

ResearchOnline@JCU

This file is part of the following reference:

Gilmour, Elaine (2014) *Stereotypy in New Zealand children who are blind: an investigation using mixed methods*. PhD thesis, James Cook University.

Access to this file is available from:

<http://researchonline.jcu.edu.au/40708/>

The author has certified to JCU that they have made a reasonable effort to gain permission and acknowledge the owner of any third party copyright material included in this document. If you believe that this is not the case, please contact

ResearchOnline@jcu.edu.au and quote
<http://researchonline.jcu.edu.au/40708/>

**Stereotypy in New Zealand Children who are Blind: An investigation
using Mixed Methods**

Thesis submitted by

Elaine GILMOUR (M.Ed.Sp.Ed. Massey University, NZ)

November 2014

for the degree of Doctor of Philosophy

in the School of Education

James Cook University

Statement on the Contributions of Others

I acknowledge the intellectual support of my supervisory team, Associate Professor Paul Pagliano and Dr Helen Boon, who provided ongoing contributions to my research design, writing, data analysis and also editorial assistance with this thesis.

I did not receive financial assistance for this thesis, however BLENNZ, The Blind and Low Vision Education Network of New Zealand, provided funding for me to attend three Australasian conferences in the course of this study program.

The research presented and reported in this thesis was conducted within the guidelines for research ethics outlined in the *National Statement on Ethical Conduct in Human Research* (2007). The proposed project received ethics clearance from the James Cook University Ethics Review Committee (approval number H3865) and was also approved by the BLENNZ Research Ethics Committee.

Signature:

Date: 12 November 2014

Acknowledgements

The inspiration, professional guidance, incredible patience and enduring positivity of my supervisor, Associate Professor Paul Pagliano at the School of Education, James Cook University, is humbly acknowledged. The time you have spent reading this work, Paul, challenging my thinking and presenting new ways of looking at aspects of this study, have allowed me to learn and grow professionally as a researcher. I shall always be grateful to you. It has been an enormous privilege to be on this journey with you beside me.

Dr Helen Boon, as my second supervisor, contributed significantly to this project, especially during the quantitative phase of the research. I thank you for your guidance, Helen.

Dr Murray Black from the Auckland University of Technology provided expertise and guidance in the analysis of the quantitative data, in the first phase of the research. Your knowledge is to be admired, Murray.

BLENNZ families and professional colleagues are to be acknowledged for their assistance, approval, agreement and openness to conducting this research. I am indebted to you all. Your interest, your willingness to be involved and your insightful contributions have made this project possible.

My very special thanks go to my family, particularly Oliver, whose unfailing love, support and technological expertise made this work possible. You had the ability to uplift me during the moments of uncertainty.

I could not have completed this thesis without the generosity of so many. My heartfelt thanks go to everyone who shared in this journey.

Dedication

I dedicate this work to the late Gwendolyn Nagel who believed in me.

Abstract

Many children who are blind regularly display stereotypic behaviour. Stereotypic behaviour is defined as persistent, predictable, pervasive, involuntary, repetitive movements of objects or body parts. The movements range from behaviours that are mild, in that there is no adverse sequelae, to problem behaviours that interfere with development and learning, to challenging behaviours that result in damage to property, injury to the child or others, and to community exclusion. Stereotypic behaviours, therefore, have the potential to seriously inhibit the child with vision impairment's educational opportunities, particularly in inclusive education settings.

A comprehensive survey of the literature determined that to date no New Zealand research into stereotypic behaviour in children who are blind has been conducted. In addition to there being no prevalence figures, no information could be found about how stereotypic behaviour might affect the education of these children when they attend inclusive education facilities in New Zealand. Also of concern was the distinct lack of information detailing which educational approaches are most effective and culturally appropriate for the New Zealand context. This lack of research information occurs within a context of educational policies and political rhetoric, namely the Education Act of 1989, Special Education 2000, and Special Education 2010. The tenor of this legislation emphasises an on-going commitment to increasing inclusive education practices while simultaneously raising educational achievement, especially for learners with special needs.

The research began with a quantitative study to provide a comprehensive, up-to-date set of prevalence figures. Fifty-nine responses were received from the 117 parents surveyed, thirty-five of whom reported stereotypic behaviour in their children. Analysis of the data offered detailed information on the prevalence, type, duration and contexts of the stereotypy. The majority of learners who are blind displayed a number of stereotypic behaviours, with those involving the hands/arms being the most common.

From the survey data, five learners were identified and qualitative case studies conducted. Data collection included interviewing the child's Resource

Teacher: Vision (RTV), examining pertinent documentation and observing the learner in a range of relevant contexts. This information was then related to the individual learner's current functioning levels in respect to the Key Competencies in the New Zealand Curriculum, especially socialisation skills.

During the progress of the research, the researcher worked in middle management in Vision Education. A number of measures were introduced in order to account for the researcher being an insider researcher. To reduce possible bias and promote reliability and validity during the quantitative phase, the survey was independently managed, and the analysis undertaken using electronic software. In the qualitative phase of the study, to assist with credibility and trustworthiness, triangulation of data occurred. This entailed the sharing of interview transcripts with all participating specialist teachers, the keeping of a journal of observations for each learner and the critical and systematic analysis of all documentation. Systematic reflection throughout this second phase aimed at ensuring that insider knowledge did not impact on the authenticity of the inquiry.

Qualitative results revealed that despite the five case study learners being enrolled in inclusive schools, they were not actually receiving an inclusive education, with the majority of their program being provided by the RTV. Also, the five learners were not functioning at age-appropriate levels; with a substantial lag identified in the two key competencies; 'Relating to Others' and 'Participating and Contributing'.

Although generalisation from the qualitative data is not possible, a number of observations and themes are notable. This research suggests that a concerning number of learners in New Zealand who are blind and who display stereotypic behaviour are being marginalised within their inclusive environments. This situation raises serious questions regarding the way the philosophy of inclusive practice, together with policies and legislation are being enacted within the New Zealand education system. It is apparent that the responsibility for some learners who are blind, and who display stereotypy, is still held by the specialist teachers who provide teaching and learning in exclusive social environments. This study indicates that in order for learners

who are blind and who display stereotypic behaviour, to reach their potential, to experience reciprocity of social interaction and personal empowerment, placement in social environments such as regular classrooms that are representative of society, is critical. Inclusive practice requires enlightened educators to develop their knowledge of this disordered behaviour in order to facilitate change. Stereotypic behaviour in children who are blind can no longer be the “elephant in the room”. While this mixed methods research helps to fill the gap in the education literature on stereotypic behaviour in New Zealand children who are blind, it also raises questions that require further research.

Publications

Gilmour, E. (2013). What is stereotypic behaviour? A brief overview of the research literature. *Journal of the South Pacific Educators in Vision Impairment*, 6(1), 71-78.

Appendices

Appendix A: Deed and Declaration of the Charitable Trust (1999)

Appendix B: Establishment of a National Database (2001)

Appendix C: National Database Booklet (2002)

Appendix D: Learner Profile (2013)

Appendix E: Learner Analysis Form (BLAF) (2013)

Appendix F: IEP Template

Appendix G: The Questionnaire

Appendix H: The Interview Schedule

Appendix I: James Cook University Ethics Approval

Appendix J: BLENNZ Ethics Approval

Appendix K: James Cook University Information/Consent Forms

Appendix L: The Pilot Survey Questionnaire

Appendix M: Stereotypic Behaviour: Information for Parents and RTVs

Appendix N: Stereotypic Behaviour: Intervention, Purpose and Guidelines

Table of Contents

Statement on the Contribution of Others.....	ii
Acknowledgements.....	iii
Dedication.....	iv
Abstract.....	v
Publications.....	viii
Appendices	ix
List of Tables.....	xviii
List of Graphs.....	xx
Chapter One	1
Painting the Picture.....	1
1.0 Introduction	1
1.1 Personal Perspective	1
1.2 Professional Perspective.....	4
1.3 Background to the Research.....	6
1.3.1 The New Zealand Setting.....	6
1.3.2 The New Zealand Disability Legislation	8
1.3.3 The New Zealand Curriculum Framework.	10
1.3.4 The BLENNZ Database	12
1.3.4.1 Placement	15
1.3.4.2 Additional Disabilities	16
1.3.4.3 Visual Conditions	16

1.3.4.4	Chronological Age.....	16
1.3.5	New Zealand Students with a Vision Concern	18
1.3.6	Research Teachers: Vision	18
1.3.7	Stereotypic Behaviour	19
1.4	Statement of the Problem	21
1.5	The Research Focus.....	23
1.6	The Conceptual Framework.....	24
1.7	Relevance and Importance of the Study	26
1.8	Benefits of the Research.....	26
1.9	Definitions.....	27
1.10	Conclusion	28
1.11	Organisation of the Thesis	29
Chapter Two		32
The Literature Review		32
2.0	Introduction	32
2.1	Chapter Overview	32
2.2	Stereotypic Behaviour: Overview	34
2.2.1	Stereotypic Behaviour: Aetiology	38
2.2.2	Stereotypic Behaviour: Aetiological Theories.....	40
2.2.3	Stereotypic Behaviour: The Impact of Vision Loss.....	42
2.3	Stereotypic Behaviour: Functionality	48
2.4	Stereotypic Behaviour in Children who are Blind: Introduction.....	52

2.4.1	Stereotypic Behaviour in Children who are Blind: Measurement Strategies	53
2.4.2	Stereotypic Behaviour in Children who are Blind: Prevalence	56
2.5	Stereotypic Behaviour in Children who are Blind: Impact on Learning	59
2.6	Intervention Strategies to Change Stereotypic Behaviour: FBA.....	63
2.6.1	Case Studies to Change Stereotypic Behaviour in Children who are Blind: Overview	65
2.6.2	Specific Studies	67
2.6.3	Divergent Theories: Is Intervention Always Required or Appropriate?	70
2.7	Implications of Mainstreaming (Inclusion) in New Zealand	72
2.8	Culturally Socially Acceptable Behaviour	74
2.9	New Zealand Studies	75
2.10	Conclusion	76
Chapter Three.....		78
The Research Design and Methods.....		78
3.0	Introduction	78
3.1	Chapter Overview	78
3.2	Theoretical Framework	80
3.2.1	Knowledge Claims	80
3.2.2	Strategies of Inquiry	82

3.3	Mixed Methods: A Definition	83
3.3.1	Mixed Methods: Overview... ..	84
3.3.2	Mixed Methods: Historical Development.....	85
3.3.3	Mixed Methods: Paradigm Wars	85
3.3.4	Mixed Methods: Stances.....	86
3.3.5	Mixed Methods: Triangulation	87
3.3.6	The Value of Mixed Methods	88
3.3.7	Mixed Methods: Design Categories	90
3.3.8	Mixed Methods: Sequential Explanatory Design.....	90
3.4	Data Collection Methods and Analysis: Survey.....	91
3.4.1	The Questionnaire.....	92
3.4.2	Specific Questions	94
3.4.3	Pilot Study.....	96
3.4.4	Sampling	97
3.4.5	Analysis of the Survey.....	98
3.5	Data Collection Method and Data Analysis: Case Study.....	99
3.5.1	Specific Methods.....	101
3.5.2	Sampling	102
3.5.3	The Interview	103
3.5.4	Review of Relevant Documentation	107
3.5.5	Non-Participant Observation	109
3.5.6	Analysis of Case Study	110
3.6	Insider Research.....	111

3.7	Ethical Issues.....	114
3.8	Assumptions and Bias.....	115
3.9	Limitations.....	116
3.10	Conclusions	117
Chapter Four.....		119
The Survey Reports		119
4.0	Introduction	119
4.1	Chapter Overview	119
4.2	Pilot Survey: Method.....	119
4.2.1	Sample.....	120
4.3	Results	121
4.3.1	Prevalence of Stereotypic Behaviour	121
4.3.2	Frequency of Stereotypic Behaviour	122
4.3.3	Duration of Stereotypic Behaviour.....	122
4.3.4	Typical Situations/Contexts of Stereotypic Behaviour.....	123
4.4	Additional Information	123
4.5	Discussion.....	124
4.6	Main Survey: Method	125
4.6.1	Sample.....	126
4.7	Results	130
4.7.1	Prevalence of Stereotypic Behaviour.....	133
4.7.2	Frequency of Stereotypic Behaviour.....	137

4.7.3	Duration of Stereotypic Behaviour.....	139
4.7.4	Typical Situations/Contexts of Stereotypic Behaviour.....	140
4.8	Chi-Square Analysis.....	142
4.8.1	Frequency: Behaviour Analysis.....	142
4.8.2	Duration: Behaviour Analysis.....	144
4.8.3	Context: Behaviour Analysis.....	148
4.9	Discussion.....	151
Chapter Five		155
The Case Study Report		155
5.0	Introduction	155
5.1	Chapter Overview	155
5.2	Method.....	155
5.2.1	Interviews.....	156
5.2.2	Observation of Each Child in the Case Studies	157
5.2.3	Relevant Documentation.....	158
5.2.4	Interpretation of the Data	158
5.3	The Cases.....	159
5.4	The Stories.....	160
5.4.1	Teri.....	160
5.4.2	Kyle	166
5.4.3	Kathryn.....	171
5.4.4	Rangi.....	176

5.4.5	Laura.....	186
5.5	Summary.....	191
5.6	Discussion.....	192
5.6.1	Current Attainment and Functioning Levels Within the New Zealand Curriculum.....	193
5.6.2	Individualised Education Plans (IEPs).....	198
5.6.3	Stereotypic Behaviour Exhibited.....	198
5.6.4	Reactions of the Peer Group to Stereotypic Behaviour Exhibited	200
5.6.5	Cultural Impact on Behavioural Expectations.....	201
5.6.6	Intervention Strategies.....	202
5.7	Conclusion	203
Chapter Six		207
6.0	Introduction	207
6.1	Chapter Overview	208
6.2	Method.....	209
6.3	Outline of the Study.....	210
6.4	Summary of the Study.....	211
6.4.1	The Quantitative Phase.....	212
6.4.2	The Qualitative Phase.....	214
6.5	Strengths of the Study.....	218
6.6	Limitations of the Study.....	219
6.7	Personal, Subjective, Objective and Emotional Challenges.....	221

6.8	Practical Implications	223
6.9	Recommendations	225
6.10	Future Research	227
6.11	Conclusion	228
References.....		230

List of Tables

Table 1.1: Students with Impaired Vision on BLENNZ National Database in relation to Visual Resource Centre Location (2009)

Table 4.1: Visual Conditions of Participants who display Stereotypic Behaviour (N=35)

Table 4.2: Visual Acuity Categories (N=59)

Table 4.3: Stereotypic Behaviour Exhibited by Individual Learners (N=59)

Table 4.4: Stereotypic Behaviour Exhibited in relation to Body Part Involved (N=194)

Table 4.5: Stereotypic Behaviour and Prevalence Descriptors (N=194)

Table 4.6: Frequency of Stereotypic Behaviour Identified through Collation of Number of Learners who Exhibit the Behaviour

Table 4.7: Duration of Stereotypic Behaviour Identified through Collation of Number of Learners who Exhibit the Behaviour

Table 4.8: Context of Stereotypic Behaviour Identified through Collation of Number of Learners who Exhibit the Behaviour

Table 4.9: Chi Squared Independence Test between Stereotypic Behaviour and Frequency of Performance (N=35)

Table 4.10: Duration of Behaviour through Collation of the Incidence of Student Behaviour

Table 4.11: Chi Squared Independence Test between Stereotypic Behaviour and Duration of Performance (N=35)

Table 4.12: Chi Square Independence Test detailing Frequency 1, Frequency 2 and Frequency 3 and 4 Combined – Stereotypic Behaviour and Duration

Table 4.13: Context and Frequencies of Behaviour

Table 4.14: Chi Squared Independence Test between Stereotypic Behaviour and Context of Performance (N=35)

Table 5.1: Key Competencies within the New Zealand Curriculum: Age Appropriate Levels and Current Attainment Levels of Case Study Participants (N=5)

Table 5.2: Stereotypic Behaviour Relevant to Body Part as Observed and Reported (N=5)

Table 5.3: Situational Context Relevant to Stereotypic Behaviour as Observed and Reported (N=5)

List of Graphs

Graph 4.1: Age and Gender of Participants (N=59)

Graph 4.2: Cultural and Ethnic Identity of Participants (N=59)

Graph 4.3: Educational Placement of Participants (N=59)

Graph 4.4: Visual Conditions of Participants (N=59)

Grade 4.5: Visual Acuities of Participants (N=59)

*Raranga ai te tuakiri o te tangata kia whatu I nga koingo o te iwi hei taupe kit e
korowai o te ngakau*

*Weave the identity of the people, sew the desires of a nation, thus to be
adorned by the cloak of the heart*

(Tuhoi Whakatauki, McLean, 2013)

Chapter One

“Painting the Picture”

1.0 Introduction

This thesis examined stereotypic behaviour in New Zealand children who were blind. This introductory chapter provides an explanation for the study, explicitly stating the problem to be considered. The focus of the research is presented and the rationale for the project is identified. The conceptual framework in respect to the use of the mixed methods of quantitative and qualitative research is discussed. Possible benefits of the project are included, based on the relevance as well as the importance of the study.

As a prelude, in the background to the study, the following contextual features are described to highlight their importance and relevance. These are: the personal and professional perspectives of the researcher; New Zealand as an inclusive setting for the education of learners who have a vision concern; the New Zealand Disability Strategy legislation, which provides the framework for services to learners with special needs; the New Zealand Curriculum Framework; BLENNZ (Blind and Low Vision Educational Network of New Zealand) database, as the primary source for information on the known population of New Zealand learners with a vision concern; and Resource Teachers: Vision (RTVs) and their role in Vision Education. Information about stereotypic behaviour is then presented in broad terms before being examined in greater detail in Chapter Two.

1.1 Personal Perspective

I have two decades of experience working in the field of educating students with vision concerns. Over this time I have come to feel considerable disquiet with a dissonance that I believe occurs between the rhetoric of my work (e.g. the policy statements of inclusion) and the reality (the actual experience of the student who is blind). My observation is that, in inclusive settings, students

who are blind and who exhibit stereotypical behaviours are excluded by their sighted students. My desire to find out more about what is happening has become my motivation for this research study. This concern is detailed later in this section, however, some important historical, contextual information is relevant in this introduction.

Children who are blind face a number of barriers to their learning. Numerous studies reiterate that 80% (Northway, 2008) of what sighted people perceive, comprehend and remember depends on the efficiency of the visual system. Children who are blind therefore may not receive sensory stimulation that provides access to variability, to flexibility and to novelty (Pagliano, 2009). They, therefore, require specialist non-visual teaching and learning approaches. They need to be provided with this through team collaboration that promotes positive outcomes (Wolffe, 2006). Much has changed over time for this sector of the population, not only legislative changes but also changes in resourcing frameworks, teaching styles, teacher education, student diversity, social demographics and technological innovations. How these changes have impacted on learners is also of interest to me.

In New Zealand, locating learners who are blind in regular settings began somewhat tentatively in the late 1980s, largely driven by proactive parents. Learning beside the peer group was an attractive proposition for all the same reasons it is today. Professional leadership in the earliest of these placements was my responsibility – it seemed a sensible proposition, very straightforward and, with naivety, no barrier was going to be too great. The alternative of relocating learners from their homes to a residential special school for the blind seemed very harsh and contradicted all that was being promoted about inclusive education. Little was discussed about how learners who are blind would integrate within the sighted peer group. The assumption was made that a mainstream placement would mean integration into the sighted world, perhaps naturally just by being there (Hatlen, 1996; Sapp & Hatlen, 2010). This was not seen to be the reality. Hatlen (1996) and Sapp

and Hatlen (2010), through their experiences at Texas School for the Blind, soon advocated for an additional parallel curriculum to contribute to new learning. This was referred to as the Expanded Core Curriculum, which would provide explicit skill development in certain areas to provide learners who are blind with additional assistance in order for them to integrate more successfully. Although not seen as a compensatory curriculum, the document was designed to complement the regular curriculum and is still of high importance. This was, and continues to be thought of as a solution to assisting learners who are blind to experience positive outcomes, especially when they are in inclusive settings (Sapp & Hatlen, 2010).

Notwithstanding acquiring additional skills identified in this curriculum, learners who are blind did not always behave in a way that was perceived to be culturally socially acceptable in their inclusive setting. I have vivid memories of Samuel, who would vigorously rock backwards and forwards when on the mat, while everyone was supposed to sit still. Louise would rub, press or poke her eyes when seated at her table area while others, with a frown from the class teacher, sat with their arms folded. Thomas would find a sunny spot in the classroom and twirl or flick his fingers in front of his eyes while his classmates were moving between activities. Richard would rub objects over his face or lick them when being handed a “show and tell” item to explore. James would spin at morning tea for the entire 20-minute break while his classmates played Four Square or Handball. Head rolling and jumping up and down while eating lunch was a favourite activity for Lynnette, despite the duty teacher insisting that everyone sit still while they ate their lunch. Eleanor sniffed people so when a classmate, parent or visitor came near her, she would reach out, hold onto the individual and sniff them. Listening to the stories of such learners became an expansion of my journey as a vision educator. Very few people seemed to be willing to publicly acknowledge that these stereotypical behaviours were problematic, nor did teachers seem to have concrete strategies in place to deal with them. For me these behaviours became “the elephant in the room”.

1.2 Professional Perspective

As a professional in this field, my view of the world and my beliefs are influenced by experiences, people and knowledge gained over time. Upon self-reflection, it is quite evident that I have an inherent desire to make a positive difference in the lives of others, especially those learners who are blind and to whom I have responsibilities. With the adoption of the mainstreaming policy in New Zealand schools in the 1980s, the initial euphoria of students who were blind learning beside their sighted peers quickly passed. A substantial number of students of this generation became socially isolated, perceived as misfits, lonely and, in many instances, unemployable. The key role of the Itinerant Teaching Service was, and is, to work in mainstream schools teaching the Expanded Core Curriculum and to facilitate inclusion into the New Zealand school system. The reality is quite the opposite. Learners who are blind are extraordinarily well supported, yet few learners are perceived as being well-integrated or well-adjusted, socially-accepted young people. Be it through lack of social stimulation/social skills, inappropriate programs, unattainable goals, unrealistic expectations, insufficient professional development, lack of role models, or a myriad of others issues, these learners are, in my professional opinion, in de facto environments that do not foster an inclusive approach to learning.

It is widely perceived that many learners who are blind display stereotypy. For me, this behaviour has been a concern for many years. Firstly, the behaviour itself is disturbing and it continues to disturb me. Similarly, it is disturbing to see the negative reaction of the peer group in withdrawing from working beside or socialising with learners who are blind. Programs such as that of Reverse Integration, whereby mainstream classes spent a week at the campus school, working beside learners who were blind who displayed stereotypic behaviour, highlighted further just how disturbing these behaviours were for learners in regular settings. The plea of “make her stop” from one

visiting student, who observed the self-injurious behaviour of head banging, was poignant.

In the 2010 Consultation Round undertaken by BLENNZ prior to the development of the Three-Year Strategic Planning Cycle (a Ministry of Education requirement), parents, *whānau* (extended family), teachers and stakeholders were asked to offer their opinions and thoughts regarding the direction of service delivery in vision education. The most memorable comments came from parents when they said, “I want my child to have a friend” (BLENNZ Board Report, 2010). This statement has affected me profoundly.

My informal requests for assistance from colleagues in understanding the inappropriate behaviour met with little reaction. Suggestions from an Orientation and Mobility Instructor, such as sending the child for a run, seemed simplistic. Others commented that this was “Just what blind kids (sic) do”. Attempts to discuss the behaviour with the children concerned brought responses such as:

- “I like it” (spinning – James, aged 10)
- “Can you see me?” (hand weaving and head rotation – Lucy, aged 8)
- “It’s exciting” (rocking – Natasha, aged 7)
- “I don’t know why I do it but it’s cool” (light gazing – Anthony, aged 10)
- “Go away” (rocking – Riya, aged 13)
- “I’m tired” (eye rubbing – Charles, aged 14)

For some learners who are blind, the behaviours are evident as a form of self-engagement (Bunning, 1998; Singer, 2009). Perhaps this was the reality for these children.

Reactions from the sighted peer group include total withdrawal, refusal to be a sighted guide, refusal to be a working buddy, nervous laughter, attempts to physically stop the behaviour being exhibited, and questioning the supervising adult as to why the behaviour is occurring.

Mainstreaming, as an inclusive practice, is here to stay. As RTVs, our responsibilities are to work with mainstream teachers to facilitate effective programs for learners who are blind. This approach is not just about equity of access to the curriculum, but it is about helping learners who are blind and display stereotypy to take their place as contributing members of society, while they are at school and into adulthood.

As the world moves towards acceptability of diversity, it is my hope that understanding more about these types of behaviours will provide greater opportunities for learners who are blind to be the best they can be in leading lives to the full. For me, that is the catalyst for my research. I perceive there are problems in inclusive settings for learners who are blind. Stereotypic behaviour is one such concern.

1.3 Background to the Research

1.3.1 The New Zealand Setting

New Zealand, *Aotearoa*, is situated in the South Pacific. The country is presumed to have been discovered in the thirteenth century by the ancestors of the *Māori*, the *tangata whenua*, who are considered to be the indigenous people of New Zealand. Large scale European settlement began following the signing of the Treaty of Waitangi in the 1840s by the British Crown and by *Māori* chiefs. New Zealand has progressed from being a colonial outpost to a multicultural Pacific nation and is increasingly international in character. This has occurred through information technology, through trade and through

access to global employment markets. Education is a critical factor in the process of developing skills and innovation to compete globally.

Demographically New Zealand is a similar size to the United Kingdom and has a population of 4.4 million. The 2013 census figures report that the population is made up of European (68%), *Māori* (15%), Asian (10%), and *Pasifika* (7%). Significant variations occur in these percentages when considering rural and urban areas as well as the North and South Island statistics. The education system for New Zealand's multicultural community is considered world class by national standards and is based on evidence and research that provides both traditional and innovative practices. It is student-centred with a focus on all students being able to develop their potential, academically and vocationally, as lifelong learners. The system reflects the uniqueness and diversity of society, with *Ka Hikitea* (Ministry of Education, 2008) and The *Pasifika* Education Plan (Ministry of Education, 2009) as education strategies woven throughout all planning.

The majority of learners in New Zealand who have special needs, including those who are blind, attend their local school. This approach reflects international trends in the education of students with special educational needs, whereby inclusion has become the dominant issue for this sector of the population and, as a concept, is central to contemporary pedagogic discourse (Mitchell, 2010). Inclusive education, both internationally and nationally, has been described as a social movement in education (Slee & Allan, 2005). Broadly, inclusion can be defined as “an ongoing process aimed at offering quality education for all, while respecting diversity and the different needs and abilities, characteristics and learning expectations of the students and communities, eliminating all forms of discrimination” (UNESCO, 2009, p. 12). It is about overcoming barriers to participation and learning for those who have historically been marginalised (Mittler, 2000). The notion of inclusion is therefore not unproblematic for it is complex, both conceptually and practically (Hegarty, 2001; Kearney, 2009; Mitchell, 2010; Slee & Allan, 2005). In New

Zealand, as with all countries, inclusive practice reflects the relationships among the “social, political, economic, cultural and historical contexts” that are present at any one time (Mitchell, 2010, p. 123). It questions the aims of education, the purposes of schools, the nature of the curriculum, approaches to assessment and accommodation of diversity (Mitchell, 2010; Mittler, 2000).

1.3.2 The New Zealand Disability Legislation

In New Zealand, following the ratification of the United Nations Convention on the Rights of Disabled (Article 24, 2006) in 2010, there has been a significant commitment to inclusive education. Although there is some ambiguity in this article (Mitchell, 2010), this commitment required the amendment of government policies and societal change, especially for leaders in education, away from the historical norms of segregated placements and exclusive practices for learners with special needs. It has required a focus on collaborative practices that embrace a wider range of student-centred pedagogy. There is now a vast body of international research that addresses the issue of inclusion for learners with special needs. This incorporates writings in respect of the concept of inclusive education and case studies with mixed outcomes, those with negative outcomes (depending upon whether or not this was the perception of the teacher, the parent or the student), and those with positive findings (e.g., Lindsay, 2003). However, overall it is generally acknowledged that inclusive education is not a trend but a basic human right (Artiles & Dyson, 2005). Stated simply, it is about learners receiving their education in age-appropriate classrooms having the appropriate supplementary aids and support services (Lipsky & Gartner, 1999). Hegarty (2001) expands on this concept with a more holistic view and writes that inclusion is about developing young people’s potential and equipping them for adult life in appropriate settings. The United Kingdom Office for Standards in Education, Children’s Services and Skills report (OFSTED, 2006) refers to inclusion as quality placement that ensures the best outcomes for learners, reminding educators of student-centred practice. This suggests that physical access does not necessarily imply effective

instructional access. The OFSTED report states that inclusion is not about excellence and it is not always about total inclusion in regular settings. Therefore, inclusive practice is a diverse concept, but it encompasses meeting the unique needs of all learners in the least restrictive environment (Mitchell, 2010) and developing skills for independence (BLENNZ Charter, 2012).

For learners in New Zealand who are blind, the BLENNZ Charter (2012) provides the supportive framework for service delivery in education. The Charter is aligned with government policies and priorities together with the New Zealand Disability Strategy, which provides the foundation for an inclusive society. In New Zealand, all legislation is guided by *Te Tiriti o Waitangi* (Treaty of Waitangi) and legislation related to education is guided by the Ministry of Education Statement of Intent (Ministry of Education, 2007). The outcome of this legislation is that policy recognises the bicultural foundation of *Aotearoa* and schools are required to be proactive in meeting the needs and aspirations of *Māori* through consultation. This is about strengthening relationships to improve educational outcomes for the *tangata whenua*.

The BLENNZ Charter aims at removing barriers for both *Māori* and *Pakeha* (European) learners who have a vision concern and to aspire to show the principles of best practice in blindness education. This Charter presents challenges for specialist teachers who strive to provide equitable access to education for learners who are blind, and likewise it presents challenges for mainstream teachers who must implement applicable and valuable learning experiences for the diverse group of learners located in regular settings (Cigman, 2007; Thomas & Loxley, 2001). Most practitioners concur that including learners who are blind in mainstream settings in New Zealand may be problematic despite intentions of effective pedagogy. When learners who are blind exhibit disordered behaviour, the reality of learning beside the sighted peer group presents further challenges.

1.3.3 The New Zealand Curriculum Framework

The New Zealand Ministry of Education's Curriculum document (Ministry of Education, 2007) identifies values of excellence, innovation, inquiry, curiosity, diversity, equity, community and participation, ecological sustainability and integrity. These values are to be "encouraged, modelled and explored" (p. 10). The document presents eight statements that set out the principles that embody the beliefs which underpin school decision-making. These put the student at the centre of teaching and learning, asserting that the curriculum will challenge and engage individuals while affirming the unique identity of New Zealand. These principles are those of:

- high expectations, to empower all to achieve personal excellence
- an acknowledgement of the Treaty of Waitangi and the bicultural nature of New Zealand
- cultural diversity that reflects and values the histories/traditions of all people
- learning to learn, which encourages self-reflection
- community engagement that is meaningful and connected to the wider lives of all
- coherence that offers a broad education to open future learning pathways
- future focus, which encourages issues such as sustainability, citizenship, enterprise and globalisation.

Inclusion is the eighth principal, and states: "The curriculum is non-sexist, non-racist and non-discriminatory; it ensures that student identities, languages, abilities and talents are recognised and affirmed and that learning needs are addressed." (p. 10)

The document identifies five key competencies that provide the capabilities for living and lifelong learning, stating that these develop in social contexts and are “shaped by interactions with people, places, ideas and things” (p. 12). The statement adds that these contexts “are increasingly wide ranging and complex” (p.12). Knowledge of these concepts is important for all educators who aspire to best practice.

The first of the competencies is Thinking, which is about using creative, critical and metacognitive processes to make sense of information, experiences and ideas (p. 9). Students who are competent in this way seek knowledge, reflect on their own learning, are intuitive, ask questions and challenge perceptions and assumptions.

The second competency is Using Language, Symbols and Texts, which is about making meaning of knowledge codes. The purpose of this competency is to enable a student to represent and communicate information, experiences and ideas. To be skilled in this area, learners have the ability “to interpret and use words, numbers, images, movement, metaphor and technologies in a range of contexts” (p. 12).

Managing Self is the third competency and is integral to self-assessment in that it is about self-motivation. Those who manage themselves are thought to be “enterprising, resourceful, reliant and resilient” (p. 12).

The fourth competency is entitled Relating to Others, which is about interacting effectively with a range of people. It is about listening, recognising others’ viewpoints, negotiating and sharing ideas. To be competent in this area means students are open to learning, with an awareness of how their words and actions affect others.

Participating and Contributing is the fifth key competency. This refers to having active involvement in communities, whether they are local, national or global. It is about being a group member, connecting with others and creating opportunities to foster connections; this suggests competency as “a sense of belonging and the confidence to participate within new contexts” (p. 13).

The Curriculum Document then identifies learning areas. These are labelled English; The Arts; Health and Physical Education; Learning Languages; Mathematics and Statistics; Science; Social Sciences; and Technology. All schools are charged with weaving the values, key competencies and learning areas into their curriculum. Guidelines are provided for assessment across curriculum levels. These relate to the number of years learners have been at school, with achievement objectives prescribed for each level.

For learners who are blind, the policy is legislated, values and principles are firmly documented, the intention is evident and the guidelines are presented. It is no different than for the sighted peer group.

1.3.4 The BLENNZ Database

To access students who are blind and their families, it was necessary to establish communication and dialogue with the Management of BLENNZ. This in turn facilitated access to the Vision Education Agency Charitable Trust, established in 1999, and subsequent documentation, whose responsibilities include:

- developing, reviewing and ensuring the aspirations of the National Plan for Learners, who are Blind and Vision Impaired are achieved
- developing policy and strategies to suit the needs and requirements of the blind and vision impaired

- developing and maintaining systems to ensure an up-to-date database of all blind and vision impaired learners is maintained

(Deed and Declaration of Charitable Trust, 1999, 4.1, refer Appendix A).

In January 2001, a Discussion Paper was presented in order to begin the process of “establishment of a National Database”, a requirement of the Ministry of Education (refer Appendix B). Following a pilot study that took place in two regions of the country and subsequent refinements, data collection was undertaken nationally with analysis commencing in 2002. Termly reviews and Information Booklets have since been amended, with information now being updated in the form of a Learner Profile Booklet (refer Appendix C); this booklet has been used since February 2009, and is amended annually as appropriate.

It was, therefore, possible to access the data required for this study using the following criteria:

- Visual Resource Centre location
- Total number of students on database

This information is presented in Table 1.1.

Table 1.1

Students with Vision Impairment on BLENNZ National Database in Relation to Visual Resource Centre Location (2009)

Regional Vision Centres	On Database
Auckland Centre	328
Hamilton Centre	103
Tauranga Centre	51
Gisborne Centre	31
Napier Centre	45
Taranaki Centre	48
Palmerston Centre	98
Wellington Centre	140
Nelson Centre	45
Christchurch Centre	256
Otago Centre	22
Southland Centre	28
Homai Campus School	41
TOTAL	1236

Accessing the data further using age and medium descriptors, there were 1236 students on the database that were known students with a vision impairment in New Zealand from birth to 21 years. According to the BLENNZ database in 2009 there were 134 Braille users of whom 128 were children aged 5 to 18 years. The balance of 6 students, to make up the 134, were those over 18 years of age.

This information presupposes that, at the time of this study, there were 128 possible parents/caregivers of school-aged students who could be surveyed. Further distinguishing characteristics in respect to this group of learners are: placement, additional disabilities, visual conditions and chronological age.

1.3.4.1 Placement

A number of educational settings are available to students who are blind aged between five and 18 in New Zealand. These include:

- Mainstream setting of a regular classroom
- Special school for students with additional disabilities
- Satellite class placement within regular school
- Homai Campus School
- Resource room in regular school
- Learning support room in regular school
- Special Needs Unit in regular school
- Home school
- Correspondence School

The placement of the child has an impact on the educational program offered; teacher–pupil ratio; the role of the RTV; resourcing; and social interaction opportunities.

1.3.4.2 Additional Disabilities

The 2013 BLENNZ National Database Learner Booklet (refer Appendix D) requires parents to indicate the communication mode (1.7), visual status and the existence of additional disabilities in their child (2.1) (Appendix D). No definitions are provided in relation to these three questions, although qualitative data are requested in relation to “additional disabilities”. This variable is considered to be particularly relevant in relation to the discussion of prevalence. Berkson, Tupa and Sherman’s (2001) research discusses the prevalence of stereotypy in individuals who are blind and who have developmental disabilities, recording that stereotypic behaviours are evident in 34–82% of this population. This variable is also pertinent to discussions of the major aetiological theories and approaches as detailed by Troster, Brambring, and Beelmann (1991b) and Singer (2009), especially the behavioural model. In this model, stereotypic behaviour is thought to emerge as part of normal child development. When development is arrested in some way for some children, stereotypy is maintained (Murdoch, 2013; Thelen, 1996).

1.3.4.3 Visual Conditions

A number of visual conditions are listed in the National Database Booklet, drawn from the Learner Booklet. As children with particular visual conditions are considered to be more likely to exhibit and/or maintain particular stereotypic behaviours, information on visual conditions is also regarded as relevant in this research (Jan, Good, Freeman, & Espezel, 1994; McHugh & Lieberman, 2003). The relevance of visual conditions continue to be addressed in more recent research, especially Murdoch’s (2013) study, where particular visual diagnoses are associated with certain stereotypes.

1.3.4.4 Chronological Age

In Developmental Theory (Troster, Brambring, & Beelmann, 1991a; Singer, 2009) chronological age is of interest, especially in relation to the aetiology of

the behaviour. In Developmental Theory the assumption is that with neuromuscular maturation behaviours may dissipate and emerge as more complex behaviour (Symons, 2000; Thelen, 1979; Wolff, 1968). This theory is discussed in more detail later in this chapter.

In order for a learner to be enrolled with BLENNZ and receive its specialist services, ophthalmic data are required to support information received from a referral agency or individual. A Functional Vision Assessment is undertaken for a referred child with established criteria for enrolment detailed. This relates to children with visual acuities equal to or less than 6/15 binocularly when corrected, to those with cortical/cerebral vision impairment and to those with a deteriorating or degenerative visual diagnosis. These criteria include legal blindness, as identified by the World Health Organisation; a visual acuity of less than 3/60 binocularly with corrective aids; or horizontal field restriction of less than 20 degrees. Recommendations for enrolment on the database are made when the specific criteria are met. The learner is then formally enrolled using a national committee process and relevant information that has been provided in consultation with the family/*whānau*/school is logged into the database.

The database has now transitioned to an electronic platform that is used as a means of accessing learner information. Details that can be requested include demographics, visual disorders, visual functioning levels, educational functioning levels in terms of the key competencies, educational placement, year levels and external examination results. Prior to this transition, when changes occurred for a learner in respect of family circumstances, year level, school placement and school leaver information, details were not always amended in a timely manner. Diagnosis details, functioning levels and media requirements have always been assured, therefore the BLENNZ database has, and continues to be considered by the New Zealand Ministry of Education, as accurate and reliable with quality content.

1.3.5 New Zealand Students with a Vision Concern

In 2013, 97% of known learners in New Zealand who had a significant vision concern were living at home and being educated in their local community (BLENNZ, Charter 2012). In 2012, 1496 identified learners aged between birth and 21 years were recorded on the BLENNZ database. These learners could be categorised as blind (4.8%), deaf/blind (1%), low vision (46.4%), or as having additional needs (47.8%). Service delivery is determined by need in relation to visual functioning, educational placement, educational progress, transitional requirements and technology needs. BLENNZ learner profiles are now used to analyse changing needs (Appendix E). This directly affects the services an individual student receives, however learners who access the curricula through the alternative medium of braille and are in mainstream placement, receive the highest level of support.

1.3.6 Resource Teachers: Vision

Specialist itinerant teachers in vision are funded through the Ministry of Education to deliver specialised support to learners with vision concerns during their years in school. They are referred to as Resource Teachers: Vision (RTVs) and are charged with providing service delivery to ensure access to the curricula and to facilitate positive learner outcomes. All teachers working as RTVs are expected to be experienced early childhood, primary or secondary teachers with postgraduate qualifications in Vision Education. Job description details refer to having the ability to demonstrate highly effective teaching techniques that provide strong motivation for learners, with expectations that value and promote learning. In 2013, 87 RTVs were employed in New Zealand, with 95% qualified in the Vision Education field. All but four were female, and ethnicities were predominantly European (97%). One teacher was of *Māori* ancestry and one was of Asian origin.

All learners who are blind have an Individualised Education Plan (IEP) (Appendix F), which identifies development across the key competencies of the New Zealand National Curriculum (Ministry of Education, 2007). In order to establish the current functioning levels of these learners, a range of formative and summative assessments are undertaken. The results of these assessments are recorded in the IEP documents. The documents also include strategies for personal growth and identify planning/management for service delivery. The responsibility for these documents has previously rested with the Ministry of Education personnel but now, as the key worker for this group of learners, it is the RTV who creates and evaluates the plans.

1.3.7 Stereotypic Behaviour

There are no figures on the BLENNZ Database that refer to whether or not the learners display stereotypy. In broad terms, stereotypy refers to repetitive body movements or repetitive movements of objects by an individual that are persistent, pervasive (Lowry & Sovner, 1991), and predictable in form, amplitude and location (Jankovic, Madisetty, & Vuong, 2004). This includes inflexible adherence to non-functional behavioural rituals and routines as well as behaviour that is a “persistent preoccupation with stimuli” (Kennedy, 2007, p. 194). They may appear to have little functional significance and are considered irrelevant to activities outside the individual (Bunning, 1998; Rapp & Vollmer, 2005). They are referred to as self-stimulatory and/or self-perpetuating and are considered operant responses maintained by automatic positive reinforcement. The behaviours, when they result in adverse sequelae, may interfere with learning and development (Rapp & Vollmer, 2005). When stereotypic behaviour lacks a clear social function and is insensitive to potentially competing social variables, it is considered a problem behaviour.

Stereotypic behaviour may also be considered a core component of symptoms for a number of disorders including Tourettes Syndrome, Autism, Parkinson’s and Huntington’s Disease (Langen, Durston, Kas, Engeland, &

Staal, 2011). However, there continues to be a somewhat equivocal picture of what constitutes stereotypic behaviour. There is agreement on the lack of functional significance and the repetitive nature of the behaviour, but there is now some ambiguity documented about the aspect of invariance of the behaviour. This relates to the context and salience of the behaviour in respect to whether it is deemed problematic. This discussion is based on the understanding that some repetitive behaviours are displayed by typically developing children in particular contexts, whereas the same repetitive behaviour may be deemed problematic depending upon the form it takes, the duration and the context. Rapp and Vollmer (2005) explain this further, stating that when repetitive behaviours are displayed across a variety of contexts, in conjunction with multiple response forms and in a manner that is highly salient to others in the environment, they may be referred to as stereotypic.

More recent research recommends dividing stereotypies into distinct groups of primary and secondary behaviours based on whether they are considered to have a neurological or developmental context (Barry, Baird, Lascelles, Bunton, & Hedderly, 2011). Primary stereotypies involve the motor system and include rocking, finger drumming, waving, hand/arm flapping – all of which classically remain stable or regress with age. They occur in typically developing children. Secondary stereotypies are considered to exist in the context of developmental delay and/or disorder. They are behaviours that are less likely to regress; they become fixed in a child's repertoire and may also be more diverse. Langen et al., (2011) refer to somewhat similar groupings and categorisation, suggesting repetitive behaviours may be thought of as being of a lower level (motor) and a higher level (cognitive). They add that this may oversimplify or falsely suggest differentiation between behaviours.

Understanding the theoretical approaches is pivotal when considering this behaviour. The four major theoretical approaches thought to be relevant to explaining stereotypical behaviour, as detailed by Singer (2009) and Troster et al., (1991b), are:

1. The Behaviorist Approach – the stereotypic behaviour is thought to be learned and then maintained by a continuing level of environmental reinforcement.
2. The Developmental Approach – the stereotypic behaviour is thought to be a typical part of maturation. The child initially repeats an action until it is mastered, then the action recedes once the child moves to the next developmental stage. For some children with certain conditions, the repetitive action however, does not recede.
3. The Arousal-Modulation Approach – the stereotypic behaviour is characterised in relation to arousal levels and is thought to provide a homeostatic function. Here the assumption is that children, who have a limited repertoire of behaviour to regulate arousal, and who receive inadequate stimulation from their environment, employ stereotypies to maintain equilibrium.
4. The Neurobiological Approach – In this theoretical approach the assumption is that the stereotypic behaviour is controlled by the central nervous system. The behaviour is thought to be an expression of neuronal or neurochemical processes and is triggered by intrinsic oscillators, then maintained when sensory feedback is not present. Flexible behaviours require the brain to respond to neuronal connections; however when this does not occur rigidity of behaviours is reinforced and become repetitive.

1.4 Statement of the Problem

Little is known about the ways stereotypy influences learning and social outcomes for children who are blind. The behaviour may be considered disordered (Kauffman, 1997; Singer, 2009) depending upon age, context, frequency and duration. It is of particular concern when it involves damage to self, other people or property or when it interferes with engagement in learning.

Therefore, this study aimed at examining stereotypic behaviour in children who are blind in New Zealand and to find out what is happening for these children in respect to their learning and social development. The children are identified on the BLENNZ database.

Information about stereotypy for this group of learners within the context of inclusive education in New Zealand is largely unknown. In particular, little is known about how or whether stereotypy affects the individual's ability to learn, to progress in an age appropriate manner and to successfully relate to others.

The following questions illustrate the focus of the research and clarify the objectives of this study:

- How prevalent is stereotypic behaviour in children who are blind in New Zealand?
- What is the type of stereotypic behaviour patterns in children who are blind in New Zealand?
- What is the extent of stereotypic behaviour patterns in children who are blind in New Zealand?
- How prevalent is stereotypy in children who are blind across different age categories?
- How do learners in New Zealand who are blind acquire culturally appropriate social skills?
- How is stereotypy in New Zealand managed by both parents and educators?

- What contexts are used for service delivery in New Zealand for children who are blind and who display stereotypic behaviour?
- What are the achievement levels in children who are blind who display stereotypy in relation to year and curriculum levels, with reference to the New Zealand Curriculum Guidelines?
- What can international comparisons tell us about the prevalence and context in respect to the learning and the acquisition of social skills for children in New Zealand who are blind who display stereotypic behaviour

1.5 The Research Focus

The study investigated the prevalence, type and context of stereotypic behaviour in New Zealand by examining information requested and supplied from parents whose children were enrolled on the national database, as collated originally by the Vision Education Agency of New Zealand and now maintained by BLENZ. The parent questionnaire was based on the Bielefeld Parent Questionnaire (Brambring, Dobbsaw, Klee, Obermann, & Troster, 1987) with stereotypic behaviours listed, using material such as Eichel's Taxonomy of Blindisms (Eichel, 1979) and Pagliano's descriptors of stereotypic behaviour (Pagliano, 2001). A parent survey is practical when considering a broad geographical area but it is acknowledged that it is not possible to eliminate bias and ensure objectivity. However, it is parents who are most likely to have both an overview of the diverse situations in which the stereotypies occur and the varied forms they take (Troster et al., 1991b). The parents gave a general outline of the type and extent of the behaviour. In defining the behaviour, parents could indicate which stereotyped behaviour they had observed from a list provided. Parents were asked to identify how frequently the behaviours occurred, and in which situational contexts. Frequency time frames and contexts were identified in the survey document. Assurances of confidentiality and anonymity for those completing the survey were critical to minimise subjectivity.

Further in-depth analysis of selected case studies identified from the survey aimed at providing information concerning the reality of the behaviour and any intervention strategies implemented to change the problem behaviour. By interviewing the RTVs of the students identified in the case studies, observing the learners in familiar contexts, reviewing the IEP of each student together with relevant documentation, I aimed at establishing information about what was happening for these children who exhibit stereotypic behaviour in respect to their learning and in their social skills acquisition. Therefore, the study, using a post-positivist mixed methods approach, sought to quantify the prevalence of the disordered behaviour among children who are blind in New Zealand, and then discuss what was happening in respect to the child's learning by examining the evidence in a constructivist manner.

1.6 The Conceptual Framework

Survey and case study strategies were used to conduct this empirical social research project. According to Babbie (2001), the quantitative survey had three objectives. These were: description, explanation and exploration. A thorough statistical analysis of the percentage of the known student population who are blind, identified on the BLENNZ database, and who displayed the full spectrum of stereotypic behaviour, was sought in relation to number, type, context and prevalence. The distribution of these stereotypic behaviours would then be compared to that of the total population of students who are blind. The second objective, making explanatory assertions about this population sample, involved reviewing this analysis in relation to number, type, context and prevalence. Descriptors of chronological age, culture, visual condition, the existence of additional disabilities, plus educational level and setting, required consideration. The third objective, exploration, aimed at providing a representative sample from where the case studies were drawn. The units of analysis were students who are blind who displayed the disordered behaviour and whose educational placement was in a mainstream

setting. The information obtained was aggregated, and a sample size of 5% of the survey respondents whose child displayed the behaviour was obtained.

The purpose of the case studies was to give a thick, rich, in-depth description of what was happening in inclusive educational settings for the child who displayed stereotypic behaviour and is blind. By referring to this research question, the aim was to investigate the relationship between the aetiology of the behaviour, its function, the conditions that elicit and maintain the behaviour, the learning levels, and on the social environment in which the student who is blind – the unit of analysis – was placed. The study intended to investigate these behaviours qualitatively using teacher information, observations and documentation. This was describing, understanding and explaining the behaviour through naturalistic inquiry in a real-life context, as advocated by Yin (1989, 2009).

The case study candidates were selected through the results of the postal survey, and were determined by the following:

- Existence and prevalence of stereotypic behaviour currently displayed
- Educational setting location
- Experience and willingness of current RTV to assist in the study
- Education setting level
- Availability of documentation.

Internal validity was assisted by triangulating the data using the following resources:

- Documentation
- Interviews with RTVs

- Non-participant observation.

1.7 Relevance and Importance of the Study

No studies of stereotypic behaviour in children who are blind in New Zealand have been undertaken or published. It was considered timely to begin to develop a cohesive body of knowledge concerning stereotypy in children who are blind, in line with documented international research.

Although blindness is a low-incidence disability in New Zealand, in 2008, there were 11,500 people with vision impairment in New Zealand (RNZFB, 2008), 128 of whom were classified as school-aged children who were Braille users. Stereotypic behaviour has been evident in this group of children who are blind across a range of educational settings and the behaviour is a cause for concern for both families and educators when it interferes with inclusion and learning.

This study is very much a preliminary step in developing professional knowledge concerning this particular behavioural issue relevant to children who are blind. It is underpinned by integrated theoretical beliefs, which incorporate a number of major theories that offer explanations of why stereotypic behaviour develops and how it is maintained.

1.8 Benefits of the Research

Locally, the study was deemed to be important since it would provide new knowledge and information to professionals and parents who currently have limited knowledge of stereotypy in students who are blind in New Zealand. Through data analysis and examination of case studies, it would be possible for educators and families to learn more, to challenge beliefs, and become

critical thinkers about the impact and the management of stereotypic behavioural concerns.

More generally, this study aimed at engendering interest and creating a precedent for longitudinal studies of stereotypic behaviour in children who are blind in New Zealand. Research of this nature aimed at contributing better learning outcomes for New Zealand's children who are blind.

1.9 Definitions

The following definitions are used throughout this study:

Blindness

Legal blindness is visual acuity less than 3/60 binocularly with corrective aids or horizontal field restriction of less than 20 degrees (World Health Organisation, 2012).

Stereotypic Behaviour

Stereotypic behaviour refers to repetitive body movements or repetitive movements of objects by an individual. These motor responses are involuntary, repetitive sequences of fixed behaviours that are persistent, predictable and pervasive (Lowry & Sovner, 1991; Singer, 2009).

Inclusion

Inclusion is the philosophy that throughout life all people have an equal right to be involved with their peers in age-appropriate activities (Miller & Schleim, 2006).

Inclusive Education

At a school and classroom level, inclusive education implies that all children attend their neighbourhood school and they are the responsibility of the

classroom teacher who works in collaboration with parents/caregivers and a range of professionals (Kearney, 2009).

Culturally Socially Acceptable Behaviour

Societies are characterised by both culture and social structure. Culture establishes the goals for those in a given society, while social structure provides the means for how people achieve their goals. In a well-integrated society, people use what is considered to be appropriate means to achieve their goal. This may be an informal understanding of the social norms whereby expectations of the community are conventionally guided (Nind & Kellett, 2002).

1.10 Conclusion

Stereotypic behaviour is displayed by some learners who are blind who are educated in inclusive environments. Particular stereotypies appear to be more frequent in this sector of the population. The behaviours have an apparent function that involves self-stimulation of some kind. Understanding the range of theoretical perspectives about the aetiology of the behaviour provides an insight into the functionality of the behaviour. This in turn assists with providing guidelines to implement intervention strategies to change the behaviour to behaviour that is more culturally and socially acceptable.

Although New Zealand has a philosophy and matching legislation about inclusive practice for learners with special education needs, the reality is somewhat at odds with this rhetoric. The expectation that learners who are blind and who are in inclusive environments will conduct themselves in a socially appropriate manner seems reasonable from a sighted person's perspective. However, for learners who are blind, because of an absence of visual corroborative evidence, truly inclusive social environments at school are not easy to achieve. For learners who are blind who display so called

‘disordered behaviour’, the challenges presented during inclusion are exacerbated. The reality is that some learners are being educated in exclusive settings, apart from their peer group, integration is infrequent and societal expectations are at odds with inclusive philosophical tenets.

The picture painted for New Zealand children lacks definition and colour for it does not provide the realities of the sighted social world for some children who are blind. Understanding the functionality of stereotypic behaviour and its contextual relevance, then considering changing the behaviour to that which is more culturally socially acceptable, is the beginning. Learning beside others is more likely to follow. Philosophically, society embraces diversity, but perhaps a project such as this identifies the lived reality.

1.11 Organisation of the Thesis

The thesis is presented in six chapters that are distinct yet are interconnected as the project unfolds.

Chapter One provides an insight into my professional life and the motivation that has led me to undertake this research project. A discussion is presented on how learners who are blind in New Zealand receive their education; who they are; who supports them; and the framework for the content of their curricula. Reference is made to the complexities that are evident for those without vision and who display stereotypic behaviour. The research focus is explained, the rationale identified and the possible benefits of the research are discussed. The chapter concludes with a description of the thesis structure.

Chapter Two presents a review of the literature from an international perspective. Definitions are presented and the characteristics of stereotypy and the issues of functionality are discussed. Aetiology and aetiological theories are presented. The impact of stereotypic behaviour on learning is described. A number of case studies are documented, including information about the use of Functional Behaviour Assessment as an intervention strategy. Discussion is included about the implications of mainstreaming and what is expected in respect to culturally socially acceptable behaviour. The chapter draws to a conclusion by referring to the lack of current research about stereotypic behaviour in children who are blind.

Chapter Three provides the research philosophy, methodology and methods used in this project. As this is a mixed methods research methodology, an explanation of the quantitative phase of the survey is provided first, followed by the qualitative phase of the case studies. Data collection and analysis are clearly discussed and ethical issues, assumptions, biases and limitations are recorded. Discussion is also included on the role of the insider researcher.

Chapter Four presents the analysis of the first phase of the project as a survey report. The type, prevalence, duration and situational contexts of stereotyped behaviour in children who are blind are surveyed through the parent/caregiver responses. Data are analysed and presented in a tabulated manner using Minitab-15 electronic software to ensure the quantitative information is accurate.

Chapter Five is introduced with an explanation of the methods chosen for data collection. It then presents the stories of five case studies as offered by the RTVs who have responsibilities for these learners; through observations of the learners; and through a review of relevant documentation. These stories describe the lived experiences for learners who are blind who

display stereotypic behaviour and who are currently in inclusive educational settings. The aim of these stories is to provide insight into and understanding of the personal experiences of the five individuals.

Chapter Six draws the project together, discussing the relevance and value of mixed methods research for this study. Sequential Explanatory Design is described, and the two phases of the study are summarised. The strengths, limitations and challenges of the study are identified. Practical limitations are noted, with recommendations offered, especially regarding future research. This chapter concludes by highlighting the ongoing challenges that some learners who are blind face in behaving in a culturally socially acceptable manner.

Chapter Two

The Literature Review

2.0 Introduction

A considerable body of international literature now recognises an association between specific disordered behaviours and certain categories of disability (Berkson & Tupa, 2000; Hagopian, Rooker, & Rolider, 2011; Hanley et al., 2003). Behaviour is described as disordered if it occurs in social environments where it is regarded as inappropriate, and/or it results in exclusion, and/or it interferes with learning (Kauffman, 1997; Lang et al., 2010). Stereotypic behaviour is one such disordered behaviour because it is often regarded as inappropriate, it can result in social exclusion, and it may interfere with learning (Wolffe, 2006). Stereotypic behaviour is thought to occur with great frequency in children who are blind (Gal & Dyck, 2009).

2.1 Chapter Overview

Research into stereotypic behaviour emerged in the 1950s and continued until the mid-1970s. This focus has been far less prominent since the move internationally towards mainstreaming, integration and inclusion, driven by landmark legislation such as the 1975 Individuals with Disabilities Act (IDEA). The early research base, largely from the USA, was behavioural and somewhat quantitative in nature. This does not translate well into the New Zealand context. Modern philosophies such as those of Skinner (1971), now question the assumptions of behaviourism in that it is not necessarily considered permissible for others to change the behaviour of an individual. It is also important to note that the student population has changed, not only in the survival rates of children with a vision impairment but also for those with additional associated disabilities. These children are most likely to live at home and to be educated in their local community. Emphasis is placed on the integrity of the individual, respecting their ability to make decisions about their

own life and behaviour. This thinking suggests a theoretical change of approach, which has in turn led to more qualitative research.

No quantitative or qualitative studies of stereotypic behaviour in children who are blind and who live in New Zealand have been undertaken or published. It is therefore considered timely, in line with the theoretical change of approach in international research, to begin to develop a cohesive body of knowledge concerning stereotypy in the New Zealand context, for the current population of children who are blind.

This chapter describes the international literature, providing a number of definitions of stereotypy with reference to both functionality and characteristics. An explanation of current observations as to how and why this self-stimulatory behaviour may be exhibited, follows. Particular stereotypies in children who are blind are discussed and the relevant terminology that relates to students who are blind is examined. Reassurances are provided that stereotypies known as “blindisms” are not necessarily exclusive to this sector of the population. However, according to the literature, specific behaviours such as eye rubbing, eye pressing, eye poking and body rocking are more prevalent in children who are blind (Blake, 2002; Murdoch, 2013; Troster, Brambring, & Beelmann, 1991b).

The chapter presents the aetiological theories in relation to stereotypic behaviour, with explanations offered for the high frequency of certain mannerisms in children who are blind. The predominant thinking is that stereotypic behaviour emerges as part of normal development, but when particular development is compromised by a sensory impairment such as blindness, these repetitive behaviours persist in the child’s behavioural repertoire and assume particular functions (Murdoch, 2013; Thelen, 1996). The importance, for educators, of understanding the functional and social dimensions of stereotypy is discussed. This relates to considerations about

prevention and/or intervention particularly in the context of mainstream schools. A number of studies are described for the purpose of highlighting the importance of Functional Behavioural Assessment and to consider aetiological theories. This aims to provide information about the use of Functional Behavioural Analysis of stereotypic behaviour in order to consider whether or not it is appropriate to change behaviour, and to consider whether any change may then increase engagement in learning.

The chapter refers to the philosophical approach that recognises the rights of the individual. This is not only about individuals managing their own behaviour and making their own decisions, but their right to be educated in an inclusive setting. The impact of vision loss on how children who are blind learn, the relevance of context and especially how they learn culturally socially acceptable behaviour, is discussed.

As a result of this review, gaps in the literature were identified. This information was used to guide the research design with the aim of developing new knowledge and fostering greater understanding in respect to the New Zealand context.

2.2 Stereotypic Behaviour: Overview

Stereotypic behaviour refers to repetitive body movements or the repetitive movements of objects by an individual. According to Barry, Baird, Lascelles, Bunton, & Hedderly (2011), Lowry and Sovner (1991) and Singer (2009), these motor responses are repetitive sequences of fixed behaviours that are persistent and pervasive. They are excessive in rate, amplitude or frequency and are pursued in an invariant manner (American Psychiatric Association, 2000; Schopler, 1995). They are cyclical and rhythmic in nature and may involve vocal sequences together with fixed movement patterns (Berkson, 1983; Daversa, 2001). The behaviours include non-functional rituals and

routines in respect to the observer as well as behaviours that display a persistent preoccupation with stimuli (South, Ozonoff, & McMahon, 2005). Barry et al., (2011) note that the behaviours are involuntary and rhythmic, with a predictable pattern, amplitude and location. The movements, according to Singer (2009) can last from seconds to minutes and they can appear multiple times a day.

Murdoch (2013) details the range of behaviours that may be considered when discussing stereotypy. These include: mouthing of objects, eye poking, light gazing, sniffing or smelling, screaming, crying or whimpering, teeth grinding, repetitive vocalisations, head movements, hair twisting or pulling, arm waving, clapping, hand flapping, hand or thumb or finger sucking, strobing light with the hand, complex hand or finger movements, throwing objects, repetitive manipulation of objects, body rocking, foot kicking, bouncing or jumping, twirling, and fantasising. Other authors also detail the range of behaviours, including Edelson (1995) and Pagliano (2001).

Pagliano (2001) lists 65 descriptors of stereotypic behaviour with observational categories provided. These relate to three behaviour subgroups: self-stimulatory, then problem behaviours that interfere with learning and development, and those that are considered challenging behaviours.

Edelson (1995) provides examples of stereotypic behaviour in relation to the sense involved. Visual stimulation may involve staring at lights, repetitive blinking, moving hand/objects in front of the eyes and hand flapping. Auditory stimulation may include ear tapping, finger snapping or making vocalisations. Rubbing the skin with hand/objects or scratching may result in tactile stimulation. Excessive rocking, forwards and backwards or side to side, results in vestibular stimulation. Taste may be stimulated by placing objects/body parts in one's mouth, or licking objects. Olfactory senses are

stimulated by smelling objects or sniffing people. Therefore, it is apparent that the behaviours are highly heterogeneous in presentation. They can be “verbal or nonverbal, fine or gross motor oriented as well as simple or complex” (Cunningham & Schreibman, 2008).

Stereotypy may be self-injurious, injurious to others, or non-injurious self-stimulation (Weyandt, 2011). Self-stimulatory behaviours that are non-injurious may take one or more of numerous possible listed forms, such as body rocking, jumping up and down and hand weaving (Lowry & Sovner, 1991). Self-stimulation resulting in atavistic behaviour, that is a re-infliction of body injury, is most likely to be displayed by individuals with complex needs (Fritz, Iwata, Rolider, Camp, & Neidert, 2012; Gedeon, 2003). Such behaviours include striking a body part against a body part, striking a body part against an object or person and aberrant consummatory behaviour, e.g., self-induced vomiting (Hagopian, Rooker, & Rolider, 2011; Lowry & Sovner, 1991).

More recent research, largely in the areas of psychiatry and neuroscience, makes reference to specific stereotypic behaviours as being recognised motor disorders within the classification of neurodevelopmental disorders (Barry et al., 2011; Kerr et al., 2013). This condition is referred to as Stereotypic Movement Disorder (American Psychiatric Association, 2013). This particular categorisation is used when the behaviours interfere with normal activity and social functioning (Lang et al., 2009; Langen, Durston, Martien, van Engeland, & Staal, 2011; Tiger, Toussaint, & Kliebert, 2009). Ellis (2013) suggests that the behaviours may be habit disorders, arguing that when this disorder is diagnosed individuals may experience a substantial functional impairment where the behaviour interferes with normal activities. As Kennedy (2013) suggests, occurrences are complex and may relate to a variety of possible reasons, but diagnosis of the behaviours as a recognised disorder is now more common.

Singer (2009) refers to a dearth of clearly defined terminology for stereotypy. He cautions that a diagnosis of stereotypic behaviour requires exclusion of other causes or disorders. Rapp and Vollmer (2005) together with Cunningham and Schreibman (2008) also observe that empirical evidence is lacking for pertinent definitions but contend that, when diagnosing stereotypy, reference to behaviours as operant responses is helpful. Singer (2009) also makes a distinction between primary and secondary stereotypies. Primary stereotypies are considered transitional, whereas secondary stereotypies are thought to “ascribe to distinct neuroanatomical localisations and biological mechanisms” (p. 77). These readings from the literature therefore, engender some caution about classifying all repetitive behaviours as stereotypies. Lanovaz and Sladeczek (2011) even make the prediction that one day it will be technology that allows people to differentiate between what is a “true” stereotypy and what is another disorder.

Some authors have argued that the behaviours have no adaptive function (Barry et al., 2011; Baumeister, 1978; Ellis, 2013; Turner, 1999), but other authors such as Ijichi, Collins, and Elwood (2013) and Nijhof, Joha, and Pekelharing (1998) maintain they have a homeostatic function that allows for control of internal surroundings to provide balance or equilibrium in suboptimal environmental conditions. Alternatively Carr and Durand (1992) and Durand (1990) suggest the behaviour might have a communicative function, particularly for some children who experience delay and or dysfunction in both receptive and expressive language. Many authors also reason that the behaviours are developmentally derived (Mandelbaum et al., 2006; Murdoch, 1996, 2013; Nafstad & Rodbroe, 1999; Singer, 2009; Thelen, 1981) with such repetitive behaviours thought to be a necessary stage of infant development, increasing and declining as part of typical behaviours (Berkson & Tupa, 2000; Murdoch, 2013). Then, as maturation occurs, the repetitive behaviours are subsumed into more complex patterns. When particular mannerisms are retained, they transform from natural movements to

pathological stereotypies. These then are the behaviours of concern – ones that are repetitive, rigid, invariant, and inappropriate (Gal, Dyck, & Passmore, 2002).

