



THE UNIVERSITY OF  
**WAIKATO**  
*Te Whare Wānanga o Waikato*

Research Commons

<http://waikato.researchgateway.ac.nz/>

## Research Commons at the University of Waikato

### Copyright Statement:

The digital copy of this thesis is protected by the Copyright Act 1994 (New Zealand).

The thesis may be consulted by you, provided you comply with the provisions of the Act and the following conditions of use:

- Any use you make of these documents or images must be for research or private study purposes only, and you may not make them available to any other person.
- Authors control the copyright of their thesis. You will recognise the author's right to be identified as the author of the thesis, and due acknowledgement will be made to the author where appropriate.
- You will obtain the author's permission before publishing any material from the thesis.

**Students with Osteogenesis Imperfecta:  
A Comparative Intergenerational Study of Inclusive Participation  
in New Zealand schools.**

**A thesis  
submitted in partial fulfilment  
of the requirements for the degree  
of  
Master of Education  
at the  
University of Waikato  
by  
Heather J. Holmes**

---

**University of Waikato  
2007**

## **ABSTRACT**

Osteogenesis imperfecta (OI) is a genetic condition commonly known as Brittle Bones. The purpose of this study was to listen to and document the experiences of those with OI to investigate if there were barriers to inclusive education for students with osteogenesis imperfecta (OI). Persons with OI are often small in stature, have limited strength and varying degrees of mobility. Adventurous behaviour or everyday activities may result in fractures. Often in the world of disability the focus is on the medical condition rather than the personal experiences of those with the condition. This study provided an opportunity to articulate the personal experiences of the participants.

In this study two specific aspects of educational experiences were examined. The first aspect explored was the way students managed physically within the educational setting, while the second aspect examined how students coped emotionally. Five major questions were used to determine if special education policies have affected the quality of inclusiveness for students with OI in New Zealand classrooms over a period of forty years. These questions examined what barriers exist in the past and whether the same barriers still exist within today's educational setting. The questions investigated what or who may be the cause of these barriers and what possible effects these barriers might have on the student. The present situation was compared with the past and finally how might these barriers be overcome was investigated.

This qualitative study focused on three individuals, each representing a different generation. The participants exemplified a particular phenomenon, specifically the daily school lives in New Zealand of those with OI. The difficulties these students faced were explored through semi-structured interviews to encourage the three participants to voice their individual experiences. All three participants gave freely of their thoughts in an articulate, thoughtful and open manner, sharing both their positive and unpleasant experiences.

This study revealed that some New Zealand schools have yet to implement recent inclusive education policies set out by the Ministry of Education. The three participants identified barriers to inclusive education from their own personal perspectives. The physical environment of school presented challenges. Distance between classrooms and assembly halls and accessibility to the playground, ramps and toilet facilities created difficulties for students with OI who did not walk independently. Attitudes of parents, teachers, and the wider school community impacted on the self-attitude of students with OI. Over-protection, fear and anxiety were identified as unintentional attitudes that placed limitations on participation of meaningful activities and added to student feelings of isolation and difference. Lack of knowledge of the medical and psychosocial aspects of students with OI could account for the continued barriers imposed by some teachers.

Barriers do still exist in some New Zealand schools for students with osteogenesis imperfecta. Improved access could result in more participation. More participation could allow for an improved quality of social interaction and thus result in greater focus on the person and less focus on the disability. Collaboration between all school staff, parents and students with OI is essential to minimise barriers and maximise academic and social opportunities.

## **ACKNOWLEDGEMENTS**

My heartfelt thanks go to the three participants. Without their openness and candour this study would not have been possible. I appreciate them sparing me the time in their full lives to chat with me about their experiences.

Second, I wish to thank my supervisor, Doctor Margaret Scratchley for her persistence and advice as she guided this sometimes-reluctant student through an incredible journey of self-discovery, and the world of research.

Also to my friend Lisa Hayes who was always there when I needed to let off steam, express my self-doubts, share moments of enthusiasm and all the coffees she made when I needed a break. This study would not have been possible without her support.

I embrace my children, Debbie, Tammy, Arnika and Adam with a myriad of hugs for the patience and consideration they demonstrated during this journey of mine. My deeply felt appreciation extends to my grandchildren, who along with their mothers never complained when I was either absent or present but absent in mind, during the last few months of this study.

Finally, I would like to dedicate this work to my sister to acknowledge the wonderful influence she has had on my life. She has enhanced my life more than she will ever know, and more I can ever express in words. Big-little-sister, this is for you.

# TABLE OF CONTENTS

	<b>Page</b>
Abstract	i
Acknowledgment	iii
Content	iv
List of Figures	vii
<b>CHAPTER ONE: INTRODUCTION</b>	<b>1</b>
Background to this study	1
Context of this study	2
Osteogenesis imperfecta described	4
Within the school context	8
Summary and purposes of this study	11
<b>CHAPTER TWO: LITERATURE REVIEW</b>	<b>14</b>
Introduction	14
The world of disability	15
Discourses of disability	15
Language of disability	16
Special education policies	18
Inclusion in an educational setting	20
Barriers to inclusive education	22
Barriers in the physical environment	22
Intentional and unintentional attitudinal barriers	23
Osteogenesis imperfecta specific	30
Summary	37
<b>CHAPTER THREE: DESIGN AND METHODOLOGY</b>	<b>39</b>
Introduction	39
Methodology	39
Relevance of qualitative research to this study	40
Theoretical framework	41
Relevance of grounded theory to this study	43
Methods	43
Case studies	44
Phenomenological studies	45
Semi-structured interviews	45
Design of this study	46
Gaining access	47
The process	47
Issues: reliability and ethics	50
Summary	53
Time Line	54

<b>CHAPTER FOUR: RESULTS</b>	<b>55</b>
EXPERIENCES, REFLECTIONS & VOICE	
Introduction	55
Facilitating the interview	55
Generating themes-Reporting data	56
Participants introduced	57
Results of themes	62
Physical environment of educational facilities	62
Attitudes	65
Parents	65
Teachers	67
Wider school community	72
Friends and classmates	74
Fractures and self attitude	76
Fractures	76
Self-attitude	78
Summary	83
<b>CHAPTER FIVE: DISCUSSION</b>	<b>85</b>
Introduction	85
Limitations of this study	86
Participants medical background	87
What barriers exist in the educational setting for students with OI?	87
Physical environment of schools	88
Distance/physical size of school	88
Accessibility to bathroom facilities	89
Ramps	90
Mobility	91
What/who might be the cause of these barriers?	93
Parents	93
Protection versus freedom	93
Collaboration	96
Teachers	96
Fear, blame and anxiety	97
Curriculum adaptations	98
Wider school community	101
What possible effects might these barriers have on the student?	105
Self-attitude	105
Compliance versus self-advocacy	105
Depression	108
How does the present compare with the past?	111
Physical environment	111
Attitudes	112
Conclusion	114

<b>CHAPTER SIX: CONCLUSION</b>	117
Introduction	117
Key findings	118
Physical/environmental barriers	118
Attitudinal barriers	119
Recommendations for education providers and policy makers	121
Suggestions for future research	122
Conclusion	123
<b>REFERENCES</b>	124
<b>APPENDICES</b>	134
Appendix I: Interview question guideline	135
Appendix II: Introductory letter to child participant	136
Appendix III: Introductory letter to participant's parents	138
Appendix IV: Introductory letter to adult participants	140
Appendix V: Consent forms	142

# LIST OF FIGURES

	<b>Page</b>
1. A sketch depicting typical OI facial features	5
2. Work to do: Painting by Johnathan Wos	10
3. Continuous data collection	42
4. Time line for this study	54
5. Improved access	114

# CHAPTER ONE

## INTRODUCTION

In New Zealand all children have the right to be educated in a regular state school and receive quality, equitable, inclusive education, that challenges them academically and socially and prepares them for life outside the classroom. There may be children who experience more difficulties in achieving continuity of learning opportunities and access to a safe, barrier free environment that maximises learning and minimise injury.

I am concerned with the difficulties that children with osteogenesis imperfecta (OI) might face in New Zealand schools. Specifically I am interested in how these children manage both physically and emotionally during their formal education. The objective of this study is to listen to the voices of people with OI. It is through documenting their stories and experiences that barriers could be identify in the contemporary educational setting for students with OI. The cause of these barriers will be explored and the possible effects of these barriers on the individual student. A comparison will be made between the past and present to identify whether special education policies have affected educational opportunities for those with OI. This study will conclude with a proposal as to how any barriers might be overcome and suggest possible implication for classroom practice and management. Finally, recommendations for areas for further research will be offered.

This chapter will firstly focus on the motivation for my interest in the experiences of students with OI. Secondly, the medical condition osteogenesis imperfecta is described, along with the significance of OI in relation to students in the classroom. Finally, an outline of the purpose of this study will be provided.

### **Background to this study**

Growing up in a family where each year, one of my three sisters spent several weeks at a time in hospital was a little different from the experience of children from other families. Added to the recurrent hospitalisations of my sister were the

frequent broken bones and seemingly endless operations it took to set those broken bones. My sister was born with osteogenesis imperfecta (OI), a rare genetic condition commonly known as “brittle bones”. Her bones would at times fracture spontaneously, or from the slightest knock.

A family where one child is extremely fragile might suggest an environment of over-protection. That was not the case. It was accepted, and even expected that my sister would break bones. She was neither closeted nor exempt from any activity within the family setting. It was expected that she would go to the local school and participate in all school activities. Handicapped or disabled were not terms I recall being used in our household. Mainstreaming, integration, and inclusion, were not words that were part of discussions regarding my sister’s education. Rather class trips, calf-club days, end of year concerts and later, exams, were the focus of my sister’s educational participation.

As an adult I had many questions about my sister’s experiences. What was it really like for her to attend school? Was she truly integrated into the school? Was her schooling truly inclusive? Were there barriers that made life difficult, set her apart, made her feel different? If so, what were those barriers? More importantly, if there were barriers, who or what caused them, and how might these barriers have been eliminated? I also questioned whether the same barriers still exist or whether introduction of education policies had created opportunities for full participation for students living with OI.

### **Context of this study**

There are relatively few people, per population, with osteogenesis imperfecta in New Zealand. For this reason I will investigate the personal stories of three participants, each from a different generation. One in five New Zealanders lives with a long-term disability and the key common factors are the lifelong barriers these people face to gain full participation in society.

Attitudes have been identified, through consultation, as the major barrier that operates at all levels of daily life in the general population. Attitudes and ignorance make their presence felt as

stigma, prejudice and discrimination (The New Zealand Disability Strategy Sector Reference Group, 2001, p.7).

There are numerous physical barriers, which may arise from attitudes and ignorance. New Zealand is considered to have high standards for physical accessibility (Minister for Disability Issues, 2001), and yet heavy doors, cobbled pavement, steps and stairs make life difficult for those persons with limited strength and mobility. I have personally experienced the frustration and difficulty of pushing my sister in her wheelchair in all of these situations. It would be so much more difficult for a person who has limited strength to attain independence when they encounter these same obstacles.

Attitudes are evident in the language we use. Words perpetuate negative stereotypes and invisibly disempower individuals who have a disability. By contrast “people first” language puts the person before the disability and describes what a person has, not what a person is (Snow, 2005). People first language was used as a matter of course in our household. For example, my sister was not handicapped or crippled, she had a physical disability. She did not ‘suffer’ from OI, she had OI. She was not ‘confined’ to a wheelchair, rather she used a wheelchair. People first language will be used throughout this study.

What the able-bodied population perceives to mean inclusion may be quite different from the perception of those who are less able. Barriers are not always recognised by those who create them. The fragility of a child with OI may present specific challenges within our educational settings. Barriers previously identified by students with different disabilities could also apply to a student with OI. In this study I will ask those who have the medical condition OI to identify the factors that they perceive create barriers to inclusive participation in New Zealand schools. Strauss and Corban (1998) believe that the most valuable learning comes from listening to the voice of the individual, the one who lives the experience. Personal stories, from students both past and present, may enable me to answer my questions.

My sister and I have shared many experiences over the years. We attended the same rural primary school, sat on the same school concrete step to drink our warm milk and played in the same playground. It is perhaps natural that my study should include my sister now in her fifties. My other participants are a young man in his early thirties and an 11-year-old child. All have the condition osteogenesis imperfecta and I will invite each one to share their school experiences.

### **Osteogenesis imperfecta described**

Any student with a physical disability presents implications for schools, teachers and other students. In this section I will first define osteogenesis imperfecta. The medical aspects of OI will then be situated in context for schools, teachers and students.

The common term for osteogenesis imperfecta is ‘brittle bones’. As the term suggests bones can fracture easily, often from little or no apparent cause. A person may have just a few or several hundred fractures in a lifetime according to the National Institute of Health Osteoporosis and Related Bone Diseases – National Resource Centre (NIH ORBD-NRC, 1997). Bones break repeatedly, often with little or no trauma. Sneezing or muscular tensing can cause bones to break. A yawn can cause a broken jaw. OI is a genetic disorder of increased bone fragility and low bone mass with a range of severity that varies widely from perinatal lethality (death in the womb or at birth) to mild forms without fractures (Rauch & Glorieux, 2004). Repeated fractures result from collagen fibres arranged incorrectly in the protein matrix, or foundation of the bone, resulting in a deficiency of the total number of bone salts, calcium and phosphorus and an insufficient amount of bone (Rauch & Glorieux, 2004). The outcome produces bones that are weak in structure. OI is a relatively rare condition that affects an estimated 20,000 to 50,000 people in the United States of America (Ripley, 2005). While there are no statistics available for New Zealand, Norway with a similar population to New Zealand of 4.65 million people has an estimated 310 persons with OI (OIFE, 2006).

It is relatively easy to recognise the physical features of a person with OI. The most distinguishing feature is a broad forehead and often pointed chin giving the

face a triangular appearance often described as a ‘pixie like’. This feature is illustrated in the sketch below.

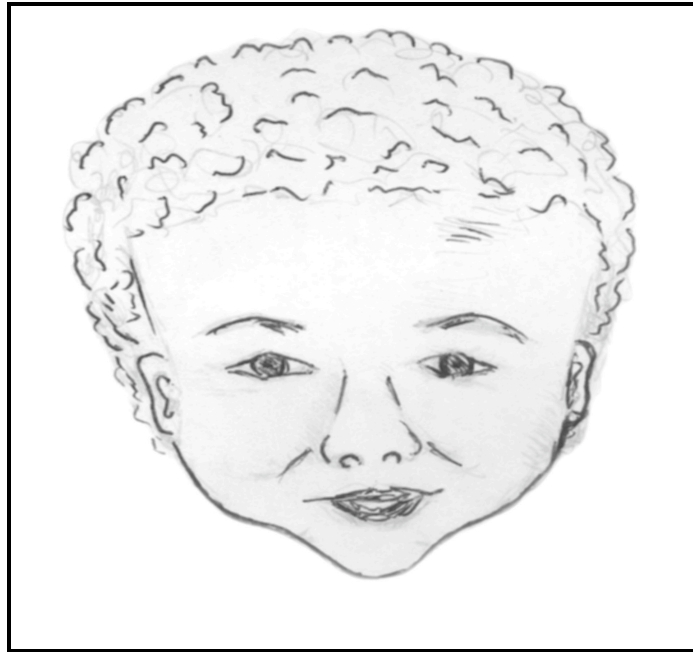


Figure 1: A sketch depicting typical OI facial features.

The Osteogenesis Imperfecta Foundation (OIF, 2005) outlines the following physical attributes. There is often evidence of a barrel shaped rib cage. The spine may become rounded (kyphosis) and/or curved (scoliosis). Some curves worsen rapidly and are possible due to the laxity of the ligaments associated with OI and deformation of the vertebral bones. Limbs are often disproportionately small and contorted due to repeated fractures.

According to the National Institutes of Health Osteoporosis and Related Bone Diseases – National Resource Centre (NIH ORBD-NRC, 1997) OI is genetic and involves a dominant mutation. When a gene with a dominant mutation is paired with a normal gene the dominant gene “dominates the normal gene” (NIH ORBD-NRC, 1997. p.1). The dominant gene can originate from either the male or female. There are times when a spontaneous dominant mutation can occur in families with no previous history of OI. Whether OI is inherited or due to a spontaneous mutation a person with OI has a 50 percent chance of passing the condition on to

each of their children. Clinical geneticists can perform biochemical (collagen) or molecular (DNA) tests and genetic counsellors can assist families to further understand the possibility of recurrence.

There is no cure for OI, although new drugs are currently being trialed. Current treatment methods are directed towards preventing or controlling symptoms and maximising independent mobility via the use of wheelchairs, braces and other mobility aids. Care of fractures and extensive surgery are often required, including the procedure of rodding. This treatment involves inserting a metal rod through the length of the long bones to strengthen them and prevent and/or correct deformities.

In addition to brittle bones there are several other symptoms often associated with this condition. The whites of the eyes usually have a blue, purple, or grey tint and people with OI often experience light sensitivity (OIF, 2005).

Hearing impairment may occur, due to the degeneration of the ossicles (bones in the inner ear). The possibility of hearing loss presents its own set of challenges and considerations within a classroom situation. Until recently hearing loss was not thought to occur until the teenage years or early twenties (Imani, Vijayasekaran, & Lannigan, 2003). Kuurila and Grenman (2004) now stress the importance of hearing tests for all children with OI from the age of 10 years, followed by repeat testing every three years.

Persons with OI may have thin and fragile skin, and be exceptionally susceptible to sunburn and can often experience periods of profound sweating. Consideration of these features of OI may be necessary when students are in the sun for even minimal amounts of time.

There are currently six recognised types of OI identified by NIH ORBD-NRC (2005) which vary in characteristics and severity. Using their definitions as the main point of reference all six types will be described in detail, using non-medical terms where possible.

### *Type I*

This is the most common and mildest type of OI where bone deformity is often absent or minimal. The bones are predisposed to fracture, with most fractures occurring before puberty. The collagen structure of the bone is normal, but the amount is less than normal. People with type I are of normal, or near-normal, stature and tend to have loose joints and muscle weakness. The whites of the eyes usually have a distinctive blue, purple, or grey tint. A triangular face is a common feature. There is a tendency toward spinal curvature, and the possibility of brittle teeth and hearing loss.

### *Type II*

Regarded as the most severe form of OI, Type II is most often lethal before, during, or shortly after birth due to respiratory complications. People with Type II are noticeably small in stature, have underdeveloped lungs and numerous fractures. Severe bone deformity is evident at the time of birth.

### *Type III*

People with Type III have bones that are easily fractured. At birth there is often evidence of healed fractures. The collagen of the bones is improperly formed. Spinal curvature and short stature is common. Adults with OI often measure less than 1 metre. Loose joints and poor muscle development in arms and legs is evident along with severe bone deformities in the long bones. People with Type III OI often have a barrel-shaped rib cage and develop frequent respiratory problems. The sclera has a blue, purple or grey tint and is a prominent feature in a triangular face. As with Type I brittle teeth and hearing loss is possible.

### *Type IV*

Type IV is between Type I and III in severity. Bones fracture easily, resulting in mild to moderate bone deformity, as the collagen in the bone formation is improperly formed. Shorter than average stature can be expected in people with Type IV and there is a tendency towards spinal curvature. A barrel shaped rib cage and triangular face associated with Type III are evident in Type IV. However the sclera, usually tinted in other types of OI are usually white or near normal colour in this instance. Again, brittle teeth and hearing loss are possible.

### *Type V*

Clinically similar to Type IV, with Type V a dense band is seen on x-rays adjacent to the growth of long bones with unusually large calluses at the sight of fractures. Calcification of the membrane between the radius and ulna (bones of forearm) often restrict forearm rotation. The bones have a ‘mesh-like’ appearance when viewed under a microscope.

### *Type VI*

The alkaline phosphatase activity level is elevated in bone forming cells and bones have ‘fish-scale’ appearance when viewed under microscope. People with type VI OI are moderately to severely affected. Fractures and deformities are relative to the degree of severity of the condition.

### **Within the school context**

Fractures are a result of OI. No person is to blame when a student with OI has a fracture while engaged in usual play or other activities. Students with OI are fragile and teachers and classmates need to know that fractures are likely to occur as a result of minimal, or no trauma. It is imperative that all staff and classmates what understand what action to take when a fracture occurs. Children are often curious and in my experience genuinely want to know why a person with OI looks ‘different’ or is ‘short’. Adults with OI often measure less than one metre in height. Once an explanation is provided to questioning children they are generally happy to accept the person for who they are. Siblings may also have questions and the need to be acknowledged. For example, as a child I often wondered if, or when, I would ‘start to break’ as my sister did. I was considered short for my age and had hearing difficulties. I was reluctant to partake in contact sports, believing in my child’s mind that this might be the situation that would reveal symptoms of OI.

Not all students with OI have regular auditory testing. The possibility of undiagnosed hearing loss has distinct relevance to the classroom. If hearing loss has been diagnosed, intervention may follow. Corrective surgery or the use of a hearing aid may be necessary. Mobility and the possible use of mobility aids require consideration of structure of our schools and the layout of the classroom. Questions include whether there is room between desks to enable the student to

manoeuvre without the additional chance of inadvertently bumping into furniture, thus causing a fracture. Short stature and limited strength may also present difficulties with reaching and resources and opening doors.

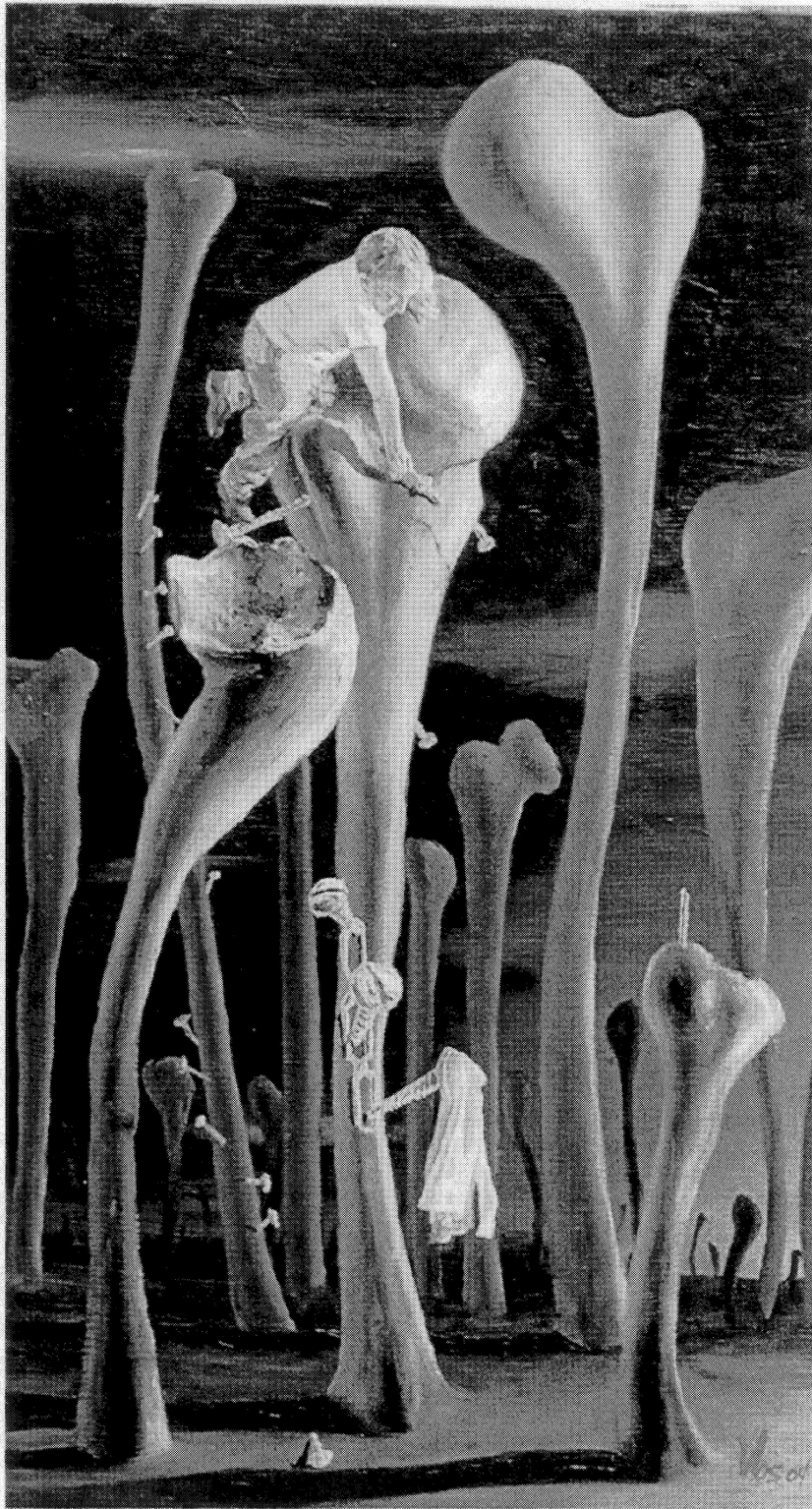
The presence of light sensitivity may mean the student will need to wear sunglasses or tinted prescription eyeglasses in and outside the classroom. Positioning of the student to avoid bright sun, or other bright sources of light, may be a matter for teachers to consider. Communication with the individual student and their parents can assist a teacher to identify their special requirements within the classroom and school in general.

Maintaining open communication and contact with a student who has OI requires extra effort from teachers. All school staff should know the emergency plan for inevitable fractures. Classmates and peers also need to be aware of the correct procedures to follow in the event of a fracture. The child with OI is often the best source of information and can often identify if medical attention is required, or the best position to place their limb while help is being arranged. Considerable absences from school due to frequent fractures present challenges to teachers who are required to fulfill their obligation of ensuring inclusive education for children with special needs. Rodding procedures often require several weeks to mend and might necessitate lengthy absences from school.

While the medical condition may place some limitations on the student and absences may frequent, teachers could minimise or eliminate the barriers possibly faced by some students who have OI, by fostering the student's wellbeing, and seeking creative ways to providing opportunities for inclusion in school activities and social interactions.

Johnathan Wos, an artist from Wisconsin, has osteogenesis imperfecta. Art is his window to life and he uses his talent to confront his limitations caused by his medical condition (Metcalf, Gervais, Dase & Griseta, 2005). With permission from the artist (Wos, J., personal communication, April 17, 2007), one of his paintings is reproduced here, to depict the creative means by which the medical condition can be expressed.

Figure 2. Work to do: Painting by Johnathan Wos



*Work to Do*, Jonathan Wos, 2004. Oil on canvas, 21 inches by 37 inches.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Continuity of learning opportunities and access to a safe, barrier free environment could be important to maximise learning and minimise injury. The above examples suggest that students' with OI have very specific physical and psychosocial needs.

### **Summary and purposes of this research**

In New Zealand students with disabilities have the same rights to a high quality education as people of the same age who do not have special education needs (Ministry of Education, 2006). This study questions what it is really like for a student with OI to attend school in New Zealand. The study investigates whether their schooling is truly inclusive. It examines whether there are aspects of school life that make life difficult, set them apart or make them feel different, and if so, what form do they take. The study examines the causes of these barriers and explores how these barriers could be minimised or eliminated. The study also examines the impact of special education policies and assesses whether they have improved the opportunities for full participation in school activities for students with OI.

To address these issues I have identified the following questions:

- What barriers exist in the educational setting for students with OI?
- What/who may be the cause of these barriers?
- What possible effects might these barriers have on the student?
- How does the present compare with the past?
- How might these barriers be overcome?

I will listen to the real experiences of two adults, each representing a different generation, and a child. I will examine the physical environment as the participants have experienced it. I will assess the effect of unintentional and intentional attitudes on those that live with OI.

This study offers the three participants the chance to talk. Through their stories, we might come to understand the world of those living with osteogenesis imperfecta. More often than not research is about the medical aspects of the condition. Each participant in this study is given a voice.

