Sam: *Mhm [he likes writing]*

Sam's mother said that his writing was good and his spelling was improving and he was now at Stage Four. She told how he was presented at school with a certificate for reading/writing. The parent said that it showed his interest in making progress in literacy and "he is progressing a lot better now especially since his reading has turned the corner." Sam's teacher said that he had difficulty with aspects of writing. "He's not very keen on writing but that again is linked back to kind of confidence in reading so that again goes back to trying to link to his interests and motivate him and try and get round the motivation. He does have a spelling problem because of his ability to recognise and blend and to link all the factors together."

Sam's teacher also said that his group of three had trouble with motor skills at different levels. They had done a lot of work, especially of a kinaesthetic nature, to improve these skills. This included writing in foam or sand and painting with water and big scale activities to get them practising and using little pieces such as those of 'Connect' or 'Lego' to build up their fine motor skills. She contended, "But this year I would say Sam is able to hold his pencil well and manoeuver it and I'm doing a lot of work on patterns and hand writing and he is really coping very well… He is just about the right stage now. He wasn't exceptionally far behind, we just had to put in that wee bit of extra support."

The karate instructor said, "No writing at all, all verbal… It's a physical assessment. No reading."

Additional support for literacy

Sam's mother said she received a book from the teacher where items were recorded and there was daily contact with the school. She had received strategies from the teacher such as identifying sounds in the outside world or using fridge magnet letters to make sounds and using hangman games to improve spelling. She said that support had been introduced as Sam needed it. There was poor communication with the school at the start and Sam had missed out because of this. Sam's parent also said that he had received support on a one-to-one basis for reading twice a week at school. She said that the only negative of this was that he had to come out of the class for support in reading. Tests were given on a computer. She thought that this raised his confidence in learning. She reflected, "There are no psychosocial effects from the extra help…. There are others receiving additional support, other pupils who are disruptive and measures have been taken to deal with this."

Sam's teacher reported, "His learning experiences are the same as every other child at that level apart from obviously his literacy is differentiated … his group, they need to be kept on task." She added that having additional support in place gave a more focused approach and gave an opportunity to assess and meet specific needs. She also said, "I would say he enjoys having the additional support because he can see the benefit of it ... at that stage and within the class at the stage they're at they don't have a negative or a kind of ostracising of other children."

The karate instructor offered no additional support except watching that Sam was keeping on task.

Numeracy Issues

Sam: *Mhm. [he likes to add things].*

Sam's mother felt that mathematics was one of Sam's strengths in the curriculum. The teacher said, "The only thing is reading the question and it depends on the way you present the problem." At the karate club mathematics was not part of the activity.

Metacognition

Sam's parent contended that he did have to think things through for example in mathematics which she felt was one of his strengths. His teacher said that he did reflect on his learning but sometimes too negatively and that he was learning to reflect on his positive experiences too. The karate instructor said that Sam did sometimes stop to think and with a bit of encouragement could finish the series of moves.

Preference for the practical subjects and outdoor learning

Sam: *I like making things …. I made a castle … I like painting big castles… Sometimes I don't like doing Lego… I think it's good sometimes but sometimes I'm not interested really.*

Sam's mother said that she thought Sam enjoyed art and building using materials such as Lego. This would suggest that perhaps he was more inclined to favour practical activities to literacy. However, the class teacher said that it was very much down to the interests of the individual child and that Sam was able and motivated to engage in reading and writing if he were given appropriate materials. In Sam's case he was interested in, for example, war and machinery.

Karate is a practical activity and Sam enjoyed participating.

Sam's mother said that her son loved working in the open air. His teacher reflected, "He enjoys it and it's a very tactile experience for him and he works really well with that, for example, using leaves and sticks to spell out words."

Social activities

Sam: *I have about four friends… We play 'Army' or we play 'Doggie games' or we play eh … at 'Spies' and that's all we play…. Sometimes I play football… I don't like doing 'Hide and Seek'…*

Sam lived on a small island. His mother said, "He has a wide range of friends – in particular there are six pupils that he plays with. Most live around our area and he plays outside after school with them. All but one of them attend the karate club." His teacher supported the view that he mixed well, "He has lots of friends. He's a very popular wee boy. He's got quite close friendships and he's friendly with everyone else. So there's no one he doesn't get along with." The karate instructor concurred, "He seems to be quite pally with most. He's got his enemies … It's a queer situation down here on the island. Kids go to nursery when they're three and they are locked in with the same kids till they are eighteen nigh on."

Teasing or Bullying

Sam: *Loads of times… Well, I always get teased by one of my friends… He says I done it … when I actually see them do it… Because they … because I don't know why.*

Sam has a cleft repair that is still slightly visible. Sam's mother said that other pupils have commented on this, sometimes asking if it was the result of an accident, but when it was explained to them, by Sam, that it was due to a medical condition they just accepted it. This is in line with medical policy. The surgeon reflected, "We would encourage the children if they are asked about the scar, they give a straightforward answer, because what you don't want to do is pique people's interest. If you become secretive about it that just makes people ask more."

There had been no incidents of teasing or bullying. At school there was a 'No Tolerance' policy and any pupil caught bullying or teasing found there was a phone call home. The teacher contended, "Never has anyone made comments about his cleft ever and if he and his friends fall out it's for a very short period of time, they're friends within ten minutes. It's very kind of trivial things they fall out about." The teacher said that one of the tasks they had worked on at the beginning of Primary Three was a peer portrait. She continued, "They were able to see they were the same in some ways but in some ways we are all different because we are all individuals. I think the children are aware of Sam's cleft but they don't see it as anything major … They just accept it. I think it's because it's been from such a young age. He's just always had it like that and never known any different."

The karate instructor said, "They're pals one week, enemies the next, then back to pals. Hard to say, all the kids have known him for a long time so it's not anything they even bat an eyelid anymore." He also said that anti bullying was a major part of karate and the rules were written down in the licence book and "it is something that is emphasised very much nigh on every week … You don't go about whacking people."

Behaviour

Researcher: *Do you ever get into trouble because you have behaved badly in class?*
Sam: *Sometimes …. I don't know what I do.*

Sam's mother said that Sam was well behaved. She said, "He can be obstinate and strong willed. Then, if he has done something wrong he goes into a quiet space to think what he has done and apologise."

Sam's teacher described him as "very bubbly and chatty, quite the life and soul" and said that he was always playing games with people. She continued, "When he's by himself he's a very well behaved wee boy. He listens, is able to follow instructions and he's able to be sensible and responsible. If he is with a certain group of friends they tend to have more of a carry on and they can be a wee bit silly but there is not any kind of seriously extreme behaviour."

The karate instructor reflected that Sam had "a few issues on the behavioural side" but the instructor was unsure if this was cleft related. The instructor continued "He tends to be a bit more exuberant. If it's something he knows he's in there before you even get a chance to mention but on the other hand if it's something that he needs to take a wee bit of time to work at he can do it – no doubt about it – but he's not overly keen on it, that's when he messes about a wee bit".

The parental role

Sam: *Sometimes me and my mum do the tricky ones … spelling and sums.*

Sam's mother helped with his homework and co-operated with the school to support him. She felt that the support varied in the sense of the content. Sam needed more support with his reading. He spent time reflecting on his mathematics to arrive at the correct answers. She discussed the school day with him and what he had learned. Sam's mother said that it was difficult to compare his sister's learning experiences with that of Sam's learning experiences because his sister was around two years old. His mother continued, "I think we spoil him and we probably treat him differently."

Parents and inter-agency relationships

Sam's mother contended, "The teachers at school don't know a lot either and I have had to explain to them what is involved. For example, Sam may have a hearing problem and is undergoing tests at the moment…." She said that CLAPA was good at the start but now the organisation was being split up and there was not so much information being given out. They did run trips which Sam attended. Sam's parent said that it would be good to share knowledge so if CLAPA or Changing Faces sent a representative to the school they could give a presentation to pupils and teachers. This would let the children understand better about cleft. She thought that Sam would not give a talk as he could be shy speaking out about cleft. It was not necessary for the karate club. She said that the instructor could check with the medical personnel if there was an issue.

Sam's mother reported, "There was originally a lack of communication with the school and that meant Sam was missing out." She felt that there should be more contact between the school and hospital. Both the surgeon and speech therapist were not averse to more contact with the school but said it would have to be on an individual basis and with parental consent. As the child grew older their consent would also have to be sought and perhaps on an ongoing basis. The surgeon said, "If we report on outcomes at age three, five and ten, should we be sharing these outcomes good or bad with the head teacher of a school? … It doesn't seem that daft that we should be perhaps sharing these outcomes in an agreed fashion with the appropriate person in Education."

Sam's class teacher said, "There's not really been a major impact on his learning as a result of his cleft, em, so there wasn't too much information to be passed on in the transition report." The teacher said that a presentation from CLAPA would be a useful CPD

opportunity as there was a lot of change in the staff and they could do with a core base of information. She was not sure of Sam's knowledge on cleft but she said that he had the confidence to give a presentation to a smaller audience rather than a large group. The teacher said that she was unaware of Sam having raised the issue in class.

The class teacher wished to highlight the cuts in speech therapy they were experiencing in the school and this was reflected in less resources and support. She said that this was having quite a big impact on the children. At an earlier stage in the interview the teacher said that there might be a connection with the way Sam was sounding out letters and his cleft but she would need to refer to someone with a more specialised knowledge to investigate the specifics of this. Considering Sam's errors could be due to cleft sounds it would be the specialist speech therapist who could identify this and Sam's case was not being investigated in this way. The teacher reflected that a little bit of reinforcement from the speech therapist would be good to make his learning more secure. The specialist cleft speech therapist interviewed for this study agreed financial cuts in speech therapy were being felt widely, but particularly in more remote areas as time and travel costs to reach the islands were higher.

The karate instructor never had to treat the boy differently or look for information for a specific purpose. Karate is a contact sport and injury to the face might occur. As Sam approached his operation for alveolar bone grafting the instructor was aware that there could be temporary safety issues. The instructor stressed the importance of communication with the parent. "To be a member of the karate there is a form you have to fill in outlining any medical issues so if there's any medical issues obviously she would put it on the form or let me know." The surgeon said that he agreed with the karate instructor's approach, to treat the boy in the same way that he treated Sam's peers and that a child should chose to do karate if he wanted to without the cleft becoming a deciding factor. Being a black belt himself in karate, the surgeon said he understood parents might worry more about the contact aspect but if the boy was doing full contact sport any protective equipment necessary would be provided by the orthodontist.

Sam had never raised the issue of his cleft at the karate class. The karate instructor contended, "Knowing the wee boy himself I don't think he would be keen to do that at all. It's something he just wants to be like one of the rest. He mucks in and gets on with it… If

there was something we had to watch for I would speak to the class about that but when there's no issues I don't see the point."

Absence

Sam: *I think [the hospital] is quite good …. We have some toys there…*
Researcher: *Do you feel you miss out at school when you go there?* Sam: *Uhu… mhm.*

Sam was attending the dental hospital for orthodontic treatment. This was causing an issue with his schooling. His mother said, "Sam sometimes slips behind and feels that catching up is like climbing a mountain. Today while at the dental hospital he will miss reading and writing. He has been absent for one day ten weeks in a row."

It was difficult to estimate the psychosocial effects of the absences. His mother reflected, "Another example of this is the out and about activities such as visiting the police station or the fire station. Everyone gets their photo taken on the visit but he is missing from the photos." She said that he didn't remember most of the treatment since it happened early in his life and that he was not frightened of anything.

The teacher was concerned about Sam's absences. She said, "Because of the level he is working at he needs a lot of reinforcement and any gaps, it is small steps every day and if you miss out one of those steps it could be really vital. It is very difficult to go back and em make sure you're pin pointing every one of them." Sam had recently been absent because of an infection in his mouth. The teacher said, "When he came back he was on medication and he was kind of a wee bit out of it because it was a bit strong and he wasn't really switched on. We're always going back and reinforcing past learning so he should make it up. It's not major."

The karate instructor said that Sam had only missed the "odd couple of lessons" because of hospital appointments. He pointed out that the sporadic absences were over a long period of time so they would not make an impact overall. Karate was a progression with repetition as key. He contended, "If we'd done something new over the two weeks he was away then obviously bring him up to speed. Like this is what we've done and do it and

then maybe four or five other people in the class doing it so basically he can see that everybody else is going up and down doing it so visually it's quite easy to pick up."

Attainment

Academic and Social Progress

Sam: *I just hang up on the wall, I get a sticker… For anything – anything.*

Sam's mother said that sometimes her son could be slow but he was very competitive. He was making progress at a faster rate now at school, especially with reading, and at the karate club was becoming more focussed. She had come to this conclusion from reading his report cards and, "at home I also can see from him reading the page on TV and reading pictures, things that he sees in everyday life."

Sam's teacher said, "Within his core Primary Three group, he's not majorly less than any other. Slightly less yes but there's quite a lot of very able children within his year group. I would definitely say he has made quite a bit of improvement this year… his confidence, his literacy, his ability, his retention, his ability to link sounds and letters and words… Whereas the past year, two years perhaps he's not really progressed at the pace you would expect for his age and stage but I think that is a lot to do with just readiness for learning." Sam had achieved the same number of belts as his peers at the karate club. The karate instructor said, "He's got his first two belts… they all go through at the same time… they've done their orange belt and they did their red." He continued, "A couple of things he seems occasionally to take slightly longer to get but I'm not sure whether that's down to memory or it's down to attention span… probably gets about the same support as the others but obviously his attention span tends to wane a wee bit so I'll maybe pay particular attention to that but that maybe isn't related to the cleft."

Sam: *I want to be a fireman.*

Sam's mother contended, "I think he is very intelligent. He needs to focus. He wants to be a policeman and I've told him he needs to get qualifications – college and university. I have ambitions for him to get into higher education."

Sam's teacher said that he was at the start of CfE Level One. As long as he was supported from home and from school in reinforcing the areas that he was finding difficulty with he would go from strength to strength as he was a confident little boy.

On further investigation the researcher found that at the karate club the instructor assessed that Sam was the weakest in his class in the tests despite being physically strong. He reflected, "He came quite confident to start with but as far as the karate side of things … If he wanted to and he put his mind to it I don't see him having any problem getting there… but I think his main battle will be with himself. If he wants that, and he decides "I want that" he has the aptitude, there's no reason why he shouldn't."

Memory and language issues in testing

Sam's mother said that it was better for her son to be given questions orally and answer orally. This was because he struggled with reading text. His teacher differentiated assessments because of his language issue. She gave him more detailed explanations and for example when researching for a study, searched for more photographs for him to work from rather than have him scrutinize lots of bits of paper replete with text.

At the karate club Sam managed to remember his moves to pass his belt and there were no written tests.

Reflections

After a slow start in making progress in his learning, Sam was now working at a faster pace. Sam's learning journey was characterised by certain difficulties, particularly within literacy and relating to his attention span but both were now being addressed and he was making more rapid strides. Sam found reading challenging. He experienced difficulty linking sounds to letter combinations in print which his teacher suggested might be related to speech issues. However, his teacher contended that this could be overcome by the use of material that was attractive to the child and he was also receiving extra support from an additional support needs teacher specifically for literacy issues. Having an extra adult in

the class working with his group was also beneficial to Sam to help him focus his attention on the task in hand. The manner in which Sam was assessed was also differentiated because of his literacy. Other tests were being implemented to discover if Sam had an issue with hearing and/or dyslexia.

There was now improved communication between the home and school including regular dialogue between the teacher and parent and the utilisation of a home/school diary to record issues from both perspectives. However, at no time did the teacher mention 'cleft sounds' and his mother perceived there was a lack of information about cleft at the school. The teacher was enthusiastic about becoming more knowledgeable about cleft as she viewed this as important for all teachers and support personnel who would come into contact with Sam throughout his years at the school.

Although Sam's difficulties were exacerbated by absences and this was demotivating for the child, this was little different from other children who miss school for a wide variety of medical reasons. The teacher felt in the long run that this could be overcome as Sam still had many years of learning ahead to make up what he had missed.

Originally Sam struggled to use writing and drawing implements which might suggest that he experienced an issue with fine motor movement. Yet, after extra support this was improving and he was almost up to the stage he should be at for his age.

There could have been subtle teasing issues as Sam did have a small residual scar from his lip repair, which was noticeable. Although his parent, teacher and karate instructor denied any knowledge of his being teased it had bothered Sam enough for him to raise the matter at his interview. However, Sam and the other parties interviewed spoke about his secure friendship circle and the adults said other children were accustomed to his cleft repair as most had known him for years.

The issues of literacy and short attention span had varying effects at the karate club. There was little literacy required to be successful in karate as the method of teaching, learning and assessment did not require it but the short attention span slowed him down slightly at the karate club. However, Sam was still keeping abreast of the other learners in his group, sitting the belts at the same time. The karate instructor had from the very start treated Sam

in exactly the same way as the other members of the club and did not have to alter his teaching strategies other than to observe if Sam's attention span was faltering. However, the instructor pointed out that at six or seven years of age this was an issue for most children.

This case study raises a number of interesting issues, for example: the possible relationship between literacy and cleft, the importance of home/school communication, the importance of well-informed teachers, school/hospital links, the attitude of parents towards a child born with anatomical issues, the role of a secure friendship group, the importance of suitable material in teaching and meeting learners' individual needs, the way material is presented to children with cleft, the role of additional support, the effects of reducing speech therapy due to financial constraints, the possible link between fine motor movement and cleft.

5.2   S A L L Y

Pen portrait of Sally

Sally was eleven years old and lived with her mother and older brother in a small village approximately twenty miles to the west of the city. (SIMD One). She attended a primary school in the village which provided education for one hundred and seventy-seven pupils. She was in her final year at primary school (P7) by this stage. Sally held the opinion that she was making progress in her learning but she was attending an after school club to improve her literacy and numeracy skills by way of additional support.

Sally had been born with CPO. This meant that there had been a hole in her palate and this had never been immediately noticeable. She had experienced two operations to close the palate with the last one at eighteen months.

Sally's mother, primary teacher and after school group tutor contributed to her case study.

Introduction

Sally was portrayed as a shy girl. Her mother reflected, "With mines it's her self-consciousness. She is not confident at all." She continued, "She doesn't like to be the centre of attention. She likes to be on the outskirts." Later Sally's mother said, "I think it is just all to do with her speech." Was her mother correct?

Literacy Issues

Listening

Researcher*: Can you always hear what the teacher is saying?* Sally*: Yes*

Sally's mother, her primary teacher and the after school tutor all said that Sally had no hearing issues. Her teacher continued, "Listening is fine. She's a very good listener actually. Instructions, a vast array of instructions only has to be repeated once."

Sally: *I like to work on my own because everybody else is noisy.*

Sally's mother highlighted the fact that her daughter appeared to be sensitive to noise. "Listening … she's sensitive, if it's too noisy. .. If it's rowdy in the class she gets really upset." Both mother and daughter agreed that this could upset Sally's concentration. If Sally had no amplified/fluctuating hearing issue then this could have been a classroom management issue. At the after school club Sally was working in a large hall which I evidenced was noisy and yet the tutor found the following, "The first year we had two halls we could go to, more spread about and you could get a quieter area. But now we're all in the big hall and it's noisier… She doesn't seem to mind. We just sit at the side and I'm kind of in between them (she was tutoring two pupils) and she just gets on with it really."

Talking

Sally: *I don't like drama… Don't know, I just don't like it…. shy.*

Sally's mother felt that her daughter was shy and this could have been connected to her speech. She said, "I think she could have done with a wee bit more help… especially with the speech side… just knowing that teachers understand what they're having to deal with… So that they understand that they have got a problem with their speech and it takes them slightly longer to maybe pronounce things." Sally's mother felt that the teachers were not well informed about the cleft.

Sally's mother said that her daughter did not like speaking in front of other people and that she felt this would have affected her when she presented information orally. She described Sally's speech as "Eh, slow" but when further questioned what she meant was "slow to speak up. Once she starts she doesn't stop but it is more confidence with her." The girl had difficulty with her /ch's/ and /sh's/. In class, Sally's mother believed that learners with speech issues should be asked to give an oral presentation or answer questions in turn but if they did not want to take part then they should be allowed to refrain from participating.

The speech therapist interviewed agreed that they should not be forced, but she also contended that young people with cleft should be encouraged to participate in activities that required speaking in just the same way as other young people.

Sally's mother said that her daughter's Primary Six teacher reflected, "I wish she would talk out more… and ask more questions." and that this could have been an issue in understanding lessons.

When asked about her speech, her Primary Seven class teacher said, "it's very quiet and can often... she speaks quite fast as well so maybe get words out as quickly as she can which then becomes quite confused and quite sort of difficult to understand at times. .. At times I have to ask her to repeat herself but obviously the Scottish accent as well. Em it is probably a mixture of both…" However, in the case of her peers he reflected, "I've sometimes during playtime or lunchtime I've been down to see how they've been getting on - she's always very talkative to a select few of her peers…they chat away no problem." The after school tutor reflected on Sally's speech, "Slightly, I have a problem understanding what she's saying… because she talks quietly as well. But if I said, "Oh speak up Sally" she will talk louder and I can hear her better then. I've not noticed anything else." She continued by saying that the other student who was working with Sally did not appear to have any issues with Sally's speech. The tutor was sure that the other student would have said if she did and would have asked Sally to repeat what she was saying. Few repetitions were necessary. She added that Sally was very reluctant to read aloud especially since the presence of the second student had meant she had an audience.

At school Sally had not spoken about the cleft and since she was a quiet person her teacher said, "I think sort of speaking in front of bigger crowds is sometimes not her forte… She will do it like in front of assembly she will get up and speak or in class... it's not to say her confidence is completely absent. It's there and it's not there." He believed that she would not want to speak in public about the cleft condition and that there was no need for CLAPA to give a presentation as he had access to a language unit located next door to the school where he could obtain any information he needed. The specialist cleft speech therapist interviewed said that the community speech therapists dealt with a wide range of speech issues and were not experts on cleft although they could liaise with those who

specialised in this field. This would have meant that the teacher was not getting first-hand information on issues relating to cleft.

When engaging in group work in class he contended, "She's lucky enough to have a good peer group in class who are very supportive and will ask her to come up and do things." The class had been involved in an enterprise study, making calendars, and Sally had found herself in the production team. Fellow group members had elected her production manager and her teacher said she had looked "visually delighted" and taken the role on no problem.

The after school tutor reflected, "You need to be patient and listen to them because sometimes they are more reserved… she was very shy at first… At the end of the session in May they get up and have a wee speech or they could sing or they could dance or anything. The tutor described Sally's progress "She didn't do that the first year. She didn't have the confidence to do it but last year she went up and said a wee story about her dog and I was quite proud of her… She was very good." The tutor said that she would not have forced the girl as her reluctance could be due to shyness and she herself would have "cringed" if someone had forced her to make such a presentation. She also reflected that all the pupils taking part had appeared nervous, including her other student, as students were required to perform in front of an audience that consisted of all the parents and the local member of parliament.

Researcher: *Do you ever take charge of a group?* Sally: *No … but I would do it.*

Sally did not like working in a group because of the noise created by other group members. Her mother agreed that, "If they're too noisy she doesn't like it and she'll not take part… If she doesn't need to she'll try and get out of it." Her mother also felt that her daughter would have made more progress if she had worked alone and this view she supported by her comments on the one-to-one approach at the after school club which Sally's mother believed benefited her daughter. The teacher thought that Sally benefited from working together especially for reading to share the comprehension of texts. His opinion was that Sally worked better in pairs. In respect of adopting a leadership role, Sally's parent said, "It would be like "Mum" and that's it. She's like not leadership at all." Yet at school she had been pleased to adopt the role of production manager in the calendar company.

Reading

Sally*: I like reading*

Sally's mother agreed with Sally, that she did like reading but "as long as it's in her room and she doesn't need to read out to folk, she's fine." Although Sally enjoyed reading, her mother said that her daughter's reading was "not up to the same level as what the other children in her class, she is maybe a couple of levels behind."

This view was reinforced by the class teacher, "she is in quite a low level of reading for her age but the comprehension skills that come from the reading are usually quite good but it's just the density of the comprehension is quite light. It's although she can gain information from quite a light page of reading. I think as the pages get bigger, sort of becomes a bit more problematic."

The after school tutor felt that Sally's reading was improving although she was not enthusiastic about reading out loud, especially in front of the other student.

Writing

Sally: *Sometimes I have problems with writing…. spelling. It's the sound.*

Sally's mother said that her daughter had difficulty with spelling because she sounded out the words differently and that was transferred into writing down the wrong symbol combinations. She had learned the words differently, as in before her operation. She had two operations, one at nine months and the other at eighteen months on her palate. Her mother contended that spelling was now difficult for her. Sally's mother gave the example of the word "flower" and said that the spelling was such that the word was incomprehensible. The after school tutor contended that Sally could write a good story but that her spelling let her down a little bit but this could have been linked to a memory issue. The tutor said that she could understand what Sally was writing despite the spelling issue and that Sally was making progress on spelling, using the Codecracker programme and practising writing stories. The tutor made up a title, for example, 'The Magic Key' and gave the two students a set time in which to write the essay.

Sally's teacher held a similar view about her spelling, "Her spelling is sort of below par. Her actual writing is OK. It is just sort of the spelling and the expression is not. I think natural expression sometimes quite hard to put on paper so it almost seems as if her sentences are sort of regimented. Eh, imaginative stories are fine." At the time of the standardized spelling test she had been eleven years five months and had the spelling equivalent to that for a child of seven years two months. The teacher continued, "It would be hard to argue the speech issue wasn't linked to the spelling issue… pupils need that base of like phonic awareness at a very early age to be able to go on then and spell tricky words." The teacher contended that in the formative years it would have been difficult for Sally to deal with phonic sounds, sight blending. He said, "The initial sort of reading and writing and comprehension and even spelling she would have difficulty with the cleft but now that we are in the senior stages of primary we move away from the phonic system." He contended that as she progressed through the senior years it was more rote learning of words so things should improve.

The speech therapist interviewed said that she could see how spelling might be affected by speech if they were saying the words in a wrong fashion but if someone else said the words and the child spelt them wrongly then that could be a phonological awareness difficulty and that might or might not be cleft related.

All parties interviewed agreed that Sally had experienced no issues with the physical act of writing. Sally's primary teacher said, "Her writing is actually quite neat. It's on the line and good ascenders and descenders and good formation. It's linked formation as well. I've noticed no, no motor skills problems."

Numeracy Issues

Sally: *I like maths*

Sally's mother said that this was one of the reasons she was attending the after school club. She wanted to work on her mathematics and this was improving, an opinion supported by the after school tutor who contended that Sally was now more confident in mathematics. Her teacher reflected, "probably the density of the questions. It could be an issue obviously with language attached to problem-solving as well. Obviously a straightforward

simple question, for example, fifty-two times eight is very much fifty-two times eight … there's a lack of ability to maybe understand mathematics at a more or less abstract way. Problem-solving can be quite difficult. I think it is because of ability in mathematics specifically, not the cleft palate."

Metacognition

Sally's mother was of the opinion that her daughter did not reflect on her learning or build strategies. Her teacher differed, "I would say yes." The tutor thought she did reflect now and again but not very often.

Additional support for literacy and numeracy

Sally's mother said that her daughter attended a reading group at school. She described this as reading support providing sessions of around fifteen minutes (she wasn't too sure about this timing). During this time around four children were removed from the class for more intensive reading practice. She said that she would have preferred her daughter to remain in the class for reading and to receive support whilst sitting amongst the other children. She wished her to be doing the same as the other children. The parent was aware that the supported group seemed to be repeating the same book over and over instead of moving onto another text. When asked if she had spoken to the class teacher about this, Sally's mother replied it was just a new teacher that Sally had and they had not had a parents' night yet.

The class teacher said that Sally received a lot of learning support, more than her mother described. By which he meant every morning from Monday to Thursday. On Monday morning she worked individually with the Network Support teacher on spelling and from Tuesday to Thursday mornings with the Raising Attainment teacher on aspects of literacy and numeracy. The class which ran Tuesday to Thursday contained around nine or ten pupils selected from both Primary Six and Primary Seven working together as they had approximately the same ability level. The class teacher said that when Sally was attending his class – in the afternoons and Friday – he was covering practical areas of the curriculum. He had searched for a deeper answer as to why she needed this support, "we don't know whether that is due to the fact of the cleft palate or is it a cognitive sort of ability? I don't

think especially for things like maths, you know I don't think it's a problem with the cleft palate." He explained the different approach being employed in the Raising Attainment class, "The pace is a lot slower and it will always be a lot more visual for example, she still very much depends on a ruler whenever she counts out so again that is a concrete, visual element of counting."

When Sally attended the after school club the purpose was to improve her literacy and numeracy. As her mathematics improved her mother changed her remit to paying particular attention to improving her spelling.

Sally's mother said that there were no psychosocial effects of having this support. The after school tutor said likewise, which is to be expected since all the students had come for extra tuition. The class teacher offered an explanation, "It's a very sort of common thing. Here, children will at some stage need additional support… there's no stigma."

Preference for the practical subjects and outdoor learning

Sally: *I like art because I like painting.*

When asked to name areas of the curriculum that her daughter enjoyed, Sally's mother said, "Art is hers… Hmm… Art and dance is hers." Sally's mother said that Sally favoured outdoor learning because, "They don't need to eh prove something. They are there to enjoy it rather than prove that they're ... having to prove themselves." Outside learning was less stressful for Sally.

Sally's teacher's reflected, "Practical subjects are fine … the level of differentiation is obviously a lot smaller… your focus isn't on number or reading and writing. It's about the application of knowledge learned and there's not an issue there at all." The implication here appeared to be that Sally was learning by visual and oral demonstration coupled with kinaesthetic activities. He said that Sally enjoyed art, "which is very practical… art in the senior stages is also very research based so there is a lot of reading, there's a lot of writing and explaining. It's not just sit down and draw a picture. We do a bit on Picasso … she seems to like art a lot because she will bring in a lot of books and show me that she's

drawn this, that and the other." Interestingly, Sally appeared to be drawing the pictures rather than reading the texts.

Sally's teacher agreed with her mother, that Sally enjoyed learning outdoors, "I think there's good engagement on it. She's part of the Eco committee." The after school club tutor said that working out of the building was not part of her remit.