Non-injurious and self-injurious self-stimulating behaviours are diverse, complex and challenging. In order to better understand such behaviours their aetiology in relation to characteristics, functionality and the range of causal theories of stereotypy was also focused upon.

2.2.1 Stereotypic Behaviour: Aetiology

The majority of literature regarding aetiology is between 10 and 20 years old, which reiterates the point that research in this area continues to be seriously neglected. One reason given for this inattention is the overwhelming focus in the current literature on inclusive education. In the literature that is available, there are diverse overlapping notions as to how and why stereotypic behaviour arises. As already stated in Chapter One, these refer to the behaviour as having no adaptive function, or as having a homeostatic function, or a communicative function, or as a developmental stalling, or having a neurobiological and genetic basis (Hollander, King, Delaney, Smith, & Silverman, 2003) or, as will be argued in this chapter, aetiology may be a possible combination of all the above.

Some authors believe stereotypic behaviour is a variation of normal behaviour (Attwood, 1998; Berkson & Tupa, 2000; Kauffman, 1997; Langen et al., 2011; Symons, 2000). Others propose that the behaviours are not homogeneous but vary in onset, timing, form, intensity and frequency, and show variability with/sensitivity to environmental change (Rapp & Vollmer, 2005; Willemsen-Swinkels, Buitelaar, Dekker, & van Engeland, 1998). Furthermore, behaviours are maintained by all or one of the senses, with the assumption being that self-reinforcing or self-perpetuating sensory feedback

occurs (Lanovaz, 2011). Lovaas, Newsom, and Hickman (1987), as well as Lowenfeld (1971), describe the behaviours as operant responses (Rapp & Vollmer, 2005) that serve as a block to excessive or aversive environmental stimulation. Supporting the notion that stereotypic behaviour regulates sensory input from the environment, Zentall and Zentall (1983) and Miller, Lane, Cermak, Anzalone, and Osten (2005) concur, pronouncing that stereotypies act as modulators to maintain an optimal state of arousal.

According to Baumeister (1978), Berkson (1983), and Troster et al., (1991b), there are four major characteristics of stereotypic movements. These are:

1. A fixed form of structure, repeated within a constant time interval.
2. A typographical invariance of pattern.
3. An invariance of environmental influence.
4. A “lack of any recognisable, adaptive significance”.

(Troster et al., 1991b, p. 570).

Finally, another notion is proposed by Edelson (1995), who theorised that the behaviours may actually release endorphins in the body that provide some form of pleasure.

In summary, the discussions on the aetiology of stereotypic behaviour are varied and indicate that the behaviour can be characterised in a number of disparate ways. Aetiological theories therefore provided support to a wide range of such notions in the literature.

2.2.2 Stereotypic Behaviour: Aetiological Theories

The literature highlights three key questions that relate to the possible aetiology of stereotypical behaviour. They are: what are the causes that contribute to the emergence of stereotypic behaviour; what are the causes that maintain the behaviours in the child's repertoire; and what are the conditions that contribute to their development (Baumeister, 1978; Berkson, 1983; Berkson & Tupa, 2000; Ijichi et al., 2013; Nind & Kellett, 2002; Rapp & Vollmer, 2005; Troster et al., 1991b)?

Troster et al.'s early analysis (1991b) of the theoretical approaches embodies much of the current thinking about aetiological theories. They list four points of view:

1. The behaviourist approach, where behaviours are maintained through contingent reinforcement.
2. The developmental perspective, where behaviours are regarded as expressions of neuromuscular maturation processes that occur in transitional stages of development.
3. The functional approach, where the behaviours are considered to be moderators of internal levels of arousal.
4. The neurobiological approach, where behaviours are seen as expressions resulting from damaged neurological or biochemical processes.

In the behaviourist approach, stereotypies are described as being operant responses that are maintained by both positive and negative reinforcers (Iwata, Dorsey, Slifer, Bauman, & Richman, 1994; Lanovaz, 2011; Willemsen-Swinkels et al., 1998). The behaviour may have evolved from normal development as a lack of adequate stimulation; however, it then continues through reinforcement (Molloy & Rowe, 2011). The behaviour may be a learning avoidance strategy, or as a cue for positive reinforcement using

discrimination learning. It might also be a self-stimulatory behaviour reinforced by the consequences of the behaviour, described in the literature as the perpetual reinforcement hypothesis.

In the developmental approach, stereotypic behaviour is explained as being an external reflection of neuromuscular maturation processes that occur transitionally (Lourie, 1949; Mandelbaum et al., 2006; Thelen, 1979; Wolff, 1968). The behaviour is considered to be an immature display of more complex movement patterns. The behaviours persist when development is blocked or delayed and become fixed (Thelen, 1979). For example, lack of vision may block or delay the process so the behaviours do not develop or manifest into mature movements (Molloy & Rowe, 2011; Troster et al., 1991a).

The functional approach has a homeostasis interpretation in that it suggests an arousal-modulation hypothesis (Baumeister, 1978; Ijichi et al., 2013; Miller et al., 2005; Nijhof et al., 1998; Willemsen-Swinkels et al., 1998; Zentall & Zentall, 1983). Authors that support the functional approach argue that there is an optimum level of arousal and the stereotypic behaviour compensates for under or over stimulation. Some children, who have a disability and a limited repertoire of alternative socially acceptable behaviours, exhibit these alternative behaviours as self-regulators. The stereotypic behaviour is therefore considered to provide the child with “tactile, proprioceptive and kinaesthetic self-stimulation” (Troster et al., 1991b, p. 572). This viewpoint is particularly aligned to children with autism; however, the child who is visually impaired may similarly experience suboptimal levels of stimulation and may resort to the behaviour to increase stimulation (Molloy & Rowe, 2011), possibly because of a more restrictive environment and reduced mobility. This functional basis for stereotypies is used to support the idea of modulating levels of arousal across a continuum (Barry et al., 2011).

According to the neurobiological approach, the behaviours are expressions of activity of neural networks, neurotransmitters or neurochemical processes that are controlled by the central nervous system. The behaviours are caused by physiological damage and an “imbalance of biochemical transmission processes in the central nervous system” (Molloy & Rowe, 2011, p. 80). Langen et al., (2011) also refer to dysfunction at the subcortical/cortical level. Lanovaz (2011) goes on to propose that neurobiology provides a topographical aetiology, where once the behaviours are triggered, they are maintained through a process. Doidge (2007) calls this “the plastic paradox” (p. 208). This explanation is based on the belief that the behaviours are neither adaptive nor functional. This approach is currently under considerable investigation and has involved trials using Dopamine and Serotonin for the purpose of neurotransmitter modulation.

These approaches are not “stand-alone” theories, as Thelen (1981), and years later Rapp and Vollmer (2005) noted, and all are useful in supplementing each other. Barry et al., (2011) suggest that it is not possible to exclude any of the viewpoints when discussing aetiological theories.

2.2.3 Stereotypic Behaviour: The Impact of Vision Loss

In the literature there is some emphasis placed on an assumption that stereotypic behaviour compensates for difficulties in sensory processing caused through vision loss (Rapp & Vollmer, 2005). Viewing the literature from an historical perspective is interesting when considering the development of ideas and thinking about the impact of this sensory loss. According to Piaget (1955), vision is the primary sense used in the construction of all sensorimotor intelligence. Therefore, without good vision from an early age, children are at risk of developing behavioural adaptations to manage their environment. Early studies by Bruner (1961) found that, for the child who is blind, the formation of adequate models and strategies to deal with the environment is extremely difficult. Thirty-five years later, Pico (1996)

reiterated these findings, placing major emphasis on environmental factors in relation to the aetiology of behaviour. Lack of appropriate environmental impressions may lead the child who is blind to turn inward for satisfying and pleasurable sensory stimulation (Abang, 1985, 1988). Complementing this research, Thurrell and Rice (1970) suggested that when there is inadequate sensory experience, behaviours that evolve from early childhood may become self-stimulatory. This self-stimulation may possibly even alter levels of consciousness (Pico, 1996; Stone, 1969), or may stabilise levels of arousal (Brambring & Troster, 1992). The child who is blind, therefore, may engage in self-stimulatory behaviour as an alternative, to try to regulate sensory information or to compensate for unexplained environmental changes.

For Gunaratne (2001), repetitive behaviour in children who are blind may be an expression of over-stimulation or under-stimulation from the environment, where the child does not have the ability to modulate environmental pressures. Miller et al. (2005) expanded on this assumption by identifying three types of sensory processing concerns, namely: disorders with sensory modulation, sensory motor or sensory discrimination. Sensory modulation refers to difficulties in regulating responses to the body and the environment. Sensory motor disorders relate to concerns with posture and motor planning and sensory discrimination denotes concerns managing spatial and temporal information. These studies focused on the compensatory aspect of the behaviour, and suggested that sensory processing dysfunction occurs as a result of the early onset of vision loss.

The stereotypical behaviours may therefore be construed as meaningful responses resulting from the child's insecurity within a sighted world (Gahbler, 2000). The insecurity resulting from a lack of vision may also lead to emotional issues such as anxiety, tension and fear. Gahbler (2000) suggested that this line of reasoning helps to validate the theory that stereotypic behaviour in children who are blind provides a compensatory function that offers an intensive perception of the body. As opposed to what is

received from the environment, this more self-contained behaviour is considered to be emotionally comforting and stabilising.

Gunaratne (2001) also maintained that visual modelling of behaviour is inaccessible to children who are blind. This lack of visual stimulation and visual social interaction is thought to be phenomenally isolating and frustrating (Carroll, 1961; Pico, 1996; Taylor, 1994). According to Deasy and Lyddy (2009), everyday visual social interaction behaviours such as eye contact are absent for these children. Boredom may therefore become a contributing factor to the functionality of the stereotypical behaviour (Troster et al., 1991b; Warren, 1994). Blindness greatly inhibits a person's ability to read visual signals from others (Bak, 1999; Wolffe, 2006). Astute guidance is, therefore, necessary to channel inappropriate energy into more rewarding self-expression (Taylor, 1994). For that reason Taylor, and more recently Deasy and Lyddy (2009), theorised that the behaviour is essentially compensatory for the lack of visual stimuli.

To sum up, stereotypical behaviour has been considered to be compensatory or adaptive behaviour that relates to an inability to control the environment (possibly due to a lack of vision or other sensory concern) and is compounded by communication deficits. This assessment is consistent with a large number of early research findings (Attwood, 1998; Lovaas et al., 1987; Lowry & Sovner, 1991; Zentall & Zentall, 1983).

According to Keefe (2004) vision impairment compromises the quality of life and can have a profound impact on a child's development. She theorises that participation in social, physical and educational opportunities are restricted because of lack of vision. While vision loss does not necessarily suggest delays in gross and fine motor development, it may alter developmental sequence and impact on cognitive development (Cass, 1996; Groenveld, 1993; Strickling, 2010). Groenveld (1993) and Keefe (2004)

emphasise that vision is the most important modality for knowledge acquisition. It is the primary learning modality and principal source of information for most children. Properties of colour, contour, size and motion are only accessible through vision. Without vision, exploration may be inhibited, there may be a lack of curiosity, and the child may experience difficulty in combining sensory information. Dyck, Farrugia, Schochet, and Holmes-Brown (2004) make reference to the lack of opportunities for motor development for those without vision, stating that additional skills such as Braille competency take precedence over physical education, thereby reducing motor experiences. This also links to possible sensory motor dysfunction, and the perceived need for stereotypic movement to regain homeostasis. Fazzi, Signorini and Lanners (2008) discuss early onset of vision impairment with reference to social and relational development, suggesting individuals may become stuck in a sensory void (Willis, 1979). This literature therefore affirms that vision loss may impact on perceptual, motor, cognitive and social-interpersonal behaviour development.

Cass (1996) wrote that there is a delay in the development of children who are totally blind in the first two years of life compared to children who have vision. The delay may involve the acquisition of both language and cognitive skills. She also notes that delays in social interactions are evident and communication may become disordered. Dale and Sonkson (2002) as well as Strickling (2010) also refer to developmental delays in cognition and language. Fraiberg (1977) reiterates much of this thinking, with Eichel's (1971, 1978) earlier studies confirming similar possible delays.

Southwell and Hunt (2011) also referred to a delay in developmental milestones for children who are blind, especially in areas of communication, language, social interaction and living skills. Because vision is considered a confirming sense, incidental learning is not so accessible, which may result in an imbalance of sensory responses. This approach suggests stereotypic behaviour is functional, helping to balance sensory responses.

Managing to make sense of the environment without visual information and developing effective relationships between people is difficult for children who are blind (Wolffe, 2006). This is reiterated by Keefe (2004), who reminds us that visual imitation does not exist for children who are blind. Compounding this issue of managing to make sense of the environment is difficulty in establishing and continuing effective interaction cycles in the mother–child relationship (Loots, Devise, & Sermijn, 2003). This relationship is often referred to in the earlier literature (Baird, Mayfield, & Baker, 1997; Bowlby, 1980; Fraiberg, 1977; Kekelis & Prinz, 1996; Loots et al., 2003). Bowlby (1980) and Malekpour (2007) wrote that a secure attachment representation for a child, guides behaviour. Early relationships are thought to act as an external system for the child’s internal regulation. Inadequate non-visual encouragement and modelling in a variety of appropriate behaviours by the maternal figure may result in the child becoming more vulnerable. This may lead to mannerisms that are attempting to recreate kinaesthetic and tactile sensations that would normally be associated with this relationship (Abang, 1985, 1988; Hoshmand, 1975; Loots et al., 2003; Pico, 1996). Reference is also made to mismatched interactions between mother and child. This suggests mothers may be less responsive to non-visual cues from an infant who is blind than those of infants who are sighted. The mother–child relationship may therefore be more “directive and intrusive” (Loots et al., 2003, p. 403). Consequently it is considered that children who are blind need greater opportunities to develop awareness of themselves and others. Abang (1988) stresses that mastery of the environment through secure mother–child relationships that allow for spontaneous exploration is essential, and for the child who is blind these need to occur in ways that involve the other senses.

Ferrell (2007) and Brambring (2007) asserted that children who are blind learn differently as they cannot rely on their vision to provide information. They gain information through their other senses; however this information may be “inconsistent, fragmented and passive” (p. 5). Hatlen (1996), Sapp and Hatlen (2010) and Strickling (2010) referred to the lack of causal,

incidental learning that occurs through visual loss and the need to understand the characteristics of the loss, which results in unique educational needs.

This contributes to the thinking that children who are blind have concerns in managing their environments. According to the literature, many children who are blind are unable to manage sensory information from the environment because of a lack of modelling of appropriate behaviour and immature communication skills. Strickling (2010) referred to concerns for learners who are blind in areas of motor development, self-concept, cognitive and language development. He wrote that because of the lack of vision there is little self-initiated mobility, an increased dependence on others for concept-defining attributes, together with relationships that are more problematic. These factors combine to contribute to the aetiological theories as summarised by Barry et al. (2011); Singer (2009) and Troster et al. (1991b). These include: the behavioural approach, where difficulties exist in communicating need; the developmental approach, where vision loss has impacted on progress through normal developmental stages as a result of environmental or physical limitations; and to a more limited extent the homeostatic approach, which is functional in nature where the behaviour is self-stimulatory to compensate for under or over stimulation. This also includes recent studies suggesting that in some cases the behaviour may be neuropathological in genesis (Langen et al., 2011; Lanova, 2011; Nind & Kellett, 2002; Singer, 2009).

In summary then, this literature has suggested that children who are blind may engage in behaviours to compensate for the difficulties experienced in managing the environment. They may engage in the behaviours from a developmental perspective because of the difficulties they have in modelling behaviour. The behaviour may emerge as a consequence of immature communication skills, and as an expression of imbalances within the central nervous system.

2.3 Stereotypic Behaviour: Functionality

The literature has provided much discussion about the possible functions of the repetitive behaviour while offering various hypotheses to support each perspective. Lourie's seminal paper, first published in 1949, refers to stereotypic behaviour as self-stimulatory, suggesting the behaviours are an attempt to experience movement as part of normal development, the function being expression and release of tension. Lourie states that there are a number of variables involved in determining the emergence of the behaviour, whether the behaviour continues, and whether there are fluctuations in the level of the behaviour. However, essentially Lourie reiterates a belief that stereotypy is self-stimulatory. This early research, therefore, laid the foundation for much of the future discussions on functionality.

Thirty years later, Eichel's (1979) research discussed the onset of mannerisms in a similar way to Lowry, in that the behaviours are considered to evolve within normal development. Her research explored functionality with reference to the body part involved, suggesting that analysis of this type will aid the understanding of the function of the behaviour. Eichel has commented that some mannerisms are maintained by unconscious, selective reinforcement and by a lack of stimuli, thereby allowing the behaviour to become self-reinforcing.

Lowry and Sovner (1991) defined functionality further, proposing the notion that stereotypic behaviour has four functions:

1. Socio-Environmental Control – the use of problem behaviour to gratify a desired need.
2. Means of Communication – a non-verbal form of conveying discomfort or a need for assistance.

3. Modulation of Physical Discomfort – a direct or indirect reaction to a reduction in comfort levels.
4. Modulation of Emotional Discomfort, which may cause irritability or over arousal, which is unpleasant, resulting in behaviour that aims to change the discomfort.

Guess and Carr (1991) drew functionality and theory together in a three-stage model. The theory is that at the first stage the behaviours begin as instinctive, involuntary responses that are internally regulated and common in normal development. The behaviours in the second stage are used to maintain sensory equilibrium in the environment and have an adaptive feature. The third stage is when the behaviours are used operantly to achieve particular outcomes as a form of control.

Attwood (1998) offered similar explanations for the functions of the behaviour, defining these as a means of communication, a pleasurable sensation, a response to anxiety, a means of hypnosis, or a movement disorder. Likewise, Weisler, Hanson, Chamberlain, and Thompson (1985) summarise that the functions of this disordered behaviour appear to relate to a method of control. The consequences of such control go on to become highly reinforcing.

Nind and Kellett (2002) referred to functionality in their research, identifying seven groupings. Firstly, that the behaviours are functional, with the functions relating to sensory input. This input could be self-stimulatory or could serve as a homeostatic function, maintaining equilibrium and stimulation levels. Miller et al. (2005), contributes to the suggestion that the movements are adaptive in that they maintain a homeostatic state of stimulation, for they consider children who are blind are under stimulated. Secondly, Nind and Kellett (2002) stated that the behaviours serve as a discharge function in the

form of a tension release, an expression of frustration or anxiety and stress. LeJune (2006) supports this thinking in her review of relevant literature, reporting that functionality is related to emotional needs and stress release. Communicative function is a third hypothesis, relating to a need for attention, tangible reinforcement, escape, or for sensory stimulation as defined by Nind and Kellett (2002). Much has been written about the fourth category – that the behaviours are learned and are maintained operantly by reinforcers. The fifth category is the neuro-pathological theory, which links the behaviour to particular visual conditions such as Retinopathy of Prematurity and Lebers Amaurosis (Hartnett, 2013). The sixth category suggests that these endogenous factors may link with environmental factors resulting in the behaviour remaining as part of a child's repertoire. This thinking supports the perspective of a number of authors in the seventh category who consider that the behaviours begin as normal development, peak, then decline over time, but display an onset and duration that differs from the norm.

More recent studies by Murdoch (2013) argued that repetitive behaviours have significant value from a developmental perspective. She considered that the behaviours are used for communication or exploration and are therefore compensating for any restrictions there may be in environmental interactions for a child who is blind. LeJune (2006) also referred to restrictions and imbalances, including that of physical needs for stimulation. Certain behaviours are considered to provide sensory feedback and predictability amid the inconsistencies of the environment. These studies reflect a three-fold view of stereotypic behaviour, similar to Guess and Carr's 1991 model: compensatory function through delayed developmental growth, the notion of modulation of the environment, and that of a lack of stimuli.

In the absence of appropriate alternative behaviour, these highly reinforcing behaviour excesses are chosen over more socially acceptable behaviour according to early studies by Thurrell and Rice (1970) and by Troster et al., (1991a), and more recently, by Rapp and Vollmer (2005). The

behaviour therefore provides access to positive and negative reinforcer functions, and offers stimulation of some kind. Clearly there are multiple functions in stereotypic behaviour, all of which need to be considered when seeking explanations (Hanley, Iwata & McCord, 2003; Kennedy, Meyer, Knowles & Shukla, 2000; Rapp & Volmer, 2005; Singer, 2009).

Divergent thinking was evident in the research in relation to the functionality of stereotypy. A number of articles on the definition, descriptors and functionality of these mannerisms were reviewed by Eichel (1978). She concluded that there was “no systematic way to refer to any specific movement pattern” (p. 20) and that the various theories in relation to aetiology are largely speculative. Eichel adds that further review of behaviours that are repetitive and that are not directed towards an observable goal is necessary, as much of the reported literature is unsound. A differing viewpoint is offered by Thelen (1979, 1981), and Troster et al., (1991a) that these behaviours are transitional. However, Thelen acknowledges that the replacement of these behaviours by more mature behaviours is more difficult when motor development is impeded. Willemsen-Swinkels et al., (1998) refer to the absence of biological explanations when considering the aetiology of these seemingly meaningless behaviours. Daversa (2001), in more recent studies, refers to stereotypic behaviour as “apparently non-functional”. Brambring and Troster (1992) summarise this literature by stating stereotyped behaviours “serve no apparent purpose” (p. 105).

In sum, functionality is considered to span the spectrum from behaviour of no apparent observable purpose to that of maintaining environmental and sensory equilibrium through to behaviours that are so highly reinforcing that they interfere with productive learning. The understanding of the functionality of stereotypy has not necessarily developed as an historical progression of ideas. However, it is clear that, most theorists consider that the behaviours are operant responses that offer some form of self-stimulation to the individual.

2.4 Stereotypic Behaviour in Children who are Blind: Introduction

Much of the literature confirms that self-stimulatory behaviours are displayed by many children who are blind (Eichel, 1971; Gal & Dyck, 2009; Guess, 1966; Jan et al., 1983; Murdoch, 2013). They are known to occur with great frequency, so much so that they have been called “blindisms”. This term lacks specificity; however, by replacing it with stereotypies or mannerisms, the fundamental aspect of the behaviour is clear, i.e., repetitiveness in order to provide a form of stimulation, as espoused by Barry et al. (2011) and Fazzi et al., (1999).

The use of the word “blindisms” is contested by a number of authors, suggesting a preference to the use the term “mannerisms”, as the behaviour is not population-specific, that is, it is not exclusive to children who are blind (Eichel, 1978; Fazzi et al., 1999). The term “blindisms” or mannerisms actually covers a broad range of habitual behavioural patterns. These behaviours may be referred to as challenging behaviour, maladaptive behaviour, problem or ritualistic behaviour, obsessive, self-active engagement or self-stimulation (Pagliano, 2001). These behaviours differ from developmental stereotypies, which contribute to a child’s growth and maturity and are normative and are evident in typical development. Berkson and Tupa (2000) consider that there is a “dependable, curvilinear relationship between age and behaviour” (p. 4). Mannerisms such as these are not normally retained beyond a particular age; they do not become aberrant, repetitive behaviour (Symons, 2000) and are not retained as a fixed, individualised repertoire (Singer, 2009).

It is these maladaptive behaviours that have at times been classified for the purpose of research by earlier theorists such as Eichel (1971), Holland (1971) and Leonhardt (1990); however, some of the literature reports that this classification process is not straightforward (Hanley et al., 2003; Rapp & Vollmer, 2005; Singer, 2009; Symons, 2000).

2.4.1 Stereotypic Behaviour in Children who are Blind: Measurement Strategies

There is no standardised scale for describing and measuring stereotypic behaviour in children who are blind. However, there is a range of measurement strategies for stereotypic behaviour in the general population using the different definitions that are currently in use (Symons, 2000).

Early research on stereotypic behaviours for children who are blind was conducted by Chevigny and Braverman (1950). While they only provided a general description of manneristic behaviour, their research did instigate a long line of research interest that led to Hayman's (1972) four categories: rocking, odd head movements, eye-involved mannerisms, and twirling. Hayman's research built on a number of earlier studies that had helped to shape our understanding of stereotypic behaviours in children who are blind. Carroll (1961), for example, identified five categories: mannerisms of posture, gait, facial expression, voice, and negative ones, whereas Cutsforth (1968) only had three, namely: degree of vision loss, tactual stimulation, and kinaesthetic stimulation. Also Stone (1969) developed a classification system based purely on observation and clinical data required for specific research, while Blank (1957) proposed that patterns of motility that appeared in the first year of life and were transitory, and behaviours that were fixations or regressions in these patterns, were important considerations. Other influential studies from this time were Roy (1967) and Thurrell and Rice (1970), who focused on specific stereotypic behaviours that involved hand and eye movement only.

By the 1970s a more comprehensive overview of stereotypic behaviours was emerging. For instance Holland (1971) used the research literature to create a classification system of all behaviours exhibited by children who are blind. This system was to be used for identification,

assessment and to provide guidelines for remediation. The five categories were:

1. Expressions of internal conflicts and insecurities.
2. Accommodations to the environment.
3. Mannerisms through lack of personal awareness or lack of understanding of socially acceptable behaviour.
4. Childhood fixations that may become habits.
5. Habit patterns.

Eichel (1979) expanded on Holland's Classification System to create a Taxonomy of Blindisms that categorised stereotypic behaviour by body part used to perform the action. In addition to the uses proposed by Holland, the purpose of the taxonomy was to assist with more systematic observation and in-depth understanding of these behaviours. Using the taxonomy of a set of 34 descriptors within five categories, Eichel's research aimed at validating a number of aetiological theories in relation to the mannerisms in children who are blind. In Eichel's words, "by testing the proposed theories of mannerisms, the effectiveness of remedial techniques may be determined" (1979, p. 168). This research indicated that stereotypy was a learned behaviour and was maintained through various levels of reinforcement. The taxonomy allowed theorists to define the behaviour and determine the body part affected so more socially acceptable behaviour could be substituted through remediation. The taxonomy, quite significantly, provided the means of identifying the specific mannerisms within the population of children who are blind.

For the purposes of her research, Leonhardt (1990) provided a detailed list of what she referred to as mannerisms exhibited by children who are blind. These were particular behaviours that were largely present only in the population of children who were congenitally blind. These were categorised as

those that related to the eyes, and those considered physical. Eight behaviours were identified: light-gazing, eye pressing/poking/pulling, movement of the head, movement of an object in front of the eyes, using a light source, postural abnormalities, and spatial abnormalities. Leonhardt also categorised the behaviours as being temporary developmental mannerisms, temporary reactional mannerisms, or permanent mannerisms and detailed a number of variables to consider when examining the behaviours.

Over the years a number of documents have been used in work in the area of stereotypic behaviour. These include the:

1. Carolina Record of Infant Behaviour (Simeonsson, 1979)
2. Timed Stereotypies Rating Scale (Campbell, 1985)
3. Atypical Rating Scale (Wehmeyer, 1994)
4. The Bielefeld Parent Questionnaire (Brambring et al., 1987)
5. Achenbach Behaviour Checklists (Achenbach, 1985)
6. The Short Sensory Profile (McIntosh, Miller, Shyu, & Dunn, 1999)
7. The Stereotyped and Self-Injurious Movement Interview (Gal et al., 2002)
8. Revised Child Autism Rating Scale (Saemundsen, Magnusson, Smari, & Sigurdardottir, 2003).

It is interesting to note that it was Thelen (1979) who first used a refined classification scheme for children who are blind to assist with the description of behaviour through observation. However, apart from Gal et al.'s 2002 interview schedule, which considers prevalence, frequency, duration and intensity to provide data for analysis, there is little known current use of these diagnostic tools.

It is evident that a standardised classification system in relation to the characteristics of stereotypic behaviour for children who are blind is yet to be adopted by researchers. Likewise, there is no internationally recognised or standardised system for determining the prevalence, type, intensity and frequency levels of stereotypic behaviour in children who are blind.

2.4.2 Stereotypic Behaviour in Children who are Blind: Prevalence

High frequency levels of stereotypic behaviour are displayed by children who are congenitally blind (Brambring & Troster, 1992; Dumont & Markovits, 1982; Eichel, 1971, 1978, 1979; Guess, 1966; Jan et al., 1983; Troster et al., 1991a). Figures indicating prevalence rates range from 52% (Gal & Dyck, 2009) to as high as 100% (Troster et al., 1991b). It is evident that some stereotypic behaviours are more prevalent than others. These particularly involve eye rubbing, eye pressing or eye poking, and are often referred to as oculodigital behaviours. Other behaviours that are often noted involve motor movements such as body rocking (Brambring & Troster, 1992; McHugh & Lieberman, 2003; Miller & Miller, 1976; Molloy & Rowe, 2011).

Oculodigital stereotypies are generally thought to result in phosphenes, a ring or spot of light produced by pressure on the eyeball or direct stimulation of the visual system other than by light. Brambring and Troster (1992) and Fazzi et al., (1999) suggest that the light flashes from oculodigital stereotypies provide visual stimulation that would not otherwise be available. Other researchers concur with this claim, making reference to eye poking as a key source of visual stimulation for children who are blind (Brambring & Troster, 1992; Brame, Martin, & Martin, 1998; Dumont & Markovits, 1982; Eichel, 1971, 1978, 1979; Guess, 1966; Jan et al., 1983; Luiselli, Myles, Evans, & Boyce, 1985; Murdoch, 2013; Raver & Dwyer, 1986; Thurrell & Rice, 1970; Troster et al., 1991b). Oculodigital mannerisms are not considered to emerge from normal behavioural patterns (Jan, Groenveld, & Connolly, 1990). This behaviour, as opposed to other developmental behaviours observed in

sighted children, emerges in the first to third year of life (Berkson & Tupa, 2000) and does not always decline with maturation. Instead, in some children who are blind, it may remain at a relatively high occurrence level (Troster et al., 1991b). Oculodigital stereotypies, when they are intense and prolonged, are of considerable concern as they may cause retinal detachment. They are also problematic from an aesthetic perspective because regular eye pressing may result in the organ taking on a sunken appearance. Furthermore, many sighted observers consider the behaviour socially unacceptable, even distasteful (Hartnett, 2013). That said, for the child who is blind there are few other behaviours that can compete with the powerful visual sensation that results from oculodigital stereotypy.

The stereotypic behaviour of head and body rocking, as stated previously, is also found to be highly prevalent in children who are blind (Brambring & Troster, 1992; Brame et al., 1998; Dave, 1992; Felps & Devlin, 1988; Jan, Freeman & Scott, 1977; McHugh & Lieberman, 2003; McHugh & Pyfer, 1999; Molloy & Rowe, 2011; Shabani, Wilder, & Flood, 2001; Transon, 1988; Troster et al., 1991b). The impact of blindness may affect a number of areas of development (Dale & Sonkson, 2002; Fazzi et al., 2008; Fraiberg, 1977; Strickling, 2010); however, the absence of an incentive for voluntary motor skills may in turn contribute to an explanation of the prevalence of rocking. When a child who is blind has little incentive to move to an activity that offers motor stimulation, a self-stimulatory alternative may develop. Berkson and Tupa (2000) state that when a maladaptive behaviour is more effective and requires less effort than an adaptive behaviour, it increases the probability of occurrences of that behaviour, across different topographies. Brambring and Troster (1992) sum up the discussion on body rocking when they purport that body rocking may create a level of arousal that cannot easily be manifested appropriately when loco-motor development is restricted through blindness.

The prevalence of other mannerisms such as repetitive hand and finger movements and repetitive manipulation of objects are common in children who are blind, especially at an early age. Head shaking and head rolling are also reported to be particularly common in children who are blind (Jan et al., 1977; Jan et al., 1990; Sallustro & Atwell, 1978; Wolff, 1968). Despite this behaviour being evident in this sector of the population (Berkson & Tupa, 2000), few studies have been undertaken to explore these particular behaviours.

Recent studies undertaken by Molloy and Rowe (2011) in their role as specialist orthoptists aimed at reviewing which behaviours are associated with specific visual conditions and which are associated with the degree of vision loss for an individual. This research also discussed the theories that attempt to explain stereotypic behaviour. Their findings link eye pressing to bilateral ocular impairments, usually retinal disorders; and eye poking and light gazing to cortical vision impairment. Body rocking is also attributed to learners with cortical vision impairment and a number of stereotypic behaviours such as body swaying, hand waving and eye poking are attributed to those with Retinopathy of Prematurity. This research challenges some of the earlier reports in respect to visual conditions and specific stereotypies. This report states that the severity of vision loss appears to influence the type of stereotypic behaviour, meaning that blindness may result in body rocking plus head/neck movements, whereas those with minimal vision display oculodigital stereotypies, while those with usable vision display fewer stereotypies.

A number of studies on the prevalence of the spectrum of behavioural problems in the total paediatric population indicate frequency rates to be 10–15% (Rutter, Graham, & Yule, 1970), although more recent research by Brauner and Stephens (2006) indicates rates between 5 and 26%. This wider range in the prevalence figures may relate to an increased number of children with vision impairment who have associated disabilities. Figures for the prevalence of stereotypic behaviour in the total paediatric population indicate

a frequency of 7% – higher in those under 6 years, and lower beyond 6 years of age. Studies by Fazzi et al. (1999), Jan et al. (1977), Tirosh, Shnitzer, Davidovitch, and Cohen (1998) and Troster et al. (1991b), all discussed the prevalence of specific behavioural problems in the form of stereotypy in children with vision impairment and indicate significantly higher frequency rates than in the general population. The study by Troster et al. (1991b) indicates a rate of up to 100%. The majority of the 85 children with congenital blindness in this particular study exhibited a single stereotypic behaviour hourly, while 25% of children displayed stereotypy on a daily basis. Studies by Jan et al., (1977), and a follow-up study by Tirosh et al. (1998), also with children who are congenitally blind, found 51% displayed problem behaviours in childhood, decreasing to 48% by adolescence. Research by Fazzi et al., (1999), again with children who are congenitally blind, found that 73% displayed this behaviour.

These past research examples, together with more recent studies by Friedman in 2011, with prevalence ratings between 48 and 100%, assist in validating the claim that there is a high frequency rate of the behaviour in children who are congenitally blind compared to the general population. However, studies reporting stereotypic behaviour for learners who are not congenitally blind in terms of being compromised in their engagement with learning are infrequently documented.

2.5 Stereotypic Behaviour in Children who are Blind: Impact on Learning

Many researchers have described stereotypic behaviour as a concern (Abang, 1988; Brambring & Troster, 1992; Coots & Ringeon, 2007; Hartnett, 2013; Hoshmand, 1975; Lowenfeld, 1971; Southwell & Hunt, 2011). Often their concerns relate to problems associated with inclusion. Without equivalent opportunities for visual imitation and modelling in an inclusive

context, social development in children who are blind may be delayed (Warren, 2000).

Much is written in the literature about the ways that a lack of vision may inhibit the development of social skills (Sacks & Silberman, 2000; Wolffe, 1999, 2000, 2006). A lack of vision may result in limited exposure to social environments, limited exposure to social rules in these environments, and make it more difficult to understand the actions of others and to recognise their feelings. This reduced access to both the quantity and quality of visual experience across a range of environments involving other children has the potential to constrain the acquisition of social skills (Wolffe, 2000). Without these social experiences, the development of appropriate skills may be compromised and may also hinder learning (Wolffe, 2006).

More recent work referred to the concept of social capital (Duncan, 2013). Social capital refers to the value one attributes to social contact; for example, the benefits people derive from effective relationships across a range of settings. It is considered that enhanced social capital correlates positively with well-being, self-esteem and self-worth, with particular importance being placed upon the development of effective reciprocal relationships for learners during the school years (Huang, Wang, Tseng, & Wang, 2010). Conversely, children with challenging behaviours may experience diminished levels of social capital. The concept of social capital therefore is yet another consideration regarding the impact of stereotypic behaviour on social interactions for this group of learners.

The drive for inclusive practice has increased the need for culturally socially acceptable behaviour (Duker et al., 1989). Educators are readying individuals for settings where socially acceptable behaviour is required. Educators therefore must work with the student to help them manage problem and challenging behaviours within the context of inclusion. The literature

suggests that stereotypic behaviour limits integration of the child who is blind into mainstream society (Tiger et al., 2009), with social isolation being the outcome (Coots & Ringeon, 2007; Hoshmand, 1975; Knight, 1972; Leonhardt, 1990). As microcosms of society, regular classrooms provide a social environment for students in which to learn and experience modelling of appropriate behaviours. Male (2003), writes that for some learners who display challenging behaviours, exclusion from the classroom is the reality.

Stereotypic behaviour is considered inappropriate and incompatible with learning (Nind & Kellett, 2002; Luiselli & Michaud, 1983) – it interferes with learning (Cunningham & Schreibman, 2008; Murdoch, 1997) and with the teacher's ability to carry out meaningful instruction, thereby introducing anxiety and tension into the teaching environment (Luiselli & Michaud, 1989; Male, 2003). Moreover, Male (2003) referred to the frustration, anger, exhaustion and the feeling of being upset for teachers in these situations. Cunningham and Schreibman (2008) also refer to the behaviour interfering in initial skill development and engagement in learning processes.

High rates of the stereotypic behaviour prevent autonomous activities (Brambring & Troster, 1992) and interfere with responsiveness to the environment, reducing the child's ability to acquire adaptive skills (Maag, Rutherford, Wolchik, & Parks, 1986). Responses to auditory stimuli (Lang et al., 2010; Lovaas, Litrownik, & Mann, 1971), spontaneous appropriate play (Koegel, Firestone, Kramme, & Dunlap, 1979) and discrimination learning are compromised (Koegel & Covert, 1972) through the child's self-absorption, suggesting that these inappropriate behaviours are performed at the expense of other behaviour (Willemsen-Swinkels et al., 1998).

Earlier studies by Cass (1996), Hoshmand (1995), Jordan (1996) and Murdoch (1997) offer similar statements suggesting that stereotypic behaviour may actually present significant obstacles for learning by compromising

educational opportunities through the child's increasing self-absorption. Recent studies by Barkoukis, Reiss and Dombek (2013), Coots and Ringeon (2007), and Ellis (2013) state that the behaviour can compromise normal activities such as learning at school.

Stereotypic behaviours are perceived negatively by others because they create feelings of discomfort and embarrassment (Estevis & Koenig, 1994; Murdoch, 1997; Nind & Kellett, 2002). They also have a negative influence on the development of self-esteem for the child who is blind (Estevis & Koenig, 1994) and lead to impoverished social relations (Duker et al., 1989; Wolffe, 2006). Coots and Ringeon (2007) even describe the behaviours as addictive, isolating and negative.

Stereotypic behaviours can be of concern in relation to social acceptability in the sighted world, perhaps even stigmatising the child who is blind unnecessarily (Brambring & Troster, 1992; Cunningham & Schreibman, 2008; Cuvo, Conall, O'Cleugh, & Wadham, 1993; Daversa, 2001; Hoshmand, 1975; McHugh & Lieberman, 2003). This stigmatisation frequently relates to the labelling of the child who is blind as autistic (Andrews & Wyver, 2005; Edelson, 1995; Lowry & Sovner, 1991), or as having an intellectual impairment or emotional disorder (Brambring & Troster, 1992). As a consequence, the negative connotations of these labels may result in marginalisation of the learner in particular social environments.

A number of social skills checklists and assessment criteria are available to establish levels of attainment of socialisation skills in relation to age in the sighted population. Two examples of checklists for learners who are blind are The Oregon Project (Anderson, Boigon, Davis, & de Waard, 2007) and the SSAT-VI (McCallum & Sacks, 1993). Use of these or similar assessments may be helpful in providing guidelines as to the current level of social skills in relation to chronological age for children who are blind.

2.6 Intervention Strategies to Change Stereotypic Behaviour: FBA

A discussion of intervention strategies used in a number of studies highlights the need to consider functionality. Kerr et al. (2013) suggested that stereotypic behaviour is a social construct and is an interaction between the person and environmental factors. This thinking provides an overall perspective for intervention discussion, as the functionality and appropriateness of the behaviour within particular environments is a key consideration. Developing strategies for effective intervention to change behaviour excesses to those that are more socially acceptable within the environment in which they occur is key to these discussions.

A large body of literature points to a relationship between social acceptability and positive educational outcomes. In the words of Beckei and Luthar (2000, p. 20), “socially acceptable behaviour in turn promotes social inclusion and a sense of belonging”. To bring about behaviour change that may lead to social acceptability within educational settings, it is essential to try to understand the purpose of the stereotypic behaviour. This is a strategy espoused by many researchers (Alberto & Troutman, 2010; Daversa, 2001; Iwata et al., 2000; Kennedy et al., 2000; Prochnow, 1997). However, as Cunningham and Schreibman (2008) caution, there are other challenges to changing stereotypic behaviour because the automatic reinforcement itself is resistant to change. If the reinforcement can also be changed, these authors consider that the strategy may lead to more positive outcomes for learners. This, therefore, involves a Functional Behaviour Assessment.

Functional Behaviour Assessment (FBA) is the systematic identification of antecedents, consequences and hypotheses regarding the behaviour (Iwata et al., 2000; Jolivet, Scott, & Nelson, 2000). This approach recognises that there is a relationship between the purpose of all behaviour and desired outcomes (Alberto & Troutman, 2010; Ayres & Hedeem, 2002;

Carr & Durand, 1992); Mace, 1994). FBA describes problematic and challenging behaviour with the aim of identifying relevant environmental factors (McEvoy & Reichle, 2000) and the settings/events, i.e., variables, that influence the probability that the challenging behaviour will occur (Hanley et al., 2003). Factors that may cause students to maintain the challenging behaviour are both identified and analysed, interventions are then planned that are the most appropriate to reduce, replace or eliminate the challenging behaviour.

It is important to remember that FBA involves collecting a set of information through direct observation, interviews and rating scales that provide quantitative analysis of the challenging behaviour in order to establish the patterns of the behaviour. This leads to valid hypotheses (Heinemann et al., 1999; Liaupsin, Scott, & Nelson, 2000; Rapp & Vollmer, 2005). This information, together with the ecological events surrounding the behaviour, is analysed to determine the function of the behaviour. An intervention is planned and observations of the behaviour, as it occurs when change is implemented, are then undertaken. Therefore, function-based assessment focuses on the purpose of the behaviour as defined by the environmental events that occasion and maintain it (Alberto & Troutman, 2010). The focus of FBA is on function and context.

All behaviour has a number of different purposes (Starin, 2004), the basis of these being a level of communication (Ayres & Hedeem, 2002). Four possible purposes are:

1. To gain attention, the function being social interaction.
2. To gain something tangible, the function being to receive an object/activity/event.
3. To gain sensory stimulation or self-regulation, the function being a sensory experience.

4. To avoid a task, an interaction or to escape from internal stimulation, the function being to avoid discomfort or pain (Alberto & Troutman, 2010; Ayres & Hedeem, 1997).

FBA therefore aims at establishing the functional relationship between the behaviour and the consequences i.e., the purpose of the behaviour. Intervention strategies such as positive/negative reinforcement, stimulus control, punishment and extinction are used to change behaviour. Interventions are based on the least intrusive (least aversive) procedure and the identified function of the challenging behaviour (Alberto & Troutman, 2010). Therefore it is seeking to understand the function of the behaviour that is regarded as important (Cunningham & Schreibman, 2008), especially when considering stereotypy.

2.6.1 Case Studies to Change Stereotypic Behaviour in Children who are Blind: Overview

Case studies have helped to demonstrate the use of intervention strategies for changing stereotypic behaviour. These studies, based on the theoretical understanding of the aetiology of the behaviour, illustrate a range of interventions, used either on their own, or in combination with a second procedure, that have proved effective in reducing and/or eliminating stereotypic behaviour.

LaGrow and Repp (1984) reviewed 60 studies of intervention strategies used to suppress stereotypic behaviour. These studies provide an interesting outline of the use of functional assessment/analysis in school-aged students. Stereotypic behaviour descriptors were categorised into 50 types with interventions sorted into four groups. These were: manipulation of settings or antecedent events, aversive procedures, positive procedures, and sensory stimulation. This review showed that aversive procedures were the most

effective, although in the current climate such procedures are not highly regarded in the school setting. In their review, positive procedures and sensory extinction were found to be less effective, with manipulation of settings plus antecedent events being minimally effective.

These findings are contrary to the more recently documented theory of Alberto and Troutman (2010), who argued that intervention beginning with the use of the least intrusive procedure is most appropriate when considering eliminating stereotypic behaviour. Procedures that are less aversive may reduce or suppress such behaviours. Punishment-based procedures such as time-out, overcorrection, response cost and contingent stimulation may actually eliminate the problem behaviour according to Iwata et al., (1994).

Ayres and Hedeon (1997) offered a contrasting viewpoint; their research indicated that punishment alone may actually stop any chance of teaching more appropriate behaviours. Pelios, Morren, Tesch, and Axelrod (1999) also noted that trends away from the use of punishment-based procedures have evolved as functional analysis of the problem behaviour has increased. Behaviour modification, using reinforcement and punishment, is now being replaced by functional assessment, coupled with a range of intervention procedures. This trend validates the outcome of studies such as those undertaken by Ayres and Hedeon (1997) and Rapp and Vollmer (2005).

Review of a number of case studies by Rapp and Vollmer (2005) over the past two decades supports the use of several antecedent and consequent interventions to reduce stereotypy. They note that the earlier LaGrow and Repp (1984) studies suggested antecedent interventions were less effective than consequence-based interventions. There is some discussion that intervention may result in a decrease in one stereotypy and an increase in another. There has been a preponderance of literature on interventions, but many such studies have only considered topographical features and not

functionality. It is functionality that is so important (Rapp & Vollmer, 2005). This review records that the most effective interventions to decrease stereotypy were environmental enrichment, differential reinforcement, and punishment.

Determining the function of the behaviour and basing the intervention on hypothesised causes increases the likelihood of changing the inappropriate behaviour (Neef & Iwata, 1994; Rapp & Vollmer, 2005). A number of authors offer similar findings and suggest behavioural function is “highly relevant” to the intervention. Failure to identify the function often results in the selection and implementation of ineffective procedures (Starin, 2004). The need for a multi-modal approach, whereby decision-making about assessment and intervention plans involves a team, is espoused by Miller, Tansey and Hughes (1998). Improvement and refinement of functional methodologies remains essential to ensuring this approach continues to show rigour (Hanley et al., 2003; Pelios et al., 1999; Rapp & Vollmer, 2005; Scott et al., 2004).

2.6.2 Specific Studies

A number of case studies highlight the use of aetiological theory and functional analysis across a number of settings, with a wide range of students who were blind. Once the function of the behaviour was established, a selection of intervention procedures was used. In most instances, the stereotypic behaviour was significantly reduced, eliminated or replaced with more appropriate behaviour. Past studies by Durand and Kishi (1987), Estevis and Koenig (1994), Freeman, Goetz, Richards, and Groenveld (1991), Gerra, Dorfman, Plaue, Schlackman and Workman (1995), Gourney (1998), Lancioni et al., (1984), Luiselli, Myles, Evans & Boyce (1985); Miller and Miller (1976), Pico (1996), Ross (1992), Thurrell and Rice (1970), Transon (1988) and Troster et al., (1991b) are noteworthy, however more recent studies provide some support for considering functionality from a behavioural perspective.

Blake (2002) reported on a case study that provided detailed information about eye pressing, rocking, bouncing, spinning and head banging in children who are blind. Her advice, as an outcome of her research, centred on acknowledging that all behaviour serves a purpose, therefore identifying the functionality of the stereotypic behaviour and replacing it with more socially acceptable behaviour that serves the same purpose or eliminates the need for the disordered behaviour is essential.

Deasy and Lyddy (2009) provided an interesting report on a nine-year-old girl who is deaf blind. She was considered to exhibit stereotypic behaviour in the form of a ritualistic sequence of signs that occurred 30–40 times daily, as well as what seemed to be repetitive hand/finger pulling. Observations across a range of contexts indicated the functionality of the repetitive signing. This was thought to be a desire for confirmation and imitation of the sign from an assigned communicator or her mother. Once the sign was imitated and an appropriate response occurred, the repetition ceased. The hand/finger pulling related to a thimble she liked to play with. The challenges of communication for those with a dual sensory loss are complex, yet identifying the function of the signing resulted in improved communication and a reduction in what was perceived to be stereotypic behaviour.

McHugh and Lieberman (2003) undertook a study of 52 children who were visually impaired, 15 of whom demonstrated stereotypic rocking, either at the time of the study, or prior to its commencement. Their studies aimed to examine developmental factors in relation to rocking using descriptive and qualitative analysis. The research concluded that rocking emerges “with a pattern of developmental factors including eye condition, early medical history together with the extent and duration of visual loss” (McHugh & Lieberman, 2003, p. 470). These outcomes are similar to those of Andrews and Wyver (2005), and reinforce the idea that analysis of functionality and consideration

of appropriate interventions that aim to eliminate rocking are necessary to ensure they are more likely to be effective.

Sharkey and Asamoto (2000) adopted an interesting approach when studying blindness in relation to hand gestures and communication. Their studies suggested that although people who are blind use hand gestures referred to as “adaptors” (tactile hand movements), these gestures are often inappropriate as they are in the form of stereotypic behaviour. The gestures impact on verbal interactions with the sighted world. They may stigmatise the person who is blind unnecessarily and inhibit communication. By analysing carefully the purpose of the hand movements, Sharkey and Asamoto discussed the need for socially appropriate communication guidelines to assist the population who is blind, which in turn may provide more effective social interactions.

Van Gendt (2009) undertook a project involving a two-year-old girl who is blind from Leber’s Congenital Amaurosis (LCA). She exhibited eye poking using her fists. Her parents feared negative aesthetic outcomes for her and were concerned about further passivity and social withdrawal. FBA confirmed eye poking occurred during specific activities but did not occur when she was in a swimming pool or a bath. The eye poking was more aggressive when she was tired, annoyed or displeased. Activities were selected where eye poking was unacceptable and an increase in activities involving cold water was trialled. Eye poking diminished when she was more active, as other play developed and when counter movements were regulated.

To summarise, this snapshot of studies highlights aetiological theory and the use of function based analysis of the stereotypic behaviour. This analysis is utilised to consider intervention strategies that are based on the operant function of the behaviour, some strategies often being used in combination. Changing inappropriate behaviour to more culturally socially

appropriate behaviour was the desired outcome in all the case studies. However, there is little recorded evidence in these studies of improved engagement in learning, improved learning outcomes or more successful peer group interactions. This, therefore, demonstrates a critical gap in this area of social research. What is happening for learners who are blind and exhibit stereotypic behaviour, in respect to their learning and in the acquisition of socially appropriate skills, remains unclear.

2.6.3 Divergent Theories: Is Intervention Always Required or Appropriate?

Divergent theories are evident in relation to intervention when stereotypy is present in children who are blind. Some adults who are blind, along with parents and teachers, offer opposing philosophies, especially in relation to issues of personal autonomy for the child who is blind (McHugh & Lieberman, 2003). One theory, as stated by McHugh and Lieberman (2003), is that “such behaviour is an idiosyncrasy or individual difference that should be ignored” (p. 472). Therefore, intervention is not justified when considering mannerisms. The belief is that this behaviour allows the child who is blind to gauge their own physical relationship within the world (De Lucia, 2003). This thinking suggests a move away from the behavioural approach to a more modern philosophy of the rights of the disabled.

Earlier literature considering aetiological theories noted that some stereotypic behaviours in children who are blind are thought to be transitory, and will disappear with maturity as more socially acceptable behaviour develops (Fazzi et al., 1999; Thelen, 1979, 1981; Troster et al., 1991a). These stereotypical behaviours therefore do not require intervention. The difficulty though is working out whether they will disappear or be retained (Brambling & Troster, 1992; McHugh & Lieberman, 2003). This literature suggests thinking about aspects of transition during critical periods of child development.

De Mario and Crowley (1994) wrote that focusing on positive behaviours will naturally reduce negative behaviours, whilst Ayres and Hedeon (1997) wrote that responding in a positive and supportive manner may assist in bringing about behavioural change. LaGrow and Repp (1984) consider that teaching a means of discrimination between times when stereotypy is considered appropriate or inappropriate is useful. Fazzi et al., (1999) and Gahbler (2002) philosophise that these behaviours are predominantly preventable, and place emphasis on early intervention procedures that prevent the stereotypic responses becoming established. Their suggestions include:

1. Increasing the child who is blind's sense of security and self-control.
2. Facilitating a greater use of the body, especially use of the hands for touching/exploring.
3. Providing increased contact with others including with others who are blind.
4. Counselling about body language.

Fazzi et al., (1999) consider such early interventions will assist the child who is blind to "re-establish contact ... and communicate with the world" (p. 527). Likewise Berkson and Tupa (2000) discuss the relationship between early and late programmes, with Koegel and Koegel (1989) suggesting prevention rather than elimination is a better option when precursors that lead to abnormal development of these behaviours can be identified. Symons (2000) questions when early intervention is appropriate or inappropriate and suggests that identifying the key variables that lead to the initial emergence of the behaviour are imperative. Early intervention becomes the focus here.

However, the decision to intervene systematically to reduce socially inappropriate behaviours that are well-established, according to Brambring and Troster (1992), is not easy for there are often negative side effects of intervention, especially in aversive procedures that may be too stressful for

the child who is blind and their family. “How much these behaviours hinder the formation of an age appropriate behavioural repertoire, or interfere with socially appropriate behaviour, or ... cause injuries, requires consideration” (Brambring & Troster, 1992, p. 105). Prevention is clearly desirable in most situations, according to Fazzi et al., (1999); however, intervention to change stereotypic behaviour remains debatable. LaGrow and Repp (1984) concur with these cautionary thoughts, suggesting that research is necessary to establish whether “elimination of the behaviour correlates with more attention and learning” (LaGrow & Repp, 1984, p. 607). Here, again, is the impetus for this study. Much of this literature is dated – however there is currently a greater emphasis on the rights of the individual, not only how they manage their own behaviour, but on the ways they receive their education.

2.7 Implications of Mainstreaming (Inclusion) in New Zealand

How then do learners in New Zealand receive their education? The Education Act 1989, Section 8 (Ministry of Education, 1989b), emphasised the rights of students with special needs to enrol and receive education in state schools. The Special Education 2000 policy was developed by the New Zealand Ministry of Education in 1995 (Ministry of Education, 1995) and provided a range of reforms, aiming to produce a world-class inclusive education system for New Zealand (Greaves, 2000). Historically, “special education” students had been excluded from state education since its inception in 1877. By 1917, special classes were introduced for students who were previously seen as unsuccessful – however, students with sensory difficulties remained in separate establishments, often hospitals. The general worldwide trend of excluding students with special needs continued until the influential 1975 Education for All Handicapped Children Act in the USA was promulgated, as human rights issues were promoted and the goal of educating students with special needs in the least restrictive environment was embraced.

Mainstreaming, with a focus on physical assimilation was adopted in New Zealand throughout the 1970s and 1980s, in line with concepts of social democracy (Dunstall, 1992). Some special classes and special schools were closed, and satellite classes established. However, control was centralised, often resulting in inefficient service delivery (Dunstall, 1992). A draft review in 1987 was prepared, which advocated the integration of students and resources into mainstream classes, yet mainstreaming options such as special schools remained. A further report entitled “Tomorrow’s Schools” (Ministry of Education, 1988), and the Education Act of 1989 (Ministry of Education, 1989a), the principles of which were equity, quality, efficiency, economy and effectiveness (Ministry of Education, 1989a), resulted in major reforms in education for all students with special needs in New Zealand schools. These reforms, supported by the Special Education 2000 policy, have resulted in a paradigm of inclusion whereby the needs of students are seen as a social construct in the interaction between student and learning environment (Davies & Pragnell, 1999). At that time these students with special needs numbered 5.5% of the school population (Wylie, 2000), with students who are blind estimated at 0.016% of the total school-age population as documented in “Snapshots of New Zealand” (Statistics NZ, 2008) and 0.3% of the special needs population.

The implications of this inclusive policy are that the majority of children who are blind are integrated into regular settings in New Zealand, the responsibility for their education resting with individual schools with the assistance of Resource Teachers: Vision and financial resourcing from the Ministry of Education. Individualised Educational Plans are recommended for students who are blind as a means of identifying needs and providing education appropriate to their needs. This presupposes that socially acceptable behaviour is required in regular settings in order for children to learn.

2.8 Culturally Socially Acceptable Behaviour

How children who are blind learn and what is meant by culturally socially acceptable behaviours has been the topic of much discussion. These children do not learn social skills incidentally or through imitation and modelling. Learners who are blind require direct instruction about socialisation skills to develop successful social interactions, self-esteem and the confidence to take risks (Wolffe, 2006). Without these skills, they are at risk of social isolation.

When considering learning contexts together with culturally socially appropriate behaviour and how social behaviour is learnt, it is of interest to consider models of social development theory. The Trait or Maturational Model refers to personality traits of an individual and how these impact on social behaviours. Gold, Shaw, and Wolffe (2010) wrote that “self-centredness, unresponsiveness to the concerns and interests of others, unusual language patterns and a preference for interaction with adults” (p. 431) are common in children who are blind. This is a somewhat controversial statement but is important to reflect upon when considering issues of social interaction.

The Molecular or Component Model refers to social skills as “observable units of learned verbal or nonverbal behaviours that when combined can foster successful interactions”. This means learning from others (Sacks & Wolffe, 2006, p. 54).

The Process Model “assumes that social skills are components of specific actions or sequences of behaviours that create specific encounters” (Sacks & Wolffe, 2006, p. 55). In particular, this third model assumes the use of vision as well as learning from others, for it relies on the ability of the individual to perceive the social environment and the internal needs of others.

Without vision, it is clear that social development becomes more challenging. Sacks and Silberman (2000) developed a hierarchy of social skills as a guide relating to learners with a vision concern. In stage one the learner needs to acquire an awareness of social environments and the use of social behaviours to make sense of the world. The second stage is interactive, where individuals learn to use their past experiences to combine social behaviours with communication to influence social encounters and exchanges. The third stage is evaluative, in that individuals have the skills to interpret social situations. The learners at this level can modify and evaluate their own social behaviour and interactions.

How these skills are learnt and in what particular context they are learnt is relevant. Initially it can be assumed that skills are learnt through family/*whānau* associations, then over time they are learnt through contact with classmates. Inclusion makes an assumption that learners who are blind will learn social behaviours in an interactive manner and, as they mature, they will learn to negotiate the intricacies of social behaviours through experiences in social environments. Therefore, both cultural identity and placement within educational settings is significant when considering how children who are blind learn social behaviours that are culturally appropriate. Information on these concerns is currently not known.

2.9 New Zealand Studies

Research in New Zealand in the broad field of Special Education has in recent years focused on a number of issues. Reviews and studies that reassess Ministry of Education policy changes and their effects have been undertaken. Inclusive education studies by Bourke and Mentis (2010), Kearney (2009) and MacArthur (2009), have contributed to this knowledge base, although little has been published that is specific to learners with a vision impairment. Godfrey and Brunning's (2009) project on the Cost of Blindness for families with a child who is blind is noteworthy, as is Higgins, Phillips, Cowan, and Tikao's (2009)

paper about New Zealand services for *Kapo* (Blind) *Māori* in respect to health and education. Earlier studies by Nagel and Raxworthy (1996) discussed collaborative practice focusing on the parent–professional relationship. However, as stated previously, there are currently no published papers on the issue of stereotypic behaviour in New Zealand children who are blind.

2.10 Conclusion

Some of the literature appears to confirm that stereotypic behaviours are not exclusive to children who are blind; however, some repetitive motor movements such as body rocking are particularly prevalent in this group of children and certain behaviours that involve the visual system are generally only exhibited by children with this sensory concern. These stereotypies are considered self-stimulatory for the child who is blind and are of concern when they compromise learning or socially isolate the child.

A number of aetiological theories are espoused to explain the causes of this behaviour, how it is maintained and what conditions contribute to the development of stereotypy. There is clearly a relationship between vision loss and the functionality of these specific maladaptive behaviours. Theorists concur that the child who is blind has concerns with environmental issues and the development of skills in a number of competencies.

There is a lack of empirical evidence endorsing the philosophy of inclusion, specifically as to whether it effectively prepares all learners who are blind to be more fully included in society. Debate continues surrounding the reality of inclusion in educational settings for learners who are blind in New Zealand – for those who have associated additional disabilities, and more so for those who also display stereotypic behaviour. Similarly, debate continues surrounding aetiological theories, functionality and the remediation of these

behaviours. This is about the rights of the individual, their cultural identity and of societal expectations.

Even in 2014 there remains the same “paucity of research” that Eichel described in her 1979 paper. She went on to argue that this paucity continues to impact on “the development of a cohesive body of knowledge ... of manneristic behaviour” in children who are blind (Eichel, 1979, p. 167). Whether there is an impact on the development of culturally acceptable behaviour for both *Māori* and children of European ethnicity in New Zealand, and how this might affect learning, continues to be a question of importance. Although international historical studies refer to intervention strategies to change behaviour, the rights of the individual are paramount in today’s world. Little is known about stereotypic behaviour and little is known about the impact of this disordered behaviour in respect to learner outcomes for children who are blind in *Aotearoa*.

Chapter Three

The Research Design and Methods

3.0 Introduction

An exploration of the methodological theory underpinning this study explains why the research design involved the use of mixed methods research methodology. The quantitative methods were used to inform the survey and case study research, while qualitative methods were used in the case studies. This research was conducted to determine the prevalence, type and context of stereotypic behaviour among school-aged children in New Zealand who are blind. Further, it investigated a sample of five children from this group to explore and describe the real-life conditions within the context of the mainstream classroom in respect to the learning environment, the curricula and achievement levels.

3.1 Chapter Overview

This chapter presents an overview of the research philosophy, methodology and methods used in this research project. Mixed methods research methodology, which involves the traditions of both the quantitative and qualitative methodologies, is discussed.

The quantitative phase of the mixed methods research was employed to provide a systematic, empirical, objective investigation of the prevalence, type and context of stereotypic behaviour in New Zealand children who are blind. The views of the parents/caregivers of school-aged children who are blind were surveyed using purposive sampling of families listed on the BLENNZ national database. This group of 128 parents/caregivers received a postal questionnaire, designed to provide specific data about their child. Data gathered from the questionnaires were analysed using descriptive statistics.

Discussion is centred upon the relationship between these statistics and those identified in international research as detailed in the literature review.

The qualitative phase of the mixed methods research was used to analyse holistically and contextually the subjective reality for five particular children who are blind. Using intensity sampling, the five students were selected using the criteria of age, ethnicity, educational placement and geographical location. The Resource Teachers: Vision (RTVs) of these students were interviewed. The purpose of these interviews was to explore and describe how and whether stereotypic behaviour impacted on the child's learning in their mainstream classroom and on the child's acquisition of appropriate socialisation skills. The collected data were examined and triangulated as described by Cohen, Manion and Morrison (2011) and Hussein (2009). Findings were interpreted in relation to existing theories and to explanations concerning stereotypic behaviour in children who are blind. The aim in using both research methodologies in a mixed methods design was to ensure a greater understanding of the identified population. Using the two research methodologies in tandem has greater overall strength than each paradigm alone, as espoused by Cresswell and Plano Clark (2007).

The chapter is separated into seven sections. First, the theoretical framework is described in respect to knowledge claims and strategies of inquiry. Second, mixed methods methodology is explained in detail, including the historical development of this methodology and the debate around the paradigm wars in respect to stances held. The value of this approach is referred to, as is the use of triangulation. The two common design categories are noted (the concurrent and sequential), and an explanation of Sequential Explanatory Design is presented. The third and fourth sections present information about data collection and analyses for both the quantitative and qualitative stages of the inquiry. The chapter in the fifth section then offers a discussion on insider research. Ethical issues, assumptions, bias and

limitations follow in the sixth section. The chapter concludes in the seventh section with a summary.

3.2. Theoretical Framework

In designing a framework for research, a number of elements and interrelated concepts inform the choice of approach. These can be considered as four questions: what epistemology informs the research; what theoretical perspectives sit behind the methodology under discussion; what methodology governs the choice and use of methods; and what methods are proposed to be used? These can be conceptualised as the philosophical assumptions that constitute knowledge claims, the strategies of inquiry and the procedures that relate to data collection, analyses and the narrative (Creswell, 2009). An understanding of how these three elements combine is essential in designing research.

3.2.1 Knowledge Claims

The first element, that of knowledge claims, involves assumptions about “how” and “what” will be learnt through the inquiry. These claims may be referred to as paradigms, philosophical assumptions, epistemologies, ontologies or research methodology. There are a number of positions surrounding the development of knowledge claims, from those of post-positivism to constructivism to advocacy/participatory to pragmatism.

Postpositivism claims challenge the positivist approach and recognise that it is not always possible to be “positive” about knowledge claims when working with human beings. Postpositivism has two forms: postpositivism as a revised form of positivism, what I shall refer to as postpositivism-positivism, and postpositivism as a new paradigm, namely constructivism. Positivism reflects a deterministic philosophy (Cresswell, 2009), suggesting that causes probably influence outcomes. It is reductionist in that information is reduced in

order to test it. The approach aims at developing “numeric” measurement. Research by postpositivist positivists continues to begin with a theory, collects data, then supports or rejects that theory. Phillips and Burbules (2000) define the key assumptions clearly. These are that knowledge is conjectural. The research makes claims then refines those claims. Data, evidence and rational considerations then shape knowledge. The research aims at developing statements to explain a situation or describe causal relationships in respect to the inquiry. The goal of the inquiry is to be as objective as possible with emphasis placed on achieving validity and reliability.