Societal attitude is one of the motivations for this study. As the researcher I also have to acknowledge my own personal experiences growing up in a family where one member has OI. This provided me with an intimate view of how society responds to those with physical disabilities. I have seen a myriad of reactions to persons with disabilities, from completely unrestricted inclusion to condescending attitudes and actions. Those who are viewed by others as ‘different’ have the right to a voice. It is their voice that can communicate the effect barriers and unhelpful attitudes have on their quality of life.

I believe there is a gap in the current literature regarding physical disabilities. For example, while undertaking a library search for physical disabilities and education more often than not only one brief chapter is located in each book. These single chapters usually refer to a variety of medical conditions such as cerebral palsy, spina bifida, muscular dystrophy and epilepsy and asthma. There also appeared to be few books or journal articles that referred directly to the pedagogical considerations for students with physical disabilities. Available literature seemed to emphasise students who have behavioural, emotional, reading, or intellectual difficulties. While special education covered a large area of special needs there seemed to be minimal studies that are specific to the needs of those who faced challenges due to orthopaedic difficulties. Of the studies that did cover physical disabilities the author often offers the views of parents, teachers’ and peers, rather than the individual that lives with a disability.

In chapter two, literature relevant to this study will be introduced. A historic summary of New Zealand education policies will contextualise my comparison of the three participants, representative of three separate generations, involved in this study. Literature that focuses on the physical environment, unintentional barriers and intentional barriers will be examined and literature specific to people with osteogenesis imperfecta. In chapter three I will outline the theoretical perspectives and the ethical issues of the chosen methodology for this study. The voices of the three participants will be share in the fourth chapter followed by a discussion on the issues the participants revealed in chapter five. The implications for best

teaching practice for a student with OI in the classroom will be examined, and suggestions for future research, will be the focus of the final chapter.

## CHAPTER TWO

### LITERATURE REVIEW

#### **Introduction**

Schools throughout New Zealand are moving towards inclusion. Students with disabilities are being educated in regular classrooms, including those with severe disabilities and challenging physical and physiological challenges. Inclusion in New Zealand schools for all children was highlighted in the 1995 guidelines for education. These guidelines recognise children with special needs as having the same rights to quality education as other children. A student who is involved in the integration process should be fully integrated not merely included. Research has shown that attitudes to this process can be the biggest barrier to equitable education for those with disabilities (Woodill, 1994). If student participation is absent, or limited opportunities are offered to contribute to the process of inclusion, barriers to equitable education might still exist that are not apparent to teachers and administration staff.

The purpose of this study is to give voice to persons with osteogenesis imperfecta (OI) and examine the barriers that might exist for these students in New Zealand schools. The study explores the educational experiences of three New Zealand born persons each of who have the condition osteogenesis imperfecta. Because each of these persons represent three different generations it might be expected that their experiences at school would be unique and governed by the educational policies at the time.

The literature chosen locates the reader in

- (a) the world of disability generally,
- (b) the way in which New Zealand has constructed policies for those individuals who seek to be involved in the mainstream classroom,
- (c) barriers identified by persons associated with physical disabilities and,
- (d) literature that is specific to osteogenesis imperfecta.

This chapter will firstly discuss historic and contemporary definitions of disability and how these definitions have impacted on those affected. An attempt will then be made to define inclusive education. Past and present government policies relevant to the education of students with disabilities will be examined for changes over the past few decades that have improved the rights of disabled students and addressed inclusive education. A review of current literature that focuses on barriers to inclusive education, both environmental and attitudinal will follow. Lastly a discussion of literature that is specific to osteogenesis imperfecta (OI) should indicate to the reader the unique considerations such students may require, including adaptations to the classroom, teaching flexibility, and the physical environment of the school.

#### **(a) The world of disability**

Literature reveals a plethora of views and definitions of the conceptual reality of disability. Historical attitudes towards those who are viewed as different have possibly influenced negative dominant discourses of disability.

##### Discourses of disability

Neilson (2000) describes past attitudes and the shift in societal acceptance of those with various disabilities. The isolation stage which Neilson refers to was a time when the ‘half witted’ or ‘deformed’ were made slave and became a form of entertainment and ridicule. This was followed by the care stage where humanitarian charities offered protection to those they viewed as ‘suffering’. Individuals were kept away from the public eye by way of institutionalisation. The rehabilitation stage emerged in the 1900’s when the notion arose that those individuals with disabilities could live outside of such closeted situations. The integration and normalisation stage “was a direct result of the increase in numbers of people with disabilities from war-related injuries” (Neilson, 2000, p.18). The final stage that Neilson proposes is the citizenship stage. Individuals with disabilities began resisting the way they were being treated. They were no longer prepared to be shut away from the rest of society. Political groups were formed to fight for the rights of those with disabilities. Likewise, individuals fought their own battles to be recognised as part of the community. Despite anti-

discrimination laws people with disabilities are still seen as inferior “especially in relation to education and employment” (Neilson, 2000, p.20).

The dominant discourses of disability also play their part in society, these being medical, charity, lay and rights. Professionals, who see disability as something abnormal and as such, able to be fixed, use the medical discourse (Neilson, 2000; Mitra, 2000). Disabilities are seen as something to be fixed to rehabilitate the individual back to normal. The charity discourse on the other hand has an institutional focus, with humanitarian connotations. The disabled are seen as passive and needy. The lay discourse regards people with disabilities as inferior, asexual and childlike and consequently life must be unpleasant and therefore not worth living.

Mitra (2000) also introduces the concept of the social model where “disability is not the attribute of the individual: instead it is created by the social environment and requires social change” (p. 237). Nagi’s (1965) model according to Mitra, refers to a limitation or inability to perform socially defined roles and tasks within society. Mitra also examined Sen’s capability approach where quality of life, personal well-being and standard of living are used as a frame-work to analyse different concepts in welfare economics. Through his analysis Mitra argues that the capability approach can be separated into two levels, deprivation of capabilities, or deprivation of functioning’s. In the capability approach “Disability occurs when an individual is deprived of practical opportunities as a result of an impairment” (Mitra, 2000, p.241) and includes what individuals value doing/being and what the individuals succeed in doing/being. Perhaps more importantly it includes concepts of desirable states of individuals.

#### Language of disability

Historic attitudes and use of language could to some degree, influence how individuals with disabilities are viewed by society. The ways in which we communicate, whether with unintentional negative connotations or thoughtfulness, consideration and respect of these individuals may play an important part in the socialisation and inclusion of students in an educational setting.

The development of person first language places emphasis on the individual, not the medical condition, thus making their disability “just one aspect of the person” (Millar & Sammons, 1999, p.26). People first language may have contributed to the changes in discourses and models of disability. Miller and Sammons indicate that the language we use may influence our attitudes. Holmes (1992) substantiates the impact words can have on those who they are directed at when she wrote “...words which have been used to describe me and others with similar differences in mobility, size, health...have shaped our lives and the way we feel about and accept ourselves” (p.1). Holmes lists some of the ways she has been referred to “crippled, handicapped, a sufferer of... inflicted by... deformed, incapacitated, confined to... a case, a patient, and the disabled” (p.1).

Words change and in recent years the language of disability has moved away from the medical approach to a social perspective. The relationship between language, the individual, their environment, interpersonal relationships, and opportunities are now shaping attitudes and demonstrate a newly developing awareness and respect for those individuals who have disabilities.

Included in the language concern is the definition of disability versus impairment. Beatson (2000) identifies disability as a biological condition whereas impairment is seen as a social identity. He offers his own definition:

An impairment is a bodily or psychological loss or abnormality which may cause suffering and which makes it difficult, dangerous or impossible to perform tasks, to participate in community life and to play social roles in the ways taken for granted by non-impaired people (p.22).

Miller and Sammons (1999) also differentiate between impairment and disability. “An impairment is a missing, damaged, deficient, or weakened body part or function” whereas “a disability is the inability to perform one or more major life activities because of an impairment” (p.26).

Being labelled as disabled “is a fact of life for all disabled people in the contemporary world” (Finkelstein, 1993, p.13) and can not be avoided.

Finkelstein believes our government agencies' processing mandates the very use of such definitions when deciding on policies involving financial support, services and policies.

The World Health Organisation (WHO) developed the International Classification of Functioning, Disability and Health (ICF) in order to present a coherent view of health from a biological, individual and social perspective (World Health Organisation, 2001). The lived experiences of individuals, that of participation and involvement in learning and applying knowledge, education, employment and self-sufficiency, are classified to measure "the actual lived experiences in which they live" (Mitra, 2006, p.238).

**(b) Special education policies**

Historically education policies reflected the accepted language and made provisions for those with disabilities. In 1925 the New Zealand government created a special branch known as Child Welfare Division (Census and Statistics Department, New Zealand, 1952-53). This newly created division made provision for the educational needs of children with disabilities and acknowledged the rights of all children to education:

In order to meet the requirements of children who are retarded in their development owing to physical or other defects, special classes have been established. These classes provide for children in certain public hospitals, for hard-of-hearing children and speech defectives, for under-nourished and physically defective children, and for children who are unable to benefit from ordinary class instruction (Census and Statistics Department, New Zealand, 1950, p.154).

Residential institutes for children and adults who were hearing impaired were provided. In addition "special classes were established in the main centres for education of hard-of-hearing children" (Census and Statistics Department, New Zealand, 1950, p.154). Similar accommodation and special classes were provided for children and adults who were blind. If children were not entered

into these institutions “by private arrangement” they were admitted “as government pupils” (p.154).

In the 1950s the primary department of The Education Department’s Correspondence School was deemed suitable for children with physical disabilities (Census and Statistics Department, New Zealand, 1952-53). By the seventies it had become preferable wherever possible for children with disabilities to be enrolled in ordinary classes (Census and Statistics Department, New Zealand, 1976). School buildings were modified to accommodate children with special needs. Specialized equipment were sought out and provided where possible to enable students to integrate into both the curriculum and school life in general. Extra staff were arranged alongside specialist assistance from Psychological Services, visiting special needs teachers and therapists. Special classes were still available for visually, intellectually and physically impaired students.

The Education Act of 1989 required all schools to accept students’ with disabilities, regardless of their degree of disability. It was not until the Special Education 2000 initiative in 1996 that students with disabilities, and their family/whanau, expected that they would be educated in a regular classroom, by a regular teacher (Beatson, 2000).

The current legal entitlement of children in New Zealand to quality, equitable, and inclusive education of the New Zealand is evident in various documents. For example, the Education Act of 1989 decreed that children with special needs had the same rights to enrol and be educated at state schools as other students (Ministry of Education, 2006). Likewise The New Zealand Disability Strategy objective 3.1 is to ensure that no child is denied access to their local, regular school because of their impairment (Office for Disability Issues, 2001). The need for teachers and other educators to understand the learning needs of disabled people is reflected in objective 3.3 of the New Zealand Disability (Office for Disability Issues, 2001).

“Equality of educational opportunities for all New Zealanders, by identifying and removing barriers to achievement” (cited in Jackson, 1996, p.3) is one of The National Education Goals (NEGs). The National Administration Guidelines (NAGs) refer to analysing barriers to learning and achievement (cited in Jackson, 1996, p.3). In December 2004 schools were advised that an additional clause was added to the NAGs that “requires the development and implementation of programmes that ‘give priority to regular quality physical activity that develops movement skills for all students, especially in years 1-6’” (MOE, 2006, p.1). The same document also outlined the responsibility for Board of Trustees to provide a safe physical and emotional environment for all students.

The New Zealand Health and Education Curriculum (Ministry of Education, 1999, p.51) states that students who have temporary or permanent disability require programmes that extend, challenge, and broaden their abilities. Further, the Ministry of Education determines that to meet the needs of students with special needs it is important that health and physical education programmes be adapted to provide access to opportunities that will develop their sense of self-worth. According to the Ministry of Education for this to be achieved it is important the student is valued by peers, teachers, the school, and the wider community and that the student helps plan programmes to meet their particular learning needs. In addition, students are to be included in regular lessons where resources or teaching approaches are adapted, as appropriate, to meet their special needs.

#### Inclusion in an educational setting

To achieve optimum self-sufficiency and inclusion in an educational setting requires what Kavale (2002) refers to as the least restrictive environment; a reality he says has not been met in American schools. Research evidence demonstrates “the requisite attitudes, accommodations, and adaptations for students with disabilities are not yet in place” (Kavale, 2002, p. 210). In New Zealand Ballard (1999) views inclusive education as giving everyone the right to participate and be included “as they wish, and to have the resources necessary to meet their needs” (p.12).

Stainback, Stainback and Ayers (1996, p.39) state:

If we want an integrated society in which all persons are considered of equal worth and as having equal rights, segregation in the schools cannot be justified. That is, no defensible excuses can be offered, and no amount of scientific research can be conducted that will in the final analysis justify segregation. Segregation has no justification.

Stainback, Stainback and Ayers (1996) admitted that achieving full inclusion of all children is a challenging undertaking, but feel that the ideology of having schools where everyone belongs is worth the challenge.

Stainback, Stainback and Ayers (1996) defined inclusive education as providing all students, including those with learning and physical disabilities, with appropriate education experiences that are challenging yet geared towards their capabilities and needs in integrated general classes. They emphasised that the focus is on how to operate classrooms and schools as supportive communities that meet the needs of everyone where the curriculum is adapted, when necessary, to meet the needs of all students.

Palmer, Fuller, Arora and Nelson (2001) offered a simplified version of inclusive education to the recipients of their survey. They explained that students with disabilities are placed in regular classrooms, in neighbourhood schools and stay there all day. Support services are offered within the regular programme to students who need them. Even severely disabled students participate in regular activities in chronological age-appropriate classrooms.

Changes to the Ministry of Education Special Education 2000 announced in 1996 (Ministry of Education, 2006) has brought New Zealand closer to the ideology of inclusive education and to improve learning outcomes for all students with special education needs. Accordingly it could be inferred that all students are entitled to a barrier free education and it is the responsibility of all people involved in the education of students to identify and remove barriers to learning and achievement of all students. School principles, administration staff, teachers, board of trustee members and parents all have an obligation to ensure students have equitable

opportunities to all areas of the curriculum and social interaction within the school environment.

### **(c) Barriers to inclusive education**

There appears to be little literature that examines barriers directly associated to students with physical disabilities. Perhaps this is because barriers are not always recognised by those creating them. “More often than not, barriers are made out of peoples’ ignorance towards something different” (Office for Disability Issues, 2001, p.1).

Pivik, McComas & Laflamme, (2002) found no studies “where students with disabilities were asked about their opinions of accessibility and inclusion within an integrated school setting” (p.99). They then conducted their own study to ascertain how inclusive Canadian schools were after twenty-five years of educational reform. Fifteen students with mobility limitations and twelve parents participated in focus groups. These individuals suggested that four recognizable barriers compromise inclusion of special education students: physical environment, intentional attitudinal barriers, unintentional attitudinal barriers and physical limitations. These key barriers form the basis of this present New Zealand study.

#### **Barriers in the physical school environment**

Ballard (1999) states there is evidence to suggest that for persons with physical disabilities the physical environment of a school interferes with full participation and inhibits full participation. Beatson (2000) believes that restrictive physical obstacles make it impossible for some individuals to participate in mainstream community life. He cites a flight of stairs as being a navigational nightmare for individuals who use a wheelchair for mobility. Likewise Pivik, McComas, LaFlamme (2002) refer to steps, heavy doors, and steep ramps as barriers to access and participation.

Hemmingson and Borell’s (2002) study of schools in Sweden revealed that although efforts have been made to address special needs of students with limited mobility some architectural barriers still existed. Lack of ramps, elevators and

automatic door openers created barriers to accessibility for eleven out of the thirty-four participants.

Knight & Wadsworth's (1993) study refers to the 41,000 American students who have special needs in education settings due to orthopaedic difficulties. They emphasize that school buildings must be entirely accessible, including lowered water fountains, handrails in all bathrooms and lowered doorknobs and ramps into all buildings to ensure maximum normalisation.

Eriksson (2005) agrees that physical environmental barriers limit students' active participation in daily life, but not to the extent that is expected. She believes activities the children have available, and are involved in, have an influence on how they, the students, perceive the influence of environmental constraints. The desire to participate may neutralise the perception of the barrier.

#### Intentional and unintentional attitudinal barriers

The focus of recent literature examining intentional and unintentional attitudinal barriers is substantial. Universally laws, policies and acts have all been developed to protect the rights of people with disabilities. Misconceptions about the behaviour, personality and achievement potential of the disabled, and feelings of uncertainty associated with how to interact with people with various disabilities can not be controlled or altered with legislation (Krahe & Altwasser, 2006). Intentional attitudinal barriers can issue from all sectors of the school, from the principal (Praisner, 2003), school staff (Pivik, McComas, LaFlamme, 2002), and other students (Ballard, 1999).

Negative reaction from the school community was an area of concern expressed by parents in Palmer, Fuller, Arora and Nelson's (2001) study. They believe that if inclusive education had been imposed through legislation, rather than embraced through ideology, adverse responses to inclusion from the school community were likely to arise.

Butler and Hodge (2004) reported aggressive behaviour towards students with disabilities in rural Midwestern United States schools. Hurtful words and name-

calling were often directed at the sixth grade students observed during physical education classes. Condescending attitudes and comments, lack of understanding and/or knowledge of a student's medical condition from teachers were evident. Total exclusion from physical education classes for some students was sanctioned due to safety issues in some instances. Butler and Hodge emphasize the culmination of these intentional barriers combines to oppose the reality of inclusion.

Ballard (1999) contends that New Zealand's special needs students frequently receive inferior learning opportunities and exclusion from the ordinary experiences enjoyed by their more able-bodied peers. Restricted participation or exclusion from some activities in class often originated from the way in which they were organized and carried out (Hemmingson & Borrell, 2002). Sports and activities conducted outdoors appeared to be the most frequently cited areas of restricted participation (Blinde & McCallister, 1998; Goodwin & Watkinson).

Flem and Keller (2000) investigated the ideology of inclusion practice in Norwegian schools. They sought to examine how inclusive education is realised and factors that hinder or support the ideology. Their qualitative study included semi-structured interviews with a total of 27 participants. All of the participants were involved in Norway's educational system at various professional levels; teachers, principals, administrators, and support services. Specialty fields included teaching students who were; blind, deaf, had emotional or behavioural disorders and general learning disabilities. Flem and Keller concluded that teachers' attitudes and characteristics influenced the classroom environment, and therefore inclusion. Support from competent networks and availability of resources were also factors that affected inclusion. Flem and Keller suggest the biggest challenge to inclusion is social rather than curriculum integration.

Cook, Tankersley, Cook and Landrum (2000) speculate that students are less likely to be rejected by peers and teachers when their disability is visible in nature. The prominent role played by parents in teacher's formation of attitudes was an unanticipated finding in their study. They recommended that teacher's take a pro-active role in facilitating meaningful communication with parents of

children with disabilities to enable teachers to understand and appreciate the uniqueness of their situation.

Teachers and classmates inadvertently restricted participation according to Goodwin's (2001) qualitative study of Canadian students with physical disabilities experiences in physical education where limited participation led to the students feeling isolated. Goodwin also found that some children were not known to the teacher by name, rather their medical diagnosis was the point of reference for these children, for example, "the wheelchair student" (Goodwin, 2001, p.16). Some teachers were found to have preconceptions of a student's inability or weakness. A student with a physical disability is perceived by some teachers not as a person but as an object likely to create extra work. Goodwin suggests that a child with physical disabilities should instead be someone who makes teaching new again and provides an opportunity to teach physical education with creativity and diversity.

Butler, and Hodge (2004) carried out a qualitative study of social inclusion in physical education classes in an American school. Observation of two 13-year old students was analysed to identify and describe the social interaction between students with and without disabilities. The male participant had a physical disability (juvenile scoliosis) and the female participant an intellectual disability (Down syndrome). Three physical education classes were selected randomly for each participant. Field notes taken during these classes found that while classmates primarily exhibited appropriate behaviour and social interaction towards the students with disabilities there were occasions when they criticised their skill level. Teachers were found to be lacking. They failed to adequately attend to the participants preparedness for the class and failed to monitor off-task behaviour. During interviews both participants expressed concern that male classmates often displayed aggressive behaviour towards them. This aggressive behaviour resulted in reduced interaction in activities and a feeling of unease for the participants.

Aggressive behaviour toward students with disabilities was also noted in Palmer, Fuller, Arora and Nelson's (2001) study where 140 American parents of children

with severe disabilities provided written comments on their views on inclusive education. Their survey revealed one common concern held by parents was the possibility of aggressive behaviour from classmates. Some parents believed that their child could be mistreated, harmed or ridiculed. Negative reactions from school staff was also a concern voiced by parents who felt that if the philosophy or ideals of inclusive education had been imposed on their community without their consent their child would not feel welcome by their teacher.

Beatson (2000) alluded to cosmetic impairments and their influence on socialising. For example, a disfigurement caused by a scar or birthmark might influence interpersonal involvement. Fear of rejection from such disfigurement may make it difficult to form relationships. Social acceptability from others may also be compromised. Beatson believes attitudes and behaviour towards people with disabilities include indifference, ignorance, embarrassment, hostility, stares and whispers.

Social approval is vital for persons with physical disabilities to attain high quality of life according to the result of Viemero and Krause (1998) who conducted their study of 45 adults with physical disabilities in Finland and Sweden. They contend that social approval of people with physical disabilities adds to their quality of life. Viemero and Krause state that individuals with physical disabilities display more pessimism, passivity and immaturity than non-disabled persons. Viemero and Krause suggest that the more social disapproval a person perceive towards their disability the more likely they are to withdraw form society. Social integration and positive attitudes were seen as vital to high-quality participation in social activities. Persons that were satisfied with their social relationships and experienced meaningful activities felt socially integrated and were less likely to experience depression.

While people's ability to perform activities and fulfil roles is affected in part from a disability, external circumstances through attitudinal barriers can be equally obstructive. In New Zealand assistant teacher aides were introduced into the classroom to assist students with disabilities but Eriksson (2005) debates the benefits of an assistant and suggests that unintentionally the assistant might inhibit

the autonomous interaction of students with disabilities. Alston (1983) also saw being shadowed by a classroom assistant as poor decision making by staff. Flem and Keller (2000) consider personal assistants might stop the inclusion process by offering too much help. They acknowledge the use of personal assistants is not always desirable and concede these assistants are sometimes employed as a poor substitute for building and classroom modification.

Autonomy is achieved by developing independence skills from an early age, however, according to Ashman & Elkins (1994) one of the most frustrating aspects of living with a disability is the restriction it places on an individuals life experiences. The assumption that a person with a disability must be protected against physical, social and psychological risk is common and a typical first reaction. In spite of this underlying desire to protect Ashman and Elkins stress that allowing a full range of learning experiences is important to develop an awareness of the persons limitations and promote self-advocacy.

A conceptual framework was developed by Test, Fowler, Wood Brewer and Eddy ((2005) to serve as a guide for the instruction of self-advocacy. The first element of this guide is knowledge of self and rights. The authors argue that it is necessary for individuals to know themselves, and to identify their own needs, before they can tell others what they want. The second component is effective communication, and lastly leadership, to enable the individual to move from self-advocacy to advocating for others.

According to MacDonald and Block (2005) it is unfortunate that children are not born with self-advocacy skills, but they can be taught. A young girl with cerebral palsy is the sole participant of their Canadian study. MacDonald and Block state “students with disabilities can suggest strategies on how they can participate more successfully in activities; and help the teacher feel more at ease about accommodating the student throughout a class” (p.46). Included in the process of learning to self-advocate was the opportunity to lead a class discussion to determine appropriate modifications to physical education activities. MacDonald and Block had several suggestions for teachers for assisting students with physical disabilities to be their own self-advocate; develop a rapport with the student,

arrange a regular meeting with the student to discuss modifications to games, listen to suggestions given by the student and provide positive feedback. Additionally, they suggest providing examples of individuals with similar disabilities who have experienced success in physical activities.

There is evidence to suggest, according to Singh (2002), that teachers do not believe they have a solid professional base of knowledge to fully include students with physical disabilities, due to limited pre and in-service training. Teacher's that participated in Singh's American study did not feel competent or adequately prepared to integrate students with physical disabilities in their classrooms. Overall, the feeling of professional readiness to integrate students with physical disabilities "points to the need for thorough and adequate teacher preparation" (Singh, 2002, p.244). The teachers' believed they lacked specialised training and adequate knowledge about available assistance and adaptive technology. Although 66% of the teachers surveyed by Singh had some knowledge of environmental adaptations that might be necessary, they were not confident with their limited knowledge of the characteristics of various physical disabilities. Over half of the teachers were also aware that "students with physical disabilities should be allowed extended time to complete learning tasks" and "should be allowed extra time to move from one location to another whole at school" (Singh, 2002, p. 243).

Lack of professional readiness could attribute to feelings of discomfort, fear and rejection, which are still prevalent even though there are numerous laws to ensure equal treatment of people with disabilities (Krahe & Altwaser, 2006). Misconceptions still exist, according to Krahe and Altwaser, about the achievement potential of those with disabilities, even though we live in a society that takes pride in tolerance and integration. In New Zealand, at the University of Waikato, inclusive education is a compulsory requirement for all Bachelor of Teaching students. A wide range of disabilities is covered in depth, along with practical strategies within a classroom context.

Soodak, Podell and Lehman (1998) sought teachers' responses to inclusive education. Their survey of 188 teachers in American schools included a

hypothetical scenario that told them they were to have a student with a disability join their class. Participants of the survey were randomly assigned one of five disability categories, hearing impairment, learning disability, intellectual disability, behaviour disorder, or a physical disability that required the use of a wheelchair. Two dimensions, hostility/anxiety and receptivity/calm were identified as common teacher characteristics. Teachers were found to be more receptive towards students with physical disabilities than emotional, behavioural or learning difficulties. However, a pattern emerged from their survey that suggested teachers were fearful and anxious towards the inclusion of students with physical disabilities. Soodak, Podell and Lehman (1998) suggest that non-disabled individuals become anxious when another individual lacks a quality considered greatly important to society, such as mobility. Another explanation for teacher fear and anxiety offered by Soodak et al. is the likelihood of teacher inexperience. Their anxiety toward physical disabilities may reflect a general fear of the unknown. Their results also showed the teachers became more fearful and anxious the lower they perceived their personal teaching efficacy. In addition, class size added to the anxiety of having a student with special needs in their classroom - the greater the overall number of students the greater the anxiety.

When Singh (2002) asked the participating teachers if they considered teachers in general had sufficient knowledge about the social needs of students with physical disabilities, only 72% reported an awareness that students need help in creating and maintaining friendships. Butler and Hodge (2004) suggest that teachers should find creative ways to foster equal status relationships between students with and without disabilities. Orr, Thein, and Aronson, (1995) investigated the concept of the tendency of persons with an orthopaedic disability to conform to others suggestions to gain social support. Their study, conducted in Israel, suggest that persons with physical disabilities use conformity as a strategy for eliciting social support from strangers but was not found to be effective with family members or in established friendships.

In New Zealand Neilson (2000) recognises the often-neglected issue of providing opportunities for children with disabilities to assist others. She believes it is important for a child to reciprocate and not be put in the position of always

accepting assistance. Millar and Sammons (1999) outline positive role modelling when interacting with students with disabilities:

- Always use person first language
- Focus on the student's abilities and competencies.
- Offer help that is appropriate.
- Provide assistance when asked or your offer is accepted.
- If the student uses a wheelchair always be respectful of personal space, whenever possible sit in order to be at eyelevel.
- Always be aware of possible barriers to inclusion: attitudinal, physical and environmental.

French (1993) discusses independence from the perspective of a person with a disability. She describes a time when a librarian saw the lack of facilities for students with limited or no sight as a violation of one's rights. The librarian believed a special computer was needed to help them find their own references. The librarian believed this would alleviate the limitations faced by students with limited vision. The librarian assumed that all people desired total independence. French saw no need for such a computer. The advantages would, in her opinion outweigh the disadvantages. First the student would need to learn to use the computer, taking up valuable study time. The computer might not suit all students with sight difficulties. Special equipment is often located in inaccessible or inconvenient places making its use impractical or undesirable. A feeling of obligation to use such equipment replaces any ideology of independence. A computer might enable the student to find the reference, but the need for a librarian to find it on the shelf would still be needed.

