MASTER OF PROFESSIONAL PRACTICE

AN INVESTIGATION INTO HOW AND WHY INFORMATION SHOULD BE STORED AND SHARED FOR PEOPLE WITH HIGH AND COMPLEX SUPPORT NEEDS.

BRIDGET MEYER

Dedication:

To Riley Bell and all the Riley Bell's in our world.

Figure 1: Archery and riding on the back of Grandad's ute during school camp. Front page. Riley listening to instructions.

Acknowledgements:

I wish to thank the following people who have supported me during my Master of Professional Practice journey.

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STUDENT NAME: Bridget Tracey Meyer

STUDENT ENROLEMENT NUMBER: 2006174

ATTESTATION OF AUTHORSHIP:

“I hereby declare that this submission is my own work and that, to the best of my knowledge and belief it contains no material previously published or written by another person (except where explicitly defined in the acknowledgments), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of an institution of higher learning”.

NAME: Bridget Meyer

SIGNATURE:

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Glossary:

MProfPrac	Master of Professional Practice
BSS	Bachelor of Social Services
UNCROPD	United Nations Convention of Rights of Persons with Disability
DIS	Disability Information Service
UN	United Nations
IMM	Independent Monitoring Mechanism
IHC	Intellectually Handicapped
ERO	Education Review Office
UPIAS	Union of the physically impaired against segregation
WHO	World Health Organisation
IPC	Interprofessional Collaboration
IPE	Interprofessional Education
IPCP	Interprofessional Community Practice
AT	Assistive Technology
CE	Chief Executive
HNC	High and Complex Needs

Note: Permission has been received to use all photos within my thesis.

1 CHAPTER ONE: Introduction

1.1 Executive Summary

My interest in completing my thesis through the Master of Professional Practice (MProfPrac) programme was inspired during my time studying within the Capable NZ undergraduate programme which is offered through the Otago Polytechnic, New Zealand. The Capable programme encourages learners, like myself, to continue to remain within their workplaces whilst learning to become critical thinkers and undertaking a research project that relates directly to their respective disciplines. This was something I was extremely interested in pursuing and although I was not supported directly through my workplace, the Halberg Foundation, and have carried out this project in my own time and at my own cost, I was able to gain support within the disability sector to ensure proper process and integrity was maintained.

The purpose of my thesis was to investigate the concept of a storing and sharing website for people with high and complex support needs within the disability sector. I was looking to gain clarity through this process and an understanding on the mechanisms that are currently available for individuals and the benefits of such. Through this process I was also seeking out the barriers that such a concept may present.

The opportunity to place this work-based concept of a storing and sharing website into an academic environment has allowed me to cast a unique lens over it. The rigour and robustness in acquiring knowledge through this method has been both enlightening and at times confronting. The findings of my research place the concept in a good position to take forward however I do recommend the intricate design and logistics of accessible features need to be explored further with a recommendation to study specific areas of the findings in more depth.

> *"Education is the most powerful weapon which you*
> *can use to change the world"*
> *Nelson Mandela*

1.2 Introduction to the researcher

I am currently employed as a Lead Adviser for the Halberg Disability Sport Foundation, a role I have been doing for the past 13 years. My core role for the Foundation is focused on breaking down barriers and creating opportunities to encourage people of all levels of ability to participate in sport and recreation in a meaningful way alongside their peers. The strengths I bring to this role are in being innovative as well as being persistent around ways in which we can turn what some people perceive as an obstacle into what I would describe as an opportunity.

Through my role I have had the opportunity to develop several programmes that have been implemented both regionally and nationally. The Adaptive Sport Mentoring programme was presented in Paris in 2011 at the International Symposium of Adapted Physical Activity whereby interest from Belgium and America was established. The programme was based on mentoring young people with physical challenges into an inclusive sport or recreational environment. The Adaptive Sport Mentoring programme has been successfully delivered through the University of Otago since 2008. A second example of innovation is I am currently working on a website that allows individuals to make informed decisions on outdoor places and spaces depending on their level of ability. I am leading this project on behalf of the Foundation and now have the Department of Conservation, Be. Accessible and Fabriko as project partners. I am particularly interested in creating programmes and platforms that encourage both independent decision making and independent engagement.

Regarding my personal values and philosophy these have developed over the course of my lifetime and through different periods of my life have been adjusted. Our family, friends and community and the experiences we have had, all contribute to my sense of who I am and how I view the world. In the social service sector, I am often working with people who are vulnerable and/or may have lifestyles that are different than my own. It is important to those of us working in this sector that we are aware of our own personal values and are mindful not to impose them on the people we are working alongside. My values are something I hold in high regard. My values guide the way I live my life and the decisions that I make along the way both on a personal and professional level.

1) Being there for my family.
2) Working to promote equality and justice in our society.
2) Being emotionally happy.
4) Making a positive contribution to the community.
5) Continuing to learn new things.
6) Being accountable and responsible.
7) Being creative and thinking beyond traditional ideas to bring about change.
8) Being honest and truthful.
9) Manners - for example, being on time.

My values act as a touchstone that I can come back to regularly. They act as my compass that keeps me operating between North and True North. I don't believe I have a compass for work and for home life, I believe they are one and the same and I conduct myself with these same values regardless of who I am engaging with.

1.3 Introduction to my Thesis

This introduction gives a brief overview of the structure of my thesis along with information that is discussed within each chapter. My thesis has five chapters (1) Introduction, (2) Review of Literature, (3) Methodology and Method, (4) Research Findings, (5) Evaluation of Study and Recommendations. At the end of each chapter, I have shared my reflective commentary of learnings gained through the MProfPrac process. Each commentary gives an insight into the various stages of my learning journey as well as other occurrences that were adding colour to the MProfPrac process. Within chapter one I will also introduce *a day in the life* of a family with two young men who have high and complex support requirements.

Chapter One includes an executive summary explaining the purpose of my research followed by an introduction of myself as the researcher where I give an insight into my values and what is important to me both professionally and personally. The background to my research is introduced along with the learning outcomes I am looking to achieve through this process. Within chapter One, I have presented my first two insights. My first insight is my early education where I have touched on some of the challenges I had during my schooling years. The second insight discusses what my education looks like now.

Chapter Two is my review of literature. Within this chapter I have looked at literature focusing on several areas that I believed relevant to my research question. These areas are (1) United Nations Convention and National Legislation (2) Lived Experiences – Advocacy and Empowerment (3) Medical Model of Disability (4) Social Model of Disability (5) Collaboration (6) Technology in an unspoken world (7) Storing and sharing information. I have given an overview of what each of these areas will encompass at the beginning of the literature review as well as a summary at the conclusion of the literature review. Chapter Two also includes my third insight titled 'dusting myself off'.

Chapter Three outlines both the methodology I used for this research and the methods used in my research. I also share the screenshots of the website concept that were used during the interview process and other pieces of relevant information. The research participants are introduced in Chapter Three as well as the research questions. I have included insights four and five into Chapter Three.

Chapter Four discusses the research findings as well as the discussion on each point of interest. The findings have been discussed through the themes that emerged during the interview process. I have also included insight six into chapter four.

Chapter Five brings my thesis to a conclusion with the evaluation of the study being discussed along with my future recommendations. Insight seven and eight are included in Chapter Five.

1.4 Background to research

The landscape in which individuals with disabilities need to traverse in terms of funding and resources are complex regardless of where on the spectrum an individual falls. For individuals that acquire an injury as opposed to a congenital disability i.e born with that disability, the framework in which they operate is very different. Many of the young people I work alongside are supported through an intersectoral partnership between the Ministry of Health, Ministry of Education and Oranga Tamariki. Each of these organisations engages with and invests financially into a strategy called High and Complex Needs (HCN), *Me mahi tahi tatou.* The goals of the HCN strategy include collaboration across joint systems, encouraging intersectoral practice and the improvement of individualised service packages. This partnership and the funding that is associated with it is supporting individuals with the highest and most complex requirements. The number of individuals that receive this level of tailored service according to the 2005 Intersectoral Strategy for Children and Young People with High and Complex Needs, *Te Kahu Tauahi Whānau,* document is around 150. (Foreword 2 Introduction 3, n.d.). The strategy hosts several different outcomes they are looking to achieve of which four are particularly pertinent to this research.

1) Strong educational foundation for lifelong learning.
2) Social interaction. Established relationships with peers. Engages positively in social situations and participates in the community.
3) Safety and security. The family/whānau/caregivers are supportive, well-informed and meet the needs of the child.
4) HCN outcomes for the sector are directed towards relationship building and setting up systems so that service providers are better able to work together.

The other avenue whereby support is accessed is through the Accident Compensation Corporation (ACC). The numbers of individuals that fit the high and complex criteria, particularly children, is not high. To be funded through the ACC model you need to have acquired your disability through an accident or medical misadventure. The support, both financially and resource-wise, is more readily available if an individual does fit within this funding stream. For the purposes of my thesis, I have attempted to research accurate data sets that represent individuals with high and complex needs; however, these are not currently available through Statistics New Zealand. The most up-to-date sets claims 24 percent of the population has a disability; however, this includes a large proportion of people over 65 years who wear either glasses or hearing aids. According to Statistics NZ, 11 per cent of children under 15 years had a disability of which a learning disability was the most common (Statistics New Zealand., n.d.).

Through my role as a lead adviser for the Halberg Disability Sport Foundation, I have been in a position where I have observed the challenges that are encountered by schools, community support organisations and sports clubs, where potential inclusive opportunities are presented yet not embraced. An example of this is when support is being provided to an individual and solutions will be created on how to modify a situation or piece of equipment. Success in that moment has been conceived and a positive outcome obtained. The ‘problem’ is that no record is made of that moment. This loss of a valuable moment in record keeping is seen as an ongoing problem. With the absence of significant information, the support staff are unable to plan, modify or adapt in any meaningful engagement for the student they are supporting to become involved with the class. The sharing of this information, had it been stored and then shared, could potentially bring an inclusive opportunity for a student. To gain an understanding of the number of people that work alongside individuals see figure 3.

My interest in attempting to find a solution comes from conversations I have had with both individuals with additional support needs, their families, schools and community support organisations, on how information can be stored and shared as a child transitions through their school years and post school. For individuals who are unable to advocate for themselves this information can be vital as they work towards creating a meaningful life experience.

In my Review of Learning document, I refer to several important goals that I would like to achieve through the MProfPrac process. Gaining clarity on the inclusive education space within New Zealand, finding a platform in which I can align my own philosophy of inclusive practice, working towards a solution focused approach that encourages collaboration and looking closely at my own professional practice.

In having a good understanding of the High and Complex Needs systems that are currently in place; the desire of organisations to work more collaboratively, and the challenges that are presented on a sometimes-daily basis for the individuals and families, I work alongside I thought there must be a way we can do things differently. If there was a way that information could be shared readily, with permission, housed safely to build a rich vault of ideas to draw on, then no-one is going to be worse off. The idea of Facebook, Google docs, Twitter all in one place could possibly, if designed well, be a valuable resource.

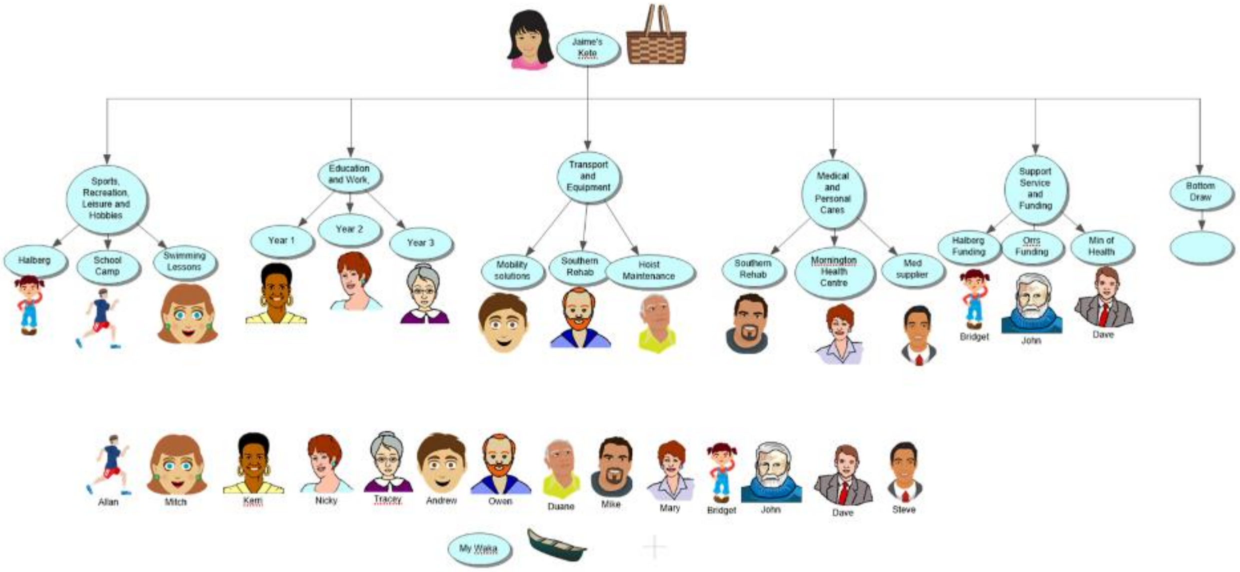


Figure 3: initial concept of idea

1.5 A day in the life of….

In order to bring as much context to my thesis as possible, I have sought permission to share what a typical day looks like for a family whom have two young men with high and complex support needs. The ages of Harry and Tom are 21 years and 18 years respectively. Harry has recently left school, while Tom is in year 13. For individuals with high and complex support needs, they can stay at school until the age of 21.

The purpose in sharing this insight is to begin to build a picture of what it is like when an individual is unable to advocate for him or herself yet has numerous support people interacting with them throughout the day. The day begins first thing in the morning, when the early morning caregiver arrives; extends through the day, when the teacher aides, gym instructors, physios, afternoon support worker have input; and moves into the evening, when the support worker leaves the family home around 9.00pm. This example is over one day. However, over the course of the week, there are different support workers coming and going along with different people who support the various activities that take place. For Tom, who is still at school, the teacher aides are relatively consistent; however, due to his additional support needs, i.e sign language, it is very challenging when they are away.

This information is used with permission.

6.30 am	Mum gets up and makes breakfast and lunches.
7.00am	The morning caregiver arrives, and she and Mum get both boys, toileted, dressed, hoisted/transferred into wheelchairs.
7.30am	Being fed breakfast.
8.00am	Loaded into van ready to drive to school.
8.30am	Drop Tom off at school. Return home and toilet Harry before his support worker arrives.
9.30am	Together they head out to catch bus to the gym.
10.45am	Mum goes to physio appointment for workplace injury through lifting.
12.00pm	Harry and support worker meet Mum at Dental School. Support worker finishes and Harry attends a dental apt.
1.00pm	Harry and Mum head home, mum toilets Harry and then walks the dog.
2.30pm	Harry and Mum head to school to pick up Tom

3.00pm	Load Tom in van and head home via supermarket.
3.30pm	Get home, unload, and have afternoon tea.
3.45pm	Physiotherapist and wheelchair rep arrives to look at Harry in his chair. Afternoon caregiver arrives and changes Tom out of his uniform and gets him on toilet.
4.30pm	Boys hoisted into their armchairs.
4.45pm	Physios and caregivers leave.
	TV watching ☺
6.15pm	Dad arrives home and we have dinner.
7.00pm	We all relax and watch an Alaskan Coast Guard show on Netflix.
8.00pm	The night-time caregiver arrives. Toileting and bedtime routine.
9.00pm	Caregiver leaves.

1.6 Learning Outcomes

The goal of my research is to investigate the concept of a storing and sharing website for people with high and complex support needs. This website concept would encourage ideas and information to be shared across a person's support networks. The website would be a platform to house relevant information that would build over time creating a dossier of rich information. I will investigate whether the concept of such a website is something that could be used by the sector and to initiate conversations with the research participant group on how such an idea of incorporating technology and encouraging interprofessional collaborative practice can benefit the disability sector as well an gaining an insight into the challenges that such a concept may present.

Secondly, my MProfPrac journey has allowed me to gain a more in-depth understanding of my own professional practice and given me time to consider where to from here. The reflective component of the MProfPrac course has enabled me the opportunity to recalibrate my own practice and question the direction I am taking within the social service sector.

Figure 4: Goal image.

("What I've Learned about Goals and Objectives - Listen Technologies," n.d.)

2 CHAPTER TWO: Literature Review

2.1 Review of Literature - Introduction

In this chapter, I summarise the areas of advocating for individuals with high and complex needs, lived experiences and empowerment, understanding interprofessional collaboration, using technology in an unspoken world and information storing and sharing websites. These areas of literature will guide my research question. I will also outline the International legislation from the United Nations Convention of the Rights of Persons with Disability along with National legislation that impacts young people with high and complex support needs within the education curriculum. I am seeking literature from these fields to be informed on how advocacy is fostered for individuals with high and complex needs; how individuals are empowered through their lived experiences; how collaboration works across varies sectors; how assistive technology can be of benefit or of detriment to an individual; and what needs to be considered in storing and sharing information.