Second are the knowledge claims of Social Constructivism (the other form of postpositivism). Constructed knowledge claims are those that assume that individuals seek understanding of the world in which they live (Creswell, 2009). This is an approach where subjective meanings are made from experiences; outcomes may be varied and complex, rather than involving the narrowing of categories. Knowledge claims relate to the individual’s viewpoint, and are often as a result of interactions with others. The constructionist approach is about the process of drawing meaning from these interactions and the contexts in which they occur. Researchers position themselves within the research, acknowledging they are shaped by their own experiences. The researcher aims at interpreting the meanings others have about the world. Theory is developed in an inductive manner, as opposed to starting with a theory as in postpositivism-positivism.

A third type of knowledge claims; critical theorists, are those that take an advocacy and participatory approach. Those who support advocacy and participatory knowledge claims have concerns about issues of social justice (Creswell, 2009). Groups that may be considered marginalised relate to this paradigm as it focuses on an agenda that aims at bringing about change, empowerment; the emancipation of structures that limit personal development; and seeks to address alienation, oppression or inequality. This approach focuses on effecting a change in practice of some type that will help

individuals who are under constraint. It is somewhat practical in that it involves collaboration with participants.

The fourth position entails pragmatic knowledge claims, whereby the focus is on the problem, not the method of research. This position most often underpins the philosophy of mixed methods research. The attention is focused on the research problem, pluralistic approaches are then used to gain knowledge about the problem (Tashakkori & Teddlie, 1998). Therefore, pragmatism does not adhere to any one particular philosophy or approach. Methods are chosen that relate to needs and purposes. The world is not seen as an absolute entity – the aim is to obtain the best understanding of the research problem, and the intended consequences of the research, in order to provide detailed information as it emerges.

3.2.2 Strategies of Inquiry

Assumptions about knowledge claims, therefore, underpin the strategies of the inquiry (Cresswell, 2009). The quantitative and qualitative research approaches have four principal axiomatic base differences. First is ontology, or the nature of reality. In the quantitative approach, a single study depicts objective reality and is dissectible into parts for testing. In the qualitative approach, the research involves multiple subjective dimensions and socially constructed realities; it is holistic and cannot be dissected. The second axiomatic base difference is epistemology, which is the relationship between the “known” and “knower”. In quantitative research, the relationship is separate and objective and in qualitative research, relationships are inseparable and interactive. Third, the purpose of research in the quantitative approach is prediction and generalisation, influenced by laws that hold across individuals, settings and times. In the qualitative approach, the purpose is contextualisation, with generalisation being unattainable, and it is the responsibility of the reader to decide whether or not transfer of information is useful and/or appropriate. The fourth difference is the nature of causation. In

the quantitative approach, causation is suggested by statistical association and in the qualitative approach, the possibility of causation is not considered relevant.

A combination of these strategies of inquiry is referred to as “mixed methods”, whereby both designs are mixed or combined in a single study to permit multiple approaches to all aspects of the research. This approach allows the researcher to make pragmatic knowledge claims. Strategies of inquiry involve data collection that can be simultaneous or sequential. Data collection involves numeric and text information, meaning the final database contains both quantitative and qualitative information.

3.3 Mixed Methods: A Definition

Mixed methods uses both quantitative and qualitative approaches in tandem and may be considered to be in the middle of the design continuum of the quantitative and qualitative paradigms (Cresswell, 2009). Creswell (2009) provides a good definition of this method of research:

... mixed methods research is a research design with philosophical assumptions as well as methods of inquiry. As a methodology, it involves philosophical assumptions that guide the direction of the collection and analysis of data and the mixture of qualitative and quantitative approaches in many phases in the research process. As a method, it focuses on collecting, analysing, and mixing both qualitative and quantitative data in a single study or series of studies. Its central premise is that the use of quantitative and qualitative approaches in combination provides a better understanding of research problems than either approach alone. (p. 5)

This field of methodology is at times referred to as the “third methodological movement” and has evolved in part due to the controversy

surrounding the quantitative and qualitative approaches, since through triangulation it uses the strengths of both (Johnson & Onwuegbuzie, 2004). Gorard and Taylor (2004) together with Tashakkori and Teddlie (2003a) suggest that mixed methods research has now become “a separate methodological orientation with its own world view, vocabulary and techniques and may soon be accorded a separate status” (p. 9).

3.3.1 Mixed Methods: Overview

However it is defined, mixed methods research and design “continues its ascent in the social and related sciences” (Bergman, 2011a, p. 271). Although there is now wide recognition of this approach, debate and discussion is prolific about the apparent absence of conventions, methodological sophistication and orthodoxy (Gorard & Taylor; 2004; Tashakkori & Teddlie, 1998). Much of this discourse has been published as a range of narratives referring to “politics, pragmatism, paradigm, third moment, methodology and triangulation” (Denzin, 2012, p. 80). It is interesting to consider that mixed methods research and design is so controversial that it has energised a plethora of literature focusing on these issues, while also aiming to justify the expanding popularity of this approach.

There is no dispute that the results of any empirical study of phenomena are influenced by the theoretical framework and research methods employed. These methods are “usually selected on their appropriateness to the research question with data collection and analysis methods strongly influencing the part of the phenomenon to be studied” (Bergman, 2011b, p. 99). In other words, any project includes epistemology, ontology, a theoretical framework, research questions, sample strategies and interpretations that are then conducive to the methods. For mixed methods research, the controversy is about the perceived absence of a recognised framework and the mixing of features that define a research design raising questions as to rigour. Bergman states that in mixed methods research and

design the rules are not clear, and at times may lead to “inconsistent and impoverished research” (Bergman, 2011b, p. 99), as “theoretical and conceptual shortcomings can translate into logical and procedural inconsistencies” (Bergman, 2011a, p. 271). Authors such as Harrits (2000) disagree with these criticisms of mixed methods research, claiming that the breadth and depth offered with this approach enhances the integrity of the findings. The approach is perceived to increase understandings, providing greater assurances of consistency and of conceptual certainty. This has not always been considered to be so.

3.3.2 Mixed Methods: Historical Development

Over time, perspectives have changed as researchers have explored the mixed methods approach. Campbell and Fiske (1959, cited in Tashakkori, 2009) are considered to be responsible for the foundations of mixed methods with their multi-trait, multi-method approach. However, since then, this methodology has continued to evolve. The literature states that until the 1990s, mixed methods researchers combined a variety of collection and analysis methods from the quantitative and qualitative approaches, unencumbered by discussions regarding incompatibility and paradigm wars (Bergman, 2011a). From the 1990s onwards, researchers such as Plano Clark, Brannen, Bryman, Cresswell, Tashakkori and Teddlie have all progressed to thinking about this methodology as being a new unified field of research with its own vocabulary, taxonomy and process description. That is, mixed methods research is its own coherent research paradigm (Harrits, 2011) and is not a combination, integration or interface with others. This thinking is not necessarily held by others, with a large number of published articles continuing to contribute to the debate.

3.3.3 Mixed Methods: Paradigm Wars

Much of this debate concerns the incompatibility of the postpositivist-positivist and constructivist central tenets. This notion is the position in which the

coherent belief structures and the assumptions about life differ greatly. For ontology, it is critical realism versus relativism; for epistemology, it is the modified, dualist, objective approach versus that of the transactional subjectivist. For methodology, it is the modified experimental versus hermeneutical, dialectical approaches (Guba & Lincoln, 2005). Therefore, the debate centres on the term “mixed”, referring to the integration or combination of the quantitative, postpositivist paradigm and the qualitative, constructivist paradigm within a single study. It is reasonable to state that quantitative and qualitative research belong in different paradigms and are underpinned by different philosophical positions, addressing different themes and questions. The approaches differ in data collection, in data analysis as well as in the interpretation of the results. Therefore, critics ask:

How can we combine a perspective that subscribes to objectivity, unbiased and value-free research and the separation between the researcher and the researched, with a perspective that emphasises subjectivity, researcher context, value-laden research and the inseparability between the researcher and the researched? (Bergman, 2011a, p. 72)

3.3.4 Mixed Methods: Stances

Three stances about this controversial aspect of mixed methods research are documented in the literature. Many authors reflect on the paradigm wars from a purist perspective. A number of authors have focused upon the ever-present ideological differences. Morgan (2007) discusses the dichotomies in relation to the inductive–subjective contextual approach versus the deductive–objective generalising approach. Lincoln (2010) sees it as an impossible incompatibility. Denzin (2012) also refers to incompatibility but then offers discussions about pragmatism as a solution to the wars.

Pragmatism is a philosophical stance that relates to observable, practical consequences, not antecedent conditions. It is concerned with what

works, and this stance aims at placing the research problem as the focus. This pragmatic stance suggests that the paradigm differences are independent and can be used in conjunction to address the research question. Sharp et al., (2012), contribute that this philosophy assists in the conflict about the two approaches. Wheeldon (2010) summarises this stance by stating:

Pragmatism allows for a more flexible, abductive approach. By focussing on solving practical problems, the debate about the existence of objective truth or the value of subjective perceptions can usually be side-stepped. As such, pragmatists have no problem with asserting both, that there is a single, real world and that all individuals have their own unique interpretations of that world. (p. 88)

This stance also has its critics. These are referred to as dialectical researchers, who state that paradigms are compatible but differences in implications must be clearly stated (Greene & Caracelli, 1997).

3.3.5 Mixed Methods: Triangulation

Much continues to be written about mixed methods research and design as an approach that transcends paradigms (Harrits, 2011) or as an approach that bridges across both traditions (Castro, Kellison, Boyd, & Kopak, 2010), or is potentially complementary (Rinne & Fairweather, 2012). These latter authors, together with Burke Johnson, Onwuegbuzie, and Turner (2007), also discuss the issue of triangulation where collaboration of approaches means using the advantages and minimising the disadvantages of any one particular approach. Castro et al., (2010) go on to state that “triangulation provides strength of confirmatory results drawn from quantitative, multivariate analyses along with a deep structure, explanatory description as drawn from qualitative results” (p. 342). Greene (2008) adds that the approach is a distinctive mixing of practice whereby there is an opportunity to compensate for method weaknesses and capitalise on method strengths. Greene, Caracelli and Graham (1989) in

earlier research considered that this process would improve the chances that threats to any inferences would be controlled.

Hussein (2009) contributes to the discussions, further referring to reaping the benefits of two paradigms and minimising the drawbacks of each through triangulation. He identifies five types of triangulation: data, theoretical, investigator, analysis and methodological. Data triangulation refers to the use of multiple data sources in the same study for the purposes of validation. Theoretical triangulation is the use of multiple theories in the same study for the purpose of refuting or supporting different theories to assist in formulating hypotheses. Investigator triangulation involves more than two researchers in the same study to assist with confirmation. Analysis triangulation is the use of more than two methods for validation purposes. Methodological triangulation is the use of more than two methods in studying the same phenomenon.

Perhaps then, addressing the challenges of how to mix the two paradigms in the same study also adds to the inherent complexity in method selection for the researcher. How does the researcher conduct studies that minimise procedural issues and permit robust analysis? It is apparent that by using clear guidelines and the process of triangulation it is possible to assume that some of the challenges documented may be minimised.

3.3.6 The Value of Mixed Methods

Denzin (2012) quoting Cresswell, reminds us that there is continuing disagreement over definitions; questions are asked about what constitutes a study using this approach, and the paradigm wars continue, including those around the privilege afforded to postpositivism. Denzin then asks, what value is added by using this approach?

Clearly the approach challenges the limits of qualitative and quantitative methods in that applications of new methods do not follow

contemporary ideologies and conventions. Definitions of mixed methods research and design seem quite simplistic in comparison to much of the controversy. Tashakkori and Cresswell's (2007) definition states that mixed methods research is one "in which the investigator collects and analyses the data, integrates the findings and draws inferences using both qualitative and quantitative approaches or methods in a single study or program of inquiry" (p. 4).

Burke Johnson et al., (2007) state that the approach has "the broad purposes of breadth and depth of understanding and corroboration" (p. 167). The rationale for mixing data is grounded in the fact that neither quantitative nor qualitative methods are sufficient by themselves to capture the trends and details of a particular situation. When used in combination, they complement each other and permit for more robust analyses. Bergman (2011a) suggests that a supplementary perspective is also evident. Complex questions may seldom be answered by one method. Cross-validation is possible, findings are complemented and outcomes may combine different strands of knowledge. Sharp et al., (2012) consider that using different theories and perspectives is a useful way to gain an understanding of people. This approach is about action not philosophy, theory is informing practice, knowledge is constructed and is based on reality. Harwell (2011) adds it is also about "expansion which may clarify results or add richness to the findings" (p. 152). This is perceived as being the value of the approach.

Therefore, this rejection of the dichotomy between the two paradigms and progression to thinking about a third movement with a "distinct, nomenclature methodology and utilisation potential" (Tashakkori & Teddlie, 2010, p. 72) is now in vogue. Harrits (2011) and Johnson and Christensen (2012) also confirm this thinking in their work. The debates continue but so does the popularity of this new method.

3.3.7 Mixed Methods: Design Categories

Tashakkori and Teddlie (2003a) refer to a number of research designs within this new methodology, however Cresswell and Plano Clarke (2003) discuss the two most common categories: the concurrent and the sequential models, of which there are six in total. Concurrent occurs when both quantitative and qualitative methods are used at the same time to collect data, whereas sequential designs involve an order that limits integration of both data forms under a unified process of data analysis.

Bryman (2007) queries the growing pluralism about the way mixed methods research is conducted, expressing concern about the variety of typologies reported. Reference is again made to the two designs, but discussion is drawn to questions about the dominance and/or equality placed upon the qualitative or quantitative methods. This contributes to complex decisions about how to choose and how to implement mixed methods designs in order to best answer research questions. Such a decision was therefore required in respect to this project.

3.3.8 Mixed Methods: Sequential Explanatory Design

This particular project presents an example of Mixed Methods Sequential Explanatory Design. The single study is a two-phase consecutive process whereby collecting and analysing quantitative data and then qualitative data occurs. The purpose of this design is to explore a phenomenon to obtain statistical quantitative results from a sample then to expand on this through qualitative findings, using a small group of individuals to provide greater depth to the results.

The rationale for mixing both kinds of data within this present study is to capture the trends and details of the situation for the individuals. Quantitative data provided through a national survey and the subsequent

questionnaire analysis, provide a general understanding of the research problem. The qualitative data provided in the five case studies using intensity sampling explain these statistical results in a contextual manner by exploring the views of participants (Cresswell, 2003). The Sequential Explanatory Design type of mixed methods research provides the advantages of straightforwardness with the opportunity to explore the quantitative results of the study in more detail. The possible disadvantages and limitations are in the length of time this design may take to implement.

Mixed methods design provides the match between the problem and the approach. This specific approach is, therefore, the most appropriate in order to answer all aspects of the research questions, as it permits data collection in the form of a questionnaire and then analysis that is largely quantitative. This process is followed by collection and analysis of qualitative data through case studies. It is possible to generalise the findings to a specific population and develop a detailed view of the meaning of the phenomenon through the voices of individuals. With a philosophy that allows pragmatic knowledge claims, this stance reflects that of the researcher. The approach respects the perspectives of both quantitative and qualitative beliefs and allows for data triangulation and expansion to enhance the validity of the project (Johnson & Christensen, 2012). Mixed methods research considers a) multiple viewpoints and b) creates a synthesis of ideas (Harrits, 2011). These are the purposes of this study.

3.4 Data Collection Methods and Data Analysis: Survey

The survey provides a systematic method for gathering information from entities for the purpose of constructing quantitative descriptors of the attributes of a larger population to which the entities belong (Groves et al., 2013). The statistics generalise to quantitative summaries of observations; some may be descriptive and others analytic. This method is grounded in mathematical science and its accuracy is dependent on factors such as the

survey design, the ways data are collected and the way the sample is drawn. In the survey, data collection may involve structured or semi-structured interviews, standardised tests of attainment or performance, and attitude scales. However, a survey in the form of a questionnaire is considered to provide the easiest known way of assembling a mass of information. The aim of this present survey as a questionnaire was to describe the nature of existing conditions, and provide information from parents/caregivers about their understanding of stereotypic behaviour in their child. The development of this document included identifying the desirable characteristics of questions, asking the relevant questions, identifying the sample population, piloting the document and then amending the questionnaire accordingly.

3.4.1 The Questionnaire

It is critically important to match the questionnaire items to the research objectives, to understand the research participants and ensure the questionnaire is a uniformly workable document. Language must be natural and familiar, with questions that are clear and unambiguous to minimise potential errors from respondents (Johnson & Christensen, 2012). To assist in the creation of this instrument, this information along with a number of guidelines provided by Scott and Usher (2011), and by Babbie (2001), were considered. These authors suggest that flexibility in the design of the items, with the use of statements and Likert Scale responses, are “profitable”. Secondly, the use of both open-ended and closed coded questions with response categories being exhaustive and mutually exclusive is critical. Thirdly, ambiguous questions, and those that are over-precise, too complex, or contain awkward phrasing, lead to confusion and may suggest that assumptions have already been made. Likewise, composite and elaborated questions may have an impact on the responses elicited. Therefore, a number of decisions are required in relation to content, wording, the form of response and the sequencing of questions when constructing any questionnaire (Cohen & Manion, 2006). The design must minimise potential errors from respondents and coders. Since people’s participation is voluntary, a questionnaire has to

engage their interest, encourage co-operation and elicit answers that are as accurate as possible.

However the document is designed, the layout must be arranged so as to maximise proper completion. Questions need to be presented in an uncluttered manner, adequately spaced with checking boxes placed carefully. Initial questions should be simple and of high interest. Likewise, those at the end of the questionnaire should have similar characteristics. Clear instructions that are repeated when necessary are useful.

The choice of question type is elaborated on well by Newby (2010) and Scott and Usher (2011). These are listed as follows:

- Simple, closed, factual questions
- Simple, open, factual questions
- Structural, factual questions
- Simple, closed, opinion questions
- Closed, structured opinion questions
- Simple, open, opinion questions
- Closed, structured statement banks
- Open description
- Open lists
- Closed list or checklist
- Structured, rank, order lists
- Open, rank, order lists
- Partial agreement, statement or question

- Partial agreement, oppositional constructs

There are two fundamental differences in the types of questions presented. Firstly, possible answers are determined beforehand, and secondly, questions are open and respondents provide information in a comprehensive manner. The survey therefore provides a flexible approach to question styles depending upon the information sought. Initially this is likely to be factual knowledge; it may be about schemas and mental constructs, about analysis of situations or possibly about values and judgements (Newby, 2010).

3.4.2 Specific Questions

Considering this information, the design of the specific questionnaire for this project used these guidelines in the following manner. Initial information was provided about the rationale and purpose of the survey. Descriptions of the behaviour under discussion were presented. These descriptors and time categories were drawn from previous published research, while contextual selections were also drawn from the literature in respect to aetiological theories. Guidelines were provided for completion and return of the document. Initial questions were simple, related to personal information that was of high interest to the respondent, and aimed to engage respondents in the questionnaire so there was a commitment to completing all sections.

The following information outlines and elaborates on what and how information was sought through the questions.

Section One – Personal Details

This section sought personal information for the purpose of demographics through the use of an open and closed list of responses. Structured factual questions were included to secure information in relation to visual condition, visual acuity, and the existence of additional disabilities. Responses requested were exhaustive and aimed to elicit the information required to produce statistical data about the sample.

Section Two – Existence of the Behaviour

This second section also presented a simple closed factual question, asking the parent/caregiver if their child displayed the defined behaviour. This response required participants to “tick” a checklist of descriptors of stereotypic behaviour. Descriptors of behaviour were clear and an option was provided to present additional information. Phrasing was simple and unambiguous.

Sections Three and Four – Frequency and Duration

In order to establish how often the behaviour had been observed and the length of time an episode of the behaviour lasted, structured ranking responses were requested. These ranked frequency and duration on a 1 to 5 scale, with information being placed on the chart provided. Response categories were exhaustive and mutually exclusive.

Section Five – Context

In this section, five possible scenarios were provided to establish information in relation to the perceived contexts that triggered the behaviour. This section used the question type of closed, structured, opinion response. Likewise, the information was to be recorded on the chart provided. Response categories were again exhaustive and mutually exclusive.

Section Six – Additional Information

The final section sought further information from the respondents. This was a forum for responses and provided opinion and description options. This was included in order to expand on any aspect of the child's behaviour that the respondent wished to offer.

3.4.3 Pilot Study

Following the designing of the instrument, implementing a pilot study is considered to be the next crucial step. There are a number of reasons for conducting such a study: it may provide information about the research protocols to be followed, may identify the inappropriateness of elements of the proposed instrument, and may highlight any practical problems in the research procedure (Johnson & Christensen, 2012; Van Teijlingen & Hundley, 2001). To improve the internal validity of this questionnaire the pilot study used the following guidelines offered by Peat, Mellis, Williams, and Xuan (2002):

- The questionnaire is to be administered in the same way as it will be in the main study
- Feedback from respondents is to be requested to identify ambiguity or difficult questions
- Discarding of unnecessary, ambiguous, difficult questions will occur
- Establishing whether responses can be interpreted to give the information sought will occur
- Checking all questions can be answered
- Rewording of questions if necessary
- Revision of the setting out will be considered.

The revised and amended questionnaire (Appendix G) was distributed by post to a sample of the population upon the completion of the pilot study analysis. Owing to the small size of this population, there was some concern about contamination since new data from pilot participants would then be included in the main study (Peat et al., 2002). Although these respondents had already been exposed to the questionnaire, it was considered that the value of including them in the main study outweighed any negative concerns.

3.4.4 Sampling

“Sampling is a cornerstone of research integrity” (Abrams, 2010, p. 537) and it is fair to say that survey research requires careful sampling. Sampling is collecting information from some members of a population that has been accurately defined as a sampling frame. To ensure a representative sample, it is critical that the population is carefully defined, an unbiased sampling frame is also carefully defined, and a sample is selected using probability sampling methods. Probability sampling involves: simple, random sampling, systematic sampling, stratified sampling and multistage cluster sampling. The choice of sample type depends on the nature of the research, the availability of funding, the desired level of accuracy and the data collection method selected. Non-probability sampling is comprised of the following categories: quota sampling, dimensional sampling, convenience sampling, purposive sampling, snowball sampling, time sampling and extreme case sampling. Non-probability sampling is used when the criteria for selecting are known and when precise representativeness is necessary. This research involves purposive sampling, as respondents were selected from the BLENNZ database using predetermined criteria of visual acuity, age and educational placement.

Sample size depends on the degree of accuracy required and the extent of variation in the population in regard to key characteristics. Therefore, the sample size must result from the consideration of the degree of diversity

within the population in relation to the key variables, the level of sampling error that is acceptable, and the reliability of the sample. The final sample size chosen needs to be large enough to ensure that sufficient individuals are surveyed to provide meaningful data analysis. The sample size for this present research was based on the number of New Zealand school-aged children who are blind and who are registered on the BLENNZ database. Figures at the time of the study indicated that there were 128 school-aged children who are blind in this sample.

Some discussion is required about response issues. It has been suggested that a well planned survey should obtain at least a 40% response rate and then, with reminders, an additional 20% is possible (Cohen & Manion, 2006). Response rates of 50% are considered adequate for analysis and reporting (Babbie, 2001), therefore a response rate of at least 50% was the aim of this project. In this project, the percentage equates to approximately 64 responses. This process involved ongoing collaboration with the administrator of the BLENNZ database, who undertook the distribution and return of the postal survey in respect of the identified sample.

3.4.5 Analysis of the Survey

Summarising the data from a questionnaire may involve descriptive statistics in the form of frequency tables, bar charts, pie charts, histograms, frequency polygons and scatter plots. These may be nominal, ordinal or interval, with descriptive statistics showing the distribution of the data as unimodal, bimodal or multimodal. Statistical treatment may also be inferential in order to draw conclusions from the sample about the population as a whole. Suggestions of causal relationships can be considered and predictions may be possible between variables.

The present project uses tables and histograms to present the data gathered from the postal questionnaire. These data relate to demographic information, frequency, prevalence and duration of stereotypic behaviour, and the identified contexts where the behaviour occurs. Chi Square analysis is used to examine associations between the stereotypic behaviour and frequency, prevalence, duration and context. Results of these statistical data are compared with those from the international literature. From this, inferences are drawn about these aspects of the population of school-aged children in New Zealand who are blind, and some insight can be gained in relation to the range of theories documented in the international literature. Discovering more about the lived experiences for some of these children through a case study approach follows.

3.5 Data Collection Method and Data Analysis: Case Study

Case studies may take an interpretive and subjective approach that provide insight, discovery and interpretation. This is the qualitative approach and reflects postpositivist-constructivism, for it is about a reality that is socially constructed rather than objectively determined. This type of research deals with understanding the subjectivity of social phenomena (Noor, 2008).

Yin (2009) as well as Brantlinger, Jimenez, Klingner, Pugach, and Richardson (2005) refer to the case study method as an empirical inquiry that investigates the qualities of a contemporary phenomenon in a systematic manner within its real-life context. Yin (2009) states that this is an umbrella approach where multiple sources of evidence are used. It is an investigation of an individual, group or phenomenon that probes deeply and explores causation in order to analyse and find underlying principles (Bogdan & Biklen, 2003). "It is a detailed examination of an event which the analyst believes exhibits the operation of some identifiable general theoretical principle" (Mitchell, 2000, p. 170). The approach does not make any attempt to claim representativeness of a population, although some assumptions may be

made. The approach may be seen as a method of testing and generating certain hypotheses.

The strengths of the qualitative methodology are that it is based on what is meaningful for the case study participants, it is embedded within contexts and it is responsive to changes that occur during the research process (Anderson, 2010). There may be a difference between what is planned and what actually occurs (Noor, 2008), and this is accommodated within an emergent design. Mason (2002) contributes to this description by recording that it is an interpretivist methodology, in that data gathering is flexible and sensitive with analysis involving an understanding of the complexity of real life situations. Simply, this methodology is about understanding someone else's world (Gillham, 2005). Cohen and Manion elaborate further, emphasising that it is about making sense out of the social interactions of others and is not abstract generalisation (Cohen & Manion, 2006). The methods of qualitative inquiry therefore need to cope with subjective human experiences.

Qualitative methodology was identified as being that which would bring new insights and enhance understandings of the multiple realities that exist for these learners who are blind. It is about viewing the situation from the perspective of the participants to better discern their understandings of the behaviour. Using an interpretivist inquiry, the focus for this aspect of the project is on how the learners and those around them, particularly their teachers make meaning of their actions.

Through spending time in familiar contexts with the learners and conversing with their teachers, the researcher wanted to be able to share their stories. With reference to Shavelson and Towne (2002), such research is about finding out what is perceived to be happening and their explanations for why or how it is happening in a given context (Gray, 2009). Without in-depth observations and subsequent conversation, the understanding of the views of

those involved will be less well informed (Cho & Trent, 2006). This lends toward a naturalistic approach, enabling the researcher to investigate a phenomenon within specific settings. The outcome sought was to build a body of knowledge that describes the individual cases (Gray, 2009) and to provide a forum where the reader could engage in interpretation of that information. This would in turn facilitate a deeper understanding about the lived experiences of these learners. This present project was aimed at informing practitioners. Qualitative methodology through a case study approach provided the means to “paint the picture” for others to reflect upon.

3.5.1 Specific Methods

The choice of instruments and approaches used for data collection is also critical. A key strength of the mixed method is that it involves multiple sources and techniques of data collection, for example; surveys, interviews, documentation reviews, observation and, at times, the collection of physical evidence. Use of this method requires a systematic approach to ensure construct validity, internal validity, external validity and reliability.

The case studies in this project involved interviews with assigned RTVs. These teachers were chosen as they have the responsibility for the implementation of the specialised program for the identified learners who are blind. They have a relationship with the learners; they are experienced, most are trained in Vision Education and are deemed to be insightful in their understanding of the lived experiences of the learners.

The approach also involved non-participant observation where the researcher observed the learners. Cohen and Manion (2006), although acknowledging multiple sources of data collection, suggest that the case study approach frequently uses this technique. The case study researcher observes the characteristics of an individual unit such as a child, a class, a community,

in order to probe deeply and to analyse intensively the phenomena that constitute the life cycle of the unit, with a view to establishing generalisations about the wider population to which the unit belongs (Cohen & Manion, 2006). These authors expand on the understanding of observation, stating that there are two principal types of observation: participant observation and non-participant observation. In participant observation, the researcher engages in the activities set out to be observed, whereas in non-participant observation, the researcher is apart from the activities to be observed. Non-participant observation was a critical component of the present research and was considered to be the most appropriate in relation to providing information about what was happening in a range of settings in which the learners were placed.

A review of relevant documentation was also crucial, as it is recognised that “documents and artefacts are very much part of people’s lives” (Glesne & Peshkin, 1992, p. 54). It was considered that these would in turn contribute to the information sought.

3.5.2 Sampling

Qualitative sampling does not necessarily “intend to be representative in the sense of seeking to approximate known population parameters” (Abrams, 2010, p. 537) but recognises that some informants will provide more insight and understanding than others. Patton (2002) has suggested that case study sampling includes four possible types – cases that show maximum variation, those that are homogeneous, those that are considered critical cases, and those that confirm/disconfirm information. Miles and Huberman (2014) clarify the thinking around case selection by stating that those chosen in the sample should be relevant, generate rich information, enhance generalisability, produce believable descriptions, be ethical and be feasible to engage with. Hancock and Algozzine (2011) state that using case study samples aims at

enhancing rigour and trustworthiness for they are used to ensure that data are credible, transferable, dependable and confirmable.

Consistent with this new methodology and approach, intensity sampling has been identified as choosing that which may manifest the chosen phenomena as much as possible (Patton, 2002). In this project, five case studies were undertaken in order to provide information about what is actually occurring with this group of children in mainstream schools in New Zealand. This selection aimed at providing a cross section of learners in relation to age, ethnicity, educational placement and geographical location. It was a manageable sample and useful data were attainable from this sample size. To find out whether or not the behaviour of these children was compromising their learning and compromising their development of socialisation skills was an objective of the study. By discussing the given situation in its real-life context, and by listening to the opinions of teachers who were responsible for specific aspects of the child's learning, it was planned that both quantitative and qualitative information, in the form of rich descriptions, would provide a greater understanding than was previously known of a sample of the population of children in New Zealand who are blind.

3.5.3 The Interview

The interview method was chosen as it can be considered to be a conversation with a purpose, that purpose being to understand the issues from the perspective of those involved (Fontana & Frey, 2008). This was the teacher describing the situation in the world of the learner who is blind from her own perspective. Considering the interviewee to be more of a participant than merely someone from whom information was received presented an approach that was less structured than a highly formalised interview. It was important to ensure reliability and validity, therefore techniques involved needed to be reproducible, systematic and transparent.

The approach for this aspect of the research involved both semi-structured questions and an in-depth schedule of questions to explore the respondents' own perceptions and understandings. This provided a platform for comparisons, reflection, clarification and probing (Lincoln & Guba, 1985). Prompts were used to expand on conversations – “What happens when that occurs?” “What do you do then?” “Can you tell me more?” It was equally important to ensure the process was credible and trustworthy. This was enhanced by ensuring the dialogue was personalised and undertaken on a one-to-one basis. Even though the interviews generated information that could well have been generated by others, it was important to acknowledge the role of the interviewer in eliciting this information by using relevant questions in an atmosphere of conversation. The interviewees chosen did not necessarily support any pre-existing bias; questions asked generated valid accounts of the situation, and anyone reading the collated data would be able to understand the collection and analysis process implemented.

The first two interview questions related to the child's achievement levels, as defined by the New Zealand Curriculum, across five identified key competencies. These were presented as structured, factual questions. Comparisons with the peer group were requested in Question 3, using a further structured question which allowed for some degree of opinion.

Questions 1–3

The questions were as follows:

1. What are the achievement levels of the learner who is blind in relation to the five key competencies of:
 - thinking
 - relating to others
 - using language, symbols, and texts

- managing self
 - participating and contributing?
2. How do these levels compare to other learners of similar chronological age or of these within the peer group?
 3. How do you identify the learning needs of the student who is blind in order to provide an appropriate program in the classroom?

Teachers were then requested to provide factual information on how the learning needs were identified for the individual child. These questions were utilised to provide information with reference to the research questions about the current learning levels of the child who is blind across all competencies, with special interest in “relating to others, managing self, participating and contributing” as detailed in The New Zealand Curriculum (Ministry of Education, 2009). This was critically important when considering the assumptions that stereotypic behaviour impacts on learning and the behaviour interferes with the development of socially acceptable behaviour.

The fourth question referred to the Individualised Education Plan (IEP); documentation that is mandatory for children in New Zealand who are blind. It was a simple, open, factual question that related to recorded data. Question 5 sought information about the teacher’s knowledge of the behaviour that the child displayed, allowing for an open description that may or may not include opinion responses. Question 6, 7 and 8 asked the teacher to consider their management of the behaviour by discussing their strategies adopted in the mainstream setting. The reactions of the child who is blind to these interventions was also sought in this open question. It is noted that a range of intervention strategies are available to classroom teachers, therefore this section invited discussion of what particular intervention strategy the teacher had or had not utilised.

Questions 4–8

4. What are the key focal areas of the learner's IEP?
5. The student who is blind displays stereotypic behaviour. This may be defined as repetitive movements that do not appear to attain any observable goals. What can you tell me about the student's stereotypy?
6. What, if any, strategies do you use to manage this behaviour in the student who is blind?
7. Why do you use this particular strategy?
8. How does the learner who is blind react when you use this strategy?

Questions 9 and 10 sought information about the responses of the peer group. The purpose of these questions was to develop further information about teacher management and the reaction of others to stereotypic behaviour.

Questions 9 and 10

9. How do other students in the class react when the learner who is blind exhibits this repetitive behaviour?
10. How do other students in the other classes react when the learner who is blind exhibits this repetitive behaviour in different contexts?

The final two questions sought information from the RTV regarding their knowledge of stereotypic behaviour and invited opinions about the implications of this behaviour. It also provided an opportunity for teachers to request appropriate resources to learn more about the behaviour, to make decisions about intervention strategies, and to seek assistance should they wish to do so.

Questions 11 and 12

11. What do you know about these repetitive behaviours in general?
12. What resource would you consider to be useful in assisting mainstream teachers who have responsibility for learners who are blind who display stereotypy?

(The Interview Schedule: Appendix H)

3.5.4 Review of Relevant Documentation

The IEP was considered to be highly relevant for each case study. Understanding the principals and characteristics of the IEP provides an understanding of how valuable the document is in building a picture of the life of the learner.

It is important to note that the IEP is created in a collaborative manner, with a number of relevant personnel, and sets the goals for each learner as they work towards progress in the key competencies. The plan is used when additional teaching strategies are needed to address a student's particular learning goals within the curriculum. The plan is defined by a number of principles, which also apply to all aspects of teaching and learning. These are that:

- The student is recognised as an active capable learner. The IEP is a way of adapting a program to fit the student.
- The needs of students can usually be met by class and school strategies, however some students require a program that captures all aspects of learning
- The “heart” of student support is around collaborative decision making
- The relationship between the teacher and student is dependent on student engagement, learning and achievement
- Culture, identity and language are important

- Effective assessment approaches inform teaching and learning.

(Ministry of Education, 2011, p. 4, Collaboration for Success).

The key characteristics of an IEP are described below.

- A plan that shows how the school program will be adapted to fit the student
- A plan that brings together knowledge and contributions, from the student and those who best know them, about the student's learning needs, aspirations, personality and cultural background
- An individualised supplement to the full-class learning program, which enriches the student's classroom, school and community experiences
- A forward-looking plan that records student achievements, where they want to go, what supports are needed (including support for team members), and what success might look like
- A succinct outline of a few priority learning goals and strategies to meet them within the classroom program
- A "living" document that team members regularly update to reflect the student's changing development and that the team refers to for guidance on their responsibilities and needs.

(Ministry of Education, 2011, p. 6, Collaboration for Success).

IEP goals are identified for individual learners who are supported through the Ministry of Education's Ongoing Resourcing Scheme (ORS). These goals are based on student's current functioning levels and they reflect specific learning outcomes as well as the strategies to attain these outcomes. They are not necessarily focused on attaining age-/year-appropriate levels within the competencies, but are focused on personal growth for the learner so that progress in the form of measurable outcomes can be identified. Setting goals requires those involved to:

- Identify the student's current strengths and successes across various settings

- Identify and agree on a few clear, achievable, measurable goals that build on current strengths and reflect next learning steps (to a maximum of four or five goals – even having one priority goal is fine)
- Identify a few success criteria for each goal that show what success might look like
- Identify opportunities for the student to engage with new ideas and practise new learning through various tasks and settings
- Initiate ongoing planning to support the achievement of goals, for example, adaptations and differentiations.

(Ministry of Education, 2011, p. 11, Collaboration for Success).

Templates are now provided by the Ministry to assist the team involved in preparing a document that is relevant for the learner and meets the requirements and goal-setting criteria. These templates aim at ensuring the document is meaningful for the learner and includes information about team communication, roles and needs, the classroom program, the specialist supports and technology plus assessment and reviews (IEP Template, Appendix I). This document, therefore, is the key source of data to be analysed.

3.5.5 Non-Participant Observation

The aim of non-participant observation for the researcher in this project was to spend time watching the learner in the familiar context of their school, at the Homai Campus and, if possible, while involved in an extracurricular activity. Although this was considered an informal observation, it was necessary to observe a number of specific things. A template was created whereby observations were conducted using the following headings:

- Contact
- Time of day
- Program content
- Adults in attendance
- Adult interactions
- Peers in attendance
- Peer interactions
- Stereotypic behaviour – type, frequency, duration
- Response/intervention by adult
- Response/reaction by peer
- Additional information/anecdotal notes

3.5.6 Analysis of Case Study

In this project, quantitative data corroborate and support the qualitative data, with the collected evidence producing analytic conclusions that answer the research questions. Analysis of the case studies first provides quantitative data in the form of statistical information about learning levels of the children who are blind. This data are compared with learning levels of the general population, with inferences being made. Qualitative data are presented in the form of an interpretive report which discusses the research findings through contextual analysis. The report is developed using a thematic analysis to organise data to a narrative.

In such research, specific themes are likely to emerge as the data are analysed. Miles and Huberman (2014) provide a useful approach that involves

the coding of data, identifying patterns and then developing propositions through commonalities. The patterns or themes may not be mutually exclusive but will emerge as material is analysed.

To assist data analysis in qualitative research there is a range of software options. One such package is NVivo, a freely available online resource, which allows the recognising and sorting of text when it is entered into a program using specific key words/phrases. This coding assists in eliminating omissions of relevant texts in order to ensure that all material is considered when reporting is undertaken. The software is designed for rigour, for it maximises accuracy and ensures validity of results in its use of thematic codes.

In this study, a combination of methods was used in the data analysis process. These relate to the electronic analysis of quantitative data, the electronic sorting of information from the interviews following manual transcription of interview content, and the personal interpretation of material as it emerged.

By exploring the case studies in depth, a narrative description of the situation as it exists can be elucidated within its natural contexts (Babbie, 2001).

3.6 Insider Research

The case study approach provides an opportunity to reflect on one's own beliefs while undertaking research. The opportunity is enhanced further when the research undertaken is within the context of a specific setting where the researcher has in-depth knowledge, insight and experience (Coghlan, 2001). This is the role of the insider researcher. When in this situation, much is usually known and understood about the organisation in which one works (Brannick & Coghlan, 2007). "The very body language, semiotics and slogan systems operating within the cultural norms of the organisation" (Edwards, 2002, p. 71) are familiar. For me personally, this knowledge exists. As a vision

educator for many years, I know the organisation within which I work, I understand the organisation and I believe in the values, principles and philosophies of that organisation. Therefore, undertaking this research within this location was for me a privilege. In addition to this sense of privilege, there was an acute awareness of the possible dilemmas of insider research, namely: “informant bias, reciprocity in interviews, and research ethics” (Mercer, 2007, p. 1).

Firstly, informants may seek to confirm, consciously or unconsciously, the perceived opinions of the interviewer (Alvesson & Skoldberg, 2009). A conscious effort needs to be made by the researcher not to publicly state any particular stance. This may be extremely important if there are ongoing professional relationships that continue beyond the research. In Mercer’s words, it is suggested that “pragmatism may outweigh candour” (Mercer, 2007, p. 8). Secondly, degrees of reciprocity will be achieved in the interview process in respect of known informants. The sharing of experiences and attitudes together with answering questions using an interactive, conversational approach may provide more meaningful and extensive data. However, it is important that contributions are not lead or manipulated by the researcher because of this intimacy. Thirdly, the research ethics of insider researcher present a dilemma as to what to tell colleagues about the research and what to report to management. There is a concern that if incidental data is shared there may be a betrayal of trust. Reporting with honesty, using information attained in an ethical manner, is critical. These three dilemmas may occur throughout the research process and require ongoing mindfulness.

As the researcher, I am employed within the BLENNZ network and have knowledge of the system, personnel and policies. This presents some challenges, such as pre-understanding and role duality. However, even by adopting the manner of a critical realist (Coghlan, 2007), it is not possible to transcend subjectivity. In the role of the researcher, the project was somewhat separate to my current role of manager of a team of RTVs. Although very much part of the mainstreaming process for learners who are blind, the roles

are very different. Having taught in the field of Vision Education for some years, I believe that I have a sound knowledge of this area of Special Education. However, in the BLENNZ Consultation Round in 2010 it was reported by parents and RTVs that there was a general concern that learners who are blind have poor socialisation skills, lack friendships and are not accepted in the sighted world. It is acknowledged that it is in the interests of all teachers and learners to become more involved in understanding the needs of this sector.

Co-operation for this research from RTVs on a national basis had previously been assured through informal discussions and emails. However, there were issues that required consideration. These included the following personal concerns:

- Practicalities of time management
- Current access to all data through the BLENNZ network
- Professional subjectivity
- Managing prior knowledge surrounding individual learners
- Managing prior knowledge surrounding individual families/*whānau*
- Managing prior knowledge surrounding individual RTVs
- Personal subjectivity in relation to learners on my caseload
- Possible criticism of postgraduate study while being employed fulltime by BLENNZ
- Politics of BLENNZ
- Future use of insider research information.

In the role of an RTV, it is the “lived experiences” of families and learners that have been, and continue to be, a reality for me. These enable me to make greater sense of personal stories shared while acknowledging the veracity of the complexity and ever-changing situation for learners who are blind who receive their education in regular settings. I understand many of the challenges of inclusion; I recognise the challenges of establishing meaningful programs and of setting and meeting achievable goals for individual learners. I have felt the responsibility for learners deemed to be unsuccessful, for learners thought to be misbehaving or not fitting in, and have in turn wanted to make a difference in the life of that learner. I have shared the frustrations of teachers when identified goals are not reached, when learners and their families are disappointed in outcomes and when legislated comparative reporting indicates a lack of attainment. The sense of failure for the individual concerned when results are compared to an age- appropriate learning goal or a National Standard is very confronting. I have also been aware of the pain of a socially isolated child who is blind longing to have a friend, wanting to be invited to a birthday party and needing to be accepted by their peers.

As a researcher working in an organisation while studying aspects of that organisation, research could seem problematic. However, this was not necessarily so. For me, it was not about an emotional journey or of being doubtful or of subjectivity clouding the issues, as suggested by Noor (2008).

3.7 Ethical Issues

This study involved the participation of both parents/caregivers and teachers, therefore, ethical issues required addressing. The most important of these within the project were that of privacy, confidentiality and cultural sensitivity. Informed consent was required from all participants, therefore detailed documentation was distributed to families and RTVs prior to the commencement of the project. No names or identifying information were disclosed, and only relevant information was collected. All participants were

offered the opportunity to seek clarification on any matter, to enlist the assistance of a counsellor if necessary, or to withdraw from the study at any point. This aimed at ensuring safety, privacy and total confidentiality with respect to information about the children who are blind.

Those involved have the potential to be vulnerable when discussing personal situations, therefore extreme care is required to ensure professional standards are always maintained, that personal judgements are not made and that any information published is strictly anonymous. The use of pseudonyms and coding in such projects is appropriate within the narrative, especially when such information is used to contribute to the richness of the script. Mason (2002) makes reference to aspects of anonymity and confidentiality. This is particularly significant when working as an inside researcher.

Ethical approval was sought and gained from James Cook University (Appendix I) and BLENNZ (Appendix J). This process clearly defined how material was to be disseminated, how privacy and confidentiality would be maintained, how cultural needs would be addressed and how data would be stored. Consent forms included an acknowledgement of the purpose of the research, and information about data collection, analysis and reporting. This approval related to both the quantitative and qualitative designs within this study.

3.8 Assumptions and Bias

Part of any research process involves the researcher. It was recognised that my own perspectives have value and have evolved from personal and professional experiences. However, although this study focused on what is termed “disordered behaviour”, stereotyping is not necessarily considered a concern by others. It is acknowledged that my personal bias surrounding this behaviour may be unique and the behaviour may not be seen as disturbing by

others. Sensitivity to the needs of learners who are blind is a commonality of those involved, likewise issues surrounding socialisation skills of learners who are blind is very much a shared concern. Therefore non-judgemental recording and careful use of anecdotal evidence were essential. The analysis would aim to remove any social bias, and reliance on triangulation as discussed previously of data aimed at ensuring the findings were credible, trustworthy and valid. By recognising my role as an insider researcher, by understanding the challenges that may arise, it was considered that deliberate steps could be identified to ensure my assumptions and biases were minimised.

3.9 Limitations

There were a number of limitations when using two research paradigms; firstly with the use of a postal survey and secondly with the use of an interview situation. There are a number of advantages and disadvantages in the use of a questionnaire. Denscombe (2010) and Newby (2010) state that there are advantages in that each person answering a particular questionnaire reads an identical set of questions, allowing for consistency and ease in processing the answers. However, it is not possible for respondents to seek clarification about a question. The responses may not be those of the perceived respondent. How truthful the responses are is unknown, and what is reported may be that which reflects the attitudes most socially appropriate (Groves et al., 2013). Therefore the value may be questioned, as truthfulness is unknown. There is also an assumption that respondents can read at the level required to answer the survey and that they have the time to do so. This may not be so. Therefore, disadvantages relate to the type of data collected and to issues of validity in that without carefully constructed questions, accuracy in the responses may be compromised. Participants' information cannot always be validated, and much of what is provided is optional.

By requesting the postal survey to be distributed and collected through the BLENNZ organisation some control was lost, as there was reliance upon others to undertake the task. It is also recognised that there may be limitations in relation to the inaccuracies in the BLENNZ database; i.e. it is possible that the figure of 128 participant families may have been incorrect.

There were also limitations with the interview process. The use of interviews conducted personally by the researcher in the five case studies may have been limited by a number of issues from the perspective of an insider researcher. Although the interview number was considered feasible by the researcher, relevant data such as the Individualised Education Plan, with references to achievement levels across key competencies, may not necessarily be available or completed. Data submitted may not always have been accurate and interview question responses may not necessarily have been truthful. The interpretation of this information was by the researcher and this may mean that the final text was limited or modified in an as yet unknown manner.

3.10 Conclusions

This mixed methods research project used a philosophy of pragmatism to quantify the prevalence of disordered behaviour among a cohort of New Zealand children who are blind from information gained through a postal survey of parents/caregivers. The project discusses what was happening for some children who are blind and displayed stereotypic behaviour in respect to their learning by examining evidence gained in interviews, through non-participant observation and through the use of relevant documentation. The qualitative stage of the approach results in analysis of the information in an interpretive manner. Furthermore, in the Critical Theory tradition, consideration of the major aetiological theories, is used to offer a synthesis of ideas that attempts to explain stereotypic behaviour in some of New Zealand's children who are blind.

Chapter Four

The Survey Reports

4.0 Introduction

Learners who are blind may exhibit stereotypic behaviour. This chapter contributes to the field by reporting on a national survey that was conducted in New Zealand between July and December 2011. The survey was analysed in January 2012 in order to report information from the perspectives of parents/caregivers of learners who are blind and who are registered on the BLENNZ national database.

4.1 Chapter Overview

This chapter discusses the pilot survey and then presents the first phase of this mixed methods research project, which is the national postal survey. Details of both the method and sample are presented. Histograms are included to represent age, gender, educational placement and ethnicity of the sample, with results recorded in table format. Chi-square analysis illustrates the links and associations between specific behaviours and frequency rates as well as giving additional information regarding duration and context. The chapter concludes with a discussion about these quantitative data in respect to the international literature and aetiological theories that relate to New Zealand children who are blind.

4.2 Pilot Survey: Method

The type, prevalence, duration and situational contexts of stereotyped behaviour in five learners who are blind were assessed through a postal survey to the five parents/caregivers of these children. All parents were known to the researcher and had indicated a willingness to contribute to this aspect of the research following the publication of an article about this project in the *Vision* magazine – a national periodical of the New Zealand Association of Parents of the Visually Impaired

(PVINZ, 2008). They were familiar with stereotypic behaviour and the possible concerns about this behaviour under certain conditions.

The questionnaire was posted to the five identified parents with a detailed accompanying letter. Guidelines for completing the questionnaire were included and a return within a three-week period was requested. The stereotypies were defined according to the body part involved and were selected based on those included in the Bielefeld Parents Questionnaire for Blind Infants and Pre-Schoolers (Brambring, Dobslaw, Klee, Obermann & Troster, 1987) and Pagliano's (2001) Descriptors of Stereotypic Behaviour. The behaviours listed were grouped together in a manner that was considered helpful to parents as noted in the Bielefeld Questionnaire. Although stereotypic movements may be considered topographically different from each other, grouping of those similar in appearance was undertaken. This means, for example, that such behaviours as side-to-side rocking, forward and backward rocking and body rotating were grouped as body rocking.

The survey instrument, (Appendix L), began with a series of questions relating to personal details of the learners in respect of age, gender, culture, vision information and educational placement. To assess the type and extent of stereotyped behaviour patterns, 17 separate stereotypies were presented in a chart format. Parents were also asked to report on the frequency (1–5 scale), duration (1–5 scale), and context of the behaviours (1–5 scale) from a list of pre-determined options. Inclusion of any additional information was requested on any aspect of the behaviour.

4.2.1 Sample

The sample of five learners included four girls and one boy, with an age range of 13 to 18 years. All five learners were registered as blind on the BLENNZ database, with visual conditions of Septo-Optic Dysplasia, Leber's Congenital Amaurosis and Optic Chiasm Glioma named. Two of the parents reported that their child had additional

disabilities, one with developmental delay, and the second with an additional sensory loss, which was an absence of a sense of smell. Ethnicities were varied and included New Zealand European (2), New Zealand *Māori* (1), and “Other” (2) All students were currently in a mainstream secondary school educational placement.

4.3 Results

4.3.1 Prevalence of Stereotypic Behaviour

In addition to the 17 stereotypies in the pilot survey, three parents reported on other behaviours. These were head/face tapping (1), vocalisation as in echoing a response (1), whole body rocking (2), and jumping up and down accompanied by hand shaking (1).

All five students displayed at least one stereotypic behaviour, with two students displaying more than five stereotypies. The stereotypic behaviour in relation to the body part involved was recorded. Stereotypies that involved the hands and arms were most common. Behaviours involving the face were reported by three respondents. Whole body involvement and stereotypies using the head were reported by two respondents while behaviours involving the legs and feet were reported from one respondent. Stereotypies involving the face were equally distributed amongst chanting, lamenting, whispering, sniffing and smelling. Face and mouth contortions were not noted by the respondents. Stereotypic behaviour involving the head in the form of rolling and shaking was reported by one respondent. A second respondent noted that the head was used but no further details were provided. Eye poking/eye rubbing, as well as twisting, flapping, fluttering and flicking of the hands was reported by three respondents. Two surveys reported hand clapping, and tapping/stroking/wiping and rubbing was evident. Object shaking and finger manipulation was reported to be displayed by one student. One parent reported stereotypic behaviour involving the legs and feet. This took the form of foot wiggling. Two respondents reported behaviour that involves the whole body. Both indicated rocking was displayed, one of the respondents stating that

jumping was also evident. This information indicated that stereotypic behaviour could be identified in relation to the body part involved.

4.3.2 Frequency of Stereotypic Behaviour

Frequency rates were assessed using a range of options that spanned timeframes of less than once a week to almost hourly. Behaviours occurred less than once a week (4), once a week (4), once a day (3), several times daily (7) and almost hourly (3). One student displayed clapping in a repetitive manner daily. A second student displayed behaviours involving the head/hands and arms less than or up to once a week. The third student displayed behaviours involving the face, hands, arms and the whole body several times daily. The fourth student displayed behaviours that involved the head/hands/arms less than once a week. However, behaviours involving the face in the form of chanting, lamenting, whispering, sniffing and smelling were noted to occur almost hourly for this student. A fifth student displayed behaviour of eye poking/rubbing several times daily and body rocking was considered to occur hourly. This information indicates that frequency rates in respect to stereotypic behaviour are able to be identified and recorded in the documented format.

4.3.3 Duration of Stereotypic Behaviour

Duration rates were assessed using a range of options that spanned timeframes of less than 1 minute to more than 10 minutes. The responses indicated that behaviours were exhibited for less than 1 minute (15), 1–3 minutes (5), every 3–5 minutes (1), 5–10 minutes (0), and for more than 10 minutes (0). The behaviours identified in the first timeframe involved the face, the head, hands and arms, and the whole body. Those that occurred in the second time frame involved the face, the hands and arms, and the whole body. The third timeframe related to behaviours that involved the legs and feet. This information indicates that duration rates in relation to the stereotypic behaviour are able to be identified in this manner.

4.3.4 Typical Situations/Contexts of Stereotypic Behaviour

The contexts or typical situations where stereotypic behaviour was observed were listed as being when the learner was angry, excited, left alone/bored; when a request was made of, or for the student; and when listening to books, and/or music. Parents stated that specific behaviours for each student were thought to occur in a number of settings. However, in general, stereotypies were considered to have relevance when the student was perceived to be angry (6), when the student was perceived to be excited (7), when the student was left alone or was perceived to be bored (11), when something was requested of, or for the student (1), and when the student was involved in listening to books/music (5). This information indicated that a range of contexts were able to be identified in this manner.

4.4 Additional Information

Parents supplied additional information about further stereotypies displayed by their adolescent children (4). Suggestions were made by the parents that included the layout of the questionnaire, and the idea of embracing *Māoridom* by incorporating *Te Reo* (*Māori* language) in the document.

No concerns were reported about the style and type of questioning; however it was suggested that on occasions, respondents did not know which option to choose from in a set list of responses. Including a “Don’t Know” response, with room for explanation/comment may therefore be appropriate. Including a section where information regarding the onset of visual condition was also suggested. Including a phrase whereby the respondents could provide information about whether the behaviour had ever been displayed was also offered. One respondent considered the option of “continuously” regarding duration would be useful.

Anecdotal information was provided about parental management of behaviours in the early years. Societal reactions were noted, for example, in that one student was told they “looked silly” which was sufficient to bring about a reduction in

a number of behaviours; another student was told “please don’t do that” when eye rubbing. A third student was either “spoken to” or given a light touch on the shoulder when any of the behaviours were displayed. A fourth student had become more aware over time of inappropriate clapping through the input of relatives, in the form of external controls.

4.5 Discussion

In summary, to obtain information about the existence, prevalence and duration of stereotypic behaviour in students who are blind as well as the contexts that elicit the behaviour, a questionnaire was posted by the researcher to a selection of volunteer parents with a defined timeframe for the return. Although the questionnaire detailed 17 descriptors of stereotypic behaviour, it was clear that some behaviours of concern were omitted. These included those that involved vocal responses, for example echolalia, as well as whole body movements, such as rocking. The information from respondents indicated that this particular data about stereotypic behaviour could be sought in this manner; however further stereotypies identified by parents and omitted in the pilot survey could be added to the list of descriptors. This way of recording would provide more detailed information about these behaviours to contribute to the findings.

Frequency and duration rates of the behaviour varied in relation to each learner and to the particular stereotypic behaviour described. Frequencies ranged from less than once a week to almost hourly, whilst duration ranged from less than 1 minute to 3–5 minutes. This method of response indicated that information about both frequency and duration rates could be recorded in this manner. The situational contexts whereby the individual students were more likely to exhibit the behaviour were recorded in periods of low and high arousal. Information about contexts was therefore, able to be reported in the situations described.

The section offering parental discussion aimed at providing some information regarding the attitude of families towards the behaviour. The information was able to be provided in this format. It was noted that a variety of strategies were used to elicit the information. Therefore, the pilot survey as a questionnaire, was amended in the following manner prior to distribution on a national basis:

- Page layout of the questionnaire
- Use of *Te Reo* in the document
- Response options to include “don’t know”
- Further descriptors of stereotypy were to be included
- Greater options for anecdotal information were to be recorded
- Inclusion of information regarding whether or not stereotypy was ever in a child’s behavioural repertoire.

4.6 Main Survey: Method

The type, prevalence, duration and situational contexts of stereotyped behaviour in learners who are blind was assessed through a national postal survey to parents/caregivers whose child was recorded on the BLENNZ database as blind, aged between 5–18 years, and was in a mainstream educational placement (Appendix G). The survey, as a questionnaire, having previously been reviewed, began with a series of questions relating to personal details of the learner, their vision information and educational setting. To assess the type and extent of stereotyped behavioural patterns, 22 separate stereotypies were presented in a chart format. The stereotypies were defined according to the body part. Parents were also asked to report on the frequency, duration and context of the behaviours from a list of pre-determined options. Inclusion of any additional information was requested on any aspect of the behaviour.

A total of 117 questionnaires were distributed. Follow-up was undertaken to parents/caregivers of this sample by Resource Teachers: Vision (RTVs), largely in the course of their regular encounters with families. This follow-up aimed at ensuring

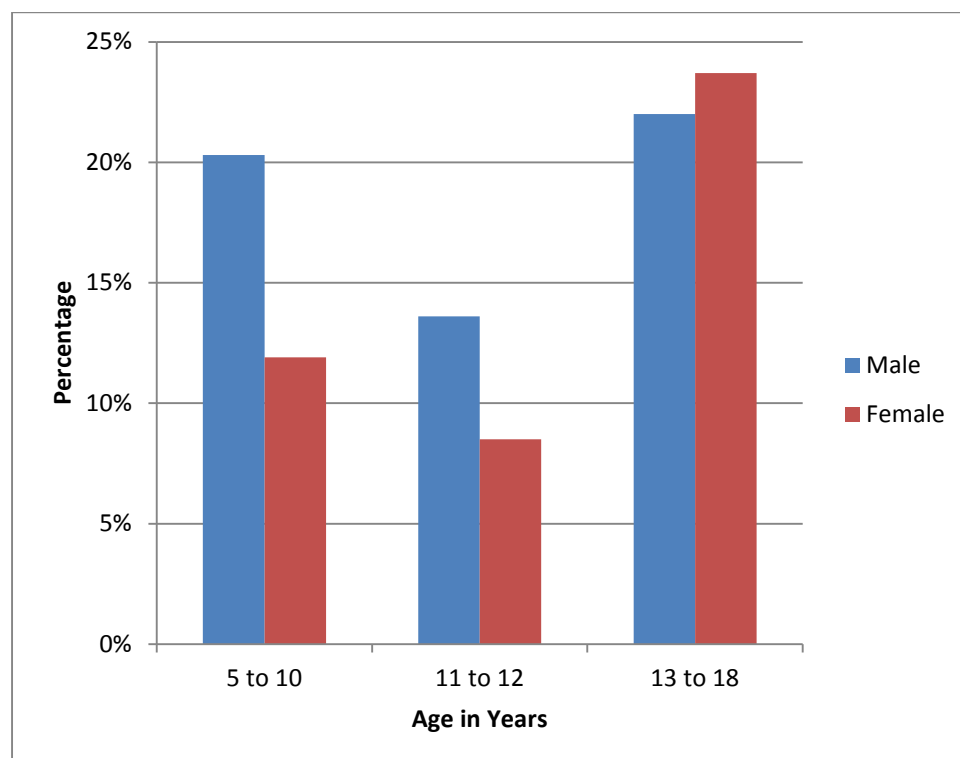
that the best possible response rate was achieved in a non-threatening manner. When it was indicated that questionnaires were not completed or returned for any reason, RTVs offered assistance with this, either in a face-to-face meeting or in completion of the questionnaire by telephone with the parent/caregiver.

4.6.1 Sample

The response rate of the questionnaire was 51%, with 60 questionnaires returned. Due to the incomplete nature of one of these responses, the results are based on 59 (50.4%) questionnaires. The information provided in the questionnaires, therefore, concerns 59 learners. Of the learners, 26 (44%) were female, and 33 (56%) were male. The distribution of the age ranges was: 19 (32%) in the 5–10 age group, 13 (22%) in the 11–12 age group and 27 (46%) in the 13–18 age group. The distribution of this aspect of the sample is presented in Graph 4.1.

Graph 4.1

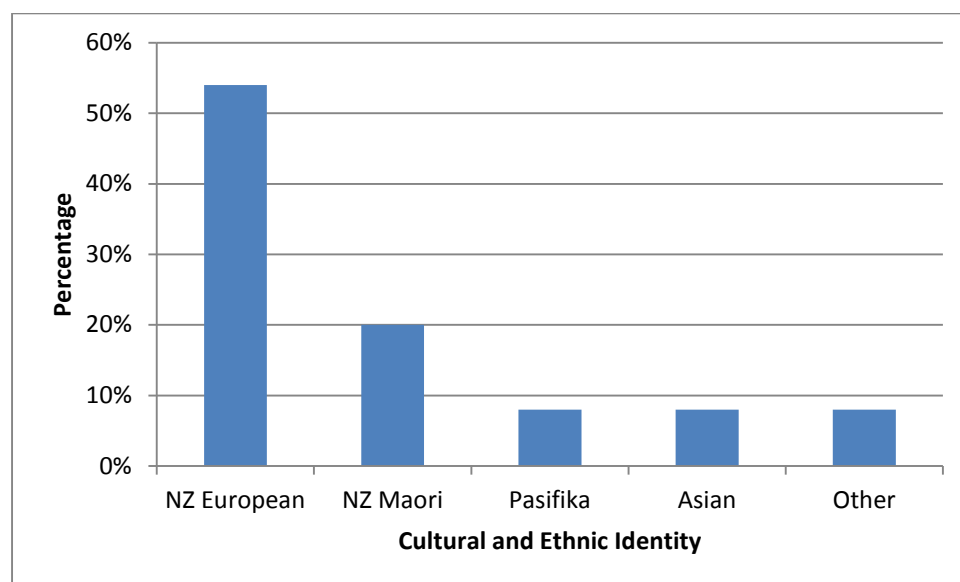
Age and Gender of Participants (N= 59)



Cultural and ethnic identities indicated a predominance of New Zealand European participants. There were 32 (54%) students in this category. New Zealand *Māori* students were recorded as 12 (20%), with *Pasifika*, Asian and other nationalities identified at 5 learners each (8%). This information is presented in Graph 4.2.

Graph 4.2

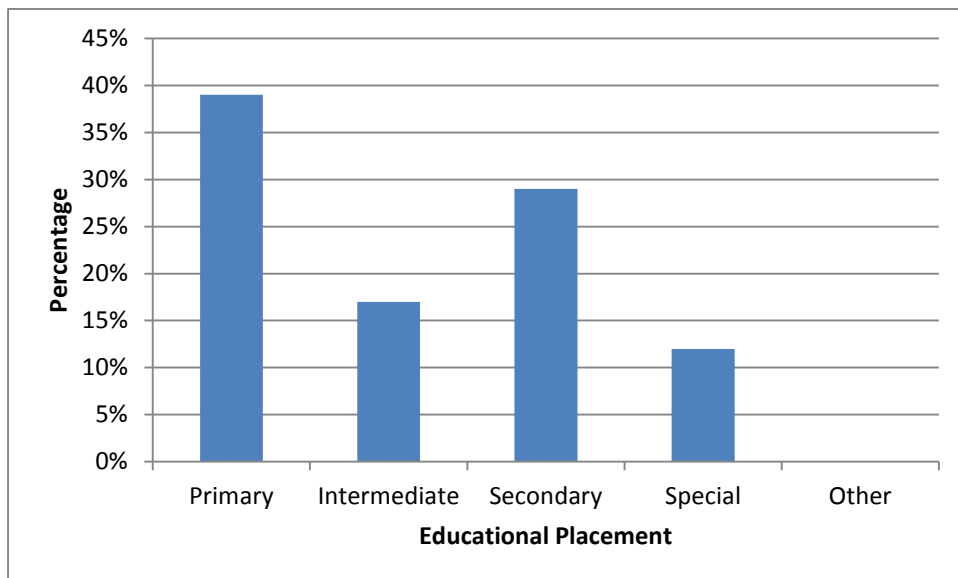
Cultural and Ethnic Identity of Participants (N=59)



Educational placements related generally to age, with 23 (39%) of students in primary school (5–10 year olds), 10 (17%) in intermediate school (11–12 year olds), 17 (29%) in secondary placements (13–18 year olds), 7 (12%) in special schools, and 2 (0.03%) learners were home schooled. This information is presented in Graph 4.3.