Social activities

Sally: *I go to Brownies ... I like their fun stuff... I have badges and dancing... tap ... you get shows, I think you get levels.*
Researcher: *The After school club?* Sally: *Em, it's like school only it helps you to learn more.*

For social interaction Sally's parent was concerned, "she just prefers her own company… she's not got close friends. She's got friends she tolerates." Her brother was a source of support, for company and for helping her with school work such as her German homework. Quite a number of pupils from her school attended the dancing class and her mother reflected, "She gets on alright with them…" but around her neighbourhood, "she's maybe got one she goes and talks to but no close friends."

At school her teacher said, "There's not many friends she would play with from school here but there are a few fellows who she's quite friendly with – three. Or she would just be around learning assistants. There's a lot of kids in the class that she just doesn't like." He added that this was peculiar to his class that year, that there were great differences in the personalities of the pupils. She may have preferred male company because she was accustomed to mixing with her brother and his friends.

Sally had joined the Eco committee at school and her teacher linked this to her liking for practical activities. He explained, "I think when the emphasis is off literacy and numeracy the confidence can grow and she can demonstrate a lot more."

The after school tutor reflected, "Sometimes when she comes and she's a wee bit down. Sometimes you have to work to bring her out of herself… She comes round well if I jolly

her on or kid her on or things like that… She's definitely coming out of her shell here. Her mum just brings her." She did not come with any of her friends but it would be unlikely that she would as it was individualised help. Sally did get on well with the other student that she was working alongside and they enjoyed a game of Connect at the end of every class. This student attended a different school from Sally so the student was previously unknown to her.

Teasing or Bullying

Researcher: *Have you ever been teased?* Sally: *No.*

There was a time lapse of eighteen months between the interview with Sally and the case study interview with her mother. By the time the latter took place Sally had been bullied by another girl in her class. However, in this instance, no clear connection could be established with cleft. When questioned about the school anti-bullying policy, the parent reflected, "I've seen it, but I've never really read it … because I don't think they're doing enough." She was not convinced that a presentation explaining cleft given by an organisation like CLAPA would have helped and when asked if her daughter gave a talk if that might have changed things she replied, "No, no chance."

When questioned about bullying, Sally's class teacher said, "She asked to move seat away from a selection of boys and girls because they "annoy me"." He believed teachers and parents had a mutual understanding and that they could discuss issues such as bullying and parents were not slow at coming forward. However, this was a different view from that of Sally's mother. There were no bullying issues at the after school club.

Behaviour

Sally*: On Fridays you get on a hot spot. Like if you didn't do it [homework] once and you didn't do it again and then you didn't do it again you get sent to a hot spot….*
Researcher*: Has that ever happened to you?*
Sally*: (nods) only once.*

All parties reported that Sally's behaviour was good. Her mother described her, "I think she's fine. Dead friendly, quiet but other than that she's a well-liked wee lassie." The after school club tutor said, "she's lovely…no problems". Her class teacher gave a more in-depth reply, "She's a model pupil. She doesn't put a foot wrong… She's got all her homework in and she completes her work on time. She hasn't had points taken off and she hasn't lost any Golden Time and I've never had to phone her mum. Never had to speak to another member of staff about her."

The parental role

Researcher: *At home, who helps with homework?* Sally: *My mum.*

Sally's mother said that when her daughter was born, "I didn't even know what a cleft palate was till I'd her." Her mother reflected, "I could have helped a lot more if I knew what I was talking about." Asked if she had ever looked to CLAPA for information she replied, "They've been good, but the CLAPA I'm only dealing with her dentistry, I'm not really involved in that…. I just thought it was, you go up to see the dentist, you see the speech therapist and that was it. Maybe a wee bit more information." She continued, "I probably did (get some information from CLAPA) but your brain is always one step ahead and you don't really stop and look. It is good to have someone to talk to rather than just hanging on to a leaflet." Sally's mother said that her advice to other parents would be to get as much information as they could, keep pushing to get more help.

Sally's mother held the opinion that mathematics, English and social skills were the most important areas of the curriculum from her daughter's point of view. She therefore encouraged her to go to the after school club for help with literacy to work to improve these skills. It had taken her three months of persistent encouragement to get Sally to attend regularly.

In respect of reading, Sally's mother tried to set an example, "For the homework I help her with it… we'll go to bed at night time together and we'll read our books together. Just so she knows I'm reading my book and she's reading her book."

Sally had an older brother. The parent said that she tried to offer her daughter more support than her sibling received. Her mother described the different way that she treated the two siblings. "He is quite smart… he's been dead grown up from a young age… whereas she's been held back. I think molly coddled… Well with her brother I let him do what he wants, when he wants, whereas I'll say to her, "No, you can't go out and play or you can't stay up late." When asked why this was she said, "Say if she goes out if folk don't understand her … she'll just go about herself so I go "Why go about yourself, just come in". She was clearly apprehensive about allowing Sally to develop to become independent and this may have curtailed Sally's life experiences.

Sally's mother reflected, "You don't push her with her work or with her school work you … just thinks that she doesn't need to do it. You've got to push her to do it. Or she thinks she can take a bit longer to do it… Just because you're mollycoddling her. Don't worry about it, it'll get done. It's just the way she is … at a slow pace. I've never pushed her."

Parents and inter-agency relationships

Sally's mother said that there was less need to receive support now compared to the beginning but that she could do with more from the school, for example, extra homework. She differed with her daughter on this, "I keep threatening her I'm going to ask for more homework and she takes a heavy fit, but I think if she had more… it would bring her on a bit better." She did have contact on a regular basis with the school because she worked there.

Sally's mother praised the Primary Six teacher saying that she "really brought her confidence on". She reflected how important the teaching role was, "If it's anything to do with school work I need to rely on the teachers to tell me, anything that they've done." She described her daughter as a "very deep child" who didn't tell her anything. Instigated at the time of the bullying incident, Sally was recording problems in a diary and showing the teacher. The parent, although encouraging this, was not to see the diary. This initiative seemed useful but when the teacher left it was discontinued.

It appeared information was not passed to the new class teacher about the cleft. Sally's mother said teachers had been back around two months and she discovered the teacher

only found out a couple of weeks before about the cleft. This the parent connected to the invisibility of CPO so no visual sign presented itself for investigation.

Sally's mother commented positively on her daughter's medical treatment and said "I think it gives her more confidence… She is deep. She is starting to not care about what other folk think about her. She is starting to come around to her own way of thinking – not worrying about other folk." And she highlighted the medical treatment as helping with this. Her daughter did not see a link between her medical treatment and her class work. Considering her last operation was at eighteen months this is perhaps not surprising but she was still receiving speech therapy and was about to receive orthodontic treatment. On the relationship between school and hospital personnel, Sally's parent said, "I think at the beginning the hospital should give them details of the problem with the child, that would be helpful… a bit more before the child goes to school." The primary teacher preferred to rely on the language unit next door and said, "I think the power of 'Google' now really helps you home in on things that I do need. It just seemed like another learning style I had to cater for."

The after school tutor said, "Maybe those above me know about it but I don't… I don't get told anything… maybe I should have been told about the cleft… I knew she had some sort of problem (signalled to her mouth) but not that… It wouldn't have made any difference. I'm quite understanding and sitting there if I didn't understand I would say… I'm kind of one hour a week you know … Why should I really have any links to the hospital?" If there were educational issues one of the teachers from Sally's primary school worked at the club some evenings and the tutor felt confident that she could refer to him although there was no specific link with the school. The tutor contended that she didn't know if Sally was using the Toe-by-Toe programme at school but if she wasn't she felt it would be beneficial to her.

Absence

Researcher: *Do you think having time off upset your school work?* Sally: *No.*

Sally's mother agreed with her daughter that she was seldom absent. This was also the view adhered to by the after school tutor, "She is quite a good attender… I would just go

back onto the work, just go back onto wherever they were." Sally's class teacher said she had one hundred percent attendance so far that term and even if she was absent, "I don't think it will affect her progress… They labour things quite hard in Raising Attainment class so she would just pick it up because they just take very small steps."

Academic and Social Progress

Sally: *Sometimes I fall behind in my work… generally.*

Compared to her brother, Sally's mother agreed that when learning her daughter needed the support withdrawn at a slower pace but this she attributed to Sally being "molly coddled". Her class teacher agreed that she worked at a slower pace and this was a reason why she was removed from class for additional support and possibly why she attended the after school club.

Researcher: *Are you doing well in class?*   Sally: *Yeah.*

Sally's mother said that her daughter was making progress although this was slow. She cited the following examples, that her daughter had volunteered for a part in the school play and that she had taken part in her first dance show. She added, "She would never have done that a year ago. She would never have gone up on stage." Sally was now attending the after school club and school regularly but previously she had been reticent to go to the former but her mother believed the relationship built up with the tutor had helped. In the case of school attendance she had been reluctant to go because of the bullying episode and it had taken a while for her to tell her mother what was wrong.

Sally's class teacher reflected that Sally was attaining the outcomes but questioned, "Whether she's attaining the outcomes across a rich and wide curriculum is difficult to say at the minute…. I would say fair. She is making progress but not at the level, not at the pace or at the level that she should. But for her ability she is making progress. Mathematics results … She did the test in May and got thirty-five percent and retook it September and got sixty-seven percent. My predictions will be CfE First Level secure and hopefully CfE Second Level developing."

Sally's after school tutor also thought that Sally was progressing. "She's doing really well, definitely… She's more outspoken than she used to be… Always keen to get on with the work. Her stories are getting a lot better. Her reading is improving and her mathematics skills are quite good… I hope by the time she leaves me in May she's confident anyway in going to the High school."

Researcher: *What would you like to do when you leave school?* Sally: *Art*

Her mother said, "Sally's wanted to be an artist for a long time. It's up to her when it comes to art because I don't know anything about art." Her teacher had also identified art as one of her strengths.

Memory and language issues in testing

Researcher: *Do you prefer writing or speaking answers in tests?* Sally: *Writing*

Sally's mother said that there should be more speaking and writing but that teachers should have more patience when testing learners with cleft. She added, "So they can put it in their own words, at their own pace." The class teacher said that he used various ways of testing learning in line with the local authority policy entitled, 'Say, Write, Make, Do' and this allowed the pupil to be given credit for their learning by selecting what method suited them. However, he also said that the pupil would be expected to respond using all four means listed over an academic session. Presumably this meant that Sally would still be tested orally at some point during the school year.

Researcher: *Do you like puzzle solving tests?   Sally nods her head.*

Sally preferred solving puzzles to straightforward recall of information. She found it difficult to remember material for tests and said that memory issues had affected her language work. The after school tutor thought that this might have affected her spelling, but strangely not her multiplication tables which she was good at remembering. Her mother and class teacher did not think Sally had issues related to her memory.

Reflections

Although Sally was making progress in her learning her teacher said that she was doing so at a slower pace than would have been expected for her age. He expected she would reach CfE Level Two developing when she left primary school. Her mother had identified speech as an important issue. However, her speech issues seemed to come to the fore only when she spoke to adults, particularly adults in authority. Her mother said that her daughter thought people could not understand her. However, to compensate for minor speech issues she used strategies such as talking quietly and lowering her head. As this made it more difficult for others regarding comprehension, communicative partners had to resort to asking Sally to repeat herself and talk louder. This simply reinforced Sally's belief that others struggled to understand her speech but in fact she was engaging in a self-fulfilling strategy.

Sally had appeared to lack confidence but her approach was now changing. This may have been a personality trait but it could equally have been cleft related due to her speech issue, or a combination of both. She was still attending speech therapy on a three monthly basis. However, the speech therapist said that if she perceived that children were not making progress with speech therapy, it was sometimes wise to ask patients to make an appointment for three months ahead and at that stage the speech therapist would try again.

Sally's teacher reflected that her "slow progress" could have been related to issues with speech and phonics which might have a negative impact on literacy. However, the fact her mother tended not to push Sally to get work done might have also have had an effect. Her mother's anxious attitude towards her going out around her area might have reduced social mixing opportunities. Her brother also provided support for her both academically and socially.

According to her teacher when the focus was on practical areas of the curriculum Sally flourished. She showed a willingness to take on a leadership role and was supported by some of her peer group. The success she experienced had encouraged her enthusiasm for learning and had increased her confidence and her participation in learning activities. Success in her dancing lessons and progress made at the after school club had further increased her confidence.

This case study raises a number of interesting issues, for example: the importance of developing confidence, the difficulty of separating personality traits and cleft and the dangers of wrongly labelling children, the importance of the peer group, the importance of well-informed teachers, moving beyond leaflets to disseminate information, the anxious parent, sibling support, the advantages of offering support in school and at outside establishments, school/hospital links.

The following chapter will document the case studies of the two young people at the early secondary school stage.

C H A P T E R   S I X

The Results of the Six Case Studies
Early secondary school stage

6.1   J E S S I C A

Pen portrait of Jessica

Jessica was thirteen years old and lived with her father in a village on the Clyde coast (SIMD Five). She was an only child. Jessica attended a secondary school with around a thousand pupils in a nearby town, travelling by school bus. She was in her second year of secondary schooling (S2). Jessica held the opinion that she was making excellent progress at school and she was receiving no extra support for her academic studies.

Jessica had been born with CPO. She had a gap in her soft palate which therefore was not immediately visible. Her father indicated that his daughter had surgery once, at age eighteen months to correct the fistula.

The adults interviewed for Jessica's case study included her father and her English and mathematics teachers.

Introduction

Jessica's father said her parents were concerned about Jessica at the start, "but we were reassured by the speech therapist and when we saw her making progress the fears we had faded away." He continued, "The teachers may not know she has had a soft palate repair as an infant… It was years ago and is an irrelevance now." Do some young people experience no learning issues related to their cleft?

Literacy Issues

Listening

Jessica: *I can mostly hear what the teacher's saying unless my ears are blocked up with wax or something like that…. No, I've never had a problem [with listening].*

Jessica's father, her English teacher and her mathematics teacher all said she was a good listener. Her father considered that she had never had any problems with hearing. Her English teacher said, "Listening fully to instructions and in group work listening to other people, she seems to take it in. There's no "Miss what are we going to do next?" or "Can you say that again?""

Talking

Jessica: *I've never stopped talking!*

Jessica had a check-up about every six months in her first years with speech therapy professionals. Since starting school she had only five-yearly audits. Jessica's father said she should be treated the same way as other pupils with regard to oral work because she had no issues with speech. Her English teacher said her speech was "exactly the way it should be" and continued, "I've not had any difficulties in understanding her or in her expressing things in class, nor have the others in the class, absolutely fine. Even when it comes to solo talks and group discussions she is really involved in all that and there doesn't seem to be any barrier." Her mathematics teacher was of a similar view, that her speech was "fine", reflecting, "Jessica socially fitted right in, verbally fits right in, academically fits right in."

Jessica: *I'm not particularly fond of reading out loud in front of the class… If I really have to do it, I will speak in class. If I've a choice I won't do it… I'm about to read and everybody's staring at me and it makes me quite uncomfortable… Some of my friends say they go through that … but not a lot of the time. I'm more nervous.*

Jessica's response at interview was not consistent with her actions at school. At primary school she told the researcher she enjoyed drama and had a part in the school production of 'Beauty and the Beast'. Her father's impression was also that she was confident in performing. He said, "She often takes part in activities – she put herself forward in a talent contest at school and got up in front of an audience and sang a song. She won second place." Her English teacher noted, "She is a very competent reader. She will offer to read out and things in class." Although Jessica's mathematics teacher said, "I don't get them reading aloud because I never liked that when I was at school. I'll ask people to volunteer answers and then I'll maybe get an answer from one kid and ask another "Did you do it differently?" He said Jessica would volunteer answers when asked and there was no problem understanding what she was saying. He continued, "I'll take a response from one group, Jessica's group is called the 'Apples' and if I do pick them Jessica is probably one of the ones that is always willing to give the answer or I've heard her say, "Well, they got this but I got that and she will mention they didn't agree."

Jessica's father said his daughter could put together a good argument and ask good questions.

Jessica: *I prefer to work alone because you can work on your own answers and put more detail into it, the way you want it. I would volunteer to take charge but I wouldn't want to as much as other people because I feel that everybody has their own opinion and you don't just rush into things and take charge of the whole group and don't let anybody say anything.*

Jessica's father said his daughter benefited from group work at primary school, although at secondary school it would depend who was in the group. He contended that the cleft made no difference to Jessica in this regard as she could work alone or in a group just like other pupils.

Jessica's English teacher said this pupil participated well in group work and gave the following example to illustrate, "Recently we did a wee editing workshop so when they had just finished their final essays on a book we had been studying they were peer assessing each other's work and shortening bits and pieces and working in groups of four, they kind of swopped and marked each other's work." But the teacher added, "I think she

just adjusts to whatever's been presented to her. She enjoys working in groups but she is very competent on her own as well." This view was endorsed by her mathematics teacher: "She sits on my left with pupil L beside her. There's a bright boy across from her and three girls sit with her who came from a different primary and they all just get involved… She works away in the group and engages with them." He illustrated his point thus, "We had an equations treasure hunt and they were working in pairs going round the room solving the wee equations and Jessica was up off her feet racing round trying to be first finished." With regard to Jessica working alone, the mathematics teacher reported, "Sometimes Jessica can just get on with the work and she wants to do it herself. I think she's got a wee determined head and she wants to understand it and she just concentrates on her own."

On the question of adopting a leadership role in the group the English teacher was uncertain, "I'm not sure about leadership role… Yeah I think maybe not in a kind of way that it seems as if she's kind of taking over things. But quite often she'll maybe pull things back on task which I suppose is a kind of element of leadership, isn't it?" The mathematics teacher made a similar statement, "I think she is one of the ones, knowing the other individuals in the group, she can be a bit more "Let's get the task done, let's get it finished" because some of the others are a bit more tentative."

Reading

Jessica: *I read quite a lot….*

Jessica's father reflected on her reading ability and attitude to reading. "Her speech has been good and when reading there have been no problems. She is a keen reader in phases and sometimes prefers watching TV to reading." Both the English and mathematics teachers also found no issues with her reading ability. In class they said she was treated just the same as other pupils and followed the subject curriculum just like all pupils in the class.

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Writing

Jessica: *I like creative writing, you get to do stories and stuff. I've got a lot of examples of when the teacher praises me but em mostly it's when I've got a good story in my language.*

Jessica's father reported, "There have been no issues with writing… she is a very neat writer....and no issues with spelling." Both her English and mathematics teachers expressed a slightly different view but considered that neither the physical act of writing nor spelling appeared to hold back her progress. Jessica's English teacher reported, "Her writing is good, maybe not the neatest writing in the world but legible. For spelling again for the level she's kind of at there are obviously some spelling mistakes from time to time but generally that is not an issue… She is kind of the same level as others in her class. She's in the top section." Her mathematics teacher said, "Well I wouldn't say she was the neatest writer but you can definitely read it. She sets it down well. Sometimes she has to put things down on big sheets of poster paper as well as in her jotter and she's fine. When we do 'show me' boards, Jessica gets everything down and the girl that sits beside her doesn't quite get the solutions through so much … I see Jessica actually helping her to fix it up. I think Jessica's probably more of a visual learner. She likes to get it down and see it completed. There's not much spelling but when I see it, it's fine."

Numeracy Issues

Jessica: *I quite enjoy mathematics. I don't get through that as quickly as for my other subjects.*

Jessica's father said that she enjoyed mathematics but that it was not exactly her strongest subject, but nevertheless she was in the top section. He continued, "She doesn't appear to have any issues specifically with problem-solving… She shows her workings and she thinks about how she got there generally." Jessica's English teacher said her programme of work did not contain much by way of numeracy type problem-solving but there was problem-solving included in the English curriculum, offering solutions to issues under discussion. In her view, Jessica was "good, she kind of takes everything on board and seems to have a real balanced view when it comes to different things."

When Jessica started secondary school she was placed in the second top mathematics class, based on her record of achievement from her primary school. Her mathematics teacher described her progress as follows: "Jessica has flourished in mathematics, she moved from the second set to my top set and she's been there ever since. We've not treated her differently from everyone else. She has fitted right in. .. She's doing very well, working at a really good pace…I've no concerns at all…. She speaks out in class, answers well and takes part in everything. She does seem very numerate."

The mathematics teacher said that her reading and understanding of questions in problem-solving "seems to be fine". He continued, "All these things are an integral part of our class lesson and some of the questions in the test have problem-solving attitude and she seems fine. She thinks things through very well. She'll offer solutions, offer ideas towards solving it." In response to a specific question, the mathematics teacher said that he had not encountered her having any memory issues.

Metacognition

Jessica: *Well, in the classroom if I've just learned something I know it for instance, if it's playtime and I go outside, em, I usually think about it in my head.*

Jessica's father and her mathematics teacher thought Jessica reflected on her learning and developed strategies for learning. Her English teacher said it was built into the learning and she thought Jessica did spend time reflecting.

Preference for the practical subjects and outdoor learning

Jessica: *I like drawing stuff and painting. I think I do best at art because I'm quite good at drawing and me and my friend are really good at it.*

Although Jessica indicated she was interested in the creative arts, her abilities stretched across the curriculum. It appeared as if her interests at secondary school had veered in a slightly different direction. Her father said, "Jessica shows strengths in English, mathematics and science, particularly biology. She is also good at languages and prefers Spanish to French. She is actually doing well in all her subjects but if I had to pick a

weakness then I would say technical – woodwork, metalwork - and PE." Jessica's poorer performance in PE could have been affected by the low muscle tone which she experienced. This meant she had to wear a special type of footwear to help her balance. Her father said this had possibly affected her psychologically, in particular, her confidence. At primary school Jessica had taken a taxi to school instead of walking but when she moved to secondary school she started taking the bus with her friend who lived several houses away.

The English teacher said that Jessica was interested in language and progressing well. Her mathematics teacher found her "very numerate" and added, "The group of friends she runs about with are achieving across the school. They are not just language based or science based or mathematics based." This does not mean Jessica would follow suit but all the evidence available in this study seemed to point to a pupil progressing well across the majority of the curriculum. The evidence for this comes from her father's view and based on the reports of teachers.

All parties agreed there would be no difference in Jessica learning outdoors to other pupils doing so.

Social activities

Jessica: *I quite enjoy playing chess and then on a Tuesday I've got a 'Run for Malawi' club... I quite enjoy school shows and singing, em speaking out, and I had a part in the play. In the playground I chat to my friends because mostly we're older, we do skipping sometimes and pass the ball…. I go to the Guides, we earn badges.*

She had an established group of friends that she had known some since toddler group. They lived in the village. She had gone through primary and now secondary school with them and it was the same group that attended the Guides.

Jessica's father and her mathematics teacher spoke of Jessica being a member of the 'Press Gang' in social subjects at school. There, in conjunction with others, she had written articles for the school newspaper. She was involved in one about a local landmark. Her

father did say that she was more of a spectator for physical activities because of the muscle issue although he also said that her close group of friends boosted her confidence levels. Jessica's mathematics teacher also spoke of Jessica's having a close group of friends who went about the school together. Jessica's English teacher said "She goes to a Film Club I take so I see her outside of the classroom environment. She has a really, really secure group of friends and they're all lovely and very supportive of each other I think. I think they came from primary school with her."

Teasing or Bullying

Jessica: *I've never been teased in school actually.*

Jessica's cleft affected her soft palate and this was invisible. Her father thought that important in that this was an invisible medical condition which did not affect her appearance. He commented, "For those with a lip and palate repair there could be a difference with the scar since people always look for differences although this may just be curiosity and not necessarily for nasty reasons."

His daughter had not had any bother with teasing or bullying either at school or at the Guides. He said, "Her self-esteem is good and that is encouraged by her friendship group. The school has an anti-bullying policy and if I ever needed to use it I would not hesitate to contact them. I would be proactive about that. For the Guides the group is so small it would be obvious and it would be dealt with immediately."

Neither the English nor mathematics teacher was aware of any bullying. The mathematics teacher believed that Jessica would have the confidence to speak out about it if there had been any instances of teasing or bullying.

Behaviour

Jessica: *In Primary Two I was caught copying somebody's work… in fact that's the only ever time I have ever got in trouble.*

Jessica's father described her personality, "She seems a normal thirteen year old girl. She is happy to go to school and wants to go with the rest on the bus. She can make the odd cheeky remark at home but is reminded this is not acceptable. Generally her behaviour is good." This view was reinforced by the English teacher, "She's very well behaved, and seems just very settled and comfortable. Yeah, just great. Not withdrawn or shy, not amongst her friends and certainly not in the English classroom…" A similar description came from her mathematics teacher, "She's a very smiley young girl… Behaviour, perfect, quiet but not disruptive. She knows when to be quiet and when to pay attention." All parties were describing an archetypical model student.

The parental role

Jessica: *Homework, I don't usually need any help because homework is quite easy.*

Jessica's father said he helped with homework and described his role as follows, "I let her know the way I expect her to behave and correct her speech if she uses the dialect. She gets help from me depending on what she needs…I offer her stability, help with homework, life experiences, verbal encouragement, set standards for discipline and let her know there are lines she cannot cross." Both teachers interviewed said her homework was of a high standard and her mathematics teacher commented, "She hands homework in religiously almost." Jessica was confident in dealing with her homework herself but if she did require assistance her father provided that.

If he was teaching her something at home her father said he would ask questions to check that she understood how she went about it. In engaging in interactive dialogue Jessica and her father adopted a constructive approach to learning.

Jessica's father maintained that the cleft did not seem to have affected her approach to life although she was still selective in her independence. There were times when she still looked for help/support.

Parents and inter-agency relationships

Jessica: *When I was younger I used to be shy to answer the questions because I didn't know my teachers well but now, em, I'm older I feel I can speak to my teacher more considering she is my neighbour.*

Jessica's father reflected that they had very little contact with the hospital and it was unnecessary in her case for the school and/or hospital and/or club to be in communication. He said it would be good for pupils in general to know about cleft from an organisation such as CLAPA but not specifically because of Jessica's case. He continued, "Her mother and I were aware of CLAPA but because the cleft presented so few difficulties we did not bother with this organisation." He said that his daughter had not given a talk about cleft at school and probably couldn't say much about it. After all, her one operation happened when she was eighteen months and she could not remember this experience.

The teachers interviewed held the same view - there was no immediate need for communication with outside agencies and any change in circumstances should be passed through Guidance department. However, the English teacher reflected, "Teachers could get a talk from CLAPA or Changing Faces. I always find anything like that ... to have someone involved to give you a bit more information about it… I suppose it is my responsibility to read up a wee bit more, for my own teaching and learning to progress." The mathematics teacher thought, "It would be good at the end of her senior years to turn round and say "Look at what I've done and this is what I went through". It might be useful for other kids to find out. I wouldn't put her through it at this stage." This teacher might have felt she would be better waiting to give a presentation until she was more mature and she could handle any questioning without embarrassment.

Absence

Jessica: *Going to the hospital – it didn't affect my work in a big way, it was just like a day. The teacher goes over the work I've missed but usually I can get on with it myself, just figure it out myself looking at the textbook page if it's mathematics.*

Jessica's father said his daughter's absences due to hospital appointments were infrequent as the main stay in hospital had been for her operation at eighteen months and she would be unable to say much about this hospital visit. He explained that since starting school "there has only been the odd day or half day so it has not made any significant difference. She had a check-up about every six months at the beginning with speech therapy. After starting school she only had five-yearly audits. She has been two or three times for x-rays, to the orthodontist and has had a couple of teeth removed. In six months or so it is likely she will have a brace fitted."

At school the English teacher reflected that Jessica had never spoken in class about her medical condition and she was not aware that Jessica had received any treatment during her time in this English class. The teacher reported, "She's been off a few times but I wouldn't say it affects her work rate because she always strives to catch up and discover where we are… One week she was off like three days and when she came back in it was a case of she approached me, "What have I missed, what chapter are we at?" and she went home that night and caught up on everything". The teacher continued, "As pupils move further up the school absence would affect them more but not more than it would affect any other pupil who missed school."

Jessica's mathematics teacher reflected, "I would say she has less than average absence because I know friend L that sits beside her is off a whole lot more… So Jessica is there an awful lot of the time."

Attainment

Academic and social progress

Jessica: *All my teachers, every single teacher I've ever had has praised me for my work because I'm so good … I'm so good my teachers say… It's very important to me because when I'm older I really want to get a good job.*

All parties interviewed agreed that Jessica was progressing well at school. Her father adopted a positive approach to learning saying that one can achieve if one tries and

reflecting, "I would say to another parent it's what a child can do that matters not what they can't do."

Jessica met his criteria for being a successful learner, "A successful learner should be self-reliant, motivated and able to do their own research. She has displayed these qualities at school by doing studies and researching information by herself. I think she's doing well in all her subjects except PE." He said she attended the Guides for relaxation and not for career based learning. Her father reflected on his daughter's learning ability in the following way, "She is a fast learner and support is withdrawn quite quickly when she is learning something new. " His ambitions for her were clear, "In the future I hope she will be happy and pick a good career… I want my daughter to go to university… On the whole the cleft has not had any impact on her learning."

The English teacher said generally she had no concerns about Jessica, "so it's not that I don't relate them to the fact she has a cleft palate it is just there have not been any issues with her. In English the cleft has not raised any challenges." She continued, "Scaffolding is removed at the same pace when she is learning something new." This teacher said that based on class work, homework and test results, Jessica was progressing in the top section. She continued, "We've written a couple of essays so far this year and there is an improvement to the level you would expect to see between one and the next." In future the teacher believed Jessica would continue to make progress and grow in confidence. Jessica's mathematics teacher reflected that Jessica was like other pupils, sometimes she solved problems faster than others, sometimes she needs a "wee nudge and away she goes." He reflected, "Jessica's on Pathway One. She's in the top. She's doing very well. In fact she is just now working on CfE Level Three and CfE Level Four work and just recently we've finished Unit Two of work and Jessica did better in her CfE Level Four test than she did in her CfE Level Three. She's doing very well… In her tests she scored in the high sixties for one and then the mid-seventies for the other." In future he predicted she would be a candidate for Higher mathematics. He added, "In fact I'm not sure anyone really notices the cleft to be honest."

Memory and language issues in testing

Jessica: *I prefer tests when I write the answer because then I can put more detail into it because I don't like speaking a lot because I get out of breath… I much prefer problem-solving tests and figuring out all the answers… because my teacher can make it into a game.*

Jessica said she preferred to write her answers to tests but only the breathing issue might have been formed from a cleft related issue. Yet, none of the adult parties interviewed mentioned Jessica's breathing as being an issue and the fact she was successfully giving oral performances in plays and confidently reading aloud in class suggests that for this to be an issue there might have had to be extensive reading involved.