The structure of this chapter will begin with an overview of the United Nations Convention on the Rights of Persons with Disabilities with a focus on Article 21, Article 24 and Article 30. I will summarise the history of inclusive education in New Zealand and introduce legislation from the New Zealand Education Act (1889). I will draw on literature that looks at how this legislation has impacted children with disabilities. In the second section, I begin by drawing on literature that gives a voice to the lived experiences of individuals through advocacy. Section two will also look to the literature to understand empowerment for individuals with high and complex needs and how this can inform and guide our practice. I will also introduce the medical model of practice and the social model of practice. After outlining the literature on lived experiences and introducing the medical and social model of practice, I will draw on literature that explains varies forms for collaboration in both a medical, education and community context. In the final section, I describe a form assistive technology that can be used in an unspoken world and examine the literature that discusses both the positive and negative outcomes of engaging with assistive technology. I introduce and draw on the literature of two recently-developed websites and discuss the findings of one of the sites. I will close this chapter by revisiting the main points that have been identified in the review.

2.2 United Nations Convention and National Legislation

The United Nations was founded in 1945 with the aim of achieving both peace and security at an international level as well as promoting social progress and engaging in human rights. Of the 195 countries in the world, 193 countries are members of the United Nations (History of the UN | United Nations Seventieth Anniversary, n.d.). There are four main purposes or focus areas of the United Nations and the work it carries out; (1) to develop peace throughout the world; (2) to develop friendly relations among nations; (3) to be a centre for harmonizing the actions of nations to achieve these goals and, lastly, (4) to help nations work together to improve the lives of poor people, to conquer hunger, disease and literacy and to encourage respect for each other's rights and freedoms. This final point, "to encourage respect for each other's rights and freedoms," is of significance to this research (History of the UN | United Nations Seventieth Anniversary, n.d.).

At an international level, the Convention on the Rights of Persons with Disabilities sits within the Division for Social Inclusive Social Development which, in turn, comes under the United Department of Economic and Social Affairs. The Convention on the Rights of Persons with Disabilities has 50 Articles relating to various aspects and fundamental rights of a person with a disability ("Convention on the Rights of Persons with Disabilities - Articles | United Nations Enable," n.d.). The global purpose of the Convention is to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity" ("Article 1 - Purpose | United Nations Enable," n.d.). There are three articles that are of relevance to this research. Article 21 – Freedom of expression and opinion, and access to information. Article 21 has five key points that highlight various ways in which information can be accessed by people with disabilities. Points B and C are of significance and relevant in that both alternative forms of communication as well as having access to information and services are recognised as a right ("Article 21 - Freedom of expression and opinion, and access to information | United Nations Enable," n.d.). The importance of education is detailed within article 24. The overarching statement of article 24 identifies an individual's right to an education without discrimination and delivered in such a way that equal opportunities are presented for all learners. This article is divided into five areas, with each area giving guidance to an individual's right within the education system and what can be expected in terms of support from both a human resource and infrastructure viewpoint. For the purposes of this research, however, point 2.e, which identifies the important of individualised support, "consistent with the goal of full inclusion;" and 3.c, stating that education is delivered in the most "appropriate mode and means of communication," are the most noteworthy ("Article 24 - Education | United Nations Enable," n.d.).

The final article within the United Nations Convention on the Rights of Persons with Disabilities is Article 30 – Participation in cultural life, recreation, leisure and sport. Article 30 pertains to accessing a variety of opportunities within an individual's community. Article 30 is divided in five sections with various points under each. The common wording throughout each of these sections is the statement of "on an equal basis with others;" therefore, implying that the accessing of cultural experiences, recreation, leisure and sport will be delivered "on an equal basis with others". Article 30 hosts several important points in relation the rights of an individual. Point five in Article 30 has the overarching statement of "enabling persons with disabilities to participate on an equal basis with others in recreational, leisure and sporting activities" ("Article 30 - Participation in cultural life, recreation, leisure and sport | United Nations Enable," n.d.) With the best of intentions however the ongoing implementation to enforce these articles and the rights within them is a constant challenge (Lyons, 2013, Selvaraj, 2015).

The Office for Disability Issues oversees the Convention on the Rights of Persons with Disabilities by providing a platform that gives visibility and legitimacy to people living with a disability within Aotearoa. To ensure the legitimacy of the convention, in 2010 the New Zealand Government implemented the Independent Monitoring Mechanism (IMM) and tasked it with evaluating the implementation of the Disability Convention in New Zealand. An example of the challenges and areas of concern in fulfilling the convention have been identified by the IMM as recently as March 2018 with six key areas being targeted as ongoing concerns. Education, access to information and communication are two of the six areas the Independent Monitoring Mechanism have recommended be closely looked at. These two areas are of interest to this research. The New Zealand Government and the Office for Disability Issues is currently guided and working towards the eight goals stated in the 2016 – 2026 New Zealand Disability Strategy (“New Zealand Disability Strategy - Office for Disability Issues,” n.d.)

Within the New Zealand education system, an individual with additional support needs is also recognised through specific legislation (Ministry of Education, 2012). The 1989 Education Act was a turning point for young people with disabilities. This legislation gave children the right to enroll in their local school with the expectation that they would receive an education alongside their peers. The act stated that “people who have special educational needs (whether because of disability or otherwise) have the same rights to enroll and receive education at State schools as people who do not – Education Act 1989 s(8)(1)” (Ministry of Education, 2012).

The inclusive education movement was initially implemented by the Labour Government during the 1930’s (Selvaraj, 2015). The goal was to create an education system that would cater for all levels of abilities within a state school system. A lofty goal and one which continues to present ongoing challenge. According to Selvaraj, the “historical developments of what became known as Special Education” (p.55) created the foundations for an education system that is deficient in clarity in what “inclusion and inclusive education” really means (p.55). There have been numerous manifestations of what best practice could potentially look like for a child with additional support needs. However, as stated by Selvaraj, “the road to inclusion has not been easy” (p. 57). The rhetoric of ideological inclusive practice versus the reality of bringing inclusion to life as opposed to lip service is also discussed by Lyon (2013). Lyon reaffirms that “the concept of inclusion itself has been largely diluted” (p.239). Although legislation and policies have been put in place “and they have been given the language to speak about inclusion, making inclusion a reality appears problematic and confusing” (p.239). The seemingly rudderless direction and confusion arising from the lack of direction continues to perplex to this day. Many professionals across several sectors including education work hard to grapple with this elusive concept of inclusion as both Selvaraj and Lyons have argued. The ideology of what is being proposed through legislation and policy and the reality of achieving the utopia of inclusion continues to evade us. To gain an understanding of the timeline that the New Zealand Education system has experienced, Table 1 demonstrates the various actions that have been undertaken over the past 142 years.

ACTION	YEAR	OUTCOME
Centrally Funded System.	1877	Centrally Funded and available to all children.
New Zealand Education Act.	1889	Children with Disabilities the right to enroll at local school
UNCROC – United Nations Conventions on the Rights of the Child.	1993	"You have the right to special education and care if you have a disability as well as the right in this convention, so you can live a full life"
Special Education Policy Guideline.	1995	Children may receive special education if they require additional support.
Special Education 2000.	1996	Aimed to achieve a world class inclusive education for New Zealand over the following decade.
New Zealand Disability Strategy.	2001	The aim of the strategy is to ensure individuals have the rights to inclusion, participation and opportunities.
ERO evaluation of inclusive schools.	2010	Education Review Office evaluated the inclusion of students with high needs in mainstream schools. 20% were fully inclusive and 35% were partially inclusive.
IHC Code for New Zealand Schools.	2010	The IHC codes draws from global and national legislation and policy.
Review of Special Education	2010	2000 responses in relation to the Ministry of Education discussion document.
Success For All – Every School, Every Child.	2010	The vision for all schools to be inclusive by 2014.
Collaboration for Success Individual Education Plans.	2011	New approach to IEPs sees the child as central with potential to learn within class and a whole school setting. Collaborative approach.
Special Education Business Plan.	2011	Eight focus areas including the 'Success For All – Every School, Every Child' initiative.
Ministry of Education Report	2014	Schools engaging in Positive Behaviour for Learning programmes (PB4L).
Ministry of Education Report	2018	Schools continue to engage in PB4L programmes.

("History Of Inclusive Education In New Zealand Timeline | adapted from Preceden," n.d.)

Table 1: My own adapted table of timeline of significant events within New Zealand Education system.

To understand the number of organisations that contribute at a high level to the conversations on inclusive education in New Zealand see figure 5. This diagram gives a tip of the iceberg understanding of the organisations that are involved; however, there will be many more who also play a significant part in decisions that are made for vulnerable young people in New Zealand.

Figure 5: My own - Organisations and Legislation in support of people with disabilities.

In bringing the literature in relation to the United Nations Conventions and the National Legislation and how it contributes to my research to a conclusion, I will now discuss the importance of lived experiences by drawing on research that examines both advocacy and empowerment.

2.3 Lived Experiences – Advocacy and Empowerment

The fundamentals of advocacy and recognising the rights of individuals is stated within the founding document of the United Nations Convention on the Rights of a Person with a Disability (*Protocol - Convention on the Rights of Persons with Disabilities and Optional Protocol*

United Nations, n.d.). Moriarity and Dew (2011) examined the participation and advocacy of a person with disability during the UN Convention from the perspective of a person with a disability. The opportunity to advocate as a person with a disability on the world stage was seen as positive with their contribution being received by all as unanimously favorable.

Without the ability to be an advocate or self-advocate, individuals with disabilities are placed at high risk in terms of community participation (Heah, Case, McGuire, & Law, 2006). According to Dillon (2013), there are five steps to advocacy ranging from knowledge on rights through to the sharing of relevant information. Mithra (2009) agrees with this, thinking with a rights-based, person-centred, watching brief as a witness/observer. Used in an everyday setting of a school environment, the advocacy skills of a teacher are seen as able to achieve inclusion which is multi-layered. According to Petrie (2018), a combination of creativity, patience and reflective practice builds the foundations of a strong advocate and advocacy relationship (Petrie, Devcich, & Fitzgerald, 2018).

In discovering the world of assistive technology, we see the empowerment opportunities, with the right support, being endless. Creating independence for individuals with high and complex support needs with assistive technology is incredibly empowering (Dalton & Hoyt-Hallett, 2013). Empowerment can be achieved through a variety of interventions and methods. It is well established that children with disabilities are at risk of limited participation opportunities (Dalton & Hoyt-Hallett, 2013, Healey-Ogden & Austin, n.d.). However, according to Townsend et al, the promotion of assistive technology can be “enabling and inclusive”. Studies carried out in a number of different environments, across a variety of ages and demographics, state that assistive technology is both welcomed and necessary in generating a sense of engagement and independence (Beyer & Perry, 2013).

Advocacy and Empowerment are both actions and outcomes respectively. To advocate in a meaningful way will produce empowering opportunities for individuals as well as having an impact on the community in which an individual is engaged.

The following section looks at both the medical model of disability and the social model of disability.

2.4 Medical Model of Disability

In drawing on literature regarding the medical model of disability, I see it has been described as a framework that is medicalized (Ba, 1990, Coles, 2001) and places the impairment or the issue of the disability with the individual. Ba (1990) argues that it is inappropriate to place disability within a medical model framework as he claims disability is a social state as opposed to something that needs to be cured. Oliver claims that the medical establishment is trained to diagnose and treat illnesses not to alleviate "social conditions or circumstances" (Ba, 1990, p.3). There is acknowledgement of tension between both the medical and disability establishments with one focusing on what has been described as the deficit model and the other as a model which draws attention to the barriers and obstacles that are created by society (Ba, 1990, Shakespeare, 2013). However, according to Fatoye at el (2018), neither the social model nor medical model of disability is effective if used alone. Figure 8 (below the definition box and over the page) gives a visual description of the differences between both the medical model and the social model.

The Medical Model of Disability according to the Oxford Dictionary of Human Resources " is the view that disability originates in a physical or mental condition that is intrinsic to the individual sufferer and who thereby experiences a reduced quality of life. The policy response that flows from this conception of disability is one that seeks to cure the underlying medical condition or alleviate its symptoms; for example, through the use of prosthetics or the prescription of drugs. Disability rights campaigners are often critical of the medical model of disability because it promotes a negative, disempowered image of people with disabilities. They tend to favor, instead, a social model of disability".
(Heery & Noon, 2017b)

MEDICAL MODEL AND SOCIAL MODEL OF DISABILITY:

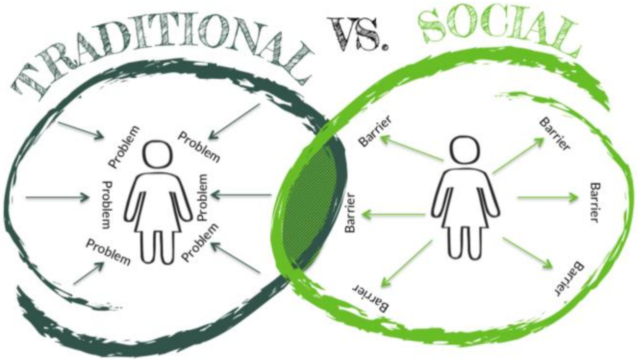


Figure 6: medical and social model diagram

("Medicine, Social, Green, transparent png image & clipart free download," n.d.)

2.5 Social Model of Disability

According to Oliver (2013), the concept of the social model of disability was developed from the Fundamentals Principals of Disability document which was first published in the 1976 by the Union of the Physically Impaired Against Segregation (UPIAS) (Oliver, 2013). The original statement from the UPIAS booklet says:

> *In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. It follows from this analysis that having low incomes, for example, is only one aspect of our oppression. It is a consequence of our isolation and segregation, in every area of life, such as education, work, mobility, housing, etc.* ("Fundamental Principles of Disability – National Disability Arts Collection & Archive," n.d.).

In the early 80's, Oliver (1983) drew on this concept to demonstrate a clear definition between what he described as the medicalization or medical model of disability and the socialization of people with impairments. Oliver's aim was to create a framework that would be easily understood by not only his students but also by professionals. The social model of disability is referred to throughout literature by both proponents for it and critics against it. Oliver admits to the social model being far from perfect, stating it was only meant to be a tool to help improve not divide people's lives (Ba, 1990). However, he also claims that with the support of human rights groups the social model of disability is gaining traction and challenging the thoughts of the medical establishment (Oliver, 2013). Shakespeare and Watson (2001) also appeal for the social model to be maintained as they too believe it is yet to be embraced fully by medical professionals as well as academics who are working within this discipline. Shakespeare (2013) claims that since the earlier academic work of Oliver (1990) among others there has been little development and goes on to state that there are a number of instances where the social model has become a hindrance to its own success.

The Social Model of Disability according to the Oxford Dictionary of Human Resources "is the view that social practices and attitudes render people disabled by making it difficult or impossible for those with physical or mental impairments to participate fully in social and economic life. The implication is that social practices, including those at the workplace, should be adjusted to allow the full inclusion of disabled people in social and economic activities. The social model of ***disability*** *is often espoused by disability rights campaigners who wish to emphasize that the problems faced by the disabled arise as much in discrimination as they do physical or mental conditions. Under pressure from campaigners, it has begun to shape disability employment law, most notably in the requirement on employers to make reasonable adjustments to accommodate those with an impairment* (Heery & Noon, 2017a).

In looking to understand both models alongside one another (See Table 2, below), I have used the work of Haegele ("Comparisons between the medical and social models of disability discourse. | Download Table," n.d.) to show how both models of practice work when presented with the same question.

In bringing both the medical model of practice and the social model of practice to a conclusion, I will now, in section 2.6, discuss the collaboration and the various models that are used across the relevant disciplines.

Table 2: Adapted from Justin A. Haegele - Comparison between the medical and social model discourse.

Topic	Medical Model	Social Model
What is a disability?	An individual or medical phenomenon that results from impairments in body functions or structures; a deficiency or abnormality	A social construct that is imposed on top of impairments by society; a difference.
Targets of intervention.	Fixing the disability to the greatest extent possibly; normalizing.	Social or political change in an effort to decrease environment barriers and increase levels of understanding.
Perceptions toward individuals with disabilities.	The individual is faulty.	The individual is unique.
Perception of disability.	Being disabled is negative.	Being disabled is neither positive nor negative.
Effects on individuals who are typically functioning.	Society remains the same.	Society evolves to be more inclusive.
The agent remedy.	The professional	Can be the individual, an advocate, or anyone who positively affects the arrangements between individual and society.

2.6 Collaboration

'Collaborative Practice' has been described by the World Health Organisation (WHO) as a way multiple health organisations can work alongside one another to promote the access of quality essential services and to support peoples participation in national health services among other key focus areas (“World Health Organisation - What we do,” n.d.).

There are several models that are referred to within the sphere of collaboration or collaborative practice which are used readily within the disability sector and across several professional disciplines including both the medical and education sectors (Golom and Frank, 2018). Golom and Frank (2018) explain the differences across the multidisciplinary team, the interdisciplinary team and the interprofessional collaborative team as being hierarchical, less hierarchical but not equal to no hierarchy or territory; all members are equal. Golom and Frank (2018) explain that the Interprofessional Collaborative Practice (IPC) model is used within the health sector or health sector framework; the Interprofessional Education (IPE) model aligns itself within an education framework, and, finally, the interprofessional collaborative practice model is used across all communities. Although the movement to interprofessional collaborative practice is still in its infancy and there are challenges that have been recognised by Golom (2018) as complex, an approach of “think globally, act locally” has been recommended (p. 10). For interprofessional collaborative practice to achieve the desired outcomes of teams working together to build better outcomes, Molyneux (2001), through her research on interprofessional teams identified three key components:

1) The desire to be part of a collaboration with a willingness to share
2) Communication within the team,
3) Development of creative working methods.

