

**Students first:**

**A trans-disciplinary team approach**

**to the education of a student**

**with Battens disease.**

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## **Abstract**

This New Zealand case study explored how ten members in one trans-disciplinary team perceive and meet the educational needs of a student with Batten's disease in an inclusive school setting and uses qualitative methodology. This report details the results of ten semi-structured interviews that were conducted with the trans-disciplinary team members. There were three themes that emerged from this research. Firstly, all the team members were in agreement that the student's happiness was of paramount importance and they wanted her to be included with her peers. Secondly, the family's goals and aspirations for the student's education had become a driving force and academic goals were conspicuous by their absence. Thirdly, the team had a holistic trans-disciplinary approach to the student's education and valued the opportunity to share information and discuss issues. Also the IEP process was adapted to support the trans-disciplinary team members as well as the planning process for a student with deteriorating physical and cognitive skills.

## Glossary of Terms

**Adaptations** – Changes made to the task, activity, materials or teaching strategies so the student can access the curriculum. This includes the technology the student uses.

**Batten’s Disease** – A neurodegenerative condition where vision impairment is usually the first symptom.

**Educational professionals** – This includes specialist members of the team such as the special education advisor (SEA), speech language therapist (SLT), physiotherapist (PT) and occupational therapist (OT). In this report it will also include the Royal New Zealand Foundation for the Blind (RNZFB) developmental orientation and mobility instructor (DOM).

**Expanded Core Curriculum** – A supplementary curriculum that has been developed to support the unique learning needs of vision impaired students and supports the standard school curriculum.

**Inclusion** – A process that “involves supporting all children and young people to participate in the cultures, curricula and communities of their local schools” (Ministry of Education, 2008a).

**Inclusive education** – “A process of increasing the participation of pupils, in and reducing their exclusion from, the cultures, curricula, and communities of their local schools” (Ainscow, 1999 cited in Higgins, McArthur & Morton, 2008, p. 174).

**Individual Education Plan (IEP)** – A formal document that is developed by the team to set goals, detail teaching strategies, identify resources needed, assign team members’ responsibility as well as monitor and evaluate progress.

**Individual Education Plan Process** – The process used by the IEP team to develop, implement and evaluate the IEP.



**Neurodegenerative condition** – A deteriorating condition affecting physical and cognitive ability that results in a shortened life expectancy and premature death

**Trans-disciplinary, Educational or IEP team** – This is made up of all the people, who have input into the child's education. It includes the parents, teachers, teacher aides and other educational professionals.

# Chapter 1

## Introduction

This qualitative research developed from my interest and experience teaching a student with Batten's disease and has a single-subject case study methodology. The purpose of this study was to investigate how a trans-disciplinary team manages to support a student with Batten's disease in an inclusive setting. I was interested to find out how they adapted the curriculum and their reporting processes to meet the regulations that are stipulated by the New Zealand Ministry of Education, as well as how they support each other, the family's goals and the student's needs. In addition I also wanted to find out the trans-disciplinary team's priorities for the education of a student with Batten's disease.

Batten's disease is a degenerative neurological condition and is the "most common neurodegenerative disorder of childhood" (Scrambler, 2005, p. 2). The onset of Batten's disease is typically between four and ten years of age with people generally living into their late teens or early twenties (The Australian Chapter of Batten's Disease Support & Research Association, 2005; Bills, Johnston, Wilhelm & Graham, 1998).

Initially, children start losing their vision (Bowman, Bowman & Dutton, 2001) and eventually become blind, usually before any other symptoms develop (Batten Disease Support & Research Association, [BDSRA], 2005; Koehlar & Loftin, 1994; Loftin & Koehlar, 1998). Besides blindness, another symptom of Batten's disease, which has an impact on the students' education, is the reduced ability to learn new, or maintain, existing skills (Johnson & Jochum, 1996). Other symptoms may include epilepsy, reduced cognitive functioning, deteriorating gross and fine motor skills, slurred speech, behavioural and personality changes as well as other psychiatric symptoms (Bäckman, Santavuori, Åberg & Aronen, 2005; Batten Disease Family Association, [BDFFA], 2008; BDSRA, 2005; Blaikie, 2001; Hofman, 1990; Johnston, 2000).

Like many other disabled students in New Zealand, students with Batten's disease are usually educated in a mainstream setting, which is supported by the 1989 Education Act (Ministry of Education, 2008b). The 1989 Education Act mandated that all students have the right to be educated in their local school and have equal access to the curriculum whether they are disabled or not (Ministry of Education, 2008b). The latest New Zealand curriculum document, which was released in 2007, reiterated New Zealand's commitment to education for all, and stated that all students' learning needs will be addressed (Ministry of Education, 2007). In New Zealand, children with high educational needs are eligible to apply for, and access, supplementary support through the Ongoing and Reviewable Resourcing Schemes (ORRS) provided that they meet the funding criteria. ORRS provides individualised funding to support the educational or physical needs of disabled students at school, which may include teacher-aide support, therapy, specialist teaching and specific programmes (O'Brien & Ryba, 2005).

Social interaction can be promoted between disabled people and their peers by spending time in inclusive environments (Closs, 2000a; MacArthur & Kelly, 2004). However, merely having disabled students in a mainstream class is not enough, because there are other ways that they may be excluded (Kearney & Kane, 2006; MacArthur, 2005). Sometimes there are barriers to the inclusion of disabled students, such as teacher inexperience, lack of facilities or support within a school as well as the suitability of the curriculum to meet their educational needs (Bills, 2006; Gallagher, 2007; Johnson & Jochum, 1996; Kelley, Gale & Blatch, 1998; MacArthur, Kelly & Higgins, 2005; Ring & Travers, 2005; Vaughn, Schumm, Jallad, Slusher & Saumell, 1994). When I was setting goals for a student with Batten's disease, that I taught, the latter became an issue for me. In addition, I discovered that a number of other issues were also raised for me.

I found that my expectation that students will progress conflicted with the cognitive decline of a student with Batten's disease. Initially, when my student first went blind, it was fulfilling to see her progress as she learnt Braille and the tactile skills needed for the future. However, after several years this progress slowed and eventually her skills started to regress. I became concerned because the effects of student regression did not fit with my underlying philosophy of education that all students can learn and

progress even if only in small steps. I relied heavily on the backing of my trans-disciplinary team, which discussed issues, shared information and had a joint problem-solving approach. As a team, we valued the support we were able to give each other and encouraged the active involvement of the family in all aspects of the student's education. However, it became difficult for the education team to set achievable goals that met the aims of the current New Zealand curriculum such as the assumption that students will make progress, which will increase their motivation and confidence (Ministry of Education, 2007) as well as "realise their full potential" (Ministry of Education, 2006). In addition to setting goals, other concerns that were raised for myself and the team included adapting the curriculum, identifying ways to support the student, her family and the team members and the difficulties finding information about the impact on the education for students with Batten's disease.

The education of severely disabled students lends itself to a trans-disciplinary team approach because the complexity of the student's needs require a diverse and cooperative team to ensure that the all student's needs are being met (Chapman & Ware, 1999; Sirvis & Caldwell, 1995). The trans-disciplinary approach enables everyone's views to be heard, their input into the decision-making process to be valued, and all team members, including the family, to be supported (Fraser, 2005).

The trans-disciplinary team compile the Individual Education Plan (IEP), which is a way of setting goals for disabled students. The IEP process prioritises the student's goals; documents the support required by the student; the strategies and adaptations needed to achieve the goals; and monitors student progress (Beattie, Jordan & Algozzine, 2006; Closs, 2000b; Moltzen, 2005; Nagel, 2005a; Riddell, 2006; Riddell, 2007; Rodger, 1995; Rokne, 2006; Sigafos & Arthur, 2002; Thomson & Rowan, 1995; Vision Education Agency, 2003; Ysseldyke, Algozzine & Thurlow, 2000).

In this study, parents, teachers and other members of the trans-disciplinary team, with first-hand knowledge of a student with Batten's disease, were interviewed to explore their experiences of meeting her educational needs (Davidson & Tolich, 1999). Team members were asked about their goals for the student's education and what adaptations and strategies they had used, the issues they had faced and their involvement as part of the IEP process. Parents' experiences were also sought

because they are an integral part of the trans-disciplinary team and the IEP process as well as having a key role in the education of their child. Other forms of educational planning were also explored.

There were three main aims of this study. The first was to develop an understanding of how one trans-disciplinary team and its individual members develop goals and identify needs for a student with Batten's disease. The second aim was to explore how the team had adapted the curriculum to meet the student's needs and the third aim was to look at what made this trans-disciplinary team work so well together and support each other.

### **Research questions**

In New Zealand, it appears that there has been no published educational research, about students with Batten's disease of which I am aware. I, therefore, wanted to take an exploratory approach that focused on the experiences of one educational team, who were involved in the education of a student with Batten's disease. The overriding research question that has guided the present study was:

- In what ways do parents, teachers and other members of the IEP team think about, adapt to, and plan for the educational needs of a student with Batten's disease?

There were four supplementary research questions:

- What are the goals that parents, teachers and other members of the IEP team have for a student with Batten's disease?
- What adaptations are made to the IEP and the IEP process to better meet the needs of a student with Batten's disease?
- What adaptations and strategies are used to accommodate a student with Batten's disease in the class?
- What are parents' perspectives on the extent of their involvement in the education of their child with Batten's disease?

The following chapters of this dissertation will describe the present study, setting it in time and place as well as reporting and discussing the results. In the glossary, you will find short descriptions of some of the terminology used in this report. Throughout this dissertation, I refer to disabled people or disabled students, rather than people with disabilities or students with disabilities, which is in line with the language used in the New Zealand Disability Strategy (Minister for Disability Issues, 2001). The New Zealand Disability Strategy stated that:

Disability is not something individuals have. What individuals have are impairments. Disability is the process which happens when one group of people create barriers by designing a world only for their way of living, taking no account of the impairments other people have.

(Ministry of Health, 2001, p. 7)

Chapter two comprises the literature review, which includes the theoretical underpinnings to this study, as well as a discussion about the research topic. The methodology and method are reported in the third chapter. There were three major themes that emerged from the results of this research and these are reported in chapter four and discussed in chapter five. Finally, chapter six is the conclusion of this dissertation and identifies some limitations of this study and highlights some areas that may warrant further research.

## Chapter 2

### Literature review

In this chapter, I will outline how the New Zealand education system supports disabled students and their families in inclusive settings and the research that has been undertaken about disabled students and social relationships. I then discuss the IEP process and the trans-disciplinary team approach. The educational implications for disabled students with neurodegenerative conditions are considered and the lack of educational research about Batten's disease is discussed.

Education has been defined in many different ways and fulfils many purposes in society. It usually refers to the "act or process of acquiring knowledge" (The Collins Concise Dictionary Plus, 1990). Mark Holmes (1990, cited in Simpson & Jackson, 1997) defined six main purposes of education. These aims included academic, cultural, social, expressive, vocational and moral or spiritual ones. Holmes agreed with other writers, who stated that the purpose of education is the acquisition of skills and knowledge and the development of "intellectual inquiry" (cited in Simpson & Jackson, 1997, p. 50), so that information can be expressed in a variety of ways. However, Holmes (cited in Simpson and Jackson, 1997) took a broader perspective and said that education was the introduction of students to their cultural heritage; learning the social and practical skills to become independent members of society; as well as moral or spiritual goals.

During the twentieth century, attitudes to education, worldwide, underwent a series of changes. Much of this change was based on the educational theories of John Dewey, who, although writing at the turn of the twentieth century, still continues to influence education today. Nowell (1992) argued that Dewey emphasised the importance of active participation in educational experiences, which is in line with the current Ministry of Education policies. Dewey felt all areas of society should be involved in education (Shaw, 2002). He wrote, "I believe that education, ... is a process of living and not a preparation for the future" (Dewey, 1897). "Everything depends on the quality of the experience" (Dewey, 1938, p. 16, cited in Hardie, 1966). Dewey

thought that the school curriculum should be individualised and fit the student rather than the student fitting the curriculum (Nelson, 1998). Berger (1965) stated that Dewey's vision was for:

A system of education that best recognizes the dignity and worth of all individuals that allows every individual to develop to his fullest, and that teaches the virtues of democracy by establishing a democratic atmosphere.  
(p. 131)

Dewey valued the parent role and stated that parents' aspirations for their children should be reflected by schools (Dewey, 1902, cited in Thrupp, 1997; Olssen, 1997) because parents have a valuable role to play in their child's education (Higgins, 2001). Currently, New Zealand educational policy reflects the principles of an education system that is parent-driven (Nutbrown & Clough, 2006). This is demonstrated in the Ministry of Education's assumption that parents will be involved in the IEP process and the educational needs of their disabled child.

There have been two main policy changes, which have had an impact upon the education of disabled students in New Zealand. The first was the 1989 Education Act (Millar & Morton, 2007; Wills, 2006), which gave all students the right to attend their local school irrespective of their impairment (Ballard, 1990; Ministry of Education, 2005). The second was Special Education 2000, which was released by the Ministry of Education in 1996 (Millar & Morton, 2007; Wills, 2006). Special Education 2000 related to "the provision of services to" disabled students (Blatch, Nagel & Cruikshank, 1998, p. 20). Its goal was to have an education system that ensured disabled students had an equitable access to resources based on their individual needs (Ministry of Education, 1998a; Quinn & Ryba, 2000). It guaranteed resourcing levels for students with high learning support needs (Blatch, et al., 1998).

Education is the key to helping students meet their full potential (Adams, Clark, Codd, O'Neill, Openshaw & Waitere-Ang, 2000; Ministry of Education, 2006). Duff (2006) asserted that "all children can learn" (p. 143) and other writers have qualified this by adding "and succeed but not all" in the same way at the same time (Meyen, 1995, p. 128; Sapon-Shevin, 2007, p. 71). The New Zealand Curriculum (Ministry of



Education, 2007) added that it should be recognised that “as all students are individuals, their learning may call for different approaches, different resourcing and different goals” (p. 39). Underlying this is an assumption that all students are able to attain achievable goals and learn skills in a forward progression and can be educated in inclusive settings.

## **Inclusion**

Inclusion is considered an important part of New Zealand’s education system, and the Ministry of Education and all schools are expected to be inclusive (Mitchell, 2000). The latest New Zealand curriculum document, launched in 2007, stated that inclusion is one of the foundation principles of New Zealand’s education system and should underpin “all school decision making” (Ministry of Education, 2007, p. 9). In an inclusive educational system, the learning needs and abilities of all students should be addressed (Bevan-Brown, 2006; Ministry of Education, 2007; Slee, 2001). However, questions are being raised about the lack of progress towards inclusion in New Zealand schools (Bevan-Brown, 2006; Higgins, MacArthur & Morton, 2008).

All students benefit from having learners with disabilities in mainstream education settings (Attfield, 2004; Bier, 2007; Henry-Beauchamp, 2007; Lipsky & Gartner, 1999; Millar & Morton, 2007; Nagel, 2005b; Sapon-Shevin, 2007). However, researchers have argued that merely placing a student in a mainstream setting does not promote inclusion (Higgins & Ballard, 2000; Higgins, et al., 2008; Kelley, et al., 1998). Higgins, MacArthur and Morton (2008) stated that there is evidence, in the literature, that “disabled students do better academically and socially, when they are taught in regular education settings, rather than in special schools or classes” (p. 182). Alternatively, some people feel students with special needs should be educated in separate settings from their peers (Elkins, 2002; Ysseldyke, Algozzine & Thurlow, 2000), such as special schools or units. Kniveton (2004) found that English parents and teachers, who had little experience of inclusion, thought that students with visual impairments, learning impairments or behavioural difficulties should not be educated in mainstream settings. In contrast, Ballard and MacDonald’s (1998) research in a New Zealand school found that teachers of disabled students supported inclusion and thought all students should attend their local school. The teachers did not question

whether disabled students should be educated anywhere else, but their local school, and they stated that the disabled students would be included even if the school resources were limited (Ballard & Macdonald, 1998).

One of the features of an “inclusive curriculum” is that the programme meets the needs of the student in a mainstream setting rather than the student being required to fit into the programme (Hall, 2004; Quinn & Ryba, 2000; Rose, 2007). Parents have definite views on how they would like their child included at school. In a French and an English study, parents stated they wanted their children welcomed and included at the school (Ebersold, 2003; Rogers, 2007). However, Rogers (2007) recognised that this was not happening for many of the English children in her study.

Students are considered fully included when they are in a class on a full-time basis with same aged peers and have the support that they need to participate fully in the social and academic life of their peers (Blatch, et al., 1998; Mitchell, 2000, Power-deFur & Orelove, 1997; Soan, 2004a; Tuttle & Ferrell, 1995; Werts, et al., 2007). MacArthur (2005) highlighted that all people benefit from having social relationships and disabled students are no exception. Students enjoy spending time with their peers and inclusive environments can help facilitate their social interactions (Closs, 2000a; MacArthur & Kelly, 2004).

Kelley, et al. (1998) argues that in order to be certain that students in the mainstream are not excluded barriers to inclusion need to be identified and curriculum adaptations made. Gallagher (2007) concurs with this and suggested that the disabled student’s needs should be integrated into the class programme. British parents identified a variety of ways that their children were excluded from mainstream classes (Rogers, 2007). These included difficulty accessing the curriculum, social isolation, difficulty maintaining friendships and being removed from class for individual work, (Rogers, 2007).