Jessica's father reflected, "There are no special considerations for Jessica as she can take tests the same way as other pupils." This view was supported by that of the English teacher, "I don't feel as though I have to differentiate anything … you know she just takes everything on board the same as everyone else in the class does." The mathematics teacher agreed that Jessica had so far required, no special arrangements, "if we have any idea that a kid couldn't cope … we would do one assessment with and one without and start a record on her, making sure whenever assessments were coming we would have support brought in but I've never needed to."

Reflections

If the cleft affects the cerebellum then this may affect the child's balance which in turn had consequences for Jessica's educational experiences in PE. Her father said this had affected her confidence to a very minor extent. Attendance at the hospital had played very little part in her childhood, at any rate the childhood she could remember, and presumably therefore she reflected little on her medical treatment. Her success in language learning meant literacy issues did not have the potential to impact on her learning of other areas of the curriculum. Jessica's motivation and resilient personality also played a role. She overcame her short absences by finding out what she had missed and took action to cover the material herself. Her father said she wanted to be like other girls from the village, to go to school by bus. She was determined to overcome issues related to balance by walking down

the road with her friend for the bus.   Her confident attitude may have been a part of her personality, or bolstered by her own previous successes - or it may have come from her social and economic class. Her father was a graduate and had university aspirations for his daughter. He and Jessica communicated with ease with educational professionals, one of whom lived next door. He had never felt that he had any reason to argue with teachers regarding additional support measures or her progress: the former were unnecessary, the latter was exemplary. Her small group of friends from the village offered a secure friendship circle which gave her social support.

This case study raises a number of interesting issues, for example: not every child born with a cleft will have issues to deal with, parental approach, the relationship between those in higher socio-economic classes and educational personnel, developing a motivated and confident attitude and a secure peer group formed from nursery schooling. This case raises the issue of cleft, balance and the cerebellum.

6.2   L I A M

Pen portrait of Liam

Liam was thirteen years old and lived with his parents, his older sister and two younger brothers in an inner city area. (SIMD One). He was in his second year at secondary school (S2). The school he attended was situated locally and provided education for eight hundred and forty pupils at the time of his case study. Liam believed he was making progress in his learning and when interviewed at primary school he was receiving an hour a day additional support from a teacher outside his classroom and using a special pencil for writing.

Liam had been born with CLP. This medical condition resulted in a cleft repair to his lip which was barely noticeable and palatal surgery that could not be seen. His mother said her son had undergone surgery to close the cleft of the lip, and had two operations on his palate, and one on his nose and had had grommets fitted a few times. A small hole remained in his palate.

Liam's case study is informed by evidence from his mother, his home economics teacher and the leader of his Boys' Brigade (BB) Company.

Introduction

Liam's mother said, "I didn't really know until Primary Two when we started noticing things… he done everything in the school." What were the implications of this?

Literacy issues

Listening

Researcher: *Can you hear what is being said?* Liam: *Not really …*

Liam experienced otitis media with effusion which affected his hearing. His mother said that, until he had grommets fitted he had to be moved to an appropriate seat in the class.

She said initially the teachers had been hesitant about dealing with the hearing issues. .His mother explained, "He said that the teacher was constantly shouting and when we went in we found his desk was right next to her and when she moved him away he is like "Oh, she's alright now". It is just the closer he is to the teacher the louder it is for him." This suggested that his hearing was amplified, perhaps because of the grommets, which could have been difficult for Liam.

Since Liam had the grommets fitted his mother said the situation had improved but there was still an issue on one side where the treatment was not successful. Liam had grommets reinserted. His mother said the hearing issue had led to him not understanding what was happening in class and this had affected his learning. However, at home, his mother said his hearing was "selective, listens to what he wants to." This suggested that Liam was ignoring what was said rather than having an inability to hear.

Liam's home economics teacher said that his listening skills were "quite good". However, she continued, "Don't know if that is because we're saying this is how we're cooking, this is what we're doing, go and do it. So he's obviously quite invested in listening because if you don't listen you can't make the product. So it's a good motivation to pay attention." This would suggest that there was no major issue with his hearing or that her teaching strategy which was oral (reading out the recipe and giving instructions) with visual demonstration of the method, suited Liam as he was able to see what was required.

The leader at the Boys' Brigade (BB) said there were no issues with Liam's hearing and I found Liam was able to hear and answer questions at his interview. However, this involved communicating at close quarters. Where Liam was listening, for example, to the police presentations at the BB, he could sit there silently and watch because he did not need to respond. Similarly if attending the cinema with the group he could see what was happening.

Talking

Liam: *I prefer to speak the answers.*

Liam's mother criticised his speech saying he spoke too quickly to avoid correction. She persisted on trying to correct him and she observed him becoming frustrated. She reflected, "It's just kind of some words, trying to get his tongue round them… He talks more through his nose rather than his mouth when he is saying things… Some people don't understand what he is saying… He's got a hole at the top of his mouth." Liam was experiencing hyper nasality possibly because of the remaining fistula. The speech therapist interviewed said that surgeons would not operate on small residual fistulae if they were not having a major impact on the patient's life. Liam had not requested further surgery.

Liam's mother said his speech would affect his class work because he was not a very talkative person and would not volunteer answers. She thought that the teachers "let them slide back in class rather than encouraging them to understand and answer it (questions)." Liam's teacher said, "I think his speech is very good to be fair. You sometimes hear a bit of a lisp and I think you can hear there is a sort of fuzz in the background. Possibly the 'th' sound. However, as long as you're not putting him on the spot and making him stand up in front of people his verbal skills are very good. I have never once asked him something and not been able to understand what he has said." Class members had not yet been presenting material individually in front of the whole group. They were just starting their Hospitality course and he was working with a partner with whom he was socially acquainted. The teacher considered, "So these things kind of help rather than being put with someone who is a stranger who could potentially judge you."

A picture emerges of Liam as a quiet boy. This may be his personality or it may be a lack of confidence due to his speaking skills. His mother doubted the teachers' approach would encourage confidence to speak. This view of Liam was reiterated by the BB leader who said the only difficulty with Liam was his speech. "That's he's a quiet boy and whether he's quiet because of his disability? Even though he's had the operation to repair the cleft, he's still a very quiet boy. Now, whether that's a throwback to the time he had it?" The leader highlighted the fact that Liam had two younger brothers who were also BB members and they were more extrovert, and did not have a cleft palate. Yet he pointed out that Liam had an older sister who did not have cleft and she was as quiet as Liam. The leader felt sure Liam would not wish to give a presentation to highlight the cleft and like many others of his age would refrain from volunteering for public speaking.

Liam: *I prefer to work in a group … because if you're stuck you get help.*

Liam's mother said that her son worked better on his own as he would concentrate better than when having to stop and interact with other people. In contrast, at the club, "It's different at the club like maybe only four of them … a wee group … So there will be so many doing one thing and so many doing another so there is only a wee group… They do one or two activities, like Bible knowledge and sport, one week, and they'll do something else next week."

In the home economics class Liam regularly worked within a pair and the teacher reflected, "His pair would give him support when needed and I have sometimes seen him if we are sitting doing a time plan, doing what we need to do in the next lesson, he will say line this here and line this there. I would say Liam gives help more during practical lessons… He is more confident in the practical work." His teacher pointed out, "He always participates. With pair work he collects some of the ingredients. I've never seen him standing about and doing nothing." It appeared Liam was happiest working in small group environments where he was familiar with his peers.

The teacher added that if the class were engaged in a group presentation he could be placed in the middle so he would not be the first or last to present and this would ease any pressure he might feel. He would be presenting for one minute on a slide.
At the BB the boys worked in mixed age groups with the group usually led by a senior member working towards their Queen's Badge. Liam took an active part in all group activities and communication was no barrier - for example, he worked as part of a team taking apart and re-assembling a bicycle.

Liam, according to the BB leader, was "more reactive than proactive". Liam "very rarely" took on a leadership role although he might do so as he got older as the leaders were often boys in their senior years at secondary school. His mother said he was starting to take responsibility at home by looking after his younger brother, aged five, when the latter was out on his bicycle. His mother told him, "You're in charge of the phone, if anything happens you phone me. You're responsible for him." The teacher said, "I wouldn't quite say yet. At the moment he has been more supporting than he has been leading, although

equal part… Yet that may change in a few months when he's a lot more confident in his ability."

Reading

Liam: *I go out the class and do 'Toe by Toe'. It helps with reading.*

Liam had been identified as having dyslexia. His mother paid privately to have him tested at the age of seven years. She said, "He'll not read out in class and things like that.   It's not that he doesn't actually know the work ... he listens and takes it in but he doesn't actually volunteer to do reading." She said his reading and writing were his weaknesses. He had additional support to help him progress in his learning. His mother reported at primary school, "He had a one to one with Mr N… not all the time just sometimes. When he was going in and out of hospital and that it was to help him catch up … He would maybe go away an hour a day." However, when Liam was interviewed for this study it had been three years since his last operation and he was still receiving support.

Liam's mother explained how it affected her son's learning, "He'll bring work home to me and he'll say before we go over this "I don't know what I'm doing". See once I would read the question, what he was to do, then he knew what he was to do. He just didn't understand it if he was left." He could not read line by line down the page.   He was using a Dictaphone to hear information rather than reading a worksheet.

From inspecting Liam's written work, the BB leader had suspected Liam was dyslexic but had received no information about this. However, the leader said, "but that doesn't feature with us because of the way we teach or learn for what we want to achieve." He explained that in the BB they believed in learning through fun activities which was deliberately not like school.

Writing

Liam: *I don't like doing writing. I find it difficult… It's making the letters.*

Liam had an issue with writing – both spelling and physically making the letters. His mother noted, "He writes words the way he sounds them not the way they're supposed to sound." She said the smaller words were harder for him. She thought, "they all just look the same and sound the same for him … 'where', 'when' and 'what'. He doesn't understand which ones he should be using at the right time." I wondered if this issue could also be attributed to Liam's hearing.

Liam's teacher compared his spelling to that of others, "His spelling isn't wonderful but you also find that a lot of his peers don't have wonderful spelling…It's certainly not as bad as others. He would be probably sitting just below average… It's not like I've ever received anything that I wouldn't be able to understand what he has said."
At the BB it did not matter if Liam had an issue with spelling as there were few written requirements.

Liam's mother explained his difficulties physically making letters, "It's his co-ordination when he holds a pencil… He can't write in the lines they give you. He has to get bigger lines between. Or we get blank paper and we draw our own lines on it. He uses a triangular pencil because he can't hold a pencil right." She said he lost interest after he wrote a sentence and that he couldn't write and think at the same time. She reflected, "It's worse than my Primary One wean's writing." At school Liam could record his responses orally using the Dictaphone rather than writing on a worksheet and he also had the use of a laptop and, for tests, the services of a scribe. His mother thought the situation had deteriorated since he progressed to secondary school. She thought this was because there was more writing at secondary school and because at primary school he was taught by the same teacher all day so he could not avoid the writing tasks. At secondary school a single period lasted fifty minutes and Liam could start the writing task but the teacher would not expect the task to be finished by the end of the period.

Liam's teacher said, "I think yeah occasionally he possibly struggles with controlling a pencil and it's maybe something we would notice a little bit more when we get into the part of the course that's more involved in written work." At this stage the class were doing more practical work rather than writing and the teacher reported that, "For stuff like time plans we sometimes cut and paste text and then add to it so he's not sitting and writing a lot of stuff out. If we're doing something that is really important the whole class will go

along to ICT and type stuff up so we'd take our notes and make it, put it on the computers." The teacher reasoned this would avoid those requiring support feeling 'different' since everyone was using computers.

The BB leader said, "His written work, in comparison with other boys his age, it's not as good as others so whether or not there's other educational matters that I've not been told about but I'm not educationally trained on all that. Just look at his writing, look at his answers and say, "That's a mess or that doesn't look right." And that may be related to when he was in primary school, when he was maybe more introverted."

All parties agreed Liam had an issue with writing. His mother considered this serious, the teacher looked for ways around this and the BB leader treated it as an irrelevance. With the advance of modern technology handwriting is likely to become progressively irrelevant. However, misunderstandings might arise from the spelling but with spellchecker this is less likely.

Additional support for literacy

Liam's mother said at the club, "As long as he can tell them, it's more verbally than writing… You don't get writing. Maybe once a year or something they'll get like a worksheet to make sure they're listening" At secondary school he received help from the additional support teacher three times a week during registration to help with writing and some homework. He had the Dictaphone and laptop, different jotters and books for reading because of dyslexia and used a big triangular pencil for writing. Liam's mother said she was not really happy with the support but didn't know if there was more could be done to help her son. She said, "I don't know if it's helping him actually not writing and doing it with the stuff … His writing is absolutely atrocious." She reflected that the amount of help had increased since he attended secondary school but at primary school it was more on a one-to-one basis.

Liam's mother said that there were two or three parents' evenings a year and she had access during these meetings only to a head of department and not to her child's class teachers. She said, "I don't even get to speak to his dyslexia teacher or nothing and all

these bits of paper from each teacher. I would rather speak to the teacher that is teaching my child."

Liam's mother was doubtful about his present additional support. "I think if he got more oral tests then he would be able to do it himself rather than writing it and presenting it… then you know it's him. I know this isn't right to say but anybody scribing it down could add their own wee bit and if he is saying it verbally then it is his work and not someone else's… It's all he can get the now … I'm happy with that but I'd rather a teacher or somebody take him in and ask him the questions and let him verbally do it than somebody else write it out for them."

The class teacher said that Liam did not really need any support as yet but the option was available to him if he wanted it, for example, material printed on coloured paper. This would have been for pupils with dyslexia. Liam had not chosen these. The teacher said she had self-evaluation sheets based on the traffic light system which pupils received every lesson and if he was showing signs of difficulty, she would have a talk with him about it.

The BB leader reflected, "We don't require it. It hasn't been an issue with Liam. You wouldn't even know he'd had a problem … computer - nothing like that. Not with us. We don't have the resources to do it anyway."

Liam's mother said, "It doesn't bother him going to all that. He's not the only one in the class". This was supported by the view of the teacher, "I think we have about forty percent to fifty percent of the students have additional support needs in that class." So from a psychological point of view Liam may not have felt different from others but the teacher highlighted he was not using the equipment provided such as the laptop so he might have been trying to avoid the issue.

Numeracy issues

Liam: *I like doing sums ….. dividing.*

Liam's mother said her son was successful in mathematics. "For some strange reason he is quite good at mathematics. Writing it down, he gets himself mucked up that way…

Algebra, he can do all that but to put it down he's not quite sure of the way he writes it." While learning in the home economics class, little mathematics was involved. The teacher said, "We don't really do it that way. The only counting type stuff we do at the moment with them would be weighing and measuring. He has not really had any problems with that." The BB leader similarly reflected there were no issues in mathematics as so little was involved.

Numeracy did not appear a major issue and all parties agreed. Questions were accessed using the Dictaphone. However, Liam's mother's surprise he could cope with mathematics raised an issue of parental attitude.

Metacognition

Researcher: *Do you think about what you have learned afterwards?*
Liam: *Hmmm ……. Yeah.*

Liam's parent was of the opinion her son might get the right answer in his work but he could never work out how he achieved a successful outcome. Liam's teacher said "I don't think so to be honest. I've never seen him do that." The BB leader said he wouldn't know but it had never been a problem.

Preference for the practical subjects and outdoor learning

Liam: *I like maths and science, art and that's it… I like drawing and blowing up stuff and doing sums.*

Liam's mother agreed that her son liked science and "experimenting with things, creating things, things that keep him amused all the time." He liked woodwork and making things rather than writing.

His teacher was of a similar opinion, "I think he would be interested in anything that is more practical, and more sort of hands on so technologies, em possibly sciences as well and probably mathematics simply because it is a lot more problem-solving based and involved in what you're doing in front of you and not working with a big group of

people… there are less language skills in things like mathematics to a degree and technologies because what you are doing is not necessarily about reading or speaking a lot." However, the teacher said that if Liam felt comfortable and confident in the class his literacy issue should not over shadow his subject choice.

At the BB there was a variety of activities but many appeared to have a practical basis and literacy was not a requirement. Again there was an indication that Liam was more interested in practical activities which could have been attributed to his issues with language.

Liam's parent thought outdoor learning would be unsuitable for Liam as he would be easily distracted. His teacher said she had one lesson where she was allowed to go outside but Liam's class had not had the experience at this stage. The BB leader said Liam had attended BB camp and he regularly went to outside events with the BB and there were no issues.

Social activities

Liam: *I play football out in the playground… I go to the BB. I have my first set of badges and I'm doing my second set and I have …. Five … Oh and basketball. It's fun.*

Liam attended the BB. His mother thought this was good for boys because, "It lets boys be boys. It does things for boys rather than just football… camping." Although there were opportunities to get involved in activities every weekend Liam was at times reluctant to go. His mother said, "He needs to be set, to know that he's doing it." She said that her son had never asked to join a club and joining the BB was "just automatic when he turned five – my girl was in the Girls' Brigade." Liam attended the BB with his brother and his mother said that on holiday she noticed, "He uses his brother to go and talk to anybody like when we go on holiday. He'll not be the first in there and make a pal and talk to people first. He uses his wee brother, he's more outgoing. I think it's to do with his confidence." Liam's mother described her son's attitude to socializing, "He would rather stay in his room. I just think it is just him. The wee boy he goes about with is quite alike when he comes in from school. There's just they two. He's got learning difficulties and all, so they help each other out."

The teacher described the situation at school differently, "He has got a group of about four or five boys that hang about. He doesn't seem any different from any of them. They are quite a nice group of lads, well-mannered." The BB leader said there were five boys the same age as Liam, they all attended different schools, and they did not have opportunities to meet outside but they all got on well. He reflected, "It's not as if Liam's shunted off to the side and ignored and excluded… they accept him for whatever he is, the same way as Liam accepts them and there's no barriers between any of them."

Again there was a difference in attitude between opinion at home and outside the home.

Teasing or Bullying

Liam: *I haven't been teased.*

Liam's mother said she was not aware of Liam having any issues in this regard. This view was supported by his teacher, "I've not seen him bullied and I've not seen him bullying." The BB leader spoke of the importance of an inclusive environment: "There are fourteen boys in that age group just now and because they've known each other for the last eight years, they've all grown up together and it's not as if we have an organisation where we have boys who would bully, we don't have that sort of an issue. Liam is accepted for being Liam."

Behaviour

Researcher: *Have you ever been in trouble for your behaviour?* Liam: *No.*

There was a marked difference in the opinions of the adults about Liam's behaviour. His mother described his behaviour as, "Outrageous. He builds things up and then explodes. Mhm, he keeps a lot of it in and then just explodes and it's an eruption. Volcanoes. Like anything can set him off… He's done that from day one … Flip of a coin, nobody would believe it till they've seen it… Out of four children he's the only one with the cleft and he's the only one that's like that." In contrast Liam's teacher described him as, "A nice boy, he is well-behaved. He is not shy, he's not too boisterous. He seems like he's polite,

has a good amount of confidence especially with his peers. He seems to be quite a settled and good pupil."

The BB leader agreed with the teacher, "I would always say he was quiet … looking back I think he may be more introverted… He's well behaved, no issues, follows orders… Liam's a lovely boy. He has a sense of humour, Liam… He's utterly responsible. If you asked Liam to do something he would do it. He never lets you down in that respect."
At home Liam may have been reacting to parental attitudes as many teenagers do or it may have been due to a deeper frustration which could come from the cleft. Liam also experienced sleep issues and his mother had invited representatives from 'Sleep Scotland' to give advice to their family. Sleep issues are documented as sometimes causing hyperactivity and behavioural issues.

The parental role

Liam: *I get help with homework from my mum, dad or my sister.*

His mother said, "He receives an awful lot of help at home. Each child gets time to themselves… more bribes and threats to get it done than actual encouragement. He wouldn't do homework to the last minute." She continued, "Twenty minutes homework can take me two hours… Aye, he just doesn't listen."

During his early primary years, Liam's class had been engaged in an activity which involved them bringing in photographs of themselves as a baby. Liam's mother said she would not let him take baby photos into school until all his operations were completed.

Liam's mother highlighted differences between Liam and his three siblings. She employed a variable approach that sought to get things done and she may have encountered teenage resistance rather than cleft related reactions. She did not use this approach with the other children.

Parents and inter-agency relationships

Liam's mother had a difficult experience engaging with the school. She said, "If they had

listened to me. It took me three years for them and I had to go private and get him tested for dyslexia… I don't think there has ever been a child at his primary school with a cleft… Listen to your heart. Mothers know better, I don't think the teachers listen, even for a normal wean."

Liam's mother had heard of CLAPA. She said, "They do a wee disco thing at Christmas for the children and do camping. He was obviously too young for the stuff. It's maybe now it would start for him but they haven't notified me or anything… Maybe it would be useful to him to know that there's other people out there the same … that have problems…" She thought that if a CLAPA representative went into the school it would help other children to understand. She reflected, "They've never seen him other than stitched up… Not him to give a talk. It's not any different to him. He doesn't know the difference between having and not having … somebody that knows more about it." She said Liam might be there to answer questions but not to give a talk as she did not think he understood cleft. However, she said that he had been asked about it by other people and had given a straightforward explanation which had been accepted by others. The surgeon interviewed for this study said that a young person would be able to describe how it affected them and that that was the salient point.

The teacher had a different view, she would prefer the consultant surgeon to come in and talk to Liam's teachers rather than a CLAPA representative. The former would know more details about Liam's precise situation. The teacher had heard of CLAPA because she had been listening to a radio programme on the way home in her car but had not consulted their website. She said that there were advantages and disadvantages to a presentation. While everyone's knowledge increased, anybody in the school with cleft might feel singled out.

The BB leader thought a presentation from CLAPA whilst interesting for the boys was not necessary. He said they were hoping to have a presentation given by 'Sense Scotland' but that was to add to the boys' knowledge and not because they had a member who was affected by hearing or visual impairment. He did not think Liam would want to give a presentation but if he did wish to do so he would not be discouraged. He felt a presentation would be well-received by the other boys of his age group.

The language used by the parent, particularly 'even for a normal wean' suggests her son was different. There did not seem to be good communication between the school and the home. In general people were positive about obtaining more information from CLAPA or the relevant surgeon but less positive about the young person giving a talk.

Absence

Researcher: *Have you experienced an issue with absence?* Liam: *Nnno.*

Liam's last operation had been three years before. His mother said the hospital personnel were accommodating in that they usually offered appointments late in the afternoon and Liam only missed about an hour of school. If he was in hospital he would receive work home from the school. Absence was not a major factor. This was borne out by the teacher's view, that he was rarely absent. She said, "When we're looking at 'Hospitality' absence is not a massive factor, you can make up those skills easily. Looking at 'Health', it's quite a fast pace subject and the learning is quite significant so a high level of absence would affect it." This could be overcome, she said, by giving Liam a pack of materials to attempt at home and he could attend supported study classes when he returned to make up the time.

The BB leader explained that absence was not an issue. "We don't operate on the basis that one block is essential to another. It's the fact that they come along when they can come along. We have boys that will miss activities … it doesn't stop them from going on to the next stage. We might have to adapt things so they can catch up – it's not going to exclude them from going further."

In Liam's case absence was not considered a major issue.

Attainment

Academic and Social Progress

Liam: *I think I'm doing well in class… I understand what I'm doing and what I get back is correct*

Liam's mother's opinion developed over the course of the interview. Early in the interview she indicated, "I don't think his cleft has interfered with his school work, just his confidence maybe…" then she added "It's just really his confidence, that's all and I think his speech with the cleft…" Then she reflected "I think he loses his confidence because like his speech and his listening and his ability to do things…" and finally "I think because he can't say it right he doesn't read it. He's not hearing right so he's not interested." She said he was not really "a school person".

Liam's mother found that sometimes "it takes that wee bit longer for him to take in what you are saying to him… it could be that he doesn't listen to you right to take in instructions… Not his hearing, just him clicking." If he didn't understand she tried a different way of explaining, for example, in mathematics. "You keep going over and over it till you lose your rag or he gets it… It could be a long process but then sometimes he could get it right away."

Although she said that the school kept telling her he was on the same level as the other children in his class she wasn't interested in the other children in his class. It was her child she was interested in. She thought he was not very successful in his school work and she thought it was his reading and hand writing holding him back. She said, "I mean he's made things and I've been like it's not very good but he has been pleased with it because he's achieved by actually finishing it." He was more successful at the club where activities were practical and he got more pleasure out of learning there.

In home economics the teacher reflected that Liam's ability was quite good and there was nothing he would be unable to do: because most of the work so far had been practical he had been just as involved as anyone else. He did work at a slower pace at times but she said he would be "more towards the top groups". Interestingly, she added, "There he's got much less of a risk of somebody making fun of him, more of a possibility of people to support and encourage him." He was enthusiastic about cooking and was never last finished. He was making good progress. In contrast, his mother said "He didn't even know how to put a cooker on."

The BB leader said, "We accept boys what they can do, what they can achieve and we don't compare them on a scale of one to ten with the other boys… he is plodding away as best he can and he comes and that's the main thing". The BB leader said, "I just look at his work from time to time and say that's not of a standard that it should be … ours is a fun programme … there is no pressure on them… We try to get all of the activities based on the core curriculum, physical, social, moral and educational, and if we tick all these boxes and we provide that over the course of the year the boys will get their awards… as long as they try."

Liam: *I'd like to be a footballer or a scientist.*

Liam's mother said she just wanted him to be happy with his career, his life, his home life. The home economics teacher said he should be presented for 'National Five' Health course and she hoped that he would stay on to study for Higher. The BB leader said that although Liam was not academic there was nothing to stop him achieving what others achieve and he would hope Liam would continue to progress through the ranks of the BB.

Memory and language issues in testing

Liam: *I like tests where I speak the answer… I just don't like writing.*

In home economics the teacher used a variety of ways of assessing pupils in her subject. She said these included oral presentations, observation, and grading practical work by looking at the finished articles and taking photographs of the products. If someone was not enthusiastic about presenting orally she said they would be supported, for example, having a small group audience.

At the BB there was little writing of assessments and, if need be, an adult would scribe for Liam.

Liam: *I find it easy to remember information for tests.*

All parties interviewed agreed Liam did not have memory issues.

Reflections

Liam's case was characterised by a distinct difference of opinion between his mother and his teacher and BB leader. Whereas the latter two parties viewed him as just another pupil/member his mother raised issues about Liam's progress. The situation appeared to be aggravated by the lack of discussion between the school and Liam's parent. His learning journey was characterised by issues in literacy, which could have been due to dyslexia and/or could have been cleft related. If the literacy issues were related to cleft sounds then the latter was more likely and Liam had had speech therapy to correct his sounds.   A series of additional support measures was introduced. The measures seemed somewhat late in implementation and Liam may have tried to avoid using the recommended equipment because he failed to bring his laptop to home economics. However, his home economics teacher appeared unaware he should have had his laptop with him and said maybe Liam realised that at present the class was mainly engaged in practical activities and little writing was involved.

Liam was a quiet boy but the reasons for him being quiet were unclear. This could have been lack of confidence which may or may not have been related to cleft or it could have been his personality. His mother insisted on correcting his speech and this may have led to frustration. His brother and his best friend provided support socially but he mixed well with other boys at school and at the BB.

This case study raises a number of interesting issues, for example: hearing issues, the link between different aspects of literacy, the issue of separating cleft from dyslexia and consequences of labelling, sleep issues and cleft, the importance of well-informed teachers, the relationships with siblings and friends, the attitude of the parent, parental and school interaction, fine motor movement and cleft, the role of motivation in learning.

The following chapter documents the case studies of the two young people at the senior stages of secondary schooling or attendance at college.

C H A P T E R   S E V E N

The Results of the Six Case Studies
The senior stage

7.1   **T U L I S A**

Pen portrait of Tulisa

Tulisa was sixteen years old and lived with her parents and three brothers – two older and one younger than herself - in a town situated around twenty-two miles to the east of the city. The area was classed SIMD Two. At the time of the case studies she was attending a large local college. She believed she was making progress but throughout her school career - since the age of ten years - she had received a variety of additional support measures to help her.

Tulisa had been born with CPO. The outcome of this medical condition was the existence of a hole in her palate which was not noticeable. Her mother reflected that her daughter had three operations on the palate to close the hole. The last operation was at around five years old.

Tulisa's case study consisted of interviews with her mother and college tutor.

Introduction

The surgeon and the speech therapist told Tulisa's mother after Tulisa's operations that there was no reason for Tulisa not to learn. Tulisa's mother reflected, "They had said that she could still lead a normal life and if anything she might be a bit slower…. I don't feel that there was any complications with the cleft palate except for the speech and obviously the hearing, ear, chest and throat infections." Did these issues have an effect on Tulisa's progress in learning?

Literacy Issues

Listening

Tulisa: *I ask to go down to the front of the class [to hear].*

Tulisa's mother said that in the past the cleft team discussed putting in grommets but Tulisa's hearing always improved by the time of her appointments so the cleft team concluded that there would be no point. Her mother said, "Because she still gets ear infections she tends to mumble. Because she says she's got amplified hearing she feels as if she's shouting." This suggested that Tulisa might be finding it difficult to gauge the correct volume of her speech. In contrast, Tulisa's mother reflected, "I think the only times she had problems was when she wasn't interested. She just shut off." The college tutor said that she was not aware of hearing issues but that Tulisa was easily distracted, particularly by her phone. When attending the college, Tulisa did not have to move seat in the teaching area and was able to work in the college internet café hearing instructions given to her in a bustling environment. There was clearly an inconsistency between Tulisa's view and that of the college tutor.

Talking

Tulisa: *I had problems with speech … I stopped speech therapy when I was twelve… I had trouble with sounds such as 't'… and 'sh' and others. After my operation [secondary surgery for cleft of the palate] I had to learn the sounds again.*

Tulisa's mother said, "Because of the cleft palate she couldn't speak so they put her in a local nursery so she could get speech and language therapy every day as part of her treatment." However, she was making good progress so Tulisa was transferred to a mainstream nursery. At transition from nursery to primary school Tulisa was waiting for corrective surgery on her palate. At this stage her speech was at times difficult to understand both for adults and her class peers. Her mother gave the example of the word 'daddy' which she pronounced 'atty' and this led to her peers regarding her as babyish. When Tulisa went to enrol in primary school she was told by the Primary One teacher that her speech was not up to an acceptable standard. Tulisa's mother disagreed and with the

support of Tulisa's doctor, she fought for her daughter to be given a place at the school. This led to a difficult relationship developing between the mother and the Primary One teacher. This was aggravated by the teacher making these comments in front of a young boy who repeated them to Tulisa, causing her distress. Tulisa's mother reported the matter to the Head teacher and the Head reprimanded the class teacher.