#### **(d) Osteogenesis imperfecta specific**

There is considerable literature that describes osteogenesis imperfecta in medical terms and how a patient is to be treated. John Hopkins School of Medicine offers comprehensive literature of the medical condition, the causes and effects, and the appropriate procedures to follow when presented with a patient displaying fractures, or other complications caused by this osteogenesis imperfecta (<http://hopkinsmedicine.org/>). There is a plethora of recent research into the affects of the several medications and other treatments currently being explored

for their potential use to treat OI. In comparison to the vast number amount of medically based research few articles are available that considers the psychosocial aspects of OI.

There is a stereotype held by some physicians and medical personal and many persons in the OI community that persons with OI tend to be exceedingly bright, articulate, assertive and euphoric (Ablon, 2003, p.202). Rich life history of fifty-five adults provided Ablon with data to analyse the possibility that the stereotype is a behavioural phenotype and to what degree the realities of life experiences for persons with OI influence their attitudes and behaviours. Ablon cited Flint's (1998) definition of the term behavioural phenotype as "the specific characteristic behavioural repertoire exhibited by patients with a genetic or chromosomal disorder" (p.201). Almost all participants interviewed by Ablon were found to be articulate and demonstrated wit. Theories from the participants on why persons with OI are seen as being intelligent, bright and articulate included lack of physical stimulus as an infant, and increased mental stimulations as compensation due to fragility. Limited participation or total exclusion from the more physical activities is often replaced with leisure activities of a less physical nature, such as reading, science projects, and stargazing.

Self-defence in medical settings is seen as another reason for children with OI being articulate at an early age. Children with OI must explain to health care workers how to move them to prevent further fractures. Self-defence and self-preservation develops early for children with OI because of the nature of their condition according to Ablon (2003). Heightened awareness and perception born out of the danger of potential fractures allows children to anticipate events and problems before they occur.

Euphoria is another term referred to by Albon (2003) in relation to persons with OI. Albon cited an early article by Reite, Davis, Solomons and Ott (1972) in which children with OI were described as being uniformly cheerful and not prone to mood swings or depression and thus had a possible metabolism due to their condition that produced a persistent mild euphoria. Albon's participants denied the stereotypical state of euphoria and suggested that any sign of euphoria was in

fact a facade to alleviate others pain. One participant in Ablon's study described the stereotype of euphoria as a "cruel joke" (p.209) and spoke of a number of people with OI who have histories of substance abuse, depression and suicide attempts, while others suggested that a mantle of cheerfulness made them more attractive to other people. One participant in Ablon's (2003) study stated; "My perseverance wasn't a choice that life offered me. It was a necessity to keep my heart beating, to keep the razor from my wrist" (p.201). Ablon contends that the assertion of a state of euphoria trivialises the significant periods of pain and suffering persons with OI experience.

Participants in Ablon's (2003) study also disclosed dimensions of their personality that reflected a search for adventure. Participants recounted recreational pursuits ranging from crawling in the woods collecting wildflowers and encountering a coyote to tubing down rivers, horseback riding and four-wheel driving. Ablon suggests advice given to parents by physicians was the reason for their spirited approach to life. Advice included letting them experience things, even at the risk of breaking or death. "If she breaks we'll fix her. We can fix a broken bone, but we can't fix her mind. If you let her be handicapped, then she's going to be handicapped" (p.205) was how one paediatrician phrased his advice.

Claesson and Brodin's (2002, p.314) study of thirty families with children with OI in Sweden exemplifies the conflict felt by some parents:

The re-occurring fractures and fragile bones cause problems for the whole family, as the child cannot participate in different activities on equal conditions as other children. Parents are often anxious and sometimes over-protect their children, but the parents often feel that it is necessary. They do what they believe is best but sometimes it prevents the child from liberation.

Parents were anxious to support their child's independence but at the same time felt they must protect the child.

Recently research has disclosed the possibility that some parents may have been wrongly accused of intentional injury (physical child abuse) towards their child. Marlowe, Pepin and Byers (2002) undertook retrospective clinical laboratory

testing and identified eleven of the 262 children studied with fractures apparently caused by non-accidental injury to be affected with OI. An equal number of children could not be excluded as being affected with OI. They estimate that 2-5% of child abuse cases could in fact be a direct consequence of OI. Two families that participated in Claesson and Brodin's (2002) study were accused of child abuse before a diagnosis was made. X-rays showing previous fractures (Marlowe, Pepin and Byers, 2002), short stature, blue/grey sclera of the eyes, hypermobility of joints, and abnormal temperature regulation (Albin, Greenspan, Reinhart, & Grix, 1990) are likely to indicate the presence of OI.

Loving parents of children with osteogenesis imperfecta in America have lost custody of their children and in some instances have been imprisoned according to Lanthrop (1992) who presents one case where parents were accused of child abuse. The police met the O'Connell's, parents of a child with undiagnosed OI, in the emergency department of a Californian hospital. A full set of x-rays revealed several other fractures that had already healed. Social services were called and an investigation began. Several weeks later a doctor in a different city made the diagnosis of OI. The parents never received an apology from the social services department, nor were they able to have their record expunged.

Not all children are diagnosed with OI at birth according to OIF (2005). Normal daily care of an infant can cause a fracture, for example, changing a diaper, clothing, or bathing, can result in one or more fractures. The infant might be several weeks old before a diagnosis is made. In some instances the child may reach the toddler stage before the first fracture occurs. A fall while learning to walk can be the first fracture to occur. Other children might not experience a fracture until they attend school and begin participating in physical education and contact sport (OIF, 2005).

While a diagnosis of OI is usually made sometime through the child's early life others may have no knowledge of the condition until adulthood. Weitzel and Percy's (2000) case report of a 30-year-old woman in the United Kingdom explained she was unaware of having OI type I until she underwent genetic counselling prior to planning a family. There was no family history of OI and

although examination of her medical history revealed multiple fractures a diagnosis had not been made. Of the thirty families of children with OI surveyed in Sweden by Claesson and Brodin (2002) three children were diagnosed between the 3 and 7 years of age.

The Osteogenesis Imperfecta Foundation offers free fact sheets on various issues, including: health and exercise and education issues ([www.oif.org](http://www.oif.org)) Regular exercise and activity are advised by OIF to promote maximum bone density, optimal physical, psychological and social well being. Research shows physical activity is important for muscle strengthening, increased muscle mass, cardiovascular fitness and an improved ability to handle infection. Shea-Landry and Cole (1986), however, warn that parents “must help the child resist the cultural imperatives to participate in sports and to take physical risks” (p. 979).

Englebert, (2001) found that the overall perception of their athletic competence of persons with OI type III was positive. They speculated that the common use of an electric wheelchair by those with type III for sports activities gave them greater autonomy. They also present the premise that children with OI type I, who are less likely to use wheelchairs, feel less competent as they are more likely to compare themselves with their peers.

To determine the educational help children with OI may need Alston (1982) studied twenty children. Her findings revealed specific areas of difficulty that students may experience:

sitting upright

- fatigue,
- an inability to physically move items,
- using pencils and pens,
- large schools,
- and steps.

Due to ligament laxity not all children with OI can sit unaided in their first few years. Ligament laxity and short arms also inhibit the child when writing. Alston suggests teachers take care to minimise this difficulty by limiting the size of paper used by the child and shorten writing tools. She also recommends listening to the

child to eliminate external factors. Alston's tests indicated children with OI showed no significant difference in intelligence or oral vocabulary than children of their matched ages. Alston believes that determining the educational needs of children with OI is difficult and often results in teachers' making inappropriate provisions. She bases this belief on the probability that a school has only one child affected with OI and teachers subsequent lack of previous experience of students with this condition.

One year later Alston (1983) further examined the literacy skills of children with OI. Observation suggested that handwriting skills should receive special attention from teachers. Forty per cent of people with OI experience excessive mobility of the digits therefore students engaged in extensive periods of writing may experience pain and possible fractures. Alston describes an incident where a student fractured her finger before her school examinations. The young lady used her other hand to write. She was given no consideration for the necessary change of hand in her examination results. One inappropriate provision Alston mentions is the placement of children with OI in special schools and the connection between significant under-achievement in mathematics and writing skills.

Teachers' good intentions towards creative methods of inclusion are not always followed through. Geisman (2005), the mother of a child with OI provides an example. She recalled an emotionally painful experience perpetrated by her son's teacher. While convalescing at their American home after surgery, an oral presentation over a telephone hook-up had been arranged for his Junior High School speech class. Dressed in his best clothes the young man gave his eloquent, humorous speech. "When his short but inspiring presentation ended, I let go of the button expecting to hear a loud clamor" (p.11). The applause was not forthcoming. The teacher had dismissed the class halfway through his speech.

Journalist Peter Douglas (2002), a young New Zealand man with OI, revealed in a short article he was asked to submit to his local paper on himself that he also encountered insensitivity and assumptions. Educationalist's questioned whether he would be able to cope with regular mainstreamed schooling and assumed he would not be taking metal work or woodwork. In spite of the limited expectations

of the activities he would be involved in while at school Douglas joined Cub Scouts and experienced being thrown over a sheep stile into the arm of terrified eight-year-olds. A few years later he too went abseiling while attending a scout jamboree. Now as a young man he lays claim to two degrees, and yet at eighty-one centimetres tall, if standing were possible, he is sometimes reminded of his limitations and finds it frustrating when there is building or bus he is unable to access.

In comparison Emily Seelenfreund, a young America woman has not met with opposition to her endeavours, especially from her parents. Emily was diagnosed within hours of her birth (Seelenfreund, 2005). Her interest in sport began at the age of five when she discovered wheelchair sports. Swimming, table tennis and racing eventually led her to wheelchair basketball, a game that her father considers to be a cross between regular hoops and bumper cars, where turned over wheelchairs are part of the game. Her father admits wheelchair basketball is possibly not the smartest choice for an athlete who has OI but her parents support her decision. Emily's enthusiasm for playing basketball has spurred the 17-year-old to search for universities in the United States that have wheelchair basketball programmes for women.

Research continues into the medical condition, for example, hearing loss is currently being debated. Until recently hearing loss was not thought to occur until the teenage years or early twenties (Imani, Vijayasekaran, & Lannigan, 2003; Tolboom, Cats, Helders, Pruijs & Engelbert, 2004). Similarly, Raunch & Glorieux (2004) report clinical evidence of hearing loss is rare in the first two decades of life even though subtle hearing abnormalities are often detected in a large proportion of children with OI. In contrast Kuurila and Grenman (2004) recommend hearing tests of all children with OI at 10 years of age followed by repeat testing every three years.

Claesson and Brodin (2002) acknowledged that most studies connected with OI focus on the medical aspects of the condition, rather than the people and their families. The pedagogical and psychosocial aspects of those with OI are often overlooked. Their study, based in Sweden, focused on families of children with

OI. Thirty families responded to their survey and ten families were interviewed. Claesson and Brodin study determined what support families wanted, and felt they lacked, to make life easier for the whole family. Technical devices, information about disability support services and up-to-date information were identified as difficult to access. Doctors and physiotherapists were considered to be lacking sufficient knowledge of this rare condition. Claesson and Brodin (2002, p.314) concluded their study by stating “Both families and children need support from a holistic perspective in which the different aspects in parent’s and children’s lives are wound together to an entirety”. They encourage further research on the psychosocial aspects of children with osteogenesis imperfecta, their families and their immediate environment.

### **Summary**

This chapter outlines some key aspect of the literature. Some key findings from the literature point to the changing attitudes towards those persons who have a physical disability. New Zealand’s movement toward inclusive education demonstrated the changing attitudes of society. The literature also suggested that the physical environment of a school, attitudes of school staff and classmates appeared to create barriers to the reality of inclusive education. There seemed to be some discrepancies regarding physical activity. Parents and teachers had different concepts from medical professionals and people with OI as to which activities were to be encouraged.

The literature reviewed exposed gaps in inclusive educational research from a student perspective. This study might inform educational practice through listening to the experiences of a small sample of those that have gone through, or are still going through, the education system. Their stories might reveal information that reveals the realities of the classroom.

This present study focuses on the real lived experiences of students with OI in New Zealand classrooms. The following research questions were devised as a result of an extensive review of the literature and my own interest in osteogenesis imperfecta:

- What barriers exist in the educational setting for students with OI?

- What/who may be the cause of these barriers?
- What possible effects might these barriers have on the student?
- How does the present compare with the past?
- How might these barriers be overcome?

The importance of this study, based on findings in the literature is giving voice to people with OI. The lack of qualitative studies that include the perspective of people with OI indicates that further studies are important to make people more aware of their unique experiences.

Chapter three will explain the chosen research method employed to give voice to those with OI and thus the opportunity to reveal their experiences in New Zealand schools.

## **CHAPTER THREE**

### **DESIGN AND METHODOLOGY**

#### **Introduction**

People born with osteogenesis imperfecta (OI) face unique challenges. Their fragility and predisposition to fractures present risks to children with OI while engaged in day to day activities. This qualitative case study will explore possible barriers to an inclusive education for those with OI. Participants will be both past and present students' from New Zealand schools so comparisons can be made between their experiences. Comparisons will also be made to determine the effects Special Education policies might have made to inclusive education opportunities and experiences for those with OI. The voices of those with OI data will inform the researcher about what it is really like for them and whether barriers do indeed exist. Qualitative methodologies appear to be the best means of conducting this research. This chapter begins by discussing qualitative research and its methodology and theoretical relevance to this study. This will be followed by an outline of the study design and process. Finally the ethical responsibilities and boundaries of the researcher during this study will be determined.

#### **Methodology**

In this study the researcher seeks to find, from three participants with OI, what they thought about their education experiences. To truly capture their feelings and experiences the data must be found through their voices as they tell their personal stories. This lends itself to qualitative rather than quantitative methodology.

Quantitative researchers believe that social facts can be defined by statistical compartmentalised classification of data (Burns, 1994). For example, a survey asking identical questions could be sent to multiple participants with OI to determine what barriers they face at school. As suggested by Burns, the questions would need to be controlled to provide unambiguous answers and eliminate confusion in meaning. By analysing the data the researcher could determine the average response. One advantage of quantitative research is the replicability of a study. The exact number of people with OI could be asked the same set of

questions under the same circumstances. It would be expected that the data would produce the same results if replicated and repeated in another time or place.

The very nature of this study where the focus is how those with OI experience their world and how they feel about their world in the school environment, lends itself to qualitative research as the preferred methodology. While quantitative methodology would provide the researcher with statistical data, the feelings and experiences those with OI have while at school would remain largely unexplored. Strauss and Corban (1998) define qualitative research as inquiring about peoples' lives and their lived experiences. It encompasses their feelings, emotions and interactions with the world. Qualitative researchers are more interested in understanding how people make sense of their world, the experiences they have in the world, and how it is lived or felt (Merriam, 1998). Denzin and Lincoln (2000, p.3) refer to making sense of interpreted meanings from how people see their world:

Qualitative research involves the studied use of empirical materials - case study; personal experience; introspection; life story; interview; artifacts; cultural texts and production; observational, historical, interactional, and visual texts – that describe routine and problematic moments and meanings in individual lives.

How people with OI view their world at school may be quite different to their parents, teachers or what researchers may observe. Their routine and problematic moments might be interpreted quite individually. What might be deemed as problematic to the observer may merely be routine to the participant, thus making it more acceptable to them. For this study qualitative methodologies will locate the researcher in the world of three participants with OI. By way of interviews and conversation their world may be interpreted and analysed.

### **Relevance of qualitative research to this study.**

Qualitative research is a “human story rather than a cold detached set of figures” (Burns, 1994, p.382). The aim of this study is that the stories of three people born with OI are told in the context of their educational experiences. For example, what experience do/did the participants have while attending school? Their lived

experiences are the essence of my study. An attempt to capture their experiences will require a flexible style to the interviews. Qualitative researchers are interested in understanding the phenomenon from the participant's perspective, the insider's perspective (Merriam, 1998). It is the feelings and experiences of those with OI that tell us what it is like for them to live with a permanent disability rather than the perceived perspective of an outsider. An insider's perspective could provide a rich description of how they view things (Merriam). In this study those born with OI are asked to communicate any barriers that might have existed, and might still exist, within the New Zealand education system. This will provide living data to inform the study.

When engaged in qualitative research, the researcher first collects data by use of responsive communication with the participant Ghesuiere, Maes, and Vandenberghe (2004). The researcher then describes the communication. Data is then evaluated and compared by creating images that give readers the impression that they have also been present. By listening to the voices of those with OI when telling their stories of life at school the reader may get a feel of what it is like for them at school and help us to understand better the possible challenges they might face.

Previous qualitative studies such as Cole, (1993), Brodin, and Millde (1991) have focused on interviews and questionnaires seeking the experiences and feelings of parents of children with OI. This study will focus on those who actually live with the disability. Bearing in mind that OI is a rare medical condition the life histories of two adults with OI and one child presently at school will be explored through semi-structured interviews. Interview data will be analysed for comparisons and differences of how each individual has experienced life at school over three generations.

### **Theoretical framework**

An important aspect of qualitative research is grounded theory. This study is firmly embedded in grounded theory in as much as "theory arises from or is 'grounded in' the data" (Mutch, 2005, p.219). Strauss and Corban (1998)

speculate that since grounded theories are derived from a series of concepts that emerge from data they are more likely to offer insight and enhance understanding.

Data is collected and analysed before more data is collected. Grounded theory relies on a continuous data collection process as demonstrated in a personally constructed diagram below.

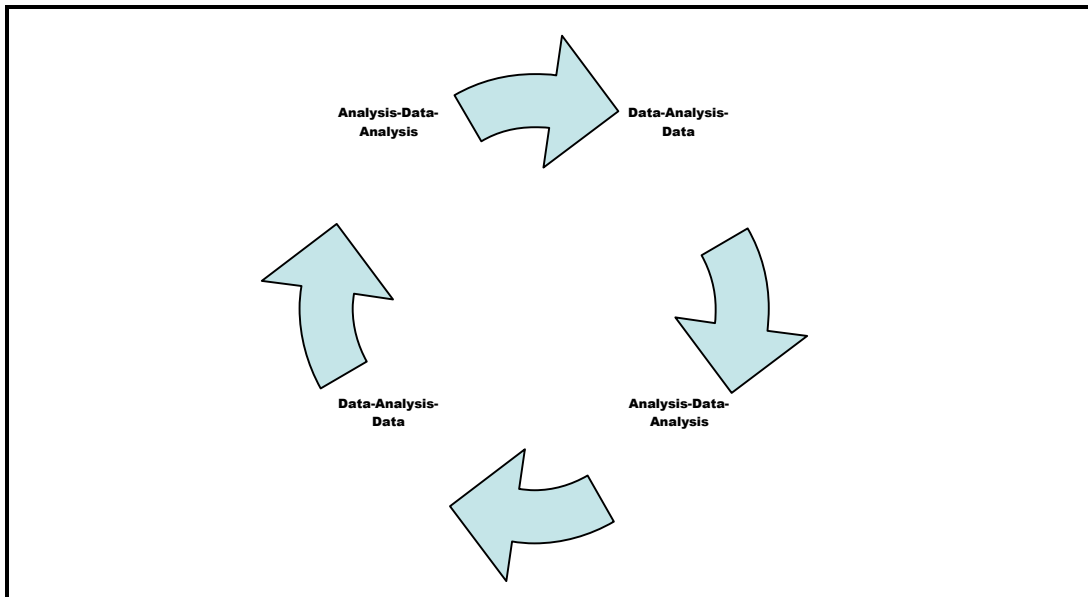


Figure 3: Continuous data collection process

Data collection initiates analysis. Until sufficient data has been gathered and analysed common themes and key issues can not be identified, compared, and subsequently developed. Glaser (1992) comments that the researcher must continually collect, code, compare and analyse as illustrated in figure 3.

Charmaz (2000, p.515) explains the process of data collection and analysis as a constant comparative process:

The constant comparative method of grounded theory means (a) comparing different people (such as their views, situations, actions, accounts, and experiences) (b) comparing data from the same individual with themselves at different points in time (c) comparing incident with incident (d) comparing data with category (e) comparing a category with another categories.

Unlike quantitative research, qualitative research uses a non-mathematical process of interpretation where data is analysed to discover concepts (Strauss, 1998). Once initial data has been collected from one person, it is compared to different people and situations. This in turn is compared to their own version of events, or interpretation of issues. Themes are then selected before being compared to other categories for connections and commonalities.

### **Relevance of grounded theory to this study**

“The grounded theorist’s analysis tells a story about people, social processes, and situations” (Charmaz, 2000, p.522). In this study participants will share their views about personal experiences and encounters through their schooling. Close examination and analysis of peoples’ stories may begin to inform us what it is really like to be a student with OI in the New Zealand education system. By comparing the experiences of three different generations it may be possible to identify whether any barriers did, or indeed do, exist for the participants in this study.

Charmaz (2000) points to the durability of grounded theory because it allows for flexibility. Emerging analysis can be modified when further data are gathered. As data is analysed so theory evolves. The qualitative grounded theory approach employs methods in which theory is grounded in data emerging from various methods such as case study, participant observation and open-ended interviews (Mutch, 2005). It is from semi-structured interview data that theory will evolve in this study.

### **Methods**

Qualitative researchers may draw on a range of strategies to collect data. In this study the writer will attempt to build a picture from each of the three participants’ experiences of school. The research questions to be answered are:

- What barriers exist in the educational setting for students with OI?
- What/who may the cause of these barriers?
- What possible effects might these barriers have on the student?
- How does the present compare with the past?
- How might these barriers be overcome?

In order to find the answers to these questions the most appropriate tools must be used which sit comfortably with the participants and which will provide data. Case studies, with elements of phenomenological case studies, using semi-structured interviews are the preferred methods.

Case studies.

Case study is used here to gain insight, into the educational experiences of people with OI. Rossman and Rallis (1998) argue that case studies are particularly useful for rich description. Tracing changes over time is one of the major strengths of the case study method (Burns, 1994; Rossman & Rallis, 1998) as in this study involving participants from three different generations. Case study method is often used when focusing on people in unique positions such as special education where a specific physical disability is worth analysing (Burns, 1994). Perhaps more importantly case study illuminates the readers' understanding and extends their comprehension of unfamiliar circumstances (Rossman & Rallis).

It is completely legitimate to study aspects of the reality of the success of inclusive education using qualitative case studies according to Ghesuiere, Maes and Vandenberghe (2004). The case study approach has enormous success in educational research allowing the researcher to "unravel the complex school and classroom realities" (Ghesuiere et al, p.172). In case studies a conversational approach is employed that is emergent in design and is a suitable method to study physical disabilities worth documenting and analysing (Burns, 1994). Semi-structured, informal interviews, with no predetermined set of questions allow the initial interview with each participant to be largely exploratory. This approach is particularly useful when the researcher does not know enough about the phenomenon to ask relevant questions (Merriam, 1998). Case studies also offer the potential to generate rich description through the use of face-to-face semi-structured interviews in Burn's view and can provide "human interest, good stories and a more humanistic mode of presentation than that of the traditional quantitative styles" (Burns, 1994, p.330).

### Phenomenological studies

A phenomenological study is a major qualitative research genre (Rossmann & Rallis, 1998). Phenomenological studies like a case study are used to understand the lived experiences of people. One significant difference between the two is that while case studies seek to understand a larger phenomenon, phenomenological studies seek to understand the lived experiences of a small number of people. The three participants involved in this study have the rare condition osteogenesis imperfecta. Also, case studies employ multiple methods to gather data on what participants are doing, and why they are doing it. Phenomenological studies on the other hand, rely on in-depth, exploratory and interactive interviews to understand what the participant has experienced and how that person understands that experience. For this study, it was considered advantageous to use phenomenological study for such a small number of participants.

### Semi-structured interviews

Conversation and semi-structured interviews will be the main means of collecting data. Interviewing serves as the nucleus of qualitative research. Interview approaches differ in degree of structure. Surveys and questionnaires offer the most structure where each respondent receives identical questions. Surveys and questionnaires are most suitable when research issues are known in general terms before the questionnaire is constructed (Scott & Usher, 1999). Information using questionnaires and surveys are more commonly used for a large number of participants who are capable of expressing their thoughts in written form (Scott & Usher). In this study the voices of three participants will recall their educational experiences in New Zealand schools.

Structured interviews differ slightly from questionnaires. Possibly the most significant difference is the flexibility for researchers to rephrase questions and prompt the participants for further responses; to elicit further and more comprehensive information (Scott & Usher, 1999). A list of questions is useful as a guideline, but not necessarily strictly adhered to.

A far less formal approach is the semi-structured interview, whereby the participant is encouraged to set the agenda (Scott & Usher, 1999). The interviewer

still prepares a list of issues to discuss. Burns (1994) maintains that the essence of semi-structured interview is quality conversation between the researcher and participant which can be subtly redirected by the researcher to maintain focused data. In addition to the questions the interviewer uses to guide the conversation, the participant is free to suggest other issues of importance to them. Burns refers to semi-structured interviews as open-ended or in-depth interviewing “that focuses in an unstructured way on the informant’s perception of themselves, of their environment and of their experiences” (p.279). Semi-structured interviews appear to allow participant voice to a higher degree than questionnaires or surveys and serves as a vehicle to elicit in-depth responses to key issues of concern to the individual.

The focus of this research is on the individual feelings and perceptions of three participants and their experiences of school life. It is hoped that semi-structured interviews will allow fluent and spontaneous conversation to take place. A prepared list of issues will be used to refocus the conversation only when necessary (Appendix 1).

### **Design of this study**

The purpose of this study is to give voice to persons with OI to discover possible barriers that faced these students within the school setting. Case studies seem to be an appropriate vehicle to adopt to engender communication through intimate conversation. This study focuses on three individuals that exemplify a particular phenomenon, specifically the daily school lives of those with the medical condition OI. First, it must be ascertained whether any barriers to inclusive education do exist. If barriers do exist, an analysis of what or who cause any these barriers will follow. Using participants from three generations a comparison will be made between the past and present. An analysis will be constructed into the possible effects these barriers have on the individual. And finally it is hoped that the participants’ responses and stories might pave the way for change, should change be needed, so that schools, teachers and policy makers might be better informed to provide a safe and inclusive learning environment for those with a disability in general and in particular for students with osteogenesis imperfecta.

### Gaining Access

This study sought involvement of participants, with osteogenesis imperfecta. Three age groups were considered sufficient to provide data for case studies. Due to time constraints and the rarity of the medical condition itself a sample of three, while small in number, represents 1 percent of the estimated 300 people in New Zealand with OI. All three participants were recruited via various family connections. The oldest participant (my sister) knew of the intention of this study from previous conversations and volunteered to be involved. She was also a source of information for others with OI who were willing to share their experiences. My sister as a participant and now in her fifties fits the senior generation of this study. Through her long-standing association with the Brittle Bones Association, members were identified that fitted the middle generation criteria, that being in their thirties and having attended a New Zealand state school. The third participant, a child presently attending a New Zealand state school, was also identified through a family connection. I did not personally know the child prior to this study.

### **The process**

Prior to beginning this study, the School of Education Ethics Committee at the University of Waikato approved the proposal. Participants were invited to take part in this study by telephone or e-mail. In the child's case first contact was initiated with her parents. On showing interest in the study the two adults, and one child, were sent a letter of introduction (appendix 2) an information sheet outlining the intention and direction of this study, and a consent form (appendix 3).

The letter of introduction was worded somewhat differently for the child participant. A chatty approach was adopted so she would better understand the intent of this study. Also outlined in the letter of introduction was a simplified version of her right to withhold information and the option of having a parent supervise the interview process was raised. She was invited to choose her own pseudonym. She chose Elizabeth.

Elizabeth gave her own written consent to take part in the study. The decision to provide a separate consent form for Elizabeth was based on the researchers underlying commitment to recognise her as an expert in her field, and as such entitled to the respect of her own ability to make her own decisions. Decision-making develops self-confidence and a sense of autonomy and allowing children to decide for themselves if they wish to take participate is not only possible – it is highly desirable (Tolich, 2002).