A framework developed by Mentis et al (2001) and Zuckerman, Gal-Oz, Tamir, & Kopelman-Rubin (2015), aptly titled *Mawhai,* meaning ‘web’ and ‘net,’ has also described the interprofessional relationship as being “when professionals from different areas learn with, from and about each other interprofessionally. They develop a shared understanding of their different areas which facilitates their practicing together” (Mentis, 2001, p. 14). This description is was also used by Golem and Frank (2018) in *The Journey to Interprofessional Collaborative Practice – Are we there yet?.* Furthermore, Mentis et al (2001) goes on to say “Learning together resulted in increased confidence and competence to practice more effectively together” (p.74).

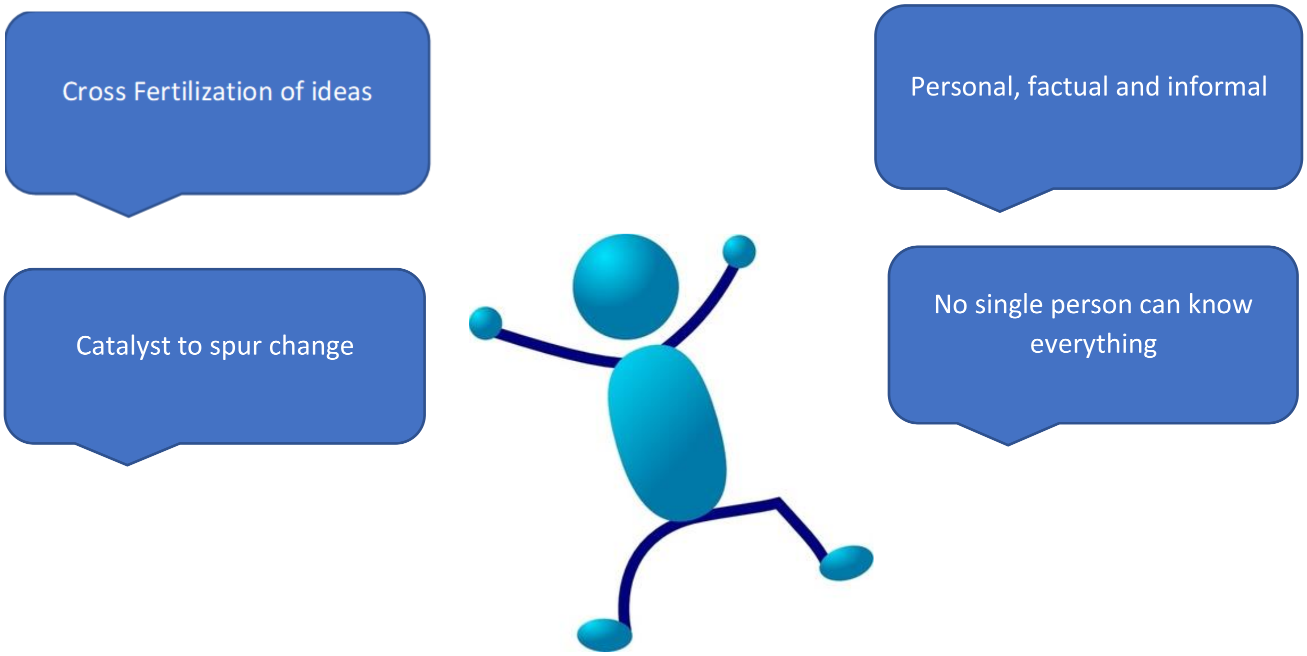
A relatively newly-coined model with the world of collaborative practice is that of community conversations. The point of difference that community conversations have in comparison to the IPC (health model), the IPE (education model) and the IPCP (community model) is that it brings all stakeholders together with a set structure in the way conversations are hosted. The community conversation model was developed from the world café model which focused on lessons in dialogue has been described “as an approach that provides a structured way of generating and prioritizing local solutions that align with a community’s cultural priority and available resources” (Carter & Bumble, 2018, p. 13). In looking at the world café and the community conversation model closely, we see there is clearly a level of duplication in the two models with the community conversation being more aligned with the social element of society. Both models, however, are working towards drawing in resources for the betterment of a situation. The literature on the community conversation model of practice can be used across several environments. The focus to date sees this model of practice being used as a way to generate change at a policy level (Flippo & Butterworth, 2018) as well as across an individual's support networks. Both are examples of two different audiences using the same model. Carter and Bumble (2018) explain in The Promise and Possibilities of Community Conversations: Expanding Opportunities for People with Disabilities, that although the practice of community conversation within the disability sector is relatively new opportunities are being created (Carter and Bumble, 2016). The sustainability of these opportunities has not been researched further however (Carter & Bumble, 2018, Trainor, 2018).

There is currently discussion around the use of 'community conversation' as a form of methodology. Carter has stated that community conversation is a unique methodology, but Trainor (2018) has countered with the idea that community conversation is not an established research methodology yet could be used as an integrated part of research projects. In building an understanding of how community conversation are practiced the benefits have been described throughout the literature as positive (Carter & Bumble, 2018, Trainor, 2018, Parker-Katz et al., 2018, Flippo & Butterworth, 2018). The research to date on the challenges is unknown but sustainability has been highlighted as a possible challenge (Parker-Katz et al, 2018).

The below figure (Figure 9, over the page) presents more ideas on that can be built upon using the community conversation approach.

In concluding this section on collaboration, I will now discuss both the benefits and challenges that lie within the world of assistive technology and how collaboration sits within this space.

Figure 7: My own figure with additional ideas on the benefits of community conversations.



2.7 Technology in an unspoken world

Figure 8; Assistive technology; image from Assistive technology Facebook page.

Assistive technology for high and complex users is becoming more and more advanced with tailored software being designed with a specific end user in mind. The spectrum of systems and software available is huge. One example, described by Batorowicz (2016), is a form of communication software called augmented alternative communication (AAC) that is becoming so finely tuned it can now be programmed to interpret utterances (Batorowicz, Mcdougall, & Shepherd, 2006). According to Wallace et al, “using both technology and strategic approaches, AAC often focuses on the restoration of cognitive-communication and/or physical speech impediments” (p. 43). Natural Language Generator is another assistive technology communication tool that can be implemented to create a story telling platform. Tintarev (2016) claims that a challenge with this software; however, is that the options for sentence construction is only as good as the pre-programmed library. If there are limited options, it can be potentially frustrating for the individual engaging with it (Tintarev, 2016). For ease of navigating a system or understanding what is required, Tintarev (2016) suggests that assistive technology is divided into subsets depending on what form of software is being created. The subsets suggested are sensor, environment, promoting and training, communication and telecare.

According to Shih (2012) "it is very important to provide collaborative working/learning opportunities in computer operation" (p. 10). Shih's research looked at relatively low-cost software modification and how individuals could use a mouse scroll wheel in a collaborative setting to communicate. Although this research and design only allows for collaborative pointing it is an option that should be considered. The mouse scroll wheel allowed for collaborative conversation between parties (Ching Hsiang Shih, n.d.). Furthermore, Hamel states that "simple devices such as a pager or a remote for the tv can have a significant impact on people's lives in that it enables them to have a sense of control" (Hammel, n.d., p. 57).

The benefits across all areas of accessibility and the power behind accessible software was highlighted throughout the literature. To be able to create a personal narrative and share thoughts through having tailored accessible functionality is galvanizing for all parties (Tintarev, 2016, Ching Hsiang Shih, n.d., Katsioloudis & Jones, 2013). According to Katsioloudis (2013), having an awareness of the benefits of assistive technology, learning about the research in a sometimes-clinical setting to truly understanding the implications of it in an individual's life certainly makes the subject very real. Hamel (2003) shared two research samples from both an assistive technology end user and a community support worker. The end user stated that

> *"Simple, I talk. I need it. When broke, I no talk"* (p. 331).

This is followed by an extract from a conversation with a community worker in sharing that -

> *"He's all over the place with his new chair. Before that he never left his room unless someone had the time to roll him over to another room. Now he's whizzing down the hall and around the block. I can't keep track of him sometime. One day they were tearing up the sidewalk outside the house and he couldn't use the new chair. It was like he was a different person again. Dependent on people to move him everywhere. It's kind of amazing to think about – with it he moves, without it he's dependent on me* (Hammel, n.d., p. 331)

Being able to access assistive technology when required is a challenge. Also having ongoing support once it is accessed is also a challenge (Hamel 2003). Through the research of Lancioni (2016) it was found that people with multiple disabilities can have serious difficulties managing their independence including both activities and communication, particularly when support people were not immediately available (Coleman, 2003, Lancioni et al., 2016, Hammel 2003, n.d. Seelman (1993) claimed through his research on *Assistive Technology Policy: A Road to Independence for Individuals with Disabilities* that the equity among people with disabilities and those of the able -bodied population were impeded. It could be argued that 26 years on the same challenges are still occurring in terms of equity and access to resources (Seelman, 1993).

In looking at the issues around the resourcing of assistive technology, slightly offshore from New Zealand, Ratliffe (2012) looked at the challenges within the Pacific Islands. Ratliffe's (2012) research found that the challenges in accessing appropriate technology was challenging although is gaining access to western media (Ratliffe, Rao, Skouge, & Peter, 2012). The difficulties seem to be two-fold in that not only accessing assistive technology is a challenge but also in knowing what assistive technology is available and an individual's rights to that (Ratliffe et al., 2012).

To achieve the development goals of building assistive technology resources that are tailored specifically for individuals with high and complex support needs information is required to be housed in a cloud-based system. The following section discusses the storing and sharing of such information.

2.8 Storing and Sharing Information

The final area of interest within the literature review is the storing and sharing of personal information. For the purposes of this research it is acknowledged that the intricacies, algorithms and other such things of security in a cloud-based storage system fall outside the scope of the research question. Security is a concern for all of us regardless of our executive functioning ability. For a growing portion of the population more and more of our personal data is being transitioned onto a cloud-based storage system. Being able to access our health information through an electronic health service, our finances through an online banking platform and education records through our education provider are to name a few. By engaging in such services, we are assuming that our information is secure.

With cloud-based storage one of the first questions that is often expressed is around security. In acknowledging this as a real concern by both Wilson, (2011) and Yaksel (2016) it was emphasized that firstly all aspects of storing and sharing information are taken very seriously, and systems are becoming more and more difficult to penetrate. Wilson (2011) has confirmed that although the security system is not flawless however "the overriding benefits from cloud computing are such that businesses could face real challenges in the future if they resist adoption" (p. 99). Yuksel (2017) agrees and states that although having access to cloud-based information has numerous advantages there are also ongoing concerns in terms of privacy, security and integrity of hosting information (Yukel, 2017). The benefits in the transitioning of information or building a personal narrative using a cloud system would see a rich dossier of information begin to emerge over a persons' lifetime. Petroulakis (2017) claims that 'life logging' on some devices is proving a challenge due to memory, resources and computer power (Petroulakis, 2017).

Conceptualizing and having the opportunity to trial the concept in a testing environment is hugely beneficial (Zuckerman et al., 2015, Miura et al., 2012). The insights gained help set the scene for further development if there is in fact a positive return on the concept. The importance of trialing a concept has been demonstrated both through the Tangi Plan (Zuckerman et al., 2015) prototype and the BarrierFree (Miura et al., 2012) website pilot concept. Zuckerman et al were able to reinforce the importance of testing. Tangiplan gathered feedback from their participant group and although small in numbers they were able to gain some sound insights. Tangiplan identified two problems which were the stability of the internet connection and battery life of the devices. These two problems are very generic in nature. Both Tangiplan (Zucket et al., 2015) and BarrierFree (Miura et al., 2012) have both implemented accessibility functions and continue to develop their platforms.

The following is a summary of my literature review where I will discuss briefly the eight areas of literature that I have engaged that have assisted in building my understanding of the intricacies of each of the disciplines.

2.9 Summary of Literature Review

In this chapter I have drawn on literature from across a variety of disciplines which inform the research question: Research the concept of a storing and sharing website for individuals with high and complex support needs. Literature selected from the area of Advocating for Individuals with High and Complex Needs, Lived Experiences and Empowerment, Understanding Interprofessional Collaboration, Using Technology in an Unspoken World and Information Storing and Sharing Websites share the solution focus approach in looking for ways to support people with high and complex support needs better.

Due to the wide range of literature covered within this review, I reinforce the importance of the community conversation model that takes into consideration a wide variety of sectors and disciplines as well as legislations and policy to help inform and give guidance where appropriate (Flippo & Butterworth, 2018). It could even be suggested that the World Café model may fit this concept as it has far wider reach (Carter & Bumble, 2018).

This literature review has provided a wide-angle lens where the document of the United Nations Convention on the Rights of Persons with Disabilities has been outlined followed by an overview of the New Zealand Education system and a timeline of the journey of ‘special education’. By looking at the wider landscape of disability and understanding the founding documents and legislation at both an international and national level, we can begin to plot a course towards understanding our current situation.

Investigating the literature of lived experiences and the benefits of advocacy and empowerment, I have been able to gain a deeper appreciation of both the challenges that are presented for individuals as well as the importance of continuing to advocate for people who are unable to represent themselves. The flow-on effect of positive advocacy is evident in the literature on empowerment and how this can impact the holistic health of an individual.

Each area of literature presented through my review has been a key in bringing together a much greater understanding of the wider world. Each discipline has its own complexities and idiosyncrasies and by gaining an understanding of the work that has gone before begins to build an important foundation of the landscape. Both the medical model and the social model of disability literature discussed in my review has brought a greater understanding of the historical context to both. What might have been described as black and white thinking within this discipline has now moved into a shade of grey where an understanding of the importance of both is now clearer for me as a research practitioner.

Collaboration both internally and across partner organisations is discussed with the benefits and challenges being brought to attention. The academic literature describes what different forms of collaboration look like within various organisations yet also acknowledges the outcome in achieving this remains elusive. Collaborative practice on paper and within organisational strategies looks quite different to what is occurring within our communities.

There is an ever-increasing world of technology being developed with access to information technology resources becoming more readily available. In this review, I have mentioned some examples of resources that are available for individuals with high and complex support needs as well as sharing examples of technology and how it was piloted in the development phase. In developing technology for individuals with specific needs certain aspects must be more considered for the resource to be fully accessible. It is an exciting time in the space of both disability and information technology as the world of virtual interaction, robotics, and augmented assistive technology becomes a normal part of our day to day world.

The storing and sharing of information are the key concept of this research project. The main area of concern that was shared regarding this was the security of such information. The literature however has identified that concerns around the security of information is not a valid reason not to pursue placing information into a cloud-based system that others could potentially have access to. The literature has suggested that no system is 100% fault proof however the technology is getter better with security being unlikely to be penetrated.

3 CHAPTER THREE: Methodology and Method

3.1 Action Research Methodology

Jean McNiff (2017) describes the action research methodology as an enquiry conducted by self into the self. As a practitioner you think about your own life work as well as asking why you do the things you do, and why you react the way you do (McNiff, Edvardsen, & Steinholt, 2018). The rationale in selecting Action Research as the methodology of choice is the relevance it has in guiding and advancing me as a professional practitioner as well as aligning itself to my research project. Action research methodology has enabled me to be both researcher and reflective practitioner as well as enabling me to work in a co-operative partnership with the research participants to look for solutions to the identified problems.

The steps taken (Figure 11) in the process of action research take a methodical path that supports the building of both evidence and data towards the research project.

Figure 9: The action research cycle.

(Adapted from: Azhar, Ahmad, & Sein, 2010)

The first step of six is in identifying the problem or selecting an area of focus. This step is vitally important as it is the first step in assembling what will become the project. The main element in step one is what do I want to investigate? For my research project I wanted to investigate if there was a way information could be shared across an individual support networks therefore, I was looking to test the concept of a website that would promote this.

The second action within this model was to identify a solution to the problem. The solution I identified was to potentially create a platform that would host relevant information that was easily accessible for stakeholders working alongside an individual. The solution would hold key pieces of information that helped inform and educate those working alongside individuals and their families.

Step three is to try out the solution in such a way that information can be gathered and considered. Step three for my research project involved sharing the concept of a website with 16 individuals across 5 different demographics. The concept of the site was presented with each interview participant sharing their thoughts on both the benefits and challenges they believed were relevant to them or their profession.

Steps four and five are the gathering and analysing of the data. For my research project interviews were recorded and transcripts transcribed. I coded the themes that emerged from the data into an excel spreadsheet by sectioning off each question then placing the relevant themes into each question. Each theme was colour coded to help in the identification.

The final stage of the action research methodology model is the writing of the report. For this part of the process I placed the information within a qualitative framework that allowed me to speak to the data using the voices of the research participants.