Graph 4.3

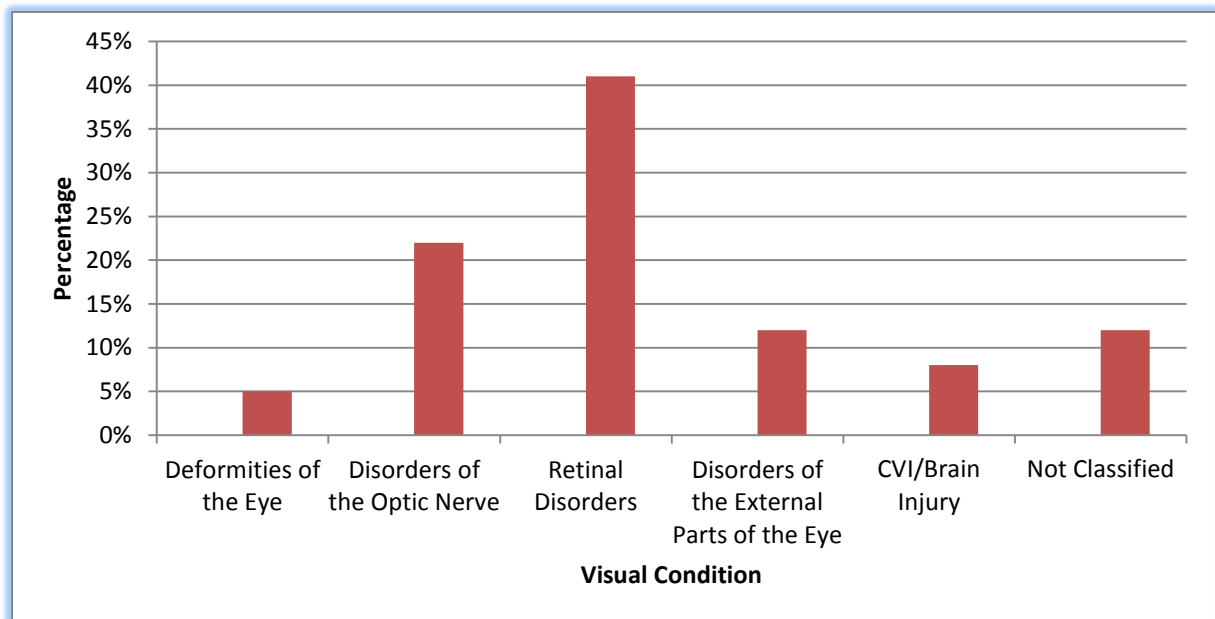
Educational Placement of Participants (N=59)



Visual conditions were recorded as Deformities of the Eye (3, 5%), Disorders of the Optic Nerve (13, 22%), Retinal Disorders (24, 41%), Disorders of the External Parts of the Eye (7, 12%). Other Conditions such as Cortical Vision Impairment (CVI) and Brain Injury was identified by 5 learners (5, 8%), with 7 learners having vision conditions that were not classifiable (7, 12%). This information is presented in Graph 4.4.

Graph 4.4

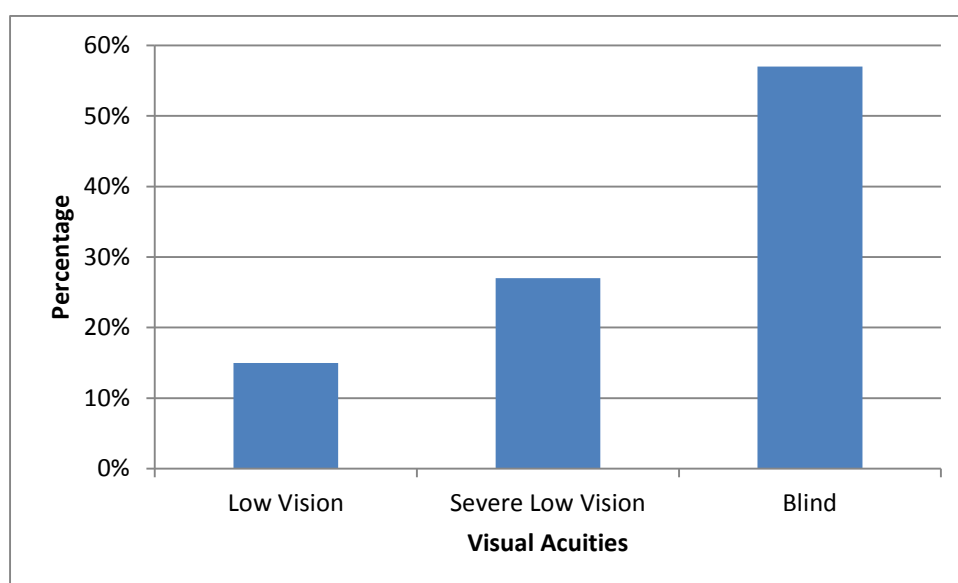
Visual Conditions of Participants (N=59)



Visual acuities were recorded as 9 (15%) with low vision, 16 (27%) with severe low vision, with the category of blind being selected for 34 (57%) learners. This information is presented in Graph 4.5.

Graph 4.5

Visual Acuities of Participants (N=59)



4.7 Results

According to parental responses, 24 (40%) indicated that stereotypic behaviour was not exhibited by the learner. These 24 responses related to learners in each age band, with 7 (29%) in the 5–10 age group, 6 (25%) in the 11–12 age group and 11 (46%) in the 13–18 age group. In total, 13 (54%) were female and 11 (46%) were male. Ethnicities recorded were 15 New Zealand European (63%), 6 New Zealand *Māori* (25%), 1 Asian (4%), with the remaining 2 (8%) categorised as Other. Eight learners (33%) were in primary school, 4 (17%) were in intermediate, 10 (42%) were in secondary placements and 2 learners (8%) were in special schools. Visual conditions were identified as Deformities of the Eye (1, 4%), Disorders of the Optic Nerve (7, 29%), Retinal Disorders (7, 29%), Disorders of External Parts of the Eye (4, 17%). Other conditions of Cortical Vision Impairment and Brain Injury were identified for 3 learners (13%), with 2 learners (8%) unable to be classified. Visual acuities were identified as 7 Blind (29%), with 3 of that group being identified as having additional disabilities (13%). Severe Low Vision was identified for 13 (54%), with 5 learners (21%) recorded as having additional disabilities. In the Low Vision category, there were 4 learners (17%), 2 of whom had additional disabilities (50%).

Of the 59 responses, 35 (59%) indicated that stereotypic behaviour was exhibited by the learner. These 35 responses related to learners in age bands as follows: 14 (40%) in the 5–10 year group; 10 (29%) in the 11–12 year group; and 11 (31%) in the 13–18 year group. In total, 14 (40%) were female and 21 (60%) were male. Ethnicities were recorded as 17 (49%) New Zealand European, 6 (17%) as New Zealand *Māori*, 4 (11%) as Asian, 5 (14%) as *Pasifika* and 3 (9%) recorded “Other” as a category. Placements were largely in the primary sector with 15 (43%) at this level, 6 (17%) at intermediate school, 7 (20%) in secondary school and there were 7 (20%) others in special schools. Visual conditions were identified as Deformities of the Eye – 2 (6%), Disorders of the Optic Nerve – 6 (17%), Retinal Disorders – 17 (49%), Disorders of the External Parts of the Eye – 2 (6%), Cortical Vision Impairment – 2 (6%) and there were 6 (17%) learners whose visual condition was unclassifiable. See Table 4.1.

Table 4.1

Visual Conditions of Participants Who Display Stereotypic Behaviour N =35

Visual Condition	Frequency	Percentage
Deformities of the Eye		6%
- Microphthalmos/ Coloboma/ Anophthalmos	2	
Disorders of the Optic Nerve		17%
- Septo-Optic Dysplasia	3	
- Optic Chiasm Glioma	1	
- Optic Atrophy	2	
- Medullo/Suprasellar Tumour	0	
Retinal Disorders		48%
- Leber's Congenital Amaurosis	5	
- Retinopathy of Prematurity	7	
- Retinoblastoma	2	
- CHARGE	1	
- Vitreous Hypoplasia	1	
- Mitochondrial Disease	1	
- Rod Cone Dystrophy	0	
Disorders of External Parts of the Eye		6%
- Nystagmus, Myopia, Hypertropia, Astigmatism	1	
- Glaucoma/Cataracts	0	
- Peters Anomaly	1	
Other		6%
- Cortical Vision Impairment	2	
- Brain Injury	0	
No Information / Unclassifiable		17%
- Totally Blind	5	
- Visually Impaired	1	

Visual acuities were recorded as 5 with low vision, with all 5 considered to have additional disabilities. There were 3 who were considered to have severe low vision,

2 of whom had additional disabilities, and 27 learners were identified as blind, with 13 considered to have additional disabilities such as developmental delay, epilepsy and hearing loss (Table 4.2).

Table 4.2

Visual Acuity Categories N=59

	Non- Stereotypic Behaviour	Stereotypic Behaviour	Total	Percentage of Total
Low Vision	4	5	9	15%
Severe Low Vision	13	3	16	27%
Blind	7	27	34	58%
Total	24	35	59	100%

4.7.1 Prevalence of Stereotypic Behaviour

Of the 59 learners, 24 did not display stereotypic behaviour while 35 did. The identified 35 learners displayed a number of stereotypes, the least being one and the greatest being 17. The following table shows the prevalence of stereotypic behaviour in this group (Table 4.3).

Table 4.3

Stereotypic Behaviours Exhibited by Individual Learners N=59

Number of Behaviours per Learner	Prevalence	Prevalence Percentage (%)
0	24	40
1	5	8
2	5	8
3	6	10
4	2	3
5	4	7
6	3	5
7	1	2
8	2	3
9	2	3
10	2	3
11	1	2
12	1	2
13	0	0
14	1	2
15	0	0
16	0	0
17	1	2
	Total: 59	100

Stereotypic behaviour in respect to the 35 learners was recorded in relation to the body part involved. Of the 194 stereotypies this group of learners displayed, behaviours relating to the face equalled 13.9%, behaviours relating to the head equalled 12.4%, behaviours relating to the hands and arms equalled 37.1%, behaviours relating to legs and feet equalled 9.8%, vocal stereotypies were recorded as 13.4% and those involving the whole body were recorded as 13.4% (Table 4.4).

Table 4.4

Stereotypic Behaviour Exhibited in Relation to Body Part Involved N=194

Body Part Involved	Number of Behaviours	Percentage (%) of Total Number of Behaviours
Face	27	13.9
Head	24	12.4
Hands and Arms	72	37.1
Legs and Feet	19	9.8
Whole Body	26	13.4
Vocal	26	13.4
Total	194	100

Table 4.5 provides more specific data in relation to the existence of the behaviours against the descriptors for each body part.

Table 4.5

Stereotypic Behaviour and Prevalence Descriptors (N=194)

Behaviour	Prevalence	Percentage (%) of Total Number of Behaviours
<u>Face</u>		
Face contortions, mouth contortions	13	6.7
Face tapping	5	2.6
Sniffing and smelling	9	4.6
Subtotal	27	13.9
<u>Head</u>		
Head banging	7	3.6
Nodding	4	2.1
Rolling and shaking	13	6.7
Subtotal	24	12.4
<u>Hands and Arms</u>		
Eye poking, eye pressing and rubbing	16	8.2
Twisting, flapping, fluttering, flicking hands/fingers	18	9.3
Clapping hands	4	2.1
Finger manipulation	9	4.6
Hand regarding	3	1.6
Object shaking	7	3.6
Slapping, hitting, punching	8	4.1
Tapping, stroking, wiping, rubbing	7	3.6
Subtotal	72	37.1
<u>Legs and Feet</u>		
Leg swinging	7	3.6
Kicking and stamping	7	3.6
Foot wiggling	5	2.6
Subtotal	19	9.8
<u>Vocal</u>		
Chanting, lamenting	10	5.2
Whispering	6	3.3
Echoing	10	5.2
Subtotal	26	13.4
<u>Whole Body</u>		
Rocking	14	7.2
Jumping up and down	12	6.2
Subtotal	26	13.4
<u>Grand Total</u>	194	100

4.7.2 Frequency of Stereotypic Behaviour

Frequency rates were assessed using a range of options which spanned timeframes of less than once a week to almost hourly. Categories were “Less than once a week”, “Once a week”, “Two–Three Times a week”, “Once a day”, “Several times daily”, “Almost hourly” and a final category of “Unsure” or “Information was not supplied”. Table 4.6 provides this information.

Table 4.6

Frequency of Stereotypic Behaviour identified through Collation of Number of Learners who Exhibit the Behaviour

Behaviour	Less than once a week	Once a week	Two—Three Times a Week	Once a day	Several times daily	Almost hourly	Unsure/ No Information
Face							
Face contortions, mouth contortions	0	3	1	0	6	3	0
Face tapping	2	0	0	1	0	2	0
Sniffing and smelling	1	0	1	1	4	2	0
Head							
Head banging	1	0	1	1	1	2	0
Nodding	1	0	0	0	2	1	0
Rolling and shaking	1	0	0	2	5	3	2
Hands and arms							
Eye poking and rubbing	1	0	2	1	6	4	2
Twisting, flapping, fluttering, flicking	1	1	0	2	9	5	0
Clapping hands	1	0	1	1	1	0	1
Finger manipulation	0	1	0	0	5	2	0
Hand regarding	0	0	0	0	2	1	0
Object shaking	0	0	0	2	4	1	0
Slapping, hitting, punching	2	0	0	0	3	1	1
Tapping, stroking, wiping, rubbing	0	1	0	0	3	2	1
Legs and feet							
Leg swinging	0	0	1	1	3	2	1
Kicking and stamping	1	0	0	1	2	2	0
Foot wiggling	0	1	1	0	0	2	1
Whole Body							
Rocking	0	0	2	2	6	4	0
Jumping	1	0	1	1	6	3	1
Vocal							
Chanting/ Lamenting	1	0	0	1	3	4	1
Whispering	0	0	0	0	1	5	1
Echoing	1	0	0	1	4	2	1
Total	15	7	11	18	76	53	13

4.7.3 Duration of Stereotypic Behaviour

Duration rates were assessed using a range of options which spanned time frames of less than 1 minute to seemingly continuous (Table 4.7). Response categories were as follows: less than 1 minute, 1–2 minutes, 3–4 minutes, 5–10 minutes, more than 10 minutes, seemingly continuous and an option of unsure.

Table 4.7

Duration of Stereotypic Behaviour identified through Collation of Number of Learners who Exhibit the Behaviour

Behaviour	Less than 1 minute	1–2 minutes	3–4 minutes	5–10 minutes	More than 10 minutes	Seemingly continuous	Unsure
Face							
Face contortions, mouth contortions	9	3	0	0	0	1	0
Face tapping	3	1	0	0	0	1	0
Sniffing and smelling	6	2	1	0	0	0	0
Head							
Head banging	2	3	0	1	0	0	0
Nodding	3	1	0	0	0	0	0
Rolling and shaking	5	5	1	1	0	1	2
Hands and arms							
Eye poking and rubbing	7	2	4	1	0	1	1
Twisting, flapping, fluttering, flicking	6	7	2	2	0	3	0
Clapping hands	4	0	0	0	0	0	1
Finger manipulation	2	3	0	0	1	2	0
Hand regarding	2	0	0	0	0	1	0
Object shaking	2	2	1	0	0	1	1
Slapping, hitting, punching	1	4	0	2	0	0	1
Tapping, stroking, wiping, rubbing	2	3	0	0	0	1	1
Legs and feet							
Leg swinging	2	2	1	0	0	2	1
Kicking and stamping	3	0	0	0	1	2	0
Foot wiggling	1	1	0	0	0	2	1
Whole Body							
Rocking	2	8	2	1	1	1	0
Jumping	8	1	1	0	1	0	0
Vocal							
Chanting/Lamenting	2	5	1	1	0	3	0
Whispering	0	1	0	0	1	3	1
Echoing	0	4	2	0	0	2	1
Total	72	58	16	9	5	27	11

4.7.4 Typical Situations/Contexts for Stereotypic Behaviour

The contexts or typical situations (Table 4.8) were listed as follows: when the learner was perceived to be angry, or perceived to be excited, when left alone, when perceived to be bored, when a request was made, when listening to books/music, when considered tired, when considered to be unsure, or other information was given. These contexts were drawn from previous studies and aetiological viewpoints.

Table 4.8

Context of Stereotypic Behaviour identified through Collation of Number of Learners who Exhibit the Behaviour

Behaviour	A Angry	B Excited	C Left Alone	D Bored	E When request made	F Listening	G Tired	H Unsure/ Other
Face								
Face contortions, mouth contortions	2	2	4	2	3	2	2	4
Face tapping	2	1	1	1	0	0	0	1
Sniffing and smelling	0	2	0	0	0	1	0	6
Head								
Head banging	5	0	0	1	0	0	1	1
Nodding	0	1	1	2	0	0	0	1
Rolling and shaking	0	4	2	3	0	1	0	5
Hands and arms								
Eye poking and rubbing	2	2	5	6	2	4	6	3
Twisting, flapping, fluttering, flicking	3	7	5	3	2	3	0	3
Clapping hands	1	5	0	0	0	1	0	0
Finger manipulation	1	1	3	4	0	2	1	4
Hand regarding	0	0	2	1	0	1	1	1
Object shaking	0	4	2	1	0	1	0	3
Slapping, hitting, punching	7	0	1	1	0	0	1	1
Tapping, stroking, wiping, rubbing	0	2	3	1	1	3	0	2
Legs and feet								
Leg swinging	2	2	2	2	1	2	0	3
Kicking and stamping	5	1	3	1	1	3	1	0
Foot wiggling	1	3	1	0	1	2	0	1
Whole Body								
Rocking	2	3	7	7	2	3	3	2
Jumping	4	3	4	1	2	0	3	0
Vocal								
Chanting/ Lamenting	0	1	3	5	1	1	1	3
Whispering	0	0	2	2	1	0	0	3
Echoing	1	1	1	2	2	1	1	3
Total	38	45	52	46	19	27	21	50

4.8 Chi-Square Analysis

To examine the links between frequency of behaviour and the body part involved, a Chi-Square analysis using Minitab-15 (University of Auckland) was undertaken with the information provided that related to the 35 learners who displayed the behaviour (N=35). Similarly this analysis was repeated to illustrate associations between duration of the behaviour and the body part involved. The analysis was then repeated to establish whether there were links between context (situations where the behaviour occurred) and the body part involved. The purpose of this analysis was directly related to the research question around the prevalence of specific stereotypes in learners who are blind and the conditions in which they occur within the real life context. The analysis aimed to establish whether the behaviours were significantly linked to specific factors.

In order to undertake the Chi-Square analysis, some categorisation changes were used to consider groupings. These were necessary to legitimise the analysis in order to avoid test distortion. The analysis presents a number of tables that refer to the body part involved, together with observed and expected counts with the Chi-Square contribution presented. The analysis is presented using frequency, duration and contextual information and suggests statistical probability.

4.8.1 Frequency: Behaviour Analysis

When analysing frequency of behaviour in relation to body part, categories involving once a day, several times daily and almost hourly were selected.

Results show that there was no statistical significance when this analysis was performed on the whole sample, as the p value was > 0.05 . It is possible, therefore, to conclude that, in the case of these participants, frequency of behaviour and stereotypic behaviour are independent (Table 4.9).

Table 4.9

Chi Squared Independence Test between Stereotypic Behaviour and Frequency of Performance (N=35)

<u>Stereotypic Behaviour</u>		< Once a Week to Once a Day	Several times daily	Almost hourly	Total
Face	Observed Count	10	10	7	27
	Expected Count	7.65	11.55	7.8	
Head	Observed Count	7	8	6	21
	Expected Count	5.95	8.98	6.07	
Hands/Arms	Observed Count	17	34	16	67
	Expected Count	18.98	28.66	19.36	
Legs/Feet	Observed Count	6	5	6	17
	Expected Count	4.82	7.27	4.91	
Whole Body	Observed Count	7	12	7	26
	Expected Count	7.37	11.12	7.51	
Vocal	Observed Count	4	8	10	22
	Expected Count	6.23	9.41	6.36	
Total		51	77	52	180

Pearson's Chi-Square = 7.555, df = 10 and p value = 0.672 > 0.05. As the p value > 0.05, it can be concluded that the frequency of stereotypic behaviour and the body part are independent.

Although there is no significant link between body part and frequency of stereotypical behaviour Table 4.9 indicates that the arms and hands are more likely to be involved in stereotypical behaviours than are other body parts.

4.8.2 Duration: Behaviour Analysis

When analysing duration of behaviour in relation to the body part involved, categorisation changes were made to use four groupings. These groups relate to behaviours that last less than 1 minute, 1–2 minutes, at least 3 minutes, and are seemingly continuous (Table 4.10).

Table 4.10

Duration of Behaviour through Collation of the Incidence of Student Behaviour

Body Part	Incidence of Student Behaviour			
	Frequency 1	Frequency 2	Frequency 3	Frequency 4
	Less than 1 minute	1–2 minutes	3 – more than 10 minutes	Seemingly Continuous
Face	18	6	1	2
Head	10	9	3	1
Hands/Arms	26	21	13	9
Legs/Feet	6	3	2	6
Whole Body	10	9	6	1
Vocal	2	10	5	8

Results showed that in this analysis, the p value was < 0.05, therefore, it is concluded that there is a significant relationship between the type of behaviour and its duration (Table 4.11).

Table 4.11

Chi Squared Independence Test between Stereotypic Behaviour and Duration of Performance (N=35)

<u>Stereotypic Behaviour</u>		< 1 minute	1–2 minutes	3– > 10 minutes	Continuous	Total
Face	Observed Count	18	6	1	2	27
	Expected Count	10.4	8.37	4.33	3.9	
Head	Observed Count	10	9	3	1	23
	Expected Count	8.86	7.13	3.69	3.32	
Hands/Arms	Observed Count	26	21	13	9	69
	Expected Count	26.57	21.4	11.07	9.96	
Legs/Feet	Observed Count	6	3	2	6	17
	Expected Count	6.55	5.27	2.73	2.45	
Whole Body	Observed Count	10	9	6	1	26
	Expected Count	10.01	8.06	4.17	3.75	
Vocal	Observed Count	2	10	5	8	25
	Expected Count	9.63	7.75	4.01	3.61	
Total		72	58	30	27	187

Pearson's Chi-Square = 34.106, df = 15 and p value = 0.003 < 0.05.

Therefore, as $p < 0.05$, it can be concluded that stereotypic behaviour and duration are linked, suggesting a significant relationship between these two variables. This means that stereotypic behaviour in relation to body part and the length of time the behaviour continues is significant.

It was considered necessary to further analyse these data as there were a number of cells (10) with expected counts less than 5, meaning the expected frequencies were too low for analysis. Combining categories of durations of behaviours that occurred for at least 3 minutes and were seemingly continuous did not alter the existence of a relationship between duration and the behaviour. Further analysis of each frequency was undertaken, which in turn confirmed that duration period and body part involved have some significance. This analysis (Table 4.12) contributes to the discussion that a range of stereotypies occur that vary in duration and intensity for participants.

Table 4.12

Chi Square Independence Test detailing Frequency 1, Frequency 2 and Frequency 3 and 4 Combined – Stereotypic Behaviour and Duration

<u>Stereotypic Behaviour</u>		< 1 minute	1–2 minutes	At least 3 minutes	Total
Face	Observed Count	18	6	3	27
	Expected Count	10.4	8.37	8.23	
Head	Observed Count	10	9	4	23
	Expected Count	8.86	7.13	7.01	
Hands/Arms	Observed Count	26	21	22	69
	Expected Count	26.57	21.4	21.03	
Legs/Feet	Observed Count	6	3	8	17
	Expected Count	6.55	5.27	5.18	
Whole Body	Observed Count	10	9	7	26
	Expected Count	10.01	8.06	7.93	
Vocal	Observed Count	2	10	13	25
	Expected Count	9.63	7.75	7.62	
Total		72	58	57	187

Pearson's Chi-Square = 24.816, df= 10, and p value = 0.006 < 0.05.

Therefore, as the p value < 0.05, this suggests there is a relationship between the body part involved and time that the body part is involved in the behaviour. The

hands and arms were not significantly linked to any duration of time, since they are prevalent across all time frames. The involvement of the face for a specific time was significant. It was more likely that the face was involved for less than 1 minute, than for a longer period of time. Similarly, a vocal response was linked to 3 minutes duration, as was the feet and legs.

4.8.3 Context: Behaviour Analysis

When analysing the context of behaviour in relation to body part, categorisation changes were made. Behaviours that were linked to and or associated with anger and excitement were grouped as the category of High Levels of Stimulation. A second category was created for behaviours exhibited at times of being left alone, when bored, when a request was made, during listening activities and through tiredness. This category is referred to as Low Levels of Stimulation. See Table 4.13.

Table 4.13

Context and Frequencies of Behaviour

Body Part Involved	Incidence of Behaviour		
	Frequency 1	Frequency 2	Frequency 3
	High Levels of Stimulation (angry/excited)	Low Levels of Stimulation (left alone/bored/when request made/listening activity/tired)	Unsure/Other
Face	9	16	11
Head	10	11	7
Hands/Arms	35	67	17
Legs/Feet	14	20	4
Whole Body	12	32	2
Vocal	3	23	9

This analysis indicated that a significant relationship existed between context and behaviour (Table 4.14).

Table 4.14

Chi Squared Independence Test between Stereotypic Behaviour and Context of Performance (N=35)

<u>Stereotypic Behaviour</u>		High Stimulation	Low Stimulation	Unsure/Other	Total
Face	Observed Count	9	16	11	36
	Expected Count	9.89	20.15	5.96	
Head	Observed Count	10	11	7	28
	Expected Count	7.7	15.67	4.64	
Hands/Arms	Observed Count	35	67	17	119
	Expected Count	32.71	66.59	19.7	
Legs/Feet	Observed Count	14	20	4	38
	Expected Count	10.44	21.26	6.29	
Whole Body	Observed Count	12	32	2	46
	Expected Count	12.64	25.74	7.62	
Vocal	Observed Count	3	23	9	35
	Expected Count	9.62	19.59	5.79	
Total		83	169	50	302

Pearson's Chi-Square = 23.755, df = 10 and p value = 0.008 < 0.05.

Therefore, as the p value < 0.05, it can be concluded that there is a relationship between stereotypic behaviour and the situational context. This relates to certain behaviours in some contexts. However, behaviours that involve the hands and arms are likely to occur in all contexts. As might be expected, the vocal, and head and

face responses are more likely to occur when the student is unsure while whole body movements are more likely when there is low stimulation.

Similarly a relationship was evident for High Levels of Stimulation, Low Levels of Stimulation and for the third category labelled Unsure/Other when analysed separately. This information contributes to the discussion that stereotypic behaviours relate to sensory overload or sensory deprivation together with a discussion that causation is not always known or able to be identified with reference to context.

4.9 Discussion

The first stage of this mixed methods project aimed at seeking information about the prevalence, duration and context of stereotypic behaviour in learners who are blind, as reported by an identified sample of parents/caregivers. Of the responses, 59% indicated this behaviour was exhibited by the learner. Learners represented age bands between 5–18 years of age, with those less than 13 years old presenting as the larger group displaying stereotypic behaviour. This figure amounted to 69% of the total sample. For those over 13 years old, 31% of learners were identified as displaying this behaviour. Similar past research studies have indicated a variance of prevalence with figures between 48% and 100%. Theory surrounding maturation of the individual in relation to prevalence as espoused by Mandelbaum et al., (2006), Murdoch (2013) and Singer (2009) is of interest. This aetiological stance refers to the behaviour as being part of normal development; however, the impact of vision loss on normal developmental milestones for some learners may mean the behaviours are retained in a self-stimulatory manner.

Information gained from participants relating to visual conditions indicated a predominance of retinal disorders, including Leber's Congenital Amaurosis, Retinopathy of Prematurity, CHARGE, Vitreous Hypoplasia and Mitochondrial Disease. This is in common with similar studies by Molloy and Rowe (2011), who discuss firstly the degree of vision loss in respect of particular visual conditions.

Molloy and Rowe then refer to particular stereotypies that are more likely to be observed in relation to the type of vision loss of an individual. This means that learners who are totally blind are unlikely to display oculodigital stereotypies as opposed to those with some useable vision, implying that those with retinal disorders and some vision are more likely to do so. This information contributes to this study in suggesting that a visual diagnosis may contribute to which stereotypies may be exhibited in a learner who is blind.

Information suggesting that the learner had additional disabilities was recorded in 20 of the 35 responses (57%) in this study. These additional disabilities related predominantly to developmental delay. This information reflects similar research outcomes by authors such as Singer (2009), who suggest stereotypic behaviour is displayed by learners with additional and/or complex needs.

In respect to the 22 stereotypies listed, parents/caregivers identified a wide range of behaviours within what is considered to be a homogeneous group. The behaviours involving the hands and arms were the most prevalent (37%). Some of these behaviours also related to use of the hands and arms with the eyes. This supports the findings of authors such as Murdoch (2013) that oculodigital stereotypy is prevalent in learners with a vision concern. Other stereotypic behaviours were referenced by Murdoch and included those identified in the literature to be predominant in children who are blind.

This study aimed at considering frequency rates of the behaviour among learners in order to establish whether or not the behaviours were likely to impact on engagement in learning. Responses regarding frequency were somewhat heterogeneous and ranged from “less than once a week”, to “almost hourly”; however it was reported that the majority of behaviours were exhibited several times daily or as frequently as hourly. Analysis of frequency rates was sought to establish whether or not stereotypies involving a particular body part had any association with

how often the behaviours were displayed. When considering all the identified timeframes, there was no association with particular stereotypes.

Duration rates of stereotypic behaviour were considered through the collation of the incidence of the behaviour across four time frames. Responses were requested across time frames of less than 1 minute, 1-2 minutes, at least 3 minutes and seemingly continuous. The hands and arms were prevalent across all time frames. Behaviours that involved the face were significant in the time frame of less than 1 minute. Vocal response and involvement of the legs/feet were linked to periods of 3 minutes.

Situational contextual information was particularly interesting since it appeared to be more difficult for parents/caregivers to define this in the survey in respect to the options provided. Some behaviours were thought to occur in a range of situations, and for other respondents, Unsure/Other was the preferred option. This latter indefinable or unknown category was selected by 25% of respondents in this section of the survey. Similar historical studies refer to rates of approximately 23% of responses where parents were asked to define the situational context of stereotypic behaviour and were unable to do so. In this current study, where responses were provided, the behaviours occurred in periods of high or low arousal. Analysis of the responses in respect to a possible association between context and stereotypic behaviour produced data that identified a significant relationship between context and behaviour. This is also evident in studies by authors such as Barry, Baird, Lascelles, Bunton, and Hedderly (2011); Miller, Lane, Cermak, Anzalone, and Osten (2005); Molloy and Rowe (2011); and Rapp and Vollmer (2005). These data provide the impetus for further investigation.

It is therefore possible to suggest that the outcomes of this survey reflect to some extent the documented international findings in the literature about the prevalence and duration of stereotypic behaviour in children who are blind. The statistical data from this aspect of the study is comparable to that previously known

in respect to published international studies and reflects the range of documented aetiological theories. However, what is clearly omitted and seemingly unknown is information in respect to contextual relevance, particularly that which relates to educational settings for this sector of the population. As the majority of these learners are educated in what is perceived to be inclusive mainstream settings, and they are likely to display stereotypic behaviours, especially those that involve the hands and arms within a range of situations, what is the reality for some of these learners in the social context of the school environment? In order to explore what is happening at school for learners who are blind and who exhibit stereotypy, the next step in this project involved considering a number of case studies that could contribute to this picture. With information from this survey about prevalence, duration and possible situational contexts of stereotypic behaviour, the focus moved towards the reality of learning and the acquisition of social skills within the mainstream learning context. What is the reality for learners who are blind in New Zealand? What are the lived experiences for some learners? This became the second stage of this mixed methods project.

Chapter Five

The Case Study Report

5.0 Introduction

Some learners who are blind may exhibit stereotypic behaviour. The second stage of this mixed methods project uses qualitative research in the form of case studies of learners who, as reported by their parents/caregivers, display these behaviours. Qualitative research is “guided by the researcher’s set of beliefs and feelings about the world and how it should be understood and studied” (Denzin & Lincoln, 2008, p. 31). This is because it is our own interactions with the world that lead us to have certain beliefs (Avis, 2003). The chapter contributes to the field by reporting on five individual learners, and aims at critically examining this issue. These five case studies were conducted in New Zealand, with data gathered during 2011–2013.

5.1 Chapter Overview

This chapter is presented as a narrative. Each case study involves a learner who is blind, the learner’s Resource Teacher: Vision (RTV) who was interviewed, researcher observations of the learner, and a review of the key competencies as documented in the child’s Individualised Education Plan (IEP). The researcher conducted the interviews, undertook observations of the five children in a number of different contexts, collected relevant artefacts such as assessment data, school reports and learning stories, then analysed and reported on the gathered data. The type and situational contexts of stereotypic behaviours exhibited were then closely examined to generate new insights.

5.2 Method

Following Cresswell’s (2003) Mixed Methods Sequential Explanatory Strategy, this second stage of the research project is based on the qualitative paradigm and uses the case study approach. This approach involved interviews with assigned RTVs,

observation of the child for each case study by the researcher and a review of relevant documentation.

5.2.1 Interviews

The interview method was chosen as it may be considered to be a conversation with a purpose, that purpose being to understand the issues from the perspective of those involved (Fontana & Frey, 2008) when working with the learner. The teachers were asked to describe from their own perspective the perceived situation in the world of the learner. The aim of this interview was to gain an insight into the teacher's thoughts, feelings, attitudes and interpretations. As the interviewee was considered to be more of a participant than simply someone from whom information was received, a less structured approach was adopted.

It was important to ensure reliability and validity, therefore techniques involved needed to be reproducible, systematic and transparent. The approach for this aspect of the research involved both semi-structured questions and an in-depth schedule of questions to explore the respondents' own perceptions and understandings. This provided a platform for comparisons, reflection, clarification and probing (Lincoln & Guba, 1985). Prompts were used to expand on conversations – "What happens when that occurs?" "What do you do then?" "Can you tell me more?"

It was equally important to guarantee that the process was credible and trustworthy. These qualities were enhanced by ensuring the dialogue was undertaken on a one-to-one basis and personalised. Even though the interviews generated information that could well have been produced by others, it is important to acknowledge the role of the interviewer. It was the interviewer who elicited this information utilising relevant questions in a comfortable atmosphere of conversation. Interviewees chosen did not necessarily support any pre-existing bias; the questions asked generated valid accounts of the situation; and anyone reading the collated data would be able to understand the collection and analysis process implemented.

The interviews themselves were conducted either by telephone, because of the geographical location of the RTV, or in a face-to-face situation. Taping was undertaken when agreement was given and note-taking of impressions and responses occurred throughout the process or at the conclusion of the session. Interview questions as per the schedule included those that sought information about current attainment and functioning levels of the case study learners in relation to the levels detailed in the New Zealand Curriculum. Questions were included to ascertain the focus of the learner's IEP, together with information about the stereotypic behaviours exhibited and the reactions of the peer group to those behaviours. Information was also sought, where applicable, about strategies that were implemented to manage or to change the behaviour of concern. Conversations with the teachers were on-going, with all interviewees being involved for a minimum of three one-hour meetings. Anecdotal notes were recorded throughout.

To ensure that this component of the research was credible, transcripts of the responses were emailed to the interviewees prior to analysis for checking and confirmation. Interviewees could then add or modify these transcripts if they wished to do so. To protect confidentiality, pseudonyms were used. The narrative reporting of the interviews that took place aimed to be sensitive and fair by describing the process as it was conveyed.

5.2.2 Observation of Each Child in the Case Studies

Observation in as unobtrusive manner as possible, was chosen as the means to gain information about the behaviour of the five learners. This approach involved creating opportunities to watch the learner within a familiar context, either at home, at school, in a specialised program or while attending an immersion course at the familiar BLENNZ Campus. All learners were observed on three occasions with a checklist used. This informal checklist referred to the following aspects: context, time of day, program/lesson content, adults in attendance, adult interactions, peer group presence, peer group interactions, stereotypic behaviours displayed, interventions and responses. Anecdotal notes were recorded at these times to contribute to a

clear chain of evidence. Minimal interaction took place with the learners on all occasions, although each was informed of the presence of a visitor in the room. The researcher remained aloof from these situations apart from social interactions in various settings that were deemed to be polite, such as a greeting. Protocols in schools exist that require students to be informed of the presence of visitors, although not informed of the purpose of the visit. Whether or not this impacted on the observation process is unknown.

The aim was to ensure that observations were of high quality; therefore sufficient time was spent in a range of settings to ensure there was clear confirmation that no new data was being observed or recorded. Notes were collected systematically, and confidentiality was aspired to at all times.

5.2.3 Relevant Documentation

Relevant documentation was obtained from RTVs; the most noteworthy being the IEP for each learner. Such documents can provide historical and contextual dimensions to observations and interviews. They enrich what is seen and heard by supporting and challenging perceptions. As a formal reporting schedule of assessment and planning, the IEP document was deemed to be contextually the most appropriate and meaningful reported evidence of the current functioning levels of the learners across areas of the curriculum.

Therefore, this research involved three major components; observation of the child, interviews with RTVs, and a review of relevant documentation.

5.2.4 Interpretation of the Data

This phase of the research aimed at answering the question “What is happening for these five children, who exhibit stereotypic behaviour, in respect to their learning and in their social skill acquisition?”

Systematic analysis occurred following the collection of the data using prescribed software QSRNVivo. However, coding of anecdotal notes and observations took place throughout the collection period as it was clear that a number of themes were emerging. The aim was to immerse myself in the study to “discern relationships and subtleties that lay below the surface” (Petersen, 2012, p. 805). These relationships are within the constructed reality of a particular individual child. In this phase of the research there is no assumption of a single objective reality.

The multiple sources of data – interview notes, observations and documentation – were gathered between April 2012 and May 2013 and then converged through the process of triangulation. The purpose of triangulation is a search for convergence and consistency from a range of sources. This process enhances a sense of trustworthiness for it increases the confidence in research findings (Denzin & Lincoln, 2008). This collated information was then reported in a narrative format, written during the period November 2012 to March 2013. Narrative is considered a powerful, personal, social and cultural phenomenon with a well-recognised potential to support and enhance learning. It can support the juncture of new knowledge with old. It can provide readers with conceptual schema to enable them to understand a situation better and to learn more (Bizzocchi & Schell, 2009). This then aimed to provide the link to the identified research question. With qualitative research it is particularly important to focus on context, to acknowledge that generalisation is unattainable, to present outcomes as tentative, and for analysis to involve ongoing re-examination of data for both confirming and disconfirming evidence.

5.3 The Cases

Five case studies were conducted. Selection criteria for each case study involved the use of intensity sampling where the focus was on maximising the likelihood that each child would manifest the chosen phenomena. To draw information that authentically

reflected the demographics as reported in the national survey, particular consideration was given to the child's gender, age, geographical location, ethnicity and educational placement.

All five learners chosen were known to the researcher, but the individuals did not have a personal relationship with the researcher. Participation was requested from the five families and from the learner's assigned RTV. All families and teachers agreed to be involved. The stories of these young people are offered as single cases, with information contributing to the whole study.

5.4 The Stories

"Every human situation is novel, emergent and filled with multiple meanings and interpretations" (Glesne & Peshkin, 1992, p. 19).

5.4.1 Teri

"He really is gifted but plays up at school because he's bored." (Margaret, Family Member, 2012).

The youngest learner in the case studies was Teri, a new immigrant of *Pasifika* origin with the conditions of Peters Anomaly and Glaucoma. Peters Anomaly is one of a number of diseases that causes central vision opacity, resulting in blurred vision and concerns with glare. It is often associated with Glaucoma, where the optic nerve has been damaged owing to raised pressures in the eye. With both opacity and optic nerve damage, the brain does not receive a sharp image and does not learn to interpret clearly what is seen. Peters Anomaly may also be associated with other physical conditions as well as learning difficulties (Blaikie, 2013). The outcome for Teri is blindness, with minimal light perception, no physical problems but some learning difficulties. Therefore, Teri requires adaptations to his educational program; he accesses the curriculum through Braille and has the use of both a Perkins and Mountbatten Braille to support this medium.

Teri was aged 6.5 years in August 2012 and he attends what was his local school prior to the family relocating to a suburban area of Wellington. The school is a co-educational full primary setting with a roll of approximately 700 children, Teri being the only child who is blind. The school itself is categorised as Decile 10, which indicates that the population is drawn from a high socioeconomic community. (In New Zealand, schools are given a Decile rating that is used to provide funding, meaning the lower the school's Decile on a 1 to 10 range, the more funding it receives). There are no other immigrant families enrolled at this school at this time. The ethnic composition of the roll is: New Zealand European/*Pakeha* 68%, Asian 12%, Other Europeans 9%, Maori 6%, Other Ethnic Groups 5% (ERO, 2012). Teri is one of the learners in a minority culture of 5%.

The school's philosophy is reflected in the phrase "*Tino Pai Ake*", which translates to "We encourage our children to be the best they can be". The school's Charter Values include those of excellence, respect, responsibility, empathy and integrity. The philosophy and values are pivotal to program development and practice. Teri's school is the largest in the city of Wellington and it is affiliated to the local College of Education in order to provide opportunities for teacher trainees to carry out the practical component of their course of study. This means that there are many adults moving in and out of the classrooms throughout the school year. The school provides a number of specialised programs that are labelled as follows: SWSA – Students with Special Abilities, CWSN – Children with Special Needs, and NESB – a program for learners of a Non-English Speaking Background. Teri is supported in the CWSN Program owing to his vision loss.

Teri also receives funding under the Ongoing Resourcing Scheme (ORS) through the New Zealand Ministry of Education because of his vision loss. He receives support from a prescribed specialist teacher, Ailsa, and 60 hours' teacher-aide time per week. He requires two teacher-aides to support his behaviour to ensure he remains safe and others remain safe from his actions. Teri's specialist

teacher, Ailsa, has been a teacher since 1994 and has a Bachelor of Teaching plus a Postgraduate Diploma in Vision Education. Since then she has always had students with special needs in her classroom, which has encouraged her interest and passion in working in Special Education. With teacher involvement in Australia and with *Te Aho o Te Kura Pounamu*, the New Zealand Correspondence School, Ailsa has considerable experience in education, which she brings to this specialist role with Teri. Neither of the two teacher-aides bring specialist training to their roles but it is considered they are developing skills as they work with the team supporting Teri.

Teri has an IEP that is similar to the template provided by the New Zealand Ministry of Education, but it includes a behaviour plan owing to the impact his non-compliant behaviour is having on his progress at school. This document begins with a description of celebrations and successes, having firstly identified those involved and their roles. This includes an orientation and mobility instructor as well as a child/family counsellor. Relevant administration requirements are also included. The plan details the modes of the Expanded Core Curriculum and refers briefly to the National Curriculum. The focus of this document is twofold: the non-compliant behaviour is detailed as well as the goal for greater engagement in the curriculum. The 2011 IEP states that Teri has minimal interest in the curriculum, with the goal being to focus on his interests to raise his engagement with learning. In the words of the IEP:

- Teri has shown consistent uncooperative and non-compliant behaviour. Even when offered choices and activities that he has enjoyed in the past, he is being disruptive.
- We are trying unsuccessfully to get Teri to explain/express why he does not want to do something.
- He is not engaging effectively in any part of the curriculum. He resists engaging and will disrupt as a solution.

Therefore, this plan is about his behaviour; it is about challenges in engagement, both of which have resulted in withdrawal from the classroom environment and the requirement of specialist support from a counsellor. With respect to the National Curriculum, the focus is the key competencies of Managing Self together with Participating and Contributing. Teri is not achieving at age- and year-appropriate levels across all key competencies, although personal growth is evident. His age-appropriate level is Level 2. Four of the key competencies are recorded at Level 1 and the fifth (Participating and Contributing) is pre-Level 1. These assessments of the competencies conclude the plan and are presented as a brief narrative. This IEP reflects few of the principles and characteristics recommended for planning; however it details some personal growth, the issues of behaviour, the personnel involved and the difficulties with acquiring skills across all learning areas. Some forward planning is evident. Perhaps this document presents the opportunity to reflect on outcomes at school for Teri.

At school, Teri follows an adapted program. As reported in the IEP, he is disengaged with learning. His impulsivity and erratic behaviour are causing serious concerns. He has “issues with coping with noise and has difficulties relating to the peer group. He is involved in parallel activities with older assigned buddies who try to engage with him. He wants control” (Ailsa, 2012). It is also thought his classmates fear him and do not engage with him socially. Teri is reported to exhibit a range of behaviours including shouting, swearing, hitting others and spitting. He also exhibits stereotypic behaviours at school that involve the face, the whole body as well as repeated vocalisations. He spins his body around in sequences, setting a designated time period which he identifies. His RTV, Ailsa, considers the spinning is vestibular stimulation due to ear problems or the common cold, as the spinning is more intense when Teri has these ailments. He also displays behaviours that Ailsa considers indicate light-stimulation by repeatedly running backwards and forth in front of a shade cloth. He eye-pokes when seated at a desk to undertake activities that require concentration. Ailsa also states he uses rhythmic vocalisations when disengaged from an activity. Ailsa reports that Teri is exerting some control over his spinning sequences and is beginning to pre-empt adult intervention for his eye- poking and vocalisations. This is thought to be positive, as Teri requires “some control over his

own behaviour before moving forward” and he “needs to learn socially acceptable behaviour” (Ailsa, 2012). In her own words, “he is often angry and frustrated”. Perhaps this implies the behaviour is hindering his progress in learning and hindering his social acceptance by others.

Teri was observed in the context of his new home, surrounded by a number of extended family members who interacted with one another in their native language although no verbal interactions were heard with Teri. The family atmosphere was both warm and welcoming, with family members openly offering to share their story. The spokesperson was the maternal figurehead, who relayed the journey the family had travelled throughout Teri’s life. Their relocation to New Zealand as immigrants, the changes that occurred as they settled into a new lifestyle and the changes in family dynamics were explained. There was also discussion about the rounds of endless professional appointments, liaison with numerous agencies and the frustrations that the family still felt in trying to find a diagnosis for Teri. Their concerns centred on a medical explanation for this young boy’s vision concerns, his frustrations and his impulsivity. His erratic school attendance was discussed and was said to be as a result of medical appointments with numerous departments at a number of hospitals, his vulnerability to childhood illnesses and the distance of the family home to the school at which he is enrolled. In the words of Margaret, Teri’s maternal grandmother:

He really is gifted but plays up at school because he’s bored. He’s a good boy at home. He loves being alone in his room, he loves listening to stories on his headphones. He needs to settle into the new house and get back into school on a positive pathway. (Margaret, Family Member, 2012)

During the course of the discussions at home, Teri came to the family area from time to time, always moving very quickly, engaging in some type of physical activity such as climbing on furniture, or rolling on the floor, then leaving the room just as rapidly. He was later discovered outdoors spinning his whole body around very fast, then indoors, seated alone at a keyboard, eye-poking while listening to

recorded music, laughing and talking to himself. At no time was Teri heard to engage in verbal communication with others, even when prompted to do so by an adult.

The overall impression of Teri was of withdrawal and non-engagement with others both at home and at school. His IEP indicated behavioural concerns from the educational team supporting him, as well as competency levels lower than expected for his age. His RTV suggested his anger and frustration were impacting on engagement with learning and social interaction with others.

For Teri, life is complex. His family have recently emigrated from a Pacific Island lifestyle to the dramatic contrast of suburban life in a large city in New Zealand. Compounding this issue, the family have moved suburbs to a new home within a short space of time resulting in further adaptations to Teri's environment. He attends a very large school where learners are deemed to come from high socioeconomic backgrounds. He previously did not attend school and was educated by family members in the rural home environment, using his native language. He now belongs to an ethnic minority group at this school and English is not his native language. He is using technology that was previously unknown to him and a medium he had previously not been exposed to. Almost all that was familiar to Teri, has changed.

Contributing to these changes, there are conflicting perspectives about his behaviour and his achievements and how they are perceived. The family talk of Teri as they see him at home. His RTV and his IEP team talk of Teri as they see him at school. While there are substantial differences in these vignettes, the expectations of Teri are in turn quite different. At home, he is given free rein to do as he wishes, whereas at school he is asked to purposefully engage in learning activities. He communicates in his native language at home, and in English at school. Cultural traditions are in place at home whereas they were not observed to be recognised at school. He also has many new people in his life now, both in the education and health systems. His absences from school are numerous, his family referring to an endless round of medical appointments. They talk of their need for a medical

diagnosis for Teri's behaviour, for that, to them would mean a defined treatment or remedy. "All would make sense then" was the comment (Margaret, family member, 2012). Teri's visual diagnosis of Peters Anomaly and the association with learning difficulties is also another consideration. Perhaps it needs to be recognised that all of these considerations contribute to the complexity of learning and of Teri's life. His "lived experiences" reflect Glesne and Peshkin's (1992) picture of a situation that has multiple meanings and interpretations.

5.4.2 Kyle

"Kyle is still upset about being blind" (IEP, 2012).

The second youngest child of the five case studies is Kyle, who has the vision condition of Retinal Dysplasia. This is a descriptive term that relates to a number of conditions depending upon the severity of the dysplasia. It is congenital in origin, resulting in abnormal growth and differentiation of the retina, where the two layers of the retina fail to form together. In a mild form, folds occur in the retina; however in a severe form the layers do not come together and retinal detachment may then occur. The degree of vision loss is dependent upon the degree of folding of the retina (Graaf, van der Valk, Moll, Schouten-van Meeteren, & Castelijns, 2007). Kyle has a severe dysplasia resulting in blindness. This means that Kyle requires adaptations to his program; he accesses the curriculum through Braille and has the use of technology to assist him in the form of both Perkins and Mountbatten Braille.

Kyle is of New Zealand European origin and was aged 7.5 years in August 2012. Kyle attends his local school and is one of several children enrolled who have a vision concern. The school is a co-educational contributing primary school with a roll of approximately 180 children and a Decile rating of 3, indicating the children who attend this school are from relatively low socioeconomic settings. The school is promoted as being a setting that cares for others, with a warm, friendly, family atmosphere within a supportive culture. A special feature of the school is the inclusion of two satellite classes from a local special school, which aims at "promoting an understanding of difference" (Morningside School Website, 2008).

This is a school where all learners are valued, interactions between parents and the school are promoted as positive, and consultation with the Maori Community is foremost. The school motto is “*Whakamana Akoranga*”, which translates to “Empowering Learning”, the focus being that all students are provided with a safe, secure environment that enhances learning opportunities. Understanding, respect and sensitivity are features of this city school and these values are aspired to by all staff. The ethnic composition of the school is Maori 47%, New Zealand European/Pakeha 44%, *Pasifika* 3% and Other Ethnic Groups 6% (ERO, 2011). Kyle is recognised as being in one of the major ethnic groups in the school.

Kyle receives ORS funding through the Ministry of Education, New Zealand, owing to his vision concerns. He receives prescribed specialist teacher input and 25 hours’ teacher-aide time weekly. Kyle’s specialist teacher is Sarah, who has been a teacher since 1974. She has held a number of positions in New Zealand schools, including primary teacher, support worker and teacher-aide. She has had experience in classrooms and in a Special Needs Unit, as well as experience across a number of geographical locations. Sarah brings a wealth of knowledge to the field of Vision Education and to her role with Kyle. Kyle’s teacher-aide has been with him since his enrolment at school at five years of age. She is currently developing her proficiency in Braille but does not have any specialist training in the field.

Kyle has an IEP that follows the design of the template provided by the New Zealand Ministry of Education. It begins with a description of the five team members and their roles and states the plan period. Strengths and successes across various settings are recorded and the document includes details of personal growth as well as review comments that are relevant to Kyle. The document is divided into both the New Zealand Curriculum key competencies and the modes of the Expanded Core Curriculum. Goals have been set in all curriculum areas, with review and ongoing planning evident for achieving the next learning steps. The main focus is on the competency of Thinking, in order to foster some independence for Kyle in managing his own frustrations and to assist him with both problem-solving and in decision-making. Reference is made to behaviour therapy to assist with head-butting and

head-banging. A referral to an ophthalmologist in relation to these behaviours is also recommended, to check eye discomfort as a possible cause of eye-poking and eye-pressing. His 2012 IEP states:

- Kyle was head-butting people or a wall when frustrated. This has reduced but he now bangs his own head when frustrated.
- Kyle will use his words more to express frustration.
- As adult contact becomes just adult supervision, Kyle will learn to solve more problems for himself.
- Continue to discourage eye pressing by gentle hand on his shoulder saying “head up” or “hands in your lap”.
- Kyle will do less flapping (except in excitement) so that he can focus better on what is being said.
- In the playground, Kyle will play without adult contact. He will interact more with other students.
- He tries to engage adults in conversation rather than carry out instructions when asked. All adults need to discourage this purposeless talking and encourage him to stay focused on what he’s doing.

The 2012 document refers to what the team perceive to be positive outcomes for Kyle.

- He is accepting that the rules are the same for him as for other students
- Kyle is becoming more independent with encouragement
- He is talking to other students now, initiating conversations and finding his own partner when asked to get into pairs.

Assessments suggest that overall teacher judgements (OTJs) have been made together with some records of formative assessment in literacy. This plan demonstrates some of the required principles and recommended key characteristics. It offers guidance to those working with Kyle and includes the family in most areas. Perhaps one of the most thought-provoking statements in this 2012 IEP is “Kyle is

still upset about being blind". Perhaps this provides some insight into thinking about Kyle's behaviour.

Kyle was observed in the familiar context of his school, both indoors and outdoors. He was also monitored several times while participating in a social skills program for primary school-aged learners who are blind, located at a setting familiar to him, and at the BLENNZ campus school while undertaking a course for "young Braille users". In the classroom setting, Kyle was seated at a table with two classmates near him and his teacher-aide beside him. There was no observed interaction with his classmates. Kyle was observed in both his literacy and numeracy programs, in topic work and in break sessions at interval and lunchtime. At all times there was an adult seated beside him or near him from whom he requested information, saying "What's happening?" "What do I do?" "What did you say?" "I don't know what to do!" "Tell me!" "I can't!" His actual engagement with independent learning, where he was asked to read a Brailled story and problem-solve simple mathematical equations with solutions of less than 20, was minimal. In a page of Brailled text, Kyle tracked eight lines of Braille in a 50-minute period. This equates to a small paragraph of a child's instructional reader. He was unable to track along a complete line of Braille without an adult prompt and required encouragement to continue, with words such as "Next line please Kyle". When asked to retell what had occurred in the story, there was no response initially, then with repeated questioning he responded correctly. In the mathematics lesson, he worked through two equations during a 40-minute period. These were " $4+3=?$ " and " $5+6=?$ ". Use of materials in mathematics resulted in experimentation with the objects and folding of the non-slip mat in use. Prompts were similar to that in the literacy program, with responses from Kyle requesting repetition of the question. Throughout these instructional sessions, Kyle displayed repetitive behaviours with his legs and feet, repetitive vocalisations and both eye pressing and poking.

The busyness of the classroom with over 30 learners, the chatter of his classmates and the voice of the Year 3 teacher surrounded him and he often seemed distracted from the verbal instructions of the assigned teacher-aide. He did

not once respond to individual instructions unless these were repeated several times. He was observed to react to increasing noise levels by flapping his hands vigorously and found it difficult to remain on task for more than 2 to 3 minutes. Kyle was also noted to eye-poke and press his eyes while at the same time opening his mouth in a wide, yawning type movement when seated at the table or on the class mat. While at the table, it was noted that his feet were touching or stroking one another almost continuously, then he foot-tapped on the floor using a leg-swaying motion or a gliding movement of his feet on nearby chair legs. In the outdoor environment Kyle moved cautiously. He seemed to be talking to himself throughout the route and did not respond to others who greeted him when passing. These behaviours were recorded across all contexts, including the Social Skills Program in an alternative setting and while attending a course at the campus school. They followed an identical pattern, as did the questioning of an adult.

His RTV, Sarah, was quite aware of the behaviours and discussed the impact these may have on the peer group in the future. However, she indicated surprise at the continuous nature of the behaviour involving Kyle's feet and legs. She made the observation that as a pre-schooler Kyle never wore shoes and explored his surroundings with his feet. Sarah stated "I don't focus on the action (of the behaviour) but I comment on new behaviour" (Sarah, 2012). Sarah uses a number of strategies to assist Kyle to behave in what she considers to be a more appropriate way. She states that:

Kyle needs to understand that others behave differently. I am concerned that as he gets older, reactions will or may differ [from the peer group]. Some of his behaviours will become less appropriate. They ignore them now. They are not really aware of it but they stare a little at the flapping (Sarah, 2012).

Kyle's intermittent engagement in learning was also commented on by Sarah who said that in her opinion, Kyle was disengaged in his learning for much of the time. This was the reality of life at school for him.

Therefore, Kyle's situation is very complex. Although he attends his local school and is in a mainstream setting with his peer group, where much of the curriculum is presented to the entire class, his program requires a number of adaptations to make the content meaningful for him. The aspirations of his family and school are similar, with learner outcomes agreed upon. His stereotypic behaviours were observed to be very frequent and his questioning of adults was almost continuous. Across contexts there was little observed difference. This included time with the sighted peer group as well as time with other learners who are blind. The outcome of these observations and discussions focus on Kyle's intermittent engagement with learning at school.

However, for Kyle, there are other things to consider. He has many adults in his life beyond school as he has a number of caregivers who are with him after school and at weekends. Observations of Kyle and the caregivers was not a reality for the researcher but this may have contributed further to the understanding of his experiences. How he interacted with others beyond school and family when activities were self-directed would be important to observe and how he responded to tasks/direction/challenges in a more relaxed context would also seem to be relevant. Further observations of his behaviour may provide more information as to what is happening in his life.

For Kyle, this is, in Glesne and Peshkin's (1992) words, a picture that is still very much an emergent story. It has varied meanings and interpretations dependent on the role an individual has with Kyle.

5.4.3 Kathryn

"Are the values of the sighted world being imposed on others such as Kathryn?"
(Anne, RTV, 2012)

The third case study is of Kathryn. She was aged 11 years in August 2012. She is of Asian origin and has the vision condition of Retinopathy of Prematurity. Retinopathy

of Prematurity is a disease that progresses in stages. There is a delay in retinal vascular growth after birth and then a regression of these existing vessels followed by hypoxia-induced pathological vessel growth. This is as a result of a decreased gestational period, where premature infants are treated with oxygen to stimulate vessel growth. Excessive oxygen in these infants is considered to be the major factor whereby new vessels create scarring in the retina. This results in blindness at an early age (Chen & Smith, 2007). This is the situation for Kathryn. She therefore requires an adapted program; she accesses the curriculum through Braille and has a range of technology including a Pacmate, Braille Apex and a Netbook to support this medium.

Kathryn attends her local school, which is a co-educational contributing primary school with a roll of approximately 255 children and a Decile rating of 7. The school's motto is "*Te Ako I Te Ora*", which translates to "Learning Through Living". The vision of the school has been incorporated in a graphic using the New Zealand native flax, the *harakeke*; the child being represented by the flax plant. The leaves of the flax plant are labelled LEARN – Learn, Empower, Achieve, Respect and Nurture and represent the values of the school. The *harakeke* proverb is central to the school's philosophy and is as follows:

Hutia te rito o te harakeke,

Kei whea e Komako e ko?

Ki mai ki ahau

He aha te mea nui o te Ao?

Maku e ki atu

He tangata, he tangata, he tangata.

If the heart of the harakeke was moved,

Where will the bellbird sing?

If I was asked, what is the most

Important thing in the world;

I would be compelled to reply,

It is the people, the people, the people

The ethnic composition of the school is as follows: New Zealand European/*Pakeha* 26%, Maori 10%, Filipino 29%, Indian 9%, Chinese 6%, African 3%, Korean 3%, Samoan 3%, Tongan 3%, Other Ethnicities 8% (ERO, 2011). Kathryn's family are Filipino – this ethnic origin constitutes almost a third of the school's population.

Kathryn receives ORS funding through the Ministry of Education. She receives prescribed specialist teacher input and 18 hours' teacher-aide input weekly. Her specialist teacher is Anna, who trained as a primary teacher in 1974 and has a wide range of Special Needs experience in both her professional and personal life. She has taught in a number of settings, has had positions of responsibility in Special Education and has served on the Board of Trustees at her local school for several years. Anna has undertaken further studies through a New Zealand University and continues to upskill her knowledge in Special Education. She is highly experienced in the field of Special Education and brings this experience to her role with Kathryn. The teacher-aide has been with Kathryn for several years. Although she has no recognised qualifications, she is very experienced in the field of Special Education, having worked in this area for two decades.

Kathryn has an IEP based on an earlier recognised template. Her current IEP document has five team members (their roles are described), and administration matters are included as are the five key competencies of the National Curriculum. All competencies have relevant goals attached, however the focus for the plan is on Managing Self, as Kathryn was transitioning to a new setting at the beginning of the 2013 school year. Specific learning outcomes are written for each competency, however these are threaded together with the concept of building independence and

self-advocacy in the new secondary school setting. The IEP assessments are presented as a brief narrative, summarising the adaptations of teaching strategies and required resources. She is achieving below her year-group optimum target of Level 3 but this is considered relevant in this group, as the whole class achievement levels are similar. The plan represents a collaborative process and is forward-looking, but learning goals are not deemed succinct. No reference is made to any perceived behaviour concerns, however passivity and a lack of involvement in activities in the classroom setting is documented. Her 2012 IEP details a number of positive comments:

- She is developing confidence and interacts well with her peers
- She is capable of doing things for herself
- She is independent at break times
- She is a popular class member

The 2012 document also includes statements such as:

- Kathryn is not a risk-taker and does not like to contribute
- She does not generally take the initiative
- She is afraid of making a mistake
- She tends to let others help her
- She needs to make decisions about what she's going to do
- She relies on her peers to help her

This document helps to create a “picture” of Kathryn as perceived by those who work with her.

Kathryn was observed in the familiar setting of her classroom, in the school playground, at a social group for young learners who use Braille, and at a course at the campus school, which is also a familiar setting for her. Kathryn was observed undertaking a number of activities that included literacy, technology, topic studies and music. In all activities indoors, she was seated at a small group setting communicating with others informally. She was observed to display particular behaviours. Kathryn was noted to exhibit behaviours that involve the whole body, the

face and the hands, in all of these contexts. Whole body rocking occurred during particular activities such as listening to music or when listening to a shared story. Eye poking and eye pressing were displayed toward the end of intensive learning periods or periods of concentration as well as at the end of the school day. Rocking was also evident when waiting for adult instruction; however her body stilled when others were talking. Rocking, in combination with hand rubbing and hand squeezing, was evident in situations that were new, such as the introduction of a new activity, or at times when Kathryn was singled out to contribute or to begin a task independently. The peer group did not react to these behaviours. Kathryn reacted differently in the large group situation of the classroom in that the stereotypic behaviours were minimal; however, in the smaller group settings the behaviours were less subtle and were readily observable, indicating some contextual relevance. No behaviour of this type was observed in an outdoor setting. Therefore it is interesting to reflect upon Kathryn's behaviours in educational settings.

Kathryn's RTV, Anna, comments that the behaviours have reduced markedly as the learner has matured but are still quite evident in quiet "downtime" moments in the classroom. Anna talks to Kathryn about her behaviour, using words to implement a change in the stereotypy with the reaction being that Kathryn stops the behaviours immediately. Anna states "there is no need for anything other than verbal information; she knows she shouldn't be doing it". In contrast to this statement, Anna queries whether the values of the sighted world are being "imposed on others such as Kathryn" and asked "do we really want to change the behaviour? Learners need behaviour that is socially acceptable in the context in which they are in or in which they relate to" (Anna, 2012).

Therefore, Kathryn's situation is interesting in that she presents as a student who is withdrawn in social settings. The New Zealand educational system must be vastly different from her original placement in the Philippines, therefore this drastic change in context may be challenging for her. Segregated schools have previously been the norm for her and inclusion in regular settings for learners who are blind does not occur in many locations in the Philippines. However, she is very intent on

achieving well at school in most subject areas. Her RTV suggests she is somewhat driven by her parents desire for her, as the child of an immigrant family, to do well. She is encouraged to be involved in a range of additional activities through adult initiation and ongoing support. Her stereotypic behaviours are minimal in the mainstream setting but are observable in settings where she is with the peer group who are blind. In 2013 she will attend a single-sex integrated religious school. The setting has a large number of students, a higher Decile rating and Kathryn will be a cultural minority. For Kathryn this will be “novel”. Her behaviours, her engagement in learning, her attainment in the skills of the key competencies, her level of inclusion, her friendships, and her extra curricula activities may change over time. Her experiences in new contexts are likely to make a difference in her life, especially as she assimilates further into the New Zealand lifestyle. How these evolve is unknown and what changes this brings for Kathryn are yet to be learnt.

5.4.4 Rangi

“I’m blind, it’s not fair.” (Rangi, 2012)

A further case study is of Rangi, who is of Maori origin and who has the vision condition of Vitreous Hypoplasia, also referred to as Persistent Hyperplastic Primary Vitreous (PHPV). This is a congenital, developmental anomaly of the eye. Under normal conditions, the area behind the lens of the eye is filled with a clear, jelly-like substance called vitreous. For those with this anomaly, the vitreous at birth is hazy and scarred, resulting in the inability of light to pass through the area to the photoreceptors of the retina. This is referred to as PHVP affecting the posterior eye, the outcome of which is severe low vision and/or blindness. Other associated conditions are cataracts, retinal detachment, glaucoma and microphthalmia. For Rangi, the outcome is blindness with no other visual conditions. She therefore requires an adapted program at school and she accesses the curriculum through Braille. A range of assistive technologies support her to do this. She uses a BrailleApex, a Netbook, software packages including Sibelius and Jaws, an iPod Shuffle and a Daisy Player.