### **Social relationships**

Friendships and social interactions are essential for “social and emotional development” (MacArthur, 2005, p. 30; MacArthur & Morton, 1999; Perske, 1988;

Sacks & Barclay, 2006; Wolffe, 2006). MacCuspie (1996) identified that friendship serves six basic functions. These are companionship; sharing information with peers; helping each other; encouragement and praise; making social comparisons; as well as affection and intimacy. Developing strategies and teaching techniques that promote inclusion as well as opportunities for social interaction are ways of increasing the involvement of disabled students in the educational setting (Higgins, 2001; MacArthur, 2002). It is not enough to simply place a disabled student “in the mainstream environment” because it “does not ensure a child will make friends and become truly involved and accepted” (Thorburn, 1999, p. 8).

Social interactions and friendships contribute to a student’s happiness (Noddings, 2003; Perske, 1988) and teachers should to be sensitive to the needs of their students if they are to be happy and fulfilled at school (Campoy, 2005; Pavri, 2001). According to Fraser (2001a), researchers have found that “learning and well-being is enhanced when peer relationships are positive” (p. 9).

The effects of social interaction on the happiness of profoundly disabled people were assessed by three quantitative American studies (Davis, Young, Cherry, Dahman & Rehfeldt, 2004; Green & Reid 1999; Logan, Jacobs, Gast, Murray, Daino & Skala, 1998). All three studies used a similar criterion to assess the happiness of people with profound disabilities. They gauged their participants’ happiness using facial expressions, such as smiling and laughing, as well as vocalisations that are typically associated with happiness amongst non-disabled people (Green & Reid, 1999). Green and Reid (1999) found that the five profoundly disabled adults, whom they studied, were happier when they were interacting with their peers as were the five elementary school students in Logan et al.’s (1998) study. Davis et al. (2004) found that social interaction also increased the happiness of their three adult participants. However, these studies need to be viewed with caution because the sample sizes were small and all the subjects were in special education settings.

“Opportunities for social interaction are important for the development and well-being of students” (Copeland, 2006, p. 98). However, friendships are not confined to the school grounds and planning for social interaction should take “wider contexts into consideration” (MacArthur, 2005, p. 364). Teaching a disabled student social skills is not enough to foster friendships because families, school staff and peers are also important parts of the process (MacCuspie, 1996). Social relationships between disabled students and their peers may need to be fostered by adults at first (Fraser, 2002; Meyer & Bevan-Brown, 2006; Rietveld, 1998; Werts, et al., 2007), so that students develop the skills to communicate and socialise with their peers independently (MacArthur, 2005; Perske, 1988; Wolffe, 2006). A wide range of teaching and learning strategies that are used in inclusive classrooms can help facilitate these interactions (Closs, 2000a; Lipsky & Gartner, 1999; MacArthur & Kelly, 2004; Wolffe, 2006). Some of the strategies are cooperative learning, peer tutoring (Dion, Fuchs & Fuchs, 2007; Fraser, 2001a; Sapon-Shevin, 2007; Udvari-Solner & Thousand, 1996), scaffolding (Gillies, 2002) and experiential activities (Lipsky & Gartner, 1999).

### **Supporting the Inclusive Environment**

Partnerships, collaboration, communication and social interactions are all factors that help make a supportive inclusive environment for disabled students (Quinn & Ryba, 2000). A New Zealand study found that a highly positive attitude to inclusion by teachers was linked with “positive academic outcomes” for all students (Monsen & Frederickson, 2004, p. 138). Fostering a good relationship between the parents, educators and the professionals involved with the child, also helps ensure the needs of the student are met (Nagel, 2005b; Spedding, 1996).

Collaboration between the education team members provides a forum for dealing with issues that have arisen through a joint problem-solving approach (Ashman, 2002; Beattie, et al., 2006; Jackson, 2000;). Good communication is essential in the process, both as a way of sharing information and planning the programme (Beattie, et al., 2006; Nagel, 2005b). Collaboration between a classroom teacher and a specialist teacher can effectively support the education of a disabled student (Bier, 2007; Bishop, 1986). The specialist teacher helps deliver the curriculum and support the

class teacher by advising on, or providing, strategies to adapt and modify the task (Dyson & Milward, 1996 cited in Higgins, 2001).

Teacher training is the key to successful inclusion of a student with special needs and should involve as many of the school staff as possible (Butt & Cosser, 2004; Jackson, 2000). However, research indicates that mainstream teachers feel they do not have the expertise needed to accommodate special needs students in their classrooms (MacArthur, Kelly & Higgins, 2005). Teachers in a French study felt it was important to have information on the student's condition before the student started in their class (Ebersold, 2003). Similarly, lack of information also appeared to be a factor for New Zealand teachers of students with vision impairment, who reported that they did not know how to help their students meet their potential and how to adapt their teaching practises (O'Brien, 1989).

In an Irish study undertaken by Ring and Travers (2005), teachers of a boy with a learning disability said they felt he needed a specialist teacher to meet his needs and access the resources that the specialist teacher provided. Similar findings were reported by Vaughn, Schumm, Jallad, Slusher and Saumell (1994) in their study on the implementation of inclusion in the United States of America. Teachers were concerned that they had neither adequate preparation nor appropriate resources to instruct students in an inclusive classroom. They thought this was detrimental to both "students with and without disabilities" (Vaughn et al. 1994, p. 28). It has been suggested that working as part of a team in a co-teaching situation may help support and increase the skills of teachers, who are unfamiliar with inclusion (Falvey, Coots, Bishop & Grenot-Scheyer, 1989, cited in Higgins 2001).

The teacher's views reported in these studies fit with the observations made by writers (Bills, 2006; Johnson & Jochum, 1996) in the United States, who said that teachers of students with Batten's disease need specialist skills and knowledge. Teachers also need to be given information and training to work with students with Batten's disease and set appropriate goals for their education (Bills, 2006; Johnson & Jochum, 1996) because of the degenerative nature of the condition.

## **Individual Education Plan**

In New Zealand the Individual Education Plan (IEP) is an “administrative requirement” (Ashman & Elkins, 2002, p. 63; Thomson & Rowan, 1995) that has been used in New Zealand schools since the early 1980’s (Williams & Nagel, 2001). Thomson and Rowan (1995) contended that the IEP process was a response to the increased need for parent involvement in their child’s education.

An IEP is a “collaborative process” (Mentis, Quinn & Ryba, 2005, p. 82) providing a formal method of accountability for disabled students (Meyen, 1995; Riddell, 2007; Thomson, Brown, Chapman, Benson & Pine, 1991) through an individualised programme (Espin, Deno & Albayrak-Kaymak, 1998). It provides a forum for setting goals; discussing teaching strategies; identifying the resources that are needed; assigning responsibility; monitoring; and evaluating progress (Beattie, et al., 2006; Closs, 2000b; Hazekamp, 1986; Moltzen, 2005; Nagel, 2005a; Riddell, 2006; Riddell, 2007; Rodger, 1995; Rokne, 2006; Sigafos & Arthur, 2002; Thomson & Rowan, 1995; Vision Education Agency, 2003; Ysseldyke, Algozzine & Thurlow, 2000). IEPs should be inclusive, age-appropriate (Ryba & Annan, 2005) and have “short-term, achievable targets” allowing the student to “progress at their own pace ensuring success” (Pickles, 2004, p. 37).

One of the strengths of the IEP process is its consultative nature (Mentis, et al., 2005; Skrtic, 1995; Thomson, et al., 1991). Each team member brings his or her expertise and experience from his or her respective fields to the team, to develop a set of goals that meet the individual needs of the student (Ministry of Education, 1998b, Moltzen, 2000; Thorburn, 1997). As part of the process, the team prioritises the goals and identifies the team member, who will be responsible for their implementation (Ashman & Elkins, 2002; East & Evans, 2006; Sailor, Gee & Karasoff, 1993; Thomson, et al., 1991).

### ***Individual Education Plan Research***

By the mid 1990s there had been a substantial amount of overseas research conducted about the IEP process, especially in the United States, but there was little in New Zealand (Thomson & Rowan, 1995). Thomson and Rowan's (1995) literature review found that the main areas of concern overseas were the content of the IEP and problems with the process, itself. In recent years attempts have been made to canvas the opinions of New Zealand teachers and parents about their involvement in, and experiences of, the IEP process to establish the effectiveness of the IEP process. Williams and Nagel (2001) canvassed seventy-five New Zealand parents' of students with a vision impairment, who were involved in the IEP process at that time. They made the point that parents wanted to be an integral part of the team. The parents and teachers in Thomson and Rowan's (1996) focus groups said that they thought the team approach was a strength of the IEP process. However, they also commented that the meetings, themselves, and the lack of training for teachers were weaknesses of the system. Parents have criticised the IEP process and have identified issues with it. Some felt disempowered or frustrated because they were not considered an integral part of the team and were discouraged by the barriers erected by professionals (Thomson & Rowan, 1995; Williams & Nagel, 2001).

Loftin and Koehlar (1998) reported on their experiences teaching students with Batten's disease in the United States, but did not mention parents as being part of their educational team. However, in New Zealand, parents have said that they want to be involved in their children's education (Fraser, 2001a; Thompson & Rowan, 1996; Williams & Nagel; 2001). Similar views were held by Australian parents of students with high support needs (Foreman & Arthur, 2002). Foreman and Arthur (2002) found that generally parents of students with high support needs have strong ideas about their child's education. This was reflected in Fraser's (2001a) research of twelve New Zealand families, who had children with cancer. She found that parents "wanted educational expectations placed on their children", goals set for them, and good communication between home and school (p. 32).

### ***The Individual Education Plan team***

The IEP team usually comprises the parent, the student (if appropriate), the teacher, teacher-aide, school staff and other professionals, who are involved with the student on a regular basis (Ministry of Education, 1998a; Moltzen, 2005). The IEP team help to develop goals to meet the needs of a student with Batten's disease and identify the resources, training and strategies that are necessary to help the student achieve their goals and retain their physical skills as long as possible (Batten's Disease Support & Research Association, 2002).

The class teacher is responsible for ensuring that a disabled student is included in the class programme and is able to meet their IEP objectives (Pierangelo 2004; Rennie, 1998). The information they share with the team is a vital component of the IEP process (Beattie, et al., 2006). They direct the teacher-aide, monitor the learner's progress and organise the overall planning (Ministry of Education, 1998b).

Teacher-aides help facilitate the student's access to the curriculum and support the student's programmes under the guidance of the teacher and specialists (Arter, Mason, McCall, McLinden & Stone, 1999; Gale, 1998; Hall, 2004). They help to include the student in activities and look "after their physical and medical needs, facilitating (their) access to the curriculum" (Pickles, 2004, p. 10). They may be involved in encouraging student independence and social interactions (Closs, 2000b).

Resource Teachers Vision (RTV) often play a lead role for a student with a vision impairment (Pagliano, 2002; BLENNZ, 2007) and are an integral part of the IEP process. They advise teachers and other professionals about vision related issues and train school staff about adaptations, strategies and resources (Davis, 2003; Pickles, 2004; Vision Education Agency, 2003). They "provide support to students," their families, school staff and other professionals sometimes needing to "act as link between these people" (Gale, 1998, p. 83; Vision Education Agency, 2003).



### *Parents' role in the Individual Education Plan process*

Parents have a vital role to play in the education of their child (Barrow, 2004; Beattie, et al., 2006; Foreman & Arthur, 2002; LaVenture, Lesner & Zabelski, 2006; Nagel, 2005a; Soan, 2004b) and have an important role to play in the decision-making process (Closs, 2000a; Higgins, 2001; Nagel, 2005a; Pagliano, 1998; Sacks & Barclay, 2006). Parents have the right to be an active participant in the education of their child and the team should ensure that they are not overwhelmed by other team members' expertise (Pagliano, 1998).

Some New Zealand parents of students with vision impairments have reported that they felt overwhelmed and disempowered by the IEP process (Williams & Nagel, 2001). Feelings of disempowerment were also reported by Finnish parents' of students with Batten's disease, who stated that it took some time before they became equal participants with professionals in the IEP process (Punkari, Eskonen & Hietaharju-Mölsä, 2006). This is reflected in an American study where parents of students with autism spectrum disorders reported feeling hesitant when dealing with education professionals (Stoner & Angell, 2006). In contrast, Stoner and Angell's (2006) study also found that parents were prepared to actively support the school if they thought the staff were "providing an effective educational programme for their children" (p. 183).

Beattie, et al. (2006) highlighted that the information that parents can provide about their child's development in conjunction with the team approach, can help develop a sequential structured programme designed to meet the student's changing needs (Johnson & Jochum, 1996). Parents provide information about the student's culture, values and how they function in a variety of environments and give an insight into problems that the child may have (Cornwall, 2004; Pagliano, 1998, Thomson et al., 1991; Turnball & Morningstar, 1993; Ware, 1999).

### **Trans-disciplinary approach**

Most disabled students in New Zealand schools have a team of educators and specialists, who are involved with them. All team members, including the parents,

school staff and specialists, should feel they are equal participants and integral to the goal-setting and decision-making process (Fraser, 2005). A strength of a trans-disciplinary team approach is the cooperative way in which all the team members work to design and implement the programme (Ainscow, 2000; Chapman & Ware, 1999; Silberman, 1986; Sirvis & Caldwell, 1995; Werts et al., 2007). They share their skills, knowledge and information with each other as well as train other members how to implement their programmes (Carpenter, 2000; Chapman & Ware, 1999; Silberman, 1986; Werts et al., 2007). However, this ideal is often far from the reality.

Asprey and Nash (2006) interviewed forty-six English parents and found that there was very little evidence of trans-disciplinary team support for these families. As a result the parents felt they needed to fight for their child's rights and for support from the various agencies involved. Similar views were expressed by six New Zealand mothers of disabled students in Brown's (1999) study. Brown (1999) found that a good relationship between the family and school was essential. Likewise, an Alabama study (Coffey & Sears, 1996) found that eighty-one parents of severely disabled students and thirty-one professionals, who were involved with severely disabled students, appeared to have similar goals for the disabled students' education. However, Brown's (1999) mothers still felt they needed to be an active advocate for their child's rights and were disempowered by some professionals.

Interagency collaboration addresses the child and family's concerns or issues "on a multi-institutional, multi-professional basis" (Ysseldyke, 2000, p. 309). It can enhance the educational outcomes for special needs students and communication between organisations is a vital component of its success (Sirvis & Caldwell, 1995). Chapman and Ware (1999) investigated the collaboration between health and education in an English school using a trans-disciplinary approach. They found that the trans-disciplinary approach was more successful than "former multi-disciplinary approaches" (Chapman & Ware, 1999, p. 104) that involved each specialist working individually with the student and giving recommendations to the classroom teacher (Silberman, 1986). For New Zealand students with a vision impairment, specialists from the Royal New Zealand Foundation for the Blind (RNZFB) may work with

schools in a trans-disciplinary approach that encompasses both education and outside agencies together to share information and support the family (Higgins, 2001).

### **Setting goals for students with neurodegenerative conditions**

There appears to be limited research about the education of students with neurodegenerative disorders. However, Deborah Fraser's (2001a) research into the educational needs of children with terminal cancer in New Zealand schools is relevant because she reflected on the importance of targeting goals to suit the situation. Fraser's (2001a) research found that teachers needed guidance and support when educating and working with students with life-limiting conditions, which was similar to Koehlar and Loftin's (1994) experience. Like other researchers Fraser (2001a) also reported that teachers mentioned that they did not know what to expect from the student academically or behaviourally. Teachers had difficulty knowing how to adapt the curriculum and learning methods to meet the needs of these children as well (Ballard & McDonald, 1999; Leaman 2000; Norris & Closs, 2003).

A number of questions have been raised for me, as an educational professional, when considering the education of a student with a neurodegenerative condition. These include questions about how the team identifies achievable learning objectives and whether the focus of the IEP changes for students with neurodegenerative conditions. Usually the IEP identifies skills that disabled students need for their future development (Ryba & Annan, 2005), but setting achievable goals for a student with a neurodegenerative condition can be challenging when the student's skills are regressing (Koehlar & Loftin, 1994; Rokne, 2006; Scrambler, 2005).

Olsén and Laine (2006) taught three students with Batten's disease in Sweden and stated that the challenge that they faced was setting goals that help maintain the student's knowledge and develop to their full potential. Teachers may need to alter the focus of their teaching to accommodate the student's deteriorating physical and cognitive abilities. Team members also need to have regular opportunities to share information with, and give emotional support to, each other (Koehlar & Loftin, 1994; Loftin & Koehler, 1998; Olsén & Laine, 2006) in order to meet the student's changing

needs. A Norwegian educator (Rokne, 2006) stated that educating teachers is an important part of the IEP process for students with Batten's disease.

### **Students with life-limiting, serious or chronic conditions in inclusive settings**

The diagnosis of a child or young adult with a chronic or life-threatening condition such as cancer and muscular dystrophy, has a huge impact on his or her family (Eiser, 2000), support people and school staff. Inclusion means that all students including those with medical conditions will be accommodated at school (Bailey & Barton, 1999). Eiser (2000) argued that it is important to recognise the psychological impact that having a severe medical condition has on students and added that schools need to be aware of the ongoing support that a student may need. These include academic support, peer support, liaison teacher and medical treatment that can be provided at school, such as physiotherapy (Eiser, 2000). Important aspects of the programme for a student with a life-limiting condition are coping with the physical and cognitive deterioration; sustaining social relationships (Fraser, 2001b); maintaining skills as long as possible; and learning new skills to compensate for those skills that are lost (Ault, Graff & Rues, 1993).

### ***Educational Implications***

There is little research about the education of students with life-limiting or serious health conditions. Bolton, Closs and Norris (2000) found most of the research was from a medical, sociological or psychological viewpoint.

In two United Kingdom studies, parents and children with serious medical conditions were interviewed about their experiences of the education system (Bolton, Closs & Norris, 2000). Bolton also interviewed school personnel (1997, cited in Bolton et al., 2000). The findings of both studies supported the inclusion of students in mainstream settings, highlighting "interpersonal relationships", collaboration between team members (in particular the parents), and acknowledged the support that was given to the trans-disciplinary team members (Bolton et al., 2000, p. 40). The issues raised related to the student's ability to keep up with schoolwork; and the professionals

development of systems for coordinating and prioritising planning as well as teaching the educators and professionals about pertinent issues.