The speech therapist said that if a child was not able to say a range of sounds, it would be difficult for teachers to work out whether he/she recognised this word or was unable to produce it correctly or had no concept of what the word meant. It might be impossible for the child to say the sound at that stage but the cleft should not be a reason for excusing them from doing tasks.

Tulisa's first two years of primary schooling were very difficult for her and her family. Tulisa cried each day, desperate to avoid attending school. Her mother attributed this to the poor relationship with the teacher and alleged that the teacher had given Tulisa up entirely. When the teacher asked Tulisa what she wanted to achieve Tulisa replied "All I want to do is get 'Star of the Week'", a little sticker given as a reward for progress. Tulisa's mother said the teacher answered, "Let's face it, you'll never achieve that." Her mother told the Head teacher she would withdraw Tulisa from the school if she was placed in the same teacher's class for the following year. Tulisa's mother had enrolled her daughter in this school because it had an excellent reputation and because her older brothers were also being educated there. In fact, Tulisa's mother explained that one of her older sons had been taught by the same teacher, "I used to think she was a great teacher … but what it is she is a brilliant teacher as long as you don't need learning support. She's no time for … she just prefers working with the ones it comes natural." However, another teacher was assigned to Tulisa's class in Primary Three. This teacher researched cleft and disseminated information about the condition to other staff members and even to Tulisa's mother. Her daughter began to make progress in learning. Tulisa had been shy to speak out in class. Her mother reasoned that this could have been because of her speech issue, or her shy personality or the fact that Tulisa had a fear of being wrong. By the time she was eight or nine years Tulisa felt confident enough to give a presentation on cleft to her class, winning the coveted 'Star of the Week' award. The surgeon said, "Some of the children we've encouraged them to do little talks about it, about their experience."

After her corrective surgery, Tulisa found she had to have intensive speech therapy as, "All her sounds were different. She had to relearn all her sounds - a whole new way of talking". (Tulisa's mother)   The speech therapist interviewed during this study stated it was unlikely that Tulisa's operation had resulted in her speech deteriorating and Tulisa having to relearn all the sounds again, but rather that at this time her main focus was on speech therapy. Her mother said receiving speech therapy on an individual basis and a group basis helped Tulisa, raising her confidence because she realised others had the same issue.

A number of her peers engaged in teasing or bullying Tulisa about her speech throughout her early years. Her mother said, "Children would call her names and say she should be back in nursery school." But after Tulisa gave a presentation on cleft, the children realised Tulisa had a medical condition and their attitude changed and they began trying to help her with her pronunciation.

During this early period Tulisa struggled with her literacy. Tulisa's mother reflected, "The teachers kept picking on her because they kept saying that she couldn't say her vowels and her sounds and that so that was holding her back… I don't know if the teacher just had it in for her you know because she was special needs." When her mother requested help for Tulisa she was told by the class teacher Tulisa "doesn't look special needs." CPO is an invisible medical condition. When Tulisa was ten years old, after testing for dyslexia, she was identified as having dyslexia and a package of support was introduced to support her literacy.

By the time Tulisa reached her Fifth year at secondary school and was sitting final examinations, she worked with a reader to allow her to gain credit for her knowledge and skills. She preferred to write her answers and if they would have been incomprehensible to the examiner they were rewritten by a scribe.

Because of her medical treatment, Tulisa said her sounds were better. Her mother reflected, "She can say whatever she wants now, she never shuts up…." Tulisa did not disclose the fact she had had a cleft palate to the college tutor. The tutor noticed her speech was slightly unusual but attributed this to the orthodontic work that Tulisa was undergoing. The tutor said she was accustomed to students having minor issues with speech because of tongue piercings and students wearing braces. Although Tulisa tended to mumble, putting

her head down at times, the tutor attributed this to a lack of confidence which she said was common at this age. "She never at any one time drew back due to her speech in any way - her speech was fine." The tutor noticed that when Tulisa was interested in a subject, she would speak "for Scotland if it was about snakes… if she is passionate about something." Everyone in class understood what she was saying and she engaged well in group work. When asked if Tulisa ever adopted a leadership role, the tutor reflected, "She did do on occasion. I think it all depends on the activity that's given." The tutor offered an example, when the groups were given the task of deciding five skills and strengths that a person should have to undertake a certain occupation. Tulisa organised her group so each had a part to play – a note taker, someone to decide on skills, someone to deal with strengths.

Tulisa's mother reflected that young people today use less speech as they communicate more using text and Blackberry messenger service (BBM). She continued that this was a language of their own that they made up and Tulisa did not find she was at a disadvantage using such text when contacting friends.

Reading

Tulisa: *My sounds are better, there's a big difference. I never read out before. I get overlays for reading.*

Tulisa found difficulty in reading. She was affected by dyslexia but the problem could also have been linked to early pronunciation issues with cleft sounds.   Her mother said that she had lots of books at home, "She'll start reading, she'll be interested but she'll not carry it on. But I've got the 'Kindle' and that's got the voice on it. She'll listen to it rather than actually read the words. She doesn't understand the big words so she'll struggle with the big words… It's the meaning of the word. She doesn't get the meaning so she'll take it as what she thinks it is and then she's convinced that is it…She'll look it up on her phone or she'll Google somebody first or BBM and she would take their meaning as gospel. We've had a few arguments about that." The college tutor reflected, "She would do it because she saw it as a means to an end." The tutor continued, "I don't know if it was a confidence thing. She always looked for reassurance." In examinations at school Tulisa was allocated a reader/scribe and this would help her understanding of the questions as the words read out would be pronounced correctly.

Writing

Tulisa: *I write the exam and the reader checks it.*

Tulisa's mother said, "She's a lovely writer", and the college tutor agreed. However, Tulisa's spelling was "terrible. I think… I think when she was younger because of the way she spoke… She would write things that way… like 'with', she used to pronounce 'wif' so she used to spell it 'w i f'. When she got the corrective surgery to stop the whistling… she'd to renew her learning technique. I think it complicated it for her." Nevertheless Tulisa's mother said, "She actually learned how to spell better on her phone because they've got spellchecker."

Tulisa's mother reflected the role of cleft in spelling issues was complex and the spelling issue could be linked to her daughter's dyslexia. She believed the dyslexia might have been inherited as she was sure Tulisa's father was dyslexic and her younger brother had also been identified as being dyslexic.

The college tutor reflected, "She always used to look for reassurance as to how to spell this. I was quite surprised often or not … she correctly spelt the words. You could see her confidence growing and I would say "Why are you asking me, you're doing absolutely fine." So whether it was a learned behaviour..?" The tutor said that Tulisa nearly always had the words correct.

Tulisa started with speech issues which affected her progress in school but with support from the medical team, empathetic teachers and peers, and her mother, her progress had improved and she moved towards coping independently.

Numeracy Issues

Tulisa: *I don't like mathematics. I have dyslexia and short-term memory problems.*

Tulisa's mother agreed that her daughter had issues with mathematics. This was reflected in Tulisa's final examination result for Access Three mathematics. Tulisa's mother said that Tulisa used a different method from herself, "I don't know if somebody's showed

her… The answer's there but to work it out to me it's a lot longer. She gets it right. The mathematics tutor was saying she's never seen it done like that but it obviously works for her." She received simple ways to deal with mathematics at primary school from an additional support teacher. Her mother said that Tulisa needed to have instructions broken down and be taught one thing at a time. This perhaps was why it took longer? At no time did her mother link her daughter's poor performance in mathematics to her absences, as Tulisa had done.   She did suggest it could be associated with the reading issues, "I think what it is, is she reads the question and maybe doesn't understand the words so she puts in what she thinks it is. She changes the sentence completely. I think the teachers thought that as well." The college tutor said her employability course did not place a heavy emphasis on numeracy, *"Unless you want to use it as part of an occupation you're fine. You're covering it very lightly but it kind of is group led."*

Metacognition

Researcher: *Do you reflect on the work you have learned afterwards?*
Tulisa: *… I do for tests*

Tulisa's parent thought Tulisa did not engage in reflection on learning but just went ahead and carried out the activity. Her college tutor said reflection was built into the course.

Additional support for literacy and numeracy

At the primary school stage, Tulisa's mother said she was told Tulisa was entitled to a one-to-one support assistant but due to lack of resources Tulisa was removed from class with another three pupils and educated in this small group. After she was identified as having dyslexia at age ten a package of support measures was introduced. At secondary school Tulisa received the help of a 'buddy' to whom she could talk and ask to explain her work in terms she might find easier to understand. She also attended a summer school for pupils about to enter secondary school to meet other pupils with additional support needs. By the time she reached her final examinations she was working with the aid of a reader/scribe to record her responses. When Tulisa started at the college she did not request support. As her course proceeded Tulisa was offered and accepted additional support for literacy and

numeracy at the college. However, the college course 'Getting Ready for Work' was principally based on oral discussion and little numeracy was required.

Tulisa's mother said that there could have been a psychosocial effect from her daughter being removed from the class because she linked this to Tulisa's panic attacks.

Preference for the practical subjects and outdoor learning

Tulisa: *I like art and design. I really like drawing.*

Tulisa seemed to prefer the practical subjects to learning language and numeracy. She did not attend classes for any modern foreign language. Perceived inadequacy in her writing abilities at the school led to Tulisa not being selected to study PE to certificate level. There was a limit on the number of pupils who were accepted into this class as it was oversubscribed. Her mother stated that her daughter liked science and "really excelled at Art and Design and they wanted to encourage her to go and do well. She done an XL course through the Prince's Trust and the animation and she won an award for it. But she found it boring. She says it takes too long. She wouldn't do it plus she always wanted to be a mechanic." Her mother appeared concerned, "She is one hundred percent concentrating on being a mechanic… She can't see outside the circle."

The college tutor agreed about Tulisa's aptitude for practical activities, "We kind of struggled to get her into a garage but we knew that was going to be her thing. It was very practical which was ideal. She liked being outside, she liked problem-solving where especially with a car if something wasn't working." This was reflected in Tulisa's desire for problem-solving tests. She received excellent feedback from her work experience placement in the garage and this led to an increase in her confidence and a desire to continue with this type of work.

Tulisa's mother reflected that there were no issues she could imagine which would prevent Tulisa engaging in outside learning and her college tutor was of the same opinion.

Social activities

Tulisa: *I hang about the school with my friends. I've started after school club [supported study] …. Nothing, I don't go to any clubs outside school, not just now.*

Although Tulisa was not involved in any clubs or organisations both Tulisa's mother and the college tutor said that Tulisa had lots of friends. Her mother pointed out that she had various groups of friends, one group from early school days. "The girls she went about with, they looked out for her, mummied her sort of thing, whereas now Tulisa would be the one to stick up for them." She also had friends that she had met at the local dancing hall and those she had met at the college. However, her mother had noticed, "She is quite popular but some of her friends have stopped coming because she won't go out." Her mother suggested this might be because of the recent death of Tulisa's grandparents or anxiety since Tulisa was prone to panic attacks. Her mother said that she did not think this regression in her daughter's social development was cleft related although she reflected it could have developed from a lack of confidence. To illustrate this point, Tulisa was aware of activities run by CLAPA but her mother said she never had the confidence to attend. Her mother said, "She is very shy but at the same time she's not… I think on familiar ground she's fine, but I think going with strangers and that … I think she can talk perfectly alright now, sometimes she just talks through her nose, but I don't know whether it's she feels herself as different or not." Tulisa's mother reflected this lack of confidence might have been due to all her hospital treatment and/or the fact she was removed from classes for additional support.

At college the tutor painted a positive picture. "She got on very well actually with everybody I would say. There was one or two who I think, one girl she was at school with and she was kind of friends on Facebook. She was part of the group, absolutely." She said that some of the students had visited Tulisa at home to see her collection of snakes and other reptiles housed in her bedroom. The tutor felt Tulisa was "keen to be seen as same, same."

Behaviour

Tulisa: *I've been suspended twice [at school]. Once for fighting and once for getting drunk*

The college tutor found Tulisa's behaviour to be "very good, very positive actually… she's a well-mannered girl." In contrast, her mother spoke of Tulisa seeking help to overcome anger issues. She said, "I don't know if it's down to my Mum and Dad dying, but she's always had like anger issues."

The parental role

Tulisa: *My mum helps me if I have problems with my homework.*

Tulisa's mother reflected, "I had to work with Tulisa more with her homework. It took longer, whereas the boys, they were quite good… They picked it up, they could read and things a lot easier."

In addition to helping with homework, Tulisa's mother found she had more contact with the school. She "fought for her to get a record of needs". She said at the beginning "I felt as if I was never away from the school…. She would never do work because she didn't know how to write down," and when the children "moved to the next class that teacher didn't know anything about the kids till either they run into a problem or parents' meeting." She said, "I think it was ignorance a lot". She continued, "If the child's been classed as a troublemaker, and they're going into the next class, it should be positive and take them at face value but if there is medical notes there then they should be given." Tulisa's mother may have tried to anticipate difficulties and taken action to avoid them occurring, "I found when Tulisa was younger and with her speech therapy, I would find me explaining to people about her speech rather than having Tulisa explaining it or people saying, "No, she can't talk right"… I found that I would say to them in a new situation… So I found that stopped her getting bullied quite a bit." When asked if she had been protective of her sons she said, "The boys, never really." This was because they didn't have the speech issue.

By the time Tulisa had reached college the tutor reflected, "After sixteen years they come to college we treat them as adults. So we wouldn't have open dialogue with her parents anyway out with giving their consent."

Parents and Inter-agency relationships

Tulisa's mother reflected on her experiences after her baby was born, "I think for a parent that's never had any dealings with anybody with cleft palate it's quite daunting for them because they don't know anything… I got handed these leaflets… Your mind runs riot, you think of this bit missing… I thought they would take a skin graft and patch it over the palate… I never realised there was all the nose, throat, oh, ear infections, chest infections, then all the dental work and obviously because she has had the surgery in her mouth they are actually moving her gums so her teeth are coming in."

Tulisa's mother highlighted differences between their experiences at the school and the hospital. "The surgery was great … all the orthodontic although it's long and drawn out it's the best care she's getting … Without the speech therapy she wouldn't be where she is today… If she hadn't had the hole repaired then I think things would have been a lot different because her speech was quite poor." But it wasn't just the treatment that Tulisa's mother praised, "You're getting specialists in hospitals and the teachers are listening to them because a higher authority sort of whereas we're just a parent. You know it doesn't matter that we know the kids better than the doctors… When you're in the hospital you're getting treated as an individual because you're going to someone that specialises in that sort of thing and they know the complications whereas you're going to a teacher, they've not got the time to give you one-to-one." The surgeon said he had on occasion written at the behest of a parent to the school to explain matters. He also reflected that the written information the hospital provided for parents was not couched in language that would be difficult to understand nor did leaflets contain technical jargon.

Tulisa's mother described a struggle particularly at the stage of primary school, "I think parents should make sure they fight for everything that she's entitled to… I had to fight for Tulisa…" Tulisa's mother thought that primary teachers "left it and thinking that she was slow – just a wee bit slow. I think by the time she was older that they realised there was a problem and I think they tried to cram too much in at the one time…" She recognised the value of the support, "I think if she had went to high school and started off the way she did at primary school I don't think she would have coped as well as she did. She gained a lot of confidence, just having that support there, because it was done discretely…" The changing requirement for support should also be recognised. "In first year she got learning

support in all the subjects and then it was just for her exams it went to… because as they're getting older, you know they're not going to be able to have scribes when they're doing anything so they try and get them to work individually…"(Tulisa's mother)

To ensure a smoother progression, increased information to relevant parties would be useful. Tulisa's mother explained how she thought this could be done, "I think it's helpful if the parent goes and maybe explains to the teacher and gets the teacher or like the adult to explain to the other kids… Once Tulisa took in photos and done her topic it helped them understand and it helped the teachers understand… I helped Tulisa with her project and I think if it had just been her on her own I don't think she would have done it… Having the back up of someone from CLAPA would be quite good… but they need to get in at primary school or even nursery school. I think if they just wait to do it at high school then I think the young person would be embarrassed." The college tutor had heard of CLAPA and Changing Faces but thought it would have been useful to consult them if Tulisa had disclosed the cleft. If a tutor was concerned about a young person with cleft they might search out information or ask someone to come in and give a talk. The tutor thought this would be beneficial for everybody.

Absence

Tulisa: *I missed school when I was at primary quite a lot… I get ear infections. I get chest and throat infections. It's because of my cleft. I was off a day when they tightened up my braces.*

Tulisa had an operation on her palate about six weeks after starting primary school. Her parent reflected, "At the beginning with the surgery the school wouldn't accept her back for six weeks because she wasn't allowed to eat solids. I felt she was missing out on mixing with her pals. The biggest problem was that when she went back… She kept saying she was the new girl." This was like starting again, relearning socially. The surgeon interviewed for this study said "We don't assess how they recover other than the physicality of it. Physically they recover quickly from the procedures but what we don't know is the longer term effects." Tulisa's mother said that because of her absences for her operation and infections, "One of the teachers had written her off completely." Her parent

collected homework to try to keep abreast of the pacing of learning within the classroom but sometimes Tulisa was in advance and sometimes behind the class.

Her mother highlighted the timing of the absences, "I think the primary school – they need to be able to be there. Just for their learning. I think if they miss too much it saps their confidence, it sets them back. I think it had an effect when she was younger. I think since she's got older obviously she can catch up and keep up with her work." However, Tulisa's mother recalled that the administrative staff at the hospital did try to arrange appointments during the holidays. Interestingly, the college tutor said, "she was just one of those ones (young people) who thought if she slept in she just didn't go to school." She had no idea Tulisa experienced sleep apnoea. Research is on-going at the moment as to possible links between sleep apnoea and cleft. Inadequate background information could create a false impression of the young person.

Tulisa's mother was aware of two factors which contributed to the absence issue. These were rescheduling of the treatment and the complexity of her daughter's treatment, "I think because she's had so much surgery and because it's ongoing but a lot of it's down to cancelled appointments. It could have been dealt with quicker but obviously it's going to take time up because it was quite complex. She's had three operations." Yet, generally the hospital notify patients of cancelled appointments before they arrive with no loss of time to the patient.

In contrast the college tutor reflected, "Tulisa's attendance was wonderful. Any absences we were given plenty prior notice … of the orthodontist. That was the main one. We gave her the full day because of the time and where her orthodontist was." However, during her college attendance Tulisa's time off consisted of regular one day appointments spread over the months and not large blocks of absence for operations. The nature of the college course was based on individualised learning such as building CVs on the computer and working individually with a college tutor.

Pain

Tulisa: *It's painful when they tighten them up [braces]. Last week I didn't go to school. I was off a day.*

Pain can affect the concentration of pupils/students when they are learning and may, if severe, cause absence. Tulisa said she experienced pain when her braces were tightened by the orthodontist. This led to her absence. Her mother disagreed with this saying that her daughter was absent because she was unwell. When asked about Tulisa experiencing pain her mother said her daughter experienced pain regularly but she was unsure if this was due to cleft related reasons, or because of an accident Tulisa had when young, falling on top of a bowling ball, or when a large iron gate swung back, fracturing Tulisa's jaw.

Attainment

Academic and Social Progress

Tulisa: *I want to learn ... they said I wasn't as good as my big brother.*

Tulisa said she kept up with the pace of work in the class but the Primary One teacher compared her unfavourably to her older brother. Tulisa's mother argued with her. "I kept saying to her, "You never ever compare kids… I've got three kids (her youngest was not yet born) and I don't compare them because each one of them's different. You should know that being a teacher." Her mother said that her daughter was a little slower than her brothers when it came to learning, for example, to walk and speak. But she added that her older brothers spoke for Tulisa if she wanted anything reducing her incentive to speak. She had now caught up with them but she was still a little naïve, her mother reasoned this may have been because of her age. Some of her friends were also naïve.

For Tulisa to become secure in her learning her mother said she had to have something explained three or four times but "at other times, if she's interested, she'll learn it quick. If she's not, if she starts something and she finds she doesn't like it then that's it, it will not get mentioned again."

Her mother said, "I used to go to parents' meetings and that was one of the problems they always said to me that she's not finishing her work in time, she's struggling." However, her mother pointed out that at primary school Tulisa was in a composite class and was

trying to do the work of the older age group. At high school she had the support of a "buddy" of her own age that she could approach if she had difficulties with school work. The college tutor said, "I think Tulisa would ...probably sit mediocre ... very average in the class … sometimes a wee bit beyond some of the others. But if she was into an activity you got one hundred percent and if she wasn't she would do the bare minimum … that was very general with that age group."

Tulisa's mother believed her daughter had "done really well." She explained that although Tulisa was afforded three chances to answer questions correctly in her examinations she always passed first time (Access examinations). However, this was not the case for Access Three mathematics. Her ambitions for Tulisa were "to be happy, healthy and enjoy what she's doing". After Tulisa completed the college course her mother saw "she has got a lot more confidence about herself because she was quite shy and then they got her a placement in the garage and she came on." In retrospect Tulisa's mother was of the opinion, "They still have the same chance as somebody that's not got the cleft but I think to fit into society they need... the help at the beginning."

Tulisa completed her 'Getting Ready for Work' course at the college. Her tutor said Tulisa went on to a full time college programme. She felt the young person had made progress and her confidence had greatly increased. The tutor said, "I see a different girl". For the future she reflected, "I would absolutely see her going as far as she was able and wanted to go. The cleft wouldn't hold her back in any way, manner or form."

Memory and language issues in testing

Tulisa: *I prefer small tests. I don't get stressed and I have memory problems.*

Tulisa's mother supported formative assessment because, "the teacher can see where Tulisa is struggling and put in extra work." The college tutor said that "they don't get assessments. In 'Getting Ready for Work', they would do an SQA Employability unit so Tulisa would have to construct a CV. She would do that with myself and another lecturer. They would get an example of a CV and have to… put in their own information, their personal profile… other bits, they have to understand their own responsibilities as an employee, and the responsibilities of the employer to them in terms of health and safety

conditions." The tutor used a variety of methods of assessing learning as the students accessed the course material – role play, question and answers and through observation. The key was to tailor the assessment procedures to the different groups of students and at no time did Tulisa receive additional support in class. Students received their awards if they completed the course activities.

Reflections

Although Tulisa's learning journey was characterised in the early stages by problems she was now described by the college tutor as a confident individual who was developing a more independent approach to life. Her progress improved as she proceeded due to medical and educational support and the benefits of new technology. The operation in Primary One helped her speech although her mother felt educationally it had temporarily affected her progress as Tulisa had to relearn her sounds. There was an implication that speech issues cascaded into issues with reading and spelling. Commenting on later secondary surgeries, the surgeon said the child had to have a vocabulary at a level such that the speech therapist could assess whether to recommend the child for surgery at that stage. The surgeon said this was one possible reason for some children having to wait for surgery.

A package of additional support measures were introduced for Tulisa but not until she was ten years old - when she was identified as having dyslexia. Tulisa also experienced sleep apnoea which the college tutor was unaware of.

By presenting information to peers and teachers alike she was able to overcome the bullying she had experienced. However, the attitude of some teachers towards parents was not conducive to working in collaborative partnerships. The surgeon had to act as an intermediary between parent and school personnel. Tulisa's mother indicated an inability on the part of some teachers to listen to parents.

As she moved towards adulthood curricular choices allowed her to specialise, exploiting her practical abilities as opposed to emphasising literacy. The courses she chose and the levels she was presented for allowed her to work at a pace that suited her.

This case study raises a number of interesting issues, for example: a diverse curriculum, the difficulty of separating cleft from dyslexia and the dangers of labelling, the importance of respectful dialogue between parents and teachers, recognising parents as partners from the beginning, the importance of well-informed teachers, the benefits of making other children aware of the implications of having cleft, instigating appropriate support sooner rather than later, regularly reviewing the support needed, the issue and dangers of labelling children by their speech, increasing dialogue between teachers and medical professionals, offering information interactively so moving beyond leaflets … being prepared rather than being reactive.

7.2   L A U R E N

Pen portrait of Lauren

Lauren was eighteen years old and lived with her parents and older brother in a house in a suburb on the outskirts of the city (SIMD Four). She attended a local comprehensive school providing education for around a thousand pupils. Lauren felt she was making progress in her learning and her examination results supported this view.

Lauren had been born with CLP. This medical condition required Lauren to have an operation to close the cleft in her lip, to undergo surgery on her palate, to have an alveolar bone graft and to have jaw surgery (for which she opted) at age seventeen years.

Lauren's case study participants included her mother, her Standard Grade English teacher, Higher mathematics and Higher art teachers, and the director of the theatre group which she attended outside of school. Her Higher English teacher was unavailable for comment being absent from school at the time of the interviews.

Introduction

Lauren said she just liked to get on with her life and her operations were "just part of the routine." Her mother confirmed this, "She just likes to get on with it, and be part of the crowd." Lauren had achieved success in her final examinations. What role, if any, did the cleft play in her learning?

Literacy Issues

Listening

Lauren: *No, I've never had a problem hearing.*

Lauren's mother, teachers and the theatre director all agreed with Lauren, that she did not have an issue with hearing and she was an attentive listener. Lauren's mathematics teacher reflected, "She appeared to pick up instructions and teaching like the rest of the pupils."

Her mother linked her daughter's listening to her attention and said, "I would say it was down to what she was interested in."

Talking

Lauren: *It was mainly acting that I enjoyed but then I saw this one and it was acting, singing and dancing which sounded better so I've been going for that for quite a few years.*

Lauren's speech was described by her mother as "fine", a view subscribed to by her English and mathematics teachers. The English teacher said that if Lauren's speech had been affected this could have been a concern because it could have impacted on the assessed elements of the English course, for example, when giving oral performances such as solo talks and engaging in group discussions. She might be reluctant to read parts out in drama. In Lauren's case her speech was never an issue. The English teacher reflected, "One of the actual grades for English was for talk. I'm pretty sure she got a Credit One or Two." Lauren's mathematics teacher said, "I don't remember anything that caused a problem. If that was the case I would ask her to repeat it as I would any other pupil… If she was uncomfortable with her speech it was not noticeable." Lauren's art teacher did point out "Sometimes I would struggle, but she's a pretty well-spoken girl. Sometimes I would hear a wee slur to her words but in the main she was very clear… I would just ask her to repeat it." The teacher said this did not affect Lauren in class.

The theatre director said that there could have been an issue in singing and acting, more than in dance, although in the latter facial expression is important and requires the correct movement of facial muscles. However, in script work and reading aloud accents have to be correct and in singing there is a timing issue. With this student she was able to attempt singing solo in class although she sometimes needed more time in drama to develop her accents, to practise pronunciation and to deliver lines. Otherwise she approached her experiences in the same way as the rest of the students.

Lauren's mother highlighted group work as one of her daughter's strengths, and this had been documented in her report card. The English teacher contended that "you do get some people who sit very quietly and don't contribute especially if there are others in the group that are competent… the pupil concerned didn't lack confidence." Lauren, she said, was

equally happy working individually and in a group. In the mathematics class the tables were arranged in groups to allow pupils to confer on mathematical problems. Lauren played an active role in her group, and the teacher noticed that her confidence to participate increased as she got to know the other pupils at her table. In the art class the teacher encouraged sharing of ideas using peer assessment of work. She said, "Lauren took part in the group crits in Sixth year and at Higher level. She worked quite closely with one of her best buddies who was also in the class and there would be a constant dialogue. She gave and received support in group work. She wasn't like the poor case."

The theatre director reflected that students perform in composite age groups and these are re-organised for runs through of the performances a couple of weeks before the production. Lauren had no difficulty adjusting to this. The director said that students learn to negotiate acting movements and the portrayal of emotions. Lauren's confidence grew: at the start she would not volunteer for anything but as she progressed she was eager to participate and always took part in group work.

The English teacher could not remember if Lauren had ever taken a leadership role in class but said she probably did do because she was always confident. The mathematics teacher said she did not adopt a leadership role. The mathematics teacher explained although pupils were encouraged to discuss problems, mathematics is a difficult, intense course where the teacher used the smart board, textbooks and jotters, no pupil presentations. The art teacher said Lauren worked as a Community Involvement helper and as such played a leadership role, setting an example within the school. Lauren's theatre director said Lauren did adopt a leadership role within the group because at times she acted as director of the group, dictating how things should be done.

Reading

Lauren: *I'm not that fond of reading very much so I think if I read more it would improve my spelling.*

Lauren said she did not particularly enjoy languages generally, and reading was not one of her favourite activities. However, her reading standard was satisfactory for she was able to take parts in drama and read out loud in class, and her comprehension must have been at

a reasonable level because she attained Higher English. At the theatre group she had played roles in 'Chicago', 'The Wizard of Oz' and 'Oliver'. It seemed she simply preferred other pursuits to reading. Some of these alternative pastimes were of a practical nature, for example, baking. All parties interviewed agreed that her reading was of a satisfactory standard. Lauren found mathematics difficult but when questioned the mathematics teacher said, "There were no particular problems in problem-solving or in the reading of questions, not any more than for some other pupils."

Writing

Lauren: *My spelling is quite bad.*

Opinions on Lauren's spelling varied. Lauren's mother said, "I wouldn't say excellent at it, she's no problems with spelling." The mathematics teacher agreed. The art teacher stated, "Her spelling didn't flag itself up from being any different from any of the others." And the theatre director said, "Very little writing was involved as the activities are performance based and it is not like school." However, the English teacher said Lauren had some issues with spelling. "Her spelling was something in her written work that would pull her mark down. It would have affected her grade. The content would have been Credit level and her technical accuracy such as spelling and punctuation would sometimes bring it down to a General."

Lauren's mother and the mathematics teacher agreed that Lauren's writing was fine. However, her English teacher reflected, "I remember her handwriting as being quite poor. So that would suggest she had some fine motor movement issues." The art teacher also commented on Lauren's handwriting but went further, "I wouldn't particularly say it was the neatest writing but it wasn't an issue. I think that's where we go back to the point of refining the skills and the making skills. The motor skills weren't there… the determination and the positivity was all there but those fine skills just weren't there." At the more advanced levels of art work the art teacher said, "She struggled getting a degree of refinement into her work. To get a kind of skill and an elegance into the work, the quality of the work, was at times a bit of a struggle. The written work was no bother." The art teacher said there was a level beyond which no amount of tutoring could help

Lauren advance further. Having said this, it should be remembered Lauren achieved a Higher art, grade A, and an Advanced Higher, grade C.