In order to empower Elizabeth it was meaningful to allow her both autonomy and respect. Consideration was given to the age and verbal communications level of Elizabeth to ensure that consent from her was indeed informed. Considerable time was spent at the initial introductory meeting explaining terms in language Elizabeth could understand. For example, “*you can withdraw at any point up until the completion of data collection*” became “*it’s ok for you to tell me that you don’t want anything you have told me to be used in my study*”. If at any stage there was any indication that Elizabeth did not understand anything from body language, hesitation, or intonation in speech, I gave her an alternative explanation.

A mock interview was recorded and played to Elizabeth to give a concrete example of a recorded interview, as suggested by Tolich (2001). This mock interview involved a member of my family (daughter) answering questions regarding her own experience as a child - of a fall from the tower in the school playground. The interview was audio-taped. The mock interview was limited to five minutes for two reasons, firstly so Elizabeth did not get bored listening to the recording, and secondly so that she did not try to duplicate the mock interview. The mock interview was played during the initial discussion held with Elizabeth and her mother when time was spent establishing an empathetic rapport, as suggested by Mutch (2005).

A total of three, one-hour semi-structured interviews were held with Elizabeth. The time structure with Elizabeth first allow her to become familiar with the process of interviews and second, to give her time get to know the researcher and feel more comfortable with telling her story. These interviews were conducted one week apart. Elizabeth, who lives locally, was interviewed first, with meetings

taking place once a week for three weeks. This timeframe enabled the researcher time to transcribe the interview, deliver the transcription to the participant for verification, and identify themes from the communication. The identified themes were further explored in the two subsequent interviews.

Similarly, the two adult participants, one male (Pseudonym, David) and one female (Pseudonym, Linda) shared their experiences in face-to-face, audio taped, semi-structured interviews. However, due to the participants locality, and social and employment commitments, adult participants required flexibility in the time frame for the interviews. The first interview was held face to face. Transcribed interviews were sent to both adult participants via e-mail for verification. Any changes were noted by the participants and returned to the researcher. Clarification and additional data were further explored with the David via the telephone and e-mail system. Linda elected to have three face-to-face interviews.

The three participants are introduced in the following chapter. A brief profile of each individual will allow the reader to get to know a little about their background first, before exploring their experiences with them.

Participant transcripts were analysed individually before being screened for common elements. Unique subject matter was ascertained. Once raw data were collected in the form of interviews, coding or classifying took place “classifying material into themes, issues, topics, concepts, propositions” (Burns, 1994, p.288). Repeated words or phrases were identified and grouped under key issues or themes (Burns, 1994; Scott & Usher, 1999). Burns refers to Miles and Huberman’s (1984) concept that coding drives ongoing data collection rather than preparing data for analysis and that coding takes place conceptually as the interviews are being conducted. Scott & Usher acknowledge that formalising these social constructs, and making inferences from them to other cases in place and time, is the most problematic part of the classification procedure.

Thematic analysis was used to find categories from the data to identify key issues and themes. Mutch (2005) outlines the formula for thematic analysis:

- Data is skim read with an open mind.

- Transcripts of interviews are read and re-read to identify what captures the writer's attention.
- Transcripts are compared to distinguish commonalities and differences, before initial coding.
- Grouping of common themes' assist in the selection of relevance and importance. Themes are then grouped into key categories.

Mutch's (2005) formula was used in this study. Twenty common themes became apparent during initial coding. These common themes were then grouped into five key categories. In the final phase of data analysis, the results of the case study were considered alongside existing literature alongside the key questions of this study.

For the purpose of this research, the method selected was the case study and semi-structured interviews. This will allow the voice of the three participants with osteogenesis imperfecta to be heard. Through their stories it might be possible to ascertain if barriers to education within New Zealand school do exist. New education policies have been introduced in New Zealand over recent years. The experiences of these three people will be representative of three different generations.

### **Issues: validity, reliability and ethics**

There will always be issues which the researchers particular attention. Three major issues are those of validity and reliability of the research methods and general ethical concerns for the study.

#### **Validity and reliability**

Janesick (2000) states "the value of the case study is its uniqueness; consequently, reliability in the traditional sense of replicability is pointless" (p.394). In an attempt to facilitate reliable and valid data all interviews will be audio taped and transcribed verbatim, with participants' permission. Ghesuiere, Maes and Vandenberghe, (2004) believe that external reliability may be addressed if data is fed back to the participants and any changes made by the participants to transcriptions must be made prior to analysis. All transcriptions were sent to the

participants for verification and any changes made, as stipulated in the consent form sent to, and signed, by all participants.

Reliability of participants' memories might have compromised the data. While this issue might have applied to not all three participants it possibly did pertain to the two adults to a larger degree. Experiences may not have had the same significance after the event. What seemed important as a child may no longer seem meaningful once that child became an adult.

Parental supervision, during interviews, was suggested in the child's consent form. The researcher recognised this might have presented difficulties during the interviews. There was a real possibility that Elizabeth may have felt constrained with a parent present. Domination of the interview from the parent was also conceivable. To limit any speculated excessive intervention from the parent the researcher suggested spending time chatting with the parent at the conclusion of each interview. This was offered as an opportunity to follow up on any comments made by Elizabeth, or voice any concerns they may have had. It was from these talks with Elizabeth's mother that the comments included in the result section were obtained. Elizabeth's mother gave her permission for her comments to be used in this study.

### Ethics

As the researcher I have identified, and disclosed, that I have a sister who has OI and consequently details of this medical condition were known to me. There was the potentiality that as the researcher I would not seek sufficient depth in the semi-structured interviews with the participants. Glaser (1992) believes there is a possibility that personal experience may influence the researcher. This makes an open mind to the participants' experiences and the emergence of the data imperative. Glaser goes on to say that, once a researcher is sensitive to the possibility of being influenced by bias and/or experience that sensitivity may provide fuller and more specific data when viewed and analysed through an open mind. Strauss and Corban (1998) agree that it is not uncommon for researchers to have beliefs, assumptions and to a certain extent bias, and that the important thing is the ability to recognise that these traits can intrude on the analysis of data.

Janesick (2000) also argues, “there is no value-free or bias-free design” (p.385) and as such the qualitative researcher must identify their biases early in their research. Janesick stresses the need for researchers to explain their own relationship with the participants so the reader can ascertain the studies “credibility while surveying the full range of evidence” (p.389). As the researcher, I have made my relationship transparent, and clearly stated my sister as one of the participants in this study.

Christians (2000) argues that “watertight confidentiality has proved to be impossible” (p.139). The possibility of a breach of confidentiality does exist. Participants could be identified due to the rarity of OI. In an attempt to protect the identification of participants, pseudonyms were used for each participant. In addition to a pseudonym, there was to be no reference made to the name, location or region of the schools attended (both at present and in the past). This action was implemented to reduce the degree of possibility of identification to any individual, family and school.

Another concern I have, as the researcher, is the possibility that this study could lose the holistic nature of listening to the stories of three people with OI and be dominated by an analysis of Special Education Policies. Their stories hold the key to this research. It is their perspective of their lived experiences that the researcher is most interested.

Blinde and McCallister (1998) recognise the value of listening to the perspectives of children to provide unique insight into the dynamics of education. They believe children’s lived experiences have largely been absent in previous studies on students’ with physical disabilities. They conclude that most of the research and writings that examine disability-related issues represent the perspective of the teacher. Blinde and McCallister provide examples of experiences and perspectives of students with disabilities and their involvement in physical education. Their qualitative study elicited in-depth responses from children to a set of semi-structured interview questions. In this study, the methods chosen to collect data

were done so with the very intention of allowing the three participants voices and encourage them to tell their story.

### **Summary**

This chapter has outlined the means by which the research questions were addressed. In this study, qualitative research was used to capture stories of what life is really like at school for persons with OI. Using grounded theory, case study method was employed to facilitate semi-structured interviews and give the participants a voice. Data were then coded and constantly compared to find common themes and issues. Written consent was obtained from all participants after verbal communication established consent was informed. All possible care was taken by the researcher to protect the identity and confidentiality of the participants.

The next chapters will present the stories of Elizabeth, David and Linda, the three participants involved in this study. Each speaks of their individual experiences of life as a student with OI at a rural New Zealand school. Their accounts, and generous insights into their world, will be followed by a discussion about their experiences in chapter five.

Figure 4 Time line for this study

TASKS	DATES
Apply for ethics approval.	Feb 2006
Meet with supervisor	Feb 2006 - April 07
Write methodology chapter	March 2006
Compile bibliography/reference list	Feb 2006 - April 07
Write literature review	Feb 2006 - April 07
Collect data	April - June 2006
Analyse data	April - August 2006
Write introduction chapter	April 2006
Write result chapter	Sept – Nov 2006
Write discussion chapter	Dec 2006 – Feb 2007
Write conclusion chapter	March 2007
Revise chapter drafts	March 2006 – April 07
Edit/proof read chapters	April 2007
Write abstract	April 2007
Write acknowledgment	April 2007
Compile table of contents	April 2007

# **CHAPTER FOUR**

## **RESULTS**

### **EXPERIENCES, REFLECTIONS & VOICE**

#### **Introduction**

This chapter begins by introducing each of the three participants and describing the interview process. The schools they each attended will then be explored to seek the participants' perspective of the physical environment. Next the attitude of the participants parents, teachers, the wider school community and classmates will be presented. Lastly, participants' individual self-attitude towards their education and their perceived limitations due to their medical condition will be explored. The purely descriptive narrative will include the use of direct quotes to allow the participants voice to be heard as they tell their individual stories.

The objective of this study is to give voice to those who live with OI and allow them to share their experiences. Comparisons between the educational experiences of three people from different generations could indicate if special education policies have altered the quality of inclusiveness for students in New Zealand classrooms over a period of 40 years. Their stories could reveal what life at school is really like for those who have osteogenesis imperfecta (OI), whether barriers exist and how they contend with those barriers. The three participants could communicate if they perceive barriers as unacceptable limitations, or something they are familiar with and accept as part of their life, or rather, a hurdle and something to be conquered. Those with OI can inform us if they as individuals view barriers as a mere hindrance or boundaries to inclusive participation, both educationally and socially. It is through their commentary and documentation that these questions could be answered, and ultimately offer a way forward to true inclusive education.

#### **Facilitating the interviews**

For this qualitative study, semi structured interviews allowed for flexible conversational exploration of the above issues with the three participants. The conversational atmosphere also enabled them to tell their stories in what appeared to be an unconstrained, informal tone. The three participants spoke articulately

and freely, at times becoming quite animated while recalling their experiences. Through speaking with the three participants it is obvious that their stories and experiences are unique.

As previously stated, data collected via the e-mail system did not result in the same quality of in depth data as the face-to-face interviews. Although the intention was to interview all participants in face-to-face interviews, this proved to be impractical for one participant. David did agree to one face-to-face interview. All other data was sought electronically via the e-mail system. This method of gathering data proved to be rather limited in comparison to the face-to-face interview held with him. His responses appeared to be guarded and carefully thought through; where as while talking to him he spoke freely. For this reason, the data collected from David does not have the same depth and the volume not as extensive as the other two participants do. This chapter reports the results of what the three participants had to say.

### **Generating themes-Reporting data**

Semi-structured interviews allowed for free-flowing conversational data collection. Transcripts were analysed for common elements, repeated words and phrases as suggested by Mutch (2005). Commonalities were then categorised into key themes. For example, when discussing with Elizabeth what assistance she received at school she mentioned friends, ramps, teachers, counselling and her mother's seemingly never-ending dedication. Initial coding placed these concepts under help and assistance. The importance Elizabeth indicated these people had in her life, and some of the contradictory comments she made in reference to these various people, led me to believe that attitudes of others were a key issue. In this way, data that was first collected from Elizabeth, then tentatively coded, before being analysed into possible key issues. The interview tapes of the other two participants were transcribed, coded and compared for any commonalities and analysed to verify issues and themes.

The research questions generated conversations from which the following four key themes were identified.

- I. Physical environment: the school physical environment includes key issues that emerged during interviews. Areas frequently mentioned were steps and ramps, bathroom facilities, and distance.
- II. Attitudes of others: parents, teachers and other school associates, and friends and classmates of the participants were also noted as a frequently raised important issue.
- III. Fractures: fractures, whether spontaneous or a result of vigorous participation is a major feature of OI and cannot be ignored. The participants' attitude towards fractures might give valuable insight into how the participants themselves viewed the importance of these events in their lives.
- IV. Self-attitude: the challenges they face from the combined physical environment, attitudes of others, and the frequent fractures they cope with could influence the attitudes of the individual participants.

### **Participants introduced**

The three participants chosen for this study span three generations (11 years of age, and 30 and 50 years of age). Each of the three participants gave freely of their time and thoughts. All three participants have Osteogenesis imperfecta and attended, or currently attend rural New Zealand school. It is through the telling of each of their stories that we can perhaps learn what life was like for them at school.

A pseudonym will be used for each of the participants. Their age, interests and form of mobility will be described, followed by their medical diagnosis, medical status and family history. Next, will be brief report of an account of the interview process chosen by each participant? Anecdotes of their pre-school years and experiences will conclude this section. The formula, youngest to eldest will be maintained throughout this chapter.

#### *Elizabeth*

Elizabeth is 11 years old and is currently in year 6 at a small rural school. An accomplished artist, having won several art competitions, Elizabeth also enjoys many forms of creative handcrafts such as making cards and jewellery. Elizabeth

describes OI as having “*bones like hokey pokey...when you are born your bones are sort of like a crunchy bar and they break really easily*”. Elizabeth is able to walk unassisted and only makes use of crutches or a wheelchair when leg fractures occur. Elizabeth unashamedly admitted to “*bum shuffling*” when it is more convenient for her than walking with or without the aid of crutches. Bum shuffling is a common term among individuals with OI and is a form of mobility that is executed by sitting on the floor, legs crossed and shuffling, or rocking, on the buttocks to move.

Elizabeth was diagnosed at birth with Type I Osteogenesis Imperfecta. Her father, auntie and grandfather also have Type I OI. Because of the family history, and subsequent chance of OI being present, her parents elected a caesarean section delivery. The caesarean prevented fractures at birth; however, there was evidence of a healed fracture that occurred during pregnancy. Elizabeth explained, “*When mum was pregnant, and I was inside her, she had a fall and I broke my thighbone...I just lay in there and it healed*”. Elizabeth is the first child in her family. There have been numerous occasions when Elizabeth’s bones have fractured from little or no trauma, “*about twenty-one, twenty-two, including the little ones*”. Accidents that are more dramatic have also occurred in the past “*that might or might not have caused breaks if it happened to other kids*”. She is slightly shorter in stature than children of her age group are. Her hearing was tested as a five-year-old, but she has not received any subsequent auditory testing.

During the introductory meeting with Elizabeth, she made it quite clear that it was her wish that her mother be present during each interview. Informal permission was given by Elizabeth’s mother to include her own unsolicited comments in this study. Elizabeth appeared to be excited at the prospect of telling her story, communicating that it would be nice to talk to someone about her life at school and expressed her wish that all three interviews take place in her family kitchen, at the table. This, she explained, was the place she felt most comfortable. Unfortunately, this proved to be impractical. Elizabeth fractured her leg two days before the first interview took place. She decided her bedroom would be the most comfortable place for her to be interviewed.

Initially Elizabeth was quite hesitant with her responses but by the end of the first interview, she had gained confidence and was more forthcoming, offering more detail to questions. During the second interview, prompts were needed less frequently. Elizabeth spoke freely about her experiences. Her gestures became expansive and she laughed and pulled faces as she told her story. The third interview was Elizabeth's opportunity to talk about the issues she wanted to raise. All hesitancy appeared to be absent. She raised issues we had not discussed before, but which she considered important.

With the decision to start Elizabeth in kindergarten, a careful selection of a suitable venue began for her parents. An environment where Elizabeth would be highly visible at all times was an essential consideration. Although Elizabeth preferred to play inside she did enjoy her times in the sandpit, but refused to play on the swings, which she considered too dangerous.

### *David*

David is in his early thirties. He appeared to be a very confident eloquent, young man who enjoys spending time on his quad-bike, riding over sand dunes and farm paddocks. It was difficult to arrange the one face-to-face interview held with David. Work, family and social commitments left little spare time in his busy life. David is married and has established his career in the world of commerce.

David was diagnosed with Type III-IV OI soon after he was born. David is the second child in his family and there is no evidence of OI in his family history. While he does not think he was born with fractures, he understands he did fracture immediately afterwards. David measures under one-metre. His limbs are deformed from repeated fractures, although surgical rodding has straightened his limbs to some degree. David has had over 50 fractures, although sometimes *"you're not sure if you have fractured"*. David explained, *"Obviously you don't go to hospital every time you have an accident when you're growing up with OI"*. David has had a *"lot of strains"* that did not require hospitalisation.

Initially it was agreed that the interview would take place at his residence. This plan changed prior to the interview. David had family commitments that meant he

would no longer be available at the prearranged time. He was willing to stop at my sister's house on the way for a one-hour interview, as he would be traveling during the previously scheduled weekend. David is unable to walk and uses an electric wheelchair. Unable to locate a house without steps for the interview to take place, his wife kindly offered to carry David into my sister's house. Subsequent communications for gathering further information or clarification were conducted via the e-mail system.

David did not attend kindergarten; instead, his mother arranged for the kindergarten teacher to come to him and his slightly younger sibling. His small electric wheelchair was his constant form of mobility. David described himself as a "*very fragile little boy*" that was "*very outgoing and social*".

#### *Linda*

Linda, aged in her fifties, also has an extremely busy social life, which she intersperses with a wide variety of handcrafts. When not out with her husband, doing housework, or volunteering for the many organisations with which she is affiliated, she finds time to enjoy "*the most important thing in life, having fun*". Linda uses a manual wheelchair sometimes and "*can walk a few steps*", but is often seen "*bum shuffling*" around her own home.

Screams of what appeared to be pain alerted her mother that there was something amiss with her second baby. Her mother repeatedly told staff at the small maternity hospital "*something was not right*". Linda and her mother were transferred to a city hospital. Linda was x-rayed at 3-days-old. At least six healed fractures were revealed, so to were 16 recent fractures. One specialist advised her parents to "*put me in a home and forget about me*" but her father said, "*We will take her home and treat her like we would any child*". Linda was taken home where "*every time they touched me something else broke. So, they built a canvas sling and left me on it for three months*". Linda was "*fed with an eye-dropper*" and no one physically picked her up, or held her, during this time. Linda was diagnosed with OI type III. Like David, there was no history of OI in her family. Auditory difficulties were later diagnosed when Linda was in her twenties.

Linda opted to conduct all three interviews on a face-to-face basis. Sitting at the kitchen table was her preferred location as she felt this is where all the best talking takes place. Linda was initially very hesitant while being interviewed and felt intimidated by the tape-recorder. She admitted that she hated being “*taped*” as it made her voice sound “*funny*”. Linda’s sense of humour is obvious from her responses and she appeared to forget about the audio equipment that initially curtailed her conversation. As Linda’s story unfolded, she became quite animated. Her eyes sparked in apparent delight as she remembered some experiences, and tears formed when she recalled other events of her life.

Linda did not think that attendance at kindergarten was common when she was a preschooler. She stated, “*anyway, I preferred fishing with my dad*” and “*riding in my pedal-car*”. Unlike David and Elizabeth, Linda used neither crutches nor a wheelchair. Although she was unable to walk without fracturing, “*they tried to get me to wear iron callipers*”. The callipers proved to be both unsuccessful, a traumatic experience, resulting in screams of pain and anger, and more fractures from falls. Linda found her own solution and reverted to her customary mode of mobility of “*bum shuffling*”. To date Linda has had “*over 150 fractures*”. Linda, like David measures “*just under one-metre, 98 centimetres to be exact*”.

When Linda was 5 years old “*the powers that be*” decided to place her in Wilson Home. This was a government run institution for children with severe disabilities. Linda, who described her experience as horrendous, was relieved when her father “*kidnapped*” her and took her home. “*Heaps of broken bones*” and “*some beastly little kid stole my Margaret doll...and paint box*” were the main reason for her hasty departure from the institution according to Linda. “*Life on our farm right on the beach was exciting and there was always heaps to do, so why would I want to go to school. That was for big kids, not me*”.

Linda did not attend school until she was 6 years old. After the disastrous outcome of Wilson Home, during a visit to the orthopaedic specialist, her mother admitted she was “*a bit afraid to send this child to school*”. His response

suggested that school was necessary and Linda was duly enrolled at the only available school – a very small, local rural school.

### **Results of themes**

During the conversational interviews there were several topics and issues that the participants frequently raised. The commonalities between the participants conversations were identified and compared to select themes. Themes were then in turn compared to other themes for connections. For example, conversations involving attitudes towards themselves from non-disabled persons at school was identified as a key issue. The attitudes of others included a range of people, parents, teachers, the wider school community, and friends. The importance of these people in the lives of the three participants indicated that each should come under a sub-heading. Self-attitude and fractures were closely linked. The frequent fractures each participant coped with and the importance they each placed on these events could influence the attitudes of the individual participants. The close link is for this reason fractures and self-attitude are combined into one theme:

- I. physical environment of educational facilities,
- II. attitudes and
- III. fractures and self-attitude.

#### **I. Physical environment of educational facilities**

The physical environment of schools might cause obstacles to inclusive participation for students with OI. The schools the participants attend/attended and the accommodations provided for students with physical disabilities might contribute to the degree of inclusion/exclusion afforded to the curriculum and social interaction. Elizabeth is currently attending school and the present tense will be used for the remainder of this chapter. David and Linda's stories will utilise the past tense. The three participants shared some ideas of the physical environment that concern/concerned them in the New Zealand school they attend/attended.

### *Elizabeth*

Elizabeth's primary school was selected using the same criteria as for the kindergarten she attended. Her parents considered the predominantly flat playground, visible from the administration block, most suitable for Elizabeth's needs. Elizabeth affirmed that with fewer students the school was the best one for her. *"If there's not so many people then I won't get crashed into"*. Both Elizabeth and her parents felt a modest roll decreased the chance of accidental knocks, thereby lessening the chances of fractures.

The school Elizabeth currently attends was not designed to accommodate children with physical disabilities. Although some ramps have been installed since Elizabeth first enrolled at school, a ramp and deck were not added to Elizabeth's classroom until recently. These additions were prompted by a fracture to Elizabeth's leg and were built during the week she was in hospital. According to Elizabeth *"we've got to be a bit careful...it's really wet...there's supposed to be this shelter over the top, but they haven't put it up yet, and it gets really slippery...it's a bit dangerous"*. Several other ramps were also installed but Elizabeth considers them too dangerous to use *"because of the mornings all frosty"* and *"the wood's all flat so you can almost go backwards on crutches"*. Elizabeth suggested that outside carpet that provides grip could solve this problem *"They've done that to one of them and it's not slippery"*.

One of Elizabeth's concerns is distance. The assembly hall is across a large school field and *"when I'm on crutches then I get quite sore"*. It falls on her mother to be available to transport her by car to the assembly hall. When Elizabeth walks she is given permission to leave before the other students but is often late. Elizabeth finds being late *"quite annoying"*. Even when she leaves early, *"they usually catch up with me anyway"*.

The bathroom appears to be major concern for Elizabeth. She admitted that she frequently does not drink during the day *"so I don't have to go"*. Teacher observation detected this practice and permission was given for Elizabeth to use the staff toilets when using crutches or during the rare times she uses a

wheelchair. When recent alterations were made to the administration block the bathroom was designed to accommodate wheelchair access.

Unlike the staff toilets there are no handrails, ramps, or automatic doors in the student toilets. Elizabeth finds the student toilets “*really scary and slippery*” and a place where extra caution is necessary. The sink frequently “*overflows and the floor gets flooded*” and has resulted in several falls for Elizabeth, falls she says are known about by all staff but are dealt with by the caretaker who “*just goes and mops up a bit*”.

To Elizabeth and her parents’ knowledge, there are no further modifications to the school physical environment planned. Past alterations and additions have proceeded without consultation with Elizabeth or her parents.

#### *David*

David began his education at his local rural school on his 5<sup>th</sup> birthday. Like Elizabeth, his mother transported him to school daily. The school community expected that David would become a student at their school. Prior to his enrolment preparations had been made. Alterations and additions were completed before his schooling began. When he enrolled at his local school “*they put in a lot ramps...I was the first kid at that school in a wheelchair*”. David experienced no problems with distance. His electric wheelchair enabled him to travel freely around the school.

Like Elizabeth, David also found the school bathrooms a challenge. When he first started school he was so fragile that he was unable to transfer from his wheelchair to the toilet unassisted. His father would often arrive at school at lunchtime to check whether “*I was all right and perhaps take me to the toilet*”. This often proved to be unnecessary and David attributes his “*Rolls-Royce bladder*” to the times at school when he “*literally used to hang on*”.

*Linda*

Linda's school did not have ramps and she could not recall any discussion involving physical changes to the school environment to accommodate her size or medical condition. "*Gosh no, there was no mention of ramps way back then*". She did not feel that ramps would have been an advantage since she "*didn't have a wheelchair anyway*".

Distance did appear to be a problem for Linda at her small rural school. "*The tennis courts were down a flight of steps. It took me a long time to bum shuffle down there and back again*". It was for this reason her mother sewed leather patches on her little rompers every day "*and every day I would wear that leather patch out*". The hall the small rural school utilised for special occasions was "*a fair hike up the road and one of the kids used to have to carry me*".

Linda too had trials using the school toilet facilities. She vividly described her visits:

*It was up the hill, up the concrete path it was, and I used to slide on my bum all the way there and all the way back, apart from when Mrs. P. used to take my hand and make me walk.*

She also attributes her ability to "*hang on*" to school toilet facilities. There were no handrails and "*I couldn't reach the hand-basin, so my hygiene regime was pretty much non-existent at school*".

## **II. Attitudes**

Parents, teachers, the wider school community and friends all had daily contact with the participants and may have brought differing attitudes into their lives

Parents

While there appears to be a natural tendency for parents to protect their child who is physically fragile and can fracture spontaneously there also seems to be a conflicting natural tendency to provide their child with equal opportunities to experience life. It appears that parents' of children with OI have different concepts of how adventurous their children should be. In turn, parental attitudes

might influence the child's level of participation. The three participants share their thoughts on the role that their parents have play in their lives.

### *Elizabeth*

Elizabeth is familiar with the swimming pool and netball court, however she appears to spend very little time in the playground and appears unsure what playground equipment is available, stating “*we've got a flying fox, I don't think we've got swings though*”. This seems to be a result of her parents and teachers combined efforts to safeguard Elizabeth from falls and knocks. Elizabeth expressed the desire to “*participate in the playground for once but, the teachers stop me from doing it, and that means that Mum and Dad stop me from doing it, because I could break something, so that's out*”. Elizabeth feels that her parents help her by “*saying I can't play contact sports, and making the teachers watch out that I'm not playing in the playground*”. Elizabeth's mother transports her to school in the family vehicle and escorts her to her classroom. Elizabeth appreciates the time her mother dedicates to transporting her to school and special school functions.

### *David*

David's parents on the other hand freely accepted that he was a “*real boy*”. He often pursued adventurous pastimes such as shooting birds with a slug-gun and go-carting. Even the skateboard did not escape David's enthusiasm. “*Yeap, I had a skate board. I used to sit on it and push myself along with sticks*”. David confessed that his parents were his role models while he was growing up. His mother in particular was credited with playing an important role in his life, dropping him off at school each morning, and then returning each afternoon to pick him up. His father would often call in at school during his lunch hour “*and check that I was alright*”.

David's was excluded from school swimming. It was not considered practical for him to take part. For David to swim at school one of his parents would have been required to attend each individual swimming lesson. The physical act of changing David into his swimsuit in a crowded changing-room in addition to the risk of injury while in the swimming pool precluded any advantage to inclusion. Instead,

swimming classes were arranged by his parents to take place in the weekend to compensate for the lack of participation at school.

### *Linda*

Linda also recognised the time and skills her mother utilised. Her sewing skill went beyond sewing leather patches onto rompers. She also sewed hundreds of small frocks, adjusting patterns to accommodate the *“hump on my back and shorter, rounder body”*. Her skills were required once again when Linda enrolled at the local High School. *“She cut the tie in half, it was the whole works. Panama hat, school tie, and home made gym frock”*.