In a later study that built on their earlier research, Norris and Closs (2003) interviewed Scottish school personnel. The teachers identified that they felt hesitant when educating a student with a serious medical condition and they were unsure how to treat them and how much to 'push' them. Relationships were better if they were able to be positive and empathise with their student. Their views supported those of the teachers reported in Bolton's study as well (1997, cited in Bolton et al., 2000). In addition, school personnel identified the need for staff development about the issues associated with having a student with a severe medical condition in their school.

Other English studies (Asprey and Nash, 2006; Lightfoot, Wright & Sloper, 1998; Mukherjee, Lightfoot & Sloper, 2000) investigated the educational needs of students with chronic or life-threatening health conditions. Data was collected from parents (Asprey & Nash, 2006; Mukherjee et al., 2000), students (Lightfoot et al., 1998; Mukherjee et al., 2000) and teachers (Mukherjee et al., 2000). Issues that were highlighted in these studies included communication between the home and school, absence from school, and the maintenance of peer relationships. Communicating medical information and issues related to the condition were identified as problematic for participants in each study because they did not know what to expect and where to get help. Students added that they wanted to have someone to talk to at school about health-related issues and they had difficulty "participating in some aspect of school life" (Lightfoot et al., 1998; Mukherjee et al., 2000, p. 64). Both teachers and parents in Mukherjee et al.'s (2000) study were concerned about the medical care of students at school, the education of school staff and the allocation of a staff member to coordinate the students' schooling. Asprey and Nash (2006) also raised the issue of increasing the skills of school staff, but parents in their study actually wanted more input from other professionals in external agencies.

### **Batten's Disease**

There is very little educational research about students with Batten's disease. However, a few writers have written about their experiences and identified a variety

of ways that they found enhanced the education of students with Batten's disease. A Swedish study (Jakobsson, 2006) of fifty students, who were diagnosed with Batten's disease found that communication and cooperation between all team members were essential to maximise the students' learning opportunities. Parents were also considered an important part of the process and often had to act as advocates for their child. Jakobsson (2006) suggested that staff working with the student need to have a flexible approach, adapting their teaching strategies and resources to meet the students' changing needs.

Koehlar and Loftin (1994) reported their experiences working with students with Batten's disease. They stated that successful programmes are dependent upon having activities for, and realistic expectations of, the student's at their current skill level. In a later report, they stated that staff working with students with Batten's disease need to have a strong positive team approach, meet regularly and provide emotional support to each other (Loftin & Koehlar, 1998).

Loftin and Koehlar (1998), found that most of the research about Batten's disease focused on "medical issues" (p. 1) and after an intensive search, I found similar results. The few articles that focused on the education of students with Batten's disease were generally reports of the authors' personal experiences and observations. These authors described their experiences regarding the student's access to the curriculum, the retention of previously learnt skills, and the student's behaviour, frustration and anxiety levels in the school environment (Bills, 2006; Loftin & Koehlar, 1998; Johnson & Jochum, 1996; Koehlar & Loftin, 1994). They also reflected on the issues that teachers and parents face, such as the difficulty that they may have when dealing with the students' cognitive and behavioural changes.

Johnson and Jochum (1996) suggested that teachers working with students with Batten's disease need to be experienced and trained specifically in special education to ensure the students educational opportunities are maximised. They also suggested that students' programmes need to be individualised and functional. Another report stated that in their writers' experience students with Batten's disease need to have consistent routines and behaviour management strategies in place (Loftin & Koehlar, 1998).

The deterioration of cognitive functioning can be very difficult to manage for the teacher because “teachers are taught to teach” (Bills et al., 1998). They are not taught how to work backwards (Johnson & Jochum, 1996), and what to do when new learning is no longer able to take place and students regress (Bills et al., 1998). Bills (2006) studied the behaviour of five students with Batten’s disease in the United States. She asserted that the source of the behaviour problems associated with students with Batten’s disease was their frustration when they lost skills and knowledge. Similarly, I have encountered these challenges in my own work as the Resource Teacher Vision of a student with Batten’s disease. In my experience, I found that it was difficult to set goals that take into account the student’s regression of skills and knowledge as well as meet the curriculum objectives.

Closs (2000a) advised teachers that a student with “cognitive deterioration needs help to remember things in different ways” (p. 105-106), and sensory or physical activities may be empowering (Closs, 2000a). Similarly, Loftin and Koehlar (1998) reported their experiences working with students with Batten’s disease. They said that it was difficult to develop educational goals to meet the students’ needs and measure progress when the students’ physical and cognitive skills were declining. They argued that the focus of the goals may shift from academic to physical and/or communication goals (Koehlar & Loftin, 1994). A New Zealand study of students with terminal cancer (Fraser, 2001a) found this shift of focus was needed. In addition, Fraser (2001a) identified the importance of social and emotional goals. She stated:

When it becomes apparent that a child will die the whole purpose of education and the point of life is called into serious question. Both parents and teachers are forced to reassess their goals for a child . . . Quality of life, attainable daily goals, pleasure, relationships and time become precious elements (p. 50).

Her remarks are relevant to those with neurodegenerative conditions because they too are faced with a life limiting illness and difficulty achieving long-term aims. Setting achievable daily objectives (Fraser, 2001a) may be a better way of assessing progress or maintaining skills rather than focussing on a six monthly IEP that may show a

deterioration of skills and achievement. A daily record highlights ‘quality of life’ and each day’s achievements, rather than failure to achieve long-term goals (Fraser, 2001a).

### **Inclusion of students with vision impairment**

In New Zealand, Higgins (2001) study of ten blind peoples’ experience of education found that they were not always included, and at times, felt socially dislocated. However, most of the participants had experienced an inclusive classroom environment at some time and noted that it had a positive effect on their learning and attitude to school because their blindness was not considered a barrier to learning. It was also noted that the vision resource teachers’ and the orientation and mobility instructors’ support were necessary for inclusion to be successful (Higgins, 2001).

Previously in 1989, O’Brien canvassed New Zealand secondary school teachers and students about mainstreaming students with vision impairment. They expressed their preference for mainstream settings with vision resource teacher support, or a resource room where students with a vision impairment were able to access the support needed. They reported that mainstream settings promoted social development and educational growth but there were difficulties making curriculum adaptations (cited in Higgins, 2001).

Overseas, Bishop’s (1986) survey of one thousand teachers, including specialist vision teachers, principals, families and students, identified a number of features that contribute to successful mainstreaming of blind students. These included the student’s abilities such as physical skills, social skills, independence, motivation, academic achievement and self-confidence. Teacher confidence and having a flexible approach to teaching was also a factor in creating successful inclusion as well as peer acceptance and interaction (Bishop, 1986, cited in Higgins, 2001).

MacCuspie (1996) explored the social interaction of five Canadian elementary school students with severe vision impairment in mainstream settings. Observations were made and the students, sighted peers, teachers and parents were interviewed to determine “the social acceptance and interaction of students” with a vision



impairment (MacCuspie, 1996, p. 54). Students with vision impairment were observed interacting more comfortably with adults than their peers. MacCuspie identified that the students had less opportunities to interact with their peers because they were more likely to be left out of playground activities; couldn't locate their peers in the school field; and were slower to complete work, so missed out on opportunities to socialise with peers between activities. Enhancement of social relationships were not a priority for the teachers involved in the research because they felt the majority of social interactions occurred in the playground and they had little control over what happened outside the classroom. It was also found that students with a vision impairment were more vulnerable to exclusion by their peers as they got older and moved class levels.

## **Summary**

In conclusion, with the increasing numbers of students with neurodegenerative conditions and, in particular Batten's disease, in mainstream settings the issues raised by Fraser (2001a), Higgins (2001) and MacCuspie (1996) are relevant to this research. Setting achievable daily objectives (Fraser, 2001a) could help develop realistic activities and expectations (Koehler & Loftin, 1994) for students with Batten's disease that will meet their changing individual needs. Also it is important to fully include all students in the educational and social life of a mainstream school (Higgins, 2001; MacCuspie, 1996). In practice, the dilemma parents and teachers of students with Batten's disease face is the need to identify goals that show academic and social progress, while knowing that the student is unlikely to maintain even their existing skills. Therefore, there is a tension between the Ministry of Education's expectation that all students will make progress and the parents' and teachers' experience that students with Batten's disease will regress cognitively, physically and emotionally. This research has developed from the issues and challenges that an educational team faced when working with a student with Batten's disease.

## **Chapter 3**

### **Methodology**

This chapter begins with a description of why I decided to undertake this study. It continues with a discussion of the methodology and describes the research methods used.

This study developed from my experience working in a school with a student with Batten's disease. I researched Batten's disease and canvassed other people's experiences but found there was very little documentation about educating students with Batten's disease. I searched the World Wide Web, libraries and the databases available to me through the University of Canterbury Education library, but I found most of the research was about the medical implications and symptoms of Batten's disease. There was very little about how to adapt the curriculum or the strategies to use to meet the needs of students with Batten's disease. As a result I felt that I was inadequately equipped to best meet the needs of the student with whom I was working. I discussed this lack of information with colleagues and then decided to embark on my own research about the educational implications for students with Batten's disease in New Zealand schools.

When I started this research, I planned to use a written survey or a questionnaire format to canvas the opinions of teachers, teacher-aides and other professionals working with New Zealand school students with Batten's disease. After contacting other Resource Teachers Vision through the Blind and Low Vision Education Network New Zealand (BLENNZ) it became evident that there were not enough students with this condition in New Zealand to use this method. After discussion with my supervisors, I decided that a qualitative single subject case study approach, rather than a quantitative one, would provide a deeper understanding of my research question.

This study aimed to explore the experiences and perceptions of teachers, parents and other education professionals to gain an understanding of how they perceived the

educational needs of a student with Batten's disease. This fitted with the aims of a qualitative approach and as Taylor and Bogdan (1998) stated, "the goal of qualitative research is to examine how things look from different vantage points" (p. 9). Qualitative research allowed me to have a broad inquiry focus (Ary, Jacobs & Razavieh, 2002) and the holistic nature of qualitative research design helped to give a broader exploration of participants' experiences in order to develop an understanding of their perspectives (Janesick, 2003). In-depth data was gathered from the trans-disciplinary team working with one student in order to develop an understanding of how the team and its individual members develop goals and identify needs for a student with Batten's disease.

A case study format was selected as it enables the researcher to investigate the thoughts and feelings of participants, and study the research question in-depth (Bell, 1999; Bennett, 2003; Best & Kahn, 2006; Cohen, Manion & Morrison, 2000; Hays, 2004; Opie, 2004a). Bogdan and Biklen (1992) commented that case study is used by both experienced and beginner researchers. It is the comprehensive study of a single subject (Bogdan & Biklen, 1992) and starts with a previously identified case (Stake, 2003). A case study can be used when there is an interest in a single case and what can be learned from it (Campoy, 2005; Hart, 2005; Stake, 2003). The design develops from "what is perceived to be the case's own issues, contexts and interpretations" (Stake, 2003, p. 140). It aims to describe, understand and explain the case investigated (Hamel, Dufour & Fortin, 1993). Stake (2003) referred to this as "an intrinsic case study" because the researcher wants "a better understanding of" (p. 136) a case (Anderson, 1990). A case study "focuses from the beginning on a specific person" and is suited to answering "how and why questions" (Kervin, Vialle, Herrington & Okely, 2006, p. 70; Yin, 2003).

Stake (2003) contended that "intrinsic case work regularly begins with cases already identified" and that are of "interest before the formal study begins" (p. 151). This single-subject case study was based on the educational needs of a student with Batten's disease from the perspectives of the trans-disciplinary team members, who worked with this student. A case study approach lends itself to the in-depth investigation of the team's experience and perspectives because Batten's disease is a rare condition and this is an unusual case (Bogdan & Biklen, 1992).

Studying the educational needs of disabled students also lends itself to a case study approach because it enables the researcher to tease out the issues and discuss the participants' experiences in detail. Participants' narratives help give an insight into how one group of people working with a student with Batten's disease think about, plan and adapt to meet the student's educational needs.

## Participants

The participants in this study were chosen using “extreme case sampling” because it is an unusual case (Ary et al., 2002, p. 429) and I selected the participants “according to the information that” was “required” (Liberty & Miller, 2003, p. 127). The participants were the key members of the trans-disciplinary team, which was involved with a fourteen year old girl with Batten’s disease, who attended a New Zealand secondary school. The participants were the student’s mother, one teacher, three teacher-aides and five key education professionals.

The table below shows the role of the participants, how often they had contact with Charlotte and how long they had been involved in her team. The table also provides information about the participants’ interview and identifies the length of the interview transcripts.

**Table 1: Participant roles, contact with Charlotte, length of team involvement and interview information.**

Name	Role	Visits to Charlotte	Length	Interview duration	Interview location	Interview transcript
Alison	Developmental O&M Instructor	3 per term	3 terms	1 hr	Interviewer’s home	8 pages
Becky	Mother	Daily	14 yrs	75 mins	Interviewer’s home	27 pages
Carol	Teacher / SENCO	Daily	1½ yrs	1 hr	School	10 pages
Diane	Teacher-aide	Daily	1½ yrs	45 mins	School	9 pages
Evelyn	Occupational therapist	2 per term	1 yr	45 mins	Interviewer’s home	8 pages
Fleur	Special Education Advisor	1 per term	2 yrs	40 mins	GSE	6 pages
Gloria	Teacher-aide	Daily	1½ yrs	45 mins	School	7 pages
Holly	Speech Language Therapist	2 per term	2 yrs	50 mins	Interviewer’s home	8 pages
Iris	Physiotherapist	3 per term	1½ yrs	50 mins	Interviewer’s home	5 pages
Joy	Teacher-aide	Daily	1½ yrs	30 mins	Participant’s home	5 pages
<b>Total</b>				<b>8 hrs 20 mins</b>		<b>93 pages</b>

Children's opinions are a valuable source of information (Gollop, 2000; MacArthur, et al., 2005; Messiou, 2002). However, children's voices are often neglected (MacArthur, et al., 2005; Messiou, 2002). According to Gollop (2000), it is desirable to gain information directly from the child. Including students' voices would have lent another dimension to the study, but there were many "practical and ethical implications" (Bolton, et al., 2000, p. 46). It was decided not to include Charlotte's voice in this study because I did not wish to draw Charlotte's attention to her deteriorating condition. Instead I focused on the adult educational team members and how they coped with the challenge of educating a student with Batten's disease. I also wanted to know how they had adapted the curriculum, their school expectations for Charlotte, and the effect on the IEP process. Charlotte had not been actively involved with the IEP process, although all her goals have been derived from her experiences and skill level.

### **Methods of data collection**

Researchers use interviews to gain an insight into how the participants view an issue and explain it in their own words (Bogdan & Biklen, 1992; Burns, 2000) and allow the researcher to study an issue in greater detail than in a questionnaire (Brown & Dowling, 1998). Flexibility in the interview design enhances the gathering of in-depth data and allows the researcher to follow specific topics as they arise (Best & Kahn, 2006; Eisner, 1991; May, 2001). Interviews highlight the participants' experiences and the issues they face and allow the researcher to develop a greater understanding of the participants' perspective (Bennett, 2003; Bouma, 2000; Brown & Dowling, 1998; Glesne, 1999; Mutch, 2005).

Data was gathered in this study using semi-structured interviews. I have defined my interviews as semi-structured because they followed a series of key questions (May, 2001) but were open-ended, which ensured I was able to enlarge on, and probe, the participants' answers (Howe, 2003; Opie, 2004b; Wragg, 2002). In this study, key questions (see Appendix A, B and C) guided the interview and gave a framework for the discussion (Mutch, 2005; Wengraf, 2001).

In-depth interviews were conducted with key trans-disciplinary team members of a student with Batten's disease as in Table 1. A total of ten interviews were held. Participants were informed that the interview might be followed with a further conversation to clarify their comments, but this did not actually occur. It was important that the interviews were conducted in an environment where the participants felt comfortable but which was free of distractions (Mutch, 2005). Therefore, each participant was given the option to decide where and when they preferred to be interviewed (Glesne, 1999). Four preferred to be interviewed at their work place, one at her home and five chose the interviewer's home.

The interview questions guided the participants' discussion and exploration of their experiences when teaching a student with Batten's disease. They were asked to share their experiences of the IEP process and identify the expectations and goals that they had for the student. Prior to the interview, each participant was given a copy of the relevant key questions (see Appendix A, B and C). They were asked whether they had any concerns regarding the interview or the questions before embarking on the interview. However, no participants had any initial concerns. The interviews took between thirty and seventy-five minutes.

Janesick (2003) stated that it is important to practice the research techniques that are being used in qualitative research before the research begins. I therefore practiced active listening and interview techniques before starting the interviews to try and minimise the effect of my inexperience as an interviewer (Kvale, 1996). I was aware that my body language, non-verbal responses and questioning techniques could inhibit the participants' responses or dissuade them from elaborating on their answers. The interview techniques I used were reflection, open-ended questioning, summarising and paraphrasing (Bolton, 1986). As the interview progressed, I tried to be sensitive to the participants' feelings and views even if they differed from my own (Walker, 1993).

It has been argued that "we can't be part of the social world without being part of it," therefore "all social research is a form of participant observation" (Tedlock, 2000, p. 465). Due to the nature of this study, I was not impartial and I did interact with participants (Angrosino & Mays de Pérez, 2000; Bell, 2005). Thus I took a

“subjective stance” in the research (Angrosino & Mays de Pérez, 2000, p. 677). However, as Tedlock (2000) stated a participant observer is simultaneously involved emotionally and as a detached observer. I used this to my advantage to elicit a deeper understanding of the participants’ views and was aware that some of the participants may not have disclosed information unless I was an “insider researcher” and in a position of “confidentiality and trust” (Busher, 2002, pp. 80-81).