Numeracy Issues

Lauren: *Probably maths … maths,, computing are the worst ones.*

Both Lauren and her mother named mathematics as an area of curricular difficulty for Lauren. Although she had achieved her Higher award she had struggled hard to do so and had extra support from home. Her mother explained, "I don't think there was really a particular side, there was just a lack of interest… we brought someone in that we knew that tutored her and we still maintain the reason she passed it was because she liked the personality of the teacher." Her mother said Lauren just did not like the subject in its entirety.

The mathematics teacher said the grade that Lauren achieved (C) was better than the standard of her class work. She continued, "If there were difficulties because many pupils find mathematics difficult then it was the same for her. For example, she failed her Differentiation section of Calculus but this was a difficult area for all."

Interestingly, Lauren's mother reflected on Lauren's difficulties with mathematics as follows, "We have never really related it to her cleft but rather from how we were. Her Dad has done really well for himself but never got his Higher English and mathematics is not my strongpoint. Her brother's English isn't great but he was great at mathematics…" Lauren's mother continued, "She just had to persevere and hard work because that is something she is very aware of. The subjects she struggled with there was no other way apart from trying. There wasn't any difference between her learning and her brother learning."

The English and art teachers and the theatre director declined to comment as numeracy was not of major importance in their areas.

Metacognition

Researcher: *Do you reflect on the work you have learned afterwards?*

Lauren: *Yeah, uhu .... Probably when I'm home and doing homework and stuff.*

Lauren's mother said "I think she goes through the process but she doesn't query the process". Her English and mathematics teachers said it was built into the course but the English teacher continued that even if reflection had not been built into the course, "She was a reflective and mature pupil so she maybe would have thought about it." The maths teacher said, "In maths you have to use strategies anyway and problems are repeated." The art teacher said there was a point beyond which Lauren couldn't see how to make things better but the teacher was doubtful if this was cleft related. The teacher continued, "She just liked to get there."

Preference for the practical subjects and outdoor learning

Lauren: *I like doing practical things rather than written*

Lauren and her mother agreed, "From day one art has been the subject she enjoyed. ICT she was quite good at but she did not really enjoy it. English was one she struggled with. Her weakness is definitely her English… and mathematics again was the same and sciences she just wasn't interested in at all." Her mother said that, apart from art, "she likes cooking, she likes making things, she has a wee job baking." On leaving school Lauren was offered a choice of course, either designing and making jewellery at college or a course at the local Art school based on marketing and art. She chose the former which her mother reflected perhaps did show Lauren's preference for the practical side of art.

Lauren's art teacher agreed with her mother's view, "My experience is in expressive arts and I felt that Lauren flourished in that area… She wasn't the best in the class by any stretch when she started but she was persistent and she would ask questions and try again. She liked making things and working with materials. I'm not actually surprised she has decided to go with the jewellery course."

The mathematics teacher said Lauren would not be advised to study mathematics beyond Higher and the English teacher said if Lauren went to university her successful completion of a course would depend on her choice of subject and she would have to work very hard. At the theatre group the curriculum was that of the performing arts – dance, drama and singing – and this too was based predominantly on practical activity.

The teachers agreed there was not a lot of outdoor learning but when Lauren did venture out, for example, to visit professional jewellers with the jewellery club she had no issues. Her mother agreed with this view.

Social activities

Lauren: *I've known some of my friends since I was very young but not all of them.*

Lauren's mother said her daughter had various groups of friends, "She has got a group of four friends she has known since primary and they have stayed together… She has friends from the drama and through her art". Lauren had just started college and she had gone out for coffee with friends from college. Her mother said that since Lauren had become older, when she had wanted something she had had the confidence to go out and do it on her own, for example joining the drama club. She reflected, "In the wee group of five friends she's the one that sorts out when they are going out and what they are doing." This matched her description of her daughter taking the lead at home, "organising her brother."

The art teacher said that Lauren was a Community Involvement helper in the art department, engaged in voluntary work, a couple of periods a week, doing general work. She added, "I would keep a sensible job for her, something trustworthy for Lauren." She was part of a jewellery club that lasted a couple of years when she was in First and Second year and they would often go on trips to see professional jewellers at work - that was the start of her cementing friendships with her peers. The art teacher thought the friends probably came with Lauren from primary school.

Lauren joined the theatre group on her own but soon made friends. At the beginning, like all other new students, she was given a 'buddy' to help her settle in. She socialized in outside activities with these girls that she befriended at the theatre group.

Teasing or Bullying

Lauren: *Bullying? I've not experienced anything but it could be a problem for others.*

Lauren's mother gave an account of the one incident that she was aware of when her daughter had been asked by a young primary pupil, "Why do you look different?" but her answer to the boy was "because I had a cleft lip and palate". Her mother said, "She is very practical with it and she has always been aware some people will have a look because she looks a bit different which is why I think this surgery that has just happened has made her more confident. I would maybe have taken it further if she had been upset about it." Lauren's mathematics teacher said, "I noticed something was wrong with her mouth. Her appearance was different and this could be a problem socially… I wouldn't have considered it as stopping or preventing her from achieving or performing in mathematics… There were no incidents of teasing or bullying." The English and art teachers said they had not been aware of any concerns in this area. The art teacher said, "I never had an incident with Lauren but I would imagine if there was something that it would be dealt with… She had a good group of buddies". Lauren's art teacher also spoke of the pleasant and protective environment that existed in the school. This would have helped as would her close group of friends. The theatre school was a 'No Bullying Zone' according to the theatre director and there had been no reports of incidents concerned with Lauren.

Behaviour

Researcher: *Have you ever been in trouble for your behaviour?*   Lauren: *No.*

Lauren's mother described her daughter as, "A typical teenager. She will help if asked and move round about it if not asked… Very messy room …. I would say her brother is the same and he didn't have a cleft and his bedroom is untidy until you tell him otherwise. Very happy personality… we've been lucky so far. I get on very well with her … we've never had the strops".

Lauren's English teacher praised her behaviour, "She was a lovely, responsible, polite, well-mannered, conscientious girl – very keen, friendly. She gave me no problems at all." The mathematics teacher thought similarly and added that Lauren was in no way

withdrawn. Her art teacher reflected on the effects of her medical condition on her personality, "I think she is an old head on young shoulders. I think what she has been through has affected her approach. I think her time management and her attitude is good. She is mature and positive. She wasn't a complainer about anything. She wasn't good at seeing what was next for herself but she would ask. She was motivated." The theatre director reflected, "The student was shy at first, but this was no different from others joining… She was well behaved, hard-working, learned all her lines, responded quickly to directions and was very committed."

The parental role

Researcher: *Does your parent help you with your homework?* Lauren: *Yes.*

Lauren's mother reflected on the role of the parent, "It's important, cleft or no cleft, just to see what level they are at and seeing if they are achieving it or if they need help. If she had issues you would need to address it differently but again it's helping at the end of the day…. We probably offered the same support to her brother – if her brother wanted the help he has been quite open if that wasn't a good result, we would help him."
There was good communication between Lauren and her mother. The latter explained how she supported her daughter's recovery after jaw surgery, "she would guide us as to how to do it… She would guide us but we were always there and we would talk about it… If I was teaching her something at home we would probably chat about it." At home, these examples show a co-constructivist approach was being employed to deal with issues.

Parents and inter-agency relationships

Lauren's parent said the family had a link with the school, "It was a school that we were all involved in so socially there was always something on and we always went to it and we were aware of the teachers and the staff and there was a sort of contact." Interestingly, this constructive approach may be linked to socio-economic class as similarities can be seen with Jessica's case study. Lauren's mother was confident that if issues had occurred she would have engaged with the school to deal with them and the educational professionals would have responded positively to resolve the issues.   Lauren's parent had worked voluntarily for CLAPA and Lauren had attended a make-up day in Edinburgh run by

Changing Faces.   She thought various groups like CLAPA or Changing Faces should send representatives into schools on an ongoing basis to educate young people about cleft. This should be undertaken in rotation along with groups representing other issues the general public might encounter.   She did not think Lauren would have wanted to give a presentation because, "I think in her case giving a presentation on cleft would have highlighted it more."

The English teacher said it was always good to raise pupil awareness of a variety of issues which pupils faced and presentations from a group like CLAPA would be useful. She felt it would be very effective if the pupil wished to make a presentation but a terrible idea if they felt embarrassed about it. She said it would be well received by other pupils. The art teacher agreed about the pupil presentation. She added it might be better in front of small groups.

Although the mathematics teacher was unsure about a pupil presentation she thought staff might do with more information from CLAPA. The art teacher said she didn't even know about CLAPA or Changing Faces or how to access information from them for example from their website. The art teacher was concerned when Lauren was engaged in photographing herself and her friend for a double portrait. The teacher said, "I underestimated her a bit as it didn't seem to faze her." She also struggled to know how to deal with Lauren's changed appearance after the jaw surgery, which the teacher described as "amazing".

The theatre director said that although the cleft was visible there were no issues arising from this if something had occurred she would have used Google to consult cleft related websites. If a presentation was made by any cleft organisation or by the pupil it might highlight the situation and cause the student embarrassment. She did acknowledge, "It may be beneficial for CLAPA or Changing Faces representatives to give a presentation to the tutors only.   The parent is always our first port of call."

Absence

Lauren: *A lot of the time was when I was quite young so it's not affected it too bad.*

Lauren's mother said her daughter had not missed many school days because of medical treatment related to her cleft. The hospital personnel had arranged Lauren's operations around holiday times and the Guidance staff had helped co-ordinate a scheme of work for Lauren so she would not fall behind in her work. The jaw surgery was an example of this. Her mother reflected, "I would say the biggest time she had was last year when she stopped in November and it was January before she went back and that was at Higher and Advanced Higher level." However, Lauren's mother said teachers from the school emailed her the work and she achieved her desired results.

The English teacher thought Lauren's attendance was quite good and was not an issue that affected her progress. The theatre director gave a similar response, adding, "If she was she would be told to go away and look at the song she missed and make up time with the support of the instructor."

Lauren's mathematics teacher and the art teachers identified absence as a problem. The former said that any absence could be a problem, even single appointments as in mathematics one concept is built on another, although a topic is revisited the next academic session, pupils are expected to know the basics before more work can be added on. It could therefore be difficult to grasp previous learning at a later stage when new material was being presented. The art teacher spoke particularly of Lauren's absence due to jaw surgery. "One of the biggies was having to take time off and come back physically changed and how you cope. We thought it was game over as far as the Advanced Higher was concerned but obviously we realised the Advanced Higher was way far down the list and she had to take the time off for surgery… We thought we would withdraw her from the Advanced Higher and she could sort of finish off some sort of body of work to take away but she proved us all wrong…" The art teacher explained that Lauren was doing a folio for the art school and an Advanced Higher at the same time as the surgery and the teacher had thought this was not possible. She highlighted that Lauren received lots of support from teachers at the school and at home but nevertheless she must have been really motivated, working hard during her convalescence. The surgeon said the timing of the jaw surgery would have been discussed with Lauren and she would have had many options open to her about the timing of the surgery.

Lauren, her mother and the three teachers agreed that the further the pupil progressed through secondary school the more absences became an issue. The mathematics teacher said, "You get a chance to revisit the work the next session but by Fifth year that is the final outcome so absence at this stage is more important." And the art teacher was concerned for the pupil's future prospects, "As pupils get older the tariffs are higher, the stakes are higher particularly if we have someone who is wanting to do a creative course in college. They are giving themselves less chance of moving on to college or university." This teacher suggested it would have been helpful for the cleft team to supply a rough estimate of the time required because without this knowledge, the art department had been about to remove Lauren's name from the list of candidates to be presented for the final examination.

Additional Support for Learning

No additional support procedures were introduced at any time in either English, mathematics or art. Her English teacher said, "Her learning experiences were just the same as the other pupils. I didn't remember at any point having to adjust any task to take account of the cleft. She just did all the same tasks, all the same assessments as all the other pupils in the class."

In contrast to the school, at the theatre group the materials were adapted for each student. This depended on speed of grasping the material and age. Learners with cleft might face challenges. The director said they might not perhaps be given a fast song to sing, and in musical theatre pronunciation is important especially in solos because the performer is telling a story. Musical theatre pronunciation has to be clearer and more precise than say a pop song. However, this did not affect Lauren who took part in 'The Wizard of Oz' and 'Chicago' including having lines to learn and deliver in these musicals.

Attainment

Academic and social progress

Lauren: *It is quite important because if I want to go on to university or anything like that and you need certain grades.*

Lauren's mother reflected "I would say she overtakes learning at the same pace as her brother." She was pleased with her daughter's academic achievements and contended that she worked hard and was lucky to achieve her grades in English and mathematics which were not her forte.

Lauren's English teacher reflected that Lauren's cleft did not really affect her classroom learning, or performance in English. She said, "As I was teaching her I wasn't really thinking of her as being a pupil with a cleft. She was a pupil the same as all the others. She progressed well over the two years, her written work did improve. She took on board what I said. She was someone who had to work quite hard but she did get there in the end. In her Higher exam I would imagine she got a scrape, a C…" However, the teacher said Lauren was studying in a top class and some of the pupils were confidently Credit whilst she had to work quite hard to achieve this standard. The pace was therefore slightly on the fast side for her but she was motivated and confident to ask questions. The teacher concluded by saying, "She probably was in that group for her ability as it was a top class but I never thought of that as related to her cleft."

Her mathematics teacher said Lauren had passed her Higher (C) with a struggle. She was a motivated learner and her hard work paid off. The teacher continued, "From the point of view of her intelligence she had reached her limit in this subject. She persevered with mathematics problems. She has taken mathematics to the limit of her capabilities and would not be advised to take mathematics say at university level." In terms of pacing, the mathematics teacher contended, "She was slower. She had to work at grasping the learning."

The art teacher's view was similar to that of the mathematics teacher. She said, "With Lauren we found that she would hit a point where she couldn't see how to make something better. I don't think that had anything to do with the cleft though. I think she had just hit a limit with the learning sometimes. She didn't reflect on how she got there, she just liked to get there. We didn't expect her to get an A in her Higher." The teacher pointed out that the difference in the grade awarded in Higher art (A) and that in Advanced Higher (C) could be explained by the "massive gap" in the standards required at each level. Another

possibility the art teacher did not mention was Lauren's level of absence while studying for the Advanced Higher. In art classes she worked at the same pace as the other pupils.

The theatre director also said Lauren had made progress in all aspects of performance and her confidence had grown. Her experience was similar to other students and she learned at the same pace as them. Grades were not given at the theatre school so the director justified her assessment thus: "My opinion is based on how she delivered her work, by observing her and by the way she interacted with others."

Lauren: *I want to be a primary teacher… I really like working with children and I think it would be fun to teach.*

When the examination results were published Lauren changed her mind about primary teaching. Lauren's mother said her daughter had chosen a college course in jewellery making which involved going straight into making the products. She felt this suited her as she seemed to enjoy practical activities.

Lauren's art teacher was glad Lauren had chosen the jewellery course if she felt unsure about the longer product design and marketing course. She added, "She's maybe thinking she enjoyed the jewellery so much she could do that for a year and then go and do a degree in jewellery… given the experience she has had so far doors should be opening for her." The theatre director said she thought Lauren would continue to do well and that her confidence will continue to develop.

Memory and language issues in testing

Lauren: *I find it easier like saying things out loud rather than writing it down.*

The reason Lauren gave for this was not related to writing issues but rather to the fact that she found it difficult at times to systematically work through questions when faced with a written test paper. Like many students when offered a choice of questions to answer she found difficulty choosing. Lauren did not need a scribe to provide legible answers. Given her excellent reports for group work and her performance skills it is perhaps natural she should choose oral responses.

Lauren: *Short tests it's like you don't have to memorise all the stuff you've been doing rather than all at once.*

Lauren preferred end of unit tests rather than one large examination at the end of the course. She said she did not have an issue remembering information but perhaps like many pupils found linking the test to material recently learned as more meaningful. None of the parties interviewed indicated she had memory issues. Lauren actually said she would prefer tests based on recall of information to problem-solving.

Reflections

Lauren was successful in achieving four Higher awards and an Advanced Higher. She was also an active and valued member of the theatre group. Lauren had a cleft lip repair which was barely noticeable and chose to have jaw surgery to improve the shape of her face. She was surrounded by a supportive family and peer group. She coped with sporadic blocks of absence for operations and regular appointments for orthodontic treatment with the support of her teachers who were aware of her longer term absences beforehand. However, Lauren did not have literacy issues other than spelling which made a difference only in English. She appeared to choose the practical subjects through preference. She enjoyed art and achieved highly in this subject area, although, according to her art teacher, there was a point beyond which she could not improve and this could have been linked to motor skills. Her positivity and motivation were driving factors in her success. According to her art teacher, her organisational skills and good time management along with a balanced approach to life may have developed from her hospital experiences. She had confidence to ask for help and clarification of learning issues. She was able to revise her career path to take account of her examination results, changing from primary teacher to making jewellery.

In this case socio-economic class may have played a part – her mother could afford to employ a tutor, her parents had little issue dealing with teachers in a constructive manner. However, this relationship was never challenged by having to confront difficult issues. All of those interviewed agreed that Lauren's cleft appeared to have little negative impact on her learning.

This case study raises a number of interesting issues, for example: the value of supportive family and peer group, the role played by hard work and motivation from the pupil's perspective, the effects of absence, the emphasis on forward planning by teachers to take account of absence, the role of confidence in learning, the possible relationship between fine motor movement and cleft, the value of communication between the young person, school and home in a constructive manner and the benefits of information sharing between school and hospital which was not happening at this stage in respect of absence.

The following chapter will offer a discussion of the findings of the study.

C H A P T E R   E I G H T

Discussion of Findings

8.1 Introduction

At the beginning of this study I identified five research questions to allow me to explore the impact of cleft lip and/or palate on the educational experiences of young people, both inside and outside of school. These questions were built using evidence emerging from two sources. The first source of evidence came from issues identified following a series of visits to the cleft clinic in Hospital A. This came from observation of activities at the clinic and discussions between medical personnel and the children during which the children were asked to share their school experiences with myself, and the cleft multidisciplinary team. In addition, parents were invited to contribute information to add depth and clarity to the child's responses. The second source of evidence occurred concurrently with my visits to the clinic and came from my initial reading of medical and educational texts. The five questions that were developed from these evidence sources were used to frame my study. They informed the literature review in chapter two of this thesis and the empirical work described in chapters four, five, six, and seven. Critically, in this chapter I draw together the evidence, identify where findings from this study are consistent with existing evidence from the literature and where new insights add to our understanding of the experiences of a group of young people who have experience of learning whilst dealing with the medical condition cleft lip and/or palate.

This thesis set out to see the world through the eyes of a cohort of twenty-four young people aged between five and eighteen years, and those people who were important to them – their parents, teachers and organisational/club leaders. The objective was to offer a kaleidoscope of views through which to try to see the world from different perspectives of each child and young person's life.

The findings from the study offer rich insights into children and young people's lives. In this chapter, four main areas are explored: educational experiences and attainment; the young learner beyond the school; through the eyes of the young learner and; relationships

and inter-agency working. The four areas identified emerged from the interplay of literature and evidence consistent with grounded theory (Glaser and Strauss, 1967).

The original five research questions have been grouped to reflect the four main areas of findings.

8.2 Educational experiences and attainment

- In what ways, if any, does having cleft lip and/or palate impact on young people's experiences in school?
- To what extent does cleft lip and/or palate impact on attainment in school?

Perhaps the most noteworthy finding of this study was that the young people's progress in learning resembled that of any group of young people without cleft.

The medical literature reviewed as part of this study suggested that young people with cleft have a tendency to underachieve (Richman, 1976; Richman and Eliason, 1982; Richman and Eliason, 1984; Persson, Becker, and Svensson, 2012). This observation was often founded on the results of intelligence testing which was heavily based on language skills (Richman and Nopoulos, 2008). Researchers have identified a range of possible reasons for this underachievement: speech and language (Richman and Eliason, 1982), cognition (Conrad et al., 2010), low self-esteem (inhibition) (Richman and Eliason, 1982) and low expectations of parents and teachers (Richman and Eliason, 1982; Moran and Pentz, 1995).

However, reflecting on the evidence emerging from conversations with the children in all three age groups and from the national examination certificates provided by the oldest age group, the evidence from this study seems to paint a similar picture of progression in learning to other young people in their age groups. Looking at the examination results of the oldest group they presented a spread of grades in accordance with what would be expected with any cohort selected from the general school population of this age group (Scottish Government, 2017). Focussing on the grades achieved using a wider educational lens, the results bore more relationship to the pattern of socio-economic class indicators (SIMD) that were documented in this study (see page 116). There is clear evidence from educational research literature, for example from Joseph Rowntree Foundation publications

(Hirsch, 2007; Goodman and Gregg, 2010) and Raffo et al., (2009) that young people from less affluent households perform less well in tests and examinations than their wealthier peers. This finding is consistent with the evidence in this study. Those young people who lived in households labelled SIMD four (Katy and Lauren) achieved a selection of higher examination passes compared to those in SIMD one (John and Mack) who did not achieve any examination passes at higher grade (see Appendix seven).

The children and young people whose voices emerge in the data for this study also challenged the evidence from the medical literature. These voices were very powerful. For example, rather than describing themselves as underachieving, Emily, from the youngest age group, reported that she did not find anything hard and Aaron, aged five, was keen to show me a certificate which said his teacher thought he was "magic". In the middle age group Andy wondered what all the fuss was about cleft as he had experienced minimal disruption to his work. Jessica reflected that all her teachers over the years said that she was "so good" at her work and the seniors were all preparing for a wide selection of SQA examinations. Most importantly, the young people perceived they were making progress because they could understand and cope with their daily work in class.

It is beyond the scope of this study to offer a definitive explanation about the differences between the evidence from the medical literature and the findings of this study. However, there are a number of issues that seem worthy of further consideration and where further research would be welcome. The studies carried out by the medical professionals were carried out within the positivist paradigm, based on intelligence and other testing, using deductive reasoning to identify possible areas of deficit. In contrast, this data drive study, based on a constructivist approach (Denzin and Lincoln, 2011) has used inductive reasoning to build conclusions from first-hand accounts of actual experiences. Where possible, additional sources of evidence were used, for example, high stakes national examination records provided by the oldest group (see Appendix seven).

Nevertheless, there were areas where issues raised in the medical literature were consistent with findings that emerged in this study – particularly speech and language (RCSLT, 2009, Peterson-Falzone, Hardin-Jones and Karnell, 2010) and cognitive issues (Nopoulous et al., 2002; Conrad et al., 2010). However, in this study, when issues emerged, they related to individuals and could not be related more generally to broader factors such as medical

condition, age or to the geographical location of the young person's domicile (except in one case, see page 169).

Kuehn and Moller (2000) list a range of physical differences which might compromise the speech of young people with cleft. Clinicians attempt to perfect the speech apparatus (Marsh, 2006) and often encourage extensive engagement in speech therapy using individualised assessment and treatment plans (Sell and Grunwell, 2005). The young people in this study were able to pronounce vocabulary at interview and use grammar structures in formats that were comprehensible (Chomsky, 1965; Bruner, 1983) although there was variation in the complexity of structures utilised. Yet this study showed speech does not have to be perfect for young people to function successfully in classes (Katy) or clubs (Sam). But where individual young people did not converse as much as others these learners risked not having points they did not understand clarified within the teaching/learning process and this could slow learning down (Sally).

Individual young people (Wayne, Sally, Katy and Kieran) did experience a lack of confidence to speak in public (Chapman and Hardin, 1990; Frederickson, Chapman and Hardin, 2006) and this was perceived to result in increased nervousness in certain circumstances, for example, when they came to give presentations. Interestingly, Jessica, who was progressing very well in her studies admitted feeling nervous when speaking out and suggested that she experienced this to a greater intensity than her friends. Although this nervousness could be linked to cleft, it could equally be linked to other influences, for example, fear of the audience, their teachers or their peers. However, there may have been a connection between cleft causing minor speech issues and fear of having to speak in front of the audience. When the audience was receptive and encouraging all these young people were more than able to present. For example, Sally gave her presentation on her pet when the audience was supportive. She chose a topic she had a vested interest in, her pet dog, and she used her artistic talent to provide a visual image of her dog to support her speech. Sally transferred her attention from her fear of presenting to wanting to share information about her much loved pet with her audience and her dog became the focus of her attention. However, there was a perception amongst some adults that rather than presenting to large audiences, the young people may feel more comfortable giving presentations to small groups (BB leader, art teacher, and Sally's class teacher) and that they worked best in smaller groups or pairs (Liam's home economics teacher, Sally's class teacher, Sam's class

teacher). There was, at times, confusion when adults tried to understand how the young person really felt. Sally's class teacher said that Sally's confidence to speak out was variable. On occasion, the evidence challenged the adults' views of the child because generally Sally's teacher viewed her as a very quiet child yet she could speak out when she chose to and this view was supported by Sally's mother who, when questioned about her daughter's speech said "Eh, slow … slow to speak up. Once she starts she doesn't stop but it is more confidence with her".

However, speech is only one form of communication used to engage in classroom activities, albeit an important one. What is most important is the communicative transfers involved in learning through meaning making such that the young person is able to personally make sense of the learning (Vygotsky, 1978; Bruner, 1983) and that learning does not take place superficially through repetition/rote learning without accompanying understanding as this can be a danger in less interactive models of learning such as behaviourism (Skinner, 1938). Communicative transfers can be achieved in a variety of ways – visually, kinaesthetically as well as orally. For example, Sally's teacher used the local authority learning and assessment procedures "Say, Write, Make, Do". This approach offered a range of ways to communicate and could be seen to offer opportunities for young people to build skills in what Gardner (1993) argued were different intelligences.

Poor speech was linked, in much of the literature, to difficulties in other areas of literacy (Berninger and Gans, 1986; Smith, 2000). Reading was identified in the cleft literature as an area where young people often have difficulties (Richman, Eliason and Lindgren, 1988). Individual children struggled with reading (Sam, Sally, Liam, Tulisa, and Katy). In some instances, it was suggested that this was due to phonic issues (Sally's teacher) enhanced by the problem of compensatory articulation disorder (Pamplona, Ysunza and Jimenez-Murat, 2001). Children in the youngest age group did not highlight reading as an area of concern but by the older age groups reading had become an issue for some individuals. Schools were commonly slow to communicate any difficulty to parents (Sam, and Liam) during the first two years of primary schooling. This slowness may have been due to difficulties not being identified in the early years. This lack of identification could lead to problems being exacerbated. The Matthew effect (Stanovich, 1986) can lead to a situation where skilled readers, race ahead and the gap between skilled and less-skilled readers widens to become a greater problem. The apparent lack of communication

between home and school may have been part of a more general problem in home-school relationships which has been a contentious area over time (Bastiani, 1989). Or, there may have been another reason, for example, it may also have been due to a desire not to label children as poor readers too quickly which could be demotivational and not consistent with the ideas of inclusive education (Thomas and Loxley, 2001). Without doubt, many children and young people with cleft do find difficulty with some sounds (Patel and Ross, 2003; Peterson-Falzone, Hardin-Jones, and Karnell, 2010). Bruner (1983) advocated speech acquisition by using the social interactionist model because this emphasised meaning making as the primary goal in communication rather than speech perfection   In a similar way, reading proficiency may be achieved more efficiently by understanding the meaning of words/phrases aided by considering the surrounding text and drawing from knowledge accumulated from past experiences (Ellis, 2015) and text illustrations. Although, care has to be taken with illustrations as they can encourage children to invent the text rather than persevering with reading the words and comprehending the meaning from the text (Sam's mother, Tulisa's mother). It is difficult in the literature to find theoretical models underlying the enactment of speech therapy but Sell and Grunwell (2005, p.239) contended that "many of the therapy techniques advocated are based on the pioneering work of Morley (1970) and on principles of behaviour modification". At the speech clinic this appeared to consist of identification of issues with sounds/words, and exercises to help improve the quality of speech (Bella), supported by observation of interactive conversations between mother and child with the clinician at times taking part. This latter was consistent with Bruner's (1983) learning language through social interactionism using ever more complex grammar structures and vocabulary. The specialist speech therapist emphasised that her remit was concerned with speech issues of children with cleft lip and/or palate and not with literacy.

There are other potential links between issues with speech attributed to cleft and expressive language skills. Writing can be compromised by poor spelling which can be related to speech development (Hart et al., 2007). Speech development can be affected by the timing of secondary surgeries (Timmy and Tulisa) and this was related to later spelling issues (Timmy's mother, Tulisa and her mother). A sizable proportion of the young people focussed attention on their poor spelling ability but only in two cases (Sally and Lauren) did it make a discernible impact on their progress (see pages 179 and 243 respectively). Spelling was perceived to be becoming less of an issue due to access to technological

devices (Tulisa's parent and college tutor). However, those whose speech had been more affected by cleft tended to produce less well developed language structures and extended writing (Sally and Tulisa).

Any issue with language skills may affect thinking in the abstract (Luria, 1973; Vygotsky, 1978), by which is meant using language to make sense of the world externally and then internalising meanings by using language. By employing higher order language for cognitive thinking the gap can be bridged between lower concrete thinking (Gray and MacBlain, 2012) and moving beyond the obvious to advanced knowledge creation that comes about from cognitive conflict (Piaget, 1985). Echoes of this thinking could be found in the experiences of some of the young people. For example, Sally struggled with language, was continuing to receive speech therapy and was reported to find it difficult to think in the abstract (Sally's teacher). The descriptions of Sally's experiences tended to reflect a model similar to Piaget's model of development. Sally was perceived to have reached concrete operational stage but was struggling to move to formal operational level. However, if an alternative theory were to be used, a social constructivist model, then the perception of Sally as a learner would change. Within Sally's ZPD and with the support of more advanced others (Vygotsky, 1978; Bruner, 1983, 1996) through scaffolding, by which is meant forms of support (Wood, Bruner and Ross, 1976) she could make progress at a faster rate. There was evidence of this when Sally engaged in more interactive sessions to improve her literacy and numeracy (see page 183).