In August 2012, Rangi was 13 years old and attending a co-educational Decile 10 full primary school with approximately 350 students. The school's Mission Statement is "Learning to Live, Living to Learn" and has core values that refer to high expectations of achievement and success through a commitment to lifelong learning in a positive environment. Respect for all and a partnership between family, school and the community are included in the school's Mission Statement. The school also has an historical relevance to the community in that it was one of the earliest to be built in the city. This was in 1881. It was later demolished after the Great War but was rebuilt and remains on the original two sites; a factor that is valued and often referred to by staff and pupils. It is a site that is very challenging to access, especially for those with a vision concern. The ethnic composition of this school is as follows: New Zealand European/*Pakeha* 94%, Asian 5%, Maori 1% (ERO, 2010). As Rangi is a Maori student, her cultural identity is very much in the minority.

She receives ORS funding through the Ministry of Education, New Zealand. She receives prescribed specialist teacher input and has 13 hours' teacher-aide time weekly. Caty, her specialist teacher, has been involved in Vision Education for 25 years. She studied for her Bachelor of Arts in English and Education some years ago and has attained postgraduate diplomas in Educational Studies and in Education of the Visually Impaired. She is well known in the field of Vision Education and brings many years of experience to her current role with Rangi. The teacher-aide times are divided between two adults, a male and a female, both of whom have supported her at school for some time. One of the aides has recognised specialist qualifications in that she is a retired teacher; the other has a number of years of experience in similar roles.

Rangi's IEP is presented as a Word document and is headed "Transition Meeting Minutes". The document includes personnel and their roles, administration requirements and detailed specialist support, together with transition requirements for 2013. These relate to subject choices, technology, storage, orientation and mobility, transport, testing requirements and resources. The document differs from a program plan in that it is purely about transition requirements. However, her 2012

IEP does include some interesting statements that alert educators to the experiences of others when thinking about the impact of change in Rangi's life:

- Communication is the key and there are so many people and so much going on...
- Stress (re: teacher-aide hours) put on the parents is unbelievable.
- Aide hours are crucial to Rangi's success".

This information suggests the importance of a collaborative approach, working together and communicating effectively to ease the transition process for Rangi. This is reflected well in the words of the Maori proverb, "*Naku te rourou nau te rourou ka ora ai te iwi*", which means "Cooperation and combination of resources to get ahead" (*Whakatauki, The Warrior Way*, 2011).

No earlier IEP documents were made available relating to curriculum adaptations or ongoing strategies for classroom management. The requirements around accessible texts were included, as were those around safe travel in a new environment. No reference was made to any behaviour concerns or to the management of any behaviour. Comments in the 2012 IEP include:

- Teachers are aware of Rangi
- Rangi has updated her "My World" Booklet
- Ryan (TA) has put together his ideas as a teacher-aide for Rangi.

The document does not expand on this information further, merely suggesting that there may be some concerns. Overall this plan indicates some key characteristics required for an IEP but does not reflect that of a "living document" for program development and change. However, it is recognised as a practical plan for transition to a new educational context and gives some indication of Rangi's experiences at school.

Rangi was observed prior to her 2013 transition in the classroom and in the playground at her current school, as well as during two residential courses at the BLENNZ campus. In the school setting, she was observed in both literacy and numeracy programs. In the literacy program, instructions for a comprehension activity were given for all class members; Rangi responded by raising her hand and stating that she didn't know what to do. Individualised assistance was given to her both by the classroom teacher and the teacher-aide. During these interchanges, Rangi rocked her body back and forth while tracking a refreshable Braille display keyboard on her BrailleApex. Further instructions and prompts were given from time to time, with Rangi continuing to track the Braille, or she placed her hands on either side of her head, covering her ears, vocalising quietly and laughing almost inaudibly. When asked to respond to a question, Rangi said "I'm reading the Hobbit". She did not undertake the lesson content requirements. Similar observations were made in the mathematics program where she remained tracking *The Hobbit* until the teacher-aide located the required mathematics page in the Brailled text. She read orally the maths explanation, raising her voice to a level beyond that of the group, then laughed loudly, clapped her hands and returned to body rocking while reading, stating "I don't get it". A maths game was introduced. She was disengaged, touching her arms in a stroking movement, hand-clapping intermittently and rocking with increasing speed as class noise levels rose. She was seated in a paired arrangement for the game and sought tactile information from her buddy by touching the peer's hair, shoulders, face and patting her arms. She then responded to one of the group questions while rocking vigorously back and forward and rubbing her eyes. Her peer said "no hands on your eyes", grabbing her hands and holding them firmly. Further teacher instructions were probably blocked by Rangi's loud vocalisations and shouting. Rangi then covered her ears and continued rocking.

Observations at immersion courses provide a similar scenario of set activities not being undertaken. Alternative, self-motivated activities were undertaken with extreme competence. Asking for repetition of instructions from adults was common, with the words "I don't know what to do", usually accompanied with other indecipherable vocalisations and frequent laughing from Rangi. When performing at musical events at these courses, Rangi epitomised an individual in total control of

her own body and her own voice, standing still while singing, yet at other times, when she was not performing, her stereotypic movements were intense, especially as volumes around her increased. A low-vision student asked her on one occasion, “What are you doing, why don’t you stop that?” to which there was no response. These responses may indicate that the behaviours may be of concern to others.

Rangi was noted to exhibit a range of behaviours in these contexts involving the whole body, her arms, hands, legs/feet and her head. She rocked vigorously back and forth, flapping her hands/arms at the same time and bounced rapidly from a sitting position to a standing position, and vice versa. This behaviour was noticed in the very quiet setting of the classroom, with no clear trigger observable. The behaviour was also noted in all other settings, in paired and small group activities in all contexts, and was usually accompanied by outbursts perceived as anger. Rocking in a rhythmic pattern from one foot to the other accompanied by head rolling/shaking was evident when Rangi was walking between classrooms, waiting in a line outside a classroom and when engaged in conversation with an adult or peer. When seated in the classroom or at a work station area Rangi would lower her head to her hands with her hands pressing on her eyes or cover her ears. Vocalisations were noted at these times and took the form of almost inaudible whispering followed by quiet laughter. Her RTV, Caty, talks of Rangi’s high aspirations for herself and the “extreme reaction” Rangi has “if immediate answers are not known in the classroom setting” (Caty, 2012). In class, Rangi was heard to say “I don’t like being told what to do”. During periods of observation, Rangi displayed these behaviours the moment she was unsure of the task requirement or when her technology did not respond immediately to a command. She also exhibited these behaviours when she did not like the content of a lesson and when she was asked to wait for a peer to complete a task. Whether these behaviours have an impact on her learning is food for thought.

A range of interventions are used with Rangi, although Caty suggests that Rangi may be unaware of her rocking at times. Caty says “Rangi, you are rocking” and the response is “Was I?” A hand is placed on her arm when these behaviours occur with an explanation that she is distracting others. As her RTV, Caty refers to

Rangi's anxiety to do well, her academic successes that are well above the norm in certain areas, and to those below the norm in other areas. She reports that Rangi is now facing some blocks to her learning that were not previously so obvious. Caty suggests these difficulties may be relevant to the intensity of her stereotypic behaviour and she states that the behaviour is comforting and self-perpetuating.

Caty also reports on other aspects of Rangi's life at school in that she enjoys leadership opportunities and has aspired to develop her skills as a leader in certain situations. Caty says "Rangi is a class representative, she is admired by the Principal, plays piano for assemblies and will participate if she is able to control the situation." Participation also depends on her mood, but she is her own worst enemy. She has had a lot of counselling regarding her blindness but has a lot of issues which impact on all she does.

"You're beautiful, you're clever, you're talented." (Caty, 2013).

Rangi aspires to do well. She aspires to achieve with excellence educationally for her own personal enhancement. In the RTV's words, "Rangi has intellectual arrogance; she has big ideas and a thirst for knowledge" (Caty, 2013).

The words of the Maori *whakatauki* crystallise this thinking:

Ma te whakaaro nui e hanga te whare

Ma te matauranga e whakau

Big ideas create the house

Knowledge maintains it

(*Te Marautanga o Aotearoa*, MOE, 2007)

In 2013, Rangi's story changed somewhat, in that some unplanned and incidental observations of the learner indicated that the stereotypic behaviours displayed within the familiar context of the campus school were almost unobservable. This prompted further discussion with the RTV, in which Caty suggested that Rangi's perceived growth in maturity and the change in her educational setting had presented a marked difference in the learner's behaviour. Therefore further observation of Rangi and a further interview occurred with the RTV in early 2013. This aimed to give a greater depth of understanding of Rangi and the complexities of her "lived experience".

Caty began by talking about Rangi's progress in the key competencies of the New Zealand Curriculum. She shared the story of Rangi's academic achievements at the conclusion of 2012 in that Rangi was the top scholar across most subjects, these huge successes bringing much satisfaction and pleasure to this learner. Therefore, in Thinking and Language, Symbols and Texts she continued to indicate a very high level of achievement. Rangi is "hungry for learning" and had asked to return to her earlier school setting as she considered it more academic than her 2012 placement. She stated "this school doesn't give me enough homework"; however she excelled in this context. Rangi expressed anxiety that the pupils from her earlier school would be ahead of her when they got to college – she didn't like that feeling, she wanted to be that top scholar again. Managing Self was interesting, as Rangi now had "brilliant time management but is anxious because of the high standards she sets for herself" (Caty, 2013). The physical side of Managing Self such as homework assignments, self-care, time management and task organisation were well done. She was proud of herself for these achievements. The emotional aspects and the social aspects of this competency were not progressing so well. Caty stated that Rangi was a very anxious child and wondered if this was linked to her visual condition. (A second student with the same condition that this RTV worked with had similar anxiety levels). In Caty's words:

Rangi places huge pressure on herself. In class, she prefers not to answer in case she's wrong. In a recent maths class, when asked to calculate a mean, she became focused on the Box and Whiskers graph and got very agitated

when asked for an answer, although she knows well how to find the mean. She was shouting and making a big fuss because she was so worried about getting everything right. She was so anxious, she couldn't control her behaviour.

Caty recalls that Rangi's mother has also been anxious and at times embarrassed about Rangi managing as a person who is blind, expressing:

How will she manage?

Will she find love?

Will anyone ever marry her?

These anxieties have never gone away and may be transferred to Rangi (Caty, 2013).

Relating to others has not been a concern for Rangi regarding adult interactions. She has a supportive and loving family with whom she shares a close relationship. She has a sister who is two years younger and a wider family network that offer her strong relationships and a wealth of experiences, including those that relate to her cultural identity. However, the anxiety for the family around their daughter's blindness remains very evident, especially at times of change. This emotion is not evident in her relationship with her RTV. Her current RTV reports that her previous RTVs, Donna and Rowena, all shared "wonderful, trusting, secure relationships with Rangi". She loves interacting on an academic basis with these women, reading the same material, sending emails in French and German, correcting foreign language pronunciation, sharing linguistic knowledge and lunching in restaurants together. The recent shared reading, facilitated through a new Kindle of the adult text "Alex's Adventures in Numberland", resulted in much banter together. Rangi's love of words and their derivations has also prompted academic conversations about Latin and Greek. Caty says "we all get on well because we are all intellectual snobs!" Her sense of humour was then discussed as being an added bonus in her interactions with adults. Rangi will also challenge adults about her rights

as a person who is blind, as occurred when an English worksheet had not been produced in an accessible format. Caty responded to the subject teacher that it would be fine, and she should assist Rangi. However, Rangi demanded that the material be given to her so she could access it as independently as possible. She communicates with adults in what is perceived as a very mature manner. She recently had a conversation about the life of people who were blind who lived in the Middle Ages. She was appalled at stories of their treatment. Closer to home, a discussion about children who are blind in Tonga, receiving no education, was shocking to her. In Rangi's words, "Why not, that's just not right!" (Rangi, 2013).

Relating to peers has always been an issue for Rangi. As a young child, she didn't particularly enjoy playing with others or with her sister. She was seen as a novelty at school, with children losing interest as time passed and drifting away from her in play situations. Her dominance and aggressive behaviour were thought to be intimidating to her peers. Behaviour such as a total refusal to listen to others' music choices by removing their CDs from the school system and playing her choice, resulted in disgruntled peers. Her vigorous stereotypies were frightening to others. More recently, she had developed a friendship with Emily, who is considered an academic child who loves reading and classical music. It was noted that Emily did not hesitate to "control" Rangi's behaviour when she chose to. This was a first for Rangi – a peer intervention. Emily and Rangi do not now attend the same school but it was hoped that some contact would continue when they attended the same college in 2014. With the peer group who are blind, Rangi has a reputation of being "the screamer", with others commenting that they hoped she would not be attending the current immersion course on offer. This attitude was not observed at a more recent secondary music immersion course, where only the less intrusive behaviours, such as rocking, hand flapping and hand twirling, were noted rather than outbursts of anger .

Her present situation in college suggests some social interactions may be occurring. In class, Rangi is totally focused, seldom interacting with others apart from her aides. In a science class at college, a shared experiment was undertaken with

the learner seated beside Rangi. Although this was adult initiated, there was conversation between the girls and a working-together approach. Relating to other peers empathetically was also highlighted by Caty with the recount of interchanges between an autistic learner at the school questioning Rangi, somewhat repeatedly, about her blindness, saying “Are you really blind?” and “You’ve got eyes, why can’t you see?” Caty stated that had this type of dialogue occurred six months ago there would have been anger, shouting and repetitive behaviour from Rangi as a response. This time, the response was answering the questions with calmness, patience and tolerance. Here is a significant change in behaviour.

The Participating and Contributing competency has also seen changes. Although some level of participation was reported in the previous interview, where the desire for control was evident, there had been an offer from Rangi to set up a pre-school music group for children with vision concerns. Rangi talks of her love of music and a desire to share this with others. This is seen as positive by those who work with her as it is an early indication of putting others ahead of herself.

Rangi considers school as a serious part of life. Recently she was “outspoken” to a teacher in science and was promptly removed from the lesson by that teacher and thereby was unable to access the requirements of the day. This withdrawal as a consequence of negative behaviour had never occurred previously. Caty suggests that this single incident led Rangi to understand the consequences and impact of her behaviour. She now believes she has some awareness that certain behaviours perceived as inappropriate means withdrawal from course content. This is a factor she does not like. No outbursts have occurred in this subject since.

Caty considers these changes in attitude and behaviour relate to a decrease in anxiety, a maturity evolving naturally and an awareness of consequence that may impact on performance. At the moment, the anxiety of transitioning to a new educational setting has dissipated. The family are now less stressed with Caty

commenting on the cycle of anxiety – less stress in the family, less anxiety for Rangi and an observed decrease in disordered behaviour. The pattern of disordered behaviour has been observed since Rangi was three years old. These changes are now occurring at 13 years old. Caty refers to Rangi's self-control, her understanding of consequence and her desire for academic excellence. Caty summarises her thoughts:

She is an outstanding young woman; she has huge potential and could be an Oxford or Cambridge scholar. The world is her oyster. She has to realise that her blindness is not an obstacle. For her, the only barriers to reaching her potential are her intellectual arrogance and she has to get her behaviour under control. "I am blind, it's not fair" consumes a lot of her thinking. I just say to her "you're beautiful, you're clever, you're talented, just get on with life".

Whether Rangi's aspirations to achieve excellence are significant, or whether family relationships, early experiences, culture, context or particular skill levels have any relevance to her displays of stereotypic behaviour, all is largely unknown. More recent observations indicate some changes to her behaviour in certain contexts which suggests any emergent explanations must always remain tentative. This *whakatauki* helps explain how we feel:

Ma pango, ma whero, ka oti te mahi

With your efforts and my efforts, the work will get done

(Whakatauki: Ngai Tahu)

5.4.5 Laura

"We need to balance the challenges and to remember she gets confused" (Maria, Teacher Aide, 2012).

Laura is the eldest of the five children in the case studies. She turned 16 in August 2012. She is of European origin and has the visual condition of Leber's Amaurosis. Leber's Amaurosis is one of the most severe retinal dystrophies and is an inherited

congenital condition that is degenerative in nature. It affects the photoreceptors (rods and cones) of the retina, which are the cells that detect light. It is not usually detected at birth but is more able to be diagnosed before the child reaches six months of age. The condition is diagnosed when there are poor pupil responses, roving eye movements, sensitivity to light and an abnormal appearance of the retina. Confirmation of the condition is possible through genetic analysis. There are a number of associations with this disorder. These are mental retardation, neural developmental delay, renal disease, skeletal disorders, cardio disorders and hydrocephalus (American Association for Paediatric Ophthalmology and Strabismus, 2012). The outcome for Laura is blindness, some light perception and developmental delay. Her blindness means that she accesses the curriculum through Braille and uses a range of technology including a Brailnote and Netbook to support this medium.

She attends a BLENNZ satellite classroom at an out-of-zone high school. This Auckland city school opened in 1968 and has the motto of “Endeavour”, with its Mission Statement referring to aspiring to produce learners with flexible minds, personal integrity, honesty, and a responsible, mature view of duty to self, family, school and country. This is a secondary school with a Decile rating of 1 and a roll of approximately 1450 pupils. It has a number of special features, including two bilingual units (Samoan and *Māori*), a Teen Parent Unit, a Satellite classroom from a local Special School, plus the BLENNZ satellite classroom for learners with a vision concern. The BLENNZ satellite classroom offers learners access to mainstream classes plus intensive one-to-one as well as group learning activities. The emphasis in the program is on personal growth, goal setting and the development of social co-operative skills as identified in the IEP Process. The ethnic composition of the school is as follows: *Māori* 44%, New Zealand European/*Pakeha* 7%, Samoan 23%, Cook Island *Māori* 8%, Indian 5%, Tongan 5%, Niuean 2%, Middle Eastern 1%, Other Pacific 4%, Other 1% (ERO, May 2010-2012). Laura is considered to be a minority group at this school.

Laura receives ORS funding from the New Zealand Ministry of Education because of her vision concerns. She is supported by a specialist teacher. She shares teacher-aide time with others in her classroom and also has access to Orientation and Mobility Instruction and Adaptive Daily Living Skills as part of her program. Laura's specialist teacher is Maria, who graduated from University in 1997 with a Bachelor of Education and a Diploma in Teaching. She has taught in mainstream, in the BLENNZ Campus School and in special needs units. Maria's diverse roles have equipped her well to understand the complexities of the learners with a vision concern who are currently educated in the BLENNZ Satellite classroom. Therefore, Maria brings considerable expertise to her role as Laura's specialist teacher. There are three teacher-aides in the Satellite Unit from whom Laura receives support, guidance and individualised instruction. The aides have worked with learners with a vision concern for some years and two of them are competent in Braille.

Laura has an IEP that is very practical, detailing specific learning tasks and goals. The plan identifies the five team members (including Laura) and their roles and includes information about resources and technology. The focus is on an adapted program that is life skills based and refers to all of the key competencies but zeroes in on Participating and Contributing as well as Managing Self. Achievement objectives are stated, present levels and skills are written as a narrative, and specific learning outcomes are included as bullet points. Teaching and assessment strategies are clearly defined, as are the responsibilities and resources that relate to specific personnel. The learning areas of the National Curriculum Framework are listed with a summary and action plan at the end of the document. Reference is made to Laura's anger and frustrations, with suggestions of counselling or input from an educational psychologist. Reference is also made to behaviour that occurs as a result of stress, which manifests as repetitive vocalisations.

This plan meets the requirements required for an IEP. Laura is currently functioning at approximately Level Two of the New Zealand Curriculum; an age-appropriate level for her would be more likely to be Level Five or Six. Her 2012 IEP

details achievement objective for Managing Self as: “To develop her sense of independence and active involvement in everyday activities by making choices, devising plans, organising resources and following a course of action.”

The plan refers to practical skills in daily activities and to her communication skills in group activities. In class, she is encouraged to take part in decision making and to respond to open-ended questions. The IEP reports that Laura sometimes shows signs of stress, repeating instructions when she is first introduced to a new activity and when she is unsure of how to give an appropriate response. In the competency of Participating and Contributing, Laura’s program also focuses on Daily Living Skills so she can participate confidently in shared activities in the community.

Perhaps one of the more pertinent statements presented in the 2012 IEP is recorded under Language, Symbols and Texts:

- She has difficulty making connections with information that is implied – such as reading between the lines.
- She has difficulty writing imaginative prose and expressing her opinion or reaction to a text or idea.

The document records the concerns of the team, with Maria stating that Laura’s “program aims to balance the challenges [for Laura] and to remember she gets confused”.

Laura was observed in her life skills program in the familiar context of her classroom, in a music lesson and at a range of activities at the Campus School. She was seen to exhibit a number of behaviours involving all body parts. Hair pulling, hair sniffing and sniffing of people were noted in the classroom when seated and when working independently on her Braillenote on a set activity. This behaviour was also evident when Laura was in conversation with others. Body patting and hand twirling

were displayed as a sequence, often accompanied by hand/arm raising and face touching in combination. These behaviours occurred at the beginning of a task, when concentration was interrupted by questions from an adult, or when concentration was interrupted when Laura was listening to the voices of her classmates. Vocalisations are frequent with Laura. These are in the form of recalling information, repetition of known words, phrases, songs and recitation of poems. Volume levels of the vocalisations vary depending upon the volume level in the context. Laura, when greeted, will respond by saying, "You said Hi Laura, I'm going to say hello to you, Hello Maria, I said Hello Maria didn't I?" Laura did not exhibit behaviours that were context-specific, although with higher sound levels across all contexts the stereotypy increased noticeably. Her engagement in learning was inconsistent, with frequent questioning of task requirements from teacher-aides nearby as she tried to refocus.

Maria considers that Laura "doesn't think abstractly" and her world is black and white. She feels that Laura relates to adults in a socially appropriate manner at times, and with peers she is successful in her current environment when prompted, but with mainstream learners the situation is quite different in that she is the centre of amusement and is ridiculed. Maria states that Laura exhibits a number of behaviours which are managed through the implementation of different strategies. Although she would like to know the trigger for Laura's behaviours, she offers that some of the behaviours may be displayed subconsciously, although body patting was thought to be seeking physical reference. Maria also stated that as one behaviour seems to reduce, an alternative behaviour will reoccur. In situations such as hair sniffing, Maria considers the behaviour is inoffensive so she does not refer to it. For other situations such as sniffing people, time out is provided to discuss the negative reaction of others. With vocalisations, Maria turns the repetitive words into a model of a phrase that is more socially acceptable. Likewise with behaviours involving body patting or inappropriate hand raisings, words are offered instead. Maria states "understanding why Laura exhibits the behaviour may help Laura herself" (Maria, 2012). This suggests some complexity in the experience of this learner.

Laura has had a range of educational experiences prior to her placement in this satellite and has had some changes to the location of her family home. As she has matured her stereotypic behaviour seems to have changed. Her family are concerned that the changes have resulted in self-injurious behaviours that are more intense and that her vocalisations are more frequent. Her interactions with the satellite peer group at school are usually considered to be successful, yet her interactions with others remain a concern. Her stereotypic behaviours are considered a significant aspect in her daily life. Further investigations about these behaviours are currently being undertaken through the hospital system as their intensity and frequency has increased and the outcomes have become atavistic. Discussions have been muted about a diagnosis of autism for Laura and the term chronic stress disorder has been suggested. Whether her visual condition and related factors has impacted on her skill acquisition across the key competencies in any way, is yet to be established. More importantly Laura is learning new skills to assist her in life's journey, However as data emerges from this case study it is clear that Laura's "lived experiences" are disturbing to many and the picture this creates is one of concern.

5.5 Summary

To summarise this information, the five learners are blind; three are female and two are male. Ages were recorded in August 2012 as 6.5 years, 7.5 years, 11 years, 13 years and 16 years. Three of the learners were in primary school, one in an intermediate placement at a full primary school and one in a secondary school. The schools range in Decile ratings from 1 to 10. Four of the learners were attending their local school while one was attending an out-of-zone school owing to the specialised vision unit facility at that school. Ethnicities represented were European (2), *Māori* (1), Pasifika (1) and Asian (1). The latter two categories of *Pasifika* and Asian refers to learners from immigrant families; one family had emigrated from Asia and been settled in New Zealand for some years, and the second family from the Pacific were relatively new immigrants. Geographical locations were across three urban areas in the North Island of New Zealand. Four of the visual conditions of the learners are retinal disorders and are documented as Retinal Dysplasia, Lebers Amaurosis, Retinopathy of Prematurity and Vitreous Hypoplasia. The fifth learner's visual

condition is recorded as Peters Anomaly and Glaucoma. Two learners have some degree of light perception, with the same two learners considered to have additional disabilities, one identified as behavioural and the second as developmental delay

All learners receive resourcing (that is allocated to their mainstream school and to BLENNZ) from the Ministry of Education's Ongoing Resourcing Scheme (ORS) because of their vision loss. ORS provides funding on behalf of individual students for specialist teacher time, specialist programs and therapies, together with paraprofessional hours and consumable items. Although specialist teacher time is pre-determined and consumable funding is finite, all other support is determined by fund managers at the district offices of the Ministry of Education, based on individual needs. To meet the criteria for eligibility for this funding learners must have a significant educational need – in this situation, vision. All five cases meet the eligibility referred to as Criteria 2.3, which means they require total adaptation of the curriculum to Braille owing to their vision loss. Each learner's program is therefore in the required format; the content of this is the New Zealand Curriculum and the Expanded Core Curriculum. All have current IEPs in place. All use a range of technology including manual and electronic braille devices to facilitate access to the curriculum and to meet assessment requirements.

All teachers are female, and teaching experience ranges from 15 to 35 years, with experience in Vision Education ranging from 3 to 25 years. Four of those interviewed have qualifications specific to the field.

5.6 Discussion

Focusing on the research questions, the drawing together of information about the cases provides further insight into the lived experiences of five learners who are blind and display stereotypic behaviour. By reviewing the Current Attainment and Functioning Levels within the New Zealand Curriculum, the IEPs, the observed and reported stereotypic behaviour, cultural impact on behavioural expectations, the

reactions of the peer group and the intervention strategies implemented for all five cases, a clearer picture emerges of the lived experiences of these five individual learners.

5.6.1 Current Attainment and Functioning Levels within the New Zealand Curriculum

In every context, it is evident that students learn best when teachers:

- Create a supportive learning environment
- Encourage reflective thought and action
- Enhance the relevance of new learning
- Facilitate shared learning
- Make connections to prior learning and experience
- Provide sufficient opportunities to learn
- Inquire into the teaching–learning relationship

(Ministry of Education, 2009, p. 34, The New Zealand Curriculum).

All RTVs aspire to effective pedagogy in order to have a positive impact on individual student learning. It is with this approach that the curriculum is taught.

For all learners in New Zealand schools, the statement of official policy relating to teaching and learning is the New Zealand Curriculum. Based on a Vision, Principles and Values, the document identifies five key competencies. These competencies are Thinking, Relating to Others, Using Language, Symbols and Texts, Managing Self, and Participating and Contributing. These are the identified measures of success for children in New Zealand. As learners progress through Years 1–13, benchmark levels are provided to review achievement in each competency. It is reasonable to assume that these competencies continue to develop over time and are shaped by the students' interactions with people and environments.

In the first category, Thinking, the New Zealand Curriculum document states that “competent thinkers ... seek, use and create knowledge. They reflect on their own learning, draw on personal knowledge and intuitions, ask questions and challenge the basis of assumptions and perceptions” (Ministry of Education, 2009, p. 12, The New Zealand Curriculum). Teri, Kyle, Kathryn and Laura were perceived to be below expected year levels in this category, with Rangi assessed as well above her year expectations. Teacher comments indicated concerns, with statements such as “Laura doesn’t think abstractly”, “Kyle is reliant on adults for input”, “Kathryn requires prompts”, “Kathryn is slow to respond”, “Laura’s responses are echolaic”, while Teri uses phrases such as “you tell me”, “you help me”. For Rangi, assessed as functioning above expected levels, her RTV, Caty, considered she preferred “intellectual conversations about philosophy and languages”, which indicated higher-level thinking. These perceptions are based on OTJs (Ministry of Education, 2011, p. 14, Collaboration for Success, where evidence is gathered through conversations, observations and, at times, formal assessments.

The second key competency in the New Zealand Curriculum of Relating to Others “is about interacting effectively with a diverse range of people in a variety of contexts ... this includes the ability to listen effectively, recognise different points of view, negotiate and share ideas” (Ministry of Education, 2011, p. 12, New Zealand Curriculum). All case studies were considered by their RTVs to relate well to adults, but all were perceived to have difficulties relating to their mainstream peer group. It was recognised that the learners wished to relate to their peers, to enjoy friendships, and be included in activities, but there were a number of issues evident. These issues were: trusting other children (for Kyle), others relating to Teri’s unpredictable behaviour, Laura wanting control as opposed to engaging in shared activities, and Kathryn’s social immaturity. Rangi was said to be “abrasive and arrogant with peers”, resulting in very real difficulties relating to others and forming friendships. With maturity, it seemed clear that all the learners were aware of their social isolation and their exclusion from the mainstream peer group. They were disappointed not to be able to play, work, have fun and be with others in class and at times such as school breaks. Parallel play and adult–child play were observed with Kyle, and some social interactions that modelled a pre-taught social story sequence were evident for Laura.

Much was discussed and observed about the difficulties the learners had in relating to their sighted peers, but there were few solutions or successful outcomes in place. However, some changes were evident over time as was noted for Rangi. Reference was made to the more positive relationships with learners who were in a similar blind peer group.

The third key competency in the New Zealand Curriculum of Using Language, Symbols and Texts is about “working with and making meaning of the codes in which knowledge is expressed” (Ministry of Education, 2009, p. 12, The New Zealand Curriculum). Students who are competent in this area “can interpret and use words, numbers, images, movement, metaphor and technology in a range of contexts” (p. 12). Teri, Kyle, Kathryn and Laura were below expected levels (for their age and year) in this competency, with this analysis being supported through data largely provided in formative assessments in numeracy and literacy. National Standards were therefore not met, which was a concern for both teachers and teacher-aides owing to the substantial individualised instruction that was occurring daily for the learners. Rangi, who achieved above her expected levels in Thinking, was also achieving at markedly higher levels than her peer group in this competency. The value of assistive technology was identified for all in relation to ease of curriculum access for this competency. It was considered that skill levels with technology impacted on achievement levels, especially around the formative assessment process.

Managing Self is the fourth key competency in the New Zealand Curriculum. This is about students who are “enterprising, resourceful, reliable and resilient” (Ministry of Education, 2009, p. 12, The New Zealand Curriculum). It is also about self-motivation and a can-do attitude. All five case study learners were below their peer group in this competency. Comments were recorded such as “Kyle prefers to have things done for him”, “Kyle is capable but slow”, “Rangi has skills but has an extreme reaction if things go wrong”, “Laura can reach goals over time through a planned process of instruction”, “Teri likes adult input”, and “Kathryn sits and waits”. Adults working with the learners indicated frustration at these attitudes. They referred

to an ongoing drive to foster some independence for each learner toward managing their own physical, social and emotional needs. Assessment was based on OTJs in this competency, although checklists and inventories were available to assist in this process.

The fifth key competency in the New Zealand Curriculum of Participating and Contributing is about learners becoming “involved in communities” (New Zealand Curriculum, p. 15), be that family/*whānau*, school or culture. There were a variety of responses in this area. With no formal early childhood education, functioning levels within this competency for Teri were thought to be pre-Level One. Kyle was selective about curricula area involvement, choosing only to participate and contribute in physical activities. For Rangi, Kathryn and Laura, it was interesting that they would choose to become involved in an activity if they had control, if they had knowledge of the expectations and felt self-confident. The preferred curriculum area for all three girls was music. Therefore participating and contributing was largely self-selective. Once again, assessment criteria were based on OTJs.

Table 5.1 details the functioning and attainment levels of the learners across the five key competencies. Age-appropriate levels are recorded, then current functioning levels across the five key competencies are displayed. Assessments indicated that one learner was achieving at above the expected levels in two competencies. All other learners are below expected levels.

Table 5.1

Key Competencies within the New Zealand Curriculum: Age Appropriate Levels and Current Attainment Levels of Cases (N=5)

Case Number	Age Appropriate Level	Key Competencies				
		Thinking	Relating to Others	Using Language, Symbols and Texts	Managing Self	Participating and Contributing
Teri	2	1	1	1	1	<1
Kyle	2	1	1	1	1	1
Kathryn	3	<3	<3	<3	2	2
Rangi	3-4	5	2	4	2	2
Laura	5-6	2	2	1-2	2	2

Therefore, considering the assessment criteria identified within the key competencies of the New Zealand Curriculum, OTJs and observations made, it is of interest that all five learners were in general not currently functioning consistently at age- and year-appropriate levels across all five competencies. RTVs were very aware of this and commented, in a somewhat punitive manner, on their feelings of personal responsibility for these lower than expected levels compared with peers. Comments such as “I don’t know what else I need to do”, “I do my best every time I am here”, “I suppose I’m not doing something right” were noted. There was no reference to learner responsibility or to learner behaviour, but some reference was made to learner attitude and lack of self-motivation in respect of Rangi, where it was stated “she’s her own worst enemy” (Caty, 2013). This indicates a concern in terms of the learners managing their own needs. It also indicates the desire of the teachers to ensure the learners achieve consistently at or above the same level as the sighted peer group.

5.6.2 Individualised Education Plans (IEPs)

As stated, all case studies had some type of IEP. Essentially, four of these were based on the key competencies of the New Zealand Curriculum and/or the skills identified in the Expanded Core Curriculum. The plans aim to provide opportunities for the development of the competencies and skills within the social contexts of school, home and the community. The plan for one of the cases, Rangi, was a transition paper and provided guidelines for her new educational placement, as opposed to a learning-needs document.

Although the format of the plans differed, Kyle's, Teri's, Kathryn's and Laura's IEP approximated some of the requirements for the content of a regular IEP as defined in the Ministry of Education's Collaboration for Success document (2011). The documents identified current levels, goals and strategies but they did not include many details about what was happening in the classroom program. The exceptional learning in the form of "adaptations and differentiations to the school and classroom curriculum" (MOE, Collaboration for Success, 2011, p. 13) was included, as was reference to technology and resources. A flexible approach was evident in all plans, especially in Rangi's, for this IEP document was about transition. It is interesting to note that most assessment information was largely determined through OTJs, not necessarily provided in a collaborative manner but by the RTV. There was little evidence of the use of a range of other assessment sources such as learning conversations, structured interviews, student/peer assessments and portfolios of work. There was little documented evidence of concerns about behaviour. All plans were student centred, but they did not all demonstrate the principles and key characteristics as detailed in the 2011 Collaboration for Success document.

5.6.3 Stereotypic Behaviour Exhibited

All five cases exhibited stereotypic behaviour. A range of behaviours were displayed and were observed in a number of contexts. These included behaviours involving the face, head, hands/arms, legs/feet, whole body and repetitive vocalisations. All behaviours were reported in interviews, were observed on at least one occasion, but

were not recorded on the IEP as being a concern or as part of a learning goal. However, although some behaviours were occurring almost continuously others were infrequent and quite subtle.

To summarise, Table 5.2 indicates the stereotypic behaviour relevant to the body part as observed and stated by RTVs for each of the five cases. The predominant behaviours were those that involved the hands/arms/eyes together with whole body rocking. This aligns with what was reported in the parent survey in respect to the predominance of behaviours involving the hands/arms/eyes.

Table 5.2

Stereotypic Behaviour relevant to Body Part as Observed and Reported (N=5)

Name	Body Part Involved					
	Face	Head	Hands/Arms (Eyes)	Legs/Feet	Whole Body	Vocal
Teri			•		•	•
Kyle	•	•	•	•	•	
Kathryn	•		•		•	
Rangi	•	•	•	•	•	•
Laura	•	•	•	•	•	•

Table 5.3 presents the situational context relevant to the stereotypic behaviour reported by the RTVs. While listening, while experiencing anger/frustration/anxiety, and when a request was made, were considered to be the most likely reasons for the behaviour to occur.

Table 5.3

*Situational Context relevant to Stereotypic Behaviour as Observed and Reported
(N=5)*

Name	Situational Contexts						
	Angry/Frustrated /Anxiety	Excited	Left Alone	Bored	When Request Made	Listening	Tired
Teri	•						
Kyle	•				•	•	
Kathryn						•	•
Rangi	•	•		•	•	•	
Laura	•	•	•	•	•	•	

5.6.4 Reactions of the Peer Group to Stereotypic Behaviour Exhibited

The reactions of the peer group seem to be influenced by the age of the peer group, the reaction of adults surrounding the learner and the behaviour itself.

For Teri and Kyle in a primary school setting, the peer group tend to ignore certain behaviours although they gave some negative responses such as staring and avoiding interaction, especially when social groupings were called for on a voluntary basis. When the behaviours become more extreme, the RTV commented that the very young children were frightened and nervous of the boys' actions, especially if the displays of stereotypic behaviour were unpredictable. In Teri's situation, he was relocated to a class level several years above his peer group in order to avoid this negative impact on younger learners. The older peer group either ignored the behaviour, laughed at him or attempted to turn the behaviour into something that was more acceptable. Kathryn was in a setting where the behaviours were

acceptable as they were considered to be subtle and were stated as being “not too dissimilar from behaviours of the peer group” (Anna, 2012). This referred to rocking in time to music and eye pressing when tired. For Kathryn, the behaviour when exhibited at home was copied by a younger sibling and became a form of amusement for that sibling. This was considered part of the family dynamics. The two older students, Rangi and Laura, displayed stereotypic behaviours that evoked a greater response from the peer group. The whole body movements that involved rocking, bouncing and hand flapping were noted to cause reactions of amusement in the form of sniggering, laughing out loud, aside comments to others and peers pointing at one’s brain to indicate mental retardation. The accompanying vocalisations were considered disruptive in the class setting, with peers and adults asking for the noise to stop or blocking their ears as the vocalisations increased in volume. During periods when the stereotypic behaviour did not occur, Rangi was often observed to be ignored although she was seated in a group setting in the classroom. Interactions just did not happen. For Laura, when behaviours involved sniffing, reactions of the peer group were immediate and were in the form of amusement and a physical withdrawal from close proximity to her. Likewise Laura’s behaviour of repetitive body patting was observed to make her a target of humour. At times Laura was asked to repeat the behaviour by the sighted peer group while they laughed loudly. Repetitive language and vocalisations were noted by the RTV, Maria, to be a concern; however she attempted to turn these behaviours into something more acceptable. Peer group reactions to these were either of amusement or disdain. An attempt was made to stop the stereotypic behaviour in one situation by a peer.

5.6.5 Cultural Impact on Behavioural Expectations

An understanding of what behaviours may be considered culturally appropriate social behaviour was not observed or recorded for each of the five case studies. Although the cases were of *Māori*, *Pasifika*, New Zealand European and Asian origin, the manner in which each accessed the curriculum and interacted with both adults and peers showed no variation in respect to culture. The schools attended by the learners indicated variance in ethnicities within their populations, however

expectations of appropriate behaviour in the mainstream setting related to what was deemed to be engagement in learning. There was no reference to cultural expectations in respect to behaviour.

5.6.6 Intervention Strategies

A range of intervention strategies was reported to be used to manage and/or change the behaviour. These strategies depended upon the nature of the adult–learner relationship, the context and the disordered behaviour itself. Some interventions were inconsistent in that when behaviours were frequent, a single strategy was not used consistently but was used only on occasions. Such intervention was used when re-engagement was deemed necessary in order to access the curriculum or to reduce the impact of the behaviour on others. All learners had more than one adult working with them on a daily basis, however the intervention essentially was observed to be the role of the RTV; it was seldom the teacher-aide, never the classroom teacher but on some occasions it was a member of the peer group and, on one occasion, a subject teacher. This also indicated the inconsistency of intervention for the behaviour, for although these behaviours were exhibited in similar situations, they were either responded to or left alone, depending upon the adult and on the context.

Interventions from adults tended to form a pattern that related to the body part involved, the social acceptability of the behaviour and the attitude of key adults working with the learner. Behaviours that involved the face, head and hands/arms invoked responses such as “put your hands down”, “leave your eyes alone” or “hands still please”, usually accompanied by a light touch to the hands or arm. Behaviours that involved larger body movements such as the legs/feet and whole body invoked responses such as “don’t do that”, “stop that, everyone’s watching”, “others don’t do that”, “you look odd”, “that’s enough”, “stop that now”, “you’re rocking again”, “you’ll hurt yourself”, “others think you look funny”. Behaviours that involve repetitive vocalisations also brought a range of differing responses. These included “you’re talking silly”, “do you want me to explain something?”, “how can I

help you?”, “what do you need?”, “that’s baby talk”, “what are you saying to yourself?” or “stop that!” There was no evidence of Functional Behavioural Assessment as an intervention tool to change or replace the behaviour or of discussions with the individual learner about their own behaviour.

Other strategies used by adults were often mirrored by the older peer group, especially those interventions that could be considered to be a prompt or a reminder to the learner of what was occurring. These were noted to have been modelled by a RTV and were repeated by a fellow classmate who was seated in the same group as the learners Laura and Rangi. This occurred with the peer who was well-known to each of the girls. This peer intervention in the form of a verbal reminder really only occurred in the satellite classroom and, on one occasion, in the mainstream setting. It presented as an action that did not make reference to the peer group impact but was deemed to be more about compliance with a behavioural norm expected in a mainstream setting.

5.7 Conclusion

The case studies provided interesting information that was pertinent to five individuals who may or may not have been a relevant cross section of the population of learners who are blind in New Zealand. Although the purpose of the case studies was never to generalise any information, it was considered important to seek data from a number of sources in order to explore and describe what was the reality for five learners who are blind and who display stereotypic behaviour. What was the reality on their learning and on the acquisition of the skills that ensure social interactions with others are meaningful?

Through the process of triangulating the data, it was quite evident that all five case study children were not achieving consistently at age-and year-appropriate levels as defined by the key competencies of the New Zealand Curriculum. This reflects much of the literature from theorists such as Strickling (2010) and Wolffe

(2006) that suggests blindness impacts on cognition and on development. All learners were entitled to and were receiving specialist input at school, together with the use of sophisticated assistive technology, in order to access the curricula. Attainment levels were not comparable to that of the sighted peer group. In some instances, RTVs reported summative assessment information suggesting that attainments were age appropriate, but this was not validated through documentation and ongoing observations of the learners.

The most informative document for each learner was the IEP, the focus being on helping the learner move from their current functioning level to the next attainable skill level. These plans were not indicative of achieving age-/year-appropriate skills but they were documents that aspired to be relevant, realistic and meaningful for the individual. Goals were set in the key competencies of the New Zealand Curriculum. The predominant focus was the key competency of “Managing Self”. Elaboration on this focus in interview conversations indicated that strategies to assist learners to take responsibility for their own learning and their own behaviour were considered important. Although personal growth was seen to be important, there remained a very real concern from RTVs that all five learners were not achieving consistently at age-appropriate levels across all competencies of the New Zealand Curriculum.

Possibly compounding the situation further, all learners exhibited stereotypic behaviour that varied in frequency and across situational contexts within a number of physical environments including the mainstream school setting. Some of the behaviours, especially those that occurred briefly, were thought to draw little attention from the peer group in the controlled setting of the classroom. These behaviours were not deemed to deviate substantially from that of the norm. However, other stereotypic behaviours, especially those that occurred more frequently and were of longer duration, attracted attention in the form of humour, embarrassment, withdrawal and avoidance of interaction from the sighted peer group. These negative responses were confirmed in interviews and further confirmed with observations of the learner in familiar contexts. They were deemed to be distressing for the adults involved. The specialist teacher and teacher-aides were

also uncomfortable when the behaviours were exhibited, with comments such as “Kyle is tired”, “Rangi is bored”, “Laura is excited”, “Kyle doesn’t like this subject”, “Laura doesn’t understand what to do”, or “Rangi is frustrated that the answers don’t come easily”, “Rangi is very anxious to do well”, “Teri is frustrated”. Apologies were offered to the researcher for the behaviour and these were accompanied by assurances that some type of intervention was in place. This suggests the adults were taking responsibility for the learner behaviour, perhaps reinforcing why the focus of the IEP was recorded by adults as being “Managing Self”. This also does not seem to be an approach that fosters empowerment of the learner through learner involvement in the intervention process.

The age/year appropriate skills of self-management were not evident in the classroom or in the playground. Social interactions across a number of settings were observed and reported on, with all interactions being adult initiated. Choosing a buddy for a paired activity or setting up a group for discussion became adult directed, as on no observed occasion was the learner who was blind selected spontaneously by a class member or invited to join a group, nor did the learner volunteer themselves to join a group. This indicated a barrier in the development of naturally occurring social interactions within which social skills are learnt. Opportunities to learn from the peer group were therefore somewhat limited.

These opportunities were further compromised by the reality of the learning environment for each learner. For large portions of the school day, usually the morning blocks, when there were observed to be periods of intensive classroom teacher-directed instruction, withdrawal of the learner who is blind was common. This involved relocation to a separate setting from the peer group and the mainstream teacher. This, often at the suggestion of the mainstream teacher, provided access and individualised instruction to particular areas of the Expanded Core Curriculum such as braille literacy and use of new technology. Stereotypic behaviour in the withdrawal setting was observed to be less prevalent in comparison with that observed in the mainstream setting. Social interaction in this situation was between adult and learner, not with the peer group.

At school break times, unless a buddy system was in place, there was no evidence of social interaction amongst the sighted peer group and the learner who is blind. It was in these unsupervised situations that stereotypic behaviour was quite prevalent, and responses to the behaviours were discernibly less restrained. There was no observed evidence of altered responses across cultural settings within each school, or in respect to the ethnicity of the learner. The peer group was observed to watch the learner, usually from a distance; the learner then becoming a target of humour with negative comments, laughing and hand signs labelling them as mentally retarded. It would seem very clear that without positive social interactions, either in the inclusive environments or the playground, it would be difficult for the learner who is blind to engage in the classroom program and to acquire the age-appropriate skills necessary to relate effectively to their peers.

All five learners in these case studies displayed stereotypic behaviours and all five experienced difficulty in consistently achieving at a level that was age-appropriate for sighted peers. RTVs displayed a strong commitment to having a positive impact on student learning through effective pedagogy. The attainment levels defined within the New Zealand Curriculum for what would be appropriate for these five learners, continues to show progress. It is assumed from the collation of the data that both blindness and stereotypic behaviour create situations where individuals may become excluded from social environments where they have opportunities to learn the appropriate skills to participate and relate to others. Therefore, for these learners their blindness, together with their stereotypic behaviour, is likely to have an impact on the acquisition of skills across all key competencies of the New Zealand Curriculum, including those that relate to socialisation.

Chapter Six

“Every now and then, one paints a picture that seems to have opened a door and serves as a stepping stone to other things”

(Pablo Picasso)

6.0 Introduction

Mixed methods design was selected for this study, which set out to investigate stereotypic behaviour in selected New Zealand children who are blind. The choice of this research method and design is succinctly explained in the following quote:

The complex nature of the social world requires a more fluid understanding and application of the relationship between philosophical paradigms, methodology and methods. (Sharp et al., 2012, p. 36)

Reflection on the research questions provided the rationale for this decision, for the phenomena to be studied indicated that the most appropriate way to collect and analyse data required both quantitative and qualitative theoretical frameworks. A pragmatic approach was adopted in order to answer the questions: “How prevalent is stereotypic behaviour in New Zealand children who are blind, and what is happening for the child who exhibits stereotypical behaviour in respect to learning and the acquisition of culturally appropriate social skills?”

Although this was a single project, it involved two quite distinct independent phases (i.e., the survey and the case studies) whereby mixed methods research and design could be potentially complementary. This selection aimed at allowing the strength of the confirmatory results drawn from the quantitative phase to provide the foundation for depth of understanding in the qualitative phase. The conflict of paradigmatic dichotomies was avoided, as

integration did not occur owing to the independent nature of the two phases and the sequential approach that was taken.

Currently, mixed methods design research is popular in the social sciences because it allows greater fluidity for researchers as they strive for comprehensive information about chosen phenomena. This project sought a variety of perspectives that required the corroboration of data. Within the New Zealand population of four million people, the percentage of learners who are blind is very small, therefore it was difficult to conduct quantitative research on its own that would provide the information sought to have confidence in any generalisations. By using both quantitative and qualitative methods, providing different perspectives, more complete sets of information were possible. This ensured a richer and more worthwhile understanding of the New Zealand situation when compared to international research. Mixed methods therefore provided the means to use the results of the quantitative research in a qualitative manner to increase contextual understanding using an explanatory process. This was the success of adopting the Sequential Explanatory Design.

6.1 Chapter Overview

The objective of Chapter Six is to provide an analysis and summary of the thesis. The chapter begins with an introduction and a discussion of the mixed methods research. Here it is argued that mixed methods enabled the researcher to investigate the research questions in a more sophisticated way than would otherwise be possible. This is because mixed methods afforded the necessarily circular use of the research outcomes of the quantitative phase to inform the qualitative phase. The Sequential Explanatory Design and the success it helped to facilitate is also explained. The chapter then goes on to describe how this design, embedded within the mixed methods approach, enhanced the integrity of the findings.

A summary of each phase of the design is outlined with a review of the methods used with the strengths noted. The limitations are also presented together with the challenges. The personal journey facilitated by the research is disclosed through self-reflection. This chapter details the practical implications of the project and the utility of the outcomes for practitioners. Several recommendations are then offered, including some for possible future research. A conclusive statement draws the chapter to a close.

6.2 Method

The quantitative research study as reported in Chapter Four, in the form of a parent survey, provided results that aligned with international research in respect of prevalence, type, duration and frequency of stereotypic behaviour in children who are blind (Troster et al., 1991b). However, respondents indicated caution when identifying contextual details of the behaviour. This supports much of what is written in the literature in that there are a number of aetiological theories, all of which may be relevant in some way depending upon the individual child (Rapp & Vollmer, 2005). The most important outcome in respect to context is considered to be that of establishing the functionality of stereotypy (Singer, 2009). For families, practitioners and those who are blind, this is thought to provide a critical insight because it may lead to consideration of interventions that foster more culturally socially appropriate behaviour.

The qualitative research study, as reported in Chapter Five, took the form of case studies. These followed an emergent design and on occasions incorporated unexpected results. In discussions with specialist teachers and in transcripts of interviews, through observations of learners and in reviewing documentation, the most surprising outcome for the researcher was to identify evidence that confirmed that in New Zealand, some learners who are blind who display stereotypy are not actually receiving their education in inclusive environments. For the majority of their school time, these particular learners are receiving tuition from specialist teachers and support personnel.

Although the government sanctioned focus in Individualised Education Plans is on positive learner outcomes in the least restrictive environment, the responsibilities for programs, assessment, teaching and behavioural intervention strategies, was not a collaborative process in a mainstream setting. Significant time for these particular children is being spent in exclusive settings with a Resource Teacher: Vision (RTV). Therefore, adult interactions are continuous – they are considered to be largely positive, yet peer integration is minimal. Emphasis in individual planning remains on indicators of learner growth, yet all learners in the case studies were not achieving consistently at age-appropriate levels in the key competencies of the New Zealand Curriculum. Access to social environments through an integrated approach to teaching and learning was restricted. This appears to have an impact on all learning and on the acquisition of culturally appropriate social skills that in turn may affect social competence. Without opportunities to experience social environments, social behaviours do not necessarily progress in an expected manner. This inhibits social interactions and successful integration into society.

6.3 Outline of the Study

Professional concern about stereotypic behaviour in learners who are blind was the catalyst for this research. According to international literature, these disordered behaviours are highly prevalent in children who are blind (Murdoch, 2013). The study set out to establish the demographics, prevalence, duration, contexts and situational causes of this behaviour in New Zealand children who are blind. Through comparisons with similar international literature, this project was designed to contribute to a “body of knowledge of manneristic behaviour” (Eichel, 1979, p. 167) by establishing statistical data on each of these aspects and then describing the lived experiences of five individuals who display this behaviour and who receive their education in an inclusive setting in New Zealand.

Stereotypy is currently considered a disordered behaviour (Rapp & Vollmer, 2005). A number of definitions are documented in the literature. However, it is generally agreed that these behaviours are self-directed actions; they are produced and received by the performer, consciously involving no one else. They are referred to as self-stimulatory, whereby automatic positive self-reinforcement occurs for the individual (Barry, Baird, Lascelles, Bunton & Hedderly (2011). This behaviour may at times be considered discordant within social environments and may result in social isolation. The current legislation in New Zealand confirms the right of students with special needs to enrol and receive education in the school of their choice. Therefore children who are blind usually attend their local school. This presupposes that socially acceptable behaviour may well be required by all children in inclusive environments to facilitate learning beside their peers.

RTVs have the responsibility for ensuring that adaptations to the curriculum are provided for children who are blind so they can access the program and learn alongside their peers. These teachers have heightened awareness of the needs of these learners and maintain a feeling of responsibility for the perceived success of the individual child across all competencies of the National Curriculum. The documentation that supports the learning and achievement of children who are blind is the responsibility of these specialist teachers. Therefore, by focusing on the experiences and perceptions of RTVs, I had hoped to discover what the reality was for this group of learners. The empathy, knowledge, together with observations of these learners provided richness and breadth to the contextual understandings sought in this project.

6.4 Summary of the Study

There is professional concern regarding the lack of published research both internationally and in New Zealand in the field of vision education. Experts such as Ferrell (2007) advocate strongly for research-based practice that fosters the

pursuit of new knowledge. She states that we are often left with best practices that are more philosophical than proven, more descriptive than empirical and more antiquated than modern. This is the situation in New Zealand, where published research in this area is somewhat dated and sparse. There is very much a need for new research in this field in New Zealand.

As a vision educator, equity of access for learners who are blind has been a constant challenge for me. The aim is to try and ensure that philosophy and practice align with one another in order to “open doors so all may learn” (BLENNZ, 2005). As an insider researcher there were artefacts to gather and stories to collect. Entrusted with this information, the purpose of the study was to develop an increased awareness of what is going on with regard to stereotypic behaviour in a child’s learning, especially in the development of socialisation skills for learners who are blind and who are educated in regular settings. This study, therefore, was a step in the journey to research-based practice in New Zealand and embraced the learner, their families and professionals.

6.4.1 The Quantitative Phase

The strength of this first aspect of the study was in the provision of descriptive data. Interpreting this data using quantitative statistics, albeit from a small sample size, aimed at providing statistical significance for the study. The goal of the quantitative phase was, therefore, to establish data in relation to type, prevalence, duration and situational contexts of stereotyped behaviours. The data were collected through a postal survey to parents/caregivers.

The criteria for selection of respondents, i.e., the sample, were that they were identified on the BLENNZ national database as having responsibility for a child aged between 5 and 18 years at the time who was functionally and/or legally blind and who was receiving their education in a mainstream setting.

The survey in the form of a questionnaire was created using items identified through previous published instruments and through an analysis of related literature. Reliability and validity were established based on a pilot and a principal survey, on Chi-Square analysis using Minitab-15, on frequency distributions and using cross tabulation.

A total of 117 questionnaires were distributed; 60 were returned, however, one return was incomplete therefore analysis of the data was based on 59 responses. Of the 59, 35 parents/caregivers indicated that stereotypic behaviour was displayed by their child. Prevalence of the behaviour was therefore reported to be 59% across all age bands, with 69% reported in children younger than 13 years. This figure is somewhat lower than that which has been reported internationally, the range being 52% (Gal & Dyck, 2009), to 100% (Troster et al., 1991b).

The predominant type of stereotypies displayed related to those that involved the hands and arms together with the eyes. The prevalence of these behaviours in children who are blind, referred to as oculodigital stereotypies, is well documented in international literature (Fazzi et al., 1999). Visual conditions were reported as those that can be termed retinal disorders, and additional disabilities in the child were recorded by over half the respondents (Berkson et al., 2001). This is comparable to that reported internationally. Frequency rates in respect to the stereotypic behaviour showed significant variance; however, duration rates averaged no longer than two minutes for each episode. Contextual information, where provided, related essentially to the sensory stimulation levels to which individuals were exposed, although much was unknown in respect to this factor. High and low levels of environmental arousal is well documented in the literature, as is that of unknown causation (Deasy & Lyddy, 2009; Miller et al., 2005; Molloy & Rowe, 2011).

The first phase of the study was undertaken to provide a framework of information and knowledge. The data were collected and analysed, providing a general understanding of the research problem. These data answered the research question “How prevalent is stereotypic behaviour in New Zealand children who are blind?” This phase of collection and analysis occurred prior to any qualitative data being collected. The quantitative data were initially perceived to be given equal status to the planned qualitative second phase of the study, however this status changed over time. The two phases became connected at this intermediate stage, for the cases selected were purposefully drawn from the survey responses. This aimed to maximise the possibility of securing richness and depth in the stories to be told. In other words, the qualitative phase was informed and guided by the analysis of the quantitative phase.

6.4.2 The Qualitative Phase

The second stage of the study, the qualitative phase, provided the opportunity to use the naturalistic paradigm, for this was about real people in real situations. The researcher had the scope to respond to data as it emerged. This was without a full understanding of what data would ultimately be meaningful. This provided freedom to look for trends that might emerge across the cases.

This second stage aimed at building on the first phase in that five case studies, using intensity sampling, were undertaken to elaborate on providing particular information relevant to aspects of the quantitative results. This meant that the five learners were deliberately chosen as they were perceived to have the characteristics that were the most relevant to the research. Multiple sources for collecting data were used, including in-depth interviews with RTVs, observations of the learners across a number of contexts and a review of relevant documentation in the form of the learner’s Individualised Education Plan (IEP).

Interviews were used to present the perspectives of RTVs and to hear their stories. These were scribed and recorded when agreed, and QSRNVivo qualitative software was trialled for data storage, coding and the development of themes. Further thematic analysis of documentation and observations were undertaken, as was coding of observations using manual techniques. Non-participant observation was used to gain a better understanding of the learners' experiences within a range of settings. The researcher was not involved directly in the activities or in the interactions observed but was physically co-present in the setting. Writing of notes from an observational checklist occurred at this time. A review of documentation included the IEP, learning stories and formative assessment data. This aimed to provide knowledge about the functioning and achievement of the learner by including the perspectives of those involved with the learner.

Trustworthiness of the qualitative data was enhanced through triangulating the different sources of information; (1) through reviewing the evidence, (2) through the thickness of the descriptions provided in the case studies and (3) through the checking of evidence recorded in documentation, transcripts and journal records.

A number of unexpected common concerns emerged in this phase of the study. These were around inclusion, access to the curriculum, achievement levels and the variations of reported behaviour in different contexts. RTVs, although assigned to learners in the mainstream, had significant responsibility for the implementation of the curriculum and its adaptations. Including learners who are blind in regular settings is policy, yet in practice the situation is reported quite differently. Although they were attending different schools, the children were the only learners who were legally blind in their schools. As the learners progressed through their schools they met a range of teachers who may have lacked the professional knowledge of how to provide an inclusive environment. Teacher attitude and involvement varied considerably. This was

reported in conversations and was evident in the IEP, where minimal input was presented or identified as that of the classroom teacher. Responsibilities for that document, the program, assessments and forward planning were that of the RTV.

Although access to the curriculum for children who are blind is through an alternative medium and the use of specialised technology is required, there was little evidence of a shared responsibility for resources and for assessments. Much of what was reported in the documentation as being overall teacher judgements was that of the RTV. Few Braille or electronic resources were presented in an appropriate or requested timeframe. This may have impacted on the manner in which curriculum content was taught.

Key competencies of the New Zealand National Curriculum were not always reported objectively, so that results at times could not be validated. Relationships between the specialist teacher and the learner who is blind are usually long term, often exclusive and may lead to the development of a feeling of responsibility on the part of the teacher for all aspects of progress for the learner. Interviews with teachers hinted at ownership of the learner's results, their progress and their stereotypic behaviour. Knowledge of this behaviour, its functionality and contextual relevance was varied. Reported behaviour and observed behaviour indicated anomalies, with RTVs offering explanations for behaviours not deemed to be socially appropriate.

It was, therefore, not unexpected that the two key competencies of Participating and Contributing plus Managing Self were highlighted by those interviewed. The reframing of questions was required to ensure that insider researcher knowledge was minimised concerning this outcome. The exclusive relationship of the specialist teacher brought about through the disquiet of the mainstream teachers to provide an inclusive environment was very real. The

resultant situation, whereby adapted programs were provided solely by the RTV in withdrawal rooms and in a parallel setting, may limit the opportunity for learners who are blind to learn beside their sighted peers in recognised social environments at school. When stereotypic behaviours are exhibited by these learners, the student is further marginalised.

Knowledge of stereotypic behaviour was somewhat limited, as was evident in teacher interviews. Reference was made to an awareness of the behaviours and the discordant nature of these behaviours in mainstream and inclusive settings, however the frequency and duration of particular stereotypies tended not to be known. Contextual information was reported by RTVs in a variety of ways, but the behaviours were noted to occur largely at times of high or low level environmental arousal. Functional information in reference to the behaviours was not referred to by the teachers, nor were intervention strategies discussed as a possible extension of behavioural analysis. Peer reactions from older students were noted, but younger pupils were considered to show little reaction. Cultural differentiation to reactions and responses were not observed or noted by RTVs. Differentiation between the stereotypic behaviour displayed in the mainstream regular classroom and in a withdrawal situation was also not referred to by the RTVs.

The qualitative phase of the study provided information suggesting that there are multiple realities for some learners who are blind and who display stereotypic behaviour. The focus for this research was both complex and broad. Reasoning was inductive in order to synthesise the data as themes emerged. The value-bound and subjective nature of insider research is again acknowledged, owing to the ongoing connection between the participants and the researcher and, at times, between the learners and the researcher.

6.5 Strengths of the Study

The strength of the mixed methods research and design was that statistical data could be presented, which formed the basis of new knowledge from which to explore an understanding of the reality of life for particular individuals at school. Previously there had been a complete lack of research information in New Zealand in respect to stereotypic behaviour in learners who are blind. The quantitative phase of the research therefore provided an important descriptive base line upon which the second phase could be built.

The strength of the qualitative phase was the flexibility the research approach enabled the researcher to explore the subjective experiences of those involved in the five case studies. This research provided the researcher with the opportunity to listen to real people, to hear their stories and develop an increased awareness of their perspectives and issues. The RTV involved wanted to be heard, to present their perspectives, to share their concerns; they welcomed a forum to talk and they had much to say.

As an insider researcher, qualitative research provided the forum to explore the complex and varied situations for teachers in mainstream, inclusive environments who had responsibilities for learners with specialised vision needs. My knowledge of the role of a RTV has developed over time. A self-reflective and introspective attitude is one to which I aspire. Therefore, I understand the journey that both teachers and learners walk. I believe that I have insight into the system. I understand the challenges and the frustrations, yet I celebrate the achievements and successes for all. I share their knowledge and share in their relationships and I relate to them. However, every story is different, every story is special and every story is valued. Insider researcher knowledge made the stories so much more poignant and so much more meaningful.

6.6 Limitations of the Study

Limitations exist within both quantitative and qualitative methods especially for a novice researcher. In quantitative research, where a survey is used, Cresswell (2009) refers to limitations for both internal and external validity. For internal validity, it is the selection process of respondents in that people who have certain characteristics are predisposed to particular responses. Secondly, the instrumentation used may change at certain stages skewing outcomes. For external validity, it is the interaction between the setting, the history and the treatment of respondents and the survey. This information suggests that interaction with respondents may impact on results, and generalising to past/future situations is not possible.

This research design aimed at attaining reliability and validity through an objective approach. This project sought respondents from a nationally recognised database, the questionnaire was analysed with rigour using recognised software and data was produced in a statistical manner. The selection of respondents indicated some inaccuracies in the database, which was disappointing and has since been addressed by the wider organisation. Although the survey document was not changed at any point in the process and analysis was robust and peer reviewed, the limitations in the first phase of the study are recognised and noted. These needed to be overcome as the study progressed.

In qualitative research, criticism may be based on bias, the small size of the sample, use of anecdotal evidence and lack of rigour. Limitations therefore require providing sufficient evidence to support any claims that are made, and doing this in a trustworthy manner. The second stage of this project had a number of limitations. The study may have been confined by the small number

of case studies, the interviewing style and questions, interview locations, inexperience of the researcher in making observations and the project being conducted by an insider researcher. There may also have been limitations in expertise in using detailed descriptive writing to present the voices of the RTVs.

A particularly noteworthy limitation is the point that what participants said might actually differ from their beliefs. The information reported only relays what the interviewees said. It is not possible for a researcher to ensure that what was said is an accurate representation of what the interviewees actually believe. For example it is possible that interviewees might have told me what they thought I wanted to hear. Therefore, what is written may contain inaccuracies and it needs to be viewed with considerable caution.

As the project involved both quantitative and qualitative research protocols, it was decided to keep the number of case studies at a manageable number. As locations were geographically varied, decision making included thinking about what realistic access to both learners and teachers was possible. This also meant that only a limited number of observations could be undertaken with each learner. It also meant the access to RTVs needed to be ongoing as new information or additional reflections were offered. Intensity sampling was used, which in turn indicates bias; however, this issue is considered to be outweighed by the breadth of data collated in the cases presented.

As an insider researcher, there were further limitations that were possibly self-imposed. Employment in a management position within the organisation where the research is carried out implies that there will be some cautiousness and loyalty to that organisation, as the risk of upsetting or offending those in the organisation is ever present. It was particularly poignant writing up case studies in the qualitative, second stage of the project, but the

statistical data was less challenging and was presented without reservation. Ongoing professional relationships with teachers are the reality therefore some degree of professional discretion was required. An assumed knowledge of Vision Education may have also limited the study. Perceived assumptions about the specialist teacher role, or that of the learner, or that of their stereotypic behaviour, or the researcher, could have impacted on the interview responses; however, respondents appeared confident, open and honest throughout the process.