Janesick (2003) also stated that it is important for the researcher to recognise the perspective that they bring to the study and this can then help the researcher to be “more reflective” and aware of how they “may shape and enrich what” they do (Bogden & Biklen, 1998, p. 34). My perspective comes from my background as a specialist teacher in New Zealand’s state education system. I support inclusion and believe that all students have the right to be educated in a mainstream school that will meet their educational needs physically, socially, emotionally and academically.

### **Reliability, validity and generalisability**

The issues of reliability, validity and generalisability in qualitative research differ from the way that they are determined in quantitative research. Janesick (2003, p. 69) stated “validity in qualitative research has to do with description and explanation and whether or not the explanation fits the description” (Anderson, Herr & Nihlen, 1994). The validity of the interviewing is also dependent on the honesty of the participants’ responses and the “quality of the interviewing itself” (Kvale, 1996, p. 237; Wragg, 2002). I checked the information obtained throughout the interview by asking questions to verify the participants’ meaning (Kvale, 1996). Stake (2003) stated that researchers cannot avoid generalisation in a qualitative and an “intrinsic case study” in the sense that they generalise their findings to future events and “other situations” (p. 141). External validity is harder to achieve because “it is very difficult to generalise on the basis of one case” (Anderson, 1990, p. 163; Bassey, 2002; Marshal & Rossman, 1989; Walker, 1993).

Anderson (1990) stated that it is argued that “the case-study method ... lacks reliability and that another researcher might come to a differing conclusion” (p. 163).



In contrast, Janesick (2003) stated that, because of the nature of qualitative research “reliability in the traditional sense” (p. 70) of replicating the study is pointless (Bloor, 1997; Burns, 2000). However, internal validity and generalisability of the study’s findings may be achieved through the readers’ understandings and conclusions about the participants’ experiences (Anderson, 1990; Stake, 2003). By providing a detailed description of the research methods and procedures that were used, I hope the reader will be able to ascertain the care and thorough attention to detail that was used within this study (Tolich & Davidson, 1999). I also aimed to address the issues of validity and generalisability with in-depth description (Schofield, 1993) of the research to “represent the case” (Stake, 2003, p. 156).

### **Ethical implications and consent process**

This study was submitted for approval to the Christchurch College of Education Academic and Ethics Committees and was not undertaken until it met their requirements. All participants were asked to give “informed consent” to take part in the research (Darlington & Scott, 2002, p. 25; Kervin et al., 2006, p. 5). They were made aware of the purpose, the requirements and the costs that their participation in the research may bring. This was achieved in two ways. Firstly, the relevant information sheet (see Appendix D and E) and interview guide (see Appendix A, B and C) were sent to each participant. Secondly, after having received the interview guide and information sheet prior to the interview, all participants were asked to sign the consent form (see Appendix F and G) and return it to me. This fits with the opinions of other writers, who have stated that it is important that the participant is informed of the purpose of the research in advance and that their participation is voluntary (Davidson & Tolich, 1999; Holloway & Wheeler, 1995).

Teachers and other key educational professionals were not approached to participate in this research until Charlotte’s mother had given her written consent for them to share Charlotte’s information. Letters were sent to the principal and Board of Trustees of Charlotte’s school, the Royal New Zealand Foundation for the Blind (RNZFB) Practice Advisor and the Group Special Education (GSE) District Manager, prior to contacting the other team members. The participants’ supervisors were

informed about the study (see Appendix H and I) and asked to give written consent (see Appendix J, K and L) for the participation of their staff member in the study.

The participants chose where and when they wished to be interviewed and were assured that their participation was voluntary (Tolich & Davidson, 1999). They had the right to withdraw from the study at any time (Kervin, et al., 2006).

Silverman (2001, p. 162) suggested that audio tapes are a useful way of recording the interview because they are able to be “replayed and the transcripts improved” (p. 162). They also keep an exact record of the conversation (Opie, 2004b; Taylor & Bogdan, 1998) thus preserving the integrity. The interviews were taped and later transcribed, at which time the participants had the opportunity to view the transcript and change or delete any part of it. One participant altered her transcript three times. The participants signed the back page of the final copy to signify that they had approved the transcript information for use in this study.

Walker (1993) stated that the participants “own the facts of their lives and should be able to control the use that is made of them in research” (p. 190). All participants were aware of their right to look at any of the information provided and access what was written about them. The family were given the final draft of this study’s results and asked to check if there were any changes or deletions that they wanted to make. I received written confirmation that no changes needed to be made.

### **Confidentiality and anonymity**

Darlington and Scott (2002) stated that it is difficult to ensure confidentiality in qualitative research, because it may lessen the real meaning of the information (Howe, 2003). Although an interviewer can treat the information provided confidentially the participants cannot be “truly anonymous” (Howe, 2003) because the interviewer will still know who said what (Tolich & Davidson, 1999, p. 77).

Because there are a small number of students with Batten’s disease in New Zealand, it was not possible to ensure the complete anonymity or confidentiality of the participants (Kervin et al., 2006). This was discussed with the participants and their

concerns addressed prior to the interview. If the participants still had reservations, they had the option to withdraw from the study. However, they were assured that no names or details identifying them would be divulged and the student would not be identified in the report. All people involved in this study have been given pseudonyms. All information was kept in a locked filing cabinet at the researcher's office and destroyed after the research was written up and completed.

### **Costs and benefits**

The cost to the participants was the time it took to complete the interview. In addition the interview brought up emotional issues for one of the participants, which caused the interview to stop. The matter was discussed and the participant given the option of terminating the interview or continuing. She decided to continue the interview.

A benefit for the participants was the opportunity to share some of their experiences when teaching a student with Batten's disease at school. A flow on effect may be the identification of factors that might enhance the educational experiences of students with Batten's disease in New Zealand.

### **Data analysis**

Qualitative research lends itself to a thematic approach because the results determine what the categories are (Mutch, 2005; Watling, 2002). Mutch (2005) refers to this approach as a "constant comparative analysis" (p. 177). At first I listened to the interviews and read the transcripts noting my initial impressions (Marshall & Rossman, 1995). I began comparing what one participant said with the others and started to look for similarities.

The transcripts were then colour coded into twenty two categories to identify topics and common words the participants had used (Mutch, 2005). After identifying four broad categories (Coffey & Atkinson, 1996) the comments from each interview were collated into these categories and formed "the basis for further analysis" (Watling, 2002, p. 272). I wanted the participants comments to "speak for themselves" (Mutch, 2005, p. 180; see also Coffey & Atkinson, 1996; Janesick, 2004; Wolcott, 1994) and

tried to ensure that the comments were kept in context by frequently referring to the transcripts throughout the data analysis. Four “descriptive themes” emerged from the initial data analysis (Anderson, 1990, p. 162; Janesick, 2004) and I found this to be the most time consuming, difficult (Marshall & Rossman, 1995) and challenging part of the whole process.

The data was organised into the four themes by colour coding all the transcripts again. The comments were grouped into the themes and analysed looking at both what was said and what wasn't said in relation to the underlying themes. Janesick (2004) stated that it is important to note what isn't said in qualitative research because it gives more depth and provides a richer description.

As I reviewed the results, it became apparent that two themes could be combined, and this resulted in three main themes. In addition, some topics and comments, although interesting, have not been recorded in this report because they did not answer my research questions, nor were they significant to this research.

## **Chapter 4**

### **Results**

This chapter begins with a description of Charlotte, whose schooling experiences provided the focus for this study. The rest of this chapter describes my research results from interviews with members of Charlotte's trans-disciplinary team. The results are organised into the following three themes that clearly emerged from my data analysis:

1. The IEP team's focus is on keeping Charlotte happy so that she enjoys her time at school.
2. The family's goals for Charlotte's education are supported by the professionals and do not focus on academic progress.
3. Flexibility and open communication within a trans-disciplinary team approach are valued.

#### **Charlotte: My description**

When I first met Charlotte she was a bright, bubbly, eight year-old girl, who loved life and was popular with her friends at school. Academically, she was achieving at an age-appropriate level and was physically able to participate in all school activities. She had an active social life and enjoyed playing with, and visiting, her friends in the local neighbourhood. She organised her friends to play the games that she wanted to play and got upset when they didn't comply, but this didn't impact on her popularity. She loved her speech and drama lessons and was a flamboyant actress.

My involvement began when her vision started to deteriorate and Charlotte needed the support of a Resource Teacher Vision. At this stage, her night and colour vision were starting to deteriorate and she sometimes needed text enlarged. However, she was able to access the curriculum with minimal assistance from her class teacher. She

began having epileptic seizures the following year, but these were controlled with medication.

Over several years, as her vision decreased and reading became more difficult. Charlotte began to learn Braille, and to use tactile and auditory methods to gain visual information. She found this extremely difficult because she was a visual learner and, at times, was still trying to get visual information through the small amount of vision that she had left, which tended to over-ride the tactile and auditory information that she was getting. She had some useable vision for mobility purposes that allowed her to see large shapes. Charlotte's formal orientation and mobility instruction began three years after I first met her. She started using the long cane to facilitate her movement in unknown environments. As time progressed and her vision deteriorated she relied on her cane more and more for independent travel in familiar environments.

As a member of the Royal New Zealand Foundation for the Blind (RNZFB), Charlotte was involved in peer support camps and activities. These gave her the opportunity to explore the equipment used by the police, fire and ambulance services as well as recreational activities, such as rock climbing and swimming, with other students with a vision impairment. She loved physical activities and had the opportunity to go kayaking and abseiling at school camp. She participated in the school triathlon by riding with a partner on a tandem bicycle.

When she was twelve, Charlotte's speech became harder to understand and finally, at the end of her primary schooling, she was diagnosed with Batten's disease. This diagnosis was the result of a trans-disciplinary team effort over six months because Charlotte's family and various team members had noticed deterioration in both her physical and cognitive functioning. The problems that the team members identified were a decline in both her fine and gross motor skills; difficulty retrieving previously learnt information; and deterioration in her expressive language. In the early stages, the team members worked in a vacuum in their own specific areas of expertise not realising that others were experiencing similar problems. The class teacher, special needs coordinator, and Resource Teacher Vision discussed the problems that they had when teaching and motivating Charlotte within the school environment. They developed programmes and strategies to help overcome some of the issues that related

to her vision loss. These programmes were based on developing skills and activities to improve and maintain her Braille, tactile discrimination skills, mathematical proficiency and her active participation in other areas of the curriculum. Peer interactions, social skills and friendships were also a focus of her programme.

Charlotte was fourteen years old at the time of the data collection for this study and lived at home with her parents and older sibling in a rural town in New Zealand. She was in year ten at a co-educational, integrated, secondary school and attended regular classes. She had ORRS funding, full-time teacher or teacher aide support and an adapted programme in all her classes. She participated in practical classes, such as cooking, art and woodwork. She was involved in the life of the school and attended social activities, such as drama or music performances. In class, Charlotte was included in discussions, but support was sometimes needed to interpret what she was saying so that her peers could understand and interact with her.

In her leisure time, she chose to watch DVDs or videos and listen to music. She loved listening to fairy stories, watching movies and going out for meals to a Thai restaurant. She was very social and enjoyed being around people and interacting with them. She had two close friends at school, who usually sat with her at morning-tea and lunch times. They sometimes acted as interpreters when Charlotte was trying to say something to other students or staff members.

In the six months prior to this study, Charlotte began using a wheelchair so that she could move quickly between classes and on community outings. At break times, when the weather was nice she sat outside in her wheelchair, which promoted social interactions with her peers and staff members. Also the wheelchair enabled Charlotte to 'walk' alongside her peers as they changed classes and participate in their conversations.

Although it was difficult to understand Charlotte's speech she was usually able to make her needs known. She enjoyed a joke and had a wicked sense of humour. She had the ability to judge how much she could 'get away with' and when to stop giving one of her peers a hard time. She especially enjoyed having a joke with the boys. However, she did get frustrated when she was trying to tell someone something and

they didn't know what she was talking about, or she thought we were not listening to her.

At the time of this study, all members of Charlotte's IEP team interacted with her in a variety of ways depending on their role within the team. Some team members visited her in class and others met with Charlotte, her family and school personnel in other settings. Overall the interviews with participants indicated that their focus and expectations for Charlotte's education had altered in response to Charlotte's deteriorating medical condition. As an alternative to developing progress-driven goals, they focused on maintaining her skills and happiness. In addition, there was an increased emphasis on supporting each other and the family's goals for Charlotte.



**Theme 1: The IEP team's focus is on keeping Charlotte happy so that she enjoys her time at school.**

Charlotte's happiness appeared to be a priority for the team. The participants thought Charlotte's happiness at school was dependent on having friends, enjoying school activities, reducing the frustrations associated with communicating her needs and interacting with her peers. Becky, her mother, was very clear about her priorities for Charlotte's education and her time at school. She stated that she wanted Charlotte...

to be included. ... [That] she's happy, she has friends. ... I think the biggest thing for me which covers all of that is that it's a really caring, wholesome, almost loving environment, and not just from the staff, but from the pupils as well and I find that brilliant.

She emphasised Charlotte's acceptance by the other students and said:

You know, I think it's great that a lot of the older students come over and spend time with her independently and that says a lot for the school I think.

Charlotte happiness at school had a positive effect on her behaviour at home. Becky said:

... Her moods are so much better and she comes home and she might be singing and I think "Yeah", you know, or she might be laughing and very animated and I think that's great. I can't understand a word she's saying (laughs). But, she's happy within herself. That's great.

Carol, Charlotte's teacher and SENCO, emphasised the importance of following the family's lead and felt that Charlotte should be involved in activities which she enjoys and which stimulate her. She stated:

The primary thing, and I take the lead from her parents, is that she is happy at school and that she's accepted and that she's safe ... and that

she's feeling included and that the activities are enjoyable and stimulating for her.

The main principle is one of acceptance. ... It's of accepting who she is, where she's at and acceptance of what her needs are on a day to day basis.

The participants' aims for Charlotte's education were that she was included at school, had friends, and was happy. For example, Diane and Gloria, Charlotte's teacher-aides, said that they wanted her to be happy and accepted at school. Diane said:

Charlotte's goals, for me, would be that she is happy within herself at school. She's happy to come to school. That she feels accepted by the staff and her peers.

Gloria felt that the IEP team was doing its best by focusing on her happiness. She said:

I just think that we're all doing the best that we can for her. It's making her life as happy as we can for her at school and that's alright.

Carol, Charlotte's teacher, said that as long as Charlotte was included and loved, then other educational goals would arise from this. She said it was important:

... that she's included, that she's feeling loved, that she feels secure, all of those sorts of things, then the goals naturally come from those long term aims.

Other team members took this further and talked about keeping Charlotte happy by avoiding things she didn't like, engaging in pleasurable activities and providing opportunities for interactions with her peers.

The IEP team were also concerned that Charlotte was not "miserable" during their lessons, and so they adapted or modified their programme plan in response to Charlotte's emotional reaction to their lessons. Carol, her teacher and SENCO, stated:

She [Charlotte] doesn't have a lot of interest in some things and sometimes she might react differently to how I expected her too, but we go with Charlotte's needs. So, it might be that she is being a bit oppositional and doesn't want to take part in the activity, but the activity may be modified and she enjoys the bit that she does do.

We don't force her to do anything that's going to make her miserable, that's going to make her feel really unsafe, and that's going to exclude her from where her peers would be and that's going to be boring for her. That's what determines where we're heading

Evelyn, the occupational therapist, was adept at presenting tasks in a variety of way to reduce the confrontation or conflict in lessons. She stated:

If she doesn't want to go to class ... then you get something else out that she enjoys doing. But I think in a case where you've got a cognitive decline alongside of it, she doesn't have the insight to reason and work through [that] you do this for this reason. So, all you do is set up a battle and, I don't believe anybody wins. So it's actually better to change your plan to accommodate how she is that day... I think it's better not to get into a confrontation situation but to divert to something else. And then sometimes you can actually work your way around back to what you wanted. Through another avenue, another activity.

Both Gloria and Diane, Charlotte's teacher-aides, also explained how they worked with Charlotte depending on her emotional and physical needs. Gloria said:

. . . as far as the learning goes, we just take each day as it comes and some days it's easier than others . . . If you know she's tired or she's a bit grumpy you won't go and send her into a group of kids. You don't put her in with a group of kids when you know she's too tired for that.

Diane stated that sometimes the more she pushed Charlotte the less compliant she became. She said:

... there's no point pushing her, because she doesn't want to do it and she gets anxious and stubborn.

Iris, the physiotherapist, commented that it is hard to motivate Charlotte when she is having a bad day. She felt that preparing Charlotte by explaining what is going to happen and giving her time to think about the activity also helps to increase her compliance. She said:

The only difficulties would be if she's not totally compliant, she has good days and bad days. If she's compliant that day, you can get quite a lot out of her and if she's not then I resist pushing her too hard and making her anti activities. I know at home they are very good at keeping her independent and making her do as much as she can herself and explaining what they're going to do. I notice that at school too they just don't steer her into something. Carol is very good at warning her, explaining, giving her time, making sure she understands, so, I'd say that's a very positive experience.

### ***Friends***

All the participants thought having friends and being part of the group was fundamental to Charlotte's happiness. Charlotte's motivation increased when she was interested and wanted to share her ideas with others. For example, Joy, one of Charlotte's teacher-aides, commented she had observed Charlotte's informal interactions with her peers. She said:

When she's really into something she's interested in, she's very coherent - like about going to Australia. She'd mumble away about something and then she'd go, "Australia" very clearly and "Gold Coast" and "roller-coaster". When she's really interested in something, her eyes do light up.