In addition to the daily provision of transport to and from school, Linda’s mother was also responsible for the frequent unplanned trips to school when fractures occurred. Her father shared these duties *“when the cows were dry”*. Farm duties took precedence for her father although he was *“always good for reading me a story in the afternoon when I was at home in plaster”*.

When I asked Linda if the school had any special plans for when she fractured at school, she laughed and said, *“Yep, ring the mother. Oh damn, she’s has broken again, ring the mother”*. Her mother’s skills did not extend to teaching. Linda had extensive periods during her school life when attending school was not practical. *“Occasionally mum would go and get me a few books to read, but I never remember having masses of school work to do”*.

### Teachers

Ultimately, it is a teacher’s responsibility for the day to day to care of their students learning and safety while they attend school. The classroom is a place of learning, not only all areas of the curriculum but also social interaction. To have a student who has OI in the classroom requires innovative and creative planning to ensure inclusive opportunities for these students. Physical education requires unique consideration and thoughtfulness to preclude exclusion. Attention to where equipment is placed in the classroom setting for accessibility is required when a student has limited strength, mobility and stature. Accommodation for limited mobility, that might include the use of a wheelchair or crutches, may also be an

issue that demands deliberation. Getting to know individual students needs, and working in collaboration with the student and their parents, might provide teachers with a solid platform from which they can base their expectations and programme modifications. The three participants share some of their experiences and thoughts of their teachers.

### *Elizabeth*

According to Elizabeth her current teacher does try to include her in physical education and sport by making her the score keeper, or “*just making sure everyone is playing fair...I’m the fair monitor*”. Often though, Elizabeth walks around the netball court as an alternative to the type of activity the class is engaged in. “*They might be doing something like long-jump that I can’t do so the teacher makes me power walk around the concrete*”. Although this is usually a solitary activity for Elizabeth “*sometimes she sends a buddy to help me and keep me company*”. Her teacher expressed concern after the last fracture Elizabeth had, believing that somehow the power walking had caused the fracture. Elizabeth’s mother assured her it was in no way connected.

There have been a few occasions when lack of participation has motivated Elizabeth to attempt to include herself to a greater degree. These self-advocacy attempts have not proved successful. Elizabeth spoke about a game they played at school recently. She suggested an alternative to the boisterous method being employed in the game that involved tagging the other team while running. In Elizabeth’s opinion slowing the game down to walking would enable her to participate in relative safety. After one trial using the new rules suggested by Elizabeth her teacher told her she “*didn’t really want me to do it anyway in case I fell over, cos I wasn’t very stable*”. Previous teachers have made more of an attempt to get Elizabeth to think of ways to slow down the game, or different ways to play games, in an attempt to include her.

At interschool athletic days special events are held for children with disabilities:

*They usually do a parallel, which is for us kids, like downs syndrome and stuff like that...which is quite good because then I have someone to race with.*

Elizabeth also enjoys her swimming lessons at school and “*that helps with my bone density*”. Her teacher allows her to change before the rest of the class to avoid the risk of “*knocks with lots of kids rushing around*”.

Elizabeth prefers that her teacher explains her medical condition to her peers, rather than having to explain herself. Her teacher recently explained that Elizabeth’s fracture was spontaneous and that no one was to blame when:

*I was just walking into school and my leg broke...I was walking quite well that morning and she was just about to comment on how well I was walking... and she [the teacher] happened to see how it snapped ...and that’s why she walked up so shocked...and she just ran past me to ring the ambulance, and all the kids grouped around so she rang the bell.*

During the times when Elizabeth is absent from school her teacher makes regular visits, spending up to an hour going over school work that Elizabeth has missed. The teacher delivers new school work and explains what Elizabeth is expected to do. Friends often accompany the teacher on these visits.

In the classroom Elizabeth’s teacher has arranged to have a spare desk placed beside her “*so then if we’re doing things with partnership they can come to me rather than me go to them*”. The extra desk and chair also allows Elizabeth’s leg to be propped up while in plaster, make writing easier than using a clipboard. Elizabeth only uses a computer when the rest of her class uses the computer suite. “*We don’t have one [computer} in the classroom*”.

Elizabeth’s circumstances are sometimes overlooked. For example, a recent fire drill resulted in her being left behind:

*I got myself into the wheelchair and then the kids came and took off my brakes and I expected them to push me out the door but they just ran out the door and left me. Mrs. K. suddenly realised I wasn’t with them and she came back and got me. And I was like, oh, what happened, and yeah, that wasn’t very good.*

Elizabeth, naturally upset “*and quite shocked*” at being left behind has decided that in the event of a real fire she will not use her wheelchair, instead she will “*bum shuffle down the steps*”.

*David*

David did understand why some of his teachers might have been apprehensive of the added responsibility he posed:

*Some were, quite frankly, scared to have me in their classroom. I can understand why. A little boy, very fragile and others fully embraced it, the whole idea, and did a great job.*

Regular contact was maintained during David’s frequent lengthy stays in hospital. “*They would send me tapes of lessons and sing me songs...I’ve still got morning-talks from my 5-year old buddies*”. David regarded himself as being a “*pretty laid back sort of person*” who did not have “*too many battles at school*”. The need for self-advocacy was not considered an issue as he had a lot of support from both friends and teachers.

Not all of David’s teachers were able to cope with some of the challenges he offered though.

*I remember that one day I wound my teacher up so much that she, um, tipped a pot of glue on my head and rubbed it in with a brush. So I must have been, yeah, pushing the limits...I was a really sensitive kid and that really did upset me.*

David also remembered being sent outside a few times for misbehaving.

David recalled taking part in all areas of the curriculum, “*obviously not the sport and P.E, but the rest, yeah*”. Although not participating in sport at school “*I remember always being involved, like I was the timekeeper for a race or...*”. Sex education was not attended during his primary schooling “*Because my parents didn’t want me to because of personal beliefs...but I did at high-school*”.

His teachers saw modern technology as an opportunity for developing David’s skills in preparation for his future. He was introduced to the computer at an early age.

*I guess it [the computer] was more looking into the future, and seeing that I would be using a computer a lot and trying to get me skilled up on my keyboard skills from a young age.*

A computer was part of his daily regime and made writing easier. Frequent fractures to his arms meant there were periods David could not write, although David did say he became ambidextrous through necessity.

*Linda*

Lengthy absences from school due to numerous fractures and surgery meant that Linda's early education was sporadic. She believes that while she was at primary school her teachers treated her "*the same as everybody else*".

No physical changes were made to Linda's classroom or furniture to accommodate her small stature. "*I used to kneel on my chair all day so I could reach my desk and sometimes by lunchtime my knees would lock up and I couldn't straighten them*". The limited length of her arms meant, "*I couldn't reach the top of the page so I turned my paper sideways*".

Linda received no home visits from her teachers. Contact was not kept during the extensive periods in hospital, or while convalescing at home. When school attendance was resumed Linda said, "*I just joined in as best I could and had no show of catching up*". Physical education was not a regular occurrence at the school. "*I remember that we used to do folk-dancing in the winter, but I couldn't do that, and swimming in summer, but I just sat on the side and paddled*". Linda did not attend sports days. There was "*not much point in going*" so she stayed at home. No adaptations were made to enable Linda to participate in school sports activities.

During her high-school education Linda found several occasions when justice demanded that she speak up for herself:

*I had a big argument with one of my teachers regarding the benefits of physical education and being out in the sun. I wanted to go outside with everyone else and she wanted me to go to the library and do more study.*

The teacher concerned was not accustomed to being answered back by a student. *“It was pretty brave to argue with a teacher back then so she stormed off to the headmaster and he said, [Linda] is quite right”*. Linda was very pleased with her victory. Not all attempts at self-advocacy were successful. Sex education was not considered appropriate for Linda to attend. *“I thought I would finally get to know all the answers to the things my mother never told me...but they [teachers] thought I should go to art classes”*.

Lack of foresight from her teachers is one aspect of Linda’s education that she holds very strong opinions.

*I don’t think my teachers’ ever thought about what I would do after I finished school. I don’t think they thought, well if she studies this, or studies that, then she could be this or that. Perhaps nobody thought I would work. I never dreamt that I wouldn’t.*

While Linda believes she *“was never going to be an A-grade student”* she does appreciate that had she been *“channelled in the right direction”* her accomplishments would have exceeded their expectations. *“Yeah, definitely, and I think that because they didn’t think I would achieve anything, that there was never a need for me to achieve”*.

#### Wider school community

While teachers’ have the ultimate responsibility and day to day care of students in their classroom the wider school community is also accountable for the safety and wellbeing of all students. Ministry of Education policy directs school principals Boards of Trustees to ensure that all children receive equitable education. School concerts, calf-club day and drama productions are often annual events in New Zealand schools. Visitors to the school, whether in an official capacity or volunteers, often assist at these annual events. These visitors’ attitudes might also influence participation and equitable educational opportunities for students with disabilities.

#### *Elizabeth*

Elizabeth’s school holds regular staff meetings to ensure all staff are kept up-to-date with her physical safety. Discussion centres around who is responsible for

monitoring Elizabeth in the playground. Counselling was arranged for the teachers and students who witnessed Elizabeth's last fracture at school, although there was no counselling made available for Elizabeth who felt that she had "*suffered worst*". Provision for Elizabeth's limited mobility within the school environment is provided after the need arises. Ramps, as previously mentioned, have been installed after the event.

#### *David*

David remembers a social worker calling "*once or twice...to make sure everything in the classroom environment was ok*". There were no special plans in place for the occasions when fractures occurred at school other than a telephone call to his parents. No teacher aides or one-on-one support were provided. David said "*I was pretty much one of the rest them [classmates]*". As previously stated David's school made provisions for his restricted mobility and use of an electric wheelchair by installing ramps prior to his enrolment,

#### *Linda*

Calf-club was a very important day in the rural school calendar. Linda competed against the other children with the hopes of winning the much-coveted champion ribbon. "*I used to take my pedal-car and my lamb would follow along beside me*". One year the ultimate prize was won, the champion ribbon was hers. It was a bitter sweet victory for Linda who was not allowed to attend the group-day, attended by all winners of several dozen small, local schools. The reason Linda was unable to attend was "*because you weren't allowed to take a pedal-car to group-day*". It seemed that to participate in group-day you had to be able to walk.

Cooking was also not included in Linda's curriculum. Attending a small country school necessitated a bus trip to the nearest town. "*They wouldn't take me [on the bus] because I was a risk*". Typing classes posed another difficulty for those in authority. Although the typing teacher had provided "*a stack of about twenty telephone books for me to sit on*" Linda's arms and hands still lacked the strength to manipulate the typewriter keys. An electric typewriter was ordered "*especially for me. I typed on it all year and then found out that for school cert exams you weren't allowed to use an electric typewriter*".

Linda was unsure who made the decisions to limit her participation in the above incidences. Neither her parents nor she questioned the validity of the decisions, or the source. *“It was just a fact of life, something you had to accept and get over”*.

#### Friends and classmates

Peer acceptance and friendship provide social engagement opportunities that promote a sense of inclusion within a classroom. (Barrett & Randall, 2004). The three participants share their thoughts on friendships.

#### *Elizabeth*

Supportive friends and classmates make life at school for Elizabeth a pleasant experience. Friends are always ready to assist when necessary, carrying her bag, opening doors and *“they stay with me so I don’t get bored”*. Elizabeth describes her best friend:

*She loves art and I love art and she gets a bit jealous because I can do art better than her. And I get a bit jealous because she can do netball and that usually ends up in a fight, but that’s ok because it works out. And she taught me to do scoobies and I taught her to make friendship bracelets, although we don’t really work that well together because we’ve both got our own opinions.*

Elizabeth feels they are good friends because *“I’m different and I help her with her school work and stuff when she gets stuck”*. When I asked Elizabeth why she considers herself to be *“different”* she responded *“for example most people can do netball and a lot of active things, whereas I can do a lot of art and crafty things”*

If Elizabeth does have social interaction difficulties, it appears that they are not connected to her physical disability. She could not recall any incidences of bullying at her school. If there is any discord in the school that directly involves Elizabeth *“it’s not about my bones, it’s just because I get grumpy with people, yeah so it’s not about my bones, they’re not nasty about that...”*. There are times when classmates hurt her feelings unintentionally. *“Well, when I had the fixator on I didn’t really like the way they said ‘it looks disgusting’. I didn’t really like that, but it’s like, they probably didn’t mean it, I know it looks disgusting, but they*

*shouldn't say things like that*". Elizabeth does not tell her classmates when they hurt her feelings. *"That would be rude. It would scare them off"*.

#### *David*

David saw the social side of sports events as the highlight of school and an opportunity not to be missed. David remembers being a spectator and great supporter on sports days. Intervals were filled with refereeing and umpiring. Both he and his friends tried to involve him in as many activities as possible by adapting games. But there were times that David did get left behind *"not very often, but I do remember it happening"*. Those times would sometimes cause a fleeting feeling of loneliness, as David said, *"I do remember feeling lonely once or twice, mostly at sports days, even though I didn't show it"*.

David considers his best memories of his time at school include his friends. *"Just the social side of it...My friends. I had lots of friends"*. Being raised in a small town meant David was well known *"because I was different, and I was accepted"*. Bullying was not an issue but David does recall *"a big burly bloke coming up to me and saying, 'Oh bro, if you ever have any problems you come to me'"*. His assistance was not required.

#### *Linda*

Linda also had a protector. Her older sister attended the same school and *"the first day I was at primary school one of the kids said something smart and my big sister decked her. That was the end of the bullying"*. Friends were Linda's main helpers at school and frequently carried her around on their hip *"which was pretty hazardous. That was before I got my first wheelchair when I went to high-school"*. Playground activities included using the bottom bar of the jungle gym, turning the rope for skipping, and umpiring tennis. Linda still has regular contact with friends she had while attending primary school. They are *"life long friends"* and Linda feels that bond is essential to a fulfilling life.

### III. Fractures and self attitude

Teacher and wider school community attitude, acceptance from classmates, the degree of inclusion whether teacher initiated or accessibility of the school physical environment all impact on a students feeling of self. Parental attitude towards inclusion versus protection might to some degree impede or encourage participation in some activities for children with OI. The people they encounter and socially interact with on a daily basis might influence how students perceive themselves as an individual. Additionally, fractures are frequent and often occur at the most inconvenient time. The three participants reveal how they feel about themselves, the risk of participation, value of friendships and school life in general. The participants spoke of issues introduced by them individually, and were important to them, as the interviews progressed. Some issues raised in this section are only relevant to an individual participant.

#### Fractures

While attending school, all three participants received fractures. The physical environment was not always instrumental. Often fractures occurred due to the actions of the participants themselves, or sometimes the actions of others. Frequently these fractures were spontaneous.

#### *Elizabeth*

The school flying fox was instrumental in two simultaneous fractures to Elizabeth's leg.

*When I was five someone put me on the flying fox at school, and what she did was she put me up there, and I was holding on, and she went around to go and pull me across, and I couldn't hold on to myself, and I just slipped off and I broke my leg.*

The person concerned was new to the school and "*she didn't know I had brittle bones*".

Not all fractures are due to an adventurous spirit. Less dramatic events are just as likely to result in fractures for children with OI. Fingers fracture when the desk lid lands on them and toes fracture from simple activities. Elizabeth recalls the time when she was 5 years old and "*I went to kick a basket-ball and I broke three*

toes”. Spontaneous fractures can be both traumatic and at the same time of little or no consequence, for example when Elizabeth’s leg fractured while she was walking into school one morning her report of the event was nonchalant. “*Yeah, I was walking quite well that morning*” and it “*snapped*”. She said they could hear her screaming at the local supermarket, “*how bad is that*”. Elizabeth laughed when she admitted that she is quite loud when she fractures. “*They usually know because I’m screaming...but I don’t scream as loud with the little ones*”.

Fractures can also be considered no more than an inconvenience. Elizabeth explained, “*I’ve probably broken my fingers about a thousand times*”. These fractures happen all the time “*just by putting my hand out and hitting something with my fingers or dropping things on my toes*”. Elizabeth is used to having fractured digits and ignores them “*unless they are really, really sore and then mum just binds them up*”.

#### *David*

David also encountered incidences at school that resulted in fractures, although he felt that fractures were just as likely to occur at home. According to David, “*everybody was pretty careful*” while he was at school. He did recall one event when a classmate bumped into him and the result was a fractured arm. One other fracture occurred when “*a kid fell on me and I broke my nose*”. Unlike some people with OI who do not immediately divulge a fracture David was emphatic that he always told someone, saying, “*No. I definitely told them*”.

While David could recall very few fractures that occurred at school he did require regular corrective surgery. “*Every year or two I would have to go away for a week or two, but generally I would often be at school with a plaster or an arm in a sling.*”

#### *Linda*

Linda recalled practicing for months to walk the length of the classroom. Her teacher had promised the class a surprise when she could successfully walk that vast distance. Three quarters of way across the room she slipped and fractured her

leg. She also remembered practicing a piece on the piano for the school concert. Once again disaster struck. The day before the big event she fell off the piano stool and fractured her arm. Linda also shared one of her more memorable escapades. This time the fracture was the result of one of her favourite pass-times:

*I can remember my sister had a pair of roller-skates and we had a path that went down hill to a gate. I used to be so little that I could sit on one skate and I'd trundle off on this one skate yelling out "look at me, look at me". Then, splat, into the gatepost. And my dad would come and pick me up with tears in his eyes and he would say 'promise me that you'll never do that again' and I say 'ok'. But, I'd do it again.*

Linda did not consider broken ribs important. Even though she frequently fractured ribs "*they don't count*" in her one-hundred-fifty plus fractures. They broke easily "*just with a sneeze or cough or knock, whatever. It only takes a few days and they come right*".

Linda did not always immediately disclose that she had fractured. She admitted that she often hid the fact "*lots, because I hate what it does to everybody else*". Instead she sometimes preferred to ignore a fracture until the right person was available to tell. At these times she elected to "*just carry on*" because "*people feel guilty...I hated it. I still hate it*".

Self-attitude

*Elizabeth*

The fractures that resulted from the fall from the flying fox have not totally extinguished Elizabeth's desire to risk a recurrent episode. Although she has not risked the flying fox again she has tried to go on two tornados. "*I see the other kids doing it and it looks like fun and I think I'll have a go*". Some past attempts were interrupted by a teacher and resulted in Elizabeth trying to act as if she was not, in fact, considering being adventurous. Not all endeavours by her teachers were successful. Elizabeth cheerfully admitted "*I had a go once and nothing happened*".

Elizabeth realises she has limitations and adjusts her life at school accordingly. She chooses projects that she can achieve without constantly being restrained by lack of mobility, or strength. There are activities that Elizabeth does not attempt. For example *“if I can’t do bits of dance or drama then I usually just sit back and watch”* and *“I did try the long-jump, but I didn’t try it again, because I felt a bit sore in my back when I did it”*. Although Elizabeth was an *“adrenaline junky”*, when she was younger, the fall from the flying fox has made her nervous of heights. School camp will present some challenges to Elizabeth who looks forward to the experience with mixed feelings. *“I’d like to do most of the things at camp...stuff like abseiling and fishing...but sometimes I get a bit sore and can’t”*.

Elizabeth gets annoyed when fractures occur. *“I was about to go into the rural schools’ cross-country, for once in my life, and that never happened because you [sic] tripped over somebodys foot”*. Elizabeth referred to her frequent fractures as similar to card making, where everything is going well and then *“it all goes bad”*. Elizabeth went through a particularly difficult period when aged between five and six years old when she had several fractures and *“it just happened out of nothing”*. It is during these periods of frequent fractures that Elizabeth gets *“the poor me’s [sic]”* and conversations with her mother revolve around *“not wanting to live any more and that life isn’t worth living like this”* (Elizabeth’s Mother, personal communication).

Elizabeth is a very gentle child. She appears to go out of her way to be pleasant and rarely risks upsetting people. She has made no attempt to suggest that carpet be added to the ramps at school to make them safer. Neither has she suggested that handrails in the bathroom could make using those facilities easier. Elizabeth is angry that others receive counselling. After her last fracture occurred at school *“and I was thinking I think I’ve suffered worst”*, counselling was considered necessary for Elizabeth’s classmates, other children that witnessed the event, and all teachers.

When asked how she felt about being interviewed Elizabeth said:

*Well it’s quite nice to tell someone how I really feel, rather than thinking oh, it’s such a pain when people say things like ‘oh your legs*

*looks disgusting'. It's quite good to say that I don't like it when they say those things, which isn't very nice.*

Elizabeth's mother volunteered that she felt the interviews had been very beneficial and therapeutic, paving the way for Elizabeth to be more open about how she feels. Her mother believes this opportunity to express her feelings might enable her to be more forthcoming with her teachers. *"It is as if by speaking openly during the interviews Elizabeth feels she now has permission to be more assertive and tell it like it really is"* (Elizabeth's mother, personal communication).

*David*

David remembers always being involved. School was full of friendships and socialising. *"I didn't have any problem that I can remember integrating or socialising"*. David had a close group of friends and did not socialise with the other children in the school that had disabilities:

*At our school we had a special class for kids with intellectual disabilities... and there was one girl who had muscular dystrophy, and a boy who had cerebral palsy, and he was in a wheelchair, but I sort of didn't socialise with them. I had my own group of friends.*

David said he participated in all areas of the curriculum, *"obviously not the sport and P.E."* but *"I was a realist and never tried to do anything that I couldn't do"* and *"I would join in on everything I could"*. When fractures occurred at school David's mother would be called but often she would *"just come and put my arm in a sling and make sure everything was ok and then I would be carrying on"*. Frequent fractures meant David needed to adapt. *"I actually ended up sort of ambidextrous. I used to be able to write with my right and left hand"*.

In David's opinion *"OI kids and disabled kids in general are pretty well catered for"* in the education system. Assistance and facilities seem to be readily available and he does not believe things could have been better for him at school. OI is such a rare condition that David does not expect teachers to be specifically trained *"or fully keyed up on it"*. He believes that each individual teacher approaches students with OI in their own way, some with more caution than others.

Linda

Linda also believes that her school years could not have been improved. She does however have very strong opinions of how societal changes have affected children with disabilities:

*I feel that they are a lot more sheltered than I was and it makes me sad to think that everything that is done for them is by paid help [teacher aides]. Like when I was at school my friends got me to class, carried my bag, made sure I got to the loo at lunchtime, whatever...but now kids aren't taught to look after each other, I don't think.*

Friends were, and still are, extremely important to Linda:

*You would think that because we need to be a bit careful that we would be a bit stand-offish with people. Because when you are a little kid [and have OI] you know that if someone knocks you, or bumps you, you will break but it seems to be the other way around, we're all really friendly, jolly people".*

Instead of walking Linda found alternative ways to gain mobility and independence. Her tin pedal-car was put to good use and tremendously important:

*It had pedals that I could use sometimes. Every year we painted it a different colour. It had a piece of bailing-twine tied to the front so my sisters could pull me along, up and down the beach and across the paddocks, which meant that I could go everywhere they went.*

Walking was simply not something Linda considered important - an attitude not shared by others:

*Back then if you were disabled everyone thought to be normal you had to be walking, so everyone placed this huge emphasis on walking instead of all the other independent living skills that you needed.*

The regular fractures that Linda received during school hours appeared to be of little consequence:

*Occasionally the kids would lift me up while I was on the steps outside and step back and we would both crash on the ground and I would fracture. It didn't seem important. It was just oops, another break No big deal, sort it out and move on.*

She does not remember being overly cautious. *“I don’t remember thinking well if I did this I risk breaking something. If I wanted to do something I did it. I didn’t really think about the consequences”*. On reflection, she believed her attitude may have been *“because I wasn’t treated any differently than anyone else I didn’t know that I was”*.

Linda admitted that during her High School years she did come to realise that she was *“somehow different from the others”*. This realisation was initiated first by the relocating to another district. The local High School refused to accept her. Their justification for their decision was, according to Linda’s memory, that she posed *“too big of a risk, and their school wasn’t equipped to handle someone in a wheelchair”*. Linda’s mother pointed out *“that legally they had to take me, and that was that”*. It wasn’t really until she was excluded from sex education classes at that school *“and all my friends started having boyfriends, and then leaving school and looking for a job that I realised I was any different”*.

It was while attending the same High School that Linda also first recognised *“that condescending sort of pity, poor little ‘crip’ [sic] thing”*. Her school principal applied for a recount on her behalf, with her knowledge, when her School certificate results were slightly below the necessary 50%. *“I was really angry because I didn’t know if I had really passed or he had written a big sob story saying ‘poor little crip [sic] girl, let her pass’”*.

High school was also the first period in Linda’s life when she experienced *“my really down times”*. Her mother frequently referred to the time she was born and the struggle to keep her alive. *“She would say ‘and we fed you with an eye-dropper and I would say ‘well, why did you bother?’ ”*.

Living life to the fullest and grabbing any opportunity to experiencing new adventures is what is important to Linda for as she said *“Pain only lasts for a little while, but good memories last forever”*.

## **Summary**

Similarities in the three participants conversations suggest that very few changes had occurred with regard to the physical environment of the New Zealand schools they each attended. In particular toilet facilities were inaccessible and at times dangerous. The distance between different areas made participation difficult for the participants that did not use mobility aids, although all three participants attended small rural schools. Access to the playground and assembly hall were the most problematic areas for the three participants in this study. Elizabeth appeared to encounter more physical environmental barriers even though her mobility was often independent of mobility aids. The addition of ramps to schools in New Zealand might have alleviated access barriers to some degree, but ramps were not always considered safe to use by one participant in this study.

Attitudes of many people connected to the participants did seem to impact on the equity Inclusive of inclusive education. The participants parental attitudes ranged from encouraging adventurous activities to insistence that their child does not participate in playground activities. Teacher attitudes varied greatly. Evidence showed some teachers went to extreme efforts to keep their student up to date with class work during times of recuperation after surgery. Adaptations to seating arrangements were considered for the comfort of the student. Evidenced was also seen of fear and anxiety, failure to recognise the special needs and ensure the safety of a student with physical disabilities in special circumstances such as fire-drill. In the past sex education and manual were denied to Linda, the oldest participant in this study, thus denying curriculum inclusion. Physical education was one area of the curriculum that all three participants shared a common feeling of exclusion. While all three participants indicated that they realises their participation in school physical education presented a challenge to teachers' David and Linda both inferred that their activities outside of school hours were of a more adventurous nature.

Fractures were a regular occurrence in the lives of all three participants and yet memories of these events seemed to be low key and of little consequence, and more like a fleeting memory, with only the more traumatic or recent events being worthy of conversation. Evidence of delaying telling someone a fracture had

occurred was forthcoming from Linda. Elizabeth on the other hand, admitted she could not conceal her fractures. Two of the three participants revealed bouts of depression. All three participants acknowledged limitations imposed by themselves to physical inclusion in some activities, while at the same time inferring that the choice to participate should ultimately be theirs to make.

The next chapter will discuss these results. A summary of what the participants said under each section will provide the basis for the discussion, while making connections to current literature and current education policy. First the effects the physical environment of the schools attended by the three participants will be discussed. Then, attitudes towards students with OI will be examined to determine if they cause unintentional barriers to inclusive education. Last, the participants feeling of self will be discussed.

# CHAPTER 5

## DISCUSSION

### **Introduction**

The intent of this study is to listen to and document the real school experiences of three persons with osteogenesis imperfecta (OI). The existence of possible barriers to inclusive education is explored. Additionally, student experiences from previous generations are compared to establish whether special education policies have affected the quality of inclusiveness. The affect any barriers had on the student is investigated. Perhaps students with OI recognise they have limitations to inclusive participation and accept these barriers as part of their life. It is equally possible that they see barriers as a challenge, and something to conquer. Semi-structured interviews provided data for comparative analysis of three different generations, Elizabeth (11), represents the youngest generation, David (30) represents the middle generation and Linda (50) represents the oldest generation in this study.