3.2 Qualitative Vs Quantitative

I have chosen to use a qualitative research approach within this research project as opposed to a quantitative research approach. In doing this, I have been able to observe and interpret my findings using a small research participant group rather than a much larger sample size. The qualitative research approach using the action research methodology has given myself as the research practitioner the opportunity to work intimately with the participants rather than being uninvolved and working at a distance. Although qualitative research has brought a certain amount of subjectivity to the discussion, I believe for the purposes of my research question, this approach was the most appropriate as the voices of the participants have been crucial in gaining an understanding as well as giving me valuable guidance of the situation. Being able to explore questions that have a 'why' value attached to them has been of value within this context. Due to the nature of the research and the demographics, i.e. being with disabilities there has also been value in face to face interviews rather than an online questionnaire.

("Strengths and weaknesses of Quantitative and Qualitative Research | WeeTech Solution Pvt Ltd," n.d.)

Figure 10: Image of quantitative vs qualitative data

According to Weetech Solutions, the pros and cons of quantitative versus qualitative data collection depends on what is looking to be achieved. For the purposes of this research project I was looking to explore an issue and gain an understanding to a problem. Therefore, with this in mind the qualitative approach is the correct one to place this research within. Qualitative and quantitative research differ with qualitative research for example focusing on the analysis of large numbers and measurements and qualitative data looking to capture the details of descriptions and observations (see Figure 12).

3.3 Research Method

The method I have used to collect data, analysis the data and report on the data is in a qualitative form. The steps I have taken are as follows.

- Ethical approval was granted by the Otago Polytechnic to carry out the research. (see appendices).
- Flyers (see figure 13) were created and distributed through the Otago Branch of CCS – Disability Action (see appendices).

Participants needed for research project.

A research project is being carried out to gauge the interest of a storing and sharing collaborative information website for people with high and complex support needs.

The goal of the project is to research the concept of a website that would allow information to be shared and stored across a web based platform among an individual's support networks.

- Dates and times for participating is flexible.
- Each interview is one hour long.
- The researcher is able to travel within the Otago region.

FOR MORE INFORMATION PLEASE CONTACT MELISSA SMITH AT MELISSA.SMITH@CCSDISABILITYACTION.ORG.NZ

WHO DO WE NEED?

3 x Individuals with high and complex support needs and their parents/ caregivers (8 – 18 yrs)

3 x Primary School Teachers

3 x Teacher Aides

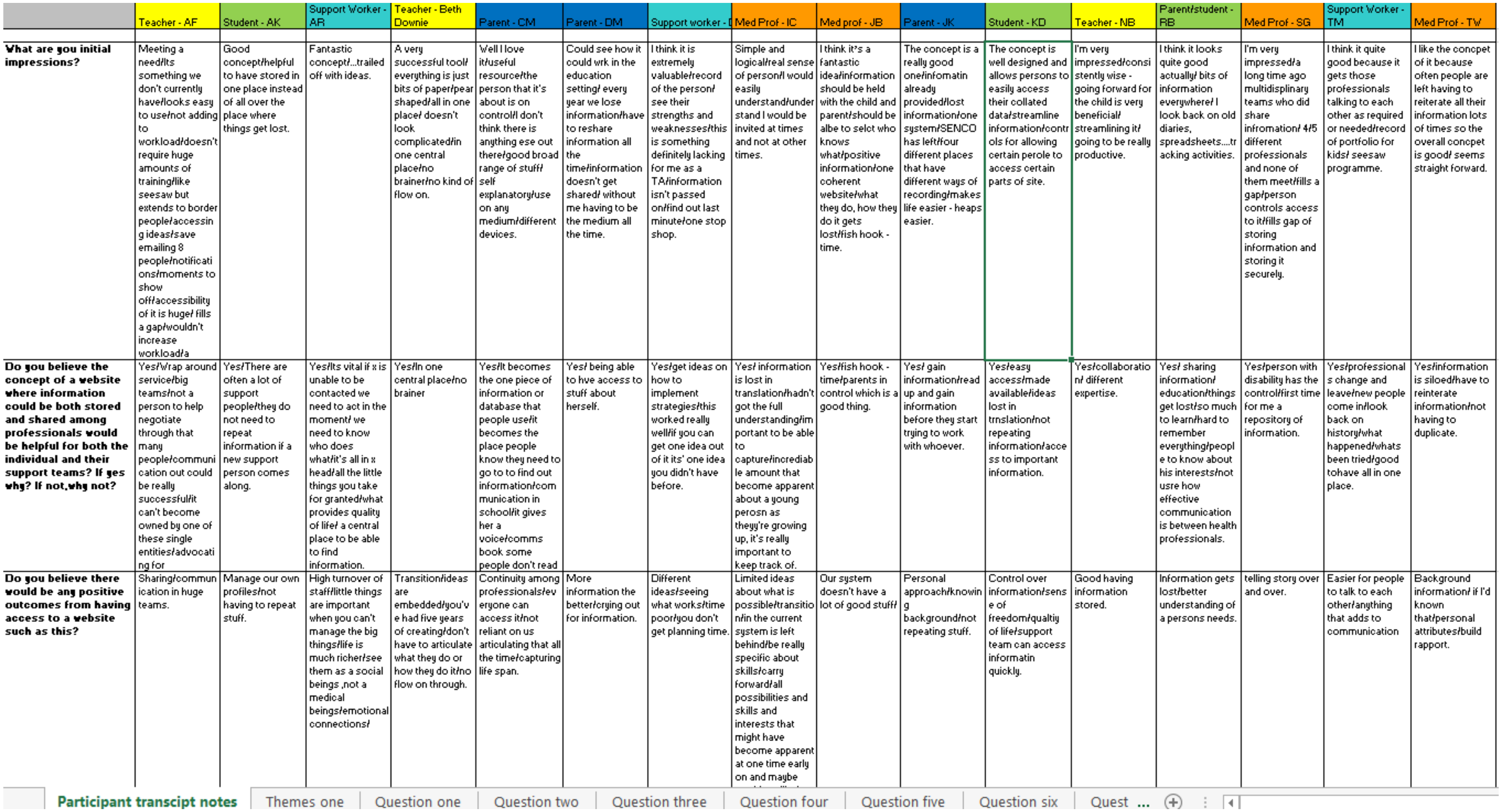
3 x Health Professionals

3 x Personal Carers

Figure 11: Flyer recruiting interview participants.

- Information did begin circulating eventually after a phone call was made to CCS.
- Participants made direct contact with me and interview times were arranged.
- Interviews were carried out at either Sport Otago (boardroom) or at the research participant's home.
- The interview participants signed the consent forms and gave permission for the interview to be recorded.
- Each interview took approximately 40 minutes.
- All interviews were recorded.

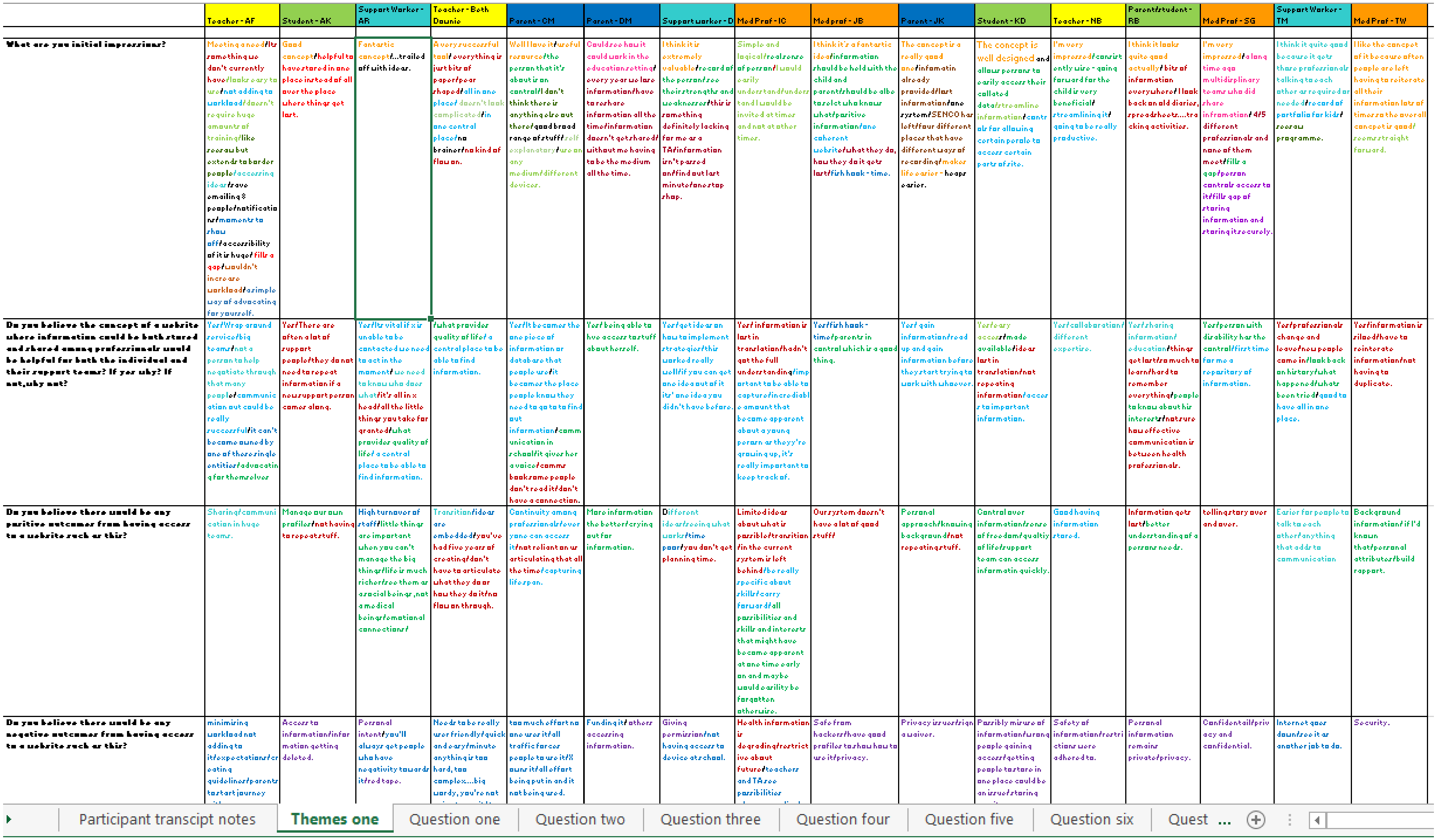
- Each participant was shown the concept of the website through screenshots of each page (see figures 5 through to 12) that I had bound into a booklet. This was originally a backup plan but became plan A due to ease.
- The interviews were transcribed.
- I explored the use of NVivo to analyse the data however due to the amount of data collected, I concluded I could create a system in a shorter amount of time that would achieve the same or a similar outcome. Table 3 shows the steps taken to group the data in the questions into themes.



	Teacher - AF	Student - AK	Support Worker - AR	Teacher - Beth Downie	Parent - CM	Parent - DM
What are you initial impressions?	Meeting a need/Its something we don't currently have/looks easy to use/not adding to workload/doesn't require huge amounts of training/like seesaw but extends to border people/accessing ideas/save emailing 8 people/notifications/moments to show off/accessibility of it is huge/ fills a gap/wouldn't increase workload/a	Good concept/helpful to have stored in one place instead of all over the place where things get lost.	Fantastic concept/...trailed off with ideas.	A very successful tool/ everything is just bits of paper/pear shaped/all in one place/ doesn't look complicated/in one central place/no brainer/no kind of flow on.	Well I love it/useful resource/the person that it's about is on control/I don't think there is anything ese out there/good broad range of stuff/ self explanatory/use on any medium/different devices.	Could see how it could wrk in the education setting/ every year we lose information/have to reshare information all the time/information doesn't get shared/ without me having to be the medium all the time.
Do you believe the concept of a website where information could be both stored and shared among professionals would be helpful for both the individual and their support teams? If yes why? If not,why not?	Yes/Wrap around service/big teams/not a person to help negotiate through that many people/communication out could be really successful/it can't become owned by one of these single entities/advocating for	Yes/There are often a lot of support people/they do not need to repeat information if a new support person comes along.	Yes/Its vital if x is unable to be contacted we need to act in the moment/ we need to know who does what/it's all in x head/all the little things you take for granted/what provides quality of life/ a central place to be able to find information.	Yes/In one central place/no brainer	Yes/It becomes the one piece of information or database that people use/it becomes the place people know they need to go to to find out information/communication in school/it gives her a voice/comms book some people don't read	Yes/ being able to hve access to stuff about herself.
Do you believe there would be any positive outcomes from having access to a website such as this?	Sharing/communication in huge teams.	Manage our own profiles/not having to repeat stuff.	High turnover of staff/little things are important when you can't manage the big things/life is much richer/see them as a social beings ,not a medical beings/emotional connections/	Transition/ideas are embedded/you've had five years of creating/don't have to articulate what they do or how they do it/no flow on through.	Continuity among professionals/everyone can access it/not reliant on us articulating that all the time/capturing life span.	More information the better/crying out for information.

	Support worker -	Med Prof - IC	Med prof - JB	Parent - JK	Student - KD	Teacher - NB
What are you initial impressions?	I think it is extremely valuable/record of the person/ see their strengths and weaknesses/this is something definitely lacking for me as a TA/information isn't passed on/find out last minute/one stop shop.	Simple and logical/real sense of person/I would easily understand/understand I would be invited at times and not at other times.	I think it's a fantastic idea/information should be held with the child and parent/should be albe to selct who knows what/positive information/one coherent website/what they do, how they do it gets lost/fish hook - time.	The concept is a really good one/infomatin already provided/lost information/one system/SENCO has left/four different places that have different ways of recording/makes life easier - heaps easier.	The concept is well designed and allows persons to easily access their collated data/streamline information/controls for allowing certain perole to access certain parts of site.	I'm very impressed/consistently wise - going forward for the child is very beneficial/ streamlining it/ going to be really productive.
Do you believe the concept of a website where information could be both stored and shared among professionals would be helpful for both the individual and their support teams? If yes why? If not,why not?	Yes/get ideas on how to implement strategies/this worked really well/if you can get one idea out of it its' one idea you didn't have before.	Yes/ information is lost in translation/hadn't got the full understanding/important to be able to capture/incrediable amount that become apparent about a young perosn as theyy're growing up, it's really important to keep track of.	Yes/fish hook - time/parents in control which is a good thing.	Yes/ gain information/read up and gain information before they start trying to work with whoever.	Yes/easy access/made available/ideas lost in trnslation/not repeating information/access to important information.	Yes/collaboration/ different expertise.
Do you believe there would be any positive outcomes from having access to a website such as this?	Different ideas/seeing what works/time poor/you don't get planning time.	Limited ideas about what is possible/transition/in the current system is left behind/be really specific about skills/carry forward/all possibilities and skills and interests that might have become apparent at one time early on and maybe	Our system doesn't have a lot of good stuff/	Personal approach/knowing background/not repeating stuff.	Control over information/sense of freedom/qualtiy of life/support team can access informatin quickly.	Good having information stored.

	Parent/student - RB	Med Prof - SG	Support Worker - TM	Med Prof - TW
What are you initial impressions?	I think it looks quite good actually/ bits of information everywhere/ I look back on old diaries, spreadsheets....tracking activities.	I'm very impressed/a long time ago multidisplinary teams who did share infromation/ 4/5 different professionals and none of them meet/fills a gap/person controls access to it/fills gap of storing information and storing it securely.	I think it quite good because it gets those professionals talking to each other as required or needed/record of portfolio for kids/ seesaw programme.	I like the concpet of it because often people are left having to reiterate all their information lots of times so the overall concpet is good/ seems straight forward.
Do you believe the concept of a website where information could be both stored and shared among professionals would be helpful for both the individual and their support teams? If yes why? If not,why not?	Yes/ sharing information/ education/things get lost/so much to learn/hard to remember everything/people to know about his interests/not usre how effective communication is between health professionals.	Yes/person with disability has the control/first time for me a repository of information.	Yes/professionals change and leave/new people come in/look back on history/what happened/whats been tried/good tohave all in one place.	Yes/information is siloed/have to reinterate information/not having to duplicate.
Do you believe there would be any positive outcomes from having access to a website such as this?	Information gets lost/better understanding of a persons needs.	telling story over and over.	Easier for people to talk to each other/anything that adds to communication	Background information/ if I'd known that/personal attributes/build rapport.