Iris, the physiotherapist, pointed out that friendships were vital to Charlotte's school life so that she was not isolated, and she also felt that the school promoted social interactions and friendships. She said:

I'd have to say Charlotte's very fortunate to be at the school she's at 'cos I see that they're very caring about her . . . She's not just one of the group. She's an individual, and they're encouraging friendships at school and relationships with the others and they're outwardly, definitely looking for those opportunities for her. So she's not isolated.

Charlotte's social relationships with her peers were also priorities for other team members. Fleur, the special education advisor, commented that fostering social interactions increased Charlotte's inclusion at school. She said:

I see her [Charlotte] very much as a valued member of the school community. . . . There are still kids that respond to [and] participate with Charlotte on a daily basis by taking classes, by greeting her, by being in her space, and they just see her as another member of the school community.

Both Diane and Gloria, who are teacher-aides, commented that Charlotte was happy when she was with her peers, and it influenced how she felt. Gloria noted, though, that Charlotte needed more time with her peers and that having an adult present did not necessarily promote natural interactions. She stated:

She's always happy when she's with other kids and I think there could be times when she's with us too often. She needs to be with some of the other kids more often, which is really good for her, and she is happy when she's with the kids and they're good with her.

Diane took it further relating Charlotte's happiness to her own job satisfaction and said:

I think if Charlotte's happy, . . . feels fulfilled, feels like she's important, feels like she's equal with the other students then I feel that I've done a good job.

Holly, the speech language therapist, identified the importance of developing good communication skills that would enable Charlotte to maintain friendships and two-way communication as long as possible so that she could participate at school and in social interactions. She stated:

I think the important thing for her is that communication is what helps her participate and be part of school life and part of having friends ... so it's really important for her participation at school that she's able to communicate with other people.

We want her to be able to communicate her basic needs and wants as successfully as possible, for as long as possible, and the method that she uses to do that may change over time, but apart from that basic goal, we want her to be able to use communication to access the world and access friends and relationships with other people really 'cos that's such an important part of life.

In summary, the entire trans-disciplinary team wanted Charlotte to be happy, included with her peers, enjoy her time at school and have friends. The team tried to keep her motivated and interested in school life. They adapted the programme, changed the task or abandoned activities to ensure that she was happy and had the opportunity to participate in social interactions.

**Theme 2: The family's goals for Charlotte's education are supported by the professionals and do not focus on academic progress.**

As well as focussing on Charlotte's happiness the educational team supported the priorities Charlotte's family had for her schooling. However, due to the degenerative nature of Batten's disease it was difficult to set educational goals for Charlotte that showed academic progress. Charlotte's mother, Becky, was clear about her aspirations for her daughter's education. She said:

[I want Charlotte] to be included. I mean not just taken to school and sat there in a corner and not really included, not getting any benefit out of her school day. She's still learning too and I realize she's never going to be an academic student, but she's still learning on her level ... there's still goals set for her which are achievable and it's recognized when they're not.

There appeared to be a number of factors that were taken into account by the educational team to support the family's goals for Charlotte's education. These included seeking information to make informed decisions for Charlotte's education; setting achievable, relevant goals; adapting the IEP process to meet Charlotte and the team's needs; and making curriculum adaptations.

***Finding information is difficult***

The participants said they struggled to find information about teaching and setting goals for students with Batten's disease. Holly, the speech language therapist, said:

I think probably the hardest thing is that it's a rare condition that not a lot of people have experience of and know about. It's really difficult to get New Zealand information, to get New Zealand experiences. ... The other thing that I think is really difficult is that you can't predict how things are going to go. You can try and plan for what Charlotte might need and when she might need it, but you can't predict [it]. ... It's really hard for planning, to know what she's going to need.

The participants tried to overcome their lack of knowledge by searching for information on Batten's disease and canvassing the experience of their colleagues, who were not part of Charlotte's educational team. They stated that at first they had had difficulty setting goals for Charlotte because they needed more information about Batten's disease and the medical symptoms associated with it. The educational team added that the literature did not help them plan for the future when they did not know how and at what rate the condition would progress. Carol, Charlotte's teacher, remarked:

I think the literature helps the adults cope with Batten's disease. There are some things that I think allow the adults to feel they've got some control over the situation, for example making a communication board or those sorts of things. I think it's the adults that feel they are doing something productive and that they have a focus. ... So, in terms of the literature, it's interesting, but everybody's different. I think it's useful to get a bit of framework, to know where some possibilities might be heading, but every student reacts differently depending on the circumstances.

The participants also commented on the low incidence of Batten's disease and, because of this, the difficulty finding information about educating a student with this condition. Holly, the speech language therapist, stated:

The best thing that we have managed to find [was] a book about Batten's disease ... around education rather than medical. I did have some medical journals and information, but those [were] all around the medical expectations, life expectation, the symptoms and the neurological - what's going on in the brain, which is not necessarily very helpful when you're planning education.

Alison, the developmental orientation and mobility instructor, remarked that:

There seems to be lots of support groups around, which is great and lots of information on the actual medical condition, but I find it difficult to find the information on how to work with children with Batten's disease and what happens .... on a day to day basis.



The participants said that they had accessed data in a variety of ways to overcome this lack of information. This included searching the World Wide Web and internet databases as well as medical journals; using the Special Education library; and accessing information that was provided from previous school personnel and the parents. Some team members had tried to find information from other professionals but found this was difficult as well. Holly, the speech language therapist, commented:

I discussed Charlotte and [the] augmentative communication side of it with some other different speech language therapists who have had experience in the area of augmentative communication. But, the specifics of the case were difficult for most of the people, who I talked to. They said, “That’s a really tricky one. I’m not sure what I would do”, which wasn’t necessarily very helpful.

However, she said that the information she received from someone, who was blind, was the most useful because Charlotte’s blindness affected her access to the activities and equipment Holly could have suggested. She said:

I talked with somebody, ... who is blind himself and that was actually really helpful ’cos he talked to me about what it was like to be blind and what different things that he would rather have or not have. So actually, that was quite helpful to give me a kind of idea of those issues. He was only blind, but, he could kind of say “This is what I think”, or “I wouldn’t try that”, so, that was kind of helpful. Apart from that, working with other people in the team is the most important thing, getting their skills and expertise, really I guess.

### ***Charlotte’s needs and interests influence goal setting***

Charlotte’s deteriorating cognitive and physical abilities, as well as her family’s objectives influenced the goals set by the educational team. Participants supported the need for flexibility when implementing Charlotte’s educational goals and forgot about them if they were no longer appropriate. Carol, Charlotte’s teacher, stated that they

supported the family by keeping Charlotte interested and motivated at school with the equipment that she needed to support her involvement in the programme. She said:

We accept Charlotte for where she is and we are trying to ensure that she has the best programme and that we are advocating to the best of our ability on her behalf and making sure that she does access the resources that she needs. And that we're aware of what's out there for her, [so] that we can support her family to the best of our ability.

Charlotte's goals and educational priorities were decided by the team and determined by her interests and well-being. Also, as time progressed, Charlotte's physical and emotional needs over-rode academic goals. Carol said:

... Some days she likes more age appropriate stories and she'll like age appropriate tapes or videos, or something that might be a lunchtime activity that might have some more teenage content and she'll like those. And other times, she'll be very fantasy orientated ... and she'll just want a familiar fairy tale context story and I'm very happy about that, because that's where she's at on that day and she needs that reassurance, she needs that familiarity, she needs that slow pace. We can modify activities, so that we're achieving some of the goals that we wish to, but, in a way that is going to be the least difficult for her and at the end of the day that we're still preserving her dignity and respecting her.

Charlotte's medical and educational needs were linked together and often determined where she was heading and the educational goals that were set. Carol, Charlotte's teacher, stated:

I don't think you can really separate them out because a lot of the education activities that we do here at school link to the medical as well in terms of physical, for example, the dexterity that we want to maintain, so we'll do educational activities that are linked towards those medical goals and vice versa. Some of Charlotte's medical needs dictate what some of her educational goals will be.

## *Life skills*

The educational team focused on teaching Charlotte life skills rather than emphasising academic goals. Charlotte's physical and cognitive skills influenced her programme at school. Becky, Charlotte's mother, commented that the life skills programme helped Charlotte maintain her existing skills by keeping her physically active and maintaining previously learnt skills, such as using her white cane and storing it correctly; undoing the zip on her bag; buttering bread; and walking to put a sandwich in the sandwich maker. She said that it was great that Charlotte gets to make

... her lunch at school. Putting everything in [her bag that] she needs and [that] she makes her lunch at school is great. I also noticed [that] when she was using her cane a lot and when she comes into class, [she was asked], "Where does your bag go? Where does your cane live?" Just small things like that but they keep her focused and on task with things.

Carol, Charlotte's teacher, commented that life skills provided the educational team with guidance and "clear goals [that] are significant" and give us direction that we can "move towards." Some of the team believed that life skills would also help Charlotte to maintain her physical and cognitive skills, and to continue to participate in every day activities of daily living. Evelyn, the occupational therapist, stated:

I'd be a really strong advocate for doing a lot more life skills particularly around cooking, using the microwave, washing and drying up the dishes. Because they're all things that will keep her fine motor skills going, they'll keep her mobility going if she's standing to dry dishes and move around, counting the plates as she puts them away, remembering where the knives go and where the forks and spoons go.

Fleur, the special education advisor, said that Charlotte needed to be included in subjects and activities at school that were more likely to "lead into recreation and leisure activities such as materials and food technology, physical education, drama and music, rather than academic subjects."

*Flexibility is needed in adapting the curriculum and the IEP process*

The team's ability to adapt their teaching methods to support Charlotte enhanced her inclusion in the school community. Fleur, the special education advisor, commented:

I think the team she has around her and her teacher-aides and teachers at school are incredibly adaptable and I think that's a thing that you're going to have to be in the future. There's no set way of doing things, there's no secret recipe or answer. There is looking at where she's at and the people around her are incredibly knowledgeable and flexible and really willing to adapt how they are used to doing things in a high school setting, to make sure that she is participating and a valued member of their school community.

The participating educational team's main focus was to maintain Charlotte's existing skills as long as possible rather than teaching her new ones. Holly, the speech language therapist, for example, was concerned it was too difficult for Charlotte to learn new skills such as using a communication device because, she said:

... [It] might not be the best and most worthwhile way to spend her time when we didn't really know if it would be helpful or not. ... I think it's really difficult because you're kind of fighting a losing battle. You can try things that might help for a while, but when somebody is going downhill ... success is not necessarily improvements. Success is that ... Charlotte is able to communicate as well as she possibly can for as long as she possibly can, rather than [that] she improves.

Some team members felt that the IEP process was important because it gave them a direction when setting goals for Charlotte even though the goals were not concerned with academic progress. Carol, Charlotte's teacher, said:

We are realistic in that we use it [the IEP] as a way of being able to document, one - where she's at, and two - where we're likely to be heading. And even though her goals are not moving forward, they're still goals that we are wanting to either maintain a skill, or they're ones that

we're looking for her being able to access things in the future, ... And if her skills are deteriorating, we've just got to be more creative in the way that we get her to class so she can be included and involved. So, the fact that they're deteriorating, I don't see it as a problem for the IEP, but, I actually think the IEP's really essential for that, because it documents and it gives us some direction as well. It's just that it's going in a different direction to where most students would be going.

Iris, the physiotherapist, commented that:

I really like it [the IEP], because it stops people from saying, "Oh, they're going to lose their mobility anyway or they're going to lose toileting skills". It makes you focus on the skill that the child has instead of giving up and saying, "We're not going anywhere".

Diane, a teacher-aide, also felt the IEP's goals gave her a direction but that this was also dependent on Charlotte's abilities on the day in regards to whether the goals were achievable. She said:

IEPs for Charlotte are a goal setting thing and some of them, I think, "Yes we can do that." And sometimes I think, "Ohh, okay." Because for me it depends on how Charlotte is on the day. ... So it is good to have the goals for the IEP, cause then you know you're working towards something and you're trying to be useful.

However, other members of the educational team felt there was no point in setting educational goals at all. Gloria, another of Charlotte's teacher-aides, for example, felt that there was no point in setting educational goals. She commented that:

I think it's got to that stage where the goals are so minimal now that's there's probably not a lot of point. ... And deciding what's the best thing to do next, as far as actual educational goals, we're at the point [now] where it's probably not making too much difference.

Some members of the educational team said that maintaining physical skills was a priority for Charlotte's educational plan. Alison, the developmental orientation and mobility instructor, stated her goals were "all around movement and just maintaining the skills that she already has." She said it was challenging though and, after consulting with a colleague, she based her specialist programme on Charlotte's current skills rather than trying to assess her ability to learn new skills. She stated that:

Ideally I was meant to do the assessment with Charlotte and then the programme plan, but I had to speak to Kelly [Alison's colleague] about that ... and so we actually decided not to do the assessment just do the programme planning with Charlotte and that really, really helped actually 'cos I was finding it really difficult.

The participating education team identified the IEP process as also essential for sharing information and a way of ensuring that Charlotte had the funding and resources necessary to support her at school. Carol, Charlotte's teacher, also stated that it was essential to have foresight and understanding in order to get the resources and equipment when, or even before, they were needed. She said:

Making sure that applications are in, that things are underway as they're needed and before they're needed and that's where things like the IEP process comes in. ... We had one just recently and we were able to broach the subject of things that might be needed in the future. So, it's about being aware and knowing that there's a need that's likely to be coming up that you don't leave it to the last minute. Making sure that we've got enough funding when we need it.

Fleur, the special education advisor, pointed out that discussions between Charlotte's family and other team members were important when she considered Charlotte's changing needs. She said:

I think that kind of discussion needs to be started in an IEP, not just to have between the family and one professional. It needs to be all professionals sitting there saying, "OK, but have you thought that if we do

this, we may be able to maintain her for longer. OK, we accept that you think you need to look at alternatives, what does everyone know about what's available?"

Similarly, Gloria, a teacher-aide, stated that it would be more suitable to have a discussion rather than an IEP meeting for Charlotte and the team. She said:

[It was] so that everybody knows how everybody's feeling and different ways that we can do things is really good, but not necessarily goal setting.

Some participants felt that the IEP process, itself, could be adapted in response to Charlotte's changing condition, in that they commented that it might be more realistic to have more frequent IEPs or team meetings. For example, Evelyn, Charlotte's occupational therapist, thought it was difficult setting goals that would remain relevant for a six month time period. She said:

[A] meeting every six months probably isn't really going to meet her needs. I think there probably needs to be more frequent mini IEPs around, how she's been for the last month, is this goal that we set ... still realistic. If she's finding it a bit hard, what's she finding hard, can we work around that or does somebody now help her? And I think that has to be a really important part, because otherwise either people aren't helping her enough when she's struggling, or they're putting too much help in and then she's not then maintaining her own skills.

Fleur, the special education advisor was also an advocate for more frequent and smaller team meetings as well as IEP meetings. She stated:

I think the IEP process has to be the major one, but certainly smaller meetings are going to happen in between times with individual professionals, but I don't think that you need to have a whole team on board any more than what the school requires and I think the school signal if they need to have it termly rather than every two terms. I think there will be times in the future when the school may well say, - "In actual fact we need to have it each term". But that hasn't come yet because I know that

there are frequent and often individual members of that team that are having meetings and just checking on progress and looking at options.

Iris, the physiotherapist, believed that the frequency of IEPs would be determined by Charlotte's needs. She said:

Probably as she deteriorates I think we'll require more meetings... rather than just set the IEP for say once a term, we may have to have the IEP when it's required as each separate independent challenge happens.

However, Becky, Charlotte's mother, felt that the frequency of IEPs did not need to change because it was manageable for her. She remarked that the IEP was able to adequately respond to Charlotte's changing situation. She said:

[The IEP is] realistic. ... And you know, as we're all aware, there can be a really rapid decline sometimes, but it's really good because it's all so changeable isn't it? We can revisit it and think, well that's not working now and reset that goal or what have you. And we have IEP's enough [so] that, that's workable too.

Fleur, the special education advisor, also fully supported the IEP process and said:

I think the most powerful thing with Charlotte is to have those long term goals set and the long term goal at the moment is that she remains at school for as long as possible.

We gauge success [because she is] still attending school full time, she has the adequate amount of support around her for the day and we have made physical adaptations to the environment to accommodate her and that's all that has needed to be done at the moment.

When questioned about Charlotte's inclusion in the curriculum, the participants spoke about the adaptations that had been made to support her inclusion in the class programme and her involvement in class with her peers. Fleur specifically stated that she felt the key competencies were more realistic for Charlotte than the standard curriculum. She said:



I see her being included through the key competency areas and less so through the high school so called curriculum. I consider her less included in things like your sciences, your social studies and more included in ... things that she can develop into leisure skills rather than, looking at striving towards a unit standard of any kind, whether it be supported unit standards, but the key competencies area is the area that the education plan is made around.

Evelyn, the occupational therapist, indicated that the secondary school curriculum was not relevant unless it was adapted to Charlotte's needs. She stated:

I haven't come from an education background, so my view when I see these kids is what they need in terms of meaningful, functional, purposeful, everyday activity. But will provide her with stimulation and occupation. I find it difficult always fitting things in with the curriculum ... Curriculum wise, I think you have to be driven a little bit by where her interests are to engage her in the process, otherwise my personal belief is that her sitting through history, geography [and] whatever other subjects that she's got could be quite meaningless to her. Socially, you're going to get her in a class with other kids. It depends if the other students involve her. In the secondary curriculum, I don't see a lot of academic subjects being useful and meaningful unless they encompass a whole lot of other things like, an individual programme around what Charlotte would like.