In addition to cleft related issues in language linked to cognition, the medical literature highlighted that young people with cleft may have other cognitive issues (Nopoulos, et al., 2002; Conrad, et al., 2010). For example, from the duplex theory of memory, it was argued that difficulties with short term memory (Ceponiene et al., 1999) could compromise information entering long term memory and in turn might reduce the quantity and quality of information passing to long term memory store (Sarah, Bella, Sally and Tulisa). Long term memory is important (Kirschner, Sweller and Clark, 2006) to facilitate metacognition and inter disciplinary thinking from a larger data store.

In conclusion, the area that appears to have the greatest influence on learning and which threads through the learning trajectories of individual children is language. Language is also the area where most support was offered. Speech therapists conscientiously assessed

each child at the clinic and offered therapy to address identified needs for nineteen young people out of a cohort of twenty-four. This could have been an influential factor in improving the literacy and therefore the attainment of some of the young people (Collett, Leroux, and Speltz, 2010). In addition, children and young people had also been supported in school in language areas when an issue had been identified, although the individual level of additional support tended to fall as the young person matured and moved from dependence to independence (Tulisa). It would thus be misleading to dismiss cleft completely as a factor influencing learning, but its effect was not such that it prevented progress in learning. If anything, it affected the speed of progress resulting in problems for individual young people (Sam, and Sally) but it did not prevent progress being made.

Therefore, in this study I started from the assumption that I would find out why children with cleft did less well in their learning. My views had been formed both by the medical literature and the understandings of the medical professionals. However, the evidence emerging from this study did not support that position. Different young people achieved different things. Some achieved more than others. Some (Katy, Lauren, Bruce and Jessica), achieved a great deal: others (Sally, Liam and Tulisa) found aspects of learning more challenging. The patterns of achievement appeared to be more closely linked to the socio-economic circumstances of the young people than to the impact of cleft. My findings suggest that the children and young people in this study were similar to the achievement patterns of young people more generally.

Some parents and some teachers who were part of this study held different views. They saw cleft as a major factor in any child with cleft's development. In a sense they saw the cleft rather than the child first. It may be that some parents (Liam's mother) and teachers (Tulisa's Primary One class teacher) who have contact with the young people with cleft reflect society's tendency to stereotype those who look or sound different from the general population which leads to speculation about their potential academic and social achievement without resorting to actual evidence. This is a small in-depth study based on a limited number of young people with cleft and further work needs to be undertaken. However, this study did include three age groups, two medical conditions and all five socio-economic classes as defined by the quintile index of the Scottish Index of Multiple Deprivation (Scottish Government, 2015b).

8.3 The young learner beyond the school

- In what ways, if any, does cleft lip and/or palate impact on educational experiences which young people have outside of school?

There were three major findings of this study:

1. Contrary to previous literature, the young people with cleft were generally as engaged with outside activities as those without cleft.
2. Outside/club activities offered a more inclusive learning experience compared to that offered in schools.
3. The expectations in relation to learning and progress of those involved with the young people at school and at clubs were different.

The medical literature documented young people with cleft as more isolated socially than those without cleft, depicting the former as often relying on one special friendship or for family as the main area for social interaction, (Peter, Chinsky and Fisher, 1975: Pillemer and Kaye, 1989). However, the evidence from this study revealed that the young people with cleft were attending a wide range of activities and pastimes with one exception (Lucy). Since it was argued in the literature that young people with cleft were less active socially, there was a corresponding lack of literature describing or analysing the social experiences of young people with cleft. In contrast, in this study, the range of activities the young people with cleft participated in included sports (including contact sports such as martial arts: Sam, and Kieran), theatre group, musical pursuits, dancing classes and youth organisations. Their participation was not curtailed in any way by the cleft and they were encouraged by the medical team at the hospital to form friendship circles at nursery school rather than relying on one special friendship. Some of the young people were members of wide social circles (Jessica and Lauren).

Social activities and clubs serve different purposes than attending school. The young people explained their motivation for attending social activities in terms of for fun and enjoyment (Jessica, Timmy, and Lauren). This was different from how they viewed attendance at school which was progressively related to achieving in tests and working towards career goals as the young people matured. By the senior stage the focus of the

participants in this study was heavily fixed on individual attainment in national examinations with a recognition of how important it was to achieve high grades in order to pursue life goals (Kieran, Katy, and Lauren). Far from being for enjoyment and relaxation or learning for its own sake, learning at school had become a stress related activity deeply connected to examination results. Attendance at clubs was viewed as a way of relaxing, a form of antidote to school life (Jessica's father).

The young people could choose which activities to pursue for social pursuits. It would be tempting given the negativity some of the young people associated with reading and writing (Sam, Sally, Liam) to say they chose their social activities (various sports, dancing, art, and activities at youth organisations) based on there being less reading and writing involved but the young people did not offer this as a reason. Nevertheless, some parents did present this line of argument (Liam's mother) and it was clear that for Lauren it was the acting/portrayal of the characters she enjoyed rather than reading of the script. On the whole, the young people did not link issues with their cleft and choice of/restrictions on attending outside activities. In effect, they approached the choice of activity in the same way other young people without cleft would have done. It was the activity they were concerned with and whether or not it would be fun. The only exception to this was Kieran who chose the martial arts and cadets especially to learn how to protect himself against bullying which he did relate to his cleft. However, he reflected that his continued attendance at both these pursuits over time, was because he enjoyed the activities. He also achieved a high standard of performance.

For those who were club/organisational members, there was a sense of belonging, for example, by wearing a uniform with pride and voluntarily engaging in membership ceremonies (Emily) and choosing to attend with friends (Jessica) or siblings (Liam). This sense of belonging was consistent with the principles of inclusion (Oliver, 1992; Dyson and Milward, 2000). The experience allowed each young person to be individually valued, provided a collaborative environment for them to explore their potential skills and talents (UNCRC, 1989). None of the young people were removed from club activities to receive additional support as was happening at school. None of the young people reported being teased/bullied at clubs or social activities in comparison to the number who suggested they had experienced teasing/bullying at school (Sam, Sarah, Bella, Kieran, Katy, and Tulisa), with negative personal reactions (Lindsay, Dockrell and Mackie, 2008). Although John

was also teased at school, he said it was in a good humoured way and it did not affect him. Teasing/bullying at clubs/organisations was actively resisted. This was done by careful monitoring and strict adherence to written policies (theatre tutor, BB leader, karate instructor). This anti-bullying policy may have been easier to enforce in the voluntary sector because, in extreme cases, members could be asked to leave if they ignored warnings to stop behaving in an unacceptable way (BB leader). The situation seemed more complex in schools where action to prevent bullying was not always taken by school authorities (Katy, Sally's mother). In schools, it was far less probable that young people would be asked to leave because school attendance is mandatory until the age of sixteen and because of pressure to keep exclusion numbers down in local authorities (Scottish Government, 2016b).

Depending on the individual social activity pursued, young people more frequently worked in teams, (Wayne, Andy, Timmy). Sometimes individual groupings were composed of young people of different ages (Liam, Lauren, Katy), something that rarely happened at school. However, group leaders (BB leader, theatre director) suggested that this approach encouraged each group member to be valued for the skills they brought to the task and helped to build a positive attitude towards achieving success. Younger members learned to respect the skills and knowledge of older members (theatre group) and leadership skills, (BB) and this offered the younger members something to which to aspire (BB leader). This approach bore similarities to Vygotsky's (1978) model of social constructivism, learning with the support of others but with a wider group of scaffolders than at school because the group contained a mix of ages who facilitated learning within the younger member's ZPD. As the young person matured they revisited their learning at a move advanced level, as in the case of Lauren who played increasingly more complex roles and building on her experiences she engaged in on stage improvisation in front of large audiences. Lauren's history of experiences appeared to have much in common with the model proposed by Bruner (1960) of learning within a spiral curriculum.

At organisations/clubs learning in context appeared to increase the meaningfulness of tasks for young learners (Bruner, 1996) permitting them to pursue learning with fewer restrictions, including moving inquiry out of doors. The boys at the BB were learning about the possible effects of the Commonwealth games (2014) on Glasgow, including taking part in visits around the city. Project work (Elwood, 2006) documented and guided

what they did next as they designed and compiled their personal folios. Being encouraged to personalise their experiences allowed the boys to follow their interests and develop their talents, and in this way to build on different intelligences (Gardner, 1983) to produce valuable work which reflected their strengths.   Each child and young person was perceived to experience a sense of satisfaction at completing tasks commensurate with their own capabilities and all members were entitled to receive rewards (BB leader). This view was supported by the reports from the young people. The standards set for the rewards at clubs varied from school standards in the following ways: there was more emphasis given to recognising the development of characteristics such as perseverance on the task and regularity of attendance (BB leader) and where there were pre-set standards to achieve such as belts in martial arts, the young people received the award by showing that they had overtaken a set body of knowledge and had demonstrated certain skills and attitudes. They were not ranked in individual order of attainment within the tests for the karate belt, and it was possible for all to achieve the standard required for the belt (karate instructor). It was a criteria referenced approach (Gipps, 1994), where each child had to achieve a pre-set standard. The lack of ranking of young people in individual order of merit meant 'difference' was less important which lessened comparisons with other children. Pajares and Schunk (2001) suggested that social-comparative school practices which encourage young people to compare their achievements with that of their peers can destroy the self-beliefs of those who are less academically successful.

Some teaching strategies employed at clubs may also have helped to overcome any disadvantages the young people might face, for example, from being absent because of hospital treatment or recuperation periods. As an example, at the BB one off topics such as presentations by the police on road safety meant the boy simply missed the experience but this knowledge was not necessary for the next session. When longer term projects were undertaken they were personalised so the boy could restart from where he previously left off. Some sports coaches suggested that progression in the sport more recently involved increased use of modelling of learning using visual demonstration and those who were absent could join in, copying the movements others were performing helped by increased practice time (karate instructor). In other arenas, there were also qualified staff available to assist in overtaking gaps in learning (theatre director). Finding it easier to resume learning counteracted any loss of motivation from falling behind due to absence (Sam's mother). This was unlike school where missing blocks of teaching could affect future progress and

motivation (Tulisa's primary school experience). This was especially true if timing was an issue in completing the curriculum for examinations (Lauren's mathematics teacher). Teachers did not seem to have the time to help and young people were sometimes simply told to copy learning from another pupil's work into their own jotters without explanations (Rihanna). However, the picture is more complex than the above analysis might suggest. For example, young people spend less time at social activities in comparison to attendance at schools and so if the young person was attending the hospital or absent for recuperation purposes, less learning was missed at clubs in comparison to at schools.

This study shows that the young people with cleft who were attending out of school social activities were engaging in an environment for learning that provided positive outcomes – having enjoyable and valuable experiences, in a more inclusive environment. It may be that some areas of society have embraced inclusion more than others or are more naturally inclusive and that more formal learning contexts, for example, schools, face different pressures. Where ranking by attainment grades is prevalent, this might seem to encourage ideas of 'difference' in respect of division (Hevey, 2004) and inferior status (Williams, 1992). The expectations of those involved with the young people in relation to learning and progress were different at clubs compared with at school. Adults organising clubs seemed more open to allowing young people to begin from where they were, were less judgemental, and were more concerned with young people enjoying the experiences than engaging in high stakes assessments – although they did provide rewards for successful demonstration of the learning which young people could opt to aim for.

8.4 Through the eyes of the young learner

- In what ways, if any, does cleft lip and/or palate impact on young people's perceptions of themselves as learners?

The key finding of this study was that the young people's perceptions of themselves as learners varied depending on the learning context they were working in, and in some cases cleft may be an indirect factor because of the reactions of others to cleft.

In his theory of motivation, Maslow (1943) suggested five levels of needs which must be met in order to achieve self-actualisation. Before young people with cleft reach level four

(self-esteem) in Maslow's model, they face potential challenges, sometimes experiencing feeding difficulties for survival (level one, physiological) at least one surgery (level two, health) and potential adverse reaction from family members and peers (level three, love and belongingness). Maslow, and other developmental psychologists such as Erikson (1995) also highlighted the importance of the first two years of a child's life in providing a foundation of stability and resilience to cope with life's challenges. The feeding difficulties and initial surgical treatments which all the young people in this study experienced took place before the age of two during this critical period. Yet, in this study, none of the young people appeared to have issues around feelings of stability. They engaged in learning experiences, sometimes with the support of others, as would be the case for young people without cleft. Maslow's theoretical perspective has been the subject of critique – Geller (1982) contended that it was reductionist in describing human behaviour and Lewis (2011) reflected that Maslow's model ignored the role of collective needs as a focus of improving the self. But, Maslow's ideas offer an interesting framework for reflection.

Nevertheless, in the medical literature, Leonard, Abrahams, Brust, Sielaff (1991) highlighted issues with the self-concept of young people with cleft and Richman and Eliason (1982) associated inhibition with underachievement in class. Cleft was cited as having the potential to influence the young person's construction of their self-perception as a learner because of speech (Strauss and Cassell, 2009), and appearance related issues (Rumsay and Harcourt, 2007). Certainly, cleft sometimes necessitates further medical treatment during primary and secondary schooling which may exacerbate feelings of 'difference' which in turn could have affected self-concept. However, in this investigation, when the young people in the two older age groups were questioned at interview they neither immediately linked their medical condition to their learning experiences nor did they relate their medical condition to feeling different or having low self-esteem. They viewed themselves and wanted to be viewed as learners just like other young people engaging with the learning process (Lauren's mother, Tulisa's college tutor, Jessica's father). This may have been because, as Liam's mother suggested, they did not know any other 'self' and could not see the differences between "having and not having (cleft)". In fact, there may have been little to invoke feelings of inability to succeed in learning because of cleft. Teachers and Tulisa's college tutor did not identify any barriers to progress relating to cleft. Similarly, in this study there was no area of social activities in which the young people could not participate because of the cleft.

Self-esteem and self-enhancement theory were originally regarded as fundamental to making progress in learning (1960s and 1970s) but were replaced by cognitive theories (1980s), however the importance of theories of self-enhancement have been recognised again in the last decades (Pajares, and Schunk, 2001). However, Baumeister, et al., (2003) claimed that high global self-esteem had no benefits and in fact may be detrimental to subsequent performance. This could be relevant in Sam's case where he came with a high level of global self-esteem to the karate club but found that when he attempted to demonstrate the moves he was not as successful as some of his peers and his self-esteem decreased (karate instructor). Focussing principally on this high level of global self-esteem is unidirectional – it suggests that the learner who has high self-esteem will perform well in any learning tasks. But, this model fails to take account of the complexity of the learning process, and of the importance of context.

Bandura (1977) suggested that it was what he called self-efficacy which was important in academic achievement rather than self-esteem. Self-efficacy is more specific, it is the individual's belief in her/his own ability to perform the task, and whereby the individual will anticipate successful completion of the task, will continue to work towards achieving a successful outcome and attribute failure to extraneous factors rather than their own ability. Academic self-efficacy beliefs correspond directly with performance of the task/subject area they are aiming at and success in one area does not mean high self-efficacy in every area of the curriculum. This could explain the preferences shown by some of the young people in this study for the practical subjects where self-efficacy was high in comparison to other areas such as the study of language (Bella, Sally, Liam, Kieran and Tulisa). In addition, it is suggested that as people grow older they become more aware of their differing domain-specific self-concepts (Pajares and Schunk, 2001). This may help to explain that the youngest group had not really identified subject areas they preferred and in the oldest age group, they had chosen areas to specialise in with more reluctance to engage in foreign language learning. The opportunity to specialise in subjects where the young people had high self-efficacy possibly raised overall examination performance grades (see Appendix seven).

Pajares and Schunk, (2001) contended that the conceptual and empirical differences between self-efficacy and the self-concept were not always clear to researchers. They

continued by defining self-efficacy in terms of confidence in one's abilities whereas self-concept can be viewed in terms of how an individual describes her/himself plus a judgment of self-worth. Marsh and Craven, (2006), using the wider term self-concept, proposed an alternative explanation of the role of self-concept (Reciprocal Effects Model) in academic achievement. They stated that the self-concept and performance were reciprocally related and mutually reinforcing constructs. Rather than global self-esteem being the dominant factor in academic achievement, the academic performance in curricular areas is linked to the self-concept of young people in that particular area and, most importantly, that these variables are reciprocal such that as one increases so does the other. This may explain why Katy was bullied throughout her school career and although this may have affected her global self-esteem, she still performed well in her examinations – she found subject areas where she could excel and as her performance improved so did her self-concept in these subject areas which in turn improved her performance even more in these areas. However, it is also possible that Katy's perception of herself as a learner was formed within the contexts in which she was learning: her ability in these subject areas to combine her areas of strength to be successful, her family's attitude, the role of teachers, of additional support offered to her to aid her reading issue, and the interactions with peers whose friendly influence outweighed that of the unpleasant ones.

In this study, it appeared that the self-perceptions of the young people as learners were influenced by the environments in which they were working and the role of others supporting them (Rogers, 1980). Dweck, (2017, p.176) reflecting on the parent/child relationship contended that "every word and action can send a message". For example, in Liam's case, at home he was learning with a parent who labelled her son as "not a school person", unlike his siblings, and she was critical of his literacy skills, an area where Liam developed low self-esteem. His parent attributed his hearing, speech and "ability to do things" as cleft related. Dweck (2017) identified this parental approach as a fixed mindset where Liam's mother created a sense of inevitability about his abilities to succeed at school, a view which could be transmitted to the child, and which indicated a lack of her being able to see the learning process through the child's eyes (Hattie, 2012). However, at school, Liam was viewed as just another pupil who attempted the learning in the same fashion as other pupils and any issues were dealt with in the classroom context (Liam's teacher). It was the issues within the learning context that mattered not the cleft within the child. At the club he presented himself as a learner in a positive light, regularly attending

and contributing to activities which he had no trouble in attempting and where the cleft was irrelevant.

Each young person's case was different. For example, in contrast to Liam's case, Lauren appeared to have high perceptions of herself as a learner in all three learning environments. At home she was motivated, adopting a growth mindset (Dweck, 2017) because she believed she would succeed in her examinations and that she would receive any support she needed, from her parents, including them paying for private tuition. At school, whilst she realised she had to work hard she regarded this as a challenge and believed that she had the ability to succeed. At the theatre school, where staff were positive and building confidence in young learners was part of their remit, Lauren flourished and took on any role asked of her and had the confidence to engage in improvisation in acting. All those who supported Lauren had the same expectations of her learning, her parents were extremely supportive and said her learning was similar to that of her brother, her teachers were also positive in their course levels but with caveats as to her future learning within their subject areas (except for the art teacher) and the theatre director was enthusiastic about the contribution Lauren had made to the theatre group and what she had achieved. What was striking was the pivotal position of the home as primary influence on the child's self-efficacy as can be seen as the major difference between Liam's and Lauren's cases. This is consistent with Hattie's (2009) view of the importance of parental expectations on the child's achievement.

Changes within even the same environment could change the self-perception of the young person as a learner. When Tulisa started primary school she met with negativity from her Primary One teacher which led to a challenging situation (see pages 224/5). Tulisa developed such negative feelings about her ability to learn, that she did not want to attend school and became very distressed. However, when Tulisa was allocated a different teacher her views of herself as a learner changed; she became more positive and she started to achieve in class. She made even further progress when she received additional support which she welcomed but which did not seem to affect her self-perception as a learner.

The role of peers was important, as the self-perception of the young people could be influenced by others. Teasing/bullying had the potential to lead to academic underachievement (Lindsay, Dockrell and Mackie, 2008). In the case of cleft, Hunt et al.,

(2007) contended it was not the cleft that reduced the self-confidence of young people with this medical condition but rather the teasing/bullying that it engendered. Individual young people were teased/bullied (Sarah, Sam, John, Bella, Tulisa, Kieran and Katy) and some negative terminology was associated with cleft and surfaced during individual interviews: vampire (Bella), freak (Katy), funny nose (Sarah). Although no child experienced physical violence they did experience psychological bullying such as name-calling. The propensity to be a subject of teasing/bullying in this study did not appear to be related to socio-economic class but was more likely to have been dependent on the attitudes of some peer groups to visual difference (Schneiderman and Harding, 1984; Tobiasen, 1987) and invisible difference and the personality characteristics of individual young people in relation to their sensitivity to the unpleasantness of others and their resilience to deal with this (Aspinall, 2006). The young people displayed different reactions to the teasing/bullying but it did seem to have the potential to negatively affect their self-perception because as Dweck (2017) reflected, it creates inferior and superior status for the bullied and bully respectively. For example, Kieran said bullying had affected him when younger, although his later surgery increased his confidence and helped him to focus on his work. This resembles Dweck's (2017) contention that bullying diverts attention away from tasks at hand. At school, compared to clubs, this negativity caused by bullying could be reinforced in the memory by the repeated experiences (Neisser, 1967) unless stopped and could interfere with learning in context as it offered a competing focus of attention (Anderson, Bjork and Bjork, 1994) to the actual learning being undertaken. This has the potential to reduce performance and therefore negatively impact on self-perceptions. In isolated communities the young people also mixed socially with the same group of peers and could not escape from being "locked in" with them throughout their youth (Sam's karate instructor). However, each young person found ways of averting any adverse effects from this. Sarah and Tulisa were defended by their mothers, Bella resorted to aggression, John laughed it off, Katy tried to ignore it but Kieran took action in the form of self-defence. In terms of Dweck's (2017) theory Kieran had developed a growth mindset whereby he realised the bullying no longer gave the bullies superior status and the issue was with the bullies not with himself. Interestingly, at watershed moments such as transition to higher education/employment some young people looked to improve their speech/appearance (Katy, and Mack) and this might indicate a fear or even an expectancy of adverse reactions in future interactive environments.

It appears from this study that it was the interplay of various factors within the learning context that affected the perception of the young people as learners. If the cleft affected their perception of themselves as a learner it was minor and generally related to interactions with unhelpful peers or adults. Important factors included: the child's ability to complete the particular activity, positive feedback from relevant adults and the environment where the learning took place. In classrooms, this was usually interactive learning within the social constructivist model of learning (Vygotsky, 1978). Research and theory highlights the importance of the attitude and skills of others supporting the learning, (Ang, 2016) and resources available to provide scaffolding (Wood, Bruner, and Ross, 1976) within the ZPD (Vygotsky, 1978). The self-perceptions of the learner may change as individual factors within the learning context can change – for example when teachers change. The situation is a fluid one over time reflecting that life consists of a series of interactive experiences from which people in general build knowledge as within the constructivist paradigm (Denzin and Lincoln, 2011).

8.5 Relationships and inter-agency working

- In what ways, if any, does cleft lip and/or palate impact on relationships with significant others who are working directly or indirectly to enhance the educational achievement of the pupils?

The principal finding of this study was that there were communication gaps between the young person and some of the parties supporting them and also amongst the agencies involved.

Young people with cleft interact with a wider range of professionals than most children. These different professions operate in separate worlds with different sets of priorities. For example, medical professionals try in vain to achieve the perfect surgical repair (Marsh, 2006) to improve speech (Peterson-Falzone, Hardin-Jones and Karnell, 2010). Yet, even without the perfect surgical repair, as long as teachers were knowledgeable about cleft speech (Tulisa's mother) and showed patience (Sally's mother) young people with cleft could make themselves understood given adequate wait time to respond. In this study the most enduring speech issue was hypernasality coming from the palatal repair (Mack), with, in some cases, a small, residual hole remaining (Sam, Liam, Rihanna). The surgeon had a

different priority regarding the remaining fistulae and would first consider if the benefits outweighed the risks before performing secondary surgeries and the speech therapist reflected that surgeons sometimes would not undertake secondary surgery unless functionality was being impeded, such as the swallowing of food. However, any residual effect of hypernasality regarding learning was eased when the person with whom the young person was interacting was known to the young person because the more interaction there was, the more accustomed the person became to any speech anomaly (Sam's karate instructor). This study illustrated that if a young person with cleft harboured a preconception of having challenging speech this often became a self-fulfilling prophecy, borne of their own actions of speaking too quickly and quietly to avoid correction of speech errors (Sally's teacher and after school tutor, Liam's mother, Tulisa's college tutor). This was overcome by requests to speak louder, and requesting information to be repeated (Sally's teacher and after school tutor).

This specific example illustrates how different professions and individuals involved with the young people, and the young people themselves, may have different priorities. It is sometimes difficult to see how these might be reconciled. One of the major ways to improve understanding across communities would be for parties to engage in meaningful communication, and to become involved in interdisciplinary working. For some young people, communication between parties was infrequent but when it was necessary, proceeded smoothly (Jessica). However, for other individuals there were issues with interpersonal communication and/or inter-agency communication (Sam, Sally, Lucy, Liam, Lauren, and Tulisa).

Bronfenbrenner's (1979) ecological system can be used to analyse where levels of communication were problematic and how this impacted on relationships with others supporting the young person with cleft with possible consequences for those with cleft.

Within the microsystem (Bronfenbrenner, 1979) the child is placed in the centre and the links between the child and parents, child and teachers and child and organisational leaders are seriously important for learning to progress (Prior, 2013). In this study, I identified two issues. The first was regarding communication between the individual young person and her/his parent and the second was the issue of communication between the individual young person and her/his teacher.

For the parent, the birth of a child with a cleft may be quite unexpected (Paterson, et al., 2011) and even when the cleft has been diagnosed prenatally, the parent/s may experience a range of emotions both before and after the birth: disbelief, shock and protectiveness (Peterson-Falzone, Hardin-Jones and Karnell, 2010). This may have consequences for the future relationship between infant/child and the parent/s, as parents may develop reduced expectations of the child from an academic viewpoint (Moran and Pentz, 1995). In this study, some parents did not receive a prenatal diagnosis of cleft and therefore did not have time to find out anything about cleft before they were informed of the baby's medical condition (Sally's mother and Tulisa's mother) and the chances to discuss the infant's future prospects were sparse as was information on the child's possible learning trajectory. However, all the parents gave the impression they wished to support their child in the journey from dependence to independence. At interview, the young people said their parents helped with homework when the parents understood the material concerned and that parents generally encouraged their children to engage in life experiences. But, during individual interviews there were caveats with unintentional consequences. Some parents displayed an overprotective attitude (Patel and Ross, 2003) which could limit the social and academic learning experiences of the child. For example, to protect her surgical repair, Lucy's parents would not let her have a bicycle to cycle about her area and Liam's mother did not encourage Liam to take pictures of himself as a baby to school until he had completed his medical treatment. In cases like these there seemed to be little discussion between the child and parent to resolve these issues – the parent made the decision. Sometimes, as in Liam's case, his parent may have regarded the child as too young to enter into meaningful discussions on this topic, (UNCRC, 1989) but sometimes, such as in Lucy's case, it may have been an unwillingness on the part of the parent to discuss the matter with the child because of the emotions and memories it would invoke (Lucy's mother).

Individual parents were not knowledgeable about what social contact their child had outside the home, thinking the child had only one special friendship or was struggling to find friends whereas teachers reported that their child was socialising satisfactorily and similarly at organisations/clubs (Sally and Liam). Lack of discussion about this issue could have led to parents building an incomplete picture of the child's situation, reinforcing low expectations (Richman and Eliason, 1982).

For the class teacher, having a child with a cleft in their class is likely to be a novel experience although the numbers of young people with cleft are growing and in future there may therefore be more chances of this occurring (Watson, 2005). Carnell and Lodge (2002) highlighted the importance of dialogue for breaking down barriers in order to work towards co-constructivist learning (Ang, 2016). All the young people said they interacted in class with their teachers and peers but again there were exceptions – Sally's Primary Six teacher reported that Sally, who experienced speech issues, did not always talk with her to clarify issues and communication between Tulisa's Primary One teacher and the child reached such a low point that Tulisa's mother had to seek advice from the Head teacher.

More generally teachers tread warily around the subject of cleft. At no time did any teacher broach the subject of cleft directly with the child, possibly trying not to draw attention to any 'difference' as a source of inequality (Williams, 1992) and division (Hevey, 2004) which might compromise the development of an inclusive teaching/learning environment (Barton, 2003). There was an uncertainty amongst individual teachers as to how to deal with situations that occurred which were cleft related. For example, Lauren's art teacher's was unsure how to react to Lauren's choice of a peer portrait for her art folio and the art teacher was unsure what to say when Lauren returned after her jaw surgery although the teacher at interview described the surgical outcome as "amazing". Sensitive issues like this present dilemmas for professionals when trying to comply with the ethos of the UNCRC (1989) regarding the importance of communication with children/young people.

Within the mesosystem (Bronfenbrenner, 1979), which refers to the relationship among adult parties involved in supporting the young people, I also identified important gaps in communication in three areas: firstly between individual parents and teachers; secondly between medical professionals and the teachers; thirdly between the after school tutor and the additional support teacher.

In Scotland, the history of parents as partners with teachers in the education of children has developed in a piecemeal fashion (Prior, 2013). Tulisa's mother criticised teachers at Tulisa's school for not having respect for a parent's knowledge of their own child, a view held more generally by parents (Crozier, 2000). Tulisa's mother referred to what she felt

was specialist knowledge the teacher should have as a member of the teaching profession (Tomlinson, 2017) - that each child is different and they should be respected as such. Tulisa's mother felt as if she was always attending the school looking for support, more so than in the case of her sons. Tulisa's mother lost her trust in the teachers, as she reflected that they failed to support her daughter and to listen to her views. Direct communication had broken down between the parties for three reasons: firstly, a lack of respectful attitude being shown to the views of the parents (Hornby, 2000) which is particularly highlighted when children have issues and secondly, teachers lacked the knowledge of cleft and thirdly they had little time to discuss issues with the parent and child. Tulisa's mother perceived medical professionals specialising in cleft, had expert knowledge in this subject area and had plenty of time for one-to-one conversations on the subject. Tulisa's mother eventually requested that the medical professionals act as intermediary between herself and the school personnel to inform the latter about issues.

That teachers showed lack of knowledge of cleft was also perceived by other parents (Sam's mother, Liam's mother and Sally's mother). On the other hand, Nina's mother knew about CLAPA, the organisation providing information about cleft to parents. Information was sent from this organisation to the primary school head teacher and class teacher and this helped Nina settle into primary school with ease and to obtain support when she was absent due to an operation within the first few weeks of Primary One. This can be compared to Liam's case where Liam's mother lacked any communication with his class teachers, and additional support teacher, rendering her unsure how to go about supporting his learning and of necessity she based her support on report cards and trying to work out what he was doing in class from his books. She expected that the difficulties he experienced with literacy would be reflected in his abilities in other subject areas but had no communication with teachers to discuss the situation or to develop a shared understanding of his progress across curricular areas.