Upon further reflection, it must be acknowledged that any research in Vision Education is difficult to conduct. The population is invariably small; it is generally geographically dispersed, the participants are heterogeneous in gender and age, a range of disorders are exhibited and placement changes are common (Ferrell, 2007). Every effort was made to consider all of these factors and minimise their impact. This is where the use of mixed methods had the greatest impact.

6.7 Personal, Subjective, Objective and Emotional Challenges

This project required both objective and subjective perspectives from myself as the researcher. As a quantitative researcher, the objectivity of the process of data collection and analysis was reassuring. However, there was some conflict for me. This occurred when data provided by identified parents/caregivers did not align with my professional knowledge in the role of an insider researcher.

Although the survey instrument was sent to a national database of parents, many of the learners and their families were known to me. What was recorded in the survey information came from those who completed the survey questionnaire. When information provided in this survey was known to be inaccurate there was a dilemma for me in recording what was provided. This

was very much a personal issue since there was a possibility that, unless recorded correctly, such information would result in inaccurate statistical data.

The experience reduced my confidence a little, about the authenticity of the data, and raised the question as to whether there might be other inaccuracies that I had not identified. Still, the reality is that all studies have limitations, and the desire for both internal and external validity is enhanced when situations arise that challenge the researcher to constantly reflect on the methodology to separate “self” from the context to ensure rigour is maximised.

As a qualitative researcher, the role was to listen to the stories of teachers, observe learners and analyse relevant documentation in a non-judgemental manner. It is my belief that I had an awareness of the personal, professional and social factors that were ever present. Therefore, the subjective perspectives of conducting a qualitative study and working as an insider researcher as well as an RTV, suggest that it was almost impossible to separate myself from the data collection and analysis process. Discernible boundaries do not really exist in this situation. We are all shaped by our own experiences and our values, meaning there will be some personal influences throughout the study, especially in the narratives presented. Many qualitative researchers believe that this is a positive thing because the insider researcher is able to provide insights that would otherwise not be available.

To ensure reliability and validity in the quantitative phase of the research, and trustworthiness and credibility in the qualitative phase, data collection/analysis were continually scrutinised. The dual roles of insider researcher and RTV were intertwined in many ways. Managing a team of RTVs, whose professional development and performance are my responsibility, presented some complexities professionally. Developing my own research skills, somewhat autonomously through doctoral studies supported from

Australia, and having accountability to the organisation together with meeting the demands of a full-time position were particularly challenging at times. The ability to study independently, with supervision from abroad, to time-manage effectively, sustain meaningful professional and personal relationships and work as a reflective practitioner called for inner strength, commitment and self-discipline.

The purpose of the study was to inform others in order to strive for best practice through effective pedagogy. It was about wanting to make a difference for learners who are blind to ensure each can reach their potential in a sighted world. My belief, drawn from my own experiences and my emotional makeup, is that learners who are blind, who display stereotypic behaviour, face a number of barriers that limit their inclusion in society.

6.8 Practical Implications

The practicalities of mainstreaming school-aged learners who are blind are challenging. Placement in what is thought to be the least restrictive environment is the philosophy of inclusion. By examining the situations for five individual learners who are blind, who experience this setting daily, I aimed at allowing RTVs to tell the story of this reality. Previous international research has espoused the value of inclusion and placement in the least restrictive environment, but no published research in New Zealand has discussed the realities of the situation for learners who are blind who exhibit discordant behaviours.

As a philosophical stance, most teachers are in agreement with including learners who are blind in regular settings. When placement is made in a class in a school, professional development is provided to the regular teacher – usually a one-day in-service course at the *Homai* Campus location, which includes generic guidelines to facilitate access to the curriculum for the learner

who uses Braille. An overwhelming range of guidelines are presented, with the result that regular teachers tend to respond in an anxious manner, with words such as “I’ll rely on you” to the specialist teacher. The reality is that regular teachers establish their own routines and classroom programs, leaving the needs of the learner who is blind to the RTV. It is considered extremely challenging to meet the demands and expectations of the diverse range of learners in their classroom even without including the learner who is blind. The “expert” is present, the learner will be fine with her, is almost the unspoken understanding.

From the first few days of classroom entry, the pattern of unintentional exclusion is often set and responsibility for the learner who is blind is delegated. This may then evolve into physical exclusion. Material may not have been made available in order to translate documents into an accessible format, technology may be seen as a barrier, verbalisation of visual learning tools may seem awkward or even impossible at times, so it becomes a better solution to expect the expert to provide the instruction, the adaptation and the assessment for the learner who is blind. This often occurs in a withdrawal room “so they can talk through work without disturbing the class” (Caty, 2013). This then becomes the most restrictive environment. Learning is not beside the peer group and opportunities to engage in social environments are minimised. This exclusive setting also contributes to the dependency relationship with the specialist teacher, and responsibility for learner successes and learner behaviours residing with that professional.

RTVs spoke in interviews of their role and their relationship with the learner. These long-term relationships were reported as being successful in that the learner related well to them and to other adults. For all case study children, there were concerns with the relationships with the peer group. The practicalities appear to be that the learner who is blind spends a significantly reduced amount of time in structured learning mainstream environments in

order to learn. Learning is not only about the curriculum but is also about learning how to relate to the peer group.

The stereotypic behaviour of the learners in the case studies varied in structured and unstructured contexts, in withdrawal areas and in the mainstream setting. This behaviour was reported by RTVs and was also observed by the researcher to differ across settings. Anomalies were particularly evident in playground settings where there was no adult in the immediate environment of the learner. The behaviours are thought to be socially isolating. Therefore, observations of the peer group were of interest in that they generally reacted in a negative manner when stereotypy was displayed. Positive social interactions in these settings were rare, and any interaction tended to enhance exclusion as opposed to social integration. When there are questions around inclusion in educational settings, with queries around what is deemed to be the least restrictive environment, it follows that there must be concerns about how children who are blind learn what is socially appropriate behaviour in real-life contexts.

Classroom teachers are challenged to manage the diverse needs of all learners in their classrooms. RTVs are located in these classrooms with the knowledge and expertise to ensure the learner who is blind has equity of access to the curriculum. When discordant behaviour compounds the situation, the learner who is blind usually receives a response from the specialist teacher. A number of strategies are used, depending upon the type of the behaviour and the context. In practical terms, the behaviour is ignored, challenged or redirected by an adult. The focus then returns to ensuring the learner is engaged in an adapted program, and that outcomes in the key competencies show growth, but not necessarily those that relate to socially acceptable behaviour.

6.9 Recommendations

The study aimed at establishing the prevalence of stereotypic behaviour in a small number of selected learners who are blind and to explore this behaviour with regards to the individual child's learning, especially in relation to socialisation skills.

A number of recommendations have been created from this mixed methods study:

- Information about stereotypic behaviour, its function and its contextual relevance, needs to be provided to RTVs and parents and caregivers (Appendix M)
- Information about stereotypic behaviour in respect to the intervention, purpose and guidelines needs to be provided to RTVs and parents/caregivers (Appendix N)
- Learners who are blind require encouragement to manage their own needs.
- Strategies to teach culturally appropriate socialisation skills to learners who are blind are imperative.
- Strategies for enskilling learners who are blind to manage their own behaviour are important.
- Opportunities to promote appropriate socialisation skill development for learners who are blind are essential.
- RTVs need to consider the length of time spent with any one learner to assist with reduction of dependency for the learner and that of total responsibility of the specialist teacher for learner outcomes.
- RTVs require guidelines to assist them to promote collaborative practice in order to shift from their perceived role as the expert and to empower others.
- For mainstream teachers who have a learner who is blind in their classroom, professional development prior to placement is essential to assist those teachers/aides to work collaboratively and in partnership with the RTV.

- The inclusion of learners who are blind in mainstream educational settings requires conceptual understanding and the enskilling of mainstream teachers to manage all learners with diverse needs.
- The long-term effects of exclusion from mainstream settings for learners who are blind who display stereotypic behaviour needs to be addressed.
- More research is required into the association between functionality and context in order to establish why particular stereotypic behaviours occur in particular contexts.

6.10 Future Research

The outcomes of this study are disturbing in that the complexity of mainstreaming learners who are blind in the school of their choice has emerged as a particularly noteworthy challenge. Although this policy has a lengthy history, this study suggests that the reality for the five learners in the case studies is contradictory to the philosophical stance of learning beside the sighted peer group. The inclusion process requires further research to review the present issues and develop strategies to facilitate successful mainstreaming for learners who are blind. Similarly, this outcome is relevant to learners who are blind who display discordant behaviour, for how do these learners assimilate what is socially appropriate behaviour if they are isolated from such environments?

The prevalence of stereotypic behaviours exhibited by learners who are blind confirms similar patterns seen in the international literature. The range of theories in respect to functionality and aetiology are clearly evidenced, however, further knowledge from longitudinal studies may contribute to a deeper understanding of these theoretical perspectives, especially in relation to situational context. Which particular behaviours have an association with which context is important. This aligns with determining the association between functionality and context in order to establish why and how stereotypic behaviour affects learning.

6.11 Conclusion

The objective of the study was to focus on stereotypic behaviour in order to create a cohesive body of knowledge about manneristic behaviour in New Zealand children who are blind. Empowered by this body of knowledge, “the elephant in the room” can be acknowledged, discussed and addressed in some way so that this sector of the population is no longer marginalised. They may then have the opportunity to take their place in a sighted world.

Mixed methods research and design strategies provided the philosophical paradigm, the methodology and the methods to address the complexities and contradictions of the research questions. The sequential explanatory strategy provided the process by which statistical data were first collected and analysed. The intermediary stage of mixing the data evolved from this point, as the numeric information informed the selection process for the qualitative phase of the case studies.

An increased awareness of the lived experiences of the five learners who are blind who display stereotypic behaviour highlighted the challenges the participants face on a daily basis. The narratives painted the picture of a somewhat exclusive approach to learning and an exclusion from social settings at school, and not only because of their discordant behaviour. This reality presents substantial challenges for learners who are blind to learn alongside their peers, and to learn culturally socially acceptable behaviour.

Although this was a small project, it was a time-rich study from a personal perspective and may yet be seen to be important. The study is significant to those in New Zealand in the field of Vision Education and it is

significant to families and children who are blind. It is from gaining factual knowledge and by listening to stories that we increase our understanding of stereotypic behaviour in children who are blind. We can all learn from one another and strive to make a difference by empowering these students to be lifelong, successful learners in a sighted world.

In an ideal world, all children would be born without disabilities but it is not an ideal world. We, as educators, may not be blind, but in the words of Helen Keller, we need to have the vision for a better future for learners who are blind. This is even more so for those who display stereotypic behaviour.

He aha te mea nui o te ao?

He tangata! He tangata! He tangata!

(Whakatauki, Aotearoa, n.d.)

What is the most important thing in the world?

It is people! It is people! It is people!

References

- Abang, T. B. (1985). Blindisms: Likely causes and preventative measures. *Journal of Visual Impairment and Blindness*, 79(9), 400-401.
- Abang, T. B. (1988). Blindisms: Possible causes and remedies. *The British Journal of Visual Impairment*, 8(3), 91-93.
- Abrams, L. S. (2010). Sampling 'hard to reach' populations in qualitative research: The case of incarcerated youth. *Qualitative Social Work*, 9(4), 536-550.
- Achenbach, T. M. (1985). *Assessment and taxonomy of child and adolescent psychopathology*. Beverly Hills, CA: Sage.
- Alberto, P., & Troutman, A. (2010). *Applied behaviour analysis for teachers* (7th ed.). Upper Saddle River, NJ: Merrill Prentice Hall.
- Alvesson, M., & Skoldberg, K. (2009). *Reflective methodology: New vistas for qualitative research: New vistas in qualitative research* (2nd ed.). London: Sage Publications.
- American Association for Pediatric Ophthalmology and Strabismus. (2012). *Eye conditions*. Retrieved from www.medscape.com/viewcollection
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed.). Washington DC: American Psychiatric Association
- American Psychiatric Association. (2013). *Stereotypic motor disorder: Diagnostic and statistical manual of mental disorders* (5th ed., 77080). Arlington, TX: American Psychiatric Publishing
- Anderson, C. (2010). Presenting and evaluating qualitative research. *American Journal of Pharmaceutical Education*, 74(8), 1-7.
- Anderson, S., Boigon, S., Davis, K., & de Waard, C. (2007). *The Oregon project for pre-school children who are blind or visually impaired* (6th ed.). Medford, OR: Southern Oregon Education Service District.

- Andrews, R., & Wyver, S. (2005). Autistic tendencies: Are there different pathways for blindness and autism spectrum disorder? *The British Journal of Visual Impairment*, 23(2), 52-57.
- Artiles, A., & Dyson, A. (2005). Inclusive education in the globalization age. The promise of comparative cultural-historical analysis. In D. Mitchell (Ed.), *Contextualising inclusive education* (pp. 37-62). Oxfordshire, England: Routledge.
- Attwood, T. (1998). *Aspergers syndrome: A guide for parents and professionals*. Albany, NY: Delmar Publishers Inc.
- Auckland University of Technology. Department of Statistics. Minitab 15 Software Access.
- Avis, M. (2003). Do we need methodological theory to do qualitative research? *Qualitative Health Research*, 13, 995-1004.
- Ayres, B., & Hedeem, D. (2002). *Special education paraprofessionals in Montana schools: A resource guide for administrators, educators and paraprofessionals*. Retrieved from www.opi.mt.gov/PDF/SpecEd/guides
- Ayres, B. J., & Hedeem, D. L. (1997). Creating positive behaviour support plans for students with significant behavioural challenges. In M. Giangregio (Ed.), *Quick guide to inclusion: Ideas for educating students with disabilities* (pp.113-137). Baltimore, MD: Paul H. Brooke.
- Babbie, E. (2001). *Operationalization: The practice of social research* (13th ed.). Belmont, CA: Wadsworth Publishing.
- Baird, S. M., Mayfield, P., & Baker, P. (1997). Mothers' interpretations of the behaviour of their infants with visual and other impairments during interactions. *Journal of Visual Impairment and Blindness*, 91, 467-483.
- Bak, S. (1999). Relationship between inappropriate behaviours and other factors in young children with visual impairments. *Re:-View*, 31(2), 84-92.

- Barkoukis, A., Reiss, N., & Dombeck, M. (2013). *Childhood mental disorders and illnesses: Disorders of childhood: Stereotypic movement disorder*. Retrieved from www.sevencounties.org
- Barry, S., Baird, G., Lascelles, K., Bunton, P., & Hedderly, T. (2011). Neurodevelopmental movement disorders – an update on childhood motor stereotypies. *Developmental Medicine and Child Neurology*, 53, 979-985.
- Baumeister, A. A., (1978). Origins and control of stereotyped movements. In E. Meyers, (Ed.), *Quality of life in severely and profoundly mentally retarded people: Research foundations for Improvement* (pp. 353-384). Washington, DC: American Association on Mental Deficiency.
- Beckei, B., & Luthar, S. (2002). Social-emotional factors affecting achievement outcomes among disadvantaged students: Closing the achievement gap. *Educational Psychologist*, 37(4), 197-214.
- Bergman, M. M., (2011a). The good, the bad, and the ugly in mixed methods research and design. *Journal of Mixed Methods Research*, 5(4), 271.
- Bergman, M. M., (2011b). The politics, fashions and conventions of research methods. *Journal of Mixed Methods Research*, 5(2), 99.
- Berkson, G., (1983). Repetitive stereotyped behaviours. *American Journal of Mental Deficiency*, 88, 239-246.
- Berkson, G., & Tupa, M. (2000). Early development of stereotyped and self-injurious behaviours. *Journal of Early Intervention*, 23(1), 1-19.
- Berkson, G., Tupa, M. & Sherman, L. (2001). Early development of stereotyped and self-injurious behaviour: I. Incidence. *American Journal on Mental Retardation*, 106, 539-547.
- Bizzocchi, J., & Schell, R. (2009). Rich-narrative case study for online PBL in medical education. *Academic Medicine*, 84(10).
- Blaikie, A., (2013). *Scottish Sensory Centre*. Retrieved from <http://ssc.education.ed.ac.uk>

Blake, S., (2002). Beating blindisms. *See/Hear*, 7(2), 7-9.

Blank, R. (1957). Psychoanalysis and blindness. *Psychoanalytic Quarterly*, 26(1), 18-21.

BLENNZ (2005) Charter, Unpublished Document.

BLENNZ (2010). Board Report. Unpublished Document

BLENNZ (2012) Charter, Unpublished Document.

Bogdan, R. C., & Biklen, S. K. (2003). *Qualitative research for education: An introduction to theory and methods* (4th ed.). Boston, MA: Allyn and Bacon.

Bourke, R., & Mentis, M. (2010). *Research and evaluation of narrative assessment and curriculum exemplars for students with special needs*. Massey, NZ: Special Education, Massey University.

Bowlby, J. (1980). *Attachment and loss: Vol. 3 Loss*. New York: Basic Books.

Brambring, M. (2007). Divergent adaptive strategies in the developmental skills in children who are blind. Retrieved from www.icevi.org/publication.

Brambring, M., Doblsaw, G., Klee, K., Obermann, S., & Troster, H. (1987). *Der bielefelde elternfragebogen fur die eltern blinder und sehender klein-und borschulkinder* (The Bielefeld parents' questionnaire for blind and sighted infants and preschoolers). Unpublished Research Report, Special Research Unit on Prevention and Intervention in Childhood and Adolescence, University of Bielefeld.

Brambring, M., & Troster, H. (1992). On the stability of stereotyped behaviours in blind infants and pre-schoolers. *Journal of Visual Impairment and Blindness*, 105-110.

Brame, C. M., Martin, D., & Martin, P. (1998). Counselling the blind or visually impaired child: An examination of behavioural techniques. *Professional School Counselling*, 1(5), 60-63.

- Brannick, T., & Coghlan, D. (2007). In defence of being 'native': The case for insider academic research. *Organisational Research Methods*, 10(1), 59-74.
- Brantlinger, E., Jimenez, R., Klingner, J., Pugach, M., & Richardson, V. (2005). Qualitative studies in special education. *Exceptional Children*, 71(2), 195-207.
- Brauner, C. B., & Stephens, B. C. (2006). *Social-emotional development in early childhood: National Center for Children in Poverty* (pp. 303-310) New York, NY: Mailman School of Public Health, Columbia University.
- Bruner, J. S. (1961). The cognitive consequences of early sensory deprivation. In P. Solomon, P. Kubzansky, P. Leiderman, J. Mendelson, R. Trumbul, & D. Wexler (Eds.), *Sensory deprivation*, Cambridge, MA: Harvard University Press.
- Bryman, A. (2007). Barriers to integrating quantitative and qualitative research. *Journal of Mixed Methods Research*, 1, 8-22.
- Bunning, K. (1998). To engage or not to engage? Affecting the interactions of learning disabled adults. *International Journal of Language and Communication Disorders* (Supplemental), 33, 387-439.
- Burke Johnson, R., Onwuegbuzie, A. J., & Turner, L. A. (2007). Toward a definition of mixed methods research. *Journal of Mixed Methods Research*, 1(2), 112-133.
- Burroughs, G. E. R. (1971). *Design and analysis in educational research*. Oxford: Educational Review.
- Caetano, A. P., & Kauffman, J. M. (1975). Reduction of rocking mannerisms in two blind children. *Education of the Visually Handicapped*, December, 101-105.
- Campbell, M. (1985). Timed stereotypies rating scale. *Psychopharmacology Bulletin*, 21, 1082.
- Campbell, D. T., & Fiske, D. W. (1959) in Tashakkori, A. (2009). Are we there yet? The state of the mixed methods community. *Journal of Mixed Methods Research*, 3, 287-291.

- Carr, E. G., & Durand, V. M. (1992). An analysis of maintenance following functional communication training. *Journal of Applied Behavior Analysis*, 24(4), 777-794.
- Carroll, T. J. (1961). *Blindness: What it is, what it does, and how to live with it?* Boston, MA: Little Brown.
- Cass, H. (1996). Visual impairment and autism: What we know about causation and early identification. *Psycho-analytic Study of the Child*, 19, 113-119.
- Castro, F. G., Kellison, J. G., Boyd, S. J., & Kopak, A. (2010). A methodology for conducting integrative mixed methods research and data analyses. *Journal of Mixed Methods Research*, (4):342-360.
- Chen, J., & Smith, L. E. (2007). *Retinopathy of prematurity*. Retrieved from www.ncbi.nlm.nih.gov/pubmed.html
- Chevigny, H., & Braverman, S. (1950). *Adjustment of the blind*. New Haven, CT: Yale University Press.
- Cho, J., & Trent, A. (2006). Validity in qualitative research revisited. *Qualitative Research*, 6, 319-338. Retrieved from <http://qrj.sagepub.com>
- Cigman, R. (2007). *Included or excluded: The challenge of the mainstream for some SEN children*. New York: Routledge.
- Coghlan, D. (2007). Insider action research: Opportunities and challenges. *Management Research News*, 30(5), 335-343.
- Cohen, L., & Manion, L. (2006). *Research methods in education* (6th ed.). London: Routledge
- Cohen, L., Manion, L., & Morrison, K. (2011). *Research methods in education* (7th ed.). London: Routledge Falmer
- Cook, B. G., Cameron, D. L., & Tankersley, M. (2007). Inclusive teachers' attitudinal ratings of their students with disabilities. *The Journal of Special Education*, 40, 230-238.
- Coots, M. N., & Ringeon, C. (2007). *Sensory play*. Retrieved from www.littlegiantsteps.com.

- Creswell, J. W. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks, CA: Sage
- Creswell, J. W. (2003). *Research design: Qualitative, quantitative and mixed methods approaches* (2nd ed.). Thousand Oaks, CA: Sage.
- Creswell J. W. (2009). *Research design: Qualitative, quantitative and mixed methods approaches* (3rd ed.), Thousand Oaks, CA: Sage.
- Creswell, J., & Plano Clark, V. (2007). *Designing and conducting mixed methods research*. Thousand Oaks, CA: Sage.
- Cunningham, A. B., & Schreibman, L. (2008). Stereotypy in autism: The importance of function. *Research in Autism Spectrum Disorders* 2, 469-479.
- Cutsforth, T. D. (1968). *The blind in school and society*. New York: American Foundation for the Blind.
- Cuvo, A., Conall, M., O'Cleugh, D. B., & Wadham, R. E. (1993). *Self-monitoring and verbal feedback to reduce stereotypic body rocking in a congenitally blind child*. Retrieved from <http://www.questia.com/PM>
- Dale, N., & Sonksen, P. (2002). Visual impairment in infancy: Impact on neurodevelopment and neurobiological processes. *Developmental Medicine and Child Neurology*, 44, 613-622.
- Dave, C. A. (1992). Effects of linear vestibular stimulation on body-rocking behaviour in adults with profound mental retardation. *American Journal of Occupational Therapy*, 46(10), 910-915.
- Daversa, R. (2001). *Self-stimulatory and stereotyped behaviour in autism: A review of behaviour analytic perspectives*. Retrieved from www.ctfeat.org/selfstimdaversa.htm
- Davies, T., & Pragnell, A. (1999). Special Education 2000: A national framework address. Paper presented at the Special Education 2000 Research Conference, Ministry of Education. Auckland, New Zealand.

- Deasy, K., & Lyddy, F. (2009). Potential for communication in individuals who are congenitally deaf blind: It's in the eye of the beholder. *The Irish Psychologist*, 35(8), 205-210.
- De Lucia, A. (2003). *The National Federation of the Blind of Connecticut: Feeling for the bottom*. Retrieved from <http://www.nfbct.org.html>
- De Mario, N. C., & Crowley, E. P. (1994). Using applied behaviour analysis procedures to change the behaviour of students with visual disabilities: A research view. *Journal of Visual Impairments and Blindness*, 88(6), 532-544.
- Denscombe, M. (2010). *The good research guide*. (3rd ed.). Buckingham: Open University Press.
- Denzin, N. K. (2012). Triangulation 2.0. *Journal of Mixed Methods Research*, (6), 80-88.
- Denzin, N. K., & Lincoln, Y. S. (2008). Introduction: The discipline and practice of qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *The landscape of qualitative research* (3rd ed.) (pp.1-45). Thousand Oaks, CA: Sage.
- Doidge, N. (2007). *The brain that changes itself: Stories of personal triumph from the frontiers of brain science*. New York, NY: Viking (Penguin).
- Duker, P. C., Boonekamp, J., Ten Brummelhuis, Y., Hendrix, Y., Hermans, M., Van Leeuwe, J., & Seys, D. (1989). Analysis of ward staff initiatives towards mentally retarded residents: Clues for intervention. *Journal of Mental Deficiency Research*, 33, 55-57.
- Dumont, M., & Markovits, H. (1982). Analyse descriptive et evaluative gestes stereotypes chez les handicaps de la vue, dans un groupe de Pairs. *Apprentissage et Socialisation*, 5, 24-31.
- Duncan, J. (2013). *Factors influencing outcomes: Social capital*. Paper presented at the Sydney Vision Conference. Sydney, Australia.
- Dunstall, G. (1992). The social pattern. In G. W. Rice (Ed.), *The Oxford history of New Zealand* (2nd ed.). Auckland: Oxford University Press.

- Durand, V. M. (1990). *Severe behaviour problems: A functional communication training approach*. New York: Guildford Press.
- Durand, V., & Kishi, G. (1987). Reducing severe behavior problems among persons with dual sensory impairments. An evaluation of a technical assistance model. *Journal of the Association for Persons with Severe Handicaps*, 12(1).
- Dyck, M. J., Farrugia, C., Schochet, I. M., & Holmes-Brown, M. (2004). Emotion recognition/understanding ability in hearing or vision-impaired children; do sounds, sights, or words make the difference? *Journal of Child Psychology and Psychiatry*, May 45(4), 789-800.
- Edelson, S. M. (1995). *Stereotypic (self-stimulatory) behaviour*. Retrieved from <http://www.autism.org/stim.html>
- Edwards, B. (2002). Deep insider research. *Qualitative Research Journal*, 2, 71-84.
- Eichel, V. J. (1971). In V. J. Eichel (1978), *Mannerisms of the blind: A review of the literature*. *Journal of Visual Impairment and Blindness*, 72(4), 125-130.
- Eichel, V. J. (1978). *Mannerisms of the blind: A review of the literature*. *Journal of Visual Impairment and Blindness*, 72(4), 125-130.
- Eichel, V. J. (1979). A taxonomy for mannerisms of blind children. *Journal of Visual Impairment and Blindness*, 73(5), 167-178.
- Ellis, C. R. (2013). *Childhood habit behaviours and stereotypic movement disorder*. Retrieved from <http://emedicine.medscape.com/article>
- ERO (2010). Retrieved from <http://www.ero.govt.nz>
- ERO (2011). Retrieved from <http://www.ero.govt.nz>
- ERO (2010-2012). Retrieved from <http://www.ero.govt.nz>

- Estevis, A. H., & Koenig, A. J. (1994). A cognitive approach to reducing stereotypic body-rocking. *Re:-View*, 26(3), 119-125.
- Fazzi, E., Lanners, J., Danova, S., Ferrarri-Ginevra, O., Gheza, C., Luparia, A., Balottin, U., & Lanzi, G. (1999). Stereotyped behaviours in blind children. *Brain and Development*, 21(88), 522-528.
- Fazzi, E., Signorini, S. G., & Lanners, J. (2008). In G. Dutton, & M. Bax (Eds.), *Vision impairment in children due to damage to the brain*. London: MacKeith Press.
- Felps, J. N., & Devlin, R. J. (1988). Modification of stereotypic rocking of a blind adult. *Journal of Visual Impairment and Blindness*, 82, 107-108.
- Ferrell, K. A. (2007). *Issues in the field of blindness and low vision*. Retrieved from www.unco.edu
- Fontana, A., & Frey, J. H. (2008). The interview: From neutral stance to political involvement. In N. K. Denzin and Y. S. Lincoln (Eds.), *Collecting and interpreting qualitative materials* (3rd ed.) (pp. 115-159). Thousand Oaks, CA: Sage.
- Fraiberg, S. (1977). *Every child's birthright*. New York: Basic Books.
- Freeman, R. D., Goetz, E., Richards, D. P., & Groenweld, M. (1991). Defiers of negative prediction: A 14 year follow-up study of legally blind children. *Journal of Visual Impairment and Blindness*, 85, 365-370.
- Fritz, J. N., Iwata, B. A., Rolider, N. U., Camp, E. M., & Neidert, P. L. (2012). Analysis of self-recording in self-management: Interventions for stereotypy. *Journal of Applied Behavioural Analysis*, (45), 55-68.
- Gage, N. L. (1989). The paradigm wars and their aftermath: A historical sketch of research on teaching since 1989. *Educational Researcher*, 18, 4-10.
- Gahbler, M. (2000). *Stereotypic movements – Meaningful peculiarities?* Retrieved from <http://www.icevi.europe.org/cracow>

- Gahbler, M. (2002). *Nordic workshop on blindisms*. Retrieved from <http://www2.skolenettet.no/skolenettet>
- Gal, E. & Dyck, M. J. (2009). Stereotyped movements among children who are visually impaired. *Journal of Visual Impairment and Blindness*, 103(11)
- Gal, E., Dyck M. J., & Passmore, A. (2002). Sensory differences and stereotyped movements in children with autism. *Behaviour Change*, 19, 207-219.
- Gedeon, A. (2003). *The child advocate: Skin picking and self-injurious behaviour*. Retrieved from <http://www.childadvocate.net>
- Gerra, L. L., Dorfman, S., Plaue, E., Schlackman, S., & Workman, D. (1995). Functional communication as a means of decreasing self-injurious behaviour: A case study. *Journal of Visual Impairment and Blindness*, 89(4), 343-348.
- Gillham, B. (2005). *Research interviewing the range of techniques*. Maidenhead, England: Open University Press.
- Glesne, C., & Peshkin, A. (1992). *Becoming qualitative researchers: An introduction*. Longman: NY.
- Godfrey, J. (2008). *Statistics*. Retrieved from www.rnzfb.org.nz
- Gold, D., Shaw, A., & Wolffe, K. (2010). *The social lives of Canadian youths with vision impairments*. Retrieved from www.blindcanadians.ca
- Gorard, S., & Taylor, C. (2004). *Combining methods in educational and social research*. England: McGraw Hill
- Gourgey, C. (1998). *Music therapy in the treatment of social isolation in visually impaired children*. Retrieved from www.eriec.org/faq/music.html
- Graaf, P., Van der Valk, P., Moll, A. C., Schouten-van Meeteren, A., & Castelijns, Y. (2007). Retinal dysplasia mimicking intraocular tumour: MR imaging findings with histopathologic correlation. *Journal of Neuroradiology*, 28(9), 1731-1733.

- Gray, D. E. (2009). *Doing research in the real world* (2nd ed.). London, England: Sage.
- Greaves, A. (2000). *Special Education 2000: Rhetoric or reform*. Retrieved from www.education.auckland.ac.nz
- Greene, J. C. (2008). Is mixed methods social inquiry a distinctive methodology? *Journal of Mixed Methods Research*, 2(1), 7-22.
- Greene, J. C., & Caracelli, V. J. (1997). *Advances in mixed methods evaluation: The challenges and benefits of integrating diverse paradigms. New directions for evaluation* (pp. 19-32). San Francisco: Jossey-Bass.
- Greene, J. C., Caracelli, V. J., & Graham, W. F. (1989). Toward a conceptual framework for mixed method evaluation design. *Educational Evaluation and Policy Analysis*, 11, 255-274.
- Groenvelde, M. (1993). Effects of visual disability on behaviour and the family. In A. R. Fielder, A. B. Best, & M. C. Bax (Eds.). *The management of visual impairment in childhood*. London: Cambridge University Press.
- Groves, R. M., Fowler, F. J., Couper, M. P., Lepkowski, J. H., Singer, E., & Tourangeau, R. (2013). *Survey methodology* (2nd ed.). New Jersey: Wiley
- Guba, E., & Lincoln, Y. S. (2005). Paradigmatic controversies and emerging confluences. In N. K. Denzin & Y. S. Lincoln (Eds.). *Handbook of qualitative research* (3rd ed.) (pp. 191-216). Thousand Oaks: CA: Sage.
- Guess, D., & Carr, E. (1991). Emergence and maintenance of stereotypy and self-injury. *American Journal of Mental Retardation*, 96, 299-319.
- Gunaratne, L. A. (2001). *Visual impairment: Its effect on cognitive development behaviour*. Retrieved from <http://www.intellectualdisability.info.html>
- Hagopian, L. P., Rooker, G. W., & Rolider, N. U. (2011). Identifying empirically supported treatments for pica in individuals with intellectual disabilities. *Research in Developmental Disabilities*, 32, 2114-2120.

- Hancock, D. R., & Algozzine, B. (2011). *Doing case study research: A practical guide for beginning researchers* (2nd ed.). New York: Teachers College Press.
- Hanley, G. P., Iwata, B. A., & McCord, B. E. (2003). Functional analysis of problem behaviour. *Journal of Applied Behavior Analysis*, 36(2), 147-185.
- Haring, T., & Kennedy, C. (1990). Contextual control of problem behaviour in students with severe disabilities. *Journal of Applied Behavior Analysis*, 23, 235-243.
- Harrits, G. S. (2011). More than method? A discussion of paradigm differences within mixed methods research. *Journal of Mixed Methods Research*, 5, 150.
- Hartnett, M. E. (2013). *Paediatric Retina*. Philadelphia: Lippincott, Williams & Wilkins.
- Harwell, M. R. (2011). Research design in qualitative/quantitative mixed methods. In C. F. Conrad & R. C. Serlin (Eds.), *The Sage handbook for research in education* (2nd ed.). CA: Sage.
- Hatlen, P. (1996). The core curriculum for blind and visually impaired students including those with disabilities. *Re:-View*, 28(1), 25-32.
- Hayman, A. (1972). *Some developmental problems in blind babies and toddlers*. Paper presented at Leonard Conference on Research into the Visually Handicapped. Cambridge, England: Cambridge University, 125-130.
- Hegarty, S. (2001). Inclusive education: A case to answer. *Journal of Moral Education*, 30(3), 243-249.
- Heinemann, M., Nolan, M., Presley, J., De Turo, L., Roberson, W., & Dunlap, G. (1999). *Facilitators guide: Positive behavioural support: Positive behavioural support project*. Florida: Department of Education.
- Higgins, N., Phillips, H., Cowan, C., & Tikao, K. (2009). New Zealand educational services for kapo (blind) Maori: What are the issues for kapo Maori and their family. *Children's Issues*, 13(1).
- Holland, L. (1971). How to deal with blindisms. *Long Cane News*, 4(5), 24-27.

- Hollander, E., King, A., Delaney, K., Smith, C. J., & Silverman, J. M. (2003). Obsessive-compulsive behaviours in parents of multiplex autism families. *Psychiatry Research* 117(1), 11-16.
- Hoshmand, L. T. (1975). Blindisms: Some observations and propositions. *Education of the Visually Handicapped*, 7(2), 56-60.
- Huang, K. P., Wang, C. H., Tseng, M. C., & Wang, K. Y. (2010). A study on entrepreneurial orientation and resource acquisition. The effects of social capital. *African Journal of Business Management*, 4(15), 3226-3231.
- Hussein, A. (2009). The use of triangulation in social sciences research: Can qualitative and quantitative methods be combined? *Journal of Comparative Social Work*, 2009/1.
- Ijichi, C. L., Collins, L. M., & Elwood, R. W. (2013). Evidence for the role of personality in stereotypy predisposition. *Animal Behaviour*, 85, 1145-1151.
- Iwata, B., Dorsey, M., Slifer, K., Bauman, K., & Richman, G. (1994). Towards a functional analysis of self-injury. *Journal of Applied Behavior Analysis*, 27, 197-209.
- Iwata, B., Wallace, M., Kahng, S., Lindberg, J., Roscoe, E., & Connors, J. et al., (2000). Skill acquisition in the implementation of functional analysis methodology. *Journal of Applied Behavior Analysis*, 33, 181-194.
- Jan, J. E., Freeman, R. D., & Scott, E. P. (1977). Stereotyped behaviour. *Visual impairment in children and adolescents*. New York: Grune and Stratton Inc.
- Jan, J. E., Freeman, R. D., McCormick, A. Q., Scott, E. P., Robertson, W. D., & Newman, D. E. (1983). Eye pressing by visually impaired children. *Developmental Medicine and Child Neurology*, 25, 755-762.
- Jan, J. E., Good, W. V., Freeman, R. D., & Espezel, H. (1994). Eye-poking. *Developmental Medicine and Child Neurology*, 36, 321-325.

- Jan, J. E., Groenvelt, M., & Connolly, M. B. (1990). Head shaking by visually impaired children: A voluntary neurovisual adaptation which can be confused with Spasmus Nutans. *Developmental Medicine and Child Neurology*, 36, 321-325.
- Jankovic, J., Madisetty, J., Vuong, K. D. (2004). Essential tremor among children. *Pediatrics*, 114:1203-1205.
- Johnson, R., & Christensen, L. (2012). *Educational research: Quantitative, qualitative and mixed approaches* (4th ed.). London: Sage
- Johnson, R. B., & Onwuegbuzie, A. J. (2004). Mixed methods research: A research paradigm whose time has come. *Educational Researcher*, 33(7), 14-26
- Jolivet, K., Scott, T. M., & Nelson, M. (2000). *The link between functional behaviour assessments (FBAs) and behavioural intervention plans (BIPs)*. Retrieved from <http://www.scholarnet.com/ERICDigestE592,EDO-00-1>.
- Jordan, R. (1996). *Autism and Visual Impairment Conference*, Edinburgh. Retrieved from <http://www.ssc.education.html>
- Kauffman, J. (1997). *Characteristics of emotional and behavioural disorders of children and youth* (6th ed.). Upper Saddle River, NJ: Prentice-Hall.
- Kearney, A. C. (2009). *Barriers to school inclusion: An investigation into the exclusion of disabled students from and within New Zealand schools*. Palmerston North: Massey University.
- Keefe, J. (2004). Childhood vision impairment. *British Journal of Ophthalmology*, 88, 728- 729.
- Kekelis, L. S., & Prinz, P. M. (1996). Blind and sighted children with their mothers: The development of discourse skills. *Journal of Visual Impairment and Blindness*, 90(6), 423-436.
- Kennedy, C. H. (2007). In P. Sturmey (Ed.). *Functional analysis in clinic treatment*. New York: Impact Academic Press.

- Kennedy, C. H., Meyer, K., Knowles, T., & Shukla, S. (2000). Analysing the multiple functions of stereotypical behaviour for students with autism: Implications for assessment and treatment. *Journal of Applied Behavior Analysis*, 33, 559-571.
- Kerr, M., Gil-Nagel, A., Glunn, M., Mula, M., Thompson, R., & Zuberi, S. M. (2013). Treatment of behavioural problems in intellectually disabled patients with epilepsy. *Epilepsia*, 54(1), 34-40.
- Knight, J. J. (1972). Mannerisms in the congenitally blind child. *New Outlook*, 9, 297-302.
- Koegel, R. & Covert, A. (1972). The relationship of self-stimulation to learning in autistic children. *Journal of Applied Behavior Analysis*, 5, 381-387
- Koegel, R. L., Firestone, P. B., Kramme, J. W., & Dunlap, G. (1979). Increasing spontaneous play by suppressing self-stimulation to learning in autistic children. *Journal of Applied Behavior Analysis*, 10, 311.
- Koegel, R. L. & Koegel, L. K. (1989). Community-referenced research on self-stimulation. In E. Cipani (Ed.), *The treatment of severe behaviour disorders* (pp. 129-150). Washington DC: American Association on Mental Retardation.
- LaGrow, S. J. & Repp, A. C. (1984). Stereotypic responding: A review of intervention research. *American Journal of Mental Deficiency*, 8(6), 595-609.
- Lancioni, G. E., Sheets, P. M., Ceccarani, P. S., Capodaglio, L., & Campanari, G. (1984). Effects of gross motor activities on the severe self-injurious tantrums of multi-handicapped individuals. *Applied Research in Mental Retardation*, 5, 471-482.
- Lang, R., O'Reilly, M., Sigafoos, J., Lancioni, G. E., Machalicek, W., Rispoli, M., & Fragale, C. (2010). The effects of an abolishing operation intervention component on play skills, challenging behavior and stereotypy. *Behaviour Modification*, 33, 267-289.
- Langen, M., Durston, S., Kas, M. J. H., van Engeland, H., & Staal, W. G. (2011). The neurobiology of repetitive behaviour....and men. *Neuroscience and Biobehavioural Reviews*, 35, 356-365.

- Lanovaz, M. J. (2011). Towards a comprehensive model of stereotypy: Integrating operant and neurobiological interpretations. *Research in Developmental Disabilities, 32*, 447-455.
- Lanovaz, M. J., & Sladeczek, I. E. (2011). Vocal stereotypy in children with autism: Structural characteristics, variability and effects of auditory stimulation. *Research in Autism Spectrum Disorders, 5*, 1159-1168.
- LeJune, B. J. (2006). *Eye-poking: Review of literature*. Retrieved from www.tsbvi.edu/instructions/resources.html
- Leonhardt, M. (1990). Stereotypes: A preliminary report on mannerisms and blindisms. *Journal of Visual Impairment and Blindness, 84*(5), 216-218.
- Liaupsin, C. J., Scott, T. M., & Nelson, C. M., (2000). *Functional behavioural assessment: An interactive training manual*. (2nd ed.). Longmont, CO: Sopris West.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage.
- Lincoln, Y. S. (1995). Emerging criteria for quality in qualitative and interpretive research. *Qualitative Inquiry, 3*, 275-289.
- Lincoln, Y. S. (2010). What a long, strange trip it's been ... 25 years of qualitative and new paradigm research. *Qualitative Inquiry, 16*, 3-9.
- Lincoln Y. S., & Guba E. G. (2000). Paradigmatic controversies, contradictions and emerging confluences. In N. K. Denzin and Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed.) (pp. 163-188). Thousand Oaks, CA: Sage.
- Lindsay, G. (2003). Inclusive education: A critical perspective. *British Journal of Special Education, 30*(1), 3-12.
- Lipsky, D. K., & Gartner, A. (1999). Inclusive education: A requirement of a democratic society. In H. Daniels and P. Garner (Eds.), *World yearbook of education*. Inclusive Education, London: Kogan Page.

- Loots, G., Devise, I., & Sermijn, J. (2003). The interaction between mothers and their visually impaired infants: An inter-subjective development perspective. *Journal of Visual Impairment and Blindness*, 97(7), 403-417.
- Lourie, R. S. (1949). The role of rhythmic patterns in childhood. *American Journal of Psychiatry*, 105, 653-660.
- Lovaas, O. I., Litrownick, A., & Mann, R. (1971). Response latencies to auditory stimuli in autistic children engaged in self-stimulatory behaviour. *Behaviour Research and Therapy*, 9, 39-49.
- Lovaas, O., Newsom, C., & Hickman, C. (1987). Self-stimulatory behaviour and perceptual reinforcement. *Journal of Applied Behavior Analysis*, 20, 45-68.
- Lowenfeld, B. (1971). *Blindisms: Consequences of environmental deprivation: Our blind children, growing and learning with them* (3rd ed.). Springfield, Illinois: Charles Thomas.
- Lowry, M., & Sovner, R. (1991). The functional existence of problem behaviour: A key to effective treatment. *The Habilitative Mental Health Care Newsletter*, 10, 59-63.
- Luiselli, J. (1994). Effects of non-contingent sensory reinforcement on stereotypic behaviours in a child with post-traumatic neurological impairment. *Journal of Behavior Therapy and Experimental Psychiatry*, 25, 435-330.
- Luiselli J. K., & Michaud, R. L. (1983). Behavioural treatment of aggression self-injury in developmentally disabled and visually handicapped students. *Journal of Visual Impairment and Blindness*, 77(6), 388-392.
- Luiselli, J. K., Myles, E., Evans, T. P., & Boyce, D. A. (1985). Reinforcement control of severe dysfunctional behaviour of blind, multi-handicapped students. *American Journal of Mental Deficiency*, 90(3), 328-334.
- MacArthur, J. (2009). *Learning better together working towards inclusive education in New Zealand schools*. Wellington, NZ: IHC, 19-27.

- McCallum, B. J., & Sacks, S. (Eds.) (1993). *Santa Clara County social skills curriculum for children with visual impairment*, SSAT-VI. Santa-Clara, CA-SCORE: Regionalisation Project.
- McEvoy, M. A., & Reichle J. (2000). Further consideration of the role of the environment on stereotypic and self-injurious behaviour. *Journal of Early Intervention*, 23(1), 22-23
- McHugh, E., & Lieberman, L. (2003). The impact of developmental factors on stereotypic rocking of children with visual impairments. *Journal of Visual Impairment and Blindness*, 97(8), 453-474.
- McHugh, E., & Pyfer, J. (1999). The development of rocking among blind children. *Journal of Visual Impairment and Blindness*, 93(2), 82-96.
- McIntosh, D. N., Miller, L. J., Shyu, V., & Dunn, W. (1999). *Short sensory profile*. San Antonio, TX: Psychological Corporation.
- McLean, R. (2013). *Tuhoi Whakatauki*, Unpublished Document.
- Maag, J. W., Rutherford, R. B., Wolchik, S. A., & Parks, B. T. (1986). Brief report: Comparison of two short overcorrection procedures on the stereotypic behaviour of autistic children. *Journal of Autism and Developmental Disorders*, 16(1), 83-87
- Male, D. (2003). Challenging behaviour: The perception of teachers of children and young people with severe learning disabilities. *Journal of Research in Special Education Needs* 3(3), 162-171.
- Malekpour, M. (2007). Effects of attachment on bearly and later development. *The British Journal of Development Disabilities*, 53(2), 81-95.
- Mandelbaum, D. E., Stevens, M., Rosenberg, E., Wiznitzer, M. Steinschenider, M., Filipek, P., et al. (2006). Comparison of sensorimotor performance in school-age children with autism, developmental language disorder or low IQ. *Developmental Medicine and Child Neurology*, 48, 33-39.
- Mason, J. (2002). *Qualitative researching* (2nd ed.). London, England: Sage.

- Mercer, J. (2007). The challenges of insider research in educational institutions: Wielding a double-edged sword and resolving delicate dilemmas. *Oxford Review of Education*, 33(1), 1-17.
- Miles, M. B., & Huberman, A. M. (2014). *Qualitative data analysis: An expanded sourcebook*. (3rd ed.). Thousand Oaks, CA: Sage.
- Miller, B. S., & Miller, W. H. (1976). Extinguishing blindisms: A paradigm for intervention. *Education of the Visually Handicapped*, VIII(1), 6-15.
- Miller, J. A., Tansy, M., & Hughes, T. L. (1998). *Functional behavioural assessment: The link between problem behaviour and effective intervention in schools*. Retrieved from <http://www3.interscience.wiley.com>
- Miller, K. D., & Schleim, S. J. (2006). *A community for all children: A guide to inclusion for out of school time*. Retrieved from www.cesncsu.edu/depts
- Miller, L. J., Lane, S. J., Cermak, S. A., Anzalone, M., & Osten, B. (2005). Regulatory-sensory processing disorders in children. In S. I. Greenspan & S. Wieder (Eds.), *Diagnostic manual for infancy and early childhood: Mental health, developmental, regulatory-sensory processing and language disorders and learning challenges (ICDL-DMIC)* (pp. 73-112). Bethesda, MD: Interdisciplinary Council on Developmental and Learning Disorders.
- Ministry of Education. (1988). *Tomorrow's Schools: The reform of educational administration in New Zealand*. Wellington: Department of Education.
- Ministry of Education. (1989a). *National administrative guidelines*. Wellington, Ministry of Education.
- Ministry of Education. (1989b). *Education Act 1989*. Wellington: Ministry of Education.
- Ministry of Education. (1995). *Special education guidelines. Special Education 2000*. Wellington: Ministry of Education.
- Ministry of Education. (2007a). *The New Zealand curriculum*, Wellington: Learning Media.

- Ministry of Education. (2007b). *Whakatauki: Te Marautanga o Aotearoa*. Unpublished Document.
- Ministry of Education (2008). *Ka Hikitea: Managing for success. The Maori education strategy 2008-2012*. Wellington: Ministry of Education.
- Ministry of Education. (2009). *Pasifika education plan 2009–2012*. Wellington: Ministry of Education.
- Ministry of Education. (2009). *The New Zealand curriculum*. Learning Media: Wellington.
- Ministry of Education. (2011). *Collaboration for success: Individual education plans*. Wellington: Ministry of Education.
- Mitchell, D. (2010). *Education that fits: Review of international trends in the education of students with special educational needs*. Retrieved from www.educationcounts.govt.nz
- Mitchell, J. C. (2000). Case and situation analysis. In R. Gomm, M. Hammersley, & P. Foster (Eds.), *Case study method: Key issues, key texts* (pp. 165-186). CA: Thousand Oaks, Sage.
- Mittler, P. (2000). *Working towards inclusive education: Social contexts*. London: David Fulton.
- Molloy, A., & Rowe, F. J. (2011). Manneristic behaviors of visually impaired children. *Strabismus*, 19(3), 77-84.
- Morgan, D. L. (2007). Paradigms lost and pragmatism regained: Methodological implications of combining qualitative and quantitative methods. *Journal of Mixed Methods Research*, (1) 48-76.
- Morningside School (2008). *About us?* Retrieved from www.morningside.co.nz

- Murdoch, H. (1996). Stereotyped behaviours in deaf and hard of hearing children. *American Annals of the Deaf*, 141, 379-386.
- Murdoch, H. (1997). Stereotyped behaviours: How should we think about them? *British Journal of Special Education*, 24, 71-75.
- Murdoch, H. (2013). *Repetitive behaviours in children with sensory impairments and multiple disabilities*. Retrieved from <http://deafblindinternational.org/review>
- Nafstad, A., & Rodbroe, I. (1999). *Co-creating communication: Perspectives on diagnostic education for individuals who are congenitally deaf-blind and Individuals whose impairments may have similar effects*. Aalberg, Denmark: Nord-Press.
- Nagel, G., & Raxworthy, G. (1996). *Stories to tell: Partnership in collaborative research*. Auckland: Special Education
- Neef, N. A., & Iwata, B. A. (1994). Current research on functional analysis methodologies: An introduction. *Journal of Applied Behavior Analysis*, 27, 211-214.
- Newby, P. (2010). *Research methods for education*. New Zealand: Pearson Education Limited.
- Nijhof, G., Joha, D., & Pikelharing, H. (1998). Aspects of stereotypic behaviour among autistic persons: A study of the literature. *British Journal of Developmental Disabilities*, 44, 3-13.
- Nind, M., & Kellett, M. (2002). Responding to individuals with severe learning difficulties and stereotyped behaviour: Challenges for an inclusive era. *Journal of Special Needs Education*, 17(3), 265-282.
- Noor, K. B. M. (2008). Case study: A strategic research methodology. *American Journal of Applied Sciences*, 5(11), 1602-1604.
- Northway, N. (2008). *The role of vision in learning*. Scottish Sensory Centre. Retrieved from <http://ssc.education.ed.ac.uk>

- OFSTED (2006). *Inclusion: Does it matter where pupils are taught?* Retrieved from www.ofsted.gov.uk
- Pagliano, P. J. (2001). *Using a multisensory environment: A practical guide for teachers*. London: David Fulton.
- Pagliano, P. J. (2009). *Success and flow in the multisensory environment*. Workshop presented at Multisensory Environments: Building on Success. London & Manchester: FloRich.
- Parents of the Visually Impaired Inc. (2008). *Vision*. Hamilton: PVINZ.
- Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage.
- Peat, J., Mellis, C., Williams, K., & Xuan, W. (2002). *Health science research: A Handbook of quantitative methods*. London: Sage.
- Pelios, L., Morren, J., Tesch, D., & Axelrod, S. (1999). The impact of functional analysis methodology on treatment choice for self-injurious and aggressive behaviour. *Journal of Applied Behavior Analysis*, 32, 185-195.
- Petersen, A. J. (2012). Imagining the possibilities: Qualitative inquiry at the intersections of race, gender, disability and class. *International Journal of Qualitative Studies in Education*, 25(6).
- Phillips, D. C., & Burbules, N. C. (2000). *Postpositivism and educational research*. Lanham, MD: Rowman and Littlefield.
- Piaget, J. (1955). *The language and thought of the child* (M. Gabain, Trans.). New York: Meridian Books, The Noonday Press. (Original work published 1926)
- Pico, E. (1996). *Study of stereotypes in blind or visually impaired children*. Retrieved from <http://www.icevi.org/publications>
- Prochnow, J. E. (1997). Functional behaviour assessment of children. *Psychological Society Bulletin*, 90, 18-21.

- Rapp, J. T., & Vollmer, T. R. (2005). Stereotypy I: A review of behavioural assessment and treatment. *Research in Developmental Disabilities, 26*, 527-547.
- Raver, S., & Dwyer, R. C. (1986). Using a substitute activity to eliminate eye poking in a 3-year old visually impaired child in the classroom. *The Exceptional Child, 33*, 65-72.
- Rinne, T., & Fairweather, J. (2012). A mixed methods approach: Using cultural modelling and consensus analysis to better understand New Zealand's international innovation performance. *Journal of Mixed Methods Research, 6*, 166-183.
- RNZFB (2008). *Services*. Retrieved from www.rnzfb.org.nz
- Ross, D. B. (1992). *A non-aversive behavioural approach to reducing and controlling hand-mouthing in students with vision impairment who also have multiple disabilities*. Texas: Tech University.
- Roy, F. H. (1967). Ocular auto-stimulation. *American Journal of Ophthalmology, 63*, 1776-1777.
- Rutter, M., Graham, P., & Yule, W. (1970). *Neuropsychiatric study in childhood*. London: Heinemann.
- Sacks, S. Z., & Silberman, R. K. (2000). Social skills. In A. J. Koenig and M. C. Holbrook (Eds.). *Foundations of Education: Instructional Strategies for Teaching Children and Youth with Visual Impairments, 11*. New York: AFB Press.
- Sacks, S. Z., & Wolffe, K. E. (2006). *Teaching social skills to students with visual impairments: From theory to practice*. New York: AFB Press.
- Saemundsen, E., Magnusson, P., Smari, J., & Sigurdardottir, S. (2003). Autism diagnostic interview – revised and the childhood autism rating scale: Convergence and discrepancy in diagnosing autism. *Journal of Autism and Developmental Disorders, 33*(3), 319-328.
- Sallustro, F., & Atwell C. W. (1978). Body rocking, head banging, head rolling in normal children. *Journal of Paediatrics, 93*, 704-708.

- Sapp, W., & Hatlen, P. (2010). The expanded core curriculum: Where we have been, where we are going and how we can get there. *Journal of Visual Impairment and Blindness*, 104(6), 338-348.
- Schleicher, A. (2013). Keynote Address: ACU Graduate Employment Network Conference, Auckland, New Zealand. Retrieved from www.acu.ac.uk
- Schloper, E. (1995). *Parent survival manual*. New York: Plenum Press.
- Scott, D., & Usher, R. (2011). *Researching education: Data, methods and theory in educational enquiry* (2nd ed.). London: Cassell.
- Scott, R. A. (1969). *The making of a blind man: A study of adult socialisation*. New York: Russell Sage Foundation.
- Scott, T. M., Bucalos, A., Liaupsin, C., Nelson, C. M., Jolivet, K., & DeShea, L. (2004). Using functional behaviour assessment in general education settings: Making a case for effectiveness and efficiency. *Behavioural Disorders*, 29(2), 189-201.
- Shabani, D. B., Wilder, D. A., & Flood, W. A. (2001). Reducing stereotypic behaviour through discrimination training: Differential reinforcement of other behaviour and self-monitoring. *Behavioural Interventions*, 16, 279-286.
- Sharkey, W., & Asamoto, P. (2000). Hand gestures of visually impaired and sighted interactants. *Journal of Visual Impairment and Blindness*, 94(9), 549-563.
- Sharp, J. L., Mobley, C., Hammond, C., Withington, C., Drew, S., Stringfield, S., & Stipanovic, N. (2012). A mixed methods sampling methodology for a multisite case study. *Journal of Mixed Methods Research*, 6, 34-54.
- Shavelson, R. J., & Towne, L. (Eds.). (2002). *Scientific research in education*. Washington, DC: National Academy Press.
- Simeonsson R. J. (1979). *The Carolina record of individual behaviour*. Chapel Hill: University of North Carolina.

- Singer, H. S. (2009). Motor stereotypies. *Seminars in Paediatric Neurology*, 16, 77-81.
- Skinner, B. F. (1971). *Beyond freedom and dignity*. Indiana: Hackett.
- Slee, R., & Allan, J. (2005). Excluding the included: A reconsideration of inclusive education. In K. S. J. Rix, M. Nind, & K. Sheehy (Eds.), *Policy and power in inclusive education: Values into practice* (pp. 13-24). London: Routledge-Falmer.
- South, M., Ozonoff, S., & McMahon, W. M. (2005). Repetitive behavior profiles in Asperger syndrome and high-functioning Autism. *Journal of Autism and Developmental Disorders*, 35, 145-158.
- Southwell, C., & Hunt, D. (2011). Untitled work. *RNIB Insight Magazine*.
- Starin, S. (2004). Functional behavioural assessments: What, why, when, where, and who. Retrieved from <http://www.wrightslaw.com/info/discipl.fab.starin.html>
- Statistics NZ. (2008). *Snapshots of New Zealand*. Retrieved from www.stats.govt.nz
- Stone, A. A. (1969). Consciousness: Altered levels in blind retarded children. *American Foundation for the Blind Research Bulletin*, 19, 235-241.
- Strickling, C. (2010). Impact of visual impairment on development. Retrieved from <http://tsbvi.edu/infants>
- Symons, F. J. (2000). Early intervention for early aberrant repetitive behaviour: Possible, plausible, probable? *Journal of Early Intervention*, 23(1), 20-21.
- Tashakkori, A. (2009). Are we there yet? The state of the mixed methods community. *Journal of Mixed Methods Research*, 3, 287-291.
- Tashakkori, A., & Creswell, J. W. (2007). Exploring the nature of research questions in mixed methods research. *Journal of Mixed Methods Research*, 1(3), 207-211.
- Tashakkori, A., & Teddlie, C. (1998). *Mixed methodology: Combining qualitative and quantitative approaches*. Thousand Oaks, CA: Sage.

- Tashakkori, A., & Teddlie, C. (2003a). *Handbook of mixed methods in social and behavioural research*, CA: Thousand Oaks, Sage.
- Tashakkori, A., & Teddlie, C. (2003b). The past and future of mixed methods research: From data triangulation to mixed models design. In A. Tashakkori and C. Teddlie (Eds.), *Handbook of mixed methods in social and behavioural research*. CA: Thousand Oaks, Sage.
- Tashakkori, A., & Teddlie, C. (2010a). *Handbook of mixed methods in social and behavioural research*. (2nd ed.). CA: Thousand Oaks, Sage.
- Tashakkori, A., & Teddlie, C. (2010b). Putting the human back in human research methodology: The researcher in mixed methods research. *Journal of Mixed Methods Research*, 4, 271-277.
- Taylor, A. (1994). Visually disabled people and non-verbal communication. *Focus May 12*. Retrieved from <http://www.rnib.org.uk>
- Thelen, E. (1979). Rhythmical stereotypies in normal human infants. *Animal Behaviour*, 27, 699-715.
- Thelen, E. (1981). Rhythmical behaviour in infancy: An ethological perspective. *Developmental Psychology*, 17, 237-257.
- Thelen, E. (1996). Normal infant stereotypes: A dynamic systems approach. In R. L. Sprague & K. M. Newell (Eds.). *Stereotyped movements: Brain and behaviour relationships* (pp. 139-165). Washington D.C: American Psychological Association.
- Thomas, G., & Loxley, A. (2001). *Deconstructing special education and constructing inclusion*. Buckingham, PA: Open University Press.
- Thurrell, R. J., & Rice, D. G. (1970). Eye rubbing in blind children: Application of a sensory deprivation model. *Exceptional Children*, 36, 325-336.
- Tiger, J. H., Toussaint, K. A., & Kliebert, M. (2009). Rituals and stereotypies. In J. L. Matson (Ed.), *Applied behaviour analysis for children with autism spectrum disorders*, 150-160. New York: Springer.

- Tirosh, E., Schnitzer, M. R., Davidovich, M., & Cohen, A. (1998). Behavioral problems among visually impaired between 6 months and 5 years. *International Journal of Rehabilitation Research*, 21, 63-70.
- Transon, R. E. (1988). Using the feedback band device to control rocking behaviour. *Journal of Visual Impairment and Blindness*, 82, 287-289.
- Troster, H., Brambring, M. (1994). The play behaviour and play materials in blind and sighted infants and preschoolers. *Journal of Visual Impairment and Blindness*, 88(1), 431-432.
- Troster, H., Brambring, M., & Beelmann, A. (1991a). The age dependence of stereotyped behaviours in blind infants and preschoolers. *Child: Care, Health and Development*, 17, 137-157.
- Troster, H., Brambring, M., & Beelmann, A. (1991b). Prevalence and situational causes of stereotyped behaviours in blind infants and preschoolers. *Journal of Abnormal Child Psychology*, 19(5), 569-590.
- Turner, M. A. (1999). Annotation: Repetitive behaviour in autism: A review of psychological research. *Journal of Child Psychology & Psychiatry*, 40, 839-849.
- UNESCO (2009). *Defining an inclusive education agenda: Reflections around the 48th session of the International Conference on Education*. Geneva: UNESCO IBE.
- van Gendt, C. J. (2009). Early intervention and stereotype behaviour. Retrieved from www.icevi-europe.org.
- van Houten, R. (1993). The use of wrist weights to reduce self-injury maintained by sensory reinforcement. *Journal of Applied Behavior Analysis*, 26, 197-203.
- van Teijlingen, E. R., & Hundley, V. (2001). The importance of pilot studies. *Social Research Update*, Winter.
- Vision Education Agency (1999). *Deed and declaration of the charitable trust*. Unpublished Document.

- Warren, A. A. (1994). *Counselling: IV Blindisms*. Retrieved from <http://www.trinity.edu/sensoryimpairment>
- Warren, D. H. (2000). Developmental perspectives: Youth. In B. Silverstone, M. A. Laing, B. P. Rosenthal, & E. L. Faye (Eds.), *The Lighthouse Handbook on Visual Impairment and Vision Rehabilitation* (pp. 325-337). New York: Oxford University Press.
- Wehmeyer, M. L. (1994). Factors related to the expression of typical and atypical repetitive movements of young children with mental retardation. *International Journal of Disability, Development and Education*, 41, 33-49.
- Weisler, N. A., Hanson, R. H., Chamberlain, T. P., & Thompson, T. (1985). Functional taxonomy of stereotypic and self-injurious behaviour. *Mental Retardation*, 23(5), 230-234.
- Weyandt, A. (2011). The effectiveness of specialized applied behaviour analysis (ABA) on daily living skills for individuals with autism and related disorders, ages 8-19. Retrieved from <http://search.proquest.com/docview>
- Whakatauki: *The Warrior Way* (2011). Retrieved from www.warriorsteambulding.com
- Whakatauki: *Nga Tahu*. Retrieved from www.naumaipalace.com
- Wheeldon, J. (2010). Mapping mixed methods research: Methods, measures and meaning. *Journal of Mixed Methods Research*, 4, 87-102.
- Willemsen-Swinkels, S. H. N., Buitelaar, J. K., Dekker, M., & van Engeland, H. (1998). Subtyping stereotypic behaviour in children: The association between stereotypic behaviour, mood, and heart rate. *Journal of Autism and Developmental Disorders*, 28(6).
- Willis, D. M. (1979). The ordinary devoted mother and her blind baby. *The Psychoanalytic Study of the Child*, 34, 31-39.

- Wolff, P. H. (1968). Stereotypic behaviour and development. *The Canadian Psychologist*, 9, 474-484.
- Wolffe, K. E. (1999). *Skills for success: A career education handbook for children and adolescents with visual impairments*. New York: AFB Press.
- Wolffe, K. E. (2000). Career education. In A. J. Koenig and M. C. Hollbook (Eds.). *Foundations of Education: Vol. 2. Instructional Strategies for Teaching Children and Youths with Vision Impairments* (2nd ed.) (pp. 679-719). New York: AFB Press.
- Wolffe, K. E. (2006). Teaching social skills to students with visual impairment. In S. Z. Sacks & K. E. Wolffe (2006), *Teaching social skills to students with visual impairment: From theory to practice*. Retrieved from www.afb.org/socialskills
- World Health Organisation. (2012). *Visual impairment and blindness*. Retrieved from www.who.int/mediacentre.html
- Wylie, K. (2000). *Wylie review of Special Education 2000*. Retrieved from www.educationcounts.govt.nz
- Yin, R. K. (1989). *Applications of case study research* (3rd ed.). Thousand Oaks, CA: Sage.
- Yin, R. K. (2009). *Case study research: Design and methods* (4th ed.). CA: Thousand Oaks, Sage Publications.
- Zentall, S. S., & Zentall, R. R. (1983). Optimal stimulation: A model of disordered activity and performance in normal and deviant children. *Psychology Bulletin*, 94, 446-471.