This chapter will discuss the results of this study. First, brief reference to the participant's medical diagnosis will be made. The effect the physical environment of school has on students with OI will then be discussed. Next, the attitudes of others, both intentional and unintentional will be examined. The participants' self-attitude will be explored - the inevitable fractures they cope with, as a result of OI, how they view themselves and their participation in classroom and social interactions. Finally, the experiences of the three participants in this study will be examined for differences and similarities in an attempt to establish if education policies have improved the opportunities for inclusion and full participation for students with OI within New Zealand classrooms.

A brief synopsis of the participants' experiences will introduce the key issues of each section. Links will be made to relevant literature throughout the discussion. Finally, each section will examine relevant policy, if appropriate, and the implications for a student with OI in the classroom or wider school community.

Under each research question, the following format of key issues will be followed:

- Issues arising
- Discussion
- Implications for the classroom and wider school community – how can barriers be minimised or eliminated

### **Limitation of this study**

The results of this study should be interpreted with caution for the following reasons. Firstly, the participants were selected for availability and convenience. Secondly the number of participant, three, might not be a true and accurate proportional representation of the population of people with osteogenesis imperfecta (OI) within New Zealand. Thirdly, the three all attend/attended a small rural school, which may affect the outcome. Fourth, the experiences and perceptions are those of each individual participant and it is unrealistic to assume that all persons with OI share their experiences and views. Despite the caveats mentioned this study is unique in that it has looked at the personal views of three people with OI over a period of forty years and their experiences and involvement as students in New Zealand classrooms.

Inexperience, as a researcher always has the potential of being an issue. Strauss and Corban (1998) make reference to the complexity of asking questions and point out that some questions are wonderfully productive and stimulate further questions or conversation. As an inexperienced researcher there is the possibility that full advantage was not taken during interviews, of subtle opportunities provided by the participants.

In addition to possibility of failing to take full advantage of subtle opportunities during interviews, time constraints may have limited the quantity of data gathered. Strauss and Corban (1998) acknowledge that saturation of data is not always possible. Participant availability and constraints of both time and energy often exist. Limited time can result in insufficient data; as a consequence the researcher could produce an underdeveloped theory which lacks variation and density.

### **Participants' medical background**

Elizabeth and David were both the first-born child in their families. Linda is the second child in her family. Elizabeth was diagnosed at birth with Type I OI. David and Linda were both diagnosed within days of being born with Type III OI.

Children do not always present with recognisable symptoms of OI at birth. It is sometimes not until a parent pulls an ankle to change a diaper or the toddler falls while learning to walk that the first fracture occurs, while other children might not experience a fracture until they attend school and begin participating in physical education and contact sport (OIF, 2004). Cole (1993) suggests that initial shock is often the immediate reaction of parents of a child born with OI, followed by anger.

Implications for the classroom or wider school community exist if parents of students with OI have received a delayed or recent diagnosis of their child's condition. Indeed, it is possible that a diagnosis has not yet been made. Where parents have received a delayed, recent diagnosis of osteogenesis imperfecta they might still be going through the grieving process. Parents might still be angry, particularly if they have experienced negative interactions with either medical or social services.

### **What barriers exist in the educational setting for students with OI?**

The results of this study suggest that there is no single answer to this first question. Several barriers to inclusive education exist for students with OI. For the purposes of this study three key issues will be addressed in turn, environmental, attitudes of others, and self-attitude.

A similar study by Pivik, McCormas and LaFlamme (2002) in Canadian schools identified four specific barrier categories, environmental, physical, intentional and unintentional attitudinal barriers and then determined the boundaries of environmental barriers as follows: doors, passageways, elevators, washrooms, stairs and ramps, water fountains and recreational areas. They defined physical barriers as the difficulties faced on a daily basis associated with the students' disability.

For the purpose of this study, environmental barriers are defined as those which prevent, or inhibit, freedom of mobility and participation in the daily routine of educational opportunity.

In this study, the writer has identified two closely linked key physical barriers that existed for three students with OI in New Zealand schools.

- The physical environment
- Mobility

Those with limited mobility experience access challenges unique to their individual circumstances. People that special access is provided for could view the level of accessibility differently than the non-disabled.

#### Physical environment of schools

The physical environment of a school could impact on the ability for a student to participate within the school community. Independent access if made difficult, or impossible, could restrict student self-esteem and social potential. Steps, heavy doors, classroom space for manoeuvring a wheelchair, distance between classes and the playground could each be regarded as possible barriers to inclusiveness. The participants in this study raised three specific areas of concern regarding the physical environment of the schools they attend/attended:

- Distance/Physical size of school
- Accessibility to bathroom/toilet facilities.
- Ramps.

#### Distance/Physical size of school

Both Elizabeth and Linda exposed the distance the participants were required to navigate as a challenge. In order for both of them to participate fully in the daily routine of their school determination and physical energy was required, far and above that required by non-disabled students. Having to allow extra time to negotiate between class and assembly-hall caused Elizabeth a degree of frustration. The solitary walk was painful, lonely and slow. During the frequent periods when Elizabeth used crutches the transition to the assembly hall became even more arduous. Linda found the tennis court and toilet difficult to access due to distance. Linda was unable to walk and did not own a wheelchair until she attended high school. She frequently bum-shuffled around the playground. She

constantly wore out the leather patches on her rompers participating in playground activities. Sometimes she relied on her friends to carry her on their hip.

In comparison David, with the use of an electric wheelchair, found independence within the school community far easier to achieve. Similarly, Engelbert, Gulmans, Uiterwaal and Helders (2001) found that people with OI type III had a positive overall perception of their athletic competence, but they speculated that the common use of an electric wheelchair by those with type III for sports activities gave them greater autonomy. David certainly found the school playground more accessible than Elizabeth and Linda. His permanent use of an electric wheelchair enabled him to cover more ground quickly.

Engelbert, Gulmans, Uiterwaal and Helders (2001) present the premise that children with OI type I, who are less likely to use wheelchairs, feel less competent and more likely to compare themselves with their peers. This study found similar results. Elizabeth spoke of how she exercised extreme care in the playground when she walks and was hesitant to walk at any speed, as if waiting for the next spontaneous fracture. Elizabeth also appeared to compare herself to her peers and resented the time it took her to transfer from one area of the school to another.

#### Accessibility to bathroom/toilet facilities

Bathroom facilities were a major focus for each of the participants. All three admitted that it was far easier to avoid using the toilet. David's father made sporadic visits to the school to check on his son's comfort. Distance to the toilet facilities made using the toilet difficult for Linda and the hand-basin was far beyond her reach. Elizabeth's school has, to date, still not made student toilets accessible for students with physical disabilities. There are no handrails, ramps, or automatic doors, and the floor is often dangerous and slippery – potential dangers that are disregarded by the school community.

Objective 3.1 in the New Zealand Disability Strategy is to ensure that no child is denied access to their local, regular school because of their impairment (Office for Disability Issues, 2001). This objective could be interpreted as either exclusion to enrolment, or that the school physical environment is prohibitive and thereby

denies access due to constrictive mobility opportunities. It could be argued that by placing limitations on the freedom of movement within the school grounds for students with physical disabilities they are being denied access to their local school. For example, if a student cannot access the toilets on account of safety issues, heavy doors, or the height of hand-basins makes them inaccessible, access to their local school could be in effect denied by reason of environmental barriers.

### Ramps

Ramps were not provided for Elizabeth until the need arose. She believes that the ramps are sometimes too dangerous and slippery to use. David considered himself lucky to have ramps built to accommodate his wheelchair when he first started school. No ramps were made available for Linda who believes that without a wheelchair ramps would have served no purpose. There has been no collaboration between school staff, Elizabeth, or her parents with regard to alterations of the physical environment of the school she attends. Indeed the modifications that have been made to date have apparently been undertaken while Elizabeth has been absent from school, recovering from surgery.

Jackson (1996) suggests that the identification and removal of physical barriers in New Zealand schools could improve the quality of educational opportunities for children with disabilities. Unless barriers are first identified and then removed equitable, quality education can not be said to be freely available to all New Zealand children. Failure to plan for wheelchair access when building or renovating a school, or failing to seek advice from students who have limited mobility, indicates unintentional attitudinal barriers (Pivik, McCormas, & LaFlamme, 2002). Lack of understanding or effort on the part of the educational system or school staff, although unintentional, creates unnecessary daily restrictions on students with limited mobility. Hand-rails in bathrooms facilitate personal hygiene and self-help skills (Knight & Wadsworth, 1993). By denying basic accessible personal hygiene facilities, the potential exists that an equitable educational opportunity is denied to students with osteogenesis imperfecta.

The physical environment of many schools presents challenges for students with OI. The physical size poses difficulties principally for students who are able to walk independently, with or without the aid of crutches, or do not use a wheelchair. Teachers should allow extra time to move from one location to another (Singh, 2002) however, the transition should include companionship and purpose. If a classmate is chosen to accompany the student and a task given to them to accomplish during the transference from one area of the school to another a purpose and companionship have been achieved. For example, the students could be given the task of finding a suitable object to sketch for the next art class.

Students' are capable of identifying physical barriers. They are the experts in their field of limited mobility. Advice sought from architects' and other professional services will provide general requirements for persons with disabilities. Literature supports that students with osteogenesis imperfecta are often very small in stature, with limited strength and joint laxity (Albin, Greenspan, Reinhart, & Grix, 1990, Engelbert, Uiterwaal, Gulmans, Pruijs & Heldres, 2000, Osteogenesis Imperfecta Foundation, 2002). Students with OI might have structural modification requirements dissimilar to other students that use wheelchairs. Linda said "*I couldn't reach the hand-basin, so my hygiene regime was pretty much non-existent at school*". The inability for Linda to use a hand-basin set at regular height is one example of modifications that needed to be addressed to enable a student with OI to participate in life at school with dignity and equity.

### Mobility

Elizabeth was able to walk independently at the time of this study, between frequent fractures. David and Linda were unable to walk independently. Although Linda was able to bear her own weight, she was unable to maintain walking beyond a few tentative steps. David used an electric wheelchair while at school, but Linda did not own a wheelchair until she attended high school. Elizabeth and Linda both referred to bum-shuffling as their preferential mode of mobility.

The mobility capability of students varies with each individual child, although to some degree mobility does relate to the OI type. Mobility ranges from walking independently or with the use of crutches or leg braces to the use of a wheelchair.

Mobility will also be dependent on the medical state of the student at any given time and might vary greatly during the year due to fractures or surgery (OIF, 1998).

The physical size of school presented challenges for two of the three participants in this study and as a result has implications for the wider school community. This study revealed that playgrounds and assembly halls are the most problematic areas to access for students who do not use a wheelchair for mobility. As schools increase in size access becomes more difficult for those who are unable to walk independently. Closure of small rural schools might not be in the best interest of those with a physical disability.

Students who use a wheelchair also appear to gain more benefit from the addition of ramps than students who walk independently, or with the aid of crutches or similar walking aids. Nevertheless, safety aspects of ramps must also be considered. Access to bathroom/toilet facilities was unsatisfactory for all three participant involved in this study. Some physical aspects of toilets were also questionable. Hand-basins that were too high to reach and slippery floors made these facilities dangerous and unsuitable for students with OI to use. Once again, distance was an issue. In the past the distance needed to access the toilet was prohibitive, or at the very least, difficult.

Mobility issues within the classroom have implications for the individual teacher. A child's preferred mobility should be considered in relation to the classroom setting. Where a child is comfortable moving within the classroom on their bottom (bum-shuffling) as much as possible their wishes should be respected. If the child ambulates, with or without the aid of crutches or other walking aids, sufficient space should be provided free access, reducing the probability of knocks or bumps. Free access may be necessary for those who use a wheelchair, requiring thoughtful setting up of classroom furniture. Variable mobility throughout the year might demand flexible arrangement of class furniture.

### **What/who might be the cause of these barriers?**

The second research question considers the effect of attitudes on those with disabilities. Attitudinal barriers can be both intentional and unintentional according to Pivik, McCormas and LaFlamme, (2002). Intentional attitudinal barriers are defined by Pivik, McCormas and LaFlamme as isolation and emotional or physical bullying compared to unintentional attitudinal barriers that encompass lack of knowledge and educational understanding or effort, excluding students from certain classes without reason and failure to plan for students with mobility difficulties. The results of this study showed that the attitudes of a small group of people associated with Elizabeth, David and Linda may have caused some concern. The group included:

- parents
- teachers and
- the wider school community.

All play a vital role in the wellbeing of a student with osteogenesis imperfecta.

#### **Parents**

Having a child with Osteogenesis Imperfecta requires an enormous amount of, physical stamina, time dedication, and emotional fortitude. Transportation of a child with OI to and from school adds to the daily tasks required by the parents to guarantee safe attendance at their chosen school. In addition to the daily regime of transport is the necessity to be available for the inevitable fractures that occur while their child is attending school.

Issues raised by the three participants regarding their parents were analysed and the following two key issues identified:

- Protection versus freedom.
- Collaboration.

#### **Protection versus freedom**

It appears that parents' of children with OI have different concepts of how adventurous their children should be. When a comparison is made between the participants it appears that Elizabeth's activities are more constrained by her parents than David and Linda's were. While it would seem to be a natural reaction

to protect their child from potential injury David's parents accepted that he was a "real boy" with a strong desire to participate in the same activities as his friends. According to David, his parents never attempted to curtail his adventurous spirit. Linda's parents also apparently did not constrain her activities and experiences, yet there did appear to be a conflict of emotions for Linda when involved in risk-taking activities. She seemed to realise that fractures incurred while playing would upset her father. This knowledge did not dissuade her from activities that she enjoyed but she did communicate regret for the pain her fractures caused her father.

Shea-Landry and Cole (1986) propose that parents should help the child resist participation in sports and risks-taking physical activities to limit injury. Elizabeth's parents do attempt to curtail her playground activities and involvement in contact sport by "*saying I can't play contact sports, and making the teachers watch out that I'm not playing in the playground*". Shea-Landry and Cole support the inference made by Elizabeth that her parents protect her by preventing her from playing contact sports playing in the playground. The Osteogenesis Imperfecta Foundation (2002) allude to the uncertainly parents experience when explaining their child's limitations when they are not certain whether fractures occur as part of everyday play, or the medical condition their child has.

Perhaps too, the method of mobility engaged in by children with OI might influence the degree that parents feel comfortable with their child participating in physical activities. Elizabeth rarely uses a wheelchair, whereas David has always used one and this may have reduced the likelihood of unintentional injury for David. Perhaps his use of a wheelchair provided a protective barrier to actual physical contacts with other children, thus minimising the risk of knocks and subsequent possible fractures.

The restriction of freedom by parents and care-givers is a common criticism among adults with disabilities, and results in a lack of opportunity to learn through life experiences (Ashman & Elkins, 1994). Advice given to parents at the time of diagnosis might influence the constraints they impose on their child. In

this study, Linda's parents were advised by a medical specialist to put her in a home for physically disabled children and forget about her. In spite of this advice, her parents made the decision to raise her as they would any other child born to them. Albon (2003) on the other hand found examples of parents being told by members of the medical profession that they were to let the children decide what they were capable of doing for themselves.

Parents might be reluctant to enroll their child in school. This study revealed that Linda's mother had not considered the possibility of her attending school. Indeed, it was only after a conversation with Linda's orthopaedic specialist that she was enrolled at her local primary school at age six. Cole (1993) reveals parents might struggle to accept that the benefits of academic and social growth outweigh the physical risk for children with osteogenesis imperfecta. A child that can easily fracture from an act as natural as sneezing could, in the eyes of parents, be too vulnerable in an educational setting. The social and academic profits could be identified as too hazardous for a physically fragile child. The frequency of absences due to surgical procedures could be construed as disruptive to their child's formal school education, particularly if the parents do not have assurance from school staff that every effort will be made to maintain contact.

The Minister for Disability Issues (2000) has documented that people with disabilities in New Zealand are less likely to have educational qualifications, less likely to be employed, have lower incomes and earning potential, and are more likely to rely on government assistance than non-disabled persons. Such a low expectation that people with disability to earn a substantial income is a major concern. If parents and their children continue to experience barriers to inclusive education any academic merits, when compared to the likelihood of fractures, might be seen as not worth the risk.

In this study socialising with peers featured as the most important aspect of school life for both David and Linda. David said "*...My friends. I had lots of friends*" and Linda said "*when I was at school my friends got me to class, carried my bag, made sure I got to the loo at lunchtime, whatever*". For these two participants the

socialisation they received while at school was invaluable. Even simple playground activities can result in fractures, as Elizabeth experienced when a classmate-new to the school instigated an adventure that resulted in a fracture. Elizabeth was accepting of her fractures and that the experience was worth the pain.

The possibility of aggressive behaviour being directed towards a child with a physical disability as discussed by Palmer, Fuller, Arora, and Nelson (2001) suggests that students with OI could easily result in multiple fractures by such actions, and yet all three participants in this study were adamant that they had not received any intentional injuries while at school. In fact all three participants commented on the total understanding and acceptance of their peers. Mildly affected children who appear “normal” but are at risk from a thoughtless shove from other children might create a dilemma for the parents (Cole, 1993). Parents of children with type I OI could consider their child vulnerable in the extreme in a school situation. Other children or staff might not easily identify them as having a physical disability. When parents do explain their child’s medical condition to teachers and other school personal they risk the child being treated different in the entirety, rather than different in relation to the tendency to fracture according to Cole (1993). Parents might wish to maintain confidentiality regarding their child’s medical condition, but the risk of not sharing that information could result in placing the child at risk.

### Collaboration

Open communication might to some extent alleviate any apprehension felt by the parents and student. Parents could provide written information about preventing fractures, and procedures to follow in the event of a fracture. To prevent malicious accusations of the student with OI being lazy, or clumsy from other students, parents could provide age appropriate information for their child’s classmates (OIF, 1998).

### Teachers

Literature suggests that teachers feel a certain amount of trepidation and fear when a child with OI is enrolled in their class. Soodak, Podell and Lehman (1998)

found teachers were fearful and anxious towards the inclusion of students with physical disabilities. To have a student who might break a rib through the simple and natural act of sneezing could cause a teacher to lean towards a natural instinct of over-protection. To include a child with OI in every aspect of the class learning, both academic and social, requires creativity, sensitivity and planning. Analyses of the most frequent comments from the participants regarding teachers indicated teacher fear/blame and anxiety, and curriculum adaptations as key issues.

### Fear, blame and anxiety

Teachers' individual attitudes towards inclusive education and previous experience with experience people with disabilities might influence the decisions they make in any necessary programme adaptations. The amount of medical information the parents offer might also impact on decision making of teachers'. Limitations set by the parents might effect how teachers react to a student with OI. For example, if parents make it quite clear that their child is to be treated with caution due to their fragile bones and likelihood of fractures it is possible the teacher will interpret this to mean the child should not take part in any physical education. For example, Elizabeth's parents insist that "*the teachers watch out that I'm not playing in the playground*". If, on the other hand, the parents insist their child are treated no differently than any other student in the school then perhaps the teacher will embrace the opportunity to develop a more creative attitude towards the implementation of their physical education programme.

David was candid about his teachers being afraid of having a student in their class as fragile as him. Although most his teachers' appeared to make a real effort to include him in all activities, and most were calm (Soodak, Podell & Lehman, 1998) and warm-hearted (Flem and Keller, 2000) they still instilled an impression that he was a liability. David's teachers, although receptive to his attendance and participation in their classroom, were nevertheless fearful of the responsibility of a student with osteogenesis imperfecta.

Elizabeth's current teacher also exhibited fear that her own actions had caused fracture. A spontaneous fracture while walking into school was misinterpreted by her teacher as the result of encouraging Elizabeth to power-walk while the rest of the class engaged in physical education. Reassurance from Elizabeth's mother was necessary to alleviate the teacher's feeling of blame and to prevent her fear of a recurrent fracture due to encouraging further physical activity. The desirable traits, receptivity and calm, do not cancel the fear teachers hold for students who have a physical disability (Soodak, Podell & Lehman, 1998). The very nature of osteogenesis imperfecta signifies that fractures will more than likely occur for students while they are at school. It is part of their world.

It is essential that teachers identify with this aspect of the student's life and do not burden them with their feelings of anxiety or fear. When Elizabeth fractured her leg recently it was unacceptable that the teacher did not attend to her needs, immediately. Instead, the teacher ran past her to telephone for an ambulance. Her teacher's first responsibility was to see that Elizabeth was as comfortable as possible and display a calm outward appearance. Asking the student for advice can help the situation by giving the child something to focus on and giving the student the status of expert in their world of fractures. Listening to the child's advice is advised by the Osteogenesis Imperfecta Foundation (1998) as the child may give instructions on whether the limb should be moved, and if so the correct procedure. Listening to the student demonstrates an understanding of their situation.

### Curriculum adaptations

The three participants in this study expressed a range of experiences and emotions when discussing their teachers. Although they each expressed positive aspects of their time in the classroom, their comments were less favourable concerning their experiences during sports events physical education. Limited participation in physical education classes was one commonality experienced by all three participants. Further, it appears that little or no attempt had been made by their teachers to include them in the regular physical education classes.

Blinde and McCallister(1998) and Goodwin and Watkinson (2000) found that outdoor sport activities frequently offer restricted participation for children with physical disabilities whose experiences of physical education classes range from inclusion in most activities to total exclusion. In comparison, this study revealed that Linda and David were both relegated to the sideline as a supporter during major school sports events and were totally excluded from all physical education classes. Elizabeth was occasionally offered the chance to compete in sports days, but only against other children who had temporary or permanent disabilities. This did provide an opportunity for Elizabeth to compete against other children of her own age, but the benefits would have been far greater if creative ways to include her in regular sports events had been identified and actioned. Organisation often restricts participation or inclusion from some activities according to Hemmingson and Borrell (2002). Organisation skills and creativity are directly connected.

The Osteogenesis Imperfecta Foundation (1998) noted that people with OI have a good sense of what they can and cannot do safely, and may prefer to risk a fracture rather than sit on the side watching others participate. Although involving a child with OI may require creativity and planning physical education teachers should make every effort to involve the child in the same activities as everyone else, rather than isolate the student by giving them a different activity (OIF, 1998).Elizabeth spoke of her feelings of isolation when she walked around the tennis court during physical education classes. These largely solitary walks were performed at times when the remainder of her class was involved in strenuous or contact sport.

It was these same walks, according to Elizabeth, that caused her teacher concern, not for the lack of inclusion, or isolation felt by Elizabeth, but the fear that walking had somehow added stress to Elizabeth's bones and caused a fracture. MacDonald and Block (2005) believe that teachers should be encouraged to set aside their own fears and assumptions and provide the same opportunities for all children to participate in physical education experiences. Physical education provides a key opportunity to build friendships and develop social skills In addition to social benefits, physical activity also helps to strengthen bones and muscles (OIF, 1998)..

Aquatic activity, in particular, is recommended by the Osteogenesis Imperfecta Foundation (1998) and yet in this study, in addition to their non-participation in physical education, David and Linda were excluded from school swimming. Elizabeth on the other hand participated in swimming activities, between fractures. Research shows that limiting physical activity to protect the student is now believed to hinder the physical development of people with OI. According to the Osteogenesis Imperfecta Foundation aerobic exercise and recreational pursuits can be designed to prevent problems and although the use of adaptive equipment might be necessary, fun and a sense of achievement are legitimate goals for an exercise programme.

To facilitate inclusion in other areas of the curriculum David was introduced to the world of technology at the earliest opportunity. His teachers possibly determined the most probable employment options for him would demand advanced computer and keyboard skills. A computer was provided for David to develop and advance knowledge and experience in the world of technology. David's teachers also maintained contact during school absences due to fractures and surgery. Teacher expectation was high and David was expected to work hard in all areas of the curriculum, with the exception of physical education.

Teacher expectation was also high for Elizabeth. Quality contact was maintained during her frequent absences from school to keep her up-to-date with her schoolwork. In Linda's interview she expressed concern regarding the lack of expectations she experienced from her teachers'. Linda said, "*Perhaps nobody thought I would work. I never dreamt that I wouldn't*". The limited effort that Linda applied to her schoolwork was possibly due to her teachers' low expectations for success. "*Yeah, definitely, and I think that because they didn't think I would achieve anything, that there was never a need for me to achieve*". Focusing on the students' potential and competency is essential to build a feeling of success in the student (Keller & Flem, 2000). The lack of expectation for success made Linda believe that she would not achieve to any degree of proficiency and "*was never going to be an A-grade student*". Extensive periods away from school, with no contact from her teachers' meant that she missed valuable learning opportunities and expected to struggle through her education,

without these skills being addressed. No extra tutoring was available or offered. Linda believes her teachers' had no expectation that she would ever be successful in gaining employment when she left school.

Additional pre-service and in-service training programmes could provide teachers with basic information about the characteristics of disabilities such as spina bifida, cerebral palsy, Osteogenesis Imperfecta and Duchenne Muscular Dystrophy (Singh, 2000). It is unrealistic to expect teachers to gain in-depth knowledge of every facet of a multitude of medical conditions. In this study, David stated that OI is such a rare condition he did not expect teachers to be specifically trained "*or fully keyed up on it*". Extensive research is required to gain even a mediocre understanding of certain medical conditions. For example, the debate on hearing loss in persons with OI is ongoing. Maturity onset of deafness is still cited in recent research articles (Tolboom, Cats, Helders, Pruijs & Engelbert, 2004) but according to Kuurila and Grenman (2004) the onset of hearing difficulties are often detected at a much earlier age.

#### Wider School Community

The responsibility of a student's inclusion within the school environment does not rest exclusively on the shoulders of their teacher. Principals, teaching staff, administration staff, ground staff and caretakers, volunteers, friends of the school, and visiting guests, all play an important role in the student's academic and social education. Ultimately, the Ministry of Education is responsible for setting policies, but the liability for implementation of policy lies with the school community. From discussions held with the participants attitudinal barriers were noted as a key issue.

Frequent communication between Elizabeth's parents and all staff at her school guaranteed they are aware of any changes in her medical status. Elizabeth's mother has stated her wishes concerning playground activities and participation and these are closely monitored. Elizabeth's school community appears to make an effort to keep up to date with her medical progress and monitor her activities in the playground. Nevertheless, in spite of frequent communication there does seem

to be a lack of collaboration between the school and Elizabeth's parents concerning the school's physical environment. The toilets remain virtually inaccessible, or at the very least hazardous. Ramps are sometimes too slippery and dangerous, especially in wet weather. These issues are yet to be addressed; no action has been taken although school staff knows that limitations are placed on Elizabeth's unconstrained mobility by these issues.

In comparison David's school anticipated his attendance. They made provision for him prior to his arrival by way of building ramps. They also monitored his physical and medical condition. David's use of an electric wheelchair appeared to give him unrestricted access to all areas of the school, with the exception of the swimming pool.

Elizabeth's school appears to be both pro-active and reactive, monitoring her activities and explaining her condition to staff and students. After Elizabeth fractured recently the school arranged counselling for staff and students. Elizabeth was in hospital at the time of counselling, therefore was excluded from these sessions. No effort was made to arrange for an individual counselling session for Elizabeth. In an informal discussion with Elizabeth's mother she acknowledged that the school community might have assumed the medical profession had provided counselling, but she thought this was rather naïve of them. Similarly Claesson and Brodin (2002) noted that parents of children with OI often complain that professionals ignore their worries. It appears that few professionals take their concerns seriously and that as a family unit they receive very little psychological support.

Linda appears to have encountered multiple attitudinal barriers from the Ministry of Education of the time, and others involved in annual school events. It is important to note that Linda attended school before the Special Education 2000 policies were instigated and when the New Zealand Correspondence School was considered a suitable alternative education source for young people with physical disabilities (Census and Statistics Department, New Zealand, 1952-53). She was not permitted to attend her local rural calf-club group day. The bus trip to manual training was prohibited and use of an electric typewriter was not permitted during

national examinations. Sex education was not considered appropriate for a young person with a physical disability. No collaboration with Linda and her parents appears to have been evident. Indeed Linda and her parents seemed to accept that there was very little they could do to change the status quo.