In conclusion, at first the participants felt helpless because they did not know what to do when faced with a student with Batten's disease in an educational setting. They supported the family by sharing information and pooling their knowledge. Charlotte's physical and emotional needs influenced the goals that were set by the team and were linked with her medical needs. Life skills and maintaining previous learnt skills became a focus of her programme. The team's flexible approach to the adaptation of the curriculum and IEP process meant that Charlotte's programme was transformed to meet her changing needs whenever necessary.

**Theme 3: Flexibility and open communication within a trans-disciplinary team approach are valued.**

Charlotte's trans-disciplinary educational team seemed to be supportive, willing to share information, and respectful of each other's expertise and knowledge. A strong feature of the team was the ability of the team members to maintain open channels of communication with each other using a variety of methods, including the IEP process, team meetings and informal discussions and conversations.

***Trans-disciplinary approaches enhance outcomes***

The professionals working with Charlotte represented a variety of disciplines and backgrounds and their trans-disciplinary approach seemed to be a key feature of the team's ethos. Participants asserted that having a team of people from different perspectives to draw on helped enhance the educational outcomes for the student. The participants stated that all team members input was seen as equally important and was valued. Diane, a teacher-aide, remarked:

None of the professionals have ever spoken down to me or treated me with any disrespect whatsoever. And they are quite open to listen to me.

Team members were also prepared to be actively involved as the need arose or to take a back-step when their input was not essential. For example, Holly, the speech language therapist, stated:

It is a situation where people need to share their different ideas and perspectives and see what is going to be possible and what's not. ... People working with her [Charlotte] have a good idea of what will work for her and what will work for them in their situation. They're the people that are responsible for looking after her and for her learning day to day and they generally have the best idea of what is going to be possible. If there are times when my knowledge and understanding will be useful, then, I can be involved.

Being an active team member did not necessarily mean that the participants were actively working ‘hands-on’ with Charlotte. Some worked in an advisory capacity within the team but they were also prepared to respond to any needs as they arose and take a more active role. Evelyn, the occupational therapist, commented:

I certainly feel part of the team and I think that’s because people do make contact. [They] will ring and ask what I think about things ... and [when an] issue crops up, school are prepared to contact me.

Sharing expertise between team members was also seen as an effective way of increasing the skills of the school staff, who had a hands-on role with Charlotte. Diane, the teacher-aide, remarked:

Alison ... has come down and she had a workshop for us explaining how to lead Charlotte when she was walking. And I mean we still do make her walk, not make her walk; encourage her to walk certain places. Lynda, you, are great support. We can put ideas to you because you know Charlotte as much as we do, if not better, and if we’re struggling with ideas or anything, you’ve got them, which is [a] great help to us.

### ***The IEP is about communication***

The IEP process was seen as an effective way of communicating by the team members. All the participants commented that part of the focus for Charlotte’s IEP meeting was to support each other and share information. For example, Alison, the developmental orientation and mobility instructor, who had recently started working with Charlotte, said that she valued the opportunity to meet with Charlotte’s team. She stated:

Everyone that works with Charlotte’s there. That’s great to get a whole load of specialists together.

Carol, Charlotte’s teacher said that the purpose of the IEP was to open up communication channels for everyone on Charlotte’s educational team. She said:

The IEP process for Charlotte is the same as for all students that require an Individual Education Plan. I find IEPs to be really effective. I think that they serve a number of purposes and one of those is to open communication between those that are involved in the care. I think that in Charlotte's case, they work extremely well, that we have all those key people that work with her involved, as much as possible.

Iris, the physiotherapist, said that sharing information and expertise was an important part of the IEP process. She commented:

Even though, we're not communicating regularly, I know that they're [the other professionals] there if I need anything clarified and I think we have enough IEPs to keep up to date with what's happening ...

If we didn't have IEPs, ... you'd be working in a vacuum. With the IEP, I feel that we're in a team and everybody bringing their own expertise is very helpful and it gears me up to changing things too.

### ***Finding other ways of communicating***

Although the IEP was the predominant way of setting Charlotte's goals there were many other meetings that took place where ongoing assessment and problem-solving strategies were shared between the team members. At school there were a variety of both formal and informal methods used. Formal methods included fortnightly teacher-aide meetings, which were chaired by the SENCO; meetings with visiting specialists and written reports or feedback. Carol, Charlotte's teacher and SENCO, remarked:

We, the teacher-aides and I, meet once a fortnight and as with all of our students, we go through on a regular basis and talk about what their needs are for the coming fortnight or ten days. We look at the strategies that we're using to be able to support what those needs are. We check timetables and what's coming up and what's going to need to be modified or adapted. Charlotte's needs always feature in these meetings.

Informal methods of communication included regular contact with the family, telephone calls, casual conversations and Charlotte's home/school diary, which is used to document anecdotal information and up-coming events. Carol, Charlotte's teacher, stated:

I have contact with, Charlotte's mother on a regular basis. We have a diary that we communicate through and that's done on a daily basis. Telephone calls. I talk to her Mum whenever there's a need. And then her Mum also comes in and sees me at different times and we interact through other people as well ... I might see one of the caregivers that drop her off and they might just pass on a message, or we might just know similar things that are going on.

There were informal methods of communication between Carol and Charlotte's teacher-aides as well. They discussed Charlotte's needs and used Charlotte's home/school diary to inform each other and the family what had happened each day. Carol, Charlotte's teacher, said:

Informally, I meet with the teacher-aides every morning after assembly and we just talk about what the day is going to hold. Making sure that we've got good cover for our teacher-aides in Charlotte's support. And during the day, I'll touch base with the teacher-aides just to see how things are going, if there's any needs. We use the diary as an informal way to be able to communicate as well and so, it might be that if a teacher-aide has not worked with Charlotte for a day, they can go back and they can read how the day's been for the family and for Charlotte and the teacher-aide as well. There are little anecdotal comments there about what's been happening.

Teacher-aides also shared information informally among themselves when they met during the school day. Joy, a teacher-aide, stated:

We three teacher-aides, all get on well and sort of pass on information if there's anything [that] needs to be passed on. ... [These meetings are]

possibly more valuable because they happen on the spot, because the IEP involves things that have happened weeks ago.

***Respecting the family's perspective and supporting each other***

There was an ethos of mutual respect among all members of this education team. The team's openness and honesty helped to foster rapport. Becky, Charlotte's mother, said:

I find it almost refreshing in a strange way that people can be open and honest and upfront with me. That's what I find really good, that we've been able to have that rapport, with everyone involved.

I think as a team ... we've all got such a good working relationship with each other that we've got that comfort level. We all feel easy enough to not only suggest things, because I realize it must be hard for someone in a professional position to suggest things to a parent that might not seem ... a very good idea, you know. Everyone's really open with their thoughts, share their thoughts, I wouldn't ever say there was any criticism or anything, but there's always thoughts in there. Well, if that's not going to work, why don't we try this? You know, and I find that really good.

And you know, everyone seems to find the common goal and work towards it and we've always found the common solution and if it hasn't turned out the way that we've thought, then we've thought, OK, we'll go with Plan B.

She said that she has never felt that the school dictated what would happen and disregarded her views because she was "just the parent". She commented:

I know that happens a lot in other schools and I really feel for those people but I haven't experienced it and I am sure I would of spoken up had I. And everyone would hear me.

She commented that her husband was also included in the decision-making process, made welcome at school and his input valued. While discussing a meeting her husband attended Becky stated:

... he really opened up and the communication levels were open to him and he felt listened to. ... He was included, on the level that he should be.

Joint problem-solving was identified as a strength of this team's approach. Becky commented:

I'd like to think that we're all doing the best for Charlotte and the fact that they say something to me about it, which might not be working so well, or they come up with an alternative idea that can be better than mine. I think that's really good.

I think collectively we operate better than one person ... and it absolutely lessens the stress load for me. Because, I mean as you know, for a while there I was trying to see all of them at different times and having it all brought together and everyone's on the same wavelength. I have to say it once, or one of you other people, as in professional, say it once rather than saying it so many times, or playing phone tag .... And because there's so many different points of view it changes the whole perspective of a one on one all the time, and I guess it makes people think about it more. Oh, I know for myself, I go, oh, I didn't think of it that way. I might not let on. Sometimes I want to say, "That's so cool!", but I don't.

Becky said that she liked the team approach because interacting with each person separately would be draining both emotionally and physically. However she found that discussing Charlotte's needs could still be upsetting even in a supportive team environment. She stated:

Sometimes, when you're feeling that vulnerable. Fragile. When you're in that state, you know, if you saw every one of those professionals individually, it's not only the energy it takes. But imagine revisiting that grief when you're in that space that many times. ... Because I can

guarantee you, for me, that it would snowball each time. And it would become worse and worse and worse. But, it's like putting another layer on. It gets deeper ... which makes those times when I have broken down and cried in front of you all, it's like I think, "Oh, damn," and I just give up to it.

Becky felt she was supported by this team's approach and it helped alleviate some of pressure placed on them. Becky said that the team approach "lessens the stress" because of ...

the time factor, the heartache. Sometimes you can say something a million times over, then one day you'll say it and you'll fall to pieces. And you don't know what's different or why it upset you that day. If I had to go around all those different people who were at the Strengthening Families Meeting at separate times and say it to each individual one ... I'd be in a psych unit now.

Although Becky commented that she felt vulnerable and stressed she did not want to be excluded from the decision-making process. She had been proactive finding information about Batten's disease and had shared it with the team. She said that she needed to know about the condition and its implications because she felt helpless when she didn't. She said:

Most of what I do [seeking information] is sheer panic because I don't know what else to do. It's not that I'm really focussed on anything. I simply don't know what else to do.

...I feel as if I am suffocating or just going to go under the water if I don't do something. And, yeah, it just destroys me.

Becky felt that she was an equal partner with the professionals in the decision-making process. She stated that parents are the experts about their children and have a vast wealth of knowledge to share with the team. She said:

I think because everyone, who is involved in that process are professionals. They know why they're there, what they can do and bring



to it, no-one's fumbling around and no-one's scared to put their cards on the table because they know they're all professionals in the same way. And I'm a professional mother.

In summary, the trans-disciplinary approach relied heavily on the goodwill of the team members, keeping the lines of communication open and they were flexible in their approach to Charlotte's education. They respected all team members' views and considered the family equal partners in the decision-making process. The IEP process was regarded as an effective way of sharing information, joint problem-solving and an opportunity to communicate in an open forum.

## **Chapter 5**

### **Discussion**

This chapter sets out to discuss the results of this qualitative research and relate them to the literature. It begins with some general comments regarding inclusion and the trans-disciplinary team approach for Charlotte's education. The themes that emerged from the results are discussed separately and the chapter ends with a discussion of the IEP process for students with Batten's disease.

This study has revealed how one education team thought about, adapted to and planned for the needs of a student with Batten's disease in a regular secondary school setting. Members of the team described how they had adapted their practice and planning, while supporting each other through a trans-disciplinary team approach, as well as actively responding to Charlotte's individual needs.

Inclusion is promoted as the best model for disabled students by the New Zealand Ministry of Education and is reflected in the new curriculum document (Ministry of Education, 2007). Although inclusion was not directly mentioned by any of the participants, there was an assumption that Charlotte would be involved and actually participate in the school's life and the team appeared to support Charlotte's inclusion in the regular education setting.

Dewey postulated that education should be tailored to meet the individual needs of all students, so that they meet their potential (Berger, 1965). In the present study, the participants' comments appeared to correspond with Dewey's philosophical views and clearly made the point that they thought an individualised programme was important when planning for the needs of a student with Batten's disease in the school setting.

Some writers have suggested that there is evidence in the literature that "disabled students do better academically and socially, when they are taught in regular education settings" (Higgins, et al., 2008, p. 182). Likewise, parents and teachers of

students with life-limiting conditions, as well as the students themselves, felt it was important for disabled students to be included in the curriculum, socialise with their peers and develop friendships (Bolton, et al., 2000; Quinn & Ryba, 2000). Similar views were expressed by the participants in the present study. They promoted Charlotte's inclusion at school by making her social life, motivation and engagement in the learning environment important aspects of her programme. None of the participants questioned whether she should be at a regular school or raised the issue that another setting would be more appropriate. However, they commented about the strategies that were used and adaptations that were made to accommodate Charlotte at school and in her classes.

The trans-disciplinary team's desire to keep Charlotte happy appeared to be the driving-force for her schooling and influenced the decision-making about her education. The focus on Charlotte's happiness seemed to have a positive impact on the way the team worked together and their united approach gave credence to the lack of emphasis on curriculum or academic goals.

Charlotte's parents had a pivotal role in the team and were actively involved in the decision-making process. Charlotte's happiness and her family's goals had become priorities for her education. The professionals and school staff adapted Charlotte's programme to increase her participation in class with her peers; foster activities that she enjoyed; and cater for her physical, cognitive and social needs.

One of the key features of this team was their trans-disciplinary approach that appeared to draw its strength from a cooperative team model that includes joint goal setting, sharing information and skills to implement the programme (Carpenter, 2000; Silberman, 1986; Sirvis & Caldwell, 1995; Werts et al., 2007). Flexibility was a key part of this team's ethos, and this was apparent in how the team adapted to Charlotte's changing needs, the goals that were set and how they had modified the IEP process. The IEP process no longer focussed on progress-driven goals, but was a forum for the trans-disciplinary team to support each other, share information and discuss issues, while setting goals to help Charlotte maintain her existing skills.

The Ministry of Education IEP guidelines state that the IEP should document student progress (1998b). However, this appears to create a tension when setting goals for a student, who has a neurodegenerative condition. The participants in this study did not specifically mention any difficulties associated with goal setting when a student has a neurodegenerative condition. Nevertheless, they appeared to place no importance on achieving the standard secondary school curriculum goals and showing progression. They emphasised maintaining Charlotte's existing skills as long as possible and supporting Charlotte's happiness at school.

Three specific themes emerged from this research. Firstly, Charlotte's happiness was the main priority. All the participants wanted her to be included with her peers, have friends, and enjoy being at school. Secondly, the family's aspirations as well as Charlotte's physical and emotional needs took priority over academic goals. Charlotte's inclusion in class with her peers was considered essential and her goals reflected this. The third theme was that communication and flexibility were key features of the trans-disciplinary team approach. The team shared information; had a joint problem-solving approach; discussed issues; and respected each others' experiences and viewpoints. The participants also adapted the IEP process so that they supported each other as well as determining Charlotte's educational needs. Each of these themes will now be discussed in detail.

**Theme 1: The IEP team's focus is on keeping Charlotte happy so that she enjoys her time at school.**

The first theme that came from this study was regarding the educational team's focus on keeping Charlotte happy so that she would enjoy school. This theme begins with a discussion about parents' priorities for the education of their disabled student. It goes on to discuss social relationships and happiness of disabled students.

Most people want their loved ones to be happy and parents often express the desire for their children to be happy at, and enjoy going to, school (Bolton, et al., 2000). Bolton, Closs and Norris (2000) found that parents wanted their children to have friends and be included with their peers. Similarly, the entire educational team in this study encouraged friendships and social interactions, between Charlotte and her peers, because they felt this was paramount to her happiness, reduced her social isolation, helped increase her quality of life and motivation.

Children's happiness at school can also have a positive influence at home. Previous research found that children's behaviour and happiness at school carries-over at home (Stoner & Angell, 2006), and neither home nor school can be viewed separately (Bolton, et al., 2000). Becky, Charlotte's mother, stated that Charlotte's happiness at school had a positive effect at home, and made her feel good as well, when Charlotte came home happy.

In addition to wanting their children to be happy at school, parents have definite views about their child's education (Foreman & Arthur, 2002). In the present study Becky, wanted her daughter's schooling to be an enjoyable experience, and for Charlotte to have a sense of achievement and maintain her existing skills for as long as possible. Her expectation was that the educational team, the IEP process, and the resulting goals would support Charlotte's happiness at school.

Teachers can have differing views from parents about students' educational needs. According to Pickles (2004), teachers are usually more concerned with the resources and adaptations that are needed to promote inclusion in the classroom, rather than the individual student's needs. Similarly, the teachers in MacCuspie's (1996) study

focussed on what happened in the classroom, but did not mention the importance of social interactions for student happiness. In contrast, the entire team in the present study, made Charlotte's happiness their priority, and placed no emphasis on academic goals. They also promoted Charlotte's inclusion with her peers. Evelyn, the occupational therapist, specifically talked about abandoning activities to increase Charlotte's happiness at school. This anomaly illustrates the significant adaptations that this team identified regarding the curriculum for students with neurodegenerative conditions.

Human beings are social animals and it is generally understood that "social relationships" are fundamental to, and increase, our quality of life (Meyer & Bevan-Brown, 2006, pp. 168-169; MacArthur, 2005). Social interaction can influence people's sense of happiness as well as their well-being and "sense of belonging" (Fraser, 2001b, p. 1) and are important because they provide company, stimulation, encouragement and "physical support" (MacCuspie, 1996, p. 23). Several investigations have shown that happiness increased for profoundly disabled students when they were involved in social interaction (Davis et al., 2004; Green & Reid, 1999; Logan et al., 1998). As discussed previously, MacCuspie's (1996) six basic functions of friendship appeared to be supported by the participants in this study. They identified that Charlotte's motivation and happiness appeared to increase when she was interacting with her peers. They also commented that having friends stopped Charlotte being socially isolated and increased her inclusion at school. However, there was no mention of the reciprocal nature of friendship, which may be due to Charlotte's regression of social skills.

Logan et al. (1998) claimed that inclusive classes can promote social interactions for disabled students, give them a better quality of life and increase their happiness. It was also found that inclusive settings had a positive effect on the education and social development of students with a vision impairment in New Zealand (Higgins, 2001; O'Brien, 1989). The participants in the present study seemed to be working from a similar premise. They wanted Charlotte to enjoy the activities she was involved in at school, be able to communicate with her friends and express her physical and emotional needs.