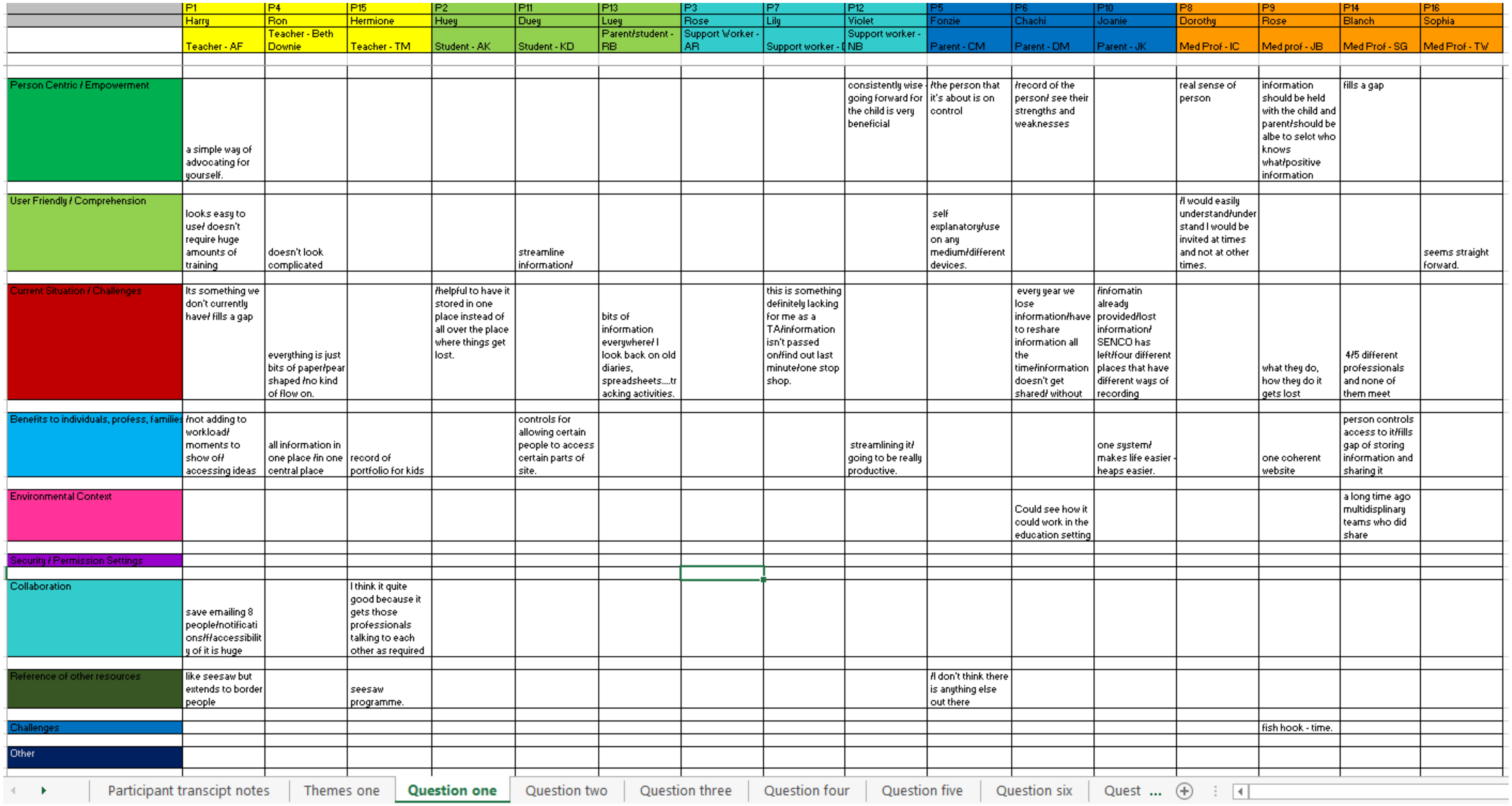


	Teacher - AF	Student - AK	Support Worker - AR	Teacher - Beth Downie
What are you initial impressions?	Meeting a need/Its something we don't currently have/looks easy to use/not adding to workload/doesn't require huge amounts of training/like seesaw but extends to border people/accessing ideas/save emailing & people/notifications/moments to show off/accessibility of it is huge/ fills a gap/wouldn't increase workload/a simple way of advocating for yourself.	Good concept/helpful to have stored in one place instead of all over the place where things get lost.	Fantastic concept/...trailed off with ideas.	A very successful tool/ everything is just bits of paper/pear shaped/all in one place/ doesn't look complicated/in one central place/no brainer/no kind of flow on.
Do you believe the concept of a website where information could be both stored and shared among professionals would be helpful for both the individual and their support teams? If yes why? If not, why not?	Yes/Wrap around service/big teams/not a person to help negotiate through that many people/communication out could be really successful/it can't become owned by one of those single entities/advocating for themselves	Yes/There are often a lot of support people/they do not need to repeat information if a new support person comes along.	Yes/Its vital if x is unable to be contacted we need to act in the moment/ we need to know who does what/it's all in x head/all the little things you take for granted/what provides quality of life/ a central place to be able to find information.	/what provides quality of life/ a central place to be able to find information.
Do you believe there would be any positive outcomes from having access to a website such as this?	Sharing/communication in huge teams.	Manage our own profiles/not having to repeat stuff.	High turnover of staff/little things are important when you can't manage the big things/life is much richer/see them as a social beings ,not a medical beings/emotional connections/	Transition/ideas are embedded/you've had five years of creating/don't have to articulate what they do or how they do it/no flow on through.
Do you believe there would be any negative outcomes from having access to a website such as this?	minimising workload not adding to it/expectations/creating guidelines/parents to start journey	Access to information/information getting deleted.	Personal intent/you'll always get people who have negativity towards it/red tape.	Needs to be really user friendly/quick and easy/minute anything is too hard, too complex...big wordy, you're not

	Parent - CM	Parent - DM	Support worker - D	Mod Prof - IC
What are you initial impressions?	Well I love it/useful resource/the person that it's about is on control/I don't think there is anything else out there/good broad range of stuff/self explanatory/use on any medium/different devices.	Could see how it could work in the education setting/ every year we lose information/have to reshare information all the time/information doesn't get shared/ without me having to be the medium all the time.	I think it is extremely valuable/record of the person/see their strengths and weaknesses/this is something definitely lacking for me as a TA/information isn't passed on/find out last minute/one stop shop.	Simple and logical/real sense of person/I would easily understand/understand I would be invited at times and not at other times.
Do you believe the concept of a website where information could be both stored and shared among professionals would be helpful for both the individual and their support teams? If yes why? If not, why not?	Yes/It becomes the one piece of information or database that people use/it becomes the place people know they need to go to to find out information/communication in school/it gives her a voice/comms book some people don't read it/don't have a connection.	Yes/ being able to hve access to stuff about herself.	Yes/get ideas on how to implement strategies/this worked really well/if you can get one idea out of it its' one idea you didn't have before.	Yes/ information is lost in translation/hadn't got the full understanding/important to be able to capture/incrediable amount that become apparent about a young persn as theyy're growing up, it's really important to keep track of.
Do you believe there would be any positive outcomes from having access to a website such as this?	Continuity among professionals/everyone can access it/not reliant on us articulating that all the time/capturing lifespan.	More information the better/crying out for information.	Different ideas/seeing what works/time poor/you don't get planning time.	Limited ideas about what is possible/transition /in the current system is left behind/be really specific about skills/carry forward/all possibilities and skills and interests that might have become apparent at one time early on and maybe would easility be forgotten otherwise.
Do you believe there would be any negative outcomes from having access to a website such as this?	too much effort no one uses it/all traffic forces people to use it/X owns it/all effort being put in and it not being used.	Funding it/ others accessing information.	Giving permission/not having access to device at school.	Health information is degrading/restrictive about future/teachers and TAs see possibilities

	Mod prof - JB	Parent - JK	Student - KD	Teacher - NB
What are you initial impressions?	I think it's a fantastic idea/information should be held with the child and parent/should be albe to select who knows what/positive information/one coherent website/what they do, how they do it gets lost/fish hook - time.	The concept is a really good one/infomatin already provided/lost information/one system/SENCO has left/four different places that have different ways of recording/makes life easier - heaps easier.	The concept is well designed and allows persons to easily access their collated data/streamline information/controls for allowing certain people to access certain parts of site.	I'm very impressed/consistently wise - going forward for the child is very beneficial/ streamlining it/ going to be really productive.
Do you believe the concept of a website where information could be both stored and shared among professionals would be helpful for both the individual and their support teams? If yes why? If not, why not?	Yes/fish hook - time/parents in control which is a good thing.	Yes/ gain information/read up and gain information before they start trying to work with whoever.	Yes/easy access/made available/ideas lost in translation/not repeating information/access to important information.	Yes/collaboration/ different expertise.
Do you believe there would be any positive outcomes from having access to a website such as this?	Our system doesn't have a lot of good stuff/	Personal approach/knowing background/not repeating stuff.	Control over information/sense of freedom/qualtiy of life/support team can access informatin quickly.	Good having information stored.
Do you believe there would be any negative outcomes from having access to a website such as this?	Safe from hackers/have good profiles to show how to use it/privacy.	Privacy issues/sign a waiver.	Possibly misuse of information/wrong people gaining access/getting people to store in one place could be an issue/storing	Safety of information/restrictions were adhered to.

	Parent/student - RB	Mod Prof - SG	Support Worker - TM	Mod Prof - TW
What are you initial impressions?	I think it looks quite good actually/ bits of information everywhere/ I look back on old diaries, spreadsheets....tracking activities.	I'm very impressed/a long time ago multidisplinary teams who did share infromation/ 4/5 different professionals and none of them meet/fills a gap/person controls access to it/fills gap of storing information and storing it securely.	I think it quite good because it gets share professionals talking to each other as required or needed/record of portfolio for kids/ seesaw programme.	I like the concept of it because often people are left having to reiterate all their information lots of times so the overall concept is good/ seems straight forward.
Do you believe the concept of a website where information could be both stored and shared among professionals would be helpful for both the individual and their support teams? If yes why? If not, why not?	Yes/sharing information/ education/things get lost/so much to learn/hard to remember everything/people to know about his interests/not sure how effective communication is between health professionals.	Yes/person with disability has the control/first time for me a repository of information.	Yes/professionals change and leave/new people come in/look back on history/what happened/whats been tried/good to have all in one place.	Yes/information is siloed/have to reinterate information/not having to duplicate.
Do you believe there would be any positive outcomes from having access to a website such as this?	Information gets lost/better understanding of a persons needs.	telling story over and over.	Easier for people to talk to each other/anything that adds to communication	Background information/ if I'd known that/personal attributes/build rapport.
Do you believe there would be any negative outcomes from having access to a website such as this?	Personal information remains private/privacy.	Confidentail/privacy and confidential.	Internet goes down/see it as another job to do.	Security.



	P1	P4	P15	P2	P11	P13	P3	P7	P12	P5	P6	P10	P8	P9	P14	P16
	Harry	Ron	Hermione	Huey	Duey	Luey	Rose	Lily	Violet	Fonzie	Chachi	Joanie	Dorothy	Rose	Blanch	Sophia
	Teacher - AF	Teacher - Beth Downie	Teacher - TM	Student - AK	Student - KD	Parent/student - RB	Support Worker - AR	Support worker -	Support worker - NB	Parent - CM	Parent - DM	Parent - JK	Med Prof - IC	Med prof - JB	Med Prof - SG	Med Prof - TW
Person Centric / Empowerment	a simple way of advocating for yourself.								consistently wise - going forward for the child is very beneficial	/the person that it's about is on control	/record of the person/ see their strengths and weaknesses		real sense of person	information should be held with the child and parent/should be albe to selct who knows what/positive information	fills a gap	
User Friendly / Comprehension	looks easy to use/ doesn't require huge amounts of training	doesn't look complicated			streamline information/					self explanatory/use on any medium/different devices.			/I would easily understand/understand I would be invited at times and not at other times.			seems straight forward.
Current Situation / Challenges	Its something we don't currently have/ fills a gap	everything is just bits of paper/pear shaped /no kind of flow on.		/helpful to have it stored in one place instead of all over the place where things get lost.		bits of information everywhere/ I look back on old diaries, spreadsheets....tracking activities.		this is something definitely lacking for me as a TA/information isn't passed on/find out last minute/one stop shop.			every year we lose information/have to reshare information all the time/information doesn't get shared/ without	/infomatin already provided/lost information/ SENCO has left/four different places that have different ways of recording		what they do, how they do it gets lost	4/5 different professionals and none of them meet	
Benefits to individuals, profess, families	/not adding to workload/ moments to show off/ accessing ideas	all information in one place /in one central place	record of portfolio for kids		controls for allowing certain people to access certain parts of site.				streamlining it/ going to be really productive.			one system/ makes life easier - heaps easier.		one coherent website	person controls access to it/fills gap of storing information and sharing it	
Environmental Context											Could see how it could work in the education setting				a long time ago multidisplinary teams who did share	
Security / Permission Settings																
Collaboration	save emailing 8 people/notifications//accessibility of it is huge		I think it quite good because it gets those professionals talking to each other as required													
Reference of other resources	like seesaw but extends to border people		seesaw programme.							/I don't think there is anything else out there						
Challenges														fish hook - time.		
Other																

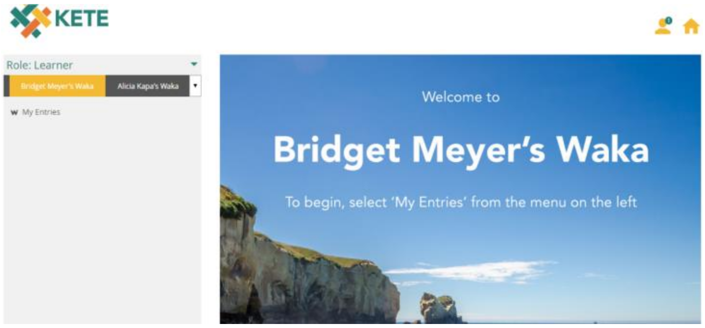
Table 3: Example of spreadsheet showing how information was captured.

- Once I had all the interviews transcribed, I read through them twice before I began my anaylsis.
- On the third reading I could see points of interest and common language begin to emerge.
- I created an excel document and headed each tab up with the research question.
- I then listed all the nine themes down the left-hand margin so as I was going over the transcripts if a theme happened to be mentioned in a question that it wasn't directly related too, I could still capture it. (See appendices).

3.4 Concept screen shots of website

Figure 12: Landing page

Figure 15: Logging in page

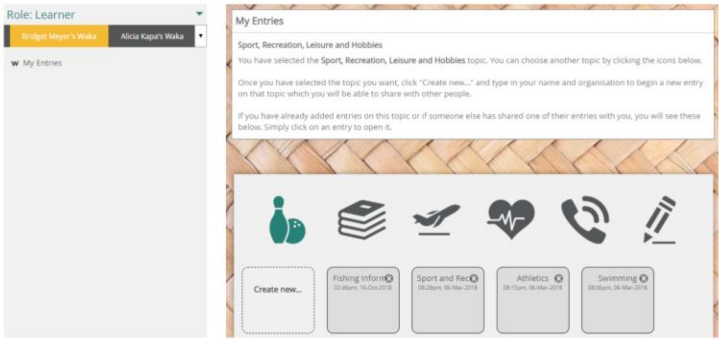


Welcome to

Bridget Meyer's Waka

To begin, select 'My Entries' from the menu on the left

Figure 13: Administrators page



My Entries

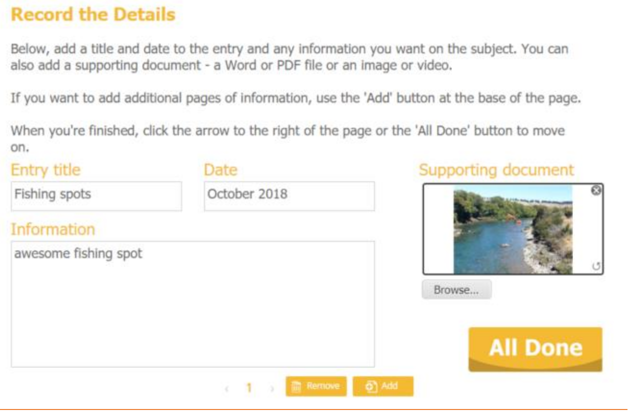
Sport, Recreation, Leisure and Hobbies

You have selected the **Sport, Recreation, Leisure and Hobbies** topic. You can choose another topic by clicking the icons below.

Once you have selected the topic you want, click "Create new..." and type in your name and organisation to begin a new entry on that topic which you will be able to share with other people.

If you have already added entries on this topic or if someone else has shared one of their entries with you, you will see these below. Simply click on an entry to open it.

Figure 14: Options of six places to house information.



Record the Details

Below, add a title and date to the entry and any information you want on the subject. You can also add a supporting document - a Word or PDF file or an image or video.

If you want to add additional pages of information, use the 'Add' button at the base of the page.

When you're finished, click the arrow to the right of the page or the 'All Done' button to move on.

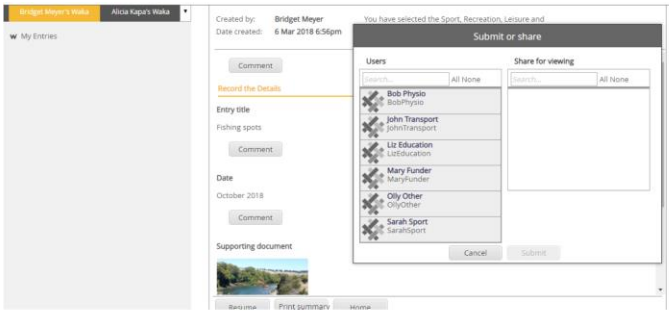
Entry title: Fishing spots

Date: October 2018

Supporting document

Information: awesome fishing spot

Figure 15: Window to house information.