Within the mesosystem (Bronfenbrenner, 1979) there were also communication issues between the schools and the medical professionals reflected in medical literature. For example, medical researchers Richman, McCoy, Conrad, and Nopoulos (2012) commented that increased risks of young people with cleft developing reading issues should be discussed with parents by craniofacial teams, paediatricians or family practice physicians,

without any mention of communicating with teachers on this issue. In this study, there was no regular contact between medical professionals and teachers.

Despite the apparent importance of speech therapy to improve reading (Patel and Ross, 2003; Collett, Leroux, and Speltz, 2010) the specialist speech therapist reflected that generally only very occasionally was contact established between specialised speech therapists and teachers. Individual teachers in this study did not know about specialist cleft speech therapists (Sally's teacher) and none of the teachers nor the college lecturer interviewed had been in contact with the specialist cleft speech therapist. This was an issue in Sam's case where the class teacher believed extra speech therapy would have been useful for Sam to help with his literacy but she had no communication with his specialist speech therapist and there was no local speech therapy for Sam on the island. The teacher cited resourcing as an issue, with funding being particularly squeezed in relation to travelling to the islands and providing resources which could have been shared with teachers.

Hartas (2004) highlighted issues with timetabling, rigid organisational structures and the mind set of both sets of professionals who assumed contact must happen at pre-set times and in predefined places. In Sam's case the additional support teacher came to support Sam with his literacy twice a week (Sam's mother), at the period the teacher had allocated for literacy although he may also have benefited from support at other times such as while working on tests when he received differentiated test materials with more visual representations instead of text. However, this might have compromised his independence in working on tests.

Similarly there was no contact between surgical or orthodontic personnel and the teachers. This would have been useful in the sense of adding to the knowledge of treatment protocols the young people were electing to undergo in the foreseeable future and the timings of this treatment. This would have helped teachers plan for the future and in some cases in this study there were discrepancies between the recommendations for the length of absence from participating in activities and the time the child actually abstained from participation (Alex) and the suitability of the timing of absences with regard to examination preparations (Lauren).

Generally, there was little desire for contact between organisational leaders and teachers. However, in one instance, there may have been merit for a connection to be established between Sally's additional support teacher and the after-school tutor because this might have led to a joint support programme being initiated and followed. For example, the after-school tutor recommended the reading programme 'Toe-by Toe' but she was not sure if Sally was working with this at school.

Legal changes (UNCRC, 1989) within the macrosystem (Bronfenbrenner, 1979) have led to policies which suggest that the views of the child having a central position in communications with parents and professional groups. This is because the young person is now seen as an autonomous and rational agent (Oswell, 2013) who is considered as an active social agent capable of making a difference in situations (James, Jenks and Prout, 1998). However, there were a number of areas in this study where evidence suggests that the child-centred approach is challenged in practice. Canady (1995) contended there should be discussions between the cleft team and the patient and the patient's parent/carer on the timing of surgery. But, in Lauren's case, there were breaks in the communication chain between the young person and the cleft team and incomplete information was given to school officials. This communication gap may have contributed to the perception amongst school officials that if the young person had to have the operation that was a health matter. Lauren would be absent for two months during an important year in her schooling, but that was inevitable. The surgeon said there was a two-year time frame, which would have allowed the operation to be scheduled for a more convenient time. The timing would have been discussed with Lauren at the clinic and she would have been given the opportunity to ask for a different date but she clearly did not. From a wider perspective, this example shows the complexity involved in implementing the rights of the child. Lauren, at seventeen years old, made the decision but it could be contended that this was detrimental to her education. The parent could have intervened for 'protective' reasons, to ensure the school work came first especially since all parties agreed Lauren had to work hard to achieve academically. However, in the end both Lauren and her mother seemed happy with her attending the course in further education after leaving school but it could be argued the timing of surgery was controversial.

Therefore, young people with cleft are involved with a greater number of professional groups because of their medical condition. These groups sometimes have different

priorities. This study illustrated that cleft can affect relationships with others supporting the young people with cleft. For example, in individual cases, by lowering parental expectations of achievement. Issues that do occur in learning require more interaction between parties to support individual children with cleft and in some cases this causes tensions to arise. This study showed that an imperfect communication flow existed between groups of individuals: young people, parents, teachers, after-school tutor and medical professionals. This illustrated both interpersonal and interdisciplinary work may be compromised with possible implications for the child/young person with cleft.

Perhaps one of the most powerful messages from this thesis is that while it is accepted that each child and young person is an individual and that each young person should have the right to be involved in the decision making process, bringing this to bear is not without complexity.

In conclusion, young people with cleft were progressing in school on an individual basis with some individuals achieving more than others and they were attending a wide range of social activities in the same manner as young people without cleft. The self-confidence of the young people varied depending on factors within their environment which were often associated with the views of others and any negativity began when they were young and their self-concept vulnerable because at that time they were heavily influenced by the views of others. Having cleft involved dealing with a wider circle of professional groups. This involved more interpersonal and interdisciplinary working to provide the support young people with issues required. However, in this study there were gaps in communication. More frequent and higher quality interactive relations between parties, where necessary, should lead to more seamless/integrated learning experiences for young people with cleft.

The last chapter will consider the conclusions that can be drawn from the study, and will include recommendations for further action for all parties concerned in this investigation.

C H A P T E R   N I N E

CONCLUSIONS

9.1 Conclusions

This has been a fascinating study into the lives of young people with cleft. It has been a privilege to learn with and from those who took part in this study. The time they invested in this study showed their recognition of the need to learn more about cleft, and to challenge some of the perceptions around cleft in the hope that future generations of young people with cleft might benefit. This has been a learning experience for all of us. In this chapter I present the key conclusions arising from the study which I hope will inform understanding for all concerned, and future professional practice. The conclusions are cross-referenced to the recommendations section which follows and the latter is presented in numerical order.

Young People with Cleft have Important Insights to Contribute

This study contributes to existing knowledge in a number of ways. Medical professionals recognised that there was a lack of knowledge about young people with cleft as they went about their daily lives. For example, Clifford (1987, p.95) reflected "We need to know more about the behaviour of our patients when they are away from our clinics and they are engaged in more typical behaviours". Only recently, 'The James Lind Alliance Cleft Lip and Palate Priority Setting Partnership' (2012) which brings together patients, carers, and clinicians to identify and prioritise areas for future research into cleft, included research into educational outcomes as part of its twelve priorities (number two and number seven). In cleft related interdisciplinary working, Moran and Pentz (1995) argue that education, and in particular the voice of the teacher, has been missing. Perhaps most crucially, in many previous studies the young people themselves were almost invisible. They were the subjects of study and commonly their voices remained unheard (Recommendation one). Therefore, this investigation sought to deepen our understanding of the lives of young people with cleft by offering new insights into aspects of their lives - social and academic learning experiences within an educational context and to do so by listening to their first-

hand accounts. This new information could help to inform future decision making by educational and medical professionals (Recommendations two, and four).

All the young people in the study were making progress in their learning at school/college

This study challenged the view presented in the medical literature that young people with cleft were underachieving in learning. The investigation showed that the young people were making progress in learning, on an individual basis, some albeit at a slower pace than others. In individual cases, language and perhaps cognitive issues did appear to be having an impact on learning, but these were not issues being faced by every child. At interview, ten young people were unhappy about their progress in spelling, although there was only evidence this was having a discernible effect on progress in two cases, five were receiving support for their reading and four acknowledged issues with memory. Even where oral or written language or both was an issue for an individual young person, in classrooms they were using other methods (oral, written, or visual) to communicate meaning, and they were often assessed in different ways, not simply through language. In addition, the effects of problems with language were offset by approaches to learning being adopted in their classrooms. Socially constructivist approaches to learning that supported the young people's learning were common in schools and the young people who took part in this study worked successfully in pairs and groups. Each learner with cleft's oral language was at a level that enabled them to be able to work collaboratively, although some contributed more than others (for example, Sally compared to Lauren). Where there were issues with reading other group members or their partner offered help with this (Sally) and at times the learner with cleft was the child offering assistance (for example, Liam with practical work). The young people also obtained additional support in individual cases where this was necessary, although for several individuals there was a time delay before appropriate support was provided. Young people with issues in speech also found that people became accustomed to their speech anomaly over time (Recommendation three). At the senior stages of learning, issues with language were also offset by specialisation in areas of the curriculum which interested the young people. In these areas, their interest in the subject was increased, their knowledge became greater, and as they made even more progress, their self-efficacy increased in that area. Cognitive issues associated with cleft were rarely

discussed at interviews: individual teachers sometimes represented cognitive issues as a lack of focus and were unaware or unsure if these issues were associated with cleft.

This finding therefore challenges the medical perspective, that most young people with cleft will experience underachievement. Medical professionals have traditionally used a positivist approach to researching children with disabilities, focusing on the pathological deficit (Christensen, 1996) which in this case is the cleft. This approach centres on research carried out *on* the child rather than by communicative interaction *with* the child and risks drawing a sketch based on limited information, rather than constructing a full, in-depth picture of the child's actual educational experiences (for example, Barton, 1997, 2003; Slee, 1998; Dyson and Milward, 2000; Allan, 2008; Riddell, 2009). This study has shown using an in-depth, qualitative approach that the achievement of young people with cleft appears consistent with that of young people in general. Within the positivist approach, the focus remains vested within the child rather than attention being transferred to the social and physical environment the child inhabits (Lang, 2001). Positivist researchers do not consider the role of the environment in which the child is learning, the support that is offered to the young people with cleft who have issues, teachers' attitudes, teaching strategies, and specialisation within the curriculum raising self-efficacy. But these can all prove important factors in the learning of young people (Hattie, 2009). To ignore the effects of these factors could have implications for perceived achievement. Better communication between education and health professionals could support individual young people, for example, by identifying where difficulties with speech are impacting on learning but can be improved by additional access to speech therapy (Recommendations one, and eighteen).

Individual teachers lacked detailed knowledge about cleft which could delay provision of support

Although speech and appearance issues were immediately obvious to teachers, it would be less easy to identify memory and hearing issues and in this study teachers displayed little awareness of these potential factors. In language where for some there was a specific issue of 'cleft sounds' and in case studies (Sam, Sally, Liam and Tulisa) where teachers could have supported the young person's language development, they did not recognise the issue and therefore took no action or inappropriate action (Tulisa's Primary One teacher). These

gaps in knowledge could have been addressed through better communication, for example by relevant literature on cleft but teachers were neither alerted to this, nor given direction on where to find knowledge, nor offered opportunities to discuss cleft with other professionals (Recommendations ten, and eleven). Teachers simply were not aware of potentially challenging circumstances that were not immediately obvious and this could have had an impact on progress because the environmental support was delayed. This could be regarded negatively. However, more positively, the teachers encountering the child with cleft had formed no preconceived ideas about the child's ability to engage in educational experiences (Recommendation nine). This latter point was consistent with the approach of not viewing children with cleft as 'different' in the sense of difference as division (Hevey, 2004). In contrast, being alert to possible issues may enable support to be implemented more quickly, without automatically labelling the child (Williams, 1992). The extra information available for teachers would be consistent with an issue being "a learning opportunity" (Melero, Mancila, and Garcia, 2016) whilst avoiding labelling which could negatively affect the young learner's self-concept. As discussed in the next section of this study, labels can be difficult to shift, self-fulfilling and the young person may submerge under this status (Thomas and Loxley, 2001). There also tended to be a lack of understanding amongst teaching staff of their own importance in providing information on teaching a child with cleft because little was available from wider educational sources. Individual teachers suggested there must be 'experts' in this subject area, possibly within the University School of Education, who might support them in their role as teachers of a child with cleft (Recommendation ten and eleven), and that teachers could receive medical reports on the pupil they teach because individuality of medical trajectory was important in this study (Recommendation fifteen).

Labelling is a contentious issue

Six young people with cleft were labelled in a negative fashion, mainly by some of their peers, and perhaps in the minds of individual parents who found their child took longer to make progress in learning than their siblings (Recommendations eight, eleven and seventeen). In contrast, some adult participants stated clearly that they did not attach any particular implications to cleft. The issue of labelling a child in any way is a contentious one and is related to how 'difference' is perceived – either as a form of division or in terms of diversity. Labels were used in this study by some peers as a form of division,

facilitating the separation of those with cleft from their peer group, taking attention away from the person and focussing on the difference. Negative labels can have a negative impact on learning if the label leads to reduced expectations for the individual (Lindsay, Dockrell and Mackie, 2008) and provide a diversion of attention away from the work (Anderson, Bjork and Bjork, 1994). In the case of some peers this related to ignorance of the medical condition and when information was given to them some perpetrators refrained from name calling (Recommendation eleven). In contrast, other people (some peers, some teachers, and all club leaders) appeared to have moved to view difference in terms of diversity and valued the variety of individuals they mixed with, viewing this as a way of increasing their knowledge, enabling them to encounter a more representative world.

Some teachers in this study often seemed unsure of how best to approach the label of 'cleft' (Recommendation ten and eleven). They seemed unwilling to champion 'diversity' by viewing cleft as a learning opportunity for all class members because they were afraid of embarrassing young learners with cleft. No teacher interviewed sought to discuss this with the young person with cleft and to involve the individual in the decision making process. However, several teachers (of Nina and of Tulisa) were reported as presenting a different approach, seeking out and disseminating information about cleft and encouraging acceptance and diversity within the classroom. In this way the focus of interest was transferred from the label 'cleft' to moving to view the issues it may or may not create and to enable support to be provided.

Different interpretations of the word 'inclusion' could have compromised learning experiences

One of the most interesting insights to emerge from this study relates to inclusion. Central to inclusion is the concept of belonging (Oliver, 1992; Dyson and Milward, 2000) and an absence of discrimination. The young people were, on the whole, entirely in tune with this perspective. Their desire was to live their lives and to develop their capabilities without being discriminated against because of their cleft.   This differed from the interpretations of teachers. They spoke positively about the idea of inclusion and said they were committed to that idea. However, in many cases they viewed inclusion in terms of equality of treatment for everyone in their class, rather than equity meaning that all young people would be treated differently, according to their needs. Finally, there was a third

interpretation of inclusion: how inclusion was enacted within the school system. All the young people in this study were attending their local primary or secondary school and were thus included within their community of learners. However, there were subtle differences within schools and these challenged the views of teachers that they were enacting inclusive principles. Several young people with cleft were removed from the main teaching area for support and whilst on the surface these young people were on the class register and therefore 'in' the class, they were not 'of' the class (Ferguson, 2008). Another variation of this separation was apparent within the class in terms of seating arrangements (Slee, 2014) where in a number of cases, children were grouped together because of their requirement for additional support (Recommendation twelve). There may have been good administrative reasons for these arrangements, for example, for classroom management. However, the reasons for these practices were not articulated as being designed for the benefit of the child. Two teachers in this study suggested they would prefer children grouped by ability rather than age. Although the focus of this study was young people with cleft, these last points raise more general questions around ideas of inclusion, of mixed ability teaching, and of attitudes to teaching every child within the same classroom area with the same curriculum framework (Melero, Mancila and Garcia, 2016). There still seems to be confusion about inclusion particularly about the implementation of the concept and this needs further dialogue amongst educational professionals to gain maximum benefits for young people with cleft.

The expectations of the three adult groups directly supporting learning differed

The expectations of potential achievement of young people with cleft was different between the three groups of adult participants – parents, teachers and club leaders. Parents, varied in their expectations depending on their early experiences with their child, but if cleft related issues remained as the infant matured to early primary school stages the parents anticipated problems arising at school and were eager to inform others, including teachers, about cleft to try to counter difficulties they envisaged might happen. This could be perceived to be highlighting 'difference'. However, the proactive approach could work for the individual to prevent the young person being disadvantaged (Nina) and could be argued as being simply a recognition of 'diversity'. All parents interviewed whose children went on to have issues recommended that teachers be informed about the cleft condition from the start of primary schooling (Recommendation ten and fifteen).

Teachers' expectations could have been influenced by the speech and appearance of the young people but all teachers and the college tutor reflected that their approach was an inclusive one with everyone being viewed equally. However, some teachers did agree with the separation of young people with cleft since they felt this offered targeted support. This exclusion from the main classroom area is not consistent with inclusive practices.

Interestingly, it was the clubs which provided the most inclusive learning environment and staff held no special expectations of young people with cleft as regards achievement or engagement. Young people with cleft communicated satisfactorily with peers and instructors. They were not compared to peers and everyone learned at their own speed and level, without labelling others. Staff working with clubs received no previous training nor had they been involved in formal discussions about the concept or implementation of inclusion. In fact, here inclusion was not implemented consciously as a policy but rather appeared to happen naturally as part of everyday life experiences.

Expectations of learners with cleft differed within the three adult groups supporting the learners. Parents adjusted differently to having a child with cleft but some experienced residual trauma long after the birth (Lucy) and others were uneasy about the implications of having a child with cleft. Teachers said they treated everyone equally, were inclusive and did not form preliminary opinions on the abilities of children who look or speak differently but some young people with cleft were separated from the main classroom. Club leaders had no preconceived notions of achievement and assumed all young people could attempt their learning activities. Some parents may need support and more information is needed to reassure parents that young people with cleft can achieve in their learning. (Recommendations eight, sixteen, and seventeen). Teachers are encouraged to think through their interpretation of 'inclusion'.

The educational and medical worlds may approach inclusion differently

Furthermore, the educational and medical worlds are part of a wider society which is apparently supportive of inclusive practices. Yet, the idea of individuals 'fitting in' because they look and sound 'normal' which seemed to be a priority for the medical community might seem to be in tension with more recent educational thinking about

inclusion. This study illustrated that in the movement from 'difference' as interpreted as division to 'difference' as diversity providing a source of new energy and variety, as a society, we still have some way to travel. This may be aided by professional groups sharing information. (Recommendations fourteen, fifteen, and eighteen).

There is a lack of discussion amongst all parties involved in cleft and education

Young people with cleft interact with a wider range of professionals than most children, but evidence from existing literature and from the data gathered for this study suggests that there is generally little discussion between medical and educational professionals working at the interface between the two areas. This is despite policy initiatives such as 'Getting It Right for Every Child' which is "a common, coordinated approach across all agencies that support the delivery of appropriate, proportionate, and timely help to all children and young people as they need it" (Scottish Government, 2009a).

Evidence from the data suggests that discussions amongst professional groups, parents and the child would be helpful for all in terms of understanding different perspectives, for the enhancement of professional practice, and for recognising and taking account of the views of the young person. Organising effective collaborative process can be challenging (Head, 2003) not least due to time constraints. But as Head (2003, p.51) pointed out "effective collaboration has a propensity to become greater than the sum of its parts". There may be particular issues in times of austerity for those working in more remote locations nevertheless technological advances at least make dialogue easier to arrange even if physical resources are harder to acquire. There seems to be a tendency for the voice of the child to be absent when issues occurred in the educational setting. The child and parent could now be included within the interface (Bronfenbrenner, 1979).

However, it must be recognised that some parents may be unwilling to engage in dialogue with professionals to overcome challenges because they have been negatively affected by the experiences they have faced in the past during the initial years of the child's life. Parents may require support to engage fully in consultation and discussion processes and a sensitive approach by professionals will be necessary to help parents to become fully engaged in the dialogue.

There is a lack of discussion amongst all parties involved in education and cleft and the experiences for young people with cleft could be improved by further sharing of information between members of groups separately (Recommendation five) and between the different groups involved (Recommendations six, seven, thirteen, and sixteen).

9.2 Recommendations

In many ways, this study represents only the beginning of a new area for research. This was a study that sought to influence and is a starting point for discussion within and amongst the communities that form the focus of the recommendations. The experiences of children with cleft appear to suggest the following areas warrant further consideration. These recommendations are at system level, they are for those involved in creating positive environments in both educational and medical contexts. The areas are classified into those which affect the child, the parent, the teacher and the medical staff.

9.2.1 Focussing on the Child

1. The views of the child, in recognition of the UNCRC (United Nations, 1989), should be placed at the centre of decision making and acted on wherever possible. The child should be able to review what actions have been taken and play a major part in making subsequent decisions. This, along with joint discussions with parents, educational and medical professionals where appropriate will encourage a more inclusive society because the voice of the child and those concerned with their wellbeing will all be heard. I am aware that current legislation and policy already supports this but practice may not yet reflect the true levels of child-centredness implied by the legislation.

2. Children if they wish should be encouraged to inform peers and adult groups about their medical condition as this could help promote the movement towards recognition and appreciation of 'diversity' within our culture.

3. If there are speech issues it would be helpful to the child to have continuity of teaching staff over several years, because they will become accustomed to any minor speech anomaly and this can be reassuring to the child. This would be

particularly useful at the primary stages of education where, in individual cases, speech therapy is still continuing.

4. Children and young people should be facilitated in making choices within their learning of curricular areas and where possible choice of ways of presenting information and engage in discussions on methods of assessing their learning (Hayward, 2012). There should also be regular discussions between the child and teachers regarding any additional support which could be helpful and evaluations of existing support that is in operation.

9.2.2 Focussing on the Parent

5. Parents should be made aware of evidence such as that coming from this thesis to emphasise that children with cleft are children first and to be aware of the dangers of labelling. Head teachers should continue to stress to staff the importance of effective communication with parents, recognising the value of the wealth of knowledge about their child which parents bring to school.

6. Parents should be made aware of the member of staff they should contact in the case of any concerns about their child; in secondary schools this may be pastoral care staff.

7. Parents should continue to be encouraged by medical personnel to enrol their child in early learning and childcare provision prior to entering primary education, to help the child build a friendship circle which would encourage social interaction, speech opportunities and have the potential to reduce teasing/bullying as the child matures.

8. In individual cases where there are issues, parents could be offered appropriate support in understanding the implications of cleft in the short and long term and to help with recognising the 'normality' of the range of emotions and reactions they may be experiencing.

9.2.3 Focussing on the Teacher

9. Teachers, should be made aware of possible issues related to cleft but should not automatically expect these to occur since each case with cleft is unique.

10. Teachers should be supported by being made aware of where information may be easily obtained, for example, the CLAPA website, and the 'Changing Faces' website. Teachers with a particular interest in cleft could be encouraged to read the Cleft Palate Craniofacial Journal to keep their knowledge updated on medical developments in cleft and to write articles for educational and medical journals about their experiences.

11. Cleft organisational representatives from CLAPA could provide continued professional development (CPD) for teachers of a child with cleft. In addition, presentations to young people in schools within the social and personal education curriculum could foster a more inclusive society by giving information about cleft and encouraging discussions about 'diversity'. This would need to be done sensitively, with consultations before the presentation if there was a child at the school with cleft. Video presentations by representatives from CLAPA could be helpful, particularly for schools in more isolated locations.

12. For young people with cleft who have need of additional support, teachers should try to maintain these young learners within the main teaching environment to foster an inclusive working environment.

13. Teachers should be facilitated to engage in inter-agency working especially with speech therapists. New opportunities with technology, for example, SKYPE, might be utilised to make this a real possibility.

9.2.4 Focussing on Medical Personnel

14. It may be valuable for the Scottish national cleft network to offer information about cleft to local education authorities.

15. The surgeon could, with parental and the child's permission send copies of audit reports at three stages in the development of the child – age three, age five and age ten – to schools for information. This information could contain factual details of treatment completed, perceived future procedures with timings including expected recuperation periods and any useful supplementary material that may enable informed decision making by educational professionals.

16. To enable every parent to support their child most effectively, all parents should have access to comprehensive, updated information about cleft in one-to-one discussions with fully trained medical professionals especially where issues have arisen. This personalisation of information is a crucial part of helping to deepen understanding of the personal nature of experiences of cleft and beginning the process of helping to empower all parents in supporting the child. This process also needs to be developed in partnership with schools.

17. Organisations like CLAPA, who have the potential to build up an extensive database of individual children's experiences in schools could offer advice to parents on what matters in promoting good educational experiences for the child in school.

18. Where the child and parents agree, head teachers, particularly of primary schools, could send copies of reports to the cleft medical team to better inform the medical staff of the child's progress. It would impact more on the primary school stage, because speech therapy and operations are still ongoing whereas by secondary school these tended to be resolved.

9.3 Contribution this study makes to knowledge

There has long been a desire amongst medical professionals for information about how their young patients with cleft have been engaging with everyday life experiences. This is the first study undertaken to explore the progress in learning of young people with cleft, by an educational professional, using qualitative methodology, listening primarily to the voices of the children. This study encompasses both social and academic learning experiences.

This study challenges the medical profession's perception of alleged underachievement of young people with cleft and provides empirical evidence to support the view that all young people within this study were making progress in learning, albeit at different speeds. The empirical evidence came from both documentation from the national examination board and from primary sources - the young people themselves and adults supporting them.

This investigation challenges the view that young people with cleft are not active participants in social life and by exploring their social activities it highlights the differences between academic and social learning.

The study highlights the individuality of the child's medical and learning trajectory and explores how labelling a child might be counterproductive for future advancement in learning.

The study identifies areas where increased inter-professional dialogue could be improved for the benefit of the young person. It has also highlighted the benefits of placing the views of the young person at the centre of decision making whilst recognising the complexity associated with this action.

9.4 What I would have done differently

If I was to undertake this research study again I could have done several things differently. Firstly, I would have trusted the young people more. I could have constructed the interview schedule for the oldest group in a less prescriptive manner, perhaps with simple headings based on the literature. This would have allowed the young people to take more control of the interview and guide the discussion in a way that suited them. However, this could have resulted in the discussion moving off task and not fulfilling the remit of the study. With hindsight, it would have been worth taking this risk.

Secondly, I could have interviewed the siblings and/or a sample of peers of the children as this may have offered further insights and perspectives.

Thirdly, I could have interviewed the additional support needs teachers to gain further knowledge on the support that was being provided.

9.5 Suggestions for future research

The following topics have been identified as possible areas for future research:

- A longitudinal study three years ahead with some of the sample participants from this study to follow up themes raised in this study.
- Further investigation into parenting the child with cleft, with emphasis on educational and medical experiences.
- An investigation of the writing of young people with cleft, to include the role of fine motor movement.
- An evaluation of different forms of additional support, including technology, which have been implemented to help young people working in an educational environment.
- Further collaborative studies involving teaching and medical staff working within this area.

9.6 My personal journey

I set out on a journey of exploration of the educational experiences of young people with cleft lip and/or palate in respect of their progress in learning. From my previous teaching experiences I had formed the view that young people with disabilities could achieve success in their learning. However, medical literature based on cleft tended to suggest otherwise, identifying possible causes for underachievement.

From my own point of view, there were two pivotal points on my journey as this study unfolded. The first point occurred during the interviewing of the young people. A significant number were not raising issues relating to cleft or they were indicating that they were only affected in a minor way. This challenged my original expectations which had been coloured by the medical literature on which I had focused. The second point arose at the completion of the interviews of the eight senior pupils. An investigation of their examination results revealed a range of results similar to what a sample of young people in general would be expected to achieve. It became clear that what was important was to recognise the individuality of each young person's learning trajectory, paying particular

attention to the complexity of the learning experiences and context rather than focussing primarily on the cleft as the defining factor in relation to educational progress.

On reflection, society tends to be divided into groups and I wondered if in my choice of subject to investigate, I was influenced by societal stereotyping because I had chosen a group who could be identified with a medical label to be the focus of my research. In retrospect, perhaps I should have instead investigated issues and the contexts the young people who formed the focus of this study experienced rather than approach this from the label 'cleft'.

Perhaps the major, overall finding of this fascinating study is that, as with many other 'labels', cleft is a secondary or in some cases almost irrelevant factor in children's educational progress and that all children and young people with cleft are children and young people first. Simple as this idea sounds, and it was clear the young people themselves understood that, it appears that as a society we are still some way from recognising the full implications of that statement and respecting them for who they are.

Richman (1983) said there was no identifiable 'cleft personality' and that, medically, each case was different in respect of surgical, and orthodontic treatment and speech therapy. There was no identifiable group called 'cleft' with an expected medical trajectory. Educationally, I rejected the medical model because it was reductionist and viewed cleft from a 'deficit' point of view. Instead, I adopted a constructivist model, building knowledge about a group called 'cleft' but I also found no identifiable trajectory in learning. Instead, individual learning journeys were at times characterised by issues for transient time periods and these may be linked to cleft. This fluidity and the complexity of each case led me to reflect that the evidence this study produced was more consistent with Slee's (1998) postmodern model of disability, documented on page eighteen, which rejects the notion of one collective group of people labelled 'disabled' and in a similar way I rejected one coherent group called 'cleft'. This lack of an identification of a group called 'cleft' in turn reinforced the need for all of us to get to a stage in our thinking where there is a realisation that we are all different in different ways and each individual should be accepted for who they are. I am grateful to the young people who participated in this study for demonstrating this so clearly.

Appendix One

INTERVIEW SCHEDULE

For five year olds

- **In what ways does having cleft lip and/or palate impact on young people's experiences in school?**
  In class, what kinds of things do you like to learn?
  What lessons do you have in class which you don't like?
  Do you have a grown-up, special helper in the school?
  Tell me about playing with your friends in the playground – what do you like doing?
  Do you go to any school clubs like swimming club or learn how to play a keyboard or sing?
  How do you feel about going to the hospital at times instead of school?

- **In what ways do cleft lip and/or palate impact on educational experiences which young people have outside school? (These experiences will be limited to those that come within the spheres documented in Curriculum for Excellence publications).**
  Tell me about your hobbies/fun things you do outside of school.

- **In what ways do cleft lip and/or palate impact on young people's perceptions of themselves as learners?**
  Do you try to answer the teacher's questions or do you sometimes feel too shy to answer?
  How do you feel if you give a wrong answer? Why?
  Can you always hear what the teacher is saying?
  How do you feel about learning new things?
  In class, do you like to work together in your group or do you like to work on your own?
  Do you ever get into trouble because you have behaved badly in class?
  Do teachers ever praise you for what you do? Can you tell me about when that has happened?
  Have you ever been teased in school?

- **In what ways do cleft lip and/or palate impact on relationships with significant others who are working directly or indirectly to enhance the educational achievement of the pupils?**
  Who do you ask for help when you have a problem with your work in class?
  Do you get homework?
  Does your Mum or Dad or the person who looks after you at home help you with your school work?
  What happens to you at school if you don't do your homework?