In conclusion, it would seem that happiness was a key determinant, for the participants in this study, when thinking about Charlotte's educational needs. Charlotte's happiness appeared to influence what happened at school and positively impacted on her educational opportunities. The educational team thought it was a priority that Charlotte was happy and that she enjoyed being at school, so consequently planned a programme to foster her happiness. Some participants also felt better knowing that Charlotte was happy and this gave them job satisfaction.

**Theme 2: The family's goals for Charlotte's education are supported by the professionals and do not focus on academic progress.**

The second theme to emerge from this study was that the educational team supported the family's goals for Charlotte and did not focus on academic progress. However, Leaman (2000) asserts that even when students are losing skills it is important that they have a sense of achievement because "lost achievements are still very real at the time they are achieved" (p. 158). It has also been reported that parents of children with significant illnesses still want high educational expectations for their children (Fraser, 2001a; Rogers, 2007). Charlotte's mother, Becky, emphasised that she wanted Charlotte to meet her potential and feel a sense of achievement. She also said that she wanted Charlotte to be involved in class rather than being just a spectator.

It is difficult to find ways that challenge students with Batten's disease and give them the opportunity to try new things and learn new skills, so they get a sense of achievement (Koehlar & Loftin, 1994). Santavuori et al. (1993, cited in Bäckman, 2006) found that the challenge educators face, when a student has Batten's disease, is to balance the student's interests with effective, "but not too demanding, teaching" practices (p. 20).

In contrast, Koehlar and Loftin (1994) argued that student's with Batten's disease should spend their time learning life skills that would be more useful in the long-term. Ault, Graff and Rees (1993) contended that learning compensatory skills and maintaining previously learnt skills as long as possible are important for the education of a student with a deteriorating condition. Similarly, the participants in the present study asserted that it was better for Charlotte to use her energy for activities that would increase her quality of life outside school rather than in academic subjects.

A key feature of the programme, for a student with a neurodegenerative condition, is that it should include realistic expectations and practical tasks (Koehlar & Loftin, 1994). Balancing consistent routines with an adaptable programme that responds to the student's fluctuating energy levels is also important (Jakobsson, 2006; Loftin & Koehlar, 1998). Becky and the school staff were in agreement that Charlotte's programme should be adapted to meet her changing needs and facilitate her inclusion



in practical classes, such as cooking, art and music. Becky also believed that the staff would give Charlotte opportunities to increase her life skills, maintain her physical and cognitive abilities, as well as interact with her peers.

According to Coffey and Sears (1996), parents should be actively involved with the school in the development and prioritising of educational objectives for their disabled child. Their study found that parents and professionals had similar educational goals for the disabled student. These included goals for “self-care, language, motor and self-direction” (Coffey & Sears, 1996, p. 553). Similarly, the teaching staff and professionals in the current study stated that they had incorporated the goals that were priorities for Charlotte’s family. The priorities that were identified by the team members for Charlotte’s programme were life skills, physical dexterity, keeping active, keeping Charlotte interested in school and maintaining her cognitive functioning as long as possible.

Although, the participants identified some educational goals, progress-driven academic or curriculum goals were conspicuous by their absence. The goals that the participants described were more in line with the New Zealand national curriculum key competencies, such as relating to others, communication, participating with the group and having a sense of belonging (Ministry of Education, 2007). Fleur, the special education advisor, specifically stated that she felt the key competency goals would be more appropriate objectives than academic ones.

In summary, academic goals in this study were not considered a priority. However, all the participants had high expectations that Charlotte would be included in all aspects of school life and that her programme would meet her individual and changing needs, as well as keep her motivated at school.

### **Theme 3: Flexibility and open communication within a trans-disciplinary team approach are valued.**

The third and final theme that developed from this study was that the trans-disciplinary team valued the flexibility and open communication that was part of their team approach. Firstly, I will discuss the difficulty that the team had finding educationally based research on students with Batten's disease. Secondly, how they used the trans-disciplinary approach to support each other and the family. Then, this section will conclude with a discussion about the IEP process and its relevance for students with neurodegenerative conditions.

Batten's disease is a rare condition and there is little educational information about it. Often when people are faced with the unknown, a way of gaining control is to become knowledgeable about the situation and find out how other people have coped in similar situations (Green, 2008). In this study, none of the participants had experienced working with a student with this condition, so they joined forces to combat 'the unfamiliar' by sharing information and supporting each other.

According to Higgins, MacArthur and Morton (2008), New Zealand based research has found that teachers need support to access information about student's impairments as well as their social and educational needs. Similarly, the participants in the present study discovered that it was difficult to find information about educating a student with Batten's disease and were unsure what to do. In the face of such uncertainty, they supported each other by using their meetings, including the IEP, to discuss issues, share information, find solutions and they provided each other with emotional support.

"A supportive school environment provides a sense of belonging" and the trans-disciplinary approach "helps foster this" (Kelley, et al., 1998, p. 33). Bills (2006), in her study of children with Batten's disease, advocated for a team approach. She stated that "no individual has all the knowledge necessary to ultimately meet the many needs of these children and their families" (Bills, 2006, p. 19). However, Asprey and Nash (2006) found that parents of students with life-limiting conditions did not feel that there was multi-agency collaboration, so the team members were working in

isolation from each other. In contrast, the education team members in the current study commented that the trans-disciplinary approach allowed all the participants to openly share ideas. They valued each other's input and commented that they felt they were heard, respected and supported by the other IEP team members. They also used the IEP meeting to co-ordinate services, share information about Charlotte's current levels of functioning and respond to her needs.

Working in a consultative team provides a way of sharing the load that is placed on families and the school (Silberman, 1996; Werts, et al., 2007). According to Carpenter (2000), the "open and honest sharing of ideas, knowledge and skills can lead to a more collaborative team process and result in better services for the child" (p. 141). It has also been suggested that open communication and joint problem-solving between team members increases the involvement of a disabled student in the learning environment (Jakobsson, 2006; Sirvis & Caldwell, 1995). Similarly, all the participants in the present study, valued opportunities to communicate with each other. They stated that they were able to support Charlotte more effectively because they met regularly to discuss issues and it kept the lines of communication open.

In some studies, both parents and teachers have reported their feelings of disempowerment when dealing with other educational and medical professionals (Asprey & Nash, 2006; Beattie, et al., 2006; Fraser, 2005). Parents have reported that they felt frustrated, lacked confidence and had to battle for services and support for their child (Asprey & Nash, 2006; Beattie, et al., 2006). Fraser (2005) said teachers commented they felt "anxious or cynical" when faced with educational professionals (p. 150). However, in contrast to these studies, neither the school staff nor the parent in the present study expressed that they felt disempowered in their dealings with the education professionals.

It has been suggested that people working with students with chronic or life-limiting conditions need emotional support (Green, 2008; Koehlar & Loftin, 1994; Leaman, 2000; Loftin & Koehlar, 1998; Mukherjee et al. 2000). Teachers may feel overwhelmed and have difficulty coping with the student's regression and their own feelings of helplessness, finding it difficult to create a positive atmosphere that increases the learning opportunities for a disabled student (Fraser, 2001a; Johnson &

Jochum, 1996; Leaman, 2000). Similarly, the participants in the present study reported that they had felt helpless not knowing what to do when faced with a student with Batten's disease. However, they all appeared to have a positive attitude towards Charlotte's education and a belief that it was in her best interest to be at school in a mainstream setting. The participants did not mention that they gained emotional support from the other team members, but their comments about supporting each other, respect, openness, rapport and sharing opinions suggested that this was the case.

Fraser (2005) stated that all members in an ideal trans-disciplinary team are valued. "There is no hierarchy of power" and they are "equal partners" that share the decision-making (Fraser, 2005, p. 150). These views were reflected by the participants in the present study. It seemed that in the face of adversity this team had united together to create a strong trans-disciplinary approach where all members input was equally valued. The team dynamics appeared to rely heavily on goodwill and the team members' respect for each other. They also valued the professionalism and skills each member, including Charlotte's mother, brought to the group and were prepared to put aside their own agendas and negotiate the best way to meet Charlotte's needs, even if it meant shelving or abandoning the goals they had identified.

The professionals adapted their practice and were willing to negotiate with other team members to achieve the best outcomes for Charlotte and her family. Sometimes goals or activities were abandoned because other priorities took precedence and the team did their utmost to include Charlotte's family in the decision-making process. Becky, Charlotte's mother, stated that she was fully involved in her daughter's education, respected as an integral part of the team and her input valued. She appreciated the relationship she had with the other team members.

In summary, a strong trans-disciplinary team approach helps to enhance the quality of life for a student with a life-limiting or neurodegenerative condition by supporting the parents and each other. Flexibility, adaptability, open communication, respect and valuing the input of all team members ensured that this trans-disciplinary team worked well together to achieve the best outcomes for both Charlotte and her family.

## **Individual Education Plans**

The IEP is recognised as a key educational document for disabled students, and family involvement is fundamental to the IEP process (Hazekamp, 1986). However, parents in previous studies have not found this to be the case. Punkari, Eskonen and Hietaharju-Mölsä (2006) stated that in their experience it took a long time before Finnish parents were able to participate on the same level as the professionals in the IEP process. Some New Zealand parents reported that they felt disempowered by the IEP process (Thomson & Rowan, 1996; Williams & Nagel, 2001). In contrast, Becky, Charlotte's mother, stated that she was an integral part of the IEP process and valued the fact that she was respected as an equal participant.

The IEP process can be flexible and “enhance inclusion” for students with disabilities (Moltzen, 2005, p. 165). Closs (2000) found that IEPs were useful in determining future directions, adaptations needed, and monitoring progress for all concerned. Similarly, the participants in this study stated that they felt the IEP process was useful for disseminating information between the trans-disciplinary team members; as a forum for discussing issues and strategies; and a way of setting goals to help Charlotte maintain her physical and cognitive skills for as long as possible.

IEPs are one way of showing a student's progress, but it is difficult to comply with these requirements when a student has a neurodegenerative condition. The whole purpose of the IEP comes into question. Rokne (2006) said that the IEP process, for a student with Batten's disease, should contribute to their quality of life and involve the whole team to ensure that the student has the resources and services needed. In addition, the IEP should include the maintenance of existing skills and knowledge (Rokne, 2006). These views appeared to be endorsed by the team in the present study.

Of interest is the fact that the teacher-aides, in the present study, queried the purpose of the IEP and felt that more frequent team meetings would be better. The opinions of the teacher-aides in this study does not appear to be supported by research overseas, possibly because there are legal mandates to have an IEP for all students with special

needs, e.g. in the United States (Riddell, 2006) and Norway (Rokne, 2006). In New Zealand, the IEP is not a legal requirement (Ashman & Elkins, 1998), which may be why some of the participants considered that only having team meetings instead of IEPs were an option. However, having regular IEP meetings and the resulting IEP documentation are a Ministry of Education requirement, for all ORRS students, and are needed when applying for discretionary resources (Thompson & Rowan, 1996). In the present study, the IEP document was used to secure funding for the on-going resources that Charlotte needed and to document the goals that were agreed by the team.

Lastly, it appeared from this study that the educational team supported both Charlotte and her family's goals through the IEP process and used the IEP forum to share information and discuss issues. They adapted the IEP process and meeting in a variety of ways. They had changed the focus of Charlotte's IEP from progress and academic goals to that of maintaining her existing skills for as long as possible. Life skills as well as Charlotte's physical, cognitive and emotional needs had also become priorities.

## **Summary**

Finally, this study revealed that the members of a trans-disciplinary team want a student with Batten's disease to be happy, have social relationships and enjoy being at school. At no time did anyone question Charlotte's right to be in a mainstream school and the trans-disciplinary team all worked together to ensure that Charlotte's education focussed on her individual needs and her happiness. The team supported each other and had adapted the IEP process to enhance Charlotte's time at school and support her family, who had an active role in the trans-disciplinary team. Open communication and a flexible approach were essential parts of this teams' philosophy, which was supportive for all team members.

## **Chapter 6**

### **Conclusion**

In conclusion, this study examined the experience of one group working with a student with Batten's disease. It has highlighted that in the face of adversity and uncertainty the educational team united to create a strong trans-disciplinary approach to Charlotte's education. It seems that the team instinctively went back to basics and naturally put Charlotte and her individual needs first. They appeared to have no qualms about ignoring the New Zealand secondary school curriculum and there seemed to be no doubt in anyone's minds that the programme would be individualised and person-centred. This study suggests that the New Zealand system and the IEP process are indeed flexible enough to be adapted to cater for students with neurodegenerative conditions in New Zealand schools.

This study has also highlighted how the education team adapted its practice to support the needs of a student with Batten's disease and her family. It appeared that as a response to the neurodegenerative nature of Batten's disease and the resulting loss of skills, they considered that Charlotte's happiness was a valid goal for her education and tried to ensure that she was included with her peers in all areas of school life. It would be fascinating to know at what point people give up academic goals and focus on quality of life.

It is interesting to note that the Ministry of Education assumes that all students with disabilities will make progress and the IEP will document it (Ministry of Education, 1998b). Although setting goals for students with neurodegenerative conditions can be problematic this does not mean the IEP should be abandoned. A flexible approach to the IEP process may help develop goals for students, who are regressing. In this study there were conflicting opinions about the IEP process for a student with Batten's disease. However, all participants valued the opportunity to meet together.

This draws attention to the need for an adapted IEP process or method of goal setting for students with neurodegenerative conditions. Norwegian parents and educators of

students with Batten's disease thought more laterally than the participants in the present study and acknowledged the need to develop another way of writing IEPs for students with neurodegenerative conditions (Rokne, 2006). Currently Norwegian research has been started about adapting the IEP for students with Batten's disease and it would also be timely to do this in a New Zealand context.

The difficulties associated with finding suitable goals in the New Zealand curriculum were highlighted in this study. The New Zealand curriculum key competencies and 'Stepping Stones' (Vision Education Agency, 2005) may provide better goals for students with a neurodegenerative conditions than the standard curriculum. 'Stepping Stones' (Vision Education Agency, 2005) is the New Zealand expanded core curriculum guidelines for students with vision impairment and it supplements the New Zealand curriculum. It focuses on the additional skills that students with vision impairment need to develop and would be especially relevant in the areas of communication, orientation and mobility, physical skills and techniques of daily living.

It appears that the lack of educational information made this team stronger and a more cohesive group because no-one knew what to do, so they all worked together to meet Charlotte and her family's needs. However, due to the small number of Ministry of Education specialists working in this rural town, most of the participants knew each other professionally, which may have contributed to the positive group dynamics. This raises the question of how other groups might cope and what would happen if they did not work together or there was a conflict within the group. It would be interesting to do further study into the group dynamics of other trans-disciplinary teams.

Since I started this project, research about the education of students with Batten's disease has become more prominent internationally. In Sweden, the 'First International Education Conference on Batten's Disease' took place in 2006 and several research projects were presented. Currently an Australian survey is being undertaken to support people, who are working with students with Batten's disease, in Australia and New Zealand. The aim is to produce a way of sharing information, knowledge and strategies between people, who have supported or do support students



with Batten's disease. An area for further research would be to solicit the perspectives of students with Batten's disease themselves, about their education programmes identifying their priorities.

### **Limitations**

There were several limitations to this study. Firstly, this represents the experiences of only one educational team, which included one parent, in one school. It would be interesting to talk to other teams about their experiences and what happens in other parts of New Zealand. Secondly, my inexperience as a researcher and interviewer may have impacted on the information that the participants shared with me, because I did not extensively probe some of their answers. Thirdly, as an integral team member, I may have neglected to overtly include my "voice" in the research and in future would try to include it, possibly by being interviewed or writing my own answers to the interview questions. Finally, I did not include Charlotte's voice in this study and this may have added weight to the research. It would have been interesting to gather her perspective on what she wanted from her schooling.

### **Final thoughts**

Based on this study, it appeared that when an educational team are supporting a student with Batten's disease in an inclusive setting, they focus on supporting each other and the family; making the student's happiness their priority; and endeavouring to work together with a trans-disciplinary approach. The trans-disciplinary team members in this study ensured there were open lines of communication between everyone involved. They had adopted a flexible approach to their planning, goal setting and inclusion, so that they could meet the student's individualised needs rather than focussing on academic goals. The IEP process had been adapted to cater for the student's needs as well as those of the trans-disciplinary team members. The parent in this study considered herself to be actively involved and included in the trans-disciplinary team and the family's aims for the student's time at school was a driving-force for the whole team.

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## APPENDIX A

### Interview guide - Parents

1. Can you tell me about your experience having \_\_\_\_\_ at school?
2. What do you think has worked well?
3. What are the goals you have for \_\_\_\_\_'s education?
4. What have been the difficulties or issues?
5. Have adaptations and strategies you have used at home been implemented at school? How successful were they?
6. Have you implemented school strategies at home? How successful were they?
7. What support have you received from the school staff or other professionals?
8. What is your experience of the IEP process for \_\_\_\_\_?
9. How involved in the process are you?
10. Do you feel you are part of the team for \_\_\_\_\_ and how do you think the team approach works for you?
11. Do you think the goals set in the IEP are relevant for \_\_\_\_\_?  
Why/why not?
12. Are there any other informal or formal educational planning processes that have been used with your child?
13. How successful have these been?
14. Is there anything else you'd like to add?