Created by: Bridget Meyer
Date created: 6 Mar 2018 6:56pm

You have selected the Sport, Recreation, Leisure and

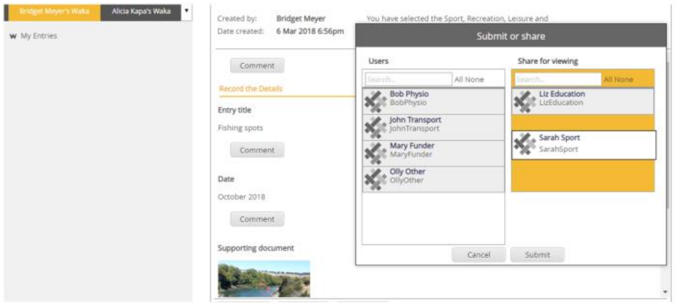
Entry title: Fishing spots

Date: October 2018

Supporting document

Bob Physio
BobPhysio
John Transport
JohnTransport
Liz Education
LizEducation
Mary Funder
MaryFunder
Olly Other
OllyOther
Sarah Sport
SarahSport

Figure 16: List of people within person's circle of support.



Created by: Bridget Meyer
Date created: 6 Mar 2018 6:56pm

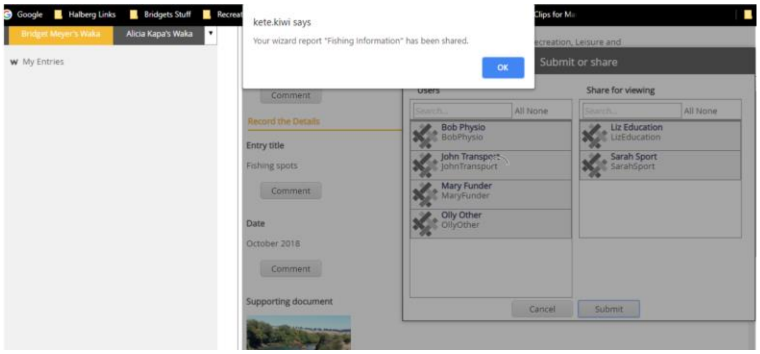
You have selected the Sport, Recreation, Leisure and

Entry title
Fishing spots

Date
October 2018

Supporting document

Figure 17: Demonstration on how to drag and drop into appropriate file.



kete.kiwi says

Your wizard report "Fishing Information" has been shared.

Entry title
Fishing spots

Date
October 2018

Supporting document

Figure 18: Wizard to say information has been shared.

3.5 Research Participants

The decision to use these specific demographics or interest groups was based on ensuring that I had diverse information from relevant stakeholders. The groups selected were individuals with high and complex support needs, parents, support workers, teachers and medical professionals.

Figure 19: Image for research questions.

Five Participant groups:

1) Individuals
2) Parents
3) Teachers
4) Support Staff
5) Medical Professionals

("Seeking Research Participants? - Graduate and Postdoctoral Studies - Simon Fraser University," n.d.)

Group One:

The three individuals were made up of one 22-year-old male, one 20-year-old female and one 12-year-old male. Both the 20-year-old and the 12-year-old were nonverbal and used communication devices to share their thoughts. The 12-year-olds' mother also helped with interpreting the information being shared. The two 20-year-olds were both studying at university and were able to grasp the concept with ease.

Group Two:

Two out of the three parents were local families with one being from out of Dunedin. The young people they supported were in intermediate, high school and tertiary education. All the parents that were interviewed were the mothers.

Group Three:

Two of the support workers were female with one male. Two worked alongside the young people they supported in the school environment and the other worked within the home environment. The two that worked with the school environment had slightly different challenges than the one who worked with the home environment.

Group Four:

All three teachers worked at different schools throughout Dunedin. All were female.

Group Five:

Of the medical professionals, three were female and one was male. Two worked for a government organisation; one was recently retired, and the fourth was in private practice.
The four medical professionals consisted of three physiologist and a physiotherapist. All were employed by a government agency.

Pseudonyms are used throughout.

3.6 Questionnaire Enquiry

The research study emerged from a set of open questionnaire questions designed to capture the thoughts of the five participant groups.

The questions were conceived with the goal of drawing out information to help facilitate the answering of the research question.

Conversations were structured around these pivot questions, with a view to generate word- and meaning-based thematic data that could be analysed later.

1) What are your initial impressions of the website concept?
2) Do you believe the concept of a website where information could be both stored and shared among professionals would be something that would help both individuals and their support teams? If yes, why? If no, why not?
3) Do you believe there would be any positive outcomes from having access to a website such as this?
4) Do you believe there would be any negative outcomes to having access to a website such as this?
5) What do you believe will be the challenges I am likely to face?
6) In terms of functionality and accessibility of the site what do you believe needs to be taken into consideration? i.e. Larger font size, voice activated instructions, visual aids etc.
7) Any further suggestions that you think I need to take into consideration?

4 CHAPTER FOUR:

4.1 Introduction to Findings:

This chapter will discuss the research findings by introducing each of the themes that became evident from the interviews. The themes were generated from the research transcripts where I was looking for points of interest that became prevalent across all 16 research participants. Although the research group was relatively small, I am confident for the purposes of this research project the representation of opinions is accurate. The method I used to capture this information is discussed in the methods chapter of my thesis. I will mention here however that the reason for nine themes is that I felt they all were worthy of discussion as opposed to blending into one another. In hindsight, however, I would do this differently and I will discuss this more in the methods chapter also. Not all themes will have a heavily weighted discussion section.

The nine themes that emerged from were:

1) Reaction

   Any reference made to the concept – good, bad, or otherwise.

2) Current Situation

   Any reference made to their present circumstances.

3) Advocacy

   Any reference made to an advocate, advocacy or support.

4) Empowerment

   Any reference made to equality, enablement, inspiration, encouragement.

5) Collaboration

   Any reference made to partnership, teamwork, relationship, alliance.

6) Resources

Any reference made to known resources that are like the research concept.

7) Accessibility

Any reference made to accessible ideas, convenience, approachability, user-friendliness etc.

8) Security

Any reference made to safety, privacy, well-being.

9) Challenges

Any references made to barriers.

4.2 Reaction

Student – Reaction theme:

Of the student group, two were able to communicate independently and one communicated through his parent. I was excited to share the concept with the students as I knew they would be brutally honest with their feedback and come up with ideas I hadn't considered.

All three made a positive affirmation statements with one elaborating on his initial reaction by stating that "allowing the person to collate their own data was a good idea" (Duey). Two of the students used a form of voice assistance technology to share their answer with the third answering directly. All three grasped the concept immediately. Although each of the students had varying degrees of support requirements, they were all able to recognise the benefits for all students with high and complex support needs.

Person	Group	Quote
Huey	Student	"Good concept"
Duey	Student	"The concept is well designed and allows persons to easily access their collated data".
Luey	Student	"I think it looks quite good".

Parent – Reaction theme:

The parents' overall reaction was positive. All three moved quickly into explaining what they currently do to retain and share information. All three parents alluded to being open to anything that is going to help make life easier. The concept was understood easily with no questions coming back once it had been explained.

In presenting the concept to the parents they, like the students, gave encouraging first impressions. There was a consensus among the parents expressing that "the concept is a really good one" along with "I think it extremely valuable" and lastly "well I love it, useful resource".

Person	Group	Quote
Fonzie	Parent	"Well I love it/useful resource"
Chachi	Parent	"I think it extremely valuable"
Joanie	Parent	"The concept is a really good one"

Support Worker – Reaction theme:

Although the lived experience of a Support Worker is not as intimate as a parent there is an investment present that must not be overlooked. A Support Worker is an entrusted member of the inner circle and due to the nature of the work and the high level of support required becomes a key component in helping to build meaningful interactions.

The support workers initial impressions were positive, and they expressed these with statements such as it was a "fantastic concept" and "I'm very impressed".

Person	Group	Quote
Daisy	Support Worker	"Fantastic concept"
Violet	Support Worker	"I'm very impressed"

Teacher and Medical Professionals – Reaction theme:

The Teachers' and Medical Professionals' initial reactions to the concept was positive. Both groups were interested in what else was available in the very early stages of the interview process and also acknowledged that they thought there was a definite gap in the market. The initial impressions were very positive with the teachers stating it was a “no brainer and a very successful tool”, along with the concept would be “meeting a need”. The medical professionals reinforced the message declaring “I think it’s a fantastic idea” and “I’m very impressed”.

Person	Group	Quote
Ron	Teacher	“A very successful tool / No brainer”
Harry	Teacher	“Meeting a need”
Rose	Medical Professional	“I think it’s a fantastic idea”
Blanche	Medical Professional	“I’m very impressed”

4.3 Discussion - Reaction

In looking at the reaction across all participant groups, I was aware that the time to digest the concept was very short and this initial heavily weighted positive reaction might have been given more from an encouraging stance on their part to me, as opposed to did they really think it was a good idea. However, I did think it was important to get participants’ immediate reaction. I was particularly interested in the reaction of the student group as the whole concept is designed with them at the forefront of my mind. If they had been perplexed within the first few minutes of the concept being explained I believe it may have been back to the drawing board.

The parent group were also excited by how this concept could make the day to day logistics of their lives more streamlined for all parties involved with their young people. Through the reaction theme the parents is the person who does the personal cares, provides transport and speaks and advocates on their behalf. The parents are pivotal in providing what many describe as ‘a good life’ and the scaffolding that brings an individual’s world to life and without this scaffolding an individual’s world can become very isolated.

The support workers described how little information they have access to yet spend many hours with the person they are supporting each day. To be able to learn what has been done previously, what has worked and what hasn’t worked would be of huge value.

The teachers all indicated positive responses and were perplexed that such an idea was not already available. The teachers wanted to support the children in their classes as best they could and were open to ways in which information could be better shared across both the school, home and health networks. The enthusiasm and energy shared by all the teaching staff was high.

The medical professionals were positive about the concept although their lethargic conversation for learning something new or having to contribute more than they already do was noticeable in comparison to the teaching staff.

Based on the 16 interview participants the overall response to the concept of a storing and sharing website for people with high and complex support needs was extremely positive. The initial impression has helped form a baseline as to whether the concept is starting in a positive space or a deficit space. The initial impressions showed movement within a positive space particularly in the student participant group. The concept is potentially worth pursuing.

To understand the reaction and the testing of a concept in the early phases of the design stage and the learnings surrounding this, I have been looking at the work of a number of assistive technology websites and journal articles to attempt to understand the importance of the initial phase of testing and secondly to see if there are concepts with similarities to the platform I am proposing.

In 2015 a prototype by the name of TangiPlan (Zuckerman et al, 2015) was created and tested with the initial impressions gathered to see if this concept did in fact achieve what the app developers were looking for. The concept of TangiPlan was to support children with executive functioning challenges in helping to manage their morning routines. TangiPlan is a time management app used on a tablet that encourages the user to set various times to complete tasks. The guidelines that TangiPlan used to develop the prototype were developed alongside experts (Zuckerman et al). The aspirations of the developers was to help reduce tension by keeping the children on task throughout their morning as well as providing a form of "flexibility and autonomy" for the children using the app (Zuckerman et al., 2015).

There are two parts of TangiPlan research that are relevant. The first area of interest that is applicable is the desire of the app developers to find a tailored solution for a learner or user group. In this case, it is children with Attention Deficit Hyperactivity Disorder (ADHD). Although there are many platforms of assistive technology that have been developed for people with executive functioning (EF) challenges such as TaskTracker, ProcedurePal and Basic Calender to help support the management of time, these platforms are not specifically designed for children with ADHD. The point of difference with TangiPlan is the breaking down of individual tasks and the tailoring of these particular tasks within each time period (Zuckerman et al, 2015).

The second part of this research that is significant is the aspiration to examine and understand the initial impression of the prototype as it was being used by children *in situ.* The research was looking to acquire some form of "validation" (Zuckerman et al) as to whether the prototype was achieving what the app developers had in mind. By testing the prototype in the very early stages of development allowed for the initial impressions and insights to be mustered as well as adjustments to be made to the design of the app. One of the challenges that was identified at the early phase of development was around the actual devices themselves. The battery life of the devices as well as the stability of the wifi were the two main challenges (Zuckerman et al, 2015).

Although the technology concepts are clearly different the alignment between both project goals is in the desire to create something for a specific user group as well as pursue feedback from the end user group. To be able to analyse a concept or a prototype from a very specific user group provides an invaluable road map in moving forward. The Tangiplan research emphasised the importance of the trial phase. To be able to use the prototype development in the children's home and speak with both the children and their parents gave the researchers a baseline to begin from. Interviewing the families both pre- and post-testing showed clear areas of improvement over the time Tangiplan was used. To have a form of assistive technology that is specific to an individual's requirements can benefit more than the individual themselves. From the Tangiplan research it can be concluded that with the correct form of intervention improvements can be made for both the individuals and those whom are supporting them.

4.4 Current Situation

Student – Current Situation:

Once the participants had given their initial impressions of the concept, they all continued to elaborate further in describing their current situation. The current situation theme is looking at what people currently have access to in terms of how they store and share relevant information. All the students had an awareness of the fiscal and human resources that were required to ensure things ran smoothly and, similar to the parent group, were frustrated at the repetitive nature of conversations. The students identified the challenges of having to remember so much information and stated as such: "hard to remember everything, so much to learn" as well as questioning how well information is passed on between the various organisations – "how effective communication is between health professionals".

Person	Group	Quote
Huey	Student	"There are often a lot of support people"
Duey	Student	"Hard to remember everything / so much to learn / not sure how effective communication is between health professionals"
Luey	Student	"Ideas are lost in translation / not repeating information"

Parent – Current Situation:

In looking across the data the parents were vocal in sharing their current situation and the impact this has on both themselves and their sons and daughters in terms of accessing assistive technology.

In presenting the concept to the parent group the current situation of information being lost was a dominant issue along with information not being shared. There was a sense of frustration among the parents and a sense that their time was not of value.

Person	Group	Quote
Chachi	Parent	"Information doesn't get shared / without me having to be the medium all the time"
Joanie	Parent	"SENCO has left / four different places have four different ways of recording"
Fonzie	Parent	"Comms book some people don't read it"

Teachers – Current Situation:

The teachers' interpretation of the current situation for the students they support was backed up by what the students had also identified as problems within the current situation. There were also additional observations from the teachers in relation to the flow on of information and the coming and going of staff. The sharing of information across the network was described as "pear shaped" with "no kind of flow on". There was also concerns raised about the turnover of staff with "professionals change and leave, new people come in". Possibly the most important learnings with the current situation is from the teachers' statement of "it's something we don't currently have, it fills a gap".

Person	Group	Quote
Ron	Teacher	"Everything is pear shape / no kind of flow on"
Harry	Teacher	"Its something we don't currently have / fills a gap"
Hermione	Teacher	"Professionals change and leave / new people come in"

Support Workers – Current Situation:

The support workers shared several frustrations about the current situation and the lack of support and training they receive to carry out their roles. There were a few statements made around planning time and the haste which is required due to the lack of planning. The information that is not shared or "it's all in X's head" as well as I "find out last minute" were clearly frustrations.

Person	Group	Quote
Daisy	Support Worker	"It's all in X's head / the little things you take for granted"
Lily	Support Worker	"You don't get any planning time / this is something lacking for me as a TA / find out last minute"

Medical Professional – Current Situation:

Like the support workers the medical professionals the shared similar frustrations in the amount of information that is not shared with gaps appearing in individual's care plans. The medical professionals identified that information is not presented in a positive light and very much sits within the medical model framework.

Person	Group	Quote
Rose	Medical Professional	What they do and how they do it gets lost.
Blanch	Medical Professional	4 or 5 different professionals are working alongside somebody and none of them meet.
Dorothy	Medical Professional	A long time ago there were multidisciplinary teams.

4.5 Discussion – Current Situation:

There was an awareness by the students of information being misplaced and the need for information to be repeated. The students were also aware of the size of the teams that were placed around them as well as questioning how effective the communication was between different organisations. Reference was made to the high level of communication that was required to keep this machine running. I sense there was a lot of guilt in the amount of resourcing that is required to ensure the flow is smooth of both information in and information out.

The interpretation of the parents is that they are often the support scaffolding that is built around an individual. They are the cog that ensures all the information is reaching the right destination in a timely manner. Along with the daily logistics of personal cares, transport arrangements and arranging support workers many hours are currently spent repeating formation that was passed on previously and liaising between the myriad of professionals who have been contracted to provide a service.

Support Workers often straddle the space between home and school. As mentioned earlier they are an integral part of the inner workings of support mechanism. In exploring the current situation and some of the challenges that the support workers have the observations that have come to the fore are in information not being passed on and time given to planning.

The current situation that medical professionals experience within the context of this research is that information "is held in siloes and stands apart from that of other professionals that are working for the betterment of an individual" (Dorothy – Medical Professional). Medical Professionals are focused on the medical challenges an individual is experiencing and therefore leaves the social or holistic well-being up to those who work with the social services or education streams. One comment from one of the medical professionals stood above the rest when the data was being analyzed was "our system doesn't have a lot of good stuff". This statement aligns with the literature in claiming that the deficit model is still well and truly alive within the medical system (Shakespeare, 2013; Oliver, 2013).