The results of this study indicate one major implication for the classroom or wider school community is that collaboration is essential for the safety and wellbeing of a student with OI. Every attempt should be made by teachers to collaborate with the student and their parents. If school staff lacks accurate information on the needs of the child they might place inappropriate and unnecessary restrictions on the child (Cole, 1993). The parents need to be treated with respect and accepted as the voice of authority in relation to their child's medical condition. Parents should be encouraged to speak openly about the physical and physiological aspects of osteogenesis imperfecta. The student's parents are experienced with dealing with fractures and therefore usually the best person to teach educators (OIF, 1998). However, assurance should also be given that all instruction given by the parents will be adhered regarding the safety of their child to.

Regular, quality physical education for all students is to be developed and implemented, according to Ministry of Education policy (Ministry of Education, 2006). This study did not find evidence of regular quality physical education. Butler and Hodge (2004) suggested that teachers must find creative ways to implement creative inclusive physical education activities to include all children in their class. This study found no evidence of creativity of teachers to find ways to include the student with OI in physical education. Ashman & Elkins (1994) stress that allowing a full range of learning experiences is important to develop an awareness of the person's limitations and promote self-advocacy. When a child is treated differently in the entirety, their education cannot be deemed inclusive. A student with OI should be made to feel they are part of the class, with teachers listening to the child (Alston, 1982). Isolation of a student because the teacher does not want that student to risk an injury when that same student could easily fracture an arm by bumping into a door could be construed as seeing the medical condition, not the student.

Singh (2002) states that in addition to medical and pedagogical considerations psychosocial aspects of each individual student must be taken into account. Over-protective teachers who make little effort to include a student with disabilities promote exclusive attitudes, whereas a teacher who shows consideration by use of people first language and creates inclusive activities and opportunities demonstrates positive role-modelling. If students observe teachers interacting with confidence and demonstrating positive approaches they might in turn emulate their behaviour. Experience as a teacher, combined with previous life experience, may influence teacher expectations for success, and enthusiasm for including a student with physical disabilities.

Generally, teachers are more receptive towards students with physical disabilities than towards students with emotional, behavioural or learning difficulties (Soodak, Podell & Lehman, 1998). Lack of support from less supportive teachers, and their subsequent failure to adapt the curriculum, continues to exclude full participation for some disabled students (Flem & Keller, 2000; Goodwin & Watkinson, 2000). Teachers' attitudes and characteristics influence the classroom environment (Flem and Keller, 2000), and therefore inclusion. Warm-hearted teachers with a high level of understanding and enthusiasm are vital to realise successful inclusive education. Careful selection of the intended teacher of student with OI should alleviate unnecessary stress on inexperienced staff.

The wider school community has an influence on inclusive participation for students with a physical disability. Research shows that other people's attitudes create many problems for people with disabilities, rather than the actual experience of living with a disability (Vienero and Krause, 1998). It cannot be expected that all members of the Board of Trustees' possess an inherent awareness of the special needs of each individual student with special needs, or an intrinsic desire to acquaint themselves with their student's needs. The Board of Trustees is responsible for providing a safe physical and emotional environment for all students (Ministry of Education, 2006). To ensure equitable, quality education for all students calls for deliberation specific to each individual student's diverse needs. For example, a student that has auditory difficulties will have quite different needs to a child with arthritis. Collaboration between parents, students

and wider school community is therefore vital to protect student rights to inclusive education.

### **What possible effects might these barriers have on the student?**

#### Self-attitude

Self-attitude was an emerging issue throughout this study as the interviews progressed. The frequent fractures each individual in this study coped with, and the importance placed on these events could influence the attitudes of the individual participants. The matter-of-fact way the participants recalled their many fractures and the resiliency they communicated could not be ignored. The stories of the three participants' lives at school and the fractures that are part of their lives illustrate their unique experiences. Bone fragility and limited mobility combined with the above-mentioned possible barriers might influence students' perception of self. Analysis of transcribed interviews revealed the following two key issues:

- Compliance versus self-advocacy,
- Depression.

#### Compliance versus self –advocacy

A sneeze, cough or seemingly insignificant bump might in one instance cause a fracture in a person with OI, and yet, on another occasion the exact same action might have no repercussions. Fingers, toes and ribs fracture frequently and are often discounted by the recipient as not worthy of medical attention and are often dealt with by themselves or their care-giver. Some people with OI minimise the pain and effect of fractures. Disclosure of fractures is not always immediate. The imminence of an important event or the absence of a suitable person to tell might forestall divulging a fracture. One reality known to people who have osteogenesis imperfect is that fractures can occur from little or no trauma.

Research indicates that people with OI should not take risks and should not become involved in physical education and play contact sport (Cole, 1993, Shealandry & Cole, 1986, Claesson & Brodin, 2002). These studies are from the perspectives of parents where there is no family history of OI. In contrast, adults

who have OI that have took part in Ablon's (2003) qualitative study say that the decision to participate in sport and other adventurous activities is theirs to make.

The implication of such conflicting views might be one of confusion for students with OI. Adventurous behaviour or everyday activities may result in fractures. Major trauma such as Elizabeth's fall from the flying fox, and Linda's skating escapades, often did result in one or more fractured bones. All three participants related that while they were cautious with their activities, and realised their own personal vulnerability and limitations, they still wished to, and often did, put themselves at risk. Elizabeth stated, "*I see the other kids doing it and it looks like fun and I think I'll have a go*". David said "*I was a realist and never tried to do anything that I couldn't do*" and Linda recalled "*I don't remember thinking well if I did this I risk breaking something. If I wanted to do something I did it. I didn't really think about the consequences*". The young American woman who played wheelchair basketball obviously felt the risk was worth the experience (Seelenfreund, 2005), so to did Douglas (2002) when he went abseiling at a scout jamboree. The participants' attitudes in this study's indicated that they felt the risks they were willing to take, to participate in an activity, although not consciously weighed up were worth the possibility of a further fracture. All three participants inferred that the decision to participate should be their choice.

Self-defence and self-preservation develops early for children with OI (Ablon, 2003). So too does heightened awareness and perception to anticipate events and possible fractures before they occur (Ablon, 2003) and yet, two of the three participants recalled events when they anticipated the possibility of fractures, but preferred to experience the thrill of the activity. All three participants understood the consequences of their actions.

Linda commented on upsetting her father when she continued to ride down the hill on a skate. Despite the promises she made to her father she would repeat the activity. Her wish to be compliant and not cause further pain to her father was perhaps evaluated subconsciously against the experience. Elizabeth too, recalled occasions when she did not comply with her teachers and parents wishes. Her attempts to experience the equipment in the school playground were often

detected. To expand social support, persons with physical disabilities often conform to turn strangers into friends, but once friendship establishes the degree of conformity reduces (Orr, Thein, & Aronson, 1995). The closer the relationship the less likely the person with a physical disability is to conform to others suggestions or ideas. It could be argued that the relationship students have with teachers and parents are perceived as an established friendship therefore the degree to which the participants felt the need to comply would be decreased. In this study Linda challenged her teacher's suggestion that she should retire to the study-room while her classmates participated in physical education. The wider school community could be termed as strangers. This could account for the lack of self-advocacy and conformity displayed by Linda when confronted with barriers to participation. For example, Linda and her parents did not challenge the decision that Linda could not go to manual or the group calf-club day. These events are organised and run by people often not familiar to students and families and could be viewed as strangers.

David and Linda stressed the importance of their friends. Friendships formed at school are conscientiously maintained. Elizabeth's circle of friends did seem to be limited to one special friend, although she sees her collective friends as being supportive and always available to prevent boredom. Elizabeth made frequent reference to not upsetting her classmates, for example "*Well, when I had the fixator on I didn't really like the way they said 'it looks disgusting'. I didn't really like that, but it's like, they probably didn't mean it, I know it looks disgusting, but they shouldn't say things like that*". Self-advocacy and assertive behaviour might risk "*frightening them away*". A tendency to conform may be an effective strategy to elicit social support (Orr, Thein, & Aronson, 1995). While classmates give help and assistance freely, conforming to their wishes might in turn make attitudes towards friendship more favourable.

David saw sports events as an opportunity for social interaction. During these events friendships were both created and strengthened. David was addiment that it was mostly on sports days that he felt lonely. He did not reveal feelings of loneliness to his classmates. David recalled, "*I do remember feeling lonely once or twice, mostly at sports days, even though I didn't show it*". Albon's (2003)

findings refuted the stereotypical state of euphoria, suggesting instead that a mantle of cheerfulness made them more attractive to other people. Viemero and Krause (1998) contend that social approval is paramount to a feeling of satisfaction of life for people with physical disabilities. David's feelings of loneliness were conceivably a result of exclusion from significant meaningful activities but by displaying a persona of euphoria, he would gain social approval and avoid alienating his friends.

Bum-shuffling down to the tennis-courts took Linda considerable time and effort and yet she persevered to maintain social contact with her classmates. Perseverance and resiliency may be a process of defence for survival (Ablon, 2003) in much the same way as the strategy of conformity (Orr, Thein, & Aronson, 1995) develop, then cement, friendships. Confronted with the challenge of accessing the tennis-court, Linda's perseverance resulted in social interaction with her classmates.

### Depression

Elizabeth and Linda both mentioned bouts of depression. Elizabeth experienced her first feelings of depression around five years of age, Linda when she was in her teenage years. Ablon (2003) reported most of the fifty-five adult participants they interviewed said they had experienced some periods of depression, but in general were cheerful considering the pain and problems they had experienced. The participants in this study by no means dwelt on this issue, rather depression was mentioned merely in passing, almost as if it was just another aspect of living with OI, and therefore expected and accepted.

Elizabeth spoke of times she gets "*the poor me's* [sic]". Conversations with her mother during periods of depression revolve around "*not wanting to live any more and that life isn't worth living like this*" (Elizabeth's Mother, personal communication). Viemero and Krause (1998) theorise that meaningful activities, social integration and psychological resources to cope with stressful situations lead to feelings of satisfaction with life. Elizabeth appears to be discouraged from meaningful activities. For example, she is monitored at school to obstruct any attempt to participate on playground equipment. Social integration opportunities

at school also appear limited for Elizabeth. Staying indoors during interval and solitary walks around the netball court in place of participating in physical education had the tendency to isolate her from her classmates. Viemero and Krause (1998) found in their study that individuals who are more dissatisfied with life were fixated on their disability and felt less socially accepted by non-disabled persons because they isolate themselves. Self imposed isolation, or isolation imposed by over-protection, impedes prospective friendships from forming. In this study it would appear that Elizabeth herself, and her teacher, instigate isolation from classmates.

The onset of periods of depression for Elizabeth at age five was considered young for such an event. In comparison, Linda was in her teen-age-years before any periods of depression were evident. Linda first recognised “*that condescending sort of pity, poor little “crip” [sic] thing*” while at high school. Barriers to her educational opportunities, and participation, became too obvious to ignore. Linda stated that it was not until her teenage years that she realised she was “*somehow different from the others*”. Her depression intensify when “*all my friends started having boy-friends*”, and “*leaving school*” and “*looking for a job*”. Unintentional attitudinal barriers that excluded Linda from equitable inclusion appeared to have affected her psychological well-being.

Linda believes that throughout her lifetime too much emphasis was placed on walking. “*Back then if you were disabled everyone thought to be normal you had to be walking, so everyone placed this huge emphasis on walking instead of all the other independent living skills that you needed*”. This attitude from professional suggests the medical discourse referred to by Neilson (2000) and Mitra (2006). Linda was seen as abnormal and as such, able to be fixed. The expectation that she should walk placed, regardless of whether she wanted to or not, set Linda further apart from her contemporaries.

The quote from one participant in Albon’s (2003) study speaks from the heart and gives an indication of the daily challenges experienced by persons with OI. Although this quote was presented in the literature review it is worthy of repetition to signify the magnitude of the challenges that face students every day

of their lives. “My perseverance wasn’t a choice that life offered me. It was a necessity to keep my heart beating, to keep the razor from my wrist” (Ablon, 2003, p.201). This quote suggests the implications for the classroom or wider school community is that barriers forced this person to persevere, rather than the medical condition OI. Attitudinal barriers might have far deeper significance than environmental factors. The capacity to cope with everyday life at school varies with each person. Multiple factors determined how each person views themselves and their place in society.

The psychosocial aspects of students with osteogenesis imperfecta are complex and varied. The social environment comprised of family, school personal and community is important for nurturing the strengths of the student for overcoming adversity (Ablon, 2003). By encouraging students with OI to join extracurricular activities, social interaction opportunities might provide occasions where the student can assist others and not be placed in the position of always accepting assistance (Neilson, 2000). Social interaction outside the classroom reinforces friendships initiated in the classroom.

Compliance might be a strategy used by persons with physical disabilities to make themselves more acceptable to others. If compliance is reserved for new acquaintances, careful observation at the start of a new school year might ascertain the degree to which the person is compliant. If extreme submissive behaviour is discovered self-advocacy could be encouraged. Classroom activities could provide an environment for promoting self-advocacy. Giving the student permission to think of alternative techniques or rules of a traditional physical education activity could give the student autonomy and build a feeling of self-esteem. In this study, the one attempt Elizabeth made was not successful. The games speed was reduced at Elizabeth’s suggestion, but her teacher “*didn’t really want me to do it anyway in case I fell over*”. The teacher failed to listen to suggestions given by the student and provide positive feedback as suggested by MacDonald and Block (2005). Indeed Elizabeth’s teacher gave her the impression that she did not want her to participate in case she injured herself, thus discouraging Elizabeth from further self-advocacy attempts.

Teachers and other school staff should also be cognisant of the possibility of depression in students with OI. While persons often display a persona of cheerfulness, fundamental feelings of loneliness, added to constant challenges presented by the physical environment, social environment, and the pain and inconvenience from constant fractures makes the life that persons with OI highly complex.

### **How does the present compare with the past?**

In this section an intergenerational comparisons will identify if the introduction of new special education policies for inclusive and equitable education for all children of New Zealand have forged noticeable change within the education sector regarding students with physical disabilities, and in particular OI. First comparisons will be made between the physical environments of the schools attended by the three participants over the last 40 years. Then attitudes encountered by the participants while attending school will be re-examined and compared.

#### Physical environment

Ramps appear to have made schools more accessible for students with physical disabilities, in particular students who use wheelchairs. In the seventies school buildings were modified to accommodate children with special needs (Census and Statistics Department, New Zealand, 1976). David, who has always used an electric wheelchair, provided evidence of increased access due to the modifications during that time. David's comments suggested he enjoyed freedom of mobility not experienced by Elizabeth or Linda. Elizabeth, who walks independently or with the aid of crutches, often finds the few ramps installed at her school unsafe to use. In comparison, Linda's school was not equipped with ramps.

Bathroom facilities continued to cause concern for the participants involved in this study. Hand-basin heights, slippery floors, heavy doors and lack of handrails present unnecessary challenges for students with OI. Neither Linda's nor David's school made any attempt to make student toilets accessible, which resulted in

these facilities being avoided by these two participants. Elizabeth also avoided using the school toilets.

Principle 1 of the Special Education Policy Guidelines states, “Young children and students with special needs have the same rights to a high quality education as people of the same age who do not have special education needs”. Schools are to be progressively upgraded to provide physical access under principle I. While it could be argued that in this study Elizabeth’s school has upgrading physical access by allowing her to use the staff toilets, she can only use them when she cannot walk independently. It could also be argued that installing ramps have upgraded the school to provide physical access, but the ramps were often, in Elizabeth’s opinion, not practical or safe to use.

#### Attitudes

The physical environment of a school may well be dictated by social attitudes. Linda, representing the oldest generation, encountered quite a different set of social attitudes than those experiences by David and Elizabeth. Linda, when first enrolled at school, was perhaps considered to be one of the “physically defective children” (Census and Statistics Department, New Zealand, 1950, p.154) and as such should not be accorded special privileges such as ramps and accessible toilets. Linda experienced attitudinal barriers to her educational options. It is possible that Linda was being viewed under the lay discourse, where people with disabilities are seen as inferior, asexual and childlike (Mitra, 2006). Curriculum areas such as sex education and cooking were not considered appropriate for a student with a physical disability. In comparison David, who first attended school some twenty years later, and Elizabeth who stated school a further twenty years later, experienced less constraints in curriculum participation as has been shown earlier in this discussion. One major exception to inclusion is that of physical education.

This study revealed significant exclusion from participation in physical education. Very few curriculum adaptations were evident. All three participants were repeatedly relegated to the sideline as spectators. Elizabeth’s participation seemed very limited, even though her mobility and strength were somewhat less limited

than either David or Linda. Swimming was the only area of the physical education curriculum where Elizabeth participated freely.

Hemmingson and Borrel (2002) believe that restricted participation or exclusion from some activities could be directly interpreted as a result of attitudinal barriers. Attitudinal barriers often perpetuate organisational limitations of the teacher. Principle 2 of the Special Education Policy Guidelines states, “The primary focus of special education is to meet the individual learning and developmental needs of the young child and student” (p.2). Within this principle is the provision for training for teachers to meet the needs of their students (principle 2.3) and the availability of specialist support and advisory services for schools, individuals and families (principle 2.5). Equally important is principle 2.7 which states “Schools and early childhood education services adapt programmes so that young children and students with special education needs are included” (p.3). The finding of this study indicates the possible failure to seek professional training and specialist support in the area of special education when necessary. The learning and developmental needs of the student are not considered to be paramount if no adaptations to programmes are being implemented.

To meet the needs of students with disabilities health and physical education programmes should be adapted to provide access to opportunities that will develop their sense of self-worth and extend, challenge, and broaden their abilities (Ministry of Education, 1999). The additional clause to the National Administration Guidelines (NAGs) requires that regular quality physical activity that develops movement skills for all students (Ministry of Education, 2004). While policies have, to some extent, improved life at school for students with OI, teachers’ fears, lack of creativity to adapt curriculum activities continue to exclude these students from some educational opportunities.

The results of this study indicate attitudinal implications for the classroom and the wider school community. The non-disabled world is still not as aware as they could be of what challenges face people with disabilities. For example, it is the responsibility of the physical education teacher to ensure the worthwhile participation of all students. Creativity might not guarantee full participation in all

activities, but combined with permission for the student to self-advocate and assist by making suggestions an environment might be achieved that raises a students self-esteem and makes them feel part of their class and valued by their school community.

### **Conclusion**

My first concern was to investigate barriers for students with osteogenesis imperfecta to inclusiveness in New Zealand schools. The results of this study showed that barriers did indeed exist. Environmental barriers and attitudes of others were found to limit participation in meaningful activities. Improved access could provide more social interaction which in turn could result in less focus on the disability, as shown in the diagram below.

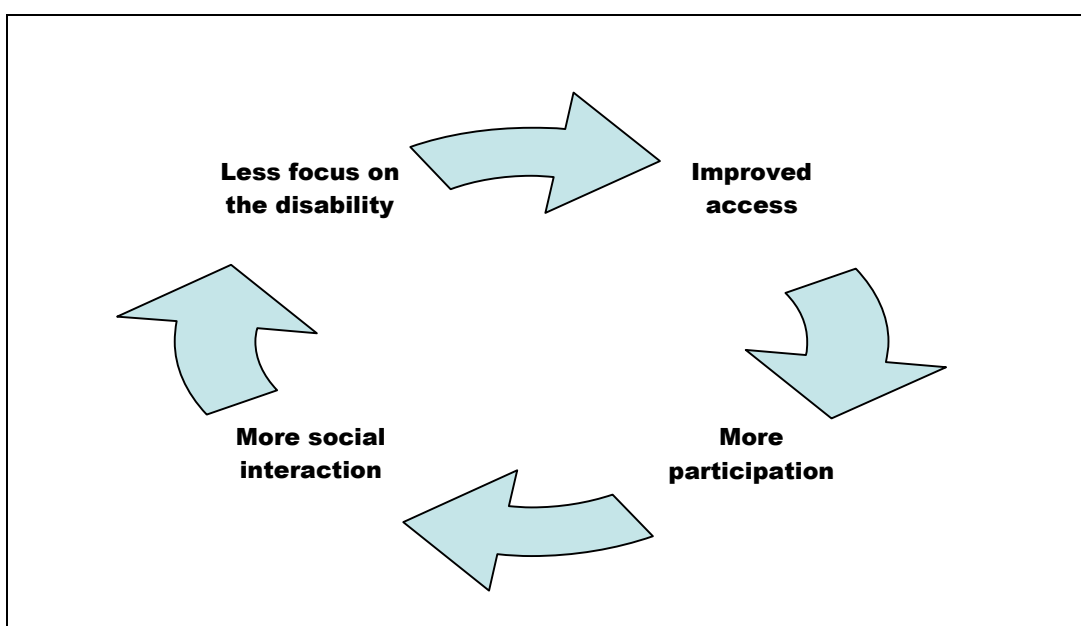


Figure 4: Improved access

Environmental barriers included the distance required to negotiate the school grounds to participate in class activities and attain social interaction with classmate during interval and lunchtime. Additionally, participation in whole school functions held at assembly halls appeared to be difficult for students with OI because of due the distance involved in traveling to these facilities. Toilets proved to be difficult to access for all three participants involved in this study. Little consideration for student's individual needs seems to have been given. Apparently, no collaboration has occurred between school staff, parents and

students to identify the special hygiene needs of students with OI. Short stature and reduced strength, combined with muscle laxity and limited mobility, pose unique needs for those with OI. To make school student toilets fully accessible these factors should be taken into account when modifications are made or new toilet blocks built. The results of this study suggest that ramps did make participation easier if the student used a wheelchair, but had limited impact on the freedom of mobility to those students who walked independently or with walking aids. Individual attitudes cannot be discounted as contributing to environmental barriers. Failure of school staff to collaborate with parents and students could indicate a lack of knowledge of the needs of students with physical disabilities. It is possible that there was no intrinsic desire to acquaint themselves with their students' needs suggesting some staff members might still view students with disabilities as inferior.

Poor knowledge of the medical and psychosocial aspects of students with OI could account for the continued barriers imposed by some teachers. All three participants in this study were excluded from physical education. Teacher fear and anxiety still seems to persist in some instances and could contribute to their failure to successfully adapt physical education activities. Once again inadequate knowledge of physical disabilities in general, and OI in particular, could attribute to feelings of fear and anxiety. Other areas showed the classroom has become more inclusive. For example, unlike forty years ago, students with OI are no longer excluded from other areas of the curriculum and participate in sex education classes and school camps.

The psychosocial wellbeing of students with OI does not appear to be a prominent concern of school staff in this study. Results showed that counselling was not offered to one participant after a traumatic fracture, even though counselling was provided for classmates and teachers who witnessed this event. Socialisation was not encouraged for one participant in this study, rather interaction during interval and lunchtime was discouraged by her teachers and parents. The lack of social interaction, and participation in meaningful activities during these times and exclusion from physical education classes could set her apart from her peers and account for her feelings of difference, thus add to her feelings of depression.

Fixation on her disability whether initiated by teachers, parents or herself isolates her from potential friendships. Encouragement and support is needed from school staff for students with OI to exercise self-advocacy skills. When those skills are enhanced students with OI could suggest ways they can become involved in meaningful activities. These changes combined with improved access to the school environment may alleviate feelings of isolation.

In the final chapter the key findings of this study will be addressed and consideration given to how existing barriers might be minimised. The contribution of this study to the teaching practice of children with osteogenesis imperfecta will be discussed. Next, the limitations of this study will be examined. Finally, implications for further research will be considered and recommendations for the future given.

# CHAPTER SIX

## CONCLUSION

### **Introduction**

This qualitative study focused on the stories of three individuals that exemplify a particular phenomenon, specifically the daily school lives of those with the medical condition osteogenesis imperfecta (OI). Their stories illustrated the high and low points of being a student with OI. Challenges they faced were explored through semi-structured interviews. Three participants were involved in this study and each was a different generation.

The focus of this study was to allow their stories to be told. Their stories enabled a comparison across three generations of individuals who had osteogenesis imperfecta. It was through a comparison of their school experiences that barriers were uncovered. Some of the difficulties these individuals encountered and the cause might encourage teachers and the wider school community to consider the implications of inclusive education in their own context. Ideally, this study will inspire teachers to ask their own students about their perceptions of barriers that limit their school participation.

This study examined two specific areas. The first area was how three individual people with OI managed physically within the educational setting, the second, how they coped emotionally during their formal education. The main objective of this study was to listen to individual narratives and to identify barriers and their causes. The possible effects barriers had on the individual student were explored. The participants' individual experiences were compared to ascertain whether changes have affected educational opportunities for those with OI. The stories from each participant provided a way of identifying barriers and then inform platform schools and teachers so that they can provide a safe and inclusive learning environment for those students with OI in New Zealand.

In order to carry out this study the following research questions were devised that encouraged the telling of the participants stories:

- 1.What barriers exist in the education setting for students with osteogenesis imperfecta?
- 2.What/who might be the cause of these barriers?
- 3.What possible effects might these barriers have on the student?
- 4.How does the present compare with the past?
- 5.How might these barriers be overcome?

The limitations of this study are stated elsewhere in this study, however the writer once again acknowledges that time constraints and inexperience as a researcher were limitations. Furthermore, the small number of participants, all of who attended small rural schools may mean that the sample was unrepresentative..

### **Key findings**

This study revealed that barriers to inclusive education for students with OI existed in the past and still exists today in New Zealand schools. The main focus of concerns identified in the experiences of the three participants were restrictions to access and participation caused by the physical environment and unintentional attitudes displayed by parents, teachers and the wider school community. Self-attitudes of the three participants also played a part in their involvement in school activities.

#### **Physical/environmental barriers**

The physical environment of schools present challenges to students with limited mobility. Three major areas of concern were evident: distance/physical size of school, ramps and accessibility to bathroom/toilet facilities. Distance between various facilities increased in proportion to the size of the school. The addition of ramps to school buildings did alleviate challenges for two students. While ramps seemingly afford freedom of movement within school grounds their effectiveness is dependent on the level of mobility of each individual student. The one participant that used an electric wheelchair gained the most benefit from the installation of ramps. Toilet facilities continued to be inaccessible or posed particular concerns for the participants involved in this study. The short stature and limited strength of those students had not been identified and the necessary modifications to their schools had not been implemented.

### Attitudinal barriers

In this study analysis of the three participants conversation identified that the major cause of barriers to inclusive, equitable education for them was attitudinal. Parents, teachers, the wider school community and self-attitude were discussed.

Individual parental attitudes towards the risks that their children should take appeared to influence student levels of participation in this study. Some parents appeared to accept that their child would fracture while involved in daily activities at school, whereas some parents felt the need to protect their child by endeavouring to limit their participation. The findings in this study differ from research by Shea-Landry and Cole (1986) who suggest that parents help the child when they encourage them to resist participation in sports and risks-taking physical activities to limit injury. Yet, Viemero and Krause (1998) found that meaningful activities combined with social integration led to feelings of satisfaction with life for persons with a physical disability. Attitudes and expectations towards what constitutes inclusive education might be different for all three parties. Collaboration between parents, the participants and their teachers was not evident in this study and indicates that parents and the student should be given the opportunity to assess and voice their own feelings on risk versus benefit.

Teacher attitudes also varied. Some teachers made an effort and found creative ways to provide resources that enabled the participants to cope with the general daily routine of the classroom. It was the opinion of the three participants that their teachers did not always encourage self-advocacy. Evidence was found of some teachers who continued to support students who were absent from the classroom during recuperation from surgery. Individual teacher expectations were shown to contribute towards student motivation and their expectation of their own achievements in one instance.

It appears that little or no attempt had been made by teachers to include the participants in the regular physical education classes in spite of clear education policies. Research indicates that additional pre-service and in-service training programmes might assist teachers to find creative ways to include students with OI in their physical education classes. This study indicated that while policy exists

to ensure students with a physical disability receive regular quality physical activity that challenges the student, develops movement skills, and values the student as part of the class, this was clearly not the case.

Barriers are not always recognised, or identified by those creating them. Teachers and the wider school community should be encouraged to collaborate with individual students and their parents. For example, the student is the best source of information to determine where ramps are needed and if existing ramps are safe to use. Knight and Wadsworth (1993) emphasise that school buildings must be made entirely accessible for students with orthopaedic difficulties to attain inclusive opportunities in educational settings.