## APPENDIX B

### Interview guide – Teachers

1. Have you worked with any other students with Batten's disease or vision impairment and neurodegenerative conditions?
2. Can you tell me about some of your experiences?
3. What adaptations and strategies have you made to accommodate this student in your class and how successful were they?
4. How is she included in the curriculum?
5. What have been the difficulties and issues having \_\_\_\_\_ in your class?
6. What support have you received from other professionals or colleagues?
7. What are the goals you have for \_\_\_\_\_'s education and how do you set them?
8. What is your experience of the IEP process for \_\_\_\_\_ and how helpful has it been?
9. Who is involved in the IEP process?
10. Are there any other informal or formal educational planning processes that you have used?
11. How successful have these been?
12. Is there anything else you'd like to add?

## APPENDIX C

### Interview guide – Educational Professionals and Paraprofessionals

1. Have you worked with any other students with Batten's disease or vision impairment and neurodegenerative conditions?
2. Can you tell me about some of your experiences?
3. What adaptations and strategies have you made or advised staff to make to accommodate \_\_\_\_\_ at school and how successful were they?
4. How is she included in the curriculum?
5. What have been the difficulties and issues working with \_\_\_\_\_ at school?
6. What support have you received from other professionals or colleagues?
7. What are the goals you have for \_\_\_\_\_'s education and how do you set them?
8. What is your experience of the IEP process for \_\_\_\_\_ and how helpful has it been?
9. Do you feel you are part of the team for \_\_\_\_\_ and how do you think the team approach works for you?
10. Is there anything else you'd like to add?

## APPENDIX D

**This information sheet had a Christchurch College of Education heading.**

### Parent Information Sheet

**Research Project: Parents and educators talk about their experiences in the school setting with a student with Batten's disease.**

My name is Lynda Williams and I am studying for my Masters of Teaching and Learning degree at Christchurch College of Education. As part of my degree I am researching the educational needs of a student with Batten's disease.

The overall aims of this study are:

- To gain an understanding of the educational needs of a student with Batten's disease,
- To gather information on adaptations and strategies used with a student, who has Batten's disease,
- To look at how the Individual Education Plan (IEP) process, or other planning processes, supports a student with Batten's disease and their family,
- To investigate alternative educational planning processes that may have been used.

This study will involve interviews with you, your child's teachers and key educational professionals, as well as the analysis of recent IEP documents. I hope to identify some of the areas that are working well and highlight some of the educational issues through your experiences and those of the educators working with your child with Batten's disease.

I would like to interview you about your experiences having a child with Batten's disease at school. The interview will cover the educational needs of your child and your experiences of the IEP process. I would also like your permission to review your child's recent IEPs and interview her teacher. I would also like to make some informal observational notes about your child's education and interactions with myself and other participants in this study.

If you consent to participate in this study, the interview should take approximately one hour and will be at a time and place at your convenience. The interview will be taped and later transcribed. There may also be a follow up conversation so I can clarify your comments. As part of this study I will be keeping a reflective diary of my own observations. With your permission I may make notes on informal conversations we have as well as comments made in formal situations such as IEPs. The information you provide will be used to write up this dissertation for the Christchurch College of Education and my examiners. Before the research is written up you will be given a copy of the transcript and you may change or delete any of it you wish. All information will be kept in a locked filing cabinet at my home and destroyed after the research is completed.

Because there are a small number of students with Batten's disease in New Zealand it is not possible to ensure your anonymity or confidentiality. However, no names or details identifying the people interviewed will be divulged and your child will not be identified.

You have the right to look at any of the information provided and access what has been written about you at any time. Your participation in this study is voluntary and you can withdraw at any time until the data is analysed.

The Christchurch College of Education Ethics Committee has reviewed and approved this study.

The College requires that all participants be informed that if they have any complaint concerning the manner in which a research project is conducted, it may be given to the researcher, or, if an independent person is preferred, to:

The Chair  
Ethical Clearance Committee  
Christchurch College of Education  
P O Box 31-065  
Christchurch  
Phone: (03 348 2059)

If you have any questions or concerns about this research please contact me or my supervisor.

If you are willing to participate in this study please fill in the enclosed consent form and return it in the stamped self-addressed envelope included by \_\_\_\_\_.

Yours faithfully

Lynda Williams



## APPENDIX E

**This information sheet had a Christchurch College of Education heading.**

### **Teacher, Educational Professional and Paraprofessional Information Sheet**

**Research Project: Parents and educators talk about their experiences in the school setting with a student with Batten's disease.**

My name is Lynda Williams and I am studying for my Masters of Teaching and Learning degree at Christchurch College of Education. As part of my degree I am researching the educational needs of a student with Batten's disease.

The overall aims of this study are:

- To gain an understanding of the participants' perspectives on the educational needs of a student with Batten's disease,
- To gather information on adaptations and strategies used with a student who has Batten's disease,
- To look at how the Individual Education Plan (IEP) process, or other planning processes, supports a student with Batten's disease and her family,
- To investigate alternative educational planning processes that may have been used.

This study will involve interviews with the identified student's parents, teachers and other key professionals as well as the analysis of recent IEP documents. I will also keep informal observational notes about my experiences, the conversations and interactions I have with the participants, about the student, during this study. Verbal permission to use this information will be sought as it occurs. I hope to identify some of the areas that are working well and highlight some of the educational issues through the experiences of teachers, parents and other members of the IEP team working with a student with Batten's disease.

I would like to interview you about your experiences teaching or working with a student with Batten's disease. Both your employers and the student's parents have given their permission for you to share information with me. The interview will cover the following:

- The educational needs of the student with whom you work
- The teaching strategies and adaptations you have used.
- Your experiences of the IEP process.
- How the IEP process is used to support the educational needs of the student.
- Alternative educational planning processes that you may have used.

If you consent to participate in this study, the interview should take approximately one hour and will be at a time and place at your convenience. The interview will be taped and later transcribed. There may also be a follow up conversation so I can clarify your comments. As part of this study I will be keeping a reflective diary of my own observations. With your permission I may make notes on informal conversations we have as well as comments made in formal situations such as IEPs. The

information you provide will be used to write up my dissertation for the Christchurch College of Education and my examiners. Before the research is written you will be given a copy of the transcript and you may change or delete any of it you wish. The information will be kept in a locked filing cabinet at my home and destroyed after the research is completed.

Because there are a small number of students with Batten's disease in New Zealand, it is not possible to ensure your complete anonymity or confidentiality. However, no names or details identifying any of the people interviewed will be divulged and the student will not be identified. All participants have the right to look at any of the information provided and access what has been written about them at any time. Your participation in this study is voluntary and you can withdraw at any time until the data is analysed.

The Christchurch College of Education Ethics Committee has reviewed and approved this study.

The College requires that all participants be informed that if they have any complaint concerning the manner in which a research project is conducted, it may be given to the researcher, or, if an independent person is preferred, to:

The Chair  
Ethical Clearance Committee  
Christchurch College of Education  
P O Box 31-065  
Christchurch  
Phone: (03 348 2059)

If you have any questions or concerns about this research please contact me or my supervisor.

If you are willing to participate in this study please fill in the enclosed consent form and return it in the stamped self-addressed envelope included by \_\_\_\_\_.

Yours faithfully

Lynda Williams

## APPENDIX F

### Consent form - Parent

**Research Project:** Parents and educators talk about their experiences in the school setting with a student with Batten's disease.

Having read and understood the information sheet I have been given, I consent to take part in an interview and a follow-up conversation if needed for the research project named above. During the research period I may also be observed interacting informally with the student and having conversations with the researcher about the student noted, provided I have given my verbal permission.

I am aware that:

- the interview will be at a time and place that suits me.
- the interview will be taped and transcribed.
- I have the right to refuse to answer any questions I wish.
- I can ask the researcher not to use our conversations or observations for this study.
- my participation is voluntary.
- I am able to withdraw from the research up until the data is analysed.
- I have the right to look at the information written about me at any time.
- the information I provide will be treated as confidentially as possible and my name and personal details will not be divulged.

I give consent for Lynda Williams to interview \_\_\_\_\_'s teacher, collect observational data and collect copies of \_\_\_\_\_'s IEPs and am aware they will be used only for the purposes of this research project.

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

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

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

**Contact details:**

**Email:** \_\_\_\_\_

**Phone:** \_\_\_\_\_

## APPENDIX G

### Consent form – Teacher, Educational Professional and Paraprofessional

**Research Project:** Parents and educators talk about their experiences in the school setting with a student with Batten’s disease.

Having read and understood the information sheet I have been given, I consent to take part in an interview and a follow-up conversation if needed for the research project named above. During the research period I may also be observed interacting informally with the student and having conversations with the researcher about the student noted, provided I have given my verbal permission.

I am aware that:

- the interview will be at a time and place that suits me.
- the interview will be taped and transcribed.
- I have the right to refuse to answer any questions I wish.
- I can ask the researcher not to use our conversations or observations for this study.
- my participation is voluntary.
- I am able to withdraw from the research up until the data is analysed.
- I have the right to look at the information written about me at any time.
- the information I provide will be treated as confidentially as possible and my name and personal details will not be divulged.

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

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

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

**Contact details:**

**Email:** \_\_\_\_\_

**Phone:** \_\_\_\_\_

## APPENDIX H

**This information sheet had a Christchurch College of Education heading.**

### **Principal and Board of Trustees information letter**

23 August 2006

Any school  
PO Box  
Timaru

Dear Principal,

I am studying for my Masters of Teaching and Learning degree at Christchurch College of Education. As part of my degree I am researching the educational needs of a student with Batten's disease.

My research project is called: Parents and educators talk about their experiences in the school setting with a student with Batten's disease.

The overall aims of this study are:

- To gain an understanding of the participants' perspectives of the educational needs of a student with Batten's disease,
- To gather information on adaptations and strategies used with a student who has Batten's disease,
- To look at how the Individual Education Plan (IEP) process, or other planning processes, supports a student with Batten's disease and their family,
- To investigate alternative educational planning processes that may have been used.

This project will involve interviews with the identified student's parents, teachers and other key professionals as well as the analysis of recent IEP documents. I will also keep informal observational notes about my experiences, the conversations and interactions I have with the participants, about the student, during this study. Verbal permission to use this information will be sought as it occurs. I hope to identify some of the areas that are working well and highlight some of the issues through the experiences of teachers, parents and other members of the IEP team working with a student with Batten's disease at school.

As we have discussed, a student in your school has been identified who will fit the criteria for my study. I am hoping you will give permission for me to interview (staff member's name), look at and get copies of (student's name)'s recent IEP documents. Written parental permission to use their child's information has been given.

The interview should take approximately one hour and will be at a time and place at the teacher's convenience. The interview will be taped and later transcribed. There may be a follow up conversation to clarify comments if needed. As part of this study I will be keeping a reflective diary of my own observations. With the participants'

permission I may make notes on informal conversations we have as well as comments made in formal situations such as IEPs. The information provided will be used to write up my dissertation for the Christchurch College of Education and my examiners. The information will be kept in a locked filing cabinet at my home and destroyed after the research is completed.

Because there are a small number of students with Batten's disease in New Zealand, it is not possible to ensure the participants' complete anonymity or confidentiality. However no names or details identifying any of the participants interviewed will be divulged and the student will not be identified. Participants have the right to look at any of the information provided and access what has been written about them at any time. Their participation in this study is voluntary and they can withdraw at any time.

The Christchurch College of Education Ethics Committee has reviewed and approved this study.

The College requires that all participants be informed that if they have any complaint concerning the manner in which a research project is conducted, it may be given to the researcher, or, if an independent person is preferred, to:

The Chair  
Ethical Clearance Committee  
Christchurch College of Education  
P O Box 31-065  
Christchurch  
Phone: (03 348 2059)

If you have any questions or concerns about this research please contact me or my supervisor.

If you are willing to support this study and allow (staff member's name) to participate in this study please fill in the enclosed consent form and return it in the stamped self-addressed envelope included by \_\_\_\_\_.

Yours faithfully

Lynda Williams

## APPENDIX I

**This information sheet had a Christchurch College of Education heading.**

**District manager (Group Special Education) and  
RNZFB Practice Advisor information letter**

District manager  
Group Special Education  
PO Box 123  
Anytown

Dear \_\_\_\_\_ ,

I am studying for my Masters of Teaching and Learning degree at Christchurch College of Education. As part of my degree I am researching the educational needs of students with Batten's disease.

My research project is called: Parents and educators talk about their experiences in the school setting with a student with Batten's disease.

The overall aims of this study are:

- To gain an understanding of the participants perspectives of the educational needs of a student with Batten's disease,
- To gather information on adaptations and strategies used with a student, who has Batten's disease,
- To look at how the Individual Education Plan (IEP) process, or other planning processes, supports a student with Batten's disease and their family,
- To investigate alternative educational planning processes that may have been used.

The study will involve interviews with an identified student's parents, teachers and other key professionals as well as the analysis of recent IEP documents. I will also keep informal observational notes about my experiences, the conversations and interactions I have with the participants, about the student, during this study. Verbal permission to use this information will be sought as it occurs. I hope to identify some of the areas that are working well and highlight some of the issues through the experiences of teachers, parents and other members of the IEP team working with a student with Batten's disease at school.

As we have discussed a student, with whom some of your staff work, has been identified as fitting the criteria for my study. I am hoping you will give permission for me to interview (staff member's name). Both school and parental permission has been attained.

The interview should take approximately one hour and will be at a time and place at to suit your staff member. The interview will be taped and later transcribed. There may also be a follow up conversation to clarify their comments if needed. As part of this study I will be keeping a reflective diary of my own observations. With the participants' permission I may make notes on informal conversations we have as well as comments made in formal situations such as IEPs. The information provided will be used to write up my dissertation for the Christchurch College of Education and my examiners. The information will be kept in a locked filing cabinet at my home and destroyed after the research is completed.

Because there are a small number of students with Batten's disease in New Zealand, it is not possible to ensure the participants' complete anonymity or confidentiality. However, no names or details identifying any of the participants interviewed will be divulged and the student will not be identified. Participants have the right to look at any of the information provided and access what has been written about them at any time. Their participation in this study is voluntary and they can withdraw at any time.

The Christchurch College of Education Ethics Committee has reviewed and approved this study.

The College requires that all participants be informed that if they have any complaint concerning the manner in which a research project is conducted, it may be given to the researcher, or, if an independent person is preferred, to:

The Chair  
Ethical Clearance Committee  
Christchurch College of Education  
P O Box 31-065  
Christchurch  
Phone: (03 348 2059)

If you have any questions or concerns about this research please contact me or my supervisor.

If you are willing to allow (staff member's name) to participate in this study please fill in the enclosed consent form and return it in the stamped self-addressed envelope included by \_\_\_\_\_.

Yours faithfully

Lynda Williams



## APPENDIX J

### Principal and Board of Trustees Consent form

**Research Project: Parents and educators talk about their experiences in the school setting with a student with Batten's disease.**

Having read and understood the information sheet I have been given, I consent to (staff member's names) participating in an interview and a follow-up conversation if needed for the research project named above. During the research period I consent to (staff member's names) being observed informally and having informal conversations about the student noted by the researcher provided they have given their verbal permission.

I am aware that:

- the interview will be at a time and place at their convenience
- the interview will be taped and transcribed.
- they have the right to refuse to answer any questions they wish.
- they can ask the researcher not to use their conversations or observations for this study.
- their participation is voluntary.
- they are able to withdraw from the research up until the data is analysed.
- they have the right to look at the information written about them at any time.
- the information provided will be treated as confidentially as possible and neither names nor personal details will be divulged.

I give consent for Lynda Williams to collect copies of \_\_\_\_\_ IEPs and am aware they will be used only for the purposes of this research project.

**School name:** \_\_\_\_\_

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

**Designation:** \_\_\_\_\_

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

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

**Contact details:**

**Email:** \_\_\_\_\_

**Phone:** \_\_\_\_\_

## APPENDIX K

### RNZFB Practice Advisor Consent form

**Research Project:** Parents and educators talk about their experiences in the school setting with a student with Batten's disease.

Having read and understood the information sheet I have been given, I consent to (staff member's name) participating in an interview and a follow-up conversation if needed for the research project named above. During the research period, I consent to (staff member's name) being observed informally and having conversations noted about the student by the researcher provided they have given their verbal permission.

I am aware that:

- the interview will be at a time and place at their convenience
- the interview will be taped and transcribed.
- they have the right to refuse to answer any questions they wish.
- they can ask the researcher not to use their conversations or observations for this study.
- their participation is voluntary.
- they are able to withdraw from the research up until the data is analysed.
- they have the right to look at the information written about them at any time.
- the information provided will be treated as confidentially as possible and neither names nor personal details will be divulged.

I am aware this information will be used only for the purposes of this research project.

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

**Designation:** \_\_\_\_\_

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

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

**Contact details:**

**Email:** \_\_\_\_\_

**Phone:** \_\_\_\_\_

**APPENDIX L**

**District Manager (Group Special Education)  
Consent form**

**Research Project: Parents and educators talk about their experiences in the school setting with a student with Batten’s disease.**

Having read and understood the information sheet I have been given, I consent to (staff member’s names) and other IEP team members, who may be identified at a later time, participating in an interview and a follow-up conversation if needed for the research project named above. During the research period, I consent to (staff member’s names) and other IEP team members being observed informally and having conversations noted about the student by the researcher provided they have given their verbal permission.

I am aware that:

- the interview will be at a time and place at their convenience
- the interview will be taped and transcribed.
- they have the right to refuse to answer any questions they wish.
- they can ask the researcher not to use their conversations or observations for this study.
- their participation is voluntary.
- they are able to withdraw from the research up until the data is analysed.
- they have the right to look at the information written about them at any time.
- the information provided will be treated as confidentially as possible and neither names nor personal details will be divulged.

I am aware this information will be used only for the purposes of this research project.

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

**Designation:** \_\_\_\_\_

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

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

**Contact details:**

**Email:** \_\_\_\_\_

**Phone:** \_\_\_\_\_