The current situation theme of all five user groups shared an element of frustration. Although each group had different concerns, the overall sense was that either information was fragmented, or the way people advocated and engaged with each other was fragmented. The current situation across all groups identified that there is a huge amount of information that is lost or not passed on to the appropriate stakeholders. The number of people whom are supporting an individual is also large and the coordination of this can at times be challenging which has been highlighted. The current situation theme within the context of this research has been drawn on through the experiences and various situations that the interview participants are experiencing.

To delve deeper into the theme of *current situation,* I have looked into the research literature to attempt to understand what has brought us to where we find ourselves today in what is perceived as disjointed and difficult system to navigate (Selvaraj, 2015, Lyons, 2013, Ministry of Education, 2012). The area of research that holds the most relevance within this research is in the realm of the educational setting.

To avoid travelling too far away from my research question, I will concentrate briefly on two areas that do have significance.

1) What has brought us to our current situation?

2) Inclusive Education – what does that even mean?

In discussing our current situation, we can look at the timeline that gives us an overview of the movement of special education or inclusive education as it is referred to in some circles.

By looking at the timeline and reading the work of Judith Selvaraj – *Inclusive education in New Zealand: rhetoric and reality* (Selvaraj, 2015), we can begin to understand that the current situation of working alongside people of all levels of ability in an attempt to be inclusive is not something that has happened, or not happened as some would argue, overnight.

In reading the history of the inclusive education movement and seeing what the government of the time was looking to implement we are able to gain a perspective that in striving towards a form of inclusion has been a work in progress for many years (Selvaraj, 2015).

> *"The Governments objective, broadly expressed, is that every person, whatever his level of academic ability, whether he be rich or poor, whether he live in the town or country, has a right as a citizen, to a free education of the kind for which he is best fitted and to the fullest of his powers* ". (New Zealand Parliament, 1939, p. 59).

From this statement we can see that we have been working to understand this 'situation' for a long time.

Our current situation is the morphing of many years of policy shaping and reshaping in the hope that we arrive at a finish line called inclusive education. The complexities of our history within this space is not something that is easy to untangle or understand. It is a difficult space to traverse. It is taxing for those 'living' in this space to define where we are going when there is still so much debate around what we are trying to achieve.

In my segue from the current situation into the abyss of inclusive education the literature that accompanies this topic is growing exponentially. To once again keep my research tight, I have just touched on the million-dollar question of 'Inclusive Education – what does that even mean?' The research is not conclusive in that there is not a single statement that affirms this is what inclusive education is or that there is a single design on an inclusion model and what this looks like within the education setting. For the most part, people are generally on the same playing field in agreeing to the concept but seeing the word on paper is where it stops. (Selvaraj, 2015, Lyons, 2013)

One premise that was noted and alluded to in Lesley Lyon's study – Transformed Understanding or Enlightened Ableism? The gap between policy and practice for children with disabilities in Aotearoa New Zealand, was the ideological versus reality of the situation of inclusive practice. Lyons (2013) stated,

> They are required by legislation and policy to be inclusive of children with disabilities, and via this legislation and policy they have been given the language to speak about inclusion, yet making inclusion a reality appears problematic and confusing (p. 247).

In referring back to the findings of the current situation theme within this research project, the micro-level of a seemingly chaotic world for the participants and those whom are supporting them is reflected at a macro-level where there is disharmony and confusion in regards to the direction we should be heading.

4.6 Advocacy

Student – Advocacy:

The enthusiasm shown by the students when discussing the advantages of having a site which would encourage personal advocacy was affirming. All the students recognised the sense of independence that could potentially be achieved if personalised information was housed on a site that they had access and control over. All three students were excited about the possibility by stating the "sense of freedom" that could be obtained as well as the "quality of life". A "better understanding of a person's needs" was also recognised as a benefit of self-advocacy. The students however didn't recognise advocacy as something beyond themselves. Their insights focused on what the platform would achieve for them as opposed to the world around them and those supporting them.

Person	Group	Quote
Huey	Student	“Manage our own profile”
Duey	Student	“Quality of Life/sense of freedom”
Luey	Student	“Better understanding of a person’s needs”

Parent – Advocacy:

The parents’ observation were that communication around advocacy between themselves and their support networks was not ideal. The challenges in advocating for their sons and daughter were met with poor internal systems and admission of “information doesn’t get shared with me having to be the medium all the time”, “communication book, some people don’t read it” as well as information across support organisations having their own unique way of recording information. An example of this was stated by one parent as having “four different places have different ways of recording information”.

Person	Group	Quote
Fonzie	Parent	“Communication book, some people don’t read it”
ChaiChi	Parent	“Information doesn’t get shared without me having to be the medium all the time”
Joanie	Parent	“Four different places have different ways of recording information”

Support Worker – Advocacy:

The advocacy theme among the support workers showed a variety of responses that alluded to the challenges of moving relevant information across networks. All groups recognised the trials of advocating on behalf of another person and went back to giving examples of the current situation. All groups made comments that could possibly fit under another theme of connection or ways to connect. The sharing of information and “emotional connections” was seen as a benefit of the concept as well as “no flow through”. The advocacy theme among the professionals came from many angles.

Person	Group	Quote
Daisy	Support Worker	Emotional connections
Lily	Support Worker	Seeing what works
Violet	Support Worker	Anything that adds to communication

Teacher – Advocacy:

The teachers' positioning on advocacy was that they understood the importance, however, were often stretched to be the child's advocate and to put in place measures where advocacy could be demonstrated at a high level. The teachers were able to give examples of when they tried to be positive advocates but the ability and time of others let the process down.

Person	Group	Quote
Harry	Teacher	Save emailing 8 people
Ron	Teacher	No flow through
Hermione	Teacher	Look back on history / what happened / what's been tried before

Medical Professionals – Advocacy:

The medical professionals made reference to the system that they currently work within creates barriers for them to practice advocacy in such a way that they will see positive results. The duplication of information is a frustrating and the sharing of the same information time and time again appears to be frustrating also.

Person	Group	Quotes
Dorothy	Medical Professional	The current system is left behind
Rose	Medical Professional	What they do and how they do it gets lost
Blanch	Medical Professional	Telling story over and over
Sophia	Medical Professional	Having to reiterate information / not having to duplicate

4.7 Discussion - Advocacy

To understand the importance of advocacy and what it means to the individuals at the center of this website concept all participants made comments that there would be a positive outcome if such a concept was created. To be able to advocate accurately on a person's behalf is critical in truly hearing the voice of the individual. The interpretation of advocacy centered on high levels of frustration in what all groups were looking to achieve for the young people they were supporting. All highlighted various scenarios on how they were required to advocate and the benefits of being a strong advocate. The challenges similar for all and pivoted around communication and how it was recorded or shared.

The purpose of exploring advocacy and the connection it has to this research is best described as something we are all doing continually for the people we work alongside. What has been identified in this research is that it is currently practiced in an *ad hoc* way with little knowledge of who is doing what, what has been done in the past, what is currently being done, who else or what other organisations are involved.

Regardless of your relationship with an individual we are all, for the most part, doing our best to advocate for the person with support needs to have a fulfilling and meaningful life. How we advocate and represent an individual who is unable to take on this role themselves is a huge honor which I think for many of us we can lose sight of in the business of our roles. For those professionals, whether that be support staff, teachers or medical professionals we are paid to give insight or pass on our opinion on how something ought to be managed for someone else. If you were to momentarily put yourself in the position of someone who was unable to speak or represent themselves would you like the person advocating for you to be informed, to know something about you or are you happy for them to decide on what they *think* is right for you based on 'feeling'. I believe most of us would opt for the first option if this scenario was presented.

The United Nations Convention article 23 emphasis the messaging of "nothing about us without us" (Moriarity & Dew, 2011). To be able to represent and advocate for people who are unable to advocate for themselves we must be able to capture their voices and wishes in such a way that they are as closely tied and unedited to the individual as possible. To build a rich tapestry and learn about the interests, traits and personality of an individual that requires additional support is an ongoing process that must work in unison with the individual (Protocol - Convention on the Rights of Persons with Disabilities and Optional Protocol UNITED *NATIONS*, n.d.)

The Social Care Institute for Excellence has identified that people with high and complex support needs "are likely to be left behind in social care provision" (Dalton & Hoyt-Hallett, 2013,

p. 32). Minimal resources are available, and the higher level of skill required to provide support is often absent. Self-advocacy among people with high and complex support needs, as supported by the investigation of Mithran (2009): “there is often a need for the involvement of an advocate to make their voices heard” (p. 32). The voices at the centre of this concept of a storing and sharing website are pivotal and at the forefront of our minds as we look to improve ways to engage and create meaningful experiences.

For many parents, the role of advocate becomes a full-time role, albeit a role that was not of their choosing. The success of their child’s day is planned down to the *n*th degree with a large team supporting the smooth turning of the cogs. As Emily Pearl alluded to in her ‘Welcome to Holland’ poem, this journey wasn’t the one that was booked however life must go on. There are windmills to see, tulips to pick, and Rembrandt, yes, even Rembrandts (Kingsley, n.d.). Being a parent comes with many challenges. Being a parent of a child with high and complex support needs comes with many additional challenges, as well as sleepless nights will only ever be understood if you are in that position yourself. The investment in time in raising a child regardless of ability is monumental. Achieving milestones, progressing alongside your peers within the often-unspoken perimeters of ‘normal’ is something that is taken for granted with limited reflection on what life might be like for those travelling on a different journey.

The advocacy required by parents to navigate the numerous systems they find themselves in commands a high level of both communication and negotiations skills. The resilience that is called upon daily to ensure the right messages are being disseminated can be, at times, overwhelming. The concept of a website whereby how and what we advocate as well as what is shared across our networks is something the parent group identified as having a positive influence. For advocacy to be powerful and on point for the people, it is intended for a streamlined approach would be beneficial for all. The parents spoken to are fully aware that they are their child’s voice. They are aware fully aware of the responsibilities of being their child’s advocate however are challenged daily around the logistics of doing this well. Chachi (parent P6) commented on “every year we lose information” and “have to reshare information all the time”. This example shows that even though parents are doing their best to advocate for their children the system is disjointed and to some degree unreliable.

With the best of intentions parents are working hard to be the mechanism in keeping this machine running smoothly. To create a platform that becomes a *'one stop shop'* with information readily available would ensure an individual's support networks are kept updated and invited to view relevant pieces of information if appropriate. Joanie (parent, P10) stated that "one system would make life easier – heaps easier".

The position of a support worker can be described as a link between home and school although many other iterations are possible. The support workers role is one which is like that of the parent and can have a huge influence on the success of the day or any given moment within the day. Support Workers carry an enormous amount of information on the young person they are working alongside. Valuable information that is not called upon as often as it possibly could be for various reasons including the level of influence that is absent in their roles. Support Workers are the eyes, ears and voice and have an often-intrinsic understanding of what is going on for the young person that is built up over time. They are the key holders to what has worked well before and what does not work. The sharing of information across a team of people is critical for several support workers. Rose (Support Worker P3) reiterated the importance of being able to advocate stating "we need to know who what does", "it is vital if x (mum) is unable to be contacted we need to act in the moment".

Advocacy, within the concept of this research, requires information to flow. Unless there is the platform or infrastructure to support this the information will sit within a silo and the opportunity to bring a richness to an individual's life will potential be lost. To be able to share their learnings on a platform that enhances and celebrates the positive moments in a child's days would be of huge value. To be able to advocate and pass on information regardless of whether it is a small win, or a life changing moment would create more meaningful purpose for the support workers as well as a positive outcome for the young person they are advocating alongside. Rose (Support Worker P3) stated the importance of advocacy and how having the right information was important: "little things are important when you can't manage the big things" and "life is much richer when we see them as social beings not medical beings".

The role of advocate within the school setting often sits with the classroom teacher. Along with the thirty other students in the classroom, whom all require pastoral care to some degree, children with high and complex support needs require more. There can in some circumstances be a team of external providers who provide support in some form to the individual which is often delivered during the school day. The coordination of these services is done in collaboration with the classroom teacher.

For the teachers to advocate and bring meaning to a situation or an opportunity it is helpful if they have all the information available. This information might be on what has been tried before and worked or what has been tried previously and not worked. Gathering up this information can be time consuming of and this time is not something that teachers have a lot of. In trying to bring meaningful learning to a child, teachers work hard to find out what has happened in the past and build on that. This, however, isn't always easy. Advocacy can be thick with challenges within the school environment. A platform that captures who has done what, what has worked, what has not worked, who has been involved previously and from what service provider, would all be helpful information to have on hand. The building of this dossier of information over time would be beneficial for all parties.

The medical professionals working alongside an individual advocate with the medical model framework in mind (Shakespeare, 2013). The medical model, through the eyes of professionals who work in the social services, work to a deficit model and focuses on what is possibly wrong rather than looking at an individual holistically and all the things that are right or going well. In terms of advocacy and the researching of the storing and sharing concept there were some interesting comments shared by those working within the medical framework. Comments such as "our system doesn't have a lot of good stuff" Rose (Medical Professional P9) and Dorothy's (Medical Professional P8) comments of "limited ideas about what is possible" and "health information is degrading and restrictive about the future" captured the theme coming through from the participants from the medical professionals. Dorothy also made the comparison between teachers and teacher aides "teachers and teacher aides see possibilities whereas medical people tend to see in that very negative model – DIS ability model rather than

ABILITY model". The medical professionals were also aware of the repetition of information sharing.

Although the medical professionals were aware of their short comings in terms of holistic health and well-being, I don't believe their focus should or would change. What I do believe would be welcomed however is a snapshot of what else is happening in a person's world. Different decisions might be made when it comes to a person's medical wellness if this information was presented but without an overall view of what is happening in a person's life that insight and information will remain absent. As Sophia (Medical Professional) alluded to…." if only I'd known that". Oliver suggests that this could be seen as an opportunity to expand the viewpoint for the medical professionals and take into consideration the social model of disability (Ba, 1990).

Although not written with the context of New Zealand in mind Suzanna Rocco Dillion's (2013) paper, "'If not you, then who?' - Advocating for Physical Education Needs of Students with Disabilities'", makes a few points that are easily transferable in terms of advocacy and what this looks like for young people with disabilities. Dillon (2013) states that advocacy "takes commitment" which is clearly relatable through the findings of my research. Dillion (2013) also asks the question 'if not you, then who' (p. 39). Her question is pitched within the context of physical education; however, I would suggest this question could be used across all areas of an individual's life. Dillon (2013) cited in the National Association of Sport and Physical education (p. 11):

> Who will protect the rights and interests of children within our physical education classes, and who will ensure *that all* children have an opportunity to be physically educated individuals with the knowledge, skills and confidence to enjoy a life time of healthful physical activity.

The relevance of my research reaffirms the importance of the papers title 'If not you, then who?'. Dillon also provides a list guiding principle on how to advocate effectively with examples of the sorts of policy and procedures individuals may find helpful. Although this paper has an American flavour to it the ideas would be easily transferable to a New Zealand context.

4.8 Empowerment

Student / Parent – Empowerment:

The messaging from both the student and the parent participant group was similar in that they understood the importance of empowerment and what such a notion would achieve for either themselves (students) or for their sons and daughters (parents). There were a range of responses across both groups on how sharing and storing relevant information on a website platform could be empowering for individuals. The parent group recognised the consequences of such and expressed the value of being able to "see their strengths and weaknesses" and that the "person that it's about is in control". The students used the word 'information' and "information sharing" a few times.

Both students and parents were able to make the connection that by sharing information a sense of empowerment would be attained.

Person	Group	Quotes
Huey	Student	So much to learn
Duey	Student	Access to important information
Luey	Student	Information sharing

Person	Group	Quotes
Fronzi	Parent	That the person that it's about is in control / it gives her a voice
Chachi	Parent	Record of the person / see their strengths and weaknesses
Joanie	Parent	Knowing background / personal approach

Support Worker/ Teacher / Medical Professional – Empowerment:

The support workers were able to make the connection between the concept of the site and how this would bring a sense of empowerment. The support workers suggested that going forward this is going to be very beneficial.

Person	Group	Quote
Daisy	Support Worker	What provides quality of life
Lily	Support Worker	Get ideas on how to implement strategies
Violet	Support Worker	Going forward for the child this is going to be very beneficial

Teacher – Empowerment:

Both teachers were able to give examples of what actions would be required to achieve a sense of empowerment for the individuals they support. Being able to share examples of what provides quality of life along with how to get ideas on how to implement strategies

Person	Group	Quotes
Harry	Teacher	Moments to show off / accessing ideas
Hermione	Teacher	Record of kids portfolio

Medical Professional – Empowerment:

The findings in relation to empowerment within the medical professionals was limited. There were positive examples of how empowerment would be achieved using the platform and examples given were in how engaging with parents more readily would create a sense of empowerment.

Person	Group	Quotes
Rose	Medical Professional	"Parents in control which is a good thing".

4.9 Discussion - Empowerment

We can't underestimate the sense and impact of empowerment. To be able to have the information on-hand and pick up where someone else has left off is hugely empowering. To also discover what works, how it works and capture that for others to benefit from is not only empowering but also extremely rewarding.

The parent group were vocal in how they viewed the concept and how this would lead to empowering their children. All parents were positive in that it was the child at the centre of the concept website and that they would be in control of who sees what information. The overarching view was that the "more information the better" and that people were "crying out for information" Chachi (parent P6). Being in a position where they were able to witness the trials and tribulations of information sharing and the benefits this would bring to their children the concept was well supported.