If you are off at hospital, does someone at school help you catch up with school work?
Do you get help from the speech therapist at the hospital or at school?
Do you talk to the surgeon about how you are getting on at school?

- **To what extent does cleft lip and/or palate impact on attainment in school?**
  In class, do you sit in a special group? Tell me about your group.
  Is your work ever hung up on the wall of the classroom?
  Do you think you are doing well in your school work?

INTERVIEW SCHEDULE

For nine to eleven year olds

- **In what ways does having cleft lip and/or palate impact on young people's experiences in school?**
  What kinds of activities do you like doing in class?
  Are there things in class that you are asked to do that you don't like doing? Why don't you like doing them?
  If you get any special help in school, do you like learning with your special teacher in class or in another room in the school where you are on your own?
  Tell me about any fun things you do at school outside lessons, perhaps with your friends - (eg sports, music, computer club, drama)
  Do you think that going to the hospital for check-ups or operations has affected your class work?
- **In what ways do cleft lip and/or palate impact on educational experiences which young people have outside school? (These experiences will be limited to those that come within the spheres documented in Curriculum for Excellence publications).**
  Do you take part in any clubs or activities outside of school? For example, Guides, Scouts, BB or Youth Club, Sports Club, Learning to play a Musical Instrument?

  Do you ever help out in the house?

- **In what ways do cleft lip and/or palate impact on young people's perceptions of themselves as learners?**
  Do you try to answer the teacher's questions or don't you try to answer them?
  How do you feel if you give a wrong answer? Why?
  Can you always hear what the teacher is saying?
  How do you feel about learning new things?
  Do you prefer to work in groups or alone in classrooms?
  Do you ever take the lead/take charge of a group?
  Have you ever been in trouble for your behaviour?
  Do teachers ever praise you for what you do? Can you give me an example of when this has happened?

Are you usually finished your work quickly?

Do you think about what you have learned afterwards?

Have you ever been teased in school?

- **In what ways do cleft lip and/or palate impact on relationships with significant others who are working directly or indirectly to enhance the educational achievement of the pupils?**

  Who do you ask for help when you have a problem with your work in class?

  Do you get homework? Who helps you with this if you can't do it yourself?

  What happens to you at school if you don't do your homework?

  If you are off school because of a hospital appointment or operation, does someone at school help you catch up with school work?

  What kind of help do you get from the speech therapist?

  In what ways have your operations and dental treatment (orthodontic) helped you in your work in class?

  Do you ever talk about how well you are getting on at school with the surgeon?

- **To what extent does cleft lip and/or palate impact on attainment in school?**

  Do you sit in a special group in class?

  Do you think you are doing well in your class work? Why do you think that?

  Is it important to you to do well in your class work?

  Is it important to you to do well in any test you take for your hobbies?

  Which is more important – to do well in class tests or to do well in tests for hobbies? Why?

  Do you prefer tests where you speak the answer or ones where you write the answer down?

  Do you find it easy to remember information for tests?

  Do you like tests that involve solving puzzles?

  What job would you like to do when you leave school?

INTERVIEW SCHEDULE

For fifteen to eighteen year olds

- **In what ways does having cleft lip and/or palate impact on young people's experiences in school?**

  What subjects do you like learning about at school?

  Are there things you are asked to do in class that you don't like doing? Why don't you like doing them?

  Do you receive any extra help from a learning support teacher? If yes, where does this help take place?

  Tell me about any social activities you take part in at school, with your friends.

  Do you feel that attending hospital for regular appointments and/or for operations has affected your school work?

- **In what ways do cleft lip and/or palate impact on educational experiences which young people have outside school? (These experiences will be limited to those that come within the spheres documented in Curriculum for Excellence publications).**
  Tell me about any clubs or activities you take part in outside of school, for example, sports clubs or dancing lessons.
  Tell me about anything you might do to help out at home.

- **In what ways do cleft lip and/or palate impact on young people's perceptions of themselves as learners?**
  During a lesson, do you try to answer the teacher's questions or do you not do so?
  How do you feel if you make a mistake and get the answer wrong?
  Have you ever had a problem hearing what the teacher has said?
  How do you feel about learning new things?
  Do you prefer to work in groups or alone in classrooms?
  Do you ever take the lead/take charge of a group?
  Have you ever been in trouble for your behaviour?
  Do teachers ever give you praise? Can you give me an example of when this has happened?
  Do you keep up with the work pace of the class?
  Do you reflect on the work you have learned afterwards?
  Do you believe teasing/bullying to be a problem for pupils with cleft?
  Have you ever asked for a surgical procedure to be carried out? If so could you tell me why?

- **In what ways do cleft lip and/or palate impact on relationships with significant others who are working directly or indirectly to enhance the educational achievement of the pupils?**
  If you have a problem with class work who do you ask for help in class?
  Are you encouraged to do homework by your parent/carer?
  Does your parent/carer help you if you have problems with your homework?
  What happens to you at school if you don't do your homework?
  If you have to attend hospital for routine appointments or operations, does anyone help you make up the work you miss at school?
  If you are receiving speech therapy, in what ways do you think this is helping you to cope in class?
  In what ways have your operations and dental treatment (orthodontic) helped you in your work in class?
  Do you ever discuss your progress at school with the surgeon or orthodontist?

- **To what extent does cleft lip and/or palate impact on attainment in school?**
  What leaving certificate (SQA) examinations are you studying for?
  Why did you choose these subjects?

Subjects like English, Maths, RE and PE are compulsory. Do you agree with this?
Which subjects are you doing well in? Which subjects, if any, are causing problems?
How important do you think it is to be successful in these examinations?
Which is more important – to do well in the SQA exams or to do well in tests you might take relating to your hobbies?
Do you prefer oral or written tests?
Do you prefer one large exam at the end of the course or shorter tests at the end of each unit?
Is it easier for you to take tests which involve remembering information or do you prefer tests which involve problem solving?
What are your long term ambitions for when you leave school?
Is there anything else you would like to add about learning in school or when you are involved with your hobbies outside of school?

Appendix Two

CHARACTERS THAT FEATURED IN INTERVIEWS

Surgeon Bear and Teacher Bear

Snow monster

Dotty the Dalmatian and Sandy the Doggie (hand puppets)

Magic the Dragon (above)

Skull (to the left)

Some items carried in a school bag for reading, writing, sums

Engaging in technological pursuits

Enjoying music.

Playing sports

Appendix Three

P L A I N   L A N G U A G E   S T A T E M E N T

TO BE READ TO YOUNG CHILDREN (EARLY PRIMARY SCHOOL STAGE)

We are asking pupils between the ages of five and eighteen if they will help us. We are trying to find out what it is like to be learning in school and sometimes have to go to hospital to get help from the doctors and speech therapists who work there. We hope to talk to twenty-four pupils.

If you decide you want to help us then we would ask you to give us your story of what school life is like for you, all the good things you enjoy and any problems you feel you have had to face. We would also like you to speak about how any hospital visits have affected your life at school.

Nobody will know what you say to us. We will not tell your teacher or the doctor or speech therapist. You can pick another name for yourself so nobody knows who you really are. We will make a note of your answers. This will take no more than forty minutes.

At any time during our talk with you, you can decide you want to finish talking. You can choose to help or not help but whatever you decide will not affect your school life or what happens to you at the hospital in any way.

We might think that some things you say are extra important and ask you to have the researcher back to see you for another visit. We will then ask some extra questions on the answers you gave the first time we met you. It is likely this will only happen to six pupils.

We will prepare a report based on what all the pupils have told us. We will send you a copy of the main points that we have found.

We are asking for your help, because your answers matter to us. Please take time to think whether you wish to talk to us.   If you want to find out more about this, or have any questions, please ask an adult to email us or ask an adult to phone us at one of the following numbers:

Email: a.giffen.1@research.gla.ac.uk

l.hayward@glasgow.ac.uk   or   margaret.mcculloch@glasgow.ac.uk

or Phone: 0141 330 7501 or 0141 330 3090.

Alicia Giffen MA M Ed,   Researcher

Appendix Four

QUESTIONS FOR PARENTS

I'd like to ask you some questions about what happened before the child started school/club or organisation:

1. How long has your child attended their current school/club or organisation?
2. What information were you given from the school or hospital personnel specifically relating to the education of a child with a cleft? Was it adequate and if not how could this be improved?
3. Could you reflect on any possible benefits of consulting different sources of information about educating a child with a cleft? For example educational or medical journals or organisations such as CLAPA or 'Changing Faces'?
4. If you were offering advice to a parent of a child with a cleft who is just about to start school/club or organisation, what would you say to that parent?
5. In the local area, what attitude do young people generally have towards learning at school/attending clubs and organisations?

I'm going to ask you some questions about the curriculum

1. Can you reflect upon the value you attach to various areas of the school curriculum? [use curriculum for excellence categories, provide copy to help parent]
2. In your opinion, which areas of the school/club curriculum does your child show strengths/weaknesses?
3. Which subject areas do you think they enjoy?
4. What challenges has the young person with cleft faced when attempting to learn the curriculum?
5. Would you care to comment on the progress of your child in the following language areas:
   - Speaking
   - Reading
   - Writing [includes spelling]
   - Listening
6. Could you describe any issues your child with cleft has had when problem-solving in Maths/involving number work?
7. Can you reflect on any special knowledge and experiences that young people with cleft can share with their fellow learners to increase the knowledge of all?

The next questions are on teaching and learning strategies:

1. To what extent are the learning experiences of the pupil with cleft similar or different to the learning experiences of their siblings? To help me

understand ... Can you give me one or more examples of what evidence you used to make that statement?

2. Can you describe the role the parent plays in the learning of the young person? Does this vary for youngsters with cleft?

3. In your view, to what extent is the method of presentation of information to the learner with a cleft important?

4. Are there any considerations which should be borne in mind when testing the learner with cleft?

5. What approach do you think should be adopted towards oral work for the learner with cleft?

6. Are open plan teaching areas and composite classes suitable for learners with cleft? To help me understand, can you give me a reason why you hold this view? What do you think about pupils with cleft learning through open air activities?

7. Could you describe any impact that absence from school/club or organisation might make in your child's progress?

8. In your opinion, would your child's learning benefit from working as part of a group when at school/at a club or organisation. Are there any specific challenges they might face?

9. Are there any advantages or disadvantages which might be experienced by your child with cleft if they are working alone?

10. The next questions are on working as part of a group at home.
    What part does the young person with cleft play in the household team? Can you give me some examples to support your opinion?

11. Can you comment on:
    - the help they receive from other household members
    - the help they give other household members
    - the pace at which support is withdrawn as they overtake their new learning?
    - Under what circumstances has the young person adopted a leadership role at home? Can you give me an example?

12. From your experience as a parent can you give any examples of how your child with cleft might reflect on the steps they took to succeed in their new learning so they can repeat this again next time?

13. At home how do you check that the child with cleft achieves a deep understanding as they go about their learning?

The following questions concern additional support which the young person might receive in class or at the club:

1. To the best of your knowledge in what ways is your child working in a supportive and inclusive learning environment at school/college/club or organisation?

2. Can you describe any additional support they are receiving in class/at the club or organisation?

3. Can you comment on what you think are the positives and negatives of these additional measures and are they sufficient?

4. Have you come across any psychosocial effects of the pupil having this 'special treatment'?

Secondary School/College

5. How does provision at secondary school/college compare with what they received at the primary stages/secondary stages?

6. Has the amount of support required for your child in their learning tasks changed according to their age? Could you expand on your answer?

Support at home

1. In what ways do you offer support to your child in his/her learning?

2. Can you compare the support offered by you to your child with a cleft and that offered to their siblings without cleft?

I'm now going to ask you about your child's social learning

1. Tell me about your child and their friendship circle? Are there any differences between the friendship circle at school and at the club/organisation?

2. Cleft lip and palate is characterised by a visible difference whereas cleft palate only by an invisible difference. In your view, what, if any, significant differences could there be when interacting with others?

3. Would you say your child was a 'spectator' or a 'participant' in outside social activities? Can you give reasons for your answer?

4. Could you describe for me any incidents of teasing/bullying that your child has experienced at school or outside activities? In what ways have they shown resilience to overcome these events?

5. Tell me about any measures the school/club/organisation has put into place to deal with any teasing/bullying incidents?

6. What advantages might there be in asking representatives from CLAPA or 'Changing Faces' to visit the school/college/club/organisation to inform young people in general about cleft? Or should the pupil/student with cleft explain by giving a talk on the medical condition?

7. Generally speaking, how would you describe the behaviour of your child? Please give me some examples to show this?

The next questions are on medical treatment and learning

1. Could you describe your feelings about the medical help that your child has received:

- speech therapy,
- surgery and
- orthodontic treatment

concentrating particularly on the benefits or problems created for the child in his/her learning?

2. How has the medical treatment and experiences the young person has received affected their approach to life in ways which might be relevant for learning at school?

The final questions are about progress in learning

1. What qualities would you say a successful learner should have?
2. Can you give examples of when your child has displayed these qualities?
3. How successful do you think your child is in his/her learning
   - at school
   - while attending the club/organisation?
4. Can you tell me on what basis you have formed this opinion on their success?
5. Could you give me your definition of the word 'underachievement'?
6. What ambitions do you have for your child's future? Have these changed over the years?
7. What three things would you suggest the hospital could do which might improve the learning experiences of the child with cleft?
8. Could you suggest three things the school might do which may improve the learning experiences of the child with cleft?
9. If there were three things the club might do which may improve the learning experiences of the child with cleft, what would they be?
10. Could you comment on the links between home/hospital/school or club and how these might be improved?

Is there anything else that you would like to tell me about your child's experiences of learning while coping with a cleft?

CASE STUDY QUESTIONS FOR TEACHERS/LECTURERS

Before the child/young person started in your class/school/college:

- For how long has the young person attended your school/been in your class or college?
- What information were you given from the parents/carer or hospital personnel (surgeon/orthodontist/speech therapist) specifically relating to the education of a child/student with a cleft? Was it adequate and if not how could this be improved?

- Could you reflect on any possible benefits of consulting different sources of information about educating a young person with a cleft? For example educational or medical journals or organisations such as CLAPA or 'Changing Faces'?
- Can you trace your impressions about the education of the learner with cleft beginning before they started school/your class/college through to the present day?
- In the catchment area of your school/college what attitude is generally prevalent amongst young people towards learning at school/college?

The following questions are about the Curriculum:

- What does your **College course/ (Secondary)** subject area/**(Primary)** Language/Mathematics/Practical subjects have to offer young people?
- Would having a cleft raise any challenges for the learner in your **Course classes/(Secondary)** subject/ **(Primary)** Language/Mathematics/Practical subjects?
- Which areas of the curriculum do you think the pupil with cleft might have a natural preference for?
- **Secondary schools** – In what ways do you think any area preferences may affect the subject choice of pupils with a cleft when they come to select subjects to study for SQA qualifications?
- Can you reflect on any special knowledge and experiences that young people with cleft can share with their fellow learners to enrich the curriculum of all?
- Could you comment on the following language skills of the pupil/student with cleft:

1. Speech
2. Reading
3. Writing (including spelling)
4. Listening

- Can you describe any issues the pupil/student with cleft has had when problem-solving in Maths/involving numeracy?

Now for some questions about teaching and learning strategies:

- To what extent are the learning experiences of the pupil/student with cleft similar or different to other people in the class? To help me understand ... Can you give me one or more examples of what evidence you used to make that statement?

- Could you describe the role of the teacher/lecturer in learning? Does this vary for learners with cleft?

- Gardner stated that there were many different types of intelligence. In what ways have you adapted your teaching strategy and/or your materials to accommodate different types of learners in your class? What adaptations do you think would be specifically beneficial for learners with cleft? Could you give me an example?

- What adaptations might you make to the assessment instrument to match the classroom preferences of young people with cleft? Could you give me an example of this?

- In what way do you go about encouraging deep understanding of the learning during whole group teaching and learning sessions?

- What approach would you adopt towards oral discussion/presentations/reading aloud and young people with speech problems?

- How do you go about checking that the learning of the task/activity is secure?

- From the point of view of the pupil/student in your class:

    1. How important is group/pair work in your class's learning journey?
       Primaries – for what kind of subject areas do you use group/pair work regularly?
    2. Is the pupil/student with cleft an active participant in group/pair work? What evidence can you cite to support your opinion?
    3. Are there any specific challenges a learner with cleft might face when engaging in group/pair work?
    4. In relation to the learner with cleft, can you comment on:
        a. Scaffolding they receive from other group members/pair
        b. Scaffolding they provide to help other group members/pair
        c. The pace at which scaffolding is withdrawn as learning becomes more secure?

    5. What evidence is there that the pupil/student with cleft engages in reflection on learning [metalearning] with other group learners?

    6. In what ways does each group/pair report back their findings?

    7. Does the pupil/student with cleft ever adopt a leadership role? Could you give examples to support your answer?

- In your opinion, are there any advantages or disadvantages for pupils/students learning alone through interaction with the environment? Would these also/especially apply to the learner with cleft?

- In what ways might the classroom organisation within the school/college be important for learners with cleft – for example, several classes in open plan area, composite classes, learning in the open air?

- What happens if the pupil/student with cleft is absent (daily appointments, short term, [up to three days] or longer term for operations)? Does that affect group work?   Is it an argument for individualised learning?
  For secondary schools – Does absence become more of a factor as the pupil progresses from junior to senior stages of secondary education? Can you give me reasons for your answer?

The next questions are about additional support needs:

- In what ways is the young person with cleft in your class learning in a supportive and inclusive environment? For example, tell me about any additional support arrangements put in place for **other** pupils/students in the class?
- Can you describe any procedure/equipment that has been put in place to enable the learner with cleft to access the curriculum?
- **[for S1 entrants from primary or college entrants from secondary schools**: During the transition of these pupils from primary to secondary school/secondary school to college, what information and equipment did the primary/secondary school provide for these pupils/students to adapt to learning at secondary school/college?]
- Can you comment on the positives and negatives of extra procedures/equipment and how they are operated? In your opinion are these procedures/pieces of equipment sufficient to help the learner with cleft?
- Can you describe any psychosocial issues which have come from the additional support offered?

The following questions refer to social learning:

- Tell me about the learner with cleft and their friendship circle?
- Cleft lip and palate is characterised by a visible difference whereas cleft palate only by an invisible difference. In your view, what, if any, significant differences could this bring about when interacting with others?
- Would you say the learner with cleft was a 'spectator' or a 'participant' in social activities? Can you give reasons for your answer?
- Can you describe any incidences where the learner with cleft has complained about teasing/bullying? What was the outcome?
  Can you give examples of any form of resilience or coping strategy invoked by the pupil to deflect any negativity relating to teasing/bullying/lack of confidence?

- Tell me about the school/college policy on teasing/bullying and your views on the robustness of this policy to deal with issues the pupil with cleft might have?
- Has the school/college ever encouraged speakers from organisations such as CLAPA or 'Changing Faces' to actively inform all pupils about the cleft condition or asked the learner with cleft to give a presentation to explain their medical condition?
- Could you reflect on the behaviour of the learner with cleft in and around the school/college? Upon what evidence have you formed your opinion?

Finally, some questions about progress in learning

- What qualities would you say a successful learner should have?
- Can you give any examples of when the pupil/student with cleft has displayed these qualities?
- Can you describe how you feel the young person with cleft in your class is progressing in their learning?
- On what evidence do you base your opinion?
- What would be your definition of 'underachievement'?
- What expectations do you have for the future for the learner with cleft in your class?
- Has any medical treatment the learner with cleft has had helped/hindered their progress in learning?
- If you had to choose three things you would change about your school/college to make the learning experience better for the pupil/student with cleft, what would they be? Why?
- What changes would you suggest to improve the links between school or college/home and hospital to make the whole learning experience better for the learner with cleft? Can you explain why, in your opinion, these changes would be beneficial?

Is there anything else that you would like to tell me in relation to learning in school/college while coping with a cleft?

CASE STUDIES - THE CLUB/ORGANISATIONAL LEADERS

Before the child/young person started at your club/organisation:

1 How long has the young person been a member of your club/organisation?
2 What information were you given from the parent/carer or hospital personnel specifically relating to the acceptance of a member with a cleft?
   Was it adequate and if not how could this be improved?

3   Could you reflect on any possible benefits of consulting different sources of information about having a young person with a cleft as a member – for example, CLAPA or 'Changing Faces'?

4   If you were offering advice to another club leader about welcoming a new member with a cleft what would you tell the other club leader?

5   In the local area, what attitude do young people generally have towards membership of clubs/organisations?

I'd like to ask you some questions about learning the curriculum of your activity:

1. What would you say the activity/organisation you are involved with has to offer young people?

   - Knowledge

   - Skills

   - Personal character development?

2. What type of challenges might the cleft raise in your activity when the member is trying to learn?

3. What types of tasks does the young person with cleft enjoy at the club/organisation?

4. Can you reflect on any special knowledge and experiences that young people with cleft can share with their fellow learners to add to the learning of all members?

Now for some questions about teaching and learning strategies:

1. To what extent are the learning experiences of the pupil with cleft similar or different to other learners in your activity? To help me understand ... Can you give me one or more examples of what evidence you used to make that statement?

2. Could you describe the role of the instructor in learning? In what ways might this vary for learners with cleft?

3. In general would you adapt your materials or teaching/learning to suit a variety of learners? In what ways might you have considered adapting your materials or teaching/learning to match the preferences of learners with cleft?

4. In what ways do you go about testing your members to see if their learning is secure? Are there any considerations which should be borne in mind when testing the learner with cleft?

5. In what way do you go about encouraging a deep understanding of the learning of your members during whole group teaching and learning sessions?

6. Can you describe the approach would you adopt towards oral discussion/presentations/reading aloud and young people with speech problems?

7. In the case of group work, from your experience:

- How important is group/pair work to your activity? Can you give me an example of when you would use this?

- In your opinion is the member with cleft an active participant in group/pair work? Can you give me an example to support your view?

- Are there any specific challenges a learner with cleft might face when engaging in group/pair work in your activity/organisation?

- In relation to the member with cleft, can you comment on:

    1. Scaffolding/support they receive from other group members/pair

    2. Scaffolding/support they provide to help other group members/pair

    3. The pace at which scaffolding/support is withdrawn as the learning becomes more secure?

- What evidence is there that the pupil/student with cleft engages in reflection on learning with other group members?

- In what ways does the group report back their findings?

- Does the member with cleft ever adopt a leadership role within the group? Could you give examples to support your answer?

8 In your opinion, from the point of view of your activity, are there any advantages or disadvantages for the members learning alone through interaction with the environment?   Would these also/especially apply to the learner with cleft?

9 In what ways might the situations in which they are learning be important for members with cleft – for example, several groups in one big hall, or engaging in activities outside or learning in composite age groups?

10 Are there essential building blocks of learning that if missed will create gaps thus affecting future learning in your activity? Does it matter if they miss activities sporadically? Does this affect group work? Is it an argument for individualised learning?

Now I'm going to ask you about additional support offered

1. In what ways is the young person with cleft in your organisation/club learning in a supportive and inclusive environment? Are there other members with issues requiring support?

2. Are there any additional support measures that you might suggest to help a young person with cleft to make progress in learning your activity?

3. If there are additional support measures can you comment on the positives and negatives of these procedures/equipment and how they are operated? In your opinion are they sufficient or could more be done to help the young person with cleft?

4. Do you think any specific additional support offered results in psychosocial issues for the young person because of their 'special treatment'?

The following questions relate to social learning:

1. Tell me about the member with cleft and their friendship circle within the club/organisation?

2. Cleft lip and palate is characterised by a visible difference whereas cleft palate only by an invisible difference. In your view, what, if any, significant differences could this bring about in interactions with others?

3. Would you say that the member with cleft is a 'spectator' or a 'participant' at your club/organisation? What reasons do you have for giving this answer?

4. Can you describe any occasions where the learner with cleft has complained about teasing/bullying? Can you give examples of any form of resilience or coping strategy invoked by the pupil to deflect any negativity relating to teasing/bullying/lack of confidence?

5. Tell me about the club/organisation policy on teasing/bullying and your views as to whether this policy is adequate to deal with issues the learner with cleft might have?

6. Has the club/organisation ever encouraged speakers from organisations such as CLAPA or 'Changing Faces' to actively inform all members about the cleft condition or asked the member with cleft to give a presentation in explaining their medical condition?

7. Could you reflect on the behaviour of the member with cleft while attending your club/organisation? In order for me to understand, can you give me an example which shows this?

The final questions are about their progress in learning:

1. What qualities would you say a successful learner should have?

2. Can you give any examples of when the member with cleft has displayed these qualities?

3. In your opinion, how would you describe the progress in learning of the member with cleft?

- Knowledge

- Skills

- Personal character development?

4. On what evidence do you base your opinion?

5. Could you give me your definition of the word 'underachievement'?

6. What are your expectations for the future learning of this member in respect of your activity?

7. Has any medical treatment the young person with cleft has had helped/hindered their progress in learning?

8. If you had to choose three things you would change about your organisation to make the learning experience better for learners with cleft, what would they be? Why?

9. Links may exist between home/organisation/hospital – Can you suggest any improvements to develop these links in order to make the experience better for the young person with cleft?

Is there anything else you would like to add about learning while coping with a cleft?

Appendix Five
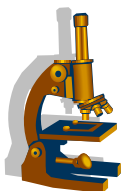
C U R R I C U L U M   A R E A S

❖ **Expressive Arts – Art and design/dance/drama/music**

❖ **Languages – English/classical/modern languages**

❖ **Mathematics**

❖ **Religious and moral education**

❖ **Sciences**

❖ **Social studies**

❖ **Technologies – ICT/business/computing/food and textiles/craft and design/engineering and graphics**

❖ *Health and Wellbeing throughout the curriculum [and PE], Literacy and Numeracy similarly*

❖

Appendix Six

MEDICAL EXPERIENCES	MEDICAL EXPERIENCES
Where a positive contribution was made	**Where pupils might face challenges**
Hospital Policy	*Absences*
Timing of appointments and surgeries Technology used to communicate with pupils	*Minimal (up to two days including travel)*
	Check-ups Five yearly audit Electropalatography
Benefits of Medical Treatment	*Moderate (short term but regular – amounts to up to three or four days per event)*
Surgical Dental Speech Therapy	Dental Treatment such as braces Speech Therapy (one to one lessons with speech therapist) Ear, throat and chest infections (chronic)
	Longer Term : *(absence of two weeks or more)*
	Secondary/Revision surgeries Alveolar Bone Graft Jaw Surgery
	Number of Surgeries: Varying from one operation to a maximum of five per individual in this study
	Invasiveness:
	Minimal
	Speech therapy Xray Dental check-ups Electropalatography
	Moderate (can be done in a day with short period of discomfort)
	Dental – extraction of teeth Fitting of braces Insertion of grommets (does require surgeon and anaesthetic, 'day surgery')

	Significant *(requires surgeon and anaesthetic and hospitalization plus recovery time)* Revision surgeries Alveolar bone graft Jaw surgery *Wait for treatment* For corrective operations – grommets For corrective orthodontics – braces

Appendix Seven

Examination Results of the Eight Senior Pupils

This table is organised alphabetically by the name of the pupil and within pupil category chronologically as they sat the examinations.

NAME	EXAMINATION	GRADE
BRUCE (Fourth Year - 2011)	**Standard Grades already achieved:** **Graphic Communication** **English, Maths, Physics, Craft and Design, and Art and Design** **French and History**	**1** **2** **3**
BRUCE (Fifth Year – 2012)	**Higher Education:** **Graphic Communication Higher** **Art and Design Higher** **Maths Intermediate Two** **English Intermediate Two** **Woodworking Skills Intermediate Two**	**B** **D** **A** **B** **B**
JOHN (Fourth Year – 2011)	**Standard Grades already achieved:** **History** **Maths, PE, English and Chemistry**	**2** **3**
JOHN (Fifth Year – 2012)	**Higher Education:** **History Higher** **Maths Intermediate One** **PE Intermediate Two** **English Intermediate Two** **Chemistry Intermediate Two**	**Fail** **A** **A** **B** **Fail**
KATY (Fourth Year – 2009)	**Standard Grades already achieved:** **Chemistry, Music, Administration and Modern Studies** **English, Maths, Art and French**	**1** **2**
KATY (Fifth Year 2010)	**Higher Education:** **Administration, Modern Studies** **Maths** **English, Chemistry**	**A** **B** **C**
KATY (Sixth Year 2011)	**Higher Education: Further Highers (not Advanced Highers)** **Biology (One year crash course)** **Philosophy (One year crash course)**	**A** **C**

KIERAN (Fourth Year - 2011)	**Standard Grades already achieved:** **Music and Biology** **Chemistry, English, Maths, PE and Spanish** **History**	**2** **3** **4**
KIERAN (Fifth Year - 2012)	**Exams being presented for this year:** **Intermediate Two History** **Intermediate Two Chemistry** **Higher Biology** **Higher Music**	*Not supplied by the pupil*
LAUREN (Fourth Year – 2011)	**Standard Grades already achieved:** **Computing** **English, Maths, Geography, French and Art** **Biology**	**1** **2** **3**
LAUREN (Fifth Year – 2012)	**Higher Education:** **Higher Art** **Higher Maths and Higher Geography** **Higher Computing** **Intermediate Two English**	**A** **C** **D** **C**
LAUREN (Sixth Year – 2013)	**Higher Education continued:** **Advanced Higher Art** **English**	**C** **C**
MACK (Fourth Year – 2010)	**Standard Grades already achieved:** **PE** **English, Maths and Home Economics** **Classical Studies and History** **Chemistry (only attempted one paper)**	**2** **4** **5** **7**
RIHANNA (Fourth Year – 2012)	**Standard Grades sat this year:** **English Credit/General** **Biology Credit/General** **Modern Studies Credit/General** **Chemistry Credit/General** **Home Economics Credit/General** **Maths Intermediate Two** **Art Intermediate Two**	*Not supplied by the pupil*
TULISA (Fourth Year – 2012)	**Examinations sat this year:** **Art Intermediate One** **Biology Intermediate One** **HE (Health and Food Technology)** **Intermediate One** **HE (Fashion and Textile Technology)** **Intermediate One** **Maths Access Three**	**B** **C** **B** **C** **No award**

	Music	Standard Grade	General	3
	English	Duke of Edinburgh Award		Completed
	English	Standard Grade	Foundation	5
	Personal Development	Intermediate One		SCQF 4

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