Appendix A

Dated 19 November 1999

DEED AND DECLARATION OF CHARITABLE TRUST

Between

**THE ROYAL NEW ZEALAND FOUNDATION FOR
THE BLIND
("the Founder")**

AND

**JUDITH ANNE DEVINE,
DAVID HEATHER,
GWENDOLYN ANNE NAGEL
JANE ELIZABETH HOLDEN
JANE LESNEY WELLS**

("the original Trustees")

CONTENTS

1.	DEFINITIONS AND INTERPRETATION.....	262
2.	VESTING OF THE TRUST FUND AND FURTHER GIFTS.....	263
3.	NAME AND REGISTERED OFFICE.....	263
4.	APPLICATION OF INCOME AND CAPITAL	264
5.	THE FOUNDER	264
6.	BOARD OF TRUSTEES.....	265
7.	PROCEEDINGS OF TRUSTEES	267
8.	DELEGATION OF POWERS.....	269
9.	CONTRACTS MANAGER OR EXECUTIVE OFFICERS, AUDITOR AND ACCOUNTS.....	269
10.	TRUSTEES CONFLICT OF DUTIES.....	270
11.	TRUSTEES' POWERS AND DUTIES	270
12.	COMMON SEAL	271
13.	TRUSTEES LIABILITY AND INDEMNITY.....	271
14.	NOTICES	272
15.	VARIATION OF THE TRUST	272
16.	WINDING UP	272
17.	CHARITABLE NATURE OF THE TRUST TO BE PRESERVED	272

THE VISION EDUCATION AGENCY CHARITABLE TRUST

DATED

1999

PARTIES

- (1) **THE ROYAL NEW ZEALAND FOUNDATION FOR THE BLIND**, a body corporate constituted by the Royal New Zealand Foundation for the Blind Act 1963 (*“the Founder”*)
- (2) **JUDITH ANNE DEVINE** of Invercargill, Volunteer Worker, **DAVID HEATHER** of Wellington, Company Director, **GWENDOLYN ANNE NAGEL** of Kaukapakapa, Senior Lecturer Special Education, **JANE ELIZABETH HOLDEN** of Auckland, Chief Executive, **JANE LESNEY WELLS** of Auckland, Deputy Principal, (*“the Trustees”*)

BACKGROUND

- A. The Founder following a process of consultation with a Working Party wishes to establish a charitable trust (*“The Trust”*) for charitable purposes with the general object of allocating and administering funding for the purpose of special education needs for the blind and vision impaired in New Zealand and with specific objectives of developing strategy and policy, and setting the education standards for the providers of services to the blind and vision impaired in New Zealand.
- B. The Trustees have agreed to become Trustees upon the trusts and with and subject to the powers and provisions contained in this Deed.
- C. It is anticipated monies, property and investments may from time to time be paid or transferred to the Trust or held or administered by the Trust.
- D. The Trustees are to hold the Trust Fund upon the trusts and with the powers hereinafter contained.

TERMS OF THIS DEED

1. DEFINITIONS AND INTERPRETATION

- 1.1 **Definitions:** In this Deed unless the context requires otherwise:

“Board” means the Trustees;

“Chairperson” means the chairperson of the Trustees elected pursuant to clause 7.1.

“Charitable Purposes” means every purpose within New Zealand, which in accordance with the law of New Zealand for the time being is charitable.

“Deed” means this document.

“Founder” means the Founder named as a party to this Deed as such and any other person to whom the Founder’s powers are delegated in terms of clauses 5.2 and 5.3.

“Property” shall have the same meaning as in the Trustee Act 1956.

“Resolution” means a resolution passed:

- (a) Where the number of the Trustees is an even number by half the Trustees plus one Trustee; or
- (b) Where the number of Trustees is an uneven number by a simple majority of Trustees,

and such resolutions may be passed in accordance with clause 7.4(d).

“Secretary” means a Secretary (if any) appointed by the Trustees pursuant to clause 7.2 as titular secretary or as an Executive Officer having that role.

“Trust” includes the Trust Fund and the trusts, duties, obligations (including contractual obligations) and rights upon which the Trustees hold the Trust Fund.

“Trustees” means the Trustees for the time being of the Trust, whether original or appointed and, as the context may require, means all, some or any such trustees.

“Trust Fund” means the property and/or funds held by the Trustees on the terms of this Deed and all other moneys, investments and property of any nature or kind which may be vested in, paid to, received, administered or acquired by the Trustees from any source for the purposes of the Trust and the money, investments and property from time to time representing the same and the income arising from it.

- 1.2 **Interpretation:** Headings to clauses shall (unless otherwise specified) be ignored when construing this Deed.

2. VESTING OF THE TRUST FUND AND FURTHER GIFTS

- 2.1 **Trust:** The Trustees acknowledge and declare that they hold the Trust Fund on trust upon the terms and conditions expressed or implied in this Deed.
- 2.2 **Further gifts:** The Trustees shall have the power in their absolute discretion to accept gifts, bequests, legacies or other acquisitions of whatever nature whether conditional or otherwise for the carrying out of the purposes of the Trust and all such gifts, bequests, legacies or acquisitions shall when accepted form part of the Trust Fund, subject in any particular case to the express terms of any such gift or vesting.

3. NAME AND REGISTERED OFFICE

- 3.1 **Name:** The Trust shall be called **“THE VISION EDUCATION AGENCY CHARITABLE TRUST”**.
- 3.2 **Registered office:** The registered office of the Trust shall be at the offices of the Royal New Zealand Foundation for the Blind at 4 Maunsell Road, Parnell, Auckland.
- 3.3 **Changes:** The Trustees, with the prior approval of the Founder, may resolve to change the name of the Trust and/or its registered office.

4. APPLICATION OF INCOME AND CAPITAL

4.1 Charitable Purposes: Subject to the express terms of any particular vesting contract or gift, the Trustees shall use and apply the income and/or the capital of the Trust Fund for Charitable Purposes and the education of the blind and vision impaired in New Zealand as they may from time to time in their absolute discretion determine including without limitation:

- (a) developing, reviewing and ensuring the aspirations of the National Plan for Learners who are Blind and Vision Impaired in New Zealand are achieved
- (b) distributing and administering/allocating funding for the purpose of special education needs
- (c) developing policy and strategies to suit the needs and requirements of the blind and vision impaired
- (d) standard setting and maintenance of education standards by service providers
- (e) assisting parents to make informed choices and advising them of the resources to meet their children's needs
- (f) assessing the various sector needs and supporting evaluative research
- (g) developing and maintaining systems to ensure an up-to-date database of all blind and vision impaired learners is maintained
- (h) developing strategies to support and foster various sector agencies and specialist teachers of learners who are blind and vision impaired to in turn develop the Expanded Core Curriculum
- (i) doing all such other things as in the opinion of the Trustees may be incidental or conducive to the attainment of the objects purposes or activities of the Trust

provided that the foregoing activities are to be conducted only in furtherance of Charitable Purposes and are not to be so construed as to authorise the pursuit of any non-Charitable Purpose.

4.2 Accumulation of income: Subject to the express terms of any vesting contract or gift the Trustees shall not be obliged to pay, apply or distribute pursuant to the terms of this Deed in any particular income or accounting year, the whole of the capital or income of the Trust Fund arising, accruing or available for payment, application or distribution but may accumulate any monies not paid, applied or distributed.

4.3 Payment of accumulations: Subject to the express terms of any vesting contract or gift the Trustees may at any time or times resort to the income accumulations of any preceding year or years and pay, apply and distribute the same as if it were income arising in the year during which it is to be paid, applied or accumulated.

5. THE FOUNDER

5.1 Founder Trustee: The Founder shall have the right to nominate a Trustee who shall hold the office subject only to the rotation provisions set out in clause 6 of this Deed for the duration of the life of the Trust.

- 5.2 **Delegation of Founder's powers:** The Founder may by Deed delegate the Founder's rights and powers under this Deed to either:
- (a) any other person including the Crown (Her Majesty the Queen in right of New Zealand); or
 - (b) the Trustees.
- 5.3 If the Founder delegates the Founder's rights and powers to any other person then such person shall be entitled to exercise the rights and powers which are reserved to the Founder under this Deed including this power of delegation. If the Founder for the time being delegates its powers to the remaining Trustees then all rights and powers vested in terms of this Deed in the Founder shall be extinguished.
6. **BOARD OF TRUSTEES**
- 6.1 **Number of Trustees:** The number of Trustees may change from time to time but shall not be less than 8 nor more than 11.
- 6.2 **Trust Board Representation:** The Board of Trustees is to be made up of the following persons:
- (a) Three nominated/appointed by the Parents of Vision Impaired New Zealand Inc.
 - (b) The nominee of the Founder
 - (c) One appointed by the Minister of Education (should the Minister so desire)
 - (d) One nominated/appointed by the Association of Teachers of Vision Impaired
 - (e) Two nominated/appointed by Maori
 - (f) One nominated/appointed by the Association of Blind Citizens
 - (g) Up to two members if co-opted by the Board by Resolution at its option.
- 6.3 **Term of Office of Trustees:** Each Trustee shall be nominated or appointed to hold office and shall hold office for a three year term, with the exception of co-opted trustees who may be appointed for a determined period of less than three years provided that in order to ensure Trustee continuity the nearest number to one-third of the Trustees (rounded up) shall on or at one year's anniversary of their initial appointment (which shall in the case of the Original Trustees be the date of this Deed) be deemed to resign and if eligible and nominated or appointed may make themselves available for Trusteeship and a further one-third shall be deemed to resign on the same terms at two years' anniversary of their initial appointment with the remaining third subject to the same provision at three years' anniversary of their initial appointment. For the avoidance of doubt and to settle any issue over which Trustees shall be cycled to resign during the first three years of the Trust, the Chairman's ruling, in the absence of agreement of the Board by Resolution shall be final and binding and further for the purposes of Trustee rotation should any Trustee replace a Trustee who has ceased to hold office under clause 6.6 of this Deed, that replacement Trustee shall be deemed to have been appointed at the time the Trustee who they have replaced was appointed.

- 6.4 A Trustee may hold office for a maximum of six years plus their initial term of appointment.
- 6.5 **Vacancies in number of Trustees:** The continuing Trustees may act at any time notwithstanding any vacancy in their number and notwithstanding that Board representation may not at any point in time constitute all or any of the categories set out in clause 6.2.
- 6.6 **Cessation of Office:**
- (a) A Trustee shall cease to be a Trustee if he or she:
- (i) resigns as a Trustee by giving (3) months notice of resignation in writing to the remaining Trustees;
 - (ii) becomes of unsound mind, becomes a person in respect of whose affairs an order under the Protection of Personal and Property Rights Act 1988 is made, or otherwise becomes unfit or unable to act as a Trustee;
 - (iii) forfeits his or her seat by failing to comply with the VEA attendance policy of the Board of Trustees;
 - (iv) is removed from office by a Resolution;
 - (v) dies.
- (b) A Trustee to whom clause 6.5(a)(iii) applies shall cease to hold office upon the passing by the Trustees of the Resolution to that effect.
- (c) A Trustee who ceases to hold office in accordance with the provisions of this clause shall cease to be a Trustee of the Trust in all respects except as to the acts and deeds (if any) necessary for the proper vesting of the Trust Fund in the continuing or new Trustees, which acts and deeds shall be done and executed at the expense of the Trust Fund.
- 6.7 Where a Trustee ceases to hold office for any of the reasons set out in clause 6.6 the Trustees shall call upon the nominator or appointor of such Trustee to appoint or nominate a replacement Trustee who shall hold office for the remainder of the term of the Trustee ceasing to hold office. If the relevant appointing body does not or cannot make such an appointment or nomination within a reasonable time or if the business or obligations of the Trust would be impaired or impeded by the non-appointment or nomination then the remaining Trustees shall first use their powers to co-op pursuant to clause 6.2(g) of this Deed and if necessary shall have the further power to nominate further Trustees by simple majority resolution of the continuing Trustees (even in the event of being non-quorate) so that the Trust may continue to operate until such time as nominated or appointed Trustees are available when such co-opted or nominated Trustees shall resign. In exercising their powers under this clause and under clause 6.2(g) the Trustees (or remaining Trustees) are to consider an appropriate balancing of skills and qualifications necessary in Trustees for the effective running of the Trust's affairs and in particular by way of example (but not limitation) and at all times in compliance their legal duties and statutory requirements, gender ethnicity and geographical and/or demographical representation.

- 6.8 **Remuneration of Trustees:** The Trustees shall be entitled to be paid from time to time for their services and reimbursed their expenses in carrying out and attending to the terms of the Trust.

7. PROCEEDINGS OF TRUSTEES

7.1 Chairperson:

- (a) The Trustees shall elect a Trustee to act as Chairperson of their meetings, either from year to year, or for such period as the Trustees may decide.
- (b) The Trustees may also elect a Trustee to act as deputy Chairperson in the absence of the chairperson from time to time, either from year to year or for such period as the Trustees may decide. In the absence of the Chairperson the deputy Chairperson (if elected) shall have and may exercise all of the powers of, and shall perform all the duties, of the Chairperson.

- 7.2 **Executive Officer:** The Trustees shall have power to employ from time to time an executive officer or officers. The Trustees shall have the power to appoint a secretary as a titular secretary who may be a Trustee. It shall however generally be the duty of the Trustees to appoint such officers or to employ such officers who shall keep the usual records of the business of the Trust and who shall undertake all other matters required of an administrative and business nature in terms of this Deed, and by statute or law in the event of incorporation pursuant to the Charitable Trusts Act 1957.

- 7.3 **Minutes:** Minutes of the proceedings of all meetings of the Trustees shall be recorded and shall be signed by the Chairperson of the meeting at which the minutes are confirmed. All minutes purporting to be so signed shall be prima facie evidence of the matters recorded.

7.4 Meetings:

- (a) Meetings of the Trustees shall be held at such intervals, and shall be convened, adjourned, and otherwise regulated in such manner, as the Trustees from time to time think fit provided that notice of any meetings shall be given in writing to the Trustees at their last known advised address (and an address may be a telefax address, an email address or a physical address) at least 48 hours prior to any meeting.
- (b) The Trustees shall in each calendar year hold a meeting as the annual general meeting of the Trust and shall specify the meeting as such in the notice covering the meeting and such meeting shall be held within five months of the end of the financial year of the Trust and notice of such annual general meeting shall be given not less than 7 days prior to such meeting to the Trustees (and without creating any legal obligation to do so to any other interested groups which the Trustees shall advise from time to time) and the notice shall call for any Trustee nominations to be tabled at least 48 hours before that meeting and shall (if not previously notified) stipulate the Trustees who during the first three years of the Trust's existence are deemed to have resigned and those Trustees whose terms of appointment are due to expire. The business of the annual general meeting shall be to consider and approve the annual accounts of the Trust and to consider any other business in respect of which notice is given

in the notice covering the meeting and to accept and confirm any changes in Trusteeship.

- (c) Except as otherwise provided in this Deed and subject to the quorum requirements as to meetings, the Trustees shall exercise their powers and discretions by Resolution.
- (d) A Resolution in writing signed by all the Trustees shall be as valid and effectual as if it had been passed at a meeting of the Trustees duly convened and held. Any such Resolution may consist of several like documents each signed by one or more Trustees. Any such document sent by a Trustee by telex, telegram, email or facsimile shall be deemed to have been duly signed by that Trustee.
- (e) In addition to the provisions for convening meetings of the Trustees from time to time established in accordance with clause 7.4(a) the Founder or any two Trustees who wish to convene a special meeting of Trustees may at any time do so by requesting the Chairperson to convene a special meeting. The Chairperson shall forward to each Trustee then in New Zealand a notice convening the proposed meeting at least seven days before the date of the proposed meeting. The notice shall state the time and place of the meeting and the nature of the business to be transacted.
- (f) The quorum for a meeting of the Trustees shall be a majority of the number of Trustees at the time of the meeting.
- (g) The contemporaneous linking together of the Trustees by telephone or other electronic means of communication (“electronic communication”) shall constitute a meeting of the Trustees and the provisions of this clause as to meetings of the Trustees shall apply to such meetings provided the following conditions are met:
 - (i) each Trustee then in New Zealand shall be entitled to notice of the meeting and to be linked by electronic communication for the purposes of the meeting;
 - (ii) each of the Trustees taking part in the meeting must be able to communicate with each of the other Trustees taking part during the whole of the meeting;
 - (iii) at the commencement of the meeting each Trustee must acknowledge his or her presence for the purpose of a meeting of the Trustees being held by electronic communication;
 - (iv) a Trustee may not withdraw from the meeting unless he or she has previously obtained the express consent of the chairperson of the meeting to do so.
 - (v) a Trustee shall be conclusively presumed to have been present and to have formed part of the quorum of the meeting at all times during the meeting by electronic communication unless he or she has previously obtained the express consent of the chairperson to withdraw from such a meeting;

- (vi) minutes of the proceedings of any such meeting by electronic communication shall be sufficient evidence of the proceedings, and of the observance of all necessary formalities, if certified to be correct by the Chairperson of the meeting.

7.5 Consultation and Reporting

- (a) The Board of Trustees shall where possible and reasonable consult affected parties (and particularly parties providing funding) on major strategy and policy affecting the education of the blind and vision impaired before any major matters are undertaken.
- (b) The Minister of Education and the Founder shall be provided with a copy of the minutes of the proceedings of all meetings of the Board of Trustees.
- (c) The Trustees shall develop and implement a communication and reporting policy the object of which is to adequately advise and inform interested sectors of the vision impaired and blind community of the Trust's roles and functions.

8. DELEGATION OF POWERS

- 8.1 **Delegation to Committees:** The Trustees may delegate to any person or committee, whether or not a Trustee or Trustees, such of the powers of the Trustees as the Trustees may decide by Resolution and may stipulate restrictions or rules by, or within which, powers are to be exercised and may revoke any such delegation, wholly or partly, at any time.

8.2 **Powers of Committees:**

- (a) Any person or committee acting under delegated power shall act in accordance with the terms of this Deed and, in the absence of proof to the contrary, shall also be presumed to be acting within the terms of the delegation.
- (b) Subject to any directions given by the Trustees, any person or committee to which any powers of the Trustees have been delegated may conduct their affairs in such manner as they may from time to time think fit.

9. CONTRACTS MANAGER OR EXECUTIVE OFFICERS, AUDITOR AND ACCOUNTS

- 9.1 The Trustees shall have power to employ or appoint from time to time executive officers. It is the intention that the Trustees shall appoint an executive officer and/or contracts manager whose duties shall be the keeping of usual and proper books of account and to report to the Trustees from time to time on the finances of the Trust and to present annual statements of account for audit and for consideration by the Trustees and that if incorporated under the Charitable Trusts Act 1957 the Trustees shall appoint such officers as are required under that Act.
- 9.2 **Financial Year:** The financial year for the Trust shall end on 30 June each year or such other date as the Trustees, may from time to time resolve.
- 9.3 **Accounting Records and Audit:** The Trustees shall cause accounting records to be kept that correctly record and explain the transactions and affairs of the Trust and that

will at all times enable the true state and condition of the Trust to be ascertained with reasonable accuracy. The Trustees may appoint from time to time a chartered accountant (not being a Trustee) to audit the accounts for the Trust and shall comply with all legal requirements in relation to accounts and accounting including those under the Charitable Trusts Act 1957 if the Trust registers under that Act.

9.4 **Annual Report and Accounts:**

- (a) Prior to each annual general meeting of the Trust the Trustees shall arrange the preparation of the annual report and accounts for the Trust. The report and accounts shall be in such form and specify such particulars as shall be necessary to give a true and fair view of the finances and activities of the Trust but in any event shall include a statement of the assets, liabilities, investments, income, expenditure and distributions of the Trust and any changes to investments since the last annual report and accounts and shall comply with the legal requirements for such accounts.
- (b) A copy of the annual report and accounts shall be provided to the Minister of Education and in a form satisfactory to the Minister in respect of any particular functions of the Trust.

- 9.5 **Bank Account:** The Trustees shall keep an account or accounts of the Trust at such bank or banks as the Trustees may decide. Cheques, withdrawals and authorities shall be signed or endorsed as resolved by the Trustees from time to time.

10. **TRUSTEES CONFLICT OF DUTIES**

- 10.1 **Conflicts:** The Trustees shall be entitled to enter into any contract and to act and exercise all of the powers hereby conferred upon them without being liable to account for any resulting income or profit, notwithstanding that their interests in any private capacity or duties as trustees of any other trust or as shareholders in or directors or officers of any company conflict with their duties as Trustees of the Trust but subject to clause 10.2 and clause 17.2 of this Deed.
- 10.2 **Declaration of Interest:** A Trustee who is in any way, whether directly or indirectly, interested in any matter in terms of clause 10.1 and/or clause 17.2 shall declare the nature of his or her interest at a meeting of the Trustees.
- 10.3 **Voting:** A Trustee, having declared his or her interest in accordance with clause 10.2 shall be counted in the quorum present at the meeting and may witness the affixing of the common seal to any contract or agreement but shall not vote in respect of the matter in which the Trustee is interested.

11. **TRUSTEES' POWERS AND DUTIES**

- 11.1 **Powers:** The Trustees, in relation to the Trust Fund and the income arising from the Trust Fund, shall have all the same powers as a natural person acting as beneficial owner of the property from time to time comprising the Trust Fund and such powers shall not be restricted by any principle of construction or rule of law except to the extent that such is obligatory.

- 11.2 **Examples of Powers:** Without limiting the generality of the preceding paragraph and merely by way of example the Trustees shall have the powers and declare that they will operate within the limitations and constraints set out in the Schedule to this Deed (which may be exercised either alone or jointly with any other person or corporation) recognising the ability, from time to time, of the Trustees to act under clause 15.1 of this Deed.
- 11.3 **Duties:** Notwithstanding the provisions of section 13C of the Trustee Act 1956 and the likelihood that the Trustees will from time to time include persons whose professions, employment or business is or includes acting as a trustee or investing money on behalf of others, it is hereby declared that the care, diligence and skill to be exercised by the Trustees in exercising any power of investment shall not be that required of such persons by section 13C but shall at all times be the care, diligence and skill that a prudent person of business would exercise in managing the affairs of others.

12. COMMON SEAL

- 12.1 **Use of the Common Seal:** If the Trust has a common seal whether by reason of the Trust becoming incorporated under the Charitable Trusts Act 1957 or otherwise the following rules shall apply to its use:
- (a) The common seal shall be in the custody of and under the control of the Trustees;
 - (b) The common seal shall not be affixed to any instrument except pursuant to a resolution of the Trustees and every affixing of the common seal shall be witnessed by either two Trustees or by one Trustee and the Secretary or in lieu of the Secretary by some other person appointed for that purpose by the Trustees.

13. TRUSTEES LIABILITY AND INDEMNITY

- 13.1 **Limited Liability:** No Trustee shall be liable for any loss not attributable to his or her own dishonesty or to the wilful commission by that Trustee of any act known by him or her to be breach of trust.
- 13.2 **Indemnity:** Every Trustee shall be absolutely indemnified out of the Trust Fund for all liabilities incurred by that Trustee in the exercise or attempted exercise of any trust, power, authority or discretion vested in the Trustees and shall have a lien on and may use moneys forming part of the Trust Fund in pursuance of this indemnity.
- 13.3 **Proceedings Against Co-Trustees:** No Trustee shall be bound to take any proceedings against any other Trustee for any breach or alleged breach of trust committed by that Trustee.
- 13.4 **Instructions from the Founder:** Notwithstanding anything to the contrary contained in this Deed or in the Trustee Act 1956, the Trustees shall be under no liability whether in tort, contract, equity or otherwise resulting from the acquisition, retention or disposal by the Trustees of an asset or investment in accordance with instructions given by the Founder, and the Trustees' duties and obligations in terms of the Trustee Act 1956 and in law and in equity shall be reduced accordingly to the intent that this

shall be a limitation and contrary intention in terms of section 13D(1) of the Trustee Act 1956 on the duties imposed on the Trustees.

14. NOTICES

- 14.1 **Service of Notices:** Any notice (but subject to the advice as to the address held pursuant to clause 7.4(a) where by way of example if an email address is given that email address may be utilised) in writing given in terms of this Deed may be delivered personally or sent by ordinary post or faxed or emailed. Notices sent by post shall be deemed to have been received three days after posting.

15. VARIATION OF THE TRUST

- 15.1 **Variation:** The Trustees by Resolution and with the prior written consent of the Founder, shall have the power to enlarge, amend or revoke the powers, authorities and discretions as set forth in this Deed provided no change may be made which would deprive the Trust of its character or nature as a charitable trust for Charitable Purposes.

16. WINDING UP

- 16.1 **Winding up of the Trust:** The Trust may be wound up or dissolved by a Resolution of all Trustees and with the prior approval of the Founder. The net assets of the Trust after payment of all liabilities and costs shall be disposed of by the Trustees by vesting those assets in such manner as shall first be required by any contractual obligation imposed on the Trust and otherwise so as to ensure the assets will be applied exclusively for such Charitable Purposes as the Trustees by Resolution and with the consent of the Founder may in their discretion select.

17. CHARITABLE NATURE OF THE TRUST TO BE PRESERVED

- 17.1 **No Private Pecuniary Profit:** No private pecuniary profit may be made by any person from the Trust, except that:
- (a) any Trustee may receive payment under clause 6.8 and full reimbursement for expenses properly incurred by him or her in connection with his or her position as a Trustee;
 - (b) the Trust may pay reasonable remuneration to any officer to the Trust (whether a Trustee or not) in return for services actually rendered to the Trust;
 - (c) any Trustee may be paid all usual professional, business or trade charges for services rendered, time expended and all acts done by him or her or by any firm or entity of which he or she is a member, employee, or associate in connection with the affairs of the Trust.
 - (d) Any such income paid shall be relative to that which would be paid in an arm's length transaction. The Trustees, in determining all reimbursements, remuneration and charges payable in the terms of this clause, shall ensure that the restrictions imposed by clause 17.2 are strictly observed.

17.2 **Recipient Not to Influence Benefits:** Notwithstanding anything contained or implied in this deed, any person who is:

- (a) a Trustee of the Trust;
- (b) a shareholder or director of any company or a member, nominee or appointee of any board, committee, society or body carrying out the Charitable Purposes of the Trust or which is a recipient or proposed recipient of funds from the Trust;
- (c) a trustee of any trust which is a shareholder of any company or is a member of any board, committee or society carrying out the Charitable Purposes of the Trust; or
- (d) an associated person (as defined by the Income Tax Act 1994) of any such Trustee, trustee, shareholder, director or member;

shall not by virtue of that capacity in any way (whether directly or indirectly) determine, or materially influence in any way the determination of the nature or the amount of any benefit or advantage or income or the circumstances in which it is or is to be received, gained, achieved, afforded or derived by that person or the board committee, society or body which they represent as Trustee.

17.3 **Professional Account and Influence:** A person who in the course of, and as part of the carrying on of, his or her business of a professional public practice shall not, by reason only of his or her rendering professional services to the Trust, or to any company by which any business of the Trust is carried on, be in breach of the terms of this clause 17.

SIGNED by
THE ROYAL NEW ZEALAND
FOUNDATION FOR THE BLIND
as Founder by the affixing of its
common seal in the presence of:

Signature

Witness

Occupation

Address

SIGNED by
JUDITH ANNE DEVINE
as original Trustee
in the presence of:

Signature

Witness

Occupation

Address

SIGNED by
DAVID HEATHER
as original Trustee
in the presence of:

Signature

Witness

Occupation

Address

SIGNED by
GWENDOLYN ANNE NAGEL
as original Trustee
in the presence of:

Signature

Witness

Occupation

Address

SIGNED by
JANE ELIZABETH HOLDEN
as original Trustee
in the presence of:

Signature

Witness

Occupation

Address

SIGNED by
JANE LESNEY WELLS
as original Trustee
in the presence of:

Signature

Witness

Occupation

Address

SIGNED by

as original Trustee
in the presence of:

Signature

Witness

Occupation

Address

SCHEDULE OF TRUSTEES SPECIFIC POWERS

1. Invest:

To invest the Trust Fund or any portion thereof, notwithstanding that it may be subject to any liability, in any property whether in New Zealand or overseas.

2. Sell:

To sell all or any part of the property comprising the Trust Fund at such price on such terms and subject to such conditions as they in their absolute discretion think fit with power to allow the whole or any part of the purchase money to remain owing as a debt to the Trust.

3. Retain Property:

To retain property forming part of the Trust Fund for so long as the Trustees think fit without being liable for any loss thereby resulting to the Trust Fund.

4. Lease:

To lease or to take on lease or licence any property on such terms and subject to such conditions as they think fit and to accept or effect such surrenders of leases and licences as they think fit.

5. Carry on Business:

To carry on any business (whether in partnership or otherwise) in which the Trust Fund may at any time be concerned or interested or for which the assets or any of the assets of the Trust Fund may be adapted for such time or times as the Trustees shall think fit with power in the case of any partnership business to become a partner therein and with further power to use and apply any part of the Trust Fund as capital in such business and remunerate all such managers, agents, servants, clerks, workmen and others as the Trustees shall from time to time think fit. The Trustees shall be absolutely indemnified by and out of the Trust Fund for and in respect of any loss or liability which they may sustain or incur by reason of their so carrying on any such business or businesses as aforesaid.

6. Government Funding and Delegated Functions:

To carry out such functions within the terms of this Trust Deed as any agency whether Government or otherwise may delegate to or contract to the Trust including and not limited to the handling management and disbursement of moneys which by contract or any other means are the responsibility of the Trust to administer and/or distribute and/or pay. Without limiting the generality of the foregoing, any funding which comes into the Trust which is sourced from Governmental sources is deemed to be included in this clause and where the terms of any such Governmental funding or the contract in relation to such funding stipulates or recognises a specific beneficial sector then in addition to any contractual duties to apply the funding to that sector, unless the terms of funding or contract are specifically varied, and in writing, the funding shall be deemed held on trust for that sector. For the avoidance of doubt any funding received for general or non-specific purposes from any sources including Government may be treated and applied by the Trustees within the general terms and discretions set out in this Deed.

7. **Borrow**

To borrow moneys on such terms and subject to such conditions as the Trustees think fit provided that the total borrowings of the Trust shall not at any time exceed the value of the Trust's realisable assets.

8. **Company Shareholdings:**

In respect of any company in which the Trust Fund holds shares notes stock or debentures:-

- (a) To nominate a Trustee or another person approved by Resolution to act as director or directors of such company.
- (b) To provide out of the Trust Fund further capital for such company either by way of advances loans deposits or otherwise (with or without security) or by taking further shares notes stocks or debentures in such company and in any case upon such terms as the Trustees think fit.
- (c) To concur on such terms as the Trustees think fit in any reconstruction or amalgamation of any company in which the Trustees hold shares notes stock or debentures or in any modification of the rights of the shareholders or others interested therein.
- (d) Generally to act in respect of any such company in such manner as the Trustees in their absolute discretion shall deem to be in the interests of the Trust Fund.

9. **Promote Companies and Seek Incorporation:**

To promote or form any company, trust, incorporated society or body or join in so doing for the purpose of its acquiring any property which or an interest in which forms part of the Trust Fund or acquiring the property of any company in which the Trustees hold shares notes stock or debentures and to sell or concur in selling any property in exchange for shares, notes, stock, debentures or other interests in any company upon such terms and conditions as the Trustees may think fit. The Trustees may seek to incorporate pursuant to the Charitable Trusts Act 1957.

10. **Determine Capital and Income:**

To determine whether any money for the purposes of the Trust is to be considered as income or capital and what expenses ought to be paid out of income and capital respectively and also to apportion blended funds.

11. **Maintain and Improve Property:**

Generally to maintain manage repair improve and develop any property which or an interest in which for the time being forms part of the Trust Fund in such manner as the Trustees shall think fit.

12. **Employ:**

To employ and pay any person firm company or corporation (including any Trustee) to do any act of whatever nature relating to the Trust or the administration thereof without being liable for loss incurred thereby.

13. **Guarantee:**

To guarantee the liability of any person or corporation and to give security in support of any such guarantee.

14. **Bank Accounts:**

To open an account or accounts at any time or times in any name or names and either on their own behalf or jointly with another at any bank and to overdraw any such account with or without giving security and in addition to the powers conferred by Section 81 of the Trustee Act 1956 to make arrangements with any Bank for the persons set out in clause 9.5 of the Deed to operate upon any account at that Bank.

15. **Insurance:**

To insure against loss or damage by any cause whatsoever any insurable property to any amount not exceeding the full insurable value thereof or the full replacement value thereof as the Trustees may in their absolute discretion from time to time think fit.

16. **Maintenance Contracts:**

To enter into contracts of any nature whatsoever for the purpose of protecting maintaining or enhancing the value of all or any assets acquired or held by the Trustees or which the Trustees have the right to acquire or hold.

17. **Prescribe Rules:**

To prescribe and alter further rules for the operation, management and administration of the Trust, the meetings of the Trustees, the mode of convening the same, the conduct of business and otherwise as the Trustees should deem expedient.

18. **Other Powers:**

To do such other acts and things as the Trustees may in their absolute discretion consider incidental or conducive to the attainment of the general purposes of the Trust.

Appendix B

Establishment of National Database **A Discussion Paper**

January 2001

Establishment of National Database

A Discussion Paper

Pilot Study

The pilot study is coming to an end with the collection of data from the first two regions nearly completed; the development of the database software by Phil Nixon; the trialling of the software is underway; entry of the data is in progress. Analysis of the data collected to date is still to be carried out and a full report outlining all aspects of the pilot study is to be prepared and presented to the Ministry and Board once each of these tasks is completed.

Second Phase of Database Establishment

It is appropriate to begin to scope out the next phase of the development of the database. The targets are to:

- Complete the first round of initial data gathering by the end of December 2001;
- Review all data on a biannual basis.

Who should be completing or facilitating the completion of the questionnaires?

There are many factors that need to be considered when determining who carries out the data gathering. In planning a range of possible options for the next phase several key issues arise:

- Consistency of process
- Time involved
- Distance involved

Consistency of Process

Concern	Possible Solutions
<ul style="list-style-type: none">• Different people interpret material differently.• The more people involved the greater the variables.• Perception can influence responses i.e. parent or staff perceptions may be different	<ul style="list-style-type: none">• Training for those collecting data.• Limit the number of people involved in data collection.• Design written guidelines for administration.• Determine which questions can/should be completed by administrative staff &/or senior teacher.• Attempt to reduce or eliminate questions that are subjective. If deemed appropriate for inclusion stipulate who is to respond.

Time involved

Concern	Possible Solutions
<ul style="list-style-type: none">• In pilot study time involved was too short.• Time spent on this takes a high level of commitment from Centre staff.• Does Ministry expectation match that of the VEA?	<ul style="list-style-type: none">• Pace out the initial round and review to a time frame that more realistically reflects the task requirements.• Increasing the number of people involved in data collection may reduce time.• If VEA staff worked in collaboration with RTVs and administration staff this would reduce load on Centres.• Check with Ministry re time frame.• Report back to Ministry on the initial findings of Pilot study.

Distance involved

Concern	Possible Solutions
<ul style="list-style-type: none">• Access to all families given distance / geography throughout some areas of New Zealand.• Cost involved in travel over such a wide area.• Distance and geography impact on time taken to consult with families.	<ul style="list-style-type: none">• Utilise existing contacts i.e. RTV contacts.• VRCs /SRCs will need to be informed well ahead of time re dates for data collection to co-ordinate visits with data collection.• Working in with RTVs would cut down on costs.• Work through which questions can be completed by the Centre and which by the family.

In the pilot study the VEA carried out the simultaneous gathering of data in two separate regions. Prior to working in the field a consistent approach was agreed upon. However some differences in the process emerged once data gathering commenced. These differences alerted the Agency to issues that would need to be addressed when redesigning the questionnaire and developing training packages. For example it is necessary to be specific about the level of parental input in relation to different sections of the questionnaire.

Terminology

Within each of the options the words preparation, data gathering, data entry and data analysis are referred to in this context they refer to the following activities:

Preparation

This includes such activities as:

- Production of Consent forms;
- Production of questionnaires;
- Mail out of consent forms to all families;
- Initial contact with the local VRC / SRC and the local parent group;
- VRC / SRC staff training for those collecting the data, if this is deemed the appropriate method of collection;
- Planning with local VRCs / SRCs re strategies for targeting total population;
- Negotiating processes for gathering entry and exit data after the first round.;
- Mail out of questionnaires to local centres;
- Checking that consent forms have been received;
- Secure storage of completed consent forms.

Data Gathering

This includes tasks such as:

- Checking that consent forms have been received;
- The actual completion of the questionnaires by families in conjunction with the Resource Teacher Vision (RTV) and administrative staff;
(This is discussed further in later sections.)
- The checking that total population has been covered;
- Secure storage of both completed consent forms and questionnaires;
- The safe return of this information to the VEA.

Data Entry

This occurs when the written material on the questionnaires is entered onto a specifically designed software package. It is envisaged that an employee of the VEA who has high-level computer skills in data entry would carry out this task.

Data Analysis

Occurs when the data that is gathered is sifted and sorted to discover information about this population of learners. It is possible through analysis to identify trends, strengths and weaknesses thereby allowing for better targeting of the resources available to the sector and to advocate more strongly on the basis of documented evidence.

Options

In developing this phase it is beneficial to explore a range of alternative ways forward. In this paper four distinct options are outlined.

Option 1:

This option rotates a four-step sequence of preparation, collection, entry and analysis of data. It does this region by region and aims to commence with the larger regions, acknowledging the time larger amounts of data will take to process. It operates on a monthly cycle. Gathering and updating of data is carried out on a region-by-region basis.

Option 2:

This option follows a process very similar to Option 1 but treats Auckland, given the large population, as four separate units and spreads the workload that that will generate throughout the first year. At this stage Auckland has been divided into Auckland 1, 2, 3, and 4 no detail is given to the areas or services they represent as consultation has as yet to take place with the various service providers. This Option also removes the analysis of data from this phase and focuses primarily on the collection and entry of data. In this option data analysis would commence in 2002.

Option 3:

This option unlike the first two devolves the responsibility of data collection totally to the VRC / SRC level and places the Agency in the role of co-ordinator, facilitator and trainer. In this option the VEA moves to its future role as the recipient rather than the gatherer of the data. It would therefore need to place a greater emphasis on training staff. In this option data can be gathered in several areas in the same time frame. Two possible schedules are presented one working on all areas of Auckland at one time the other spreading the Auckland gathering across the year. A small stipend may be made available in this option, contingent on the completion of the data gathering.

Option 4:

This option along with Options 1 and 2 acknowledges that not all Centres have the same capacity to respond to an opportunity such as that presented in Option 3. It provides Centres the opportunity to select the option that best fits their available resource. Centres are able to choose between gathering data on the Agencies behalf or with the assistance of the Agency.

The following pages outlines, in broad terms, the four options in greater detail. Each option will be developed with reference to its time schedule, preparation involved, method of data gathering with particular reference to who is involved in the process, data entry, and data analysis in terms of time frame.

In developing all of the options three key aspects have been considered in formulating the plan for the second phase of this project. Firstly, the time frame, one year has been set aside to establish the database. Secondly, the continuous nature of the task and the impact this has on the workload of the VEA staff and level of commitment of Centre staff. Thirdly, the purpose of the database is to provide up to date information to the Ministry in a timely and accurate manner. This paper attempts to describe how these aspects will be addressed within each of these options.

Option 1

This option seeks to address the three key aspects by firstly, addressing the issue of timing, Table 1 outlines a possible timeframe for the initial data gathering and subsequent data reviews, and secondly Table 2 outlines the continuous nature of the task and proposes a schedule that would allow for different tasks to be occurring within the same time frame. This would allow for a spread of workload for VEA and sector staff, also predictability of the process for VRC/SRC staff and families. It would also address the third aspect and provide a degree of consistency in the timeliness, and in turn the accuracy, of information being presented to the Ministry. In any month the oldest data would be six months out of date and the newest would be less than a month out of date.

Table 1 Indicating schedule of data gathering for each Region.

Centre	Initial Data Gathered	1st biannual review	2 nd biannual review
Southland	December 2000	June 2001	December 2002
Palmerston North	January 2001	July 2001	January 2002
	February 2001	August 2001	February 2002
Auckland	March 2001	September 2001	March 2002
Nelson	April 2001	October 2001	April 2002
Christchurch	May 2001	November 2001	May 2002
Tauranga	June 2001	December 2001	June 2002
Hamilton	July 2001	January 2002	July 2002
Wellington	August 2001	February 2002	August 2002
Dunedin	September 2001	March 2002	September 2002
Gisborne	October 2001	April 2002	October 2002
Napier	November 2001	May 2002	November 2002
New Plymouth	December 2001	June 2002	December 2002

This initial rotation has been mapped to indicate a pathway for achieving the establishment of the database within a one-year time frame. A further breakdown of how this process will be worked through is laid out in Table 2. It would be possible to move to a biannual schedule of delivery as outlined in Table 4 at any time after the completion of the first round. For example from 2002/3 onwards all Centres could be expected to provide data to the VEA at the end of March and the end of September.

Table 2 A schedule of work broken into monthly task allocations.

The columns indicate the month in which the task will occur. The process is broken down into four steps: Preparation; Data Gathering; Data Entry and Data Analysis

Key: Bold text indicates the Initial Round of data gathering.

Plain text indicates the first Update Round of data gathering.
This is scheduled to occur six months after the Initial Round.

Italics text indicates the second Update Round of data gathering.
This is scheduled to occur a year after the initial round.

Option 1 (continued)

Table 2 A schedule of work broken into monthly task allocations.

Month	Preparation	Data Gathering	Data Entry	Data Analysis
November2000	Southland PalmerstonNth			
December2000		Southland PalmerstonNth		
<i>January2001</i>				
February	Auckland		Southland PalmerstonNth	
March	Nelson	Auckland		Southland PalmerstonNth
April	Christchurch	Nelson	Auckland	
May	Tauranga	Christchurch	Nelson	Auckland
	Southland PalmerstonNth			
June	Hamilton	Tauranga	Christchurch	Nelson
		Southland PalmerstonNth		
July	Wellington	Hamilton	Tauranga	Christchurch
			Southland PalmerstonNth	
August	Dunedin	Wellington	Hamilton	Tauranga
	Auckland			Southland PalmerstonNth
September	Gisborne	Dunedin	Wellington	Hamilton
	Nelson	Auckland	Auckland	
October	Napier	Gisborne	Dunedin	Wellington
	Christchurch	Nelson	Nelson	Auckland
November	New Plymouth	<i>Napier</i>	<i>Napier</i>	<i>Dunedin</i>
	Tauranga	Christchurch	Christchurch	Nelson
<i>December</i>		<i>New Plymouth</i>		<i>Napier</i>
	<i>Hamilton</i>	Tauranga	Tauranga	Christchurch
	Southland etc Palmerston Nth			

January 2002			New Plymouth	
	Wellington	Hamilton		New Plymouth
		Southland etc Palmerston Nth		
Feb	Dunedin	Wellington	Hamilton	
			Southland etc Palmerston Nth	
March	Gisborne	Dunedin	Wellington	Hamilton
				Southland etc Palmerston Nth
April	Napier	Gisborne	Dunedin	Wellington
May	New Plymouth	Napier	Gisborne	Dunedin
June		New Plymouth	Napier	Gisborne
July			New Plymouth	Napier
August				New Plymouth
September				

In this option the process of data collection, entry and analysis follows a cyclic pattern. By June 2002 all Centres are completed the 1st Update Round. It would also be possible with this option to move to a biannual review at the beginning of either 2002 or 2003. Table 4 provides an alternative option for this.

Detailed Explanation of Table 2

Table 2 contains five columns:

Month	Preparation	Data Gathering	Data Entry	Data Analysis
-------	-------------	----------------	------------	---------------

Month

This indicates the month in which any task is occurring within any centre.

e.g.

May	Tauranga	Christchurch	Nelson	Auckland
	Southland PalmerstonNth			

In May 2001 the VEA will be:

- Preparing to collect data from Tauranga.
- Preparing to collect update data from Southland and Palmerston North.
- Gathering Data from Elmwood VRC based in Christchurch.
- Entering the data previously collected from Nelson VRC.
- Analysing the data from Auckland.

The schedule is planned over a 12 month calendar with the realisation that data collection over the December / January period may have to be flexible given the changes in term dates and the pressures on families and staff at that time of year in New Zealand.

Option 1

Preparation

Most of the tasks list in the terminology section would apply to this option. Discussion would need to take place in each Centre around who is to be involved in facilitating the efficient gathering of information. The varying size and geographic spread makes it impossible for the two VEA staff members to be involved in data gathering, especially in areas with a very high population. Therefore training may need to be included.

Data Gathering

It is envisaged that given the size of the population in some of the Regions, especially Auckland, it would be necessary to engage the assistance of the service providers. In Auckland this would involve the Visual Resource Centre, Homai and Manurewa High.

Data Entry

A month has been allowed for this in the initial rounds due to the volume of data and the importance, in all phases of collection, for accuracy and coverage of the total population. Overtime this process may speed up and the time frame be reduced.

Data Analysis

This task will no doubt be ongoing depending on Ministry requirements. The time frame for review would ensure that no data is out of date by more than six months. In the initially phases data could only be analysed region by region as information came on line. Once all data is in analysis will be able to occur across the sector at any given time as well as trends in each region could be ascertained as new data is entered.

Reservations relating to Option 1

The workload given the enormity of the task especially in the Auckland Region gives rise for some concern.

Option 2

This option adopts the same cyclic approach as Option 1 but reallocates the volume of work generated by Auckland and removes the component of analysis from the first round placing the emphasis on data gathering.

Table 2 *A schedule of work for broken into monthly task allocations*

Month	Preparation	Data Gathering	Data Entry
November2000	Southland PalmerstonNth		
December2000		Southland PalmerstonNth	
<i>January2001</i>			Southland PalmerstonNth
February	Auckland 1		
March	Nelson Christchurch	Auckland 1	
April	Auckland 2 Tauranga	Nelson Christchurch	Auckland 1
May	Hamilton	<i>Auckland 2 Tauranga</i>	Nelson Christchurch
	Southland PalmerstonNth		
June	Wellington	Hamilton	Auckland 2 Tauranga
		Southland PalmerstonNth	
July	Auckland 3 Dunedin	Wellington	Hamilton
	Auckland 1		Southland PalmerstonNth
August	Gisborne	Auckland 3 Dunedin	Wellington
	Nelson Christchurch	Auckland 1	
September	Auckland 4 Napier	Gisborne	Auckland 3 Dunedin
	Auckland 2 Tauranga	Nelson Christchurch	Auckland 1
October	NewPlymouth	Auckland 4 Napier	Gisborne
	Hamilton	Auckland 2 Tauranga	Nelson Christchurch
November		<i>NewPlymouth</i>	<i>Auckland 4 Napier</i>

		Hamilton	Auckland 2 Tauranga
December			<i>NewPlymouth</i>
			Hamilton

Refer to Table 4 for a possible schedule for updating once all data is collected .

Option 2

Preparation

In this option the generic aspects of preparation as outlined earlier in the paper will occur. In this option as in Option 1 the process is completed in conjunction with the Agency. Training may need to be arranged if staff other than Agency staff are directly involved in data gathering.

Data Gathering

In larger Centres the volume of work may involve assistance from RTVs and possibly administrative staff, when employed in a Centre. Such arrangements would be decided in consultation with the larger centres. The Agency therefore would either take on a direct roll or one of advice and support to those collecting the data. This option, by spacing the collection of data from Auckland the largest Centre should balance out the flow of data coming in and distribute the workload more evenly across the year.

Data Entry

As with all options the Agency will be responsible for entering the data in the first round.

Data Analysis

In this option data analysis commences in 2002 once the first round of gathering is complete.

Reservations

Nil

Option 3

Option 3 differs from the others in that it devolves the responsibility of data gathering to the local Centres. Each Centre would be contracted to gather the data for their region. The sum offered would of course not reflect the true cost of work involved but be a stipend that seeks to acknowledge, in a small way, the work and co-operation of the Centre for the benefit of the sector. The contract would be deemed completed once all data is gathered and supplied in full to the Agency.

The process would occur over a year but in four distinct time frames that follow the four school terms. This model acknowledges the volume of work that will be generated in Auckland.

Outlined in the Tables are two variations of this option. The first demonstrates a possible schedule that starts with a focus on Auckland. The second spreads the Auckland workload throughout the year.

Table 3a

This option is based on a term-by-term approach and starts with Auckland.

2001	Preparation and Gathering	Entry
Term 1 February March April 6 th	Auckland 1 Auckland 2 Auckland 3 Auckland 4 382 + 54 + 21 = 457	Southland Palmerston North

<i>Term 2</i> April 23 rd May June 29 th	Nelson Christchurch Tauranga Hamilton	39 163 45 <u>111</u> 358	Auckland 1 Auckland 2 Auckland 3 Auckland 4
<i>Term 3</i> July 16 th August September 21 st	Wellington Dunedin Southland Palmerston North	120 56 37 <u>69</u> 282	Nelson Christchurch Tauranga Hamilton
<i>Term 4</i> October 8 th November December 18 th	Gisborne Napier New Plymouth	21 44 <u>43</u> 108	Wellington Dunedin Southland Palmerston North
<i>December</i> <i>January</i>			Gisborne Napier New Plymouth

Option 3 (continued)

Table 3b *This option is based on a term by term approach and spreads the*

Auckland workload across the year.

2001	Preparation and Gathering	Entry
Term 1 February March April 6 th	Auckland 1 ? Nelson 39 Christchurch <u>163</u> 202 + ?	Southland Palmerston North
Term 2 April 23 rd May June 29 th	Auckland 2 ? Tauranga 45 Hamilton 111 Southland <u>37</u> 193 + ?	Auckland 1 Nelson Christchurch
Term 3 July 16 th August September 21 st	Auckland 3 ? Wellington 120 Dunedin 56 Palmerston North <u>69</u> 245+ ?	Auckland 2 Tauranga Hamilton Southland
Term 4 October 8 th November December 18 th	Auckland 4 ? Gisborne 21 Napier 44 NewPlymouth <u>43</u> 108 + ?	Auckland 3 Wellington Dunedin Palmerston Nth
December January		Auckland 4 Gisborne Napier New Plymouth

Preparation

This option offers the standard elements of preparation that are generic to all the options such as production and distribution of consent forms and questionnaires. In this option training is provided to the staff in each centre they will in turn carry out the data gathering independently with the Agency acting an advisory capacity.

Data Gathering

Each itinerant teacher is responsible for the gathering the data on their caseload. This phase would aim to be completed one week before the end of the term in which the contract was initiated.

Data Entry

As for all options Agency staff will enter the data. In this option data entry would occur in the term following the gathering process.

Data Analysis

Data analysis will be carried out by the Agency and will commence once all data is gathered.

Reservations

Training will need to be detailed with prescriptive written guidelines accompanying the questionnaire to ensure minimum deviations in interpretation. Training would need to be occurring for several Centres at the same time. The cost of either Agency representatives travelling to the various locations or pulling all parties in to a central location would need to be considered. The cost of training is a factor both to the Agency and to the Centres. Cost can be interpreted as financial and in terms of workload. The questionnaire will also need to be carefully scrutinised to ensure that there is minimum opportunity for variations in question interpretation or response mechanisms.

Option 4

This option follows exactly the same schedule as Option 3, therefore no table is provided. Where it differs from the previous option is that it also offers Centres the opportunity of declining the stipend in favour of Agency assistance with the process. It has been developed with a desire to address the needs of those Centres that have only one full time staff member. The Agency acknowledges the extra pressures that come to bear on teachers working in this capacity and while some may wish to take up Option 3 the Agency is very aware that there may be a need to provide a higher level of support during the initial round for these Centres.

Preparation

As for Option 3 but Centres that take this Option will organise the timing of the gathering in conjunction with the Agency. The Agency may in fact carry out parts of the generic preparation tasks, this would be negotiated with the Centres RTV.

Data Gathering

The RTV and the Agency representative would work in the field together. The time frame for this would be determined dependent on the size and location of students on the Centres roll.

Data Entry

Data will be entered as per Option 3 through the Agency and in the term following that of data collection.

Data Analysis

Will be carried out once all data is collected and entered.

Reservations

The potential that Centres other than those with only one full time staff member may take up this option. If this occurs the simultaneous workload for the Agency would be potentially unmanageable. This option increases the workload of the Agency staff in that training and supervision will be taking place for, on average three centres and hands on data collection of another one simultaneously. In the fourth term, the Agency may potentially be working hands on with three smaller Centres.

Biannual Update

This table displays a schedule that can fall into place once all data is on the database and the schedule is to be one of Biannual Update. This could commence from 2002 or 2003. This has the potential to be able to be used in relation to any of the options. It would however be necessary, during the transition phase, to accommodate those Centres that may have had recent updates or be over due for an update.

Table 4 *Schedule for Biannual Updating of Data across New Zealand*

February	<i>Preparation</i> Wellington Dunedin Gisborne Napier New Plymouth Southland PalmerstonNth Auckland Nelson Christchurch Tauranga Hamilton			
March	<i>Data Gathering</i> Wellington Dunedin Gisborne Napier New Plymouth Southland PalmerstonNth Auckland Nelson Christchurch Tauranga Hamilton			
April May	<i>Data Entry</i>			
June/ July	<i>Data Analysis</i>			

August	<i>Preparation</i> Wellington Dunedin Gisborne Napier New Plymouth Southland PalmerstonNth Auckland <i>Nelson</i> <i>Christchurch</i> <i>Tauranga</i> <i>Hamilton</i>
September	<i>Data Gathering</i> Wellington Dunedin Gisborne Napier New Plymouth Southland PalmerstonNth Auckland <i>Nelson</i> <i>Christchurch</i> <i>Tauranga</i> <i>Hamilton</i>
October November	<i>Data Entry</i>
December January	<i>Data Analysis</i>

Before moving to this schedule all Centres would need to have and be able to operate efficiently the appropriate software. Mechanisms would also need to be addressed for the efficient management of entry and exit procedures as learners are enrolled or withdrawn from a Centres roll.

This issue also needs to be addressed within the initial round.

Training

A training package needs to be developed as soon as possible as all options require some degree of devolution of responsibility in the data gathering progress due to the time frame and the numbers and geographical spread of the population. It may be advantageous to have other people involved in the training sessions with a view to building a network of support for the process. In various communities people may, because of their mana / status be in a position of gatekeeper. Involving such people in the process will improve the quantity of access and quality of data. The RNZFB Whanau Worker would be an obvious case in question.

Costing

Costs are incurred in all phases and steps of the process. At this stage detailed costing can not be determined until a way forward is decided upon but costs may be incurred in the following areas.

Preparation

In this area there is the cost of paper, photocopying, postage, clerical work, communication and training. The last two may well involve travel the cost of which

would vary dependent on the option selected and the method of delivering the training.

Gathering

This may involve a payment of a stipend as in Options 3 and 4 to Centres that opt to collect data on behalf of the Agency. There will also be travel costs for Agency staff if they are working alongside Centres.

Entry

All options involve the same total volume of data and therefore would incur the same costs in data entry.

Analysis

Data analysis while falling into the realms of the Agencies research contract may also incur extra costs if analysis tools such as NUDIST or SSAS? are involved.

Biannual Update Phase

In this phase each Centre requires the software package that is being used by the Agency if it is to become a partner in the maintaining the database. Centre staff, especially administrative staff if they are employed by the Centre, will need training to ensure efficient use of the software.

In Summary

There is no one correct way of completing this task as the issues involved are complex and the impact of the process on each region varies greatly according to the roll number, number of staff, level of administrative support, willingness of staff to participate, location of each regions Visual or Sensory Centre, and the distribution of the roll across each region.

The Agency realises that the first round, given the volume of data to be collected and entered, will be more time consuming than future updates and additions. Also consideration has been given to ensure that the other duties of the Vision Education Agency are accommodated within staff workloads. Also the commitment of Centre staff to accommodate this additional workload is valued and appreciated.

In scoping out these options it has become evident that the work involved in gathering all of the data in the first round and in light of the other duties of the Agency, appears to outweigh the Agency's ability to carry out any analysis until the first round is complete and Centres are equipped to take over the role of gathering and updating data. There is also concern that the data is of little value on a National level until all data is in, especially given the heterogeneous nature of this low incidence population.

The options presented outline the utilisation of a small range of strategies. They touch on issues such as size of Centre, timing of the process and the ability to analyse data. The possible permutations are endless, this paper set out to highlight a small range to generate ideas and initiate some possible pathways forward.

Next Steps

1. Share these options with other VEA staff and seek feedback.
2. Consult with the sector either by presenting possible options to a cross section of the sector or to the whole sector to gauge the range of response.
3. Determine a way forward.
4. Start the process.

While working through these issues it is possible to continue to develop:

1. Refine the questionnaire.
2. A training package for data gathering.

Establishment of National Database

Pilot Study

The pilot study is coming to an end with the collection of data from the first two regions nearly completed; the development of the database software by Phil Nixon; the trialling of the software is underway; entry of the data is in progress. Analysis of the data collected to date is still to be carried out and a full report outlining all aspects of the pilot study is to be prepared and presented to the Ministry and Board once each of these tasks is completed.

Second Phase of Database Establishment

It is appropriate to begin to scope out the next phase of the development of the database. The targets are to:

- Complete the first round of initial data gathering by the end of November 2001;
- Review all data on a biannual basis.

Two key aspects have been considered in formulating the plan for the second phase of this project. Firstly, timing, Table 1 outlines a possible timeframe for the initial data gathering and subsequent data reviews, secondly Table 2 outlines the continuous nature of the task and proposes a schedule that would allow for different tasks to be occurring within the same time frame. This would allow for a spread of workload for VEA and sector staff, predictability of the process for VRC/SRC staff and families, and a degree of consistency in the timeliness, and in turn the accuracy, of information being presented to the Ministry. In any month the oldest data would be six months out of date and the newest would be less than a month out of date.

Table 1 **Indicating schedule of data gathering for each Region.**

Centre	Initial Data Gathered	1st biannual review	2 nd biannual review
Palmerston North	December 2000	June 2001	December 2001
Southland	January 2001	July 2001	January 2002
Auckland	February 2001	August 2001	February 2002
Dunedin	March 2001	September 2001	March 2002
Christchurch	April 2001	October 2001	April 2002
Hamilton	May 2001	November 2001	May 2002
Tauranga	June 2001	December 2001	June 2002
Wellington	July 2001	January 2002	July 2002
Nelson	August 2001	February 2002	August 2002
Gisborne	September 2001	March 2002	September 2002
Napier	October 2001	April 2002	October 2002
New Plymouth	November 2001	May 2002	November 2002

Comment:

This initial rotation has been mapped to indicate a pathway for achieving the establishment of the database within a one-year time frame. Timing has been scheduled with the realisation that the first round, given the volume of data to be collected and collated, will be more time consuming than future updates and additions. Also consideration has been given to ensure that the other duties of the

Vision Education Agency are accommodated within staff workloads. A further breakdown of how this process will be worked through is laid out in Table 2.

Table 2 A schedule of work broken into monthly task allocations.

The columns indicate the month in which the task will occur. The process is broken down into four steps: Preparation; Data Gathering; Data Entry and Data Analysis

Key: **Bold text indicates the Initial Round of data gathering.**

Plain text indicates the first Review Round of data gathering.
This is scheduled to occur six months after the Initial Round.

Italics text indicates the second Review Round of data gathering.
This is scheduled to occur a year after the initial round.

Month	Preparation	Data Gathering	Data Entry	Data Analysis
December2000	Southland	PalmerstonNth		
<i>January2001</i>	Auckland	Southland	PalmerstonNth	
February	Dunedin	Auckland	Southland	PalmerstonNth
March	Christchurch	Dunedin	Auckland	Southland
April	Hamilton	Christchurch	Dunedin	Auckland
May	Tauranga	<i>Hamilton</i>	Christchurch	Dunedin
	PalmerstonNth			
June	Wellington	Tauranga	Hamilton	Christchurch
	Southland	PalmerstonNth		
July	Nelson	Wellington	Tauranga	Hamilton
	Auckland	Southland	PalmerstonNth	
August	Gisborne	Nelson	Wellington	Tauranga
	Dunedin	Auckland	Southland	PalmerstonNth
September	Napier	Gisborne	Nelson	Wellington
	Christchurch	Dunedin	Auckland	Southland
October	NewPlymouth	Napier	Gisborne	Nelson
	Hamilton	Christchurch	Dunedin	Auckland
November	Tauranga	<i>NewPlymouth</i>	<i>Napier</i>	<i>Gisborne</i>
		Hamilton	Christchurch	Dunedin
December	Wellington	Tauranga	<i>NewPlymouth</i>	<i>Napier</i>
	PalmerstonNth		Hamilton	Christchurch
<i>January 2002</i>	Nelson	Wellington	Tauranga	<i>NewPlymouth</i>
	Southland	<i>PalmerstonNth</i>		Hamilton
February	Gisborne	Nelson	Wellington	Tauranga
	Auckland	<i>Southland</i>	<i>PalmerstonNth</i>	
March	Napier	Gisborne	Nelson	Wellington
	Dunedin	Auckland	<i>Southland</i>	<i>PalmerstonNth</i>
April	New Plymouth	Napier	Gisborne	Nelson
	Christchurch	Dunedin	Auckland	<i>Southland</i>

May		New Plymouth	Napier	Gisborne
		Christchurch	Dunedin	Auckland
June			New Plymouth	Napier
			Christchurch	Dunedin
July				New Plymouth
				Christchurch

Detailed Explanation of Table 2

Table 2 contains five columns:

Month	Preparation	Data Gathering	Data Entry	Data Analysis
-------	-------------	----------------	------------	---------------

Month

This indicates the month in which any task is occurring within any centre.

e.g.

March	Christchurch	Dunedin	Auckland	Southland
--------------	---------------------	----------------	-----------------	------------------

In March the VEA will be:

- Preparing to collect data from Elmwood VRC based in Christchurch.
- Gathering Data from Otago's VRC based in Dunedin.
- Entering the data previously collected from Auckland VRC.
- Analysing the data from Southland.

The schedule is planned over a 12 month calendar with the realisation that data collection over the December / January period may have to be flexible given the changes in term dates and the pressures on families and staff at that time of year in New Zealand.

Preparation

This includes such activities as:

- Production of Consent forms;
- Production of questionnaires;
- Mail out of consent forms to all families;
- Initial contact with the local VRC / SRC and the local parent group;
- VRC / SRC staff training for those collecting the data, if this is deemed the appropriate method of collection;
- Planning with local VRC / SRC re strategy for targeting total population;
- In future this would alter to planning re. New students and process for updating information;
- Mail out of questionnaires to local centres;
- Checking that consent forms have been received;
- Secure storage of completed consent forms.

Data Gathering

This includes tasks such as:

- Checking that consent forms have been received;
- The actual completion of the questionnaires by families in conjunction with the Resource Teacher Vision (RTV);
(This is discussed further in a later section.)
- The checking that total population has been covered;
- Secure storage of both completed consent forms and questionnaires;
- The safe return of this information to the VEA.

Data Entry

A month has been allowed for this in the initial rounds due to the volume of data and the importance, in all phases of collection, for accuracy and coverage of the total population. Overtime this process may speed up and the time frame reduced. It is envisaged that an employee of the VEA who has high-level computer skills in data entry would carry out this task.

Data Analysis

This task will no doubt be ongoing depending on Ministry requirements. The time frame for review would ensure that no data is out of date by more than six months. Analysis will be able to occur across the sector at any given time as well as trends in each region could be ascertained as new data is entered.

AN EXPLORATION OF SOME KEY ISSUES

Who should be completing or facilitating the completion of the questionnaires?

There are several areas that need to be considered when determining who carries out this data gathering such as:

- Consistency of process
- Time involved
- Distance involved

In the pilot study two staff members of the VEA carried out the simultaneous gathering of data each working in a separate region. Issues that arose from this were: inconsistency in method of collection; length of time to collect all the information; time involved away from other duties for both VEA and VRC / SRC staff; availability of families to participate; ability of families to participate; willingness of families to participate.

Consistency of Process

Concern	Possible Solutions
<ul style="list-style-type: none">• Different people interpret material differently.• The more people involved the greater the variables.• Perception can influence responses i.e. parent vs staff	<ul style="list-style-type: none">• Training for those collecting data.• Limit the number of people involved in data collection.• Design written guidelines for administration.• Determine which questions can/should be completed by administrative staff &/or senior teacher.• Attempt to reduce or eliminate questions that are subjective. If deemed appropriate for inclusion stipulate who is to respond.

Time involved

Concern	Possible Solutions
<ul style="list-style-type: none">• In pilot study time involved was underestimated.• Time spent on this takes Centre staff away from other duties.• Does Ministry expectation match that of the VEA?	<ul style="list-style-type: none">• Pace out the initial round and review to a time frame that more realistically reflects the task requirements.• Increasing the number of people involved in data collection may reduce time.• If VEA staff worked in collaboration with RTVs and administration staff this would reduce load on Centres.• Check with Ministry re time frame.

	<ul style="list-style-type: none"> • Report back to Ministry on the initial findings of Pilot study.
--	---

Distance involved

Concern	Possible Solutions
<ul style="list-style-type: none"> • Access to all families given distance / geography throughout some areas of New Zealand. • Cost involved in travel over such a wide area. • Distance and geography impact on time taken to consult with families. 	<ul style="list-style-type: none"> • Utilise existing contacts i.e. RTV contacts. • VRCs ? SRCs would need to be informed well ahead of time re dates for data collection to co-ordinate visits with data collection. • Working in with RTVs would cut down on costs. • Work through which questions can be completed by the Centre and which by the family.

In Summary

There is no one correct way of completing this task as the issues involved are complex and the impact of the process on each region varies greatly according to the roll number, number of staff, level of administrative support, willingness of staff to participate, location of each regions Visual or Sensory Centre, and the distribution of the roll across each region.

It is suggested at this stage that a variety of strategies are utilised. In a large Centre such as Auckland it would be appropriate to train a number of staff to assist in the process this may possibly include all itinerant teachers or focus on the senior staff members. Given the number of students involved two VEA employees would be utilised. For the other areas the Project Manager could work through the issues with each of the Centres to develop procedures that allow for a high degree of consistency but take into account the roll number, geographic spread and staffing levels.