A predisposition to fracture does not negate the ability of a person with OI to assess risk. Some of the results of this study are similar to qualitative research by Ablon (2003) who believes people with OI have heightened awareness and perception born out of the danger of potential fractures that allows children to anticipate events and problems before they occur. In keeping with Ablon's findings, in this study the participants' individual attitudes indicated that they felt the risks they were willing to take to participate in an activity were worth the possibility of a further fracture, but these risks were mostly taken outside school hours. There was however, a feeling of conflict inferred by two of the three participants between their desire to take risks and conform to the wishes of others. In spite of feelings of conflict, the two adult participants in this study made it clear that if they decided the experience of any given activity was more valuable to them than to be excluded because of the possibility of a fracture, the choice should be theirs. Ablon (2003) maintained that one reason for the spirited approach to life for people with OI is the desire to experience things, even at the risk of breaking or death. One participant in this study stated, "Pain only lasts for a little while, but good memories last forever".

Pedagogical considerations in relation to students with OI should include their psychological and psychosocial wellbeing. The results of this study revealed periods of depression are possible from a very young age for students with OI. Viemero and Krause (1998) stress that self-imposed isolation, or isolation

imposed by over-protective parents, or teachers, leads to a person with a physical disability feeling less socially accepted by non-disabled persons. Being isolated from classmates, both physically and psychologically can exacerbate feelings of loneliness and difference.

### **Recommendations for education providers and policy makers**

The results of this study indicate that barriers for students with OI to the physical environment of New Zealand schools are yet to be clearly identified and minimised. Schools are yet to provide physical access of a standard that allows equality of educational opportunities for all New Zealanders. Changes to attitudinal barriers are still not established allowing for equity within our educational setting. The last focus question in this study is how might these barriers be overcome? The following recommendations result from the findings in this study.

1. Collaboration between parents, student and teachers is vital to access risk versus benefit of participation.
2. Encourage self-advocacy and implement suggestions where possible.
3. Support students when convalescing after surgery.
4. Additional pre-service and in-service training programmes could assist teachers to find creative ways to include students with OI.
5. Collaboration between parents, students and the wider school community could help identify barriers not recognised by the non-disabled population.
6. Toilet facilities and ramps need to be fully accessible for all students.
7. Psychosocial and medical dimensions are important pedagogical considerations for teachers who have a student with OI in their class.
8. Students with OI should be encouraged to participate in all classroom activities, but ultimately the choice must be theirs to make.

A holistic approach towards students with OI might alleviate the barriers that continue to make life at school challenging for these students. Academic inclusion should go hand in hand with social interaction and meaningful activities. The student should be encouraged to self-advocate assisting all school staff and the

wider school community to provide inclusive access and opportunities in all school activities.

Teachers should take an active role in initiating regular meeting between themselves, parents and the student. The student should be encouraged to take an active, self advocating role within these regular meeting thus creating an open discussion on risk versus benefit of participation. Together they can identify areas that present access difficulties such as toilets and ramps, and suggest creative ways to participate fully in all class activities. Special staff meetings should be held on a regular basis to give the teacher the opportunity to further discuss any suggestion made by the student or their parents. In-service training programmes should be initiated, and included in these meetings, to encourage all staff to find practical, creative ways to include their student with OI in all school activities and support the student during frequent absences from school.

### **Suggestions for future research**

This qualitative study articulated the stories of three people with osteogenesis imperfecta. It was through their voices and their experiences that an intergenerational comparison was made of their experiences in New Zealand schools. The results from this study suggest that there is potential for further research in the area of students with physical disabilities, from a student perspective, within the education system in New Zealand. The major focus of current literature from European countries, Canada and America is explored through the eyes of teachers and parents of students with disabilities. This study focused on students with OI within the New Zealand education setting. The literature review exposed a gap in research that examines the psychosocial needs of the individual with OI.

1. Future research could examine teacher failure to include students with physical disabilities in physical education classes within New Zealand school.
2. Research could explore ways to include students with OI in physical education classes.

3. Research could examine the effects of conformity versus self-advocacy of students with physical disabilities in relationship to their classmates.
4. Research could investigate whether the emphasis that doctors and parents place on children with OI being able walk is matched by the views of the child themselves.
5. Research could explore the effect of previous family history versus spontaneous OI to determine the level of participation of children and young people.

It is essential that further qualitative research explore the psychosocial aspect of people with special needs from their perspective. It is from their voices that we can truly understand how they view their world, the experiences that bring them pleasure and the challenges they face.

### **Conclusion**

This study has revealed that equitable, inclusive education has not yet been achieved for students with osteogenesis imperfecta in New Zealand schools. In spite of recent special education policy physical education in particular remains one area of the curriculum that has apparently been overlooked. Additionally the physical environment continues to present challenges for students with OI. Toilet facilities, ramps and the physical distance of school facilities and playgrounds were identified as a major environmental barrier for students with OI. Collaboration between the students, parents and wider school community to address these issues is essential. To conclude, students with OI would benefit academically and psychosocially from challenging and meaningful inclusive education experiences where self-advocacy is encouraged, and suggestions for inclusion sought, and actioned.

## REFERENCES

- Ablin, D.S., Greenspan, A., Reinhart, M., & Grix, A. (1990). Differentiation of child abuse from osteogenesis imperfecta. [Electronic version]. *American Journal of Roentgenology*. 154, 1035-1046
- Ablon, J. (2003). Personality and stereotype in osteogenesis imperfecta: Behavioral phenotype or response to life's hard challenges. [Electronic version]. *American Journal of Medical Genetics*, 122A, 201-214.
- Alston, J. (1982). Children with brittle bones. [Electronic version]. *Special Education: Forward Trends*, 9(2), 29-32.
- Alston, J. (1983). Children with brittle bones; an examination of their educational needs and progress. [Electronic version]. *Special Education: Forward Trends*. 10 (4), 19-23.
- Ashman, A., & Elkins, J. (1994). Providing learning opportunities for all children. In A. Ashman & J. Elkins, (Eds.) *Educating Children with Special Needs*. 2<sup>nd</sup> Edition. Australia: Prentice Hall.
- Ballard, K. (1999). *Inclusive education in an exclusive society: Some challenges to ideology and practice*. *Inaugural Professorial Lecture*. Wednesday, 21 July, 1999.
- Barrett, W., & Randall, L. (2004). Investigating the circle of friends approach: Adaptations and implications for practice. [Electronic version]. *Educational Psychology in Practice*, 20 (4), 253-268.
- Beatson, P. (2000). *The disability revolution in New Zealand: A social map*. Palmerston North, New Zealand: Massey University.
- Blinde, E.M., & McCallister, S.G. (1998). Listening to the voices of students with physical disabilities: Experiences in the physical education classroom.

[Electronic version]. *Journal of physical education, recreation and dance*. 69 (6).

Brittle Bone Association. (2003). *Handle with care*. New Zealand: Brittle Bones Association of NZ. Inc.

Brodin, J., & Millde, K. (1991). Three preschool children with osteogenesis imperfecta—Interviews with parents. [Electronic version]. *Handicap Research Group Report No. 5*. ED331196.

Burns, R.B. (1994). *Introduction to Research Methods*. Australia: Longman.

Butler, R.S., & Hodge, S.R. (2004). Social inclusion of students with disabilities in middle school physical education classes. *Research in Middle Level Education Online*, 10848959, Apr2004, Vol 27, Issue 1.

Census and Statistics Department, New Zealand. (1950). *The Official Year Book 1950*. Wellington, New Zealand: Government Printer.

Census and Statistics Department, New Zealand. (1953). *The Official Year Book 1952-53*. Wellington, New Zealand: Government Printer.

Census and Statistics Department, New Zealand. (1976). *The Official Year Book 1976*. Wellington, New Zealand: Government Printer.

Charmaz, K. (2000). Grounded theory: Objectivist and constructivist methods. In N.K Denzin, & Y.S. Lincoln (Eds.), *Handbook of Qualitative Research* (pp. 509-536). California: Sage.

Claesson, I.B., & Brodin, J. (2002). What families with children with brittle bones want to tell. [Electronic version]. *Child: Care, Health & Development*, 28 (4). 309-315.

Cole, E.C. (1993) Psychosocial aspects of osteogenesis imperfecta: An update. [Electronic version] *American Journal of Medical Genetics*, 45, 207-211.

- Cook, B.G., Tankersley, M., Cook, L., & Landrum. (2000). Teachers' attitudes toward their included students with disabilities. [Electronic version]. *Exceptional Children*, 67 (1), 115-134.
- Christians, C.G. (2000). Ethics and politics in qualitative research. In N.K Denzin, & Y.S. Lincoln (Eds.), *Handbook of Qualitative Research* (pp.133-155). California: Sage.
- Denzin, N.K., & Lincoln, Y.S. (2000). *Handbook of Qualitative Research*. California: Sage.
- Douglas, P. (2002, January 14). Fighting battles. *The Press*, Edition 2. Retrieved March 17, 2006, from <http://io.knowledge-basket.co.nz.ezpoxy.waikato.ac.nz:2048/magz/ema/cma.pl?id=23>
- Engelbert, R.H., Gulmans, V.A., Uiterwall, C.S. & Helders, P.J. (2001). Osteogenesis imperfecta in childhood: Perceived competence in relation to impairment and disability. [Electronic version]. *Archives of Physical Medicine and Rehabilitation*, 82, 943-948.
- Eriksson, L. (2005). The relationship between school environment and participation for students with disabilities. [Electronic version]. *Pediatric Rehabilitation*, 8, (2), 130-139.
- Flem, A., & Keller, C. (2000). Inclusion in Norway: a study of ideology in practice. [Electronic version]. *European Journal of Special Needs Education*, 15 (20), 188-205.
- French, S. (1993). What's so great about independence? In Swain, J., Finkelstein, V., French, S & Oliver, M. (Eds). *Disabling barriers-Enabling environments*. London; Sage.

- Finkelstein, V. (1993). The terminological minefield. In Swain, J., Finkelstein, V., French, S & Oliver, M. (Eds). *Disabling barriers-Enabling environments*. London; Sage.
- Geisman, G. (2005). How breakthrough got its name. *Breakthrough*, Spring 2005, 10-12
- Ghesuiere, P., Maes, B., & Vandenberghe, R. (2004). The usefulness of qualitative case studies in research on special needs education. . [Electronic version]. *International Journal of Disability, Development and Education*, 51 (2), 171-184.
- Glaser, B.G. (1992). *Basics of Grounded Theory Analysis*. California, USA. Sociology Press
- Goodwin, D.L. (2001). Pedagogic reflections on how children with physical disabilities experience physical education. [Electronic version]. *Physical & Health Education Journal*, 67 (1), 14-19.
- Hemmingson, H., & Borell, L. (2002). Environmental barriers in mainstream schools. [Electronic version]. *Child Care, Health and Development*, 28 (1), 57-63.
- Holmes, C. (1992). *Hillary commission assignment*. (unpublished).
- Hunt, P., Soto, G., Maier, J., & Doering, K. (2003). Collaborative teaming to support students at risk and students with severe disabilities in general education classrooms.[Electronic version]. *Exceptional Children*, 69 (3), 315-332.
- Imani, P., Vijayasekaren, S., & Lannigan, F. (2003). Is it necessary to screen for hearing loss in pediatric population with osteogenesis imperfecta? [Electronic version]. *Clinical. Otolaryngology*, 28, 199-202.

- Jackson, S. (1996). *Special Education 2000; Update One*. July, 1996. Wellington. New Zealand: Ministry of Education.
- Janesick, V.J. (2000). The choreography of qualitative research design: minuets, improvisations, crystallizations. In N.K. Denzin, & Y.S. Lincoln (Eds.), *Handbook of Qualitative Research*, 379-400. California, USA: Sage.
- Kavale, K.A. (2002). Mainstreaming to full inclusion: from orthogenesis to pathogenesis of an idea. *International Journal of Disability, Development and Education*, 49 (2), 201-214.
- Knight, D., & Wadsworth, D. (1993). Physically challenged students: Inclusion classrooms. [Electronic version]. *Childhood Education*, 69 (4), 211-215.
- Krahe, B., & Altwaser, C. (2006). Changing negative attitudes towards persons with physical disabilities: an experimental intervention. [Electronic version]. *Journal of Community and Applied Social Psychology*, 16, 59-69.
- Kuurila, K., & Grenman, R. (2004). Response to “is it necessary to screen for hearing loss in the paediatric population with osteogenesis imperfecta?”. [Electronic version]. *Clinical Otolaryngology*, 29, 287.
- Lanthrop, D.P. (1992). Child abuse: a fragile issue. [Electronic version]. *Accent on Living*, 37 (3), 30-35.
- MacDonald, C., & Block, M.E. (2005). Self-advocacy in physical education for students with physical disabilities. [Electronic version]. *Journal of Physical Education, Recreation & Dance*, 76 (4), 45-48.
- Marlowe, Pipin, & Byers, (2002). Testing for osteogenesis imperfecta in cases of suspected non-accidental injury. [Electronic version]. *Journal of Medical Genetics*, 39 (6), 382-386.

- Merriam, S.B. (1998). *Qualitative Research and Case Study Applications in Education*. California, USA: Jossey-Bass Inc.
- Metcalf, S., Gervais, J., Dase, M., & Griseta, L. (2005). Dis/abilities through artists' eyes. [Electronic version]. *Art Education*, 58 (4), 25-32.
- Miller, N., & Sammons, C. (1999). *Everybody's different: Understanding and changing our reaction to disabilities*. Baltimore, Maryland, USA: Paul H Brooks Publishing Company.
- Minister for Disability Issues. (2001). *A Brief Summary of the Analysis of Submissions to the New Zealand Disability Strategy Discussion Document. Making a World of Difference: Whakanui Oranga*. Wellington, New Zealand: Ministry of Health.
- Ministry of Education. (1999). *Health and Physical Education in the New Zealand Curriculum*. Wellington, New Zealand: Learning Media Limited.
- Ministry of Education. (2006) *The National Administration Guidelines (NAGs)*. Wellington, New Zealand. Retrieved January 11, 2007, from <http://mined.govt.nz>
- Ministry of Education. (2006) *The New Zealand Curriculum Framework*. Wellington, New Zealand. Retrieved January 11, 2007, from <http://mined.govt.nz>
- Ministry of Education. (2006) *Special Education Policy Guidelines*. Wellington, New Zealand. Retrieved January 11, 2007, from <http://mined.govt.nz>
- Mitra, S. (2006). The capability approach and disability. [Electronic version]. *Journal of Disability Policy Studies*, 6 (4), 236-247.
- Mutch, C. (2005). *Doing Educational Research: A Practitioner's Guide to Getting Started*. Wellington, New Zealand: NZCER Press.

National Institute of Health Osteoporosis and Related Bone Diseases-National Resource Centre. (1997). OI Issues: Education. Retrieved March 16, 2004, from <http://www.oif.org/site/pageserver?pagename=educat>.

National Institute of Health Osteoporosis and Related bone Diseases- National Resource Centre. (1997). OI Issues: Psychosocial Needs of the Family. Retrieved March 16, 2004, from <http://www.oif.org/site/pageserver?pagename=educat>

Neilson, W. (2000). Disability; Attitudes, history and discourses. In D., Fraser, R. Moltzen., & K.Ryba. *Learners with Special Needs in Aotearoa/New Zealand*. New Zealand: Dunmore Press.

Office for Disability Issues. (2001). *New Zealand Disability Strategy – Objectives*. Wellington, New Zealand: Ministry of Social Development. Retrieved May 19, 2005, from <http://www.odi.govt.nz.ezproxy.waikato.ac.nz:2048/publications/nzds/objective3.html>

OIFE. (2006). *OIFE Statistics*. Retrieved May 19, 2006, from <http://www.oife.org/oife/oifestat.html>

Orr, Thein, & Aronson, (1995). Orthopedic disability, conformity, and social support. [Electronic version]. *The Journal of Psychology*, 129 (2), 203-212

Osteogenesis Imperfecta Foundation. (1998). Plan for success: An educator's guide to students with osteogenesis imperfecta. A companion brochure to the plan for success video. Retrieved March 13, 2006, from <http://ostoe.org/newfile>.

Osteogenesis Imperfecta Foundation. (2002). OI Issues: Education. Retrieved March 13, 2006, from <http://ostoe.org/newfile>

- Osteogenesis Imperfecta Foundation. (2004). *OI Issues: Psychosocial Needs of the Family*. Retrieved March 13,2006, from <http://ostoe.org/newfile>
- Palmer, D.S., Fuller, K., Arora, T., & Nelson, M. (2001). Taking sides: Parent views on inclusion for their children with severe disabilities. [Electronic version]. *Exceptional Children*, 67 (4), 467-484.
- Pivik, J., McComas, J., & LaFlamme, M. (2002). Barriers and facilitators to inclusive education. [Electronic version]. *Exceptional children*: 69, (1), 97-107.
- Praisner, C. (2003). Attitudes of elementary school principals towards the inclusion of students with disabilities. *Exceptional Children*: 69, (2), 135-145.
- Powney, J., & Watts, M. (1987). *Interviewing in Educational Research*. London: Routledge.
- Rauch, F., & Glorieux, F.H. (2004). Osteogenesis Imperfecta. [Electronic version]. *The Lancet*, 363, 1377-85.
- Ripley, R. (2005). Shriners hospitals opens brittle bones disease clinic. *Journal of Business, Spokane*, 20 (13), B2.
- Rossmann, G.B., & Rallis, S.F. (1998). *Learning in the Field: An Introduction to Qualitative research*. California, USA: Sage.
- Scott, D., & Usher, R. (1999). *Researching Education: Data, Methods and Theory in Educational Enquiry*. London, England: Continuum.
- Seelenfreund, B. (2005). Wheelchair kids can't jump. *Breakthrough*. Spring 2005. 13-15.

- Shea-Landry, & Cole, (1986). Psychosocial aspects of osteogenesis imperfecta. *Canadian Medical Association Journal*, 135, 977-981
- Singh, D.K. (2000). Regular educators and students with physical disabilities. [Electronic version]. *Education: Winter 2002*, 123 (2), 236-245.
- Snow, K. (2005). *To ensure inclusion, freedom and respect for all, we must use people first language*. Retrieved April 10, 2006, from <http://www.kidstogether.org/pep-1<sup>st</sup>.htm>
- Soodak, Podell, & Lehman, (1998). Teacher, student, and school attributes as predictors of teacher responses to inclusion. [Electronic version]. *The Journal of Special Education: Winter 1998*, 31 (4), 480-497
- Stainback, S., Stainback, W., & Ayers, B. (1996). School as inclusive communities. In W. Stainback, & S. Stainback, *Controversial Issues Confronting Special Education: Divergent Perspectives*. (2<sup>nd</sup> ed). America. Pearson Education.
- Strauss, A.L. & Corban, J.M. (1998). *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. USA: Sage.
- Test, D.W., Fowler, C.H., Wood, W.M., Brewer, D.W., & Eddy, S. (2005). A conceptual framework of self-advocacy for students with disabilities. [Electronic version]. *Remedial and Special Education*, 26 (1), 43-52.
- The New Zealand Disability Strategy Sector Reference Group (2001). *The New Zealand Disability Strategy. Making a World of Difference: Whakanui Oranga*. Wellington, New Zealand: Ministry of Health.
- Tolboom, N., Cats, E.A., Helders, P.J.M., Pruijs, J.E.H., & Engelbert, R.H.H. (2004). Osteogenesis imperfecta in childhood: effects of spondylodesis on functional ability, ambulation and perceived competence.[Electronic version]. *European Spine Journal*, 13, 108-113.

- Tolich, M. (2002). *Research ethics in Aotearoa New Zealand: Concepts, Practices, Critique*. Auckland, New Zealand: Longman.
- Viemero, V., & Krause, C. (1998). Quality of life in individuals with physical disabilities. *Psychotherapy and Psychosomatics*, 67, 317-322.
- Weitzel, S.H. & Percy, A.J. (2000). Transient Osteoporosis of the hip associated with pregnancy and osteogenesis imperfecta. *Orthopedics*, 23(12), 1291-1292
- Whyte, B. & Scratchley, M. (1995). Physical disabilities. In D. Fraser, R. Moltzen, & K. Ryba, (Eds.). *Learners with special needs in Aotearoa/New Zealand*. Palmerston North, New Zealand: Dunmore Press.
- World Health Organisation. (2001). *International classification of functioning disability and health*. Geneva, Switzerland: Author.
- Woodill, G. (1994). The social semiotics of disability. In M.H. Rioux., M. Bach., & Roeher Institute (Eds.). *Disability is Not Measles: New Research Paradigms in Disability*. 202-226
- Wos, J. (2004). Work to do [Painting in oil]. In S. Metcalf., J. Gervais., M. Dase., & L. Griseta. *Dis/abilities through artists' eyes*. [Electronic version]. *Art Education*, 58 (4), 25-32.
- Yin, R.K. (1989). *Case study research: Design and methods. Revised Edition. Applied Social Research Methods Series*. Vol. 5. London, England; Sage Publications.

## Appendices

## **Appendix I: Interview Question Guideline**

When you were born how did your parents know you had osteogenesis imperfecta

What sort of things did you like doing at home before you went to school?

Can you tell me about that time and what sort of things you did there?

What sort of things do children your age like to do at school?

What things do you do together?

Could you tell me about anything you would like to do at school that you can't?

What stops you from doing the things you can't do?

Who are the people that help you the most at school?

What things do they do to help?

Do you feel that you need their help?

Do you ever need to ask for help?

Who do you ask and how do they react.

How easy is it for you to get around at school?

Are there places that you can't go or are difficult to get to?

Is there any equipment that you can't use? Why can't you use these things?

Sometimes there is equipment that people need to use to help them do things. Do you have anything at school that helps you in some way?

Tell me about the times you have fractured at school.

Tell me about the times when you haven't been able to go to school because of fractures?

What do you do about school work during the times you are away from school?

How does your teacher keep in touch with you when you are away from school?

What do you do on special days like sports days?

Tell me about your friends.

What are your best memories of school?

What sort things would have made things better for you at school?

## **Appendix II:** Introductory letter to child participant

Date

Address

Dear (Child's name)

Hello, my name is Heather Holmes and I am a student at the University of Waikato. I am doing a special project at the moment and I wondered if you would like to help me. I have decided that I would like to do my project on children that have osteogenesis imperfecta and what sort of stuff they do at school. I have a sister with osteogenesis imperfecta and I really enjoy talking to her about what school was like for her.

I would like to visit you at home to chat about the things you like doing at school and the things you don't like. We would talk about the things you find easy to do at school and things that are not so easy and a bit of a challenge. I would love to hear about what you want to do when you leave school. I would need to chat with you three or four times over a few weeks. Your mum or dad could be there while we talked, if you would like them to be, or if they would like to be there. You wouldn't have to answer any questions that you didn't want to and it would be okay if you told me that you had had enough talking for the day. Your name, and the name of your school, would be kept secret. You could choose a name that I could use instead of yours, if you decide that you would like to help with my research project.

We would be using a tape recorder when we talk, so I can listen to it again and write down what we are saying, but we would have a bit of fun with the tape recorder first so we can both get used to it. Maybe you have dreams of becoming a rapper or movie star and it would be a great way to practice hearing your own voice.

We wouldn't have to talk at your house. We could go somewhere else if you wanted to. Maybe you would like to go to the park, or somewhere you think is really neat. Maybe you would like to show me around your school. I am going to be a teacher when I finish my project and enjoy looking at classrooms.

My special research project will help kids everywhere who have osteogenesis imperfecta, and even though it will take me whole year to do, and lots of hard work, I am really excited about it. So little is known about how children with osteogenesis imperfecta get on at school that our talks will hopefully help not only other children, but teachers too. That is why I want to talk about the things you find hard to do, as well as the good things. Maybe, if I do a really good job, I could even get my research published in an educational journal.

I will phone you in a few days and you could let me know then if you would like to meet me and talk to me about my research project and your experiences at school. You can ask me as many questions as you like about my project and I won't mind.

Yours truly,

Heather Holmes

### **Appendix III:** Introductory letter to participant's parents

Date

Address

Dear (Parents)

Hello, my name is Heather Holmes and I am an Honours Student currently studying at the University of Waikato. This letter is to provide you with background to my research interest and to seek your child's involvement in this research project.

My research interest is in what, if any, barriers students with osteogenesis imperfecta encounter at school. Your child's thoughts would be invaluable to me. My intention is to define if barriers exist, and if they do what causes these barriers. My research would include an analysis of these barriers and suggestions of how they may be overcome. I would need to interview your child, using a tape recorder, for no longer than 1 hour, 3 or 4 times over several weeks. These interviews could be conducted at your home, or some other place selected by you or your child. You could, of course, be present during these interviews if you or your child wished. Your child would have the right to withdraw from this research at any point up to the end of data collection. This could be done contacting my supervisor. There would also be no obligation for your child to answer any question that they did not wish to. Interview times would be arranged to suit you and your child.

I will also be conducting interviews with two adults, of differing generations who have also osteogenesis imperfecta, to compare their experiences with those of your child. In this way I will be able to analyse if things have changed in the education system over the years for children with physical disabilities, and in particular with osteogenesis imperfecta.

My research is intended as a four-paper thesis for the completion of my Masters. However, there is the possibility that in addition to the publication of my thesis

further publications may follow. In the event of further publications these would be limited to educational journals.

Every attempt will be made to ensure confidentiality and identification of your child and the school that your child attends. A pseudonym will be used for your child, if your child agrees to participate in my research. Additionally, no mention will be made of the name, location, or region of the school.

The University of Waikato has given ethical approval for this research. If you have any questions about this research project please do not hesitate to call me on (Phone number) or e-mail me at [hjh8@waikato.ac.nz](mailto:hjh8@waikato.ac.nz) or contact my supervisor Dr Margaret Scratchley at the University of Waikato.

Thank you in advance for your time and helpful participation.

Yours truly,

Heather Holmes

#### **Appendix IV:** Introductory letter to adult participants

Date

Address

Dear (Adults)

Hello, my name is Heather Holmes and I am an Honours Student currently studying at the University of Waikato. This letter is to provide you with background to my research interest and to seek your involvement in this research project.

My research interest is in what, if any, barriers students with osteogenesis imperfecta encounter at school. You are invited to participate in this research. Your participation will involve three interviews with myself. These interviews could be held in your own home or any other place selected by you. I would be using a tape-recorder and all conversation will be transcribed. Your thoughts would be invaluable to me. I will also be interviewing a student currently at school. Your thoughts would enable me to define if barriers existed, what barriers existed, and what caused these barriers. My research would include an analysis of your experiences and compare them to today's educational setting. You would have the right to withdraw from this research at any point up to the end of data collection by contacting my supervisor.

My research is intended as a four-paper thesis for the completion of my Masters. However, there is the possibility that in addition to the publication of my thesis further publications may follow. In the event of further publications these would be limited to educational journals.

Every attempt will be made to ensure your confidentiality and identification. A pseudonym will be used for you, if you agree to participate in my research. Additionally, no mention will be made of the name, location, or region of the school/s you attended in the past.

The University of Waikato has given ethical approval for this research. If you have any questions about this research project please do not hesitate to call me on (Phone number) or e-mail me at [hjh8@waikato.ac.nz](mailto:hjh8@waikato.ac.nz) or contact my supervisor Dr Margaret Scratchley at the University of Waikato.

.  
Thank you in advance for your time and helpful participation.

Yours truly,

Heather Holmes

## Appendix V: Consent forms

### Participant

**Title: Comparative Generational study of Barriers Faced by Students with Osteogenesis Imperfecta.**

Researcher: Heather Holmes

I \_\_\_\_\_ agree to taking part in the study and understand that all issues regarding my privacy will be adhered to by the researcher.

Participant's Name \_\_\_\_\_

Signature \_\_\_\_\_

Date \_\_\_\_\_

---

### Participant's Parents

**Title: Comparative Generational study of Barriers Faced by Students with Osteogenesis Imperfecta.**

Researcher: Heather Holmes

We/I am happy to give consent for \_\_\_\_\_ to take part in the study and understand that all issues regarding our/my child's privacy will be adhered to by the researcher.

Name: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_