It is envisaged that three key procedures could be developed the first involving Auckland and possibly Christchurch, the second involving Centres with 2 or more fulltime staff, and the third involving those centres with only one full time employee. For example it may be appropriate to train and support RTVs and administrators from a Centre the size and spread of Christchurch but be unreasonable to expect the RTV in Tauranga to undertake this task without hands on support.

Next Steps

1. Seek feedback from Gwen re thoughts to date.
2. Flesh out the three possible options for data gathering.
3. Amend the questionnaire post Pilot study.
4. Plan training package ensuring consensus between VEA staff and consistency between others collecting data when VEA staff are not directly involved.

5. Contact VRCs and SRCs prior to circulating both for feedback.
6. Initiate contact with Auckland VRC as we are already behind schedule with this one.
7. Initiate contact with Dunedin/Otago VRC.

Appendix C

National Database for Learners who are Blind and Vision Impaired

1. Personal Information

1.1 Name of the student

Family name: _____

First name: _____ Middle names: _____

Also known as: _____ Gender: ☐ M ☐ F

Date of Birth: _____ No. chn in family: _____ Place _____

1.2 Parents/Guardian _____ Parents/Guardian _____

Name: _____ Name: _____

Address: _____ Address: _____

Phone Home: _____ Phone Home: _____

Any special communication needs of parents e.g. Braille, large print

1.3 Region (please tick)

☐ Northland

☐ Auckland

☐ Waikato

☐ Thames/Coromandel

☐ King Country

☐ Bay of Plenty

☐ East Cape/Poverty Bay

☐ Hawkes Bay

☐ Taranaki

☐ Central Districts Nth Island

☐ Wellington

☐ Marlborough

☐ Nelson/Buller

☐ Canterbury

☐ West Coast

☐ Otago

☐ Southland

1.4 Nationality: _____ Home Language: _____

1.5 Ethnic group

- ☐ NZ European/Pakeha
- ☐ NZ Maori
- ☐ Cook Island Maori
- ☐ Samoan
- ☐ Tongan
- ☐ Niuean
- ☐ Fijian
- ☐ Tokelauan
- ☐ Other Pacific Island (please specify) _____
- ☐ Other Groups (please specify) _____
- ☐ Iwi _____
- ☐ European (e.g. English/German)
- ☐ Indian
- ☐ Chinese
- ☐ Other Asian

1.6 Whakapapa

Ko _____	te ingoa
Ko _____	te maunga
Ko _____	te awa
Ko _____	te iwi
Ko _____	te hapu
Ko _____	te whanau
Ko _____	marae
Ko _____	maatua

1.7 Communication Mode

Written Communication

Braille user

- ☐ Yes
- ☐ Not yet determined
- ☐ Tactile user
- ☐ Potential Braille user
- ☐ Braille user

Print user

- ☐ Yes
- ☐ Not yet determined
- ☐ Regular print
- ☐ Large print
- ☐ Use of visual aids

☐ Dual Communication Mode (Print/Braille)

Interpersonal Communication

Does the learner use speech to communicate?

- ☐ Yes ☐ No ☐ Not yet determined

If the answer was 'no' please complete the following.

Does the learner use a communication mode other than speech?

- ☐ Yes ☐ No ☐ Not yet determined

☐ Signing system

(please specify) _____

☐ Augmentative and alternative communication system

(please specify) _____

☐ Other

(please specify) _____

2. Information on Vision Impairment

2.1 Nature of Vision Impairment

Ophthalmic Report: ☐ Yes ☐ No

Ophthalmologist: _____ Date of last appointment: _____

Optometrist: _____ Date of last appointment: _____

Congenital: ☐ Yes ☐ No

Age of Onset of Visual Loss: _____

Visual Acuity Right Eye _____ Visual Acuity Left Eye _____

Visual Acuity Binocular _____ Visual Fields _____

Visual Status: ☐ Blind ☐ Low vision ☐ Deafblind

Vision impaired with additional disabilities ☐ Yes ☐ No
(Please specify) _____

RNZFB membership ☐ Yes ☐ No

2.2 Eye Condition

- | | | |
|---|---|--|
| <input type="checkbox"/> Albinism | <input type="checkbox"/> Keratoconus | <input type="checkbox"/> Retinal Detachment |
| <input type="checkbox"/> Amblyopia | <input type="checkbox"/> Glaucoma | <input type="checkbox"/> Retinitis Pigmentosa |
| <input type="checkbox"/> Aniridia | <input type="checkbox"/> Hemianopia | <input type="checkbox"/> Retinoblastoma |
| <input type="checkbox"/> Anophthalmia | <input type="checkbox"/> Hypermetropia | <input type="checkbox"/> Keratitis |
| <input type="checkbox"/> Aphakia | <input type="checkbox"/> Iritis | <input type="checkbox"/> Scotoma |
| <input type="checkbox"/> Astigmatism | <input type="checkbox"/> Lebers Amaurosis | <input type="checkbox"/> Septo Optic Dysplasia |
| <input type="checkbox"/> Cataract | <input type="checkbox"/> Microphthalmus | <input type="checkbox"/> Stargardts |
| <input type="checkbox"/> Choroiditis | <input type="checkbox"/> Myopia | <input type="checkbox"/> Strabismus (Squint) |
| <input type="checkbox"/> Coloboma | <input type="checkbox"/> Nystagmus | <input type="checkbox"/> Subluxated Lenses |
| <input type="checkbox"/> Colour Vision Loss | <input type="checkbox"/> Optic Atrophy | |
| <input type="checkbox"/> Cortical Vision Impairment | <input type="checkbox"/> Optic Nerve Hypoplasia | |
| <input type="checkbox"/> Macular Degeneration | <input type="checkbox"/> Retinopathy of Prematurity | |

Other (please specify) _____

2.3 Functional Vision Assessment: Date _____ Assessor _____

Visual Acuity: ____ R ____ L ____ Bi ____ Visual Field: ____

3. Education: Setting

3.1 School or Early Childhood Centre Attending:

Name: _____ School Number _____

Address: _____

Phone: _____ Fax: _____ Email: _____

Decile Rating: _____ Learner's Year level: _____

Principal/ Head Teacher: _____

Contact Teacher/Person: _____

Special Needs Co-ordinator: _____

Number of previous schools/centres attended _____

3.2 Type of Setting (Tick as many boxes as appropriate)

☐ Early Childhood

☐ Kohanga Reo

☐ Primary

☐ Kura Kaupapa

☐ Intermediate

☐ Bilingual setting

☐ Full Primary

☐ Immersion setting

☐ Secondary

☐ Area School

☐ Junior High

☐ Special Education Unit

☐ Special School

☐ Home School setting

☐ Other (please state) _____

3.3 Transition

What was the last transition for the learner:

- ☐ Home to Early Childhood Setting
- ☐ Early Childhood to School
- ☐ Primary to Intermediate
- ☐ Intermediate to Secondary
- ☐ Secondary to Tertiary
- ☐ Secondary to Work
- ☐ Other (please specify) _____

PARENT or LEARNER comments on the following:
(Circle the parent or learner as appropriate.)

Support Provided

Who provided support? _____

What problems did the learner or the family encounter? _____

What went well? _____

What would you like to see happen next time? _____

3.4 Is the learner likely to leave school this year?

- ☐ Yes ☐ No

4. Education: Individual Education Programme

4.1 Frequency of IEP meetings:

- ☐ Termly ☐ Half Yearly
☐ Yearly ☐ Other (Please state) _____
☐ No IEP in place

Who was responsible for:

Co-ordinating the last IEP meeting _____

Writing the last IEP _____

4.2 Date of last IEP: Day _____ Month _____ Year _____

4.3 Attendance at the last IEP

(Please tick the appropriate boxes)

- ☐ Mother
- ☐ Father
- ☐ Caregiver
- ☐ Learner (who the IEP was for)
- ☐ Support person e.g. family or whanau member, friend, advocate
- ☐ Class or early childhood teacher
- ☐ Part-time teacher
- ☐ Teacher aide, Kaiawhina, or Education support worker
- ☐ Special needs coordinator
- ☐ Principal
- ☐ Assistant principal or deputy principal
- ☐ Early intervention teacher
- ☐ Visual or Sensory Resource Teacher
- ☐ Specialist Education Services (SES) representative
- ☐ Speech language therapist (SLT)
- ☐ Advisor/teacher of the deaf
- ☐ Resource Teacher of Learning and Behaviour (RTLb)
- ☐ Physiotherapist
- ☐ Occupational therapist
- ☐ Neurodevelopmental therapist
- ☐ Orientation and Mobility (O&M) specialist
- ☐ Techniques of Daily Living (TDL) specialist
- ☐ RNZFB Child and Family Social Worker
- ☐ RNZFB Whanau Worker
- ☐ CCS representative ☐ IHC representative ☐ ACC representative

Others (please list) _____

5. Education: Funding

5.1 Ongoing Reviewable Resourcing Scheme Funding

Status: ☐ Very High ☐ High ☐ Transitional

Verification year: _____

Date of last verification review: _____

5.2 Moderate Needs

(For learners in the compulsory sector not verified as ORRS status)

Please indicate whether:

The learner is currently receiving support from a VRC/SRC, ☐ Yes ☐ No
Homai and Manurewa High School

An application for ORRS is in process. ☐ Yes ☐ No

An application for ORRS has previously been declined. ☐ Yes ☐ No

5.3 Fundholder

☐ Own School

☐ Another School

☐ Specialist Education Services

☐ Other (please specify) _____

5.4 Travel

Uses transport assistance ☐ Yes ☐ No

Parent / Caregiver provides transport and claims travel Allowance. ☐ Yes ☐ No

5.5 Accident Compensation Corporation

Claimant of ACC ☐ Yes ☐ No

6. Education: Services

6.1 Referring Agent

Referring agents for vision education services:

- | | |
|---|--|
| <input type="checkbox"/> Education Setting | <input type="checkbox"/> Optometrist |
| <input type="checkbox"/> Family of Learner | <input type="checkbox"/> Paediatrician |
| <input type="checkbox"/> General Practitioner | <input type="checkbox"/> Plunket Nurse |
| <input type="checkbox"/> Neurodevelopmental Therapist | <input type="checkbox"/> RNZFB |
| <input type="checkbox"/> Ophthalmologist | <input type="checkbox"/> SES |
| <input type="checkbox"/> Other (please specify) _____ | |

6.2 Special Education Service Provider/s

- ☐ Visual Resource Centre
- ☐ Sensory Resource Centre
- ☐ Homai National School for the Blind and Vision Impaired
- ☐ Royal New Zealand Foundation for the Blind
- ☐ Specialist Education Services
- ☐ Other (please specify) _____

6.3 Resource Teacher Vision

Indicate the Average hours per term:	Current Need	Current Provision
Direct Teaching		
Assessment		
Consultation, meetings and appointments		
Programme preparation, report writing and follow up		
Preparation of special format and resource materials		
TOTAL HOURS PER TERM		

Number of visits per term (to educational setting or home): _____

Distance of learner from centre. _____kms

Average time taken travelling to learner _____hrs _____ mins

6.4 Specialist Services

(Identified need evidenced by assessment or the learner's IEP)

- | <input type="checkbox"/> <u>Identified Need</u> | <input type="checkbox"/> <u>Input Currently Received From</u> |
|--|--|
| <input type="checkbox"/> Orientation and Mobility | <input type="checkbox"/> & M Specialist |
| <input type="checkbox"/> Techniques of Daily Living | <input type="checkbox"/> TDL Specialist |
| <input type="checkbox"/> Use of technology skills | <input type="checkbox"/> Technology Advisor |
| <input type="checkbox"/> Sport and Recreation | <input type="checkbox"/> Sport and Recreation Specialist |
| <input type="checkbox"/> Physiotherapy | <input type="checkbox"/> Physiotherapist |
| <input type="checkbox"/> Speech/Language therapy | <input type="checkbox"/> Speech/Language Therapist |
| <input type="checkbox"/> Occupational therapy | <input type="checkbox"/> Occupational Therapist |
| <input type="checkbox"/> Deaf Education | <input type="checkbox"/> Advisor of Deaf Children |
| | <input type="checkbox"/> Itinerant Teacher of Deaf Children |
| <input type="checkbox"/> Learning and Behaviour Management | <input type="checkbox"/> Resource Teacher Learning and Behaviour |
| | <input type="checkbox"/> Psychologist |
| <input type="checkbox"/> Family Services | <input type="checkbox"/> Child and Family Social Worker |
| | <input type="checkbox"/> Psychologist |
| <input type="checkbox"/> Whanau Services | <input type="checkbox"/> RNZFB Whanau Worker |
| <input type="checkbox"/> Neurodevelopmental Therapy | <input type="checkbox"/> Neurodevelopmental Therapist |
| <input type="checkbox"/> Other (please specify) _____ | |

6.5 School Based Support

- | | |
|--|------------------|
| <input type="checkbox"/> ORRS Part time teacher | _____ Hours/week |
| <input type="checkbox"/> Teacher Aide, Education Support Worker, Kaiawhina | _____ Hours/week |
| <input type="checkbox"/> Special Needs Coordinator | _____ Hours/week |
| <input type="checkbox"/> Material production | _____ Hours/week |
| <input type="checkbox"/> Other (please specify.) _____ | _____ Hours/week |

6.6 Other Agencies Involved List services provided:

- | | |
|--------------------------------|-------|
| <input type="checkbox"/> IHC | _____ |
| <input type="checkbox"/> CCS | _____ |
| <input type="checkbox"/> Other | _____ |

7. Education: Accessing the Curriculum

7.1 The Learner Requires the Following Adaptations to the Learning Environment, for example:

- | | |
|---|--|
| <input type="checkbox"/> Lighting | <input type="checkbox"/> Seating position |
| <input type="checkbox"/> Colour contrast | <input type="checkbox"/> Size of materials |
| <input type="checkbox"/> Tactile contrast | <input type="checkbox"/> Area for technology equipment |
| <input type="checkbox"/> Identification of classroom hazards | |
| <input type="checkbox"/> Storage area for large print and Braille books | |
| <input type="checkbox"/> Consistent layout of the classroom | |
| <input type="checkbox"/> Access to visual/tactile materials | |
| <input type="checkbox"/> Other (please specify) _____ | |

Comment: _____

7.2 The Learner Requires the Following Adaptations of Teaching and Learning Approaches (for example)

- | | |
|--|---|
| <input type="checkbox"/> Use of concrete experiences | <input type="checkbox"/> Use of real objects |
| <input type="checkbox"/> Additional time | <input type="checkbox"/> Adjusted workload |
| <input type="checkbox"/> Teacher verbalisation | <input type="checkbox"/> Co- activity |
| <input type="checkbox"/> Modelling with the learner | <input type="checkbox"/> Buddy support |
| <input type="checkbox"/> Provision of desk copies | <input type="checkbox"/> Task analysis |
| <input type="checkbox"/> Reverse chaining | <input type="checkbox"/> Individual Instruction |
| <input type="checkbox"/> Small group instruction | |
| <input type="checkbox"/> Other (please specify) | |

Comment: _____

7.3 Special Format Materials

Please indicate which of the following areas are applicable by CIRCLING or HIGHLIGHTING the word or the abbreviated title:

If another supplier is used please note in the space next to 'RNZFB'.

The Learner requires the Following Special Format Materials			This material is currently supplied by				
Collage and tactile materials	Yes	No	Pre/school	VRC /SRC	HNSBVI	MHSVRR	RNZFB
Braille	Yes	No	Pre/school	VRC /SRC	HNSBVI	MHSVRR	RNZFB
CD Rom	Yes	No	Pre/school	VRC /SRC	HNSBVI	MHSVRR	RNZFB
Large print	Yes	No	Pre/school	VRC /SRC	HNSBVI	MHSVRR	RNZFB
Audio tapes	Yes	No	Pre/school	VRC /SRC	HNSBVI	MHSVRR	RNZFB
Electronic text files by disk or email	Yes	No	Pre/school	VRC /SRC	HNSBVI	MHSVRR	RNZFB
Other (please specify)			Pre/school	VRC /SRC	HNSBVI	MHSVRR	RNZFB
			Pre/school	VRC /SRC	HNSBVI	MHSVRR	RNZFB

Comment: _____

7.4 The Expanded Core Curriculum.

Please indicate which of the following areas are applicable by *CIRCLING* or *HIGHLIGHTING* the word or the abbreviated title:

Communication Modes	Identified learner need.	Is a programme being implemented?	Who is responsible on a day to day basis for delivering the programme? If 'Other' please state their role / title.
Braille Codes: Literary	Yes No	Yes No	RTV TA CT ORRST Other
Maths	Yes No	Yes No	RTV TA CT ORRST Other
Science	Yes No	Yes No	RTV TA CT ORRST Other
Languages	Yes No	Yes No	RTV TA CT ORRST Other
Music	Yes No	Yes No	RTV TA CT ORRST Other
Computer	Yes No	Yes No	RTV TA CT ORRST Other
Concept development	Yes No	Yes No	RTV TA CT ORRST Other
Handwriting	Yes No	Yes No	RTV TA CT ORRST Other
Listening skills	Yes No	Yes No	RTV TA CT ORRST Other
Tactile skills	Yes No	Yes No	RTV TA CT ORRST Other
Keyboard skills	Yes No	Yes No	RTV TA CT ORRST Other
Computer use	Yes No	Yes No	RTV TA CT ORRST Other
Sign Language	Yes No	Yes No	RTV TA CT ORRST Other
Augmentative & Alternative Communication	Yes No	Yes No	RTV TA CT ORRST Other
Electronic speech	Yes No	Yes No	RTV TA CT ORRST Other
Tangible symbols	Yes No	Yes No	RTV TA CT ORRST Other
Other (specify)	Yes No	Yes No	RTV TA CT ORRST Other

7.4 The Expanded Core Curriculum (continued)

Please indicate which of the following areas are applicable by **CIRCLING** or **HIGHLIGHTING** the word or the abbreviated title:

Visual Efficiency Skills	Identified learner needs	Is a programme being implemented?	Who is responsible on a day to day basis for delivering the programme? If 'Other' please state their role / title.
Development of residual vision	Yes No	Yes No	RTV TA CT ORRST Other
Visual perception skills	Yes No	Yes No	RTV TA CT ORRST Other
Use of low vision aids Optical	Yes No	Yes No	RTV TA CT ORRST Other
Non optical	Yes No	Yes No	RTV TA CT ORRST Other
Development of compensatory skills	Yes No	Yes No	RTV TA CT ORRST Other
Other (specify)	Yes No	Yes No	RTV TA CT ORRST Other

Physical Abilities	Identified learner need	Is a programme being implemented?	Who is responsible on a day to day basis for delivering the programme? If 'Other' please state their role / title.
Postural control	Yes No	Yes No	RTV TA CT ORRST Physio OT Other
Physical strength and endurance	Yes No	Yes No	RTV TA CT ORRST Physio OT Other
Gross motor development	Yes No	Yes No	RTV TA CT ORRST Physio OT Other
Fine motor development	Yes No	Yes No	RTV TA CT ORRST Physio OT Other
Other (specify)	Yes No	Yes No	RTV TA CT ORRST Physio OT Other

7.4 The Expanded Core Curriculum (continued)

Please indicate which of the following areas are applicable by **CIRCLING OR HIGHLIGHTING** the word or the abbreviated title:

Orientation and Mobility	Identified learner need	Is a programme being implemented?	Who is responsible on a day to day basis for delivering the programme? If 'Other' please state their role / title.
Development of orientation	Yes No	Yes No	O&M RTV TA ORRST CT Other
Development of mobility	Yes No	Yes No	O&M RTV TA ORRST CT Other
Use of mobility devices	Yes No	Yes No	O&M RTV TA ORRST CT Other
Formal strategies for travel	Yes No	Yes No	O&M RTV TA ORRST CT Other
Other (specify)	Yes No	Yes No	O&M RTV TA ORRST CT Other

Social Skills	Identified learner need	Is a programme being Implemented?	Who is responsible on a day to day basis for delivering the programme? If 'Other' please state their role / title.
Development of reasons for interacting	Yes No	Yes No	RTV TA CT ORRST SLT Other
Skills for interaction	Yes No	Yes No	RTV TA CT ORRST SLT Other
Socially acceptable Behaviour	Yes No	Yes No	RTV TA CT ORRST SLT Other
Self esteem	Yes No	Yes No	RTV TA CT ORRST SLT Other
Self confidence	Yes No	Yes No	RTV TA CT ORRST SLT Other
Self advocacy	Yes No	Yes No	RTV TA CT ORRST SLT Other
Interpersonal skills	Yes No	Yes No	RTV TA CT ORRST SLT Other
Recreation and Leisure skills	Yes No	Yes No	RTV TA CT ORRST SLT Other
Other	Yes No	Yes No	RTV TA CT ORRST SLT Other

7.4 The Expanded Core Curriculum (continued)

Please indicate which of the following areas are applicable by CIRCLING or HIGHLIGHTING the word or the abbreviated title:

Daily Living Skills	Identified learner need	Is a programme being implemented?	Who is responsible on a day to day basis for delivering the programme? If 'Other' please state their role / title.
Self care skills	Yes No	Yes No	RTV TA OT ORRST CT Other
Organisational skills	Yes No	Yes No	RTV TA OT ORRST CT Other
Time management skills	Yes No	Yes No	RTV TA OT ORRST CT Other
Decision making skills	Yes No	Yes No	RTV TA OT ORRST CT Other
Money management	Yes No	Yes No	RTV TA OT ORRST CT Other
Vocational & Career skills	Yes No	Yes No	RTV TA OT ORRST CT Other
Advocacy	Yes No	Yes No	RTV TA OT ORRST CT Other
Awareness & access to Community resources	Yes No	Yes No	RTV TA OT ORRST CT Other
Other	Yes No	Yes No	RTV TA OT ORRST CT Other

Technology and Resources	Identified learner need	Is a programme being implemented?	Who is responsible on a day to day basis for delivering the programme? If 'Other' please state their role / title.
Use of low vision aids	Yes No	Yes No	RTV TA OT SLT ORRST CT Other
Use of low technology aids	Yes No	Yes No	RTV TA OT SLT ORRST CT Other
Use of high technology equipment	Yes No	Yes No	RTV TA OT SLT ORRST CT Other
Use of assistive and adaptive devices	Yes No	Yes No	RTV TA OT SLT ORRST CT Other
Other	Yes No	Yes No	RTV TA OT SLT ORRST CT Other

7.5 Adaptation of the Regular Curriculum

Please identify adaptations to the content of Te Whaariki or the New Zealand Curriculum by writing in the Level, Goal, or Stage of the learner and then **CIRCLING** or **HIGHLIGHTING** the appropriate word or abbreviated title as appropriate.

Te Whaariki

Strand	Goal 1-4	Stage I/T/Y C	Adaptations Required		Adaptations Implemented		Who is responsible on a day to day basis for delivering the programme? If 'Other' please state their role / title
			Environmental	Teaching Strategies	Environmental	Teaching Strategies	
Wellbeing			Yes No	Yes No	Yes No	Yes No	RTV ESW ECE EISp Other
Belonging			Yes No	Yes No	Yes No	Yes No	RTV ESW ECE EISp Other
Contribution			Yes No	Yes No	Yes No	Yes No	RTV ESW ECE EISp Other
Communication			Yes No	Yes No	Yes No	Yes No	RTV ESW ECE EISp Other
Exploration			Yes No	Yes No	Yes No	Yes No	RTV ESW ECE EISp Other

Comment _____

New Zealand Curriculum

Years 1-10	Level	Adaptations Required		Adaptations Implemented		Who is responsible on a day to day basis delivery the programme? If 'Other' please state their role/title
		Environmental	Teaching Strategies	Environmental	Teaching Strategies	
English Written Language		Yes No	Yes No	Yes No	Yes No	RTV CT TA ORRST Other
Oral Language		Yes No	Yes No	Yes No	Yes No	RTV CT TA ORRST Other
Reading		Yes No	Yes No	Yes No	Yes No	RTV CT TA ORRST Other
Other Languages		Yes No	Yes No	Yes No	Yes No	RTV CT TA ORRST Other
Mathematics		Yes No	Yes No	Yes No	Yes No	RTV CT TA ORRST Other
Science		Yes No	Yes No	Yes No	Yes No	RTV CT TA ORRST Other
Technology		Yes No	Yes No	Yes No	Yes No	RTV CT TA ORRST Other
Social Studies		Yes No	Yes No	Yes No	Yes No	RTV CT TA ORRST Other
Health & Physical Education		Yes No	Yes No	Yes No	Yes No	RTV CT TA ORRST Other
The Arts Music		Yes No	Yes No	Yes No	Yes No	RTV CT TA ORRST Other
Drama		Yes No	Yes No	Yes No	Yes No	RTV CT TA ORRST Other
Art		Yes No	Yes No	Yes No	Yes No	RTV CT TA ORRST Other
Other (please specify)		Yes No	Yes No	Yes No	Yes No	RTV CT TA ORRST Other

Comment: _____

New Zealand Curriculum

Years 11-13 Subject (please specify)	Level	Adaptations Required		Adaptations Implemented		Who is responsible on a day to day basis delivery the programme? If 'Other' please state their role/title
		Environmental	Teaching Strategies	Environmental	Teaching Strategies	
		Yes No	Yes No	Yes No	Yes No	RTV TA ORRST CT Other
		Yes No	Yes No	Yes No	Yes No	RTV TA ORRST CT Other
		Yes No	Yes No	Yes No	Yes No	RTV TA ORRST CT Other
		Yes No	Yes No	Yes No	Yes No	RTV TA ORRST CT Other
		Yes No	Yes No	Yes No	Yes No	RTV TA ORRST CT Other
		Yes No	Yes No	Yes No	Yes No	RTV TA ORRST CT Other

Comment: _____

8. Education: Equipment

Equipment, Visual Aids and Information Communication Technology

If the child has their own equipment tick the box.

If they have access only to the equipment then write 'A'.

- | | |
|--|--|
| <input type="checkbox"/> Braille e.g. Perkins, Mountbatten, Eureka, Braille Lite (please specify type/s) | |
| <input type="checkbox"/> Cassette Recorder | <input type="checkbox"/> Tactile Kits e.g. Geometry |
| <input type="checkbox"/> Abacus | <input type="checkbox"/> Large print or talking calculator |
| <input type="checkbox"/> Braille 'n Print | <input type="checkbox"/> Scanner |
| <input type="checkbox"/> Drawing frame | <input type="checkbox"/> Talking book machine |
| <input type="checkbox"/> Computer with voice synthesis (please specify type) _____ | |
| <input type="checkbox"/> Embosser | |
| <input type="checkbox"/> Other (please specify) _____ | |

- | | |
|--|--|
| <input type="checkbox"/> Computer (please specify type) _____ | |
| <input type="checkbox"/> Large Print Software (please specify) _____ | |
| <input type="checkbox"/> Star writer | <input type="checkbox"/> Printer |
| <input type="checkbox"/> Monocular | <input type="checkbox"/> Miniscope |
| <input type="checkbox"/> Stand Magnifier | <input type="checkbox"/> Hand held magnifier |
| <input type="checkbox"/> Other Magnifier (please specify) _____ | |
| <input type="checkbox"/> CCTV | |
| <input type="checkbox"/> Low technology equipment e.g. angle poised lamp, tilt top desk reading stand, dark lined pads. Please list) _____ | |

Augmentative and Alternative Communication Technology

- | | |
|--|---|
| <input type="checkbox"/> Concept keyboard | <input type="checkbox"/> Switches |
| <input type="checkbox"/> Touch Screen Computer | <input type="checkbox"/> Other (please specify) _____ |

What equipment is needed that the student does not currently have issued or access to _____

INFORMATION RELEASE FORM

When you have completed the form and are confident that to the best of your knowledge the information is accurate please sign in the space provided and send to the Vision Education Agency (VEA.)

The position of the person who gathered the data. (Please circle as appropriate.)

RTV VEA Staff Member Other (please specify) _____

Method of Data gathering (tick appropriate method/s)

- ☐ face to face interview with parent /learner
- ☐ telephone interview with parent / learner
- ☐ use of existing files
- ☐ other (please specify) _____

Signature of Parent
(and/or Learner if appropriate)

Date:

Signature of Data Gatherer

Date:

Signature of Senior Teacher
(as appropriate)

Date:

Comment: _____

To be completed by VEA:

Received by VEA on Day _____ Month _____ Year _____

Signature: _____

Personal Information

Name of the student

Family name: _____

First name: _____

Middle names: _____

Date of Birth: _____

9. Exit Information (for school leavers only)

9.1 Exiting Level

School _____

Year level on leaving school _____

Date of leaving _____

Age of learner _____

9.2 Achievement

A statement of achievement

9.2 Achievement (continued)

Academic Achievement

School Certificate

Sixth Form Certificate

Bursary

NZQA - Unit Standards

International Achievements e.g. Baccalaureate

Other Areas of Achievement (e.g. Sporting, Cultural)

9.3 Area of Involvement Upon Leaving School

- | | |
|---|--|
| <input type="checkbox"/> Tertiary Education | <input type="checkbox"/> Other ongoing educational programme e.g. TOPS |
| <input type="checkbox"/> Employment | <input type="checkbox"/> Supported employment |
| <input type="checkbox"/> Work Experience | <input type="checkbox"/> Voluntary work |
| <input type="checkbox"/> No Employment | <input type="checkbox"/> Day services/activities |
| <input type="checkbox"/> Kickstart | |
| <input type="checkbox"/> Other (please specify) | |

9.4 Living Circumstances

Living independently in the community:

- | | | |
|-----------------------------------|-----------------------------------|---|
| <input type="checkbox"/> Flatting | <input type="checkbox"/> Own home | <input type="checkbox"/> Not applicable |
|-----------------------------------|-----------------------------------|---|

Living interdependently in the community:

- | | |
|---|---|
| <input type="checkbox"/> Supported living | <input type="checkbox"/> Living at home |
| <input type="checkbox"/> Other | |

- ☐ Not applicable

Other Community Affiliations (please specify)

Comments_____

INFORMATION RELEASE FORM

When you have completed the form and are confident that to the best of your knowledge the information is accurate please sign in the space provided and send to the Vision Education Agency (VEA.)

Position of the person who gathered the data. (Please circle as appropriate.)

RTV VEA Staff Member Other (please specify) _____

Method of Data gathering (tick appropriate method/s)

- ☐ Face to face interview with parent /learner
- ☐ Telephone interview with parent / learner
- ☐ Use of existing files
- ☐ Other (please specify) _____

Signature of Parent
and Learner if appropriate.

Date:

Signature of the Data Gatherer

Date:

Signature of Senior Teacher
as appropriate.

Date:

Comment:

To be completed by VEA:

Received by VEA on _____ Day _____ Month _____ Year

Signature: _____

Appendix D

**BLIND AND LOW VISION EDUCATION
NETWORK NZ**

Te Kōtuituinga Mātauranga Pura o Aotearoa

*A National Network of Services for Children
and Young People*



Learner Profile

_____Centre

RTV Caseload:**1. Personal Information**

Surname:		Date of Birth:	
First Name:		Gender:	

Parent / Caregiver**Parent / Caregiver**

Name(s):		Name(s):	
Address:		Address:	
Telephone		Telephone	
Home:		Home:	
Mobile:		Mobile:	
Email:		Email:	
Work:		Work:	
Fax :		Fax :	

Home language:

Ethnicity:

Iwi:

Health alert eg. allergies, epilepsy:

Hospital number (NHI):		ORRS number – if appropriate:		National Student number – if appropriate:	
------------------------	--	-------------------------------	--	---	--

2. Information on Vision Impairment

Eye Condition:

Functional Vision Information

Date of last report:

<u>Distance</u>					
RE:		LE:		Binocular:	
<u>Near-Print Size</u>					
Minimum:		Functional:		Preferred Print Size:	

Visual Fields:

3. Educational Setting

Name of Setting:		
Address:		
Telephone/Fax Number:		
Email:		
Principal/ Head Teacher:		
Contact Teacher (Role):		

4. Educational Funding

Funding status:

Early Childhood:	Moderate Needs:	ORRS High:	ORRS Very High:
------------------	-----------------	------------	-----------------

Fundholder Name:

Other Funding:

ACC:	High Health:		
------	--------------	--	--

Privacy consent completed: Yes/ No

Date:

Enrolment Form completed: Yes/ No

Date enrolled:

5. BLENNZ Category:

	Braille
	Severe Low Vision (6/60 or less)
	Moderate Low Vision (6/18 - >6/60)
	Dual Sensory (Deafblind)
	Complex-interrelated needs

Additional Disability:

Medical condition (if appropriate):

6. Clinical Information

Optometrist:	
Orthoptist:	
Paediatrician:	
Other:	

Stability of Visual Condition:	Stable		Deteriorating	
Visual Functioning:	Stable		Fluctuating	

Low Vision Aids:

Print size with low vision aids:

7. RNZFB

Registration: Yes / No

Membership Number (if applicable):

Homai Special Formats Library Member: Yes / No

RNZFB Services Received e.g. Developmental O&M, CFSW, Developmental Instructor

Services	Date of Referral	Date Assessment Report Received	Date Services Started	Date Services Completed

8. Educational Information

Year level (compulsory sector only)

Year 0		Year 4		Year 8		Year 12	
Year 1		Year 5		Year 9		Year 13	
Year 2		Year 6		Year 10			
Year 3		Year 7		Year 11			

IP/IEP

IP/IEP Frequency:

Termly		6 monthly		Annually		None	
--------	--	-----------	--	----------	--	------	--

IEP Date	IP/IEP Coordinator

<u>Educational level</u>		<u>Date of move</u>	<u>Educational setting</u>	
Early Childhood:			Regular setting:	
Primary:			Special unit:	
Intermediate:			Special school:	
Secondary:			Kurakaupapa:	
Tertiary transition:			Kohanga Reo:	
			Language Nest:	
			Maori Immersion/Bilingual Class:	
			Dual enrolled:	
			Correspondence School:	
			Home Schooled:	

Secondary Subjects Being Studied	Yes / No	Year Level
Maths		
Science		

9. Technology

Type of Equipment	Funded By	Application Made By	Date of Funding Allocation	Serial Numbers

VRC equipment on loan

Type of Equipment	Date Issued	Date Returned	RTV	Serial Numbers

10. Educational Services

Date	Teacher Aide/Education Support Worker Name	Hours Allocated

Date	Specialist ORRS Teacher Name	Hours Allocated

Other agencies involved (e.g. GSE, CCS, IHC)

Date	Therapist (SLT/VNT/OT)Name	Phone Contact

Date	Key Worker Name	Phone Contact

11. BLENNZ Services used

Nature of Service	Date Service Received

12. Literacy Profile (In learner's preferred medium.)

Please circle appropriate figure.

<1 1 2 3 4 5 6 7 8 >8

Reading Age (In learner's preferred medium.)

Please circle appropriate figure

<5 5 6 7 8 9 10 11 12 13 >14

Sensory Channels

Primary		Secondary	
<input type="checkbox"/>	Visual	<input type="checkbox"/>	Visual
<input type="checkbox"/>	Visual – deteriorating condition	<input type="checkbox"/>	
<input type="checkbox"/>	Tactual	<input type="checkbox"/>	Tactual
<input type="checkbox"/>	Auditory	<input type="checkbox"/>	Auditory
<input type="checkbox"/>	Not yet determined	<input type="checkbox"/>	Not yet determined

Stage of Literacy Development

In this section indicate the primary source of information that the learner obtains meaning from.

<input type="checkbox"/>	Real objects
<input type="checkbox"/>	3 dimensional items (objects of reference)
<input type="checkbox"/>	2 dimensional picture or tactual cue (objects of reference)
<input type="checkbox"/>	Text symbols -printed or embossed (Print, Braille, Moon)

If using text symbols please tick the mode used.

<input type="checkbox"/>	Print	<input type="checkbox"/>	Braille G1	<input type="checkbox"/>	Dual Modality Print & Braille G1
<input type="checkbox"/>	Moon	<input type="checkbox"/>	Braille G2	<input type="checkbox"/>	Dual Modality Print & Braille G2

Type of Literacy Programme Required

<input type="checkbox"/>	Functional	<input type="checkbox"/>	Conventional	<input type="checkbox"/>	Not yet determined
--------------------------	------------	--------------------------	--------------	--------------------------	--------------------

Level of Participation in Literacy Activities

<input type="checkbox"/>	Exposure	<input type="checkbox"/>	Awareness	<input type="checkbox"/>	Emergent	<input type="checkbox"/>	Early	<input type="checkbox"/>	Fluent
--------------------------	----------	--------------------------	-----------	--------------------------	----------	--------------------------	-------	--------------------------	--------

Accuracy level _____% Comprehension level _____%


Appendix E






BLENNZ Learner Analysis Form (BLAF)

Learner: _____ DOB: _____ Year level/Age: _____ Completed by: _____ Date: _____ Date Reviewed: _____

February 2014

	0	1	2	3	4	TOTAL
MEDICAL	<ul style="list-style-type: none"> 6/6 - 6/18 with full visual field No significant pathology 	<ul style="list-style-type: none"> possible progressive disease but one eye still within normal limits mild/intermittent nystagmus bilateral strabismus other severe temporary eye treatments 	<ul style="list-style-type: none"> 6/18 - 6/36 restricted visual field affecting ability to function in learning environment Cortical vision impairment progressive disease bilateral significant/consistent nystagmus 	<ul style="list-style-type: none"> 6/36 - 6/60 field of 20 degrees or less 	<ul style="list-style-type: none"> 3/60 or poorer visual field of 10 degrees or less 	
FUNCTIONAL VISION STATUS	<ul style="list-style-type: none"> Visual skills adequate to access curriculum 	<ul style="list-style-type: none"> visual skills maintained in most settings 	<ul style="list-style-type: none"> visual skills fluctuate depending on activity or setting 	<ul style="list-style-type: none"> new visual skills being introduced or developed deteriorating eye condition 	<ul style="list-style-type: none"> can not access the curriculum through vision 	
ASSISTIVE TECHNOLOGY (HIGH/LOW)	<ul style="list-style-type: none"> No visual aids 	<ul style="list-style-type: none"> mastery of visual aids no instruction necessary for high/low technology 	<ul style="list-style-type: none"> maintain use of high technology equipment refine or introduce new skills using low technology equipment 	<ul style="list-style-type: none"> competent but requiring ongoing instruction teach use of new low vision device 	<ul style="list-style-type: none"> introduction of high technology equipment/skills trialing of and/or application for equipment 	
USING SYMBOLS AND TEXT	<ul style="list-style-type: none"> Regular print no modification 	<ul style="list-style-type: none"> low vision reading at chronological age regular print with occasional modification 	<ul style="list-style-type: none"> large print required consistently 	<ul style="list-style-type: none"> Early print/braille/tactile literacy programme Literacy stages exposure, awareness, emergent 	<ul style="list-style-type: none"> Braille medium Literacy stages early, fluent Print to braille 	
ENVIRONMENTAL - ADAPTATIONS/ COMMUNICATION	<ul style="list-style-type: none"> no adaptations needed communication student responsibility 	<ul style="list-style-type: none"> advising classroom teacher in material modification, seating and lighting 	<ul style="list-style-type: none"> occasional need to adapt material student needing extra support for exams or tests pertinent individuals need termly/monthly communication 	<ul style="list-style-type: none"> frequent and ongoing need to adapt material weekly communication with learners relevant team members 	<ul style="list-style-type: none"> needs all curricular material in braille and/or tactile, electronic format paraprofessional need significant support in materials modification and braille production intensive communication with appropriate individuals in multiple settings 	
TRANSITION	<ul style="list-style-type: none"> No transition at this time 	<ul style="list-style-type: none"> Low vision student changing classrooms within a school 	<ul style="list-style-type: none"> Blind student changing classrooms within a school Moderate needs student starting school 	<ul style="list-style-type: none"> Low vision moving to intermediate, secondary or tertiary setting Preparing for transition from school 	<ul style="list-style-type: none"> moving from home to EC setting Moving from EC setting to EC setting/school Blind student moving to new educational setting New enrolment 	

 <h1>Appendix F</h1> <h2>[Student name]</h2> <h3>Individual Education Plan</h3>		<h4>Student thumbnail profile</h4> <p>Hobbies/interests [add here]</p> <p>Favourite subject [add here]</p> <p>Likes [add here]</p>		<p>[insert school logo]</p>	
<p>Name</p> <p>Age</p> <p>Language</p>		<p>Year</p>		<div> <p>Student thumbnail</p> <p>This is the 'About me' information</p> </div>	

<h3>[Student's] IEP Team</h3>						
	I am...	[Name]	[Name]			
	My role is...	Class teacher	School team (specialist teacher, SENCO, teacher's aide, other)	Parent, whānau	Specialist services	Student
	I will...					
	Present					
<p>Actions Agreement Responsibilities</p>						

<p>'I will...'</p> <p>Return to here when the new IEP goals have been agreed to say who, what and how for each team member.</p> <p>List any other team contributors – who, what and how?</p>
<p>Actions, agreement and responsibilities</p> <p>The IEP team agrees: How we will make it work. Agree about joint planning, programming, assessment, review - when/who/where?</p> <p>Who is going to do what? How are they doing it and by when? Are there any specialist services we need to access? How will we communicate with each other/let each other know how things are going?</p>

Meeting date:
Review date:
Apologies:

Looking back

Current achievement

What were the learning successes?

[add here]

What were the learning challenges?

[add here]

Goal	Review – How successful?	Comment	Action
1			
2			
3			
4			
5			

Looking forward

Vision | Dreams | Hopes

[add here]

Learning priorities for team

[add here]

Looking back

Input from all the team members across all aspects of life
What has gone well?
What was challenging?

Current achievement

If this is a first IEP consider where student is currently within the New Zealand Curriculum – assessments completed, specialist reports etc.

Goal

Goals from previous IEP

How successful?

How successful were we in meeting each goal?

Vision | Dreams | Hopes

What do we need to plan towards – are there any changes coming up? for the student ? in the team?

Learning priorities

What are the main areas of learning you would like to see some development in? for the student, family/whānau and team?

School/classroom programme for term

Learning area	Learning tasks including key competency development	Learning opportunities	Teaching and learning for differentiation/adaptation	Priority
[add here]	[add here]	[add here]	[add here]	[add here]
[add here]	[add here]	[add here]	[add here]	[add here]

New goals [Add here]	What will success look like? [add here]	Key teaching and learning (T&L) strategies [add here]
-------------------------	--	--

School/classroom programme
What is the school and classroom programme for the next term(s)? What are the learning activities that accompany the school/ class programme? What are the learning opportunities for this student that these contexts provide? What IEP format do we want to use?
Learning area
Consider learning areas of New Zealand Curriculum - What are our priorities for this IEP? – is there any information we need? Are any assessments needed?
Learning tasks
Class/school/community-based activities. Provided by classroom teacher
Learning opportunities
Skills/learning opportunities for student generated by the team
Differentiation/adaptation
Need for any differentiation to be successful? Need for adaptation to promote access/responding? Are there any assistive technology needs?
Priority
Will it be one of the 3-4 goals? Goals should reflect an immediate learning priority
How to... guides
How to write a goal.
What will success look like?
How will success be shown?
Key T & L strategies
This is the place to signal team goals and needs. Brief overview only (additional planning/ specific programming added /attached e.g. SLT programme).

Appendix G

Survey – Elaine Gilmour

BLENNZ



Blind and Low Vision Education Network NZ

Te Kōtuituinga Mātauranga Pura o Aotearoa

A National Network of Services for Children and Young People

131 Browns Road, Manurewa, Manukau 2102 Phone: 09-266 7109

Private Bag 801, Manurewa, Manukau, 2243 Fax: 09-268 3211

New Zealand

Email: avrc@blennz.school.nz

April 29, 2011

Dear Parent/Caregiver,

Re: Survey – Stereotypic Behaviour in New Zealand Children who are Blind

International literature suggests that Stereotypy or repetitive self-stimulatory behaviour occurs with great frequency in children who are blind. This is a survey which asks parents/caregivers to provide information about their child.

The survey has been approved by the BLENNZ Ethics Committee and the Ethics Committee of James Cook University in Australia, and is part of the requirements for PhD study by Elaine Gilmour.

As your child is enrolled on the BLENNZ Database, you are being asked to complete the attached survey. Any information you provide is strictly confidential. The survey is in three sections. Firstly, there are questionnaire guidelines; secondly, there is an Informed Consent Form; and thirdly, there is the Survey with accompanying chart.

Please work through the survey and return it in the enclosed envelope by June 15th, 2011.

Many thanks for your co-operation

Elaine Gilmour
BLENNZ Auckland

Questionnaire Guidelines – Section A

Section One – Personal Details of the Child

This information relates to age/birth date, gender, ethnicity, visual condition, visual acuity, existence of additional disabilities, educational placement.

Section Two – Existence of the Behaviour

The behaviours may be referred to in a number of ways. Terms such as manneristic behaviour, non-purposeful behaviour, blindisms, ritualistic, self-active engagement, and self-stimulation, are all ways to describe this behaviour, that is highly repetitive and appears to be irrelevant outside the individual.

You will be asked if your child displays, or has ever displayed, any of the behaviours listed on the attached chart.

Section Three - Frequency

This section involves rating the frequency of this behaviour. You will be asked how often you observe this behaviour in your child, using a rating of 1-7, as indicated by the descriptors:

Less than once a week, Once a week, Two/Three times a week, Once a day, Several times a day, Almost hourly, Unknown

Section Four – Duration

This section involves rating the length of time that an episode of the behaviour lasts. You will be asked how long an episode of the behaviour would normally occur, using a rating of 1-7 as detailed by the following descriptors.

Less than one minute, 1-3 minutes, 3-5 minutes, 5-10 minutes, More than 10 minutes, Continuously, Unable to determine.

Section Five – Context

This section involves thinking about when and why the behaviour occurs. There is a list of seven possible scenarios. You will be asked to identify which one(s) are relevant to your child.

These descriptors include:

When your child is angry, When your child is excited, When your child is left alone, When your child is bored, When you request something of or for your child, When your child is listening to books/music, Unsure

Section Six – Additional Information

You will be asked to add any comments you would like to make about this behaviour in your child such as whether it concerns you, how you may have managed the behaviour in your child, and how you think others react to this behaviour?

Thank you for your assistance with this survey. Your completion of the attached questionnaire will be greatly appreciated.

Section B

INFORMED CONSENT FORM PARENTS (QUESTIONNAIRE ONLY)

PRINCIPAL INVESTIGATOR	Elaine Gilmour
PROJECT TITLE:	Stereotypy in Children who are Blind in New Zealand
SCHOOL	Education

I understand the aim of this research study is to find out statistical data on the prevalence of stereotypy in children who are blind in New Zealand and to detail how these behaviours are managed in mainstream settings in order to provide guidelines to further best practice. I consent to participate in this project, the details of which have been explained to me, and I have been provided with a written information sheet to keep.

I understand that my participation will involve a survey questionnaire. I agree that the researcher may use the results as described in the information sheet.

I acknowledge that:

- taking part in this study is voluntary and I am aware that I can stop taking part in it at any time without explanation or prejudice and to withdraw any unprocessed data I have provided;
- that any information I give will be kept strictly confidential and that no names will be used to identify me with this study without my approval;

(Please tick to indicate consent)

I consent to complete a questionnaire

☐

Yes

☐

No

Name: *(printed)*

Signature:

Date:

Section C

Survey of Prevalence of Stereotypic Behaviour in New Zealand Children who are Blind

Please circle the correct information.

Section One – Personal Details

Age/Birth Date:	5-10	11-12	13-18
Gender:	Male	Female	
Ethnicity:	NZ European/NZ Maori/Pacific Island/ Asian/Other		
Educational Placement:	Primary/Intermediate/Secondary/Special		

Please record details or circle as appropriate

Visual Condition: _____

Is this condition congenital? Yes No

If no, when/how did the condition develop?

Was your child premature? Yes No

If yes, by how long? _____

Please record details or circle as appropriate

Visual Acuity

Blind / Severe Low Vision / Low Vision

Has your child's sight deteriorated/changed? Yes No

If yes, please give details

Does your child have additional disabilities? Yes No

Please circle the correct response

Existence of the Behaviour

Does your child display, or has ever displayed, this behaviour?

Yes No

If your child no longer exhibits the behaviour, at what age did they stop?

2-4 5-10 11-13 14-18

If you answered no to the question regarding existence of behaviour, the survey has been completed. Thank you.

Please post the entire document in the envelope enclosed.

*If you answered yes to the question regarding existence of behaviour, **please proceed to the chart on pages 9 and 10.***

*There is a list of descriptions of stereotypic behaviour, categorised by body part. Please tick **Column One** if you have observed this behaviour in your child.*

Please complete Column Two of the Chart on pages 9 and 10

Frequency

Please rate how often you have observed the behaviour in your child, using the Scale 1 to 7 below. This information is to be placed in Column 2.

1. Less than once a week
2. Once a week
3. Two/Three times a week
4. Once a day
5. Several times a day
6. Almost hourly
7. Unsure

Please complete Column Three of the Chart on pages 9 and 10

Duration

Please rate the length of time that an episode of this behaviour lasts using the Scale 1 to 7 below. This information is to be placed in Column 3.

1. Less than one minute
2. 1-3 minutes
3. 3-5 minutes
4. 5-10 minutes
5. More than 10 minutes
6. Seemingly continuous
7. Unsure

Please complete Column Four of the Chart

Context

Please identify, from the list of 8 possible scenarios, the contexts that are relevant to your child in relation to the behaviour. This information should be placed in Column 4 of the chart on pages 9 and 10.

1. When your child is angry
2. When your child is excited
3. When your child is left alone
4. When your child is bored
5. When you request something of or for your child
6. When your child is listening to books/music
7. When your child is tired
8. Unsure

Please add comments as necessary

Additional Information

Please add any comments you would like to make about this behaviour in your child. Does it concern you? How have you managed the behaviour in your child? How do you think others react to this behaviour? Use the space below.

Does it concern you?

How have you managed the behaviour?

How do others react?

Any other comments

Thank you for completing the questionnaire. Please post the documents in the envelope provided. Your time is greatly appreciated.

Stereotypic Behaviour in Children who are Blind

	<u>Section Two</u>	<u>Section Three</u>	<u>Section Four</u>	<u>Section Five</u>
Behaviour	Existence	Frequency 1-7	Duration 1-7	Context 1-8
<u>Face</u>				
Face contortions, mouth contortions				
Face tapping				
Sniffing and smelling				
<u>Head</u>				
Head banging				
Nodding				
Rolling and shaking				
<u>Hands and Arms</u>				
Eye poking, eye pressing and rubbing				
Twisting, flapping, fluttering, flicking hands/fingers				
Clapping hands				
Finger manipulation				
Hand regarding				
Object shaking				
Slapping, hitting, punching				
Tapping, stroking, wiping, rubbing				

<u>Legs and Feet</u>				
Leg swinging				
Kicking and stamping				
Foot wiggling				
<u>Vocal</u>				
Chanting, lamenting				
Whispering				
Echoing				
<u>Whole Body</u>				
Rocking				
Jumping up and down				

Appendix H

Interview Schedule

The New Zealand Curriculum has the function of setting the direction for student learning, with a vision of developing competencies that “allow young people to become confident, connected, actively involved life-long learners.” It is considered that people use these competencies to live, learn, work, and contribute as active members of their communities. Opportunities to develop these competencies occur in social contexts and are shaped by interactions with people, places, ideas and things. With reference to this document:

1. What are the achievement levels of the learner who is blind in relation to the five key competencies of:
 - thinking
 - relating to others
 - using language, symbols, and texts
 - managing self
 - participating and contributing
2. How do these levels compare to other learners of similar chronological age or of these within the peer group?
3. How do you identify the learning needs of the student who is blind in order to provide an appropriate programme in the classroom?
4. What are the key focus areas of the learner’s IEP?
5. The student who is blind displays stereotypic behaviour. This may be defined as repetitive movements that do not appear to attain any observable goals. What can you tell me about the student’s stereotypy?
6. What, if any, strategies do you use to manage this behaviour in the student who is blind?
 - Why do you use this particular strategy?
 - How does the learner who is blind react when you use this strategy?
7. Why do you use this particular strategy?
8. How does the learner who is blind react when you use this strategy?
9. How do other students in the class react when the learner who is blind exhibits this repetitive behaviour?
10. How do other students in the other classes react when the learner who is blind exhibits this repetitive behaviour in different contexts?
11. What do you know about these repetitive behaviours in general?
12. What resource would you consider to be useful in assisting mainstream teachers, who have responsibility for learners who are blind who display stereotypy?

This administrative form
has been removed

This administrative form
has been removed

Appendix J
BLENNZ Ethics Committee

This administrative form
has been removed

Appendix K

INFORMATION SHEET FOR PARENTS (QUESTIONNAIRE and CASE STUDY)

PROJECT TITLE: Stereotypy in Children who are Blind in New Zealand: Prevalence and Case Study Analysis

You are invited to take part in a research project about stereotypy in children who are blind in New Zealand.

Stereotypy is non-purposeful behaviour that can be referred to in a number of ways. Terms such as blindisms, ritualistic behaviour, self-active engagement, and self-stimulation are commonly used. Whichever term is used, this behaviour is highly repetitive and appears to be irrelevant outside the individual.

The aim of this research study is to find out statistical data on the prevalence of stereotypy in children who are blind in New Zealand and to detail how these behaviours are managed in mainstream settings in order to provide guidelines to further best practice. The study is being conducted by Elaine Gilmour and it will contribute to a research thesis in the Doctor of Philosophy at James Cook University.

If you agree to be involved in the study, you will complete a survey questionnaire and give permission for your child's teacher to be interviewed about how your child's stereotypy is managed. Taking part in this study is completely voluntary and you can stop taking part in the study at any time without explanation or prejudice. You may also withdraw any unprocessed data from the study. While it is unlikely that you will find the questions distressing if you do feel upset or distressed in any way please advise the researcher and you will be referred to someone who can help you or the researcher will provide the contact details (of an appropriate counselling service for you). Your responses and contact details will be strictly confidential. The data from the study will be used in research publications. You will not be identified in any way in these publications.

If you have any questions about the study, please contact Elaine Gilmour (see details below)

Principal Investigator: Elaine Gilmour
PhD Student
School of Education
James Cook University, Townsville 4811 AUSTRALIA
Phone: 61 747815424
Email: Elaine.Gilmour@jcu.edu.au

Supervisor: Associate Professor Paul Pagliano
School: School of Education
James Cook University, Townsville 4811 AUSTRALIA
Phone: 61 747815424
Email: paul.pagliano@jcu.edu.au

INFORMATION SHEET FOR PARENTS (QUESTIONNAIRE)

PROJECT TITLE: Stereotypy in Children who are Blind in New Zealand: Prevalence and Case Study Analysis

You are invited to take part in a research project about stereotypy in children who are blind in New Zealand.

Stereotypy is non-purposeful behaviour that can be referred to in a number of ways. Terms such as blindisms, ritualistic behaviour, self-active engagement, and self-stimulation are commonly used. Whichever term is used, this behaviour is highly repetitive and appears to be irrelevant outside the individual.

The aim of this research study is to find out statistical data on the prevalence of stereotypy in children who are blind in New Zealand and to detail how these behaviours are managed in mainstream settings in order to provide guidelines to further best practice. The study is being conducted by Elaine Gilmour and it will contribute to a research thesis in the Doctor of Philosophy at James Cook University.

If you agree to be involved in the study, you will complete a survey questionnaire. This should take about 15 minutes to complete.

Taking part in this study is completely voluntary and you can stop taking part in the study at any time without explanation or prejudice. You may also withdraw any unprocessed data from the study.

While it is unlikely that you will find the questions distressing if you do feel upset or distressed in any way please advise the researcher and you will be referred to someone who can help you or the researcher will provide the contact details (of an appropriate counselling service for you).

Your responses and contact details will be strictly confidential. The data from the study will be used in research publications. You will not be identified in any way in these publications.

If you have any questions about the study, please contact Elaine Gilmour (see details below)

Principal Investigator: Elaine Gilmour
PhD student
School of Education
James Cook University, Townsville 4811 AUSTRALIA
Phone: 61 747815424
Email: Elaine.Gilmour@jcu.edu.au

Supervisor: Associate Professor Paul Pagliano
School: School of Education
James Cook University, Townsville 4811 AUSTRALIA
Phone: 61 747815424
Email: paul.pagliano@jcu.edu.au

INFORMATION SHEET FOR TEACHERS

PROJECT TITLE: Stereotypy in Children who are Blind in New Zealand: Prevalence and Case Study Analysis

You are invited to take part in a research project about stereotypy in children who are blind in New Zealand.

Stereotypy is non-purposeful behaviour that can be referred to in a number of ways. Terms such as blindisms, ritualistic behaviour, self-active engagement, and self-stimulation are commonly used. Whichever term is used, this behaviour is highly repetitive and appears to be irrelevant outside the individual.

The aim of this research study is to find out statistical data on the prevalence of stereotypy in children who are blind in New Zealand and to detail how these behaviours are managed in mainstream settings in order to provide guidelines to further best practice. The study is being conducted by Elaine Gilmour, and it will contribute to a research thesis in the Doctor of Philosophy at James Cook University.

If you agree to be involved in the study, you will be invited to be interviewed about a child you work with who is blind and displays stereotypy. Permission will also be obtained from the child's parents for you to talk about their child's behaviour. The interview, with your consent, will be audio-taped, and should only take approximately 1 hour of your time. The interview will be conducted at a venue of your choice.

Taking part in this study is completely voluntary and you can stop taking part in the study at any time without explanation or prejudice. You may also withdraw any unprocessed data from the study.

While it is unlikely that you will find the questions distressing if you do feel upset or distressed in any way please advise the researcher and you will be referred to someone who can help you or the researcher will provide the contact details (of an appropriate counselling service for you).

Your responses and contact details will be strictly confidential. The data from the study will be used in research publications. You will not be identified in any way in these publications.

If you have any questions about the study, please contact Elaine Gilmour (see details below)

Principal Investigator: Elaine Gilmour
PhD student
School of Education
James Cook University, Townsville 4811 AUSTRALIA
Phone: 61 747815424
Email: Elaine.Gilmour@jcu.edu.au

Supervisor: Associate Professor Paul Pagliano
School: School of Education
James Cook University, Townsville 4811 AUSTRALIA
Phone: 61 747815424
Email: paul.pagliano@jcu.edu.au

INFORMED CONSENT FORM TEACHERS

PRINCIPAL INVESTIGATOR	Elaine Gilmour
PROJECT TITLE:	Stereotypy in Children who are Blind in New Zealand: Prevalence and Case Study Analysis
SCHOOL	Education

I understand the aim of this research study is to find out statistical data on the prevalence of stereotypy in children who are blind in New Zealand and to detail how these behaviours are managed in mainstream settings in order to provide guidelines to further best practice. why some adults have trouble reading and writing and to investigate ways of improving these skills. I consent to participate in this project, the details of which have been explained to me, and I have been provided with a written information sheet to keep.

I understand that my participation will involve an **interview** and I agree that the researcher may use the results as described in the information sheet. I also understand that the child's parents have given their written permission for me to be interviewed about the management of the child's stereotypy.

I acknowledge that:

- any risks and possible effects of participating in the **interview** have been explained to my satisfaction;
- taking part in this study is voluntary and I am aware that I can stop taking part in it at any time without explanation or prejudice and to withdraw any unprocessed data I have provided;
- that any information I give will be kept strictly confidential and that no names will be used to identify me with this study without my approval;
- confidentiality cannot be assured in focus groups.

(Please tick to indicate consent)

I consent to be interviewed

☐

Yes

☐

No

I consent for the interview to be audio taped

☐

Yes

☐

No

Name: *(printed)*

Signature:

Date:

INFORMED CONSENT FORM PARENTS (QUESTIONNAIRE and CASE STUDY)

PRINCIPAL INVESTIGATOR	Elaine Gilmour
PROJECT TITLE:	Stereotypy in Children who are Blind in New Zealand
SCHOOL	Education

I understand the aim of this research study is to find out statistical data on the prevalence of stereotypy in children who are blind in New Zealand and to detail how these behaviours are managed in mainstream settings in order to provide guidelines to further best practice. I consent to participate in this project, the details of which have been explained to me, and I have been provided with a written information sheet to keep.

I understand that my participation will involve a survey **questionnaire and my permission for a teacher to discuss how my child's stereotypy is being managed**. I agree that the researcher may use the results as described in the information sheet.

I acknowledge that:

- taking part in this study is voluntary and I am aware that I can stop taking part in it at any time without explanation or prejudice and to withdraw any unprocessed data I have provided;
- that any information I give will be kept strictly confidential and that no names will be used to identify me with this study without my approval;

(Please tick to indicate consent)

I consent to complete a questionnaire	<input type="checkbox"/>	Yes	<input type="checkbox"/>	No
I consent to my child's teacher being interviewed about how my child's stereotypy is managed	<input type="checkbox"/>	Yes	<input type="checkbox"/>	No

Name: <i>(printed)</i>	
Signature:	Date:

INFORMED CONSENT FORM PARENTS (QUESTIONNAIRE ONLY)

PRINCIPAL INVESTIGATOR	Elaine Gilmour
PROJECT TITLE:	Stereotypy in Children who are Blind in New Zealand
SCHOOL	Education

I understand the aim of this research study is to find out statistical data on the prevalence of stereotypy in children who are blind in New Zealand and to detail how these behaviours are managed in mainstream settings in order to provide guidelines to further best practice. I consent to participate in this project, the details of which have been explained to me, and I have been provided with a written information sheet to keep.

I understand that my participation will involve a survey **questionnaire**. I agree that the researcher may use the results as described in the information sheet.

I acknowledge that:

- taking part in this study is voluntary and I am aware that I can stop taking part in it at any time without explanation or prejudice and to withdraw any unprocessed data I have provided;
- that any information I give will be kept strictly confidential and that no names will be used to identify me with this study without my approval;

(Please tick to indicate consent)

I consent to complete a questionnaire

☐

Yes

☐

No

Name: *(printed)*

Signature:

Date:

Appendix L

Pilot Survey of Prevalence of Stereotypic Behaviour in New Zealand Children who are Blind

Section One – Personal Details

Please circle the correct information.

Age/Birth Date:	5-10, 11-12, 13-18
Gender:	Male/Female
Ethnicity:	NZ European/NZ Maori/Pacific Island/ Asian/Other
Educational Placement:	Primary/Intermediate/Secondary/Special

Please record details as appropriate

Visual Condition:
Visual Acuity:
Existence of Additional Disabilities:

Section Two – Existence of the Behaviour

Please circle the correct response

Does your child display this behaviour? Yes/No

If yes, please continue. If no, the survey has been completed.

*Go to the chart below of descriptions of stereotypic behaviour, categorised by body part.
Please tick the first column if you have observed this behaviour in your child.*

Section Three – Frequency

*Please rate how often you have observed the behaviour in your child, using the scale below.
This information is to be placed in column 2.*

1. Less than once a week
2. Once a week
3. Once a day
4. Several times a day
5. Almost hourly

Section Four – Duration

Please rate the length of time that an episode of this behaviour lasts using the scale below. This information is to be placed in column 3.

1. Less than one minute
2. 1-3 minutes
3. 3-5 minutes
4. 5-10 minutes
5. More than 10 minutes

Section Five – Context

Please identify, from the list of possible scenarios, the contexts that are relevant to your child in relation to the behaviour.

1. When your child is angry
2. When your child is excited
3. When your child is left alone or is bored
4. When you request something of or for your child
5. When your child is listening to books/music

Section Six – Additional Information

Please add any comments you would like to make about this behaviour in your child, such as whether it concerns you, how you have managed the behaviour in your child, and how you think others react to this behaviour. Use the space below.

Thank you for completing the questionnaire. Please post the documents in the envelope provided. Your time is greatly appreciated.

Stereotypic Behaviour in Children who are Blind

Behaviour	Existence	Frequency 1-5	Duration 1-5	Context 1-5
Face				
Face contortions, mouth contortions				
Chanting, lamenting, whispering				
Sniffing and smelling				
Head				
Head banging				
Nodding				
Rolling and shaking				
Hands and Arms				
Eye poking and rubbing				
Twisting, flapping, fluttering, flicking				
Clapping hands				
Finger manipulation				
Hand regarding				
Object shaking				
Slapping, hitting, punching				
Tapping, stroking, wiping, rubbing				
Legs and Feet				
Leg swinging				
Kicking and stamping				
Foot wiggling				

Appendix M

Stereotypic Behaviour: Information for Parents/Caregivers and RTVs

- Stereotypic behaviour is very common in children who are blind
- Stereotypic behaviour refers to repetitive body movements or repetitive movements of objects by an individual
- The movements appear to have little functional significance apart from to the individual
- Stereotypic behaviour may be of concern when it interferes with learning and the development of culturally socially acceptable behaviour
- Descriptors of the behaviour are usually considered in respect to the body part involved –
eg: hands/arms – flapping, flicking fingers, eye pressing
Eg: head rolling, head shaking, head nodding
- Four major theoretical approaches are documented that offer explanations as to the aetiology of the behaviour.
 - a) Behavioural: learned and maintained
 - b) Developmental: part of maturation and remains
 - c) Arousal-modulation: environmental stimulation levels
 - d) Neurobiological: controlled by the brain
- All approaches may be relevant

Appendix N

Stereotypic Behaviour: Intervention Purpose and Intervention Guidelines

Purpose

- Engagement in learning
- Enhanced learner outcomes
- Empowerment of the learner
- Improved social interaction
- Enhanced social capital

Guidelines

- Functional Behavioural Assessment
- Learner involvement in decision making
- Congruent to learner needs
- Ethically defensible
- Change or replacement behaviour
- Approach for learner empowerment
- Collaborative and consultative process
- Beneficence and non-maleficence