The support workers view in relation to how empowering opportunities would be created if personalized information was on hand was described best by Lily saying that "if you can get one idea out of it it's one idea you didn't have before".

Like advocacy responsibilities, we are consistently looking for prospects where we can create present, participating and learning opportunities which in turn is empowering.

Lily (Support Worker P7) described the benefits of the concept and how it could be used to empower an individual as a "one stop shop".

Empowerment opportunities must be embraced when presented within this sector and particularly within this group of young people. The empowerment opportunities are not glaringly obvious therefore when identified need to be nurtured. For children with high and complex support needs 90 percent, maybe higher, of what they do each day is decided for them by others. From the moment they wake up someone else will decide what they wear, what they will eat for breakfast, when they will go to the bathroom, how they'll travel to school and what they will do once they get there. All of this is before the 9 o'clock bell goes.

Empowerment can be subtle, and communication can be subtle, but we must look for it. For a child that is unable to vocalize their wishes and uses a nod, a blink or the poke of a tongue to convey a message, tuning into this unspoken form of communication can in turn lead to the opportunity to empower. To decipher that the blink of an eye, the twitch of the head or the poke of a tongue all mean 'yes' we can begin to build a rich tapestry of ideas for others to use and continue to build a dossier of tailored knowledge. To have accurate information on hand is hugely empowering for the individual. As a professional you are saying or demonstrating that "I know you" and "I know what you are capable of". As opposed to "now where did we get to last term" or "what did your last school do".

4.10 Collaboration

Student – Collaboration:

The student group didn't use the terminology of collaboration *per se;* however, one student was able to make the connection that the website would allow for information to be distributed and "education" across their support network.

Person	Group	Quotes
Luey	Student	Education

Parent – Collaboration:

One parent talked about the continuity among professionals as being a positive outcome in using the platform as well as the platform being a place that everyone can access.

Person	Group	Quotes
Fonzie	Parent	Continuity among professionals / everyone can access

Teacher – Collaboration:

The teachers identified several practical advantages in using the platform. Examples of these are "saves emailing eight people", "communication out could be really successful" as well as stating that it would "get those professionals talking to each other as required or needed".

Person	Group	Quotes
Harry	Teacher	Save emailing eight people / notifications / accessibility of it is huge / communication out could be really successful / communication in huge teams
Hermione	Teacher	I think it is quite good because it gets those professionals talking to each other as required or needed.
Ron	Teacher	Transition

Support Worker – Collaboration:

The support workers identified that the benefits would be being able to draw on the different expertise of people right across the individuals support network. It could potentially act as a "one stop shop".

Person	Group	Quotes
Lily	Support Worker	Information isn't passed on / one stop shop.

Medical Professional – Collaboration:

One medical professional confessed that of the "4 to 5 different professionals and none of them meet" as well as a second medical professional sharing that "what they do and how they do it gets lost".

Person	Group	Quotes
Rose	Medical Professional	What they do and how they do it gets lost.
Blanche	Medical Professional	4/5 different professionals and none of them meet.

4.11 Discussion - Collaboration

The teachers were able to see the benefits of having the storing and sharing website and how this would be of benefit not only within the education system but the more comprehensive network that engage with an individual.

One teacher made the connection that in having access to a website that held information on an individual and that the information was made available to different support networks when appropriate would be of benefit, "I think it is quite good because it gets those professionals talking to each other as required or needed". This was backed up by one of the medical professionals with her statement of "4 – 5 different professionals and none of them meet".

Another teacher was excited by the thought that his days of emailing eight different people might be coming to an end and that the site would also have the ability to notify him if relevant information was uploaded. Harry recognised that not only would the site have information coming in, it would also be a means of getting information out to relevant parties. The benefits of communicating with huge teams was also alluded to. All participant groups understood and saw the benefits of working collaboratively.

With the best of intentions most individuals working alongside and advocating for people with high and complex support needs are open to and do see the benefits of collaboration. However, the reality of a collaborative approach varies greatly among the different support networks involved in a person with high and complex support needs life.

The benefits of working collaboratively within the mainstream population is huge and great things are achieved when stakeholders come together for the greater good of a cause or movement. To work towards some form of high-level collaboration is, in my view, more so important when the person at the centre is unable to present or represent their views and thoughts independently.

In order to work collaboratively and share information, we need to have access to information in the first instance. The current situation which has been referred to throughout this research is that it is “pear shaped, and everything is bits of paper with no flow on”. It can be extremely challenging to pass on information when in fact there is nothing recorded, or people have moved on. Building a dossier of information for people with high and complex support needs is crucial in building what can be termed as a “good life”. A rich file of information that can be created over a person’s life and then being able to share this information where appropriate allows a person’s support network to see the person as an individual who has had experiences that can be built on as opposed to starting from scratch at each turn.

A large body of literature has been researched with the theme of *community conversations* emphasizing the importance of across organisational collaborative engagement. In the Journal of Disability Policy Studies, Audrey Trainor (2018) describes community conversations “by harnessing the expertise and motivation of key stakeholders” (p. 2). This concept of 'community conversations' would support the concept of my research topic in that it encourages the sharing of ideas across an individual support network.

Although the concept of Community Conversation is met with the best of intentions Carter (2018) emphasized that this model of practice may be ineffective if delivered in insolation. The Community Conversation model and the collaboration of stakeholders is effective at "spurring change" (p. 199) however the sustainability of such a model is currently unknown.

Supporting the Community Conversation research theme and collaborative partnership model, the study by Flippo and Butterworth, (2018) shared a similar belief of Carter (2018), in that the concept generated by the community conversation model was effective as a "catalyst for system change" (p. 10). Flippo and Butterworth (2018) lay emphasis on the importance of a holistic approach across all stakeholders is required for change to take place.

4.12 Resources

Teacher and Parent - Resources:

Only the teachers were able to identify a site that is used within the educational space and this site is used across all students or all abilities. This site is called Seesaw. There was no other reference to a storing and sharing sites across any of the other participant groups. One parent referred to this with a statement of "I don't think there is anything else out there" during R Q 1.

Person	Group	Quotes
Harry	Teacher	Like seesaw but extends to a border people.
Hermione	Teacher	Seesaw
Fonzie	Parent	I don't think there is anything else out there.

4.13 Discussion - Resources

The resource theme did not emerge with a lot of information which was enlightening and may have been a good reason to leave it out as a theme. However, the deficiency of knowledge gave more reason to include 'resource' as a theme. In speaking with all participant groups and for there to be such minimal reference to a platform where information can be shared and stored was helpful. Across the six interview questions there was very limited information coming forward on how information is shared and stored for our most vulnerable students. The effort and energy that is required to manage the logistic of the day is what the focus appears to be on as opposed to researching what assistive technology or any other resources might be available is not a priority. This information showed that there potentially is an opportunity to take this concept to the next phase.

Upon reflection, this could or should have been a direct research question. It may have triggered the memory of the participants and we could have drilled down more into what they knew rather than it floating to the surface nonchalantly and then being recognised as an important piece of information.

Unless there is a high level of advocacy from parents, caregivers or support networks who have the skills to be proactive in terms of seeking out information and tailoring it to the needs of the individual then seems to be a *laisse faire* approach.

The awareness of what is available for individual and families across the assistive technology environment is minimal.

Assistive Technology for people with high and complex support needs sits at what could be described at the pointy end of the stick. The population of users is a lot smaller and the intricacies of specific designs is high end and tailored to the individual as opposed to off the shelf software or an off the shelf product.

The absence of ideas across all participant groups on what resources are available showed evidence that there is in fact nothing available on the market or that there potentially are products available, but the support networks are not able to seek out what is available.

4.14 Accessibility

Student – Accessibility:

All the student participants spoke from a personal point of view in sharing what they would or do find helpful in accessing various websites. The students covered all the traditional accessibility features including larger font, eye tracking or eye gaze as well as both voice activation and facial recognition.

Person	Group	Quotes
Huey	Student	Large font / voice activation
Duey	Student	Facial recognition / eye tracking / audio cues / quick search / universal design.
Luey	Student	Eye gaze

Parent – Accessibility:

The parent group was particularly insightful and had clearly experienced assistive technology in all forms. Feedback included the size of the buttons; a clean and simple design was preferred over something busy. Compatibility across various devices including it being accessible through an app was emphasized.

Person	Group	Quotes
Fonzie	Parent	Big buttons / functional on iPad / not too much noise / buttons not too close together / clean / simple.
Chaichi	Parent	Make it so it's an app / touch screen rather than mouse.
Joanie	Parent	Needs to be accessed by every form of communication device / compatible with all different forms of software.

Teacher – Accessibility:

The teachers alluded to the platform being accessible from a "not being blocked on the server" angle. They all gave examples of what accessibility looked like from an end user view point however the main focus was on the "ease of access", "easy to upload" and "available to everyone" were the key messages.

Person	Group	Quotes
Harry	Teacher	Font / hearing considerations / some form of translate.
Ron	Teacher	Not blocked on server / easy to upload / don't create work for teachers / available to everyone.
Hermione	Teacher	Visual aids / ease of access.

Support Worker – Accessibility:

Like both the student and the parents the support workers mentioned the traditional forms of assistive technology necessities including "very succinct clear and concise" layout as well as adding the idea of "ways to personalize it" and "take ownership of it".

Person	Group	Quotes
Daisy	Support Worker	Ways to personalize it / take ownership of it.
Lily	Support Worker	Larger font.
Violet	Support Worker	Keep English very simple / very succinct, clear and concise.

Medical Professional – Accessibility:

Three out of the four medical professionals indicated the need for the platform to be "very simple" with "basic instructions". The idea of "pictorial clips of young people doing things" or "something that shows up their strengths" was also discussed. Like the other participant groups ideas such as "visual, but not too visual", "eye gaze" and "voice activation" was raised.

Person	Group	Quotes
Dorothy	Medical Prof	Graphs, tables. Pictorial, video clips of young people doing things / not long written reports / introductory page / something that shows up strengths.
Rose	Medical Prof	Visual without being over visual / sensory issues / if too complicated we won't use it.
Blanch	Medical Prof	Vision / voice activated instructions / basic instructions.
Sophia	Medical Prof	Eye gaze / font size / very simple.

4.15 Discussion - Accessibility

The responses from all interview participants on the importance of accessibility of the platform and the types of features that needed to be considered was highly populated. The suggestions ranged from font size and colour through to eye-gaze options. There were many suggestions with each user group having a specific interest depending on their own personal or professional experience.

The findings across all participants covered a range of topics and point of interest. Each group was coming from their own lived experience and what mattered to them as either an individual with additional support requirements or as a person who supports provides support.

All groups had an awareness of the traditional forms of assistive technology such as voice activation and eye gaze. The parental group had a much higher awareness of what would better serve their young people such as the larger buttons, less chaotic screens and device compatibility. The accessibility of assistive technology varies greatly across individuals with additional support needs.

The term 'assistive technology' was first mooted in 1988 in the Technology Related Assistance for Individuals with Disabilities Act. It was amended and replaced in 1998 with the Assistive Technology Act 1998 and has been described as “any item, piece of equipment, or product system, whether acquired commercially, modified or customized that is used to increase, maintain or improve functionality capabilities of individuals with disabilities” (p. 26) (Assistive Technology Act, 1998 cited in Assistive Technology – Fixing Humans) (Katsioloudis & Jones, 2013).

The various options of accessibility features have been discussed by Katsioloudis and Jones (2013) with examples given across a spectrum of disabilities. Examples include computer-assistive technology where eye gaze and breath are features, through to augmentative and alternative communication devices (AAC). AAC is using voice to text or text to voice depending on the requirements of the individual (Katsioloudis & Jones, 2013).

The functionality of a platform particularly for a person with high and complex needs is made or stalled in this initial stage “is it accessible to me or not”? The design around the personalized accessibility of the platform needs to have many considerations made to it.

Due to the sometimes-complicated nature of an individual with high and complex needs the accessible considerations fall outside the generic programming of someone with less support needs? The recommendations made by the participants alluded to accessible ideas that fall outside the 'off the shelf' models. Eye gaze and voice activation would be examples of this. The tailored needs must be taken into consideration for the platform to be accessible. Without this the site is redundant for the individual.

Consideration must be well thought out regarding the layout of the platform to ensure easy navigation for the end user. The opportunity to create a personalized platform would give a strong sense of empowerment to the end user.

The opportunity to explore the current situation and seek out other platforms that are being used by individuals with high and complex support needs within the assistive technology world is exciting. In relation to assistive technology Paul Wise's research (Wise, 2010), *Emerging Technologies and their impact of disability,* discusses the influence assistive technology has on children with disabilities and the equality that is being leveraged through the advancement of assistive technology. Wise (2010) states that "all technologies attempt to address some deficiency in human capacity or the human condition" (p. 171). Wise also identifies the "rapid evolution" of assistive technology that is currently being produced at an expediential rate. Another claim that Wise (2010) makes is in the use of his term 'social engagement' and the benefits of assistive technology has for all.

4.16 Security

Student – Security:

The students were very aware of the risks of having such sensitive information stored on a cloud base platform. All the students were able to articulate examples of security risks and what these might present as. Examples that were shared in relation to security were "possible misuse of information", "wrong people gaining access", "storing sensitive information with certain people".

Person	Group	Quotes
Huey	Student	Access to information / information getting deleted.
Duey	Student	Possible misuse of information / wrong people gaining access / getting people to store in one location could be an issue / storing sensitive information with certain people.
Luey	Student	Personal information remains private / privacy.

Parents – Security:

Both parents identified privacy as being a security concern or other people accessing their child’s information. The suggestion of having all people who become a part of a young person’s platform sign a waiver was suggested.

Person	Group	Quotes
Chaichi	Parent	Others accessing information.
Joanie	Parent	Privacy issues / sign a waiver.

Teachers – Security:

The teachers shared the same concern as the parents regarding how safe the information would be and what restrictions would be in place to ensure the information housed on the site was secure. “Safety of information” was expressed.

Person	Group	Quotes
Harry	Teacher	Safety of information / restrictions were adhered to.

Support Worker – Security:

The theme of permission or “giving permission” was indicated as a concern by a support worker as well as having to negotiate through “red tape” to have access to the platform. The reference to red tape is in relation people accessing the site and the permission settings.

Person	Group	Quotes
Daisy	Support Worker	Personal intent / red tape.
Lily	Support Worker	Giving permission

Medical Professional – Security:

The same concerns were shared among the medical professionals regarding confidentiality as well as the additional concern of “hackers”.

Person	Group	Quotes
Dorothy	Medical Prof	
Rose	Medical Prof	Safe from hackers / have good profiles to show how to use it / privacy.
Blanche	Medical Prof	Confidential / privacy and confidential.
Sophia	Medical Prof	Security.

4.17 Discussion - Security

Security was a concern right across all groups with a range of examples given. There was nothing hugely surprising coming out of the theme around security. All participants shared concerns around the level of privacy the individuals would have in using a concept such as the one being proposed and how this would be managed. Some valuable insights were gained in speaking particularly to the young people themselves and how they viewed their own information and the importance of both privacy and security.

The protection of personal information is something very much at the forefront of our minds for most individuals when we are housing information online. So much of what we do and who we are in housed in a cloud base website. There will always be an element of risk around this.

The security of websites and how this is managed is a separate piece of research however as stated throughout the literature the benefits of housing information and sharing it across a cloud based platform, far outweigh the risk (Petroulakis, 2017; Wilson, 2011). Understanding there is a concern is important and that there are ways for this to be managed. Exploring how this could potentially be administered falls outside this immediate research due to the enormity of it. This research is testing the concept of an idea the logistics are not ready to be investigated at present. The feedback from all participant groups indicated some form of security being of concern to them.

4.18 Barriers

Student – Barriers:

The students were aware of the barriers that may be presented in getting people to agree to use the site and stated that some medical people may "prefer the traditional method of paper". The accuracy of information was also stated as a potential obstacle.

Person	Group	Quotes
Huey	Student	Getting professionals such as medical people to agree to use it as some might prefer the traditional paper method.
Duey	Student	Making sure information is accurate.

Parent –Barriers:

Each of the parents had different views on what the possible barriers could arise ranging from "people who decide it wouldn't work because it's never been used that way" through to the "marketing" of the site and "letting people know how it works". The "funding" of the site was also raised as an obstacle.

Person	Group	Quotes
Fonzie	Parent	Maintaining passion and commitment to it / get people who own it to help drive it / marketing and letting people know it works.
Chaichi	Parent	Funding it / people who don't want others to have access to their information.
Joanie	Parent	People who decide it wouldn't work because it's never been used that way.

Teacher – Barriers:

The teacher raised concern around the "buy in" from people and getting people to use the site. "Red tape" was also mentioned in the context of people having easy access to the site. One teacher raised the question around ownership of the site and maintained it "can't become owned by one of these single entities".

Person	Group	Quotes
Harry	Teacher	Buy in from people / it can't become owned by one of these single entities.
Harry	Teacher	Funding it / buy in / red tape.
Harry	Teacher	Buy in / Time.

Support Worker – Barriers:

Like the teachers the support workers identified three different areas that could create possible obstacles. The "amount of different people doing it" was seen as an obstacle as well at the platform being "really complex". The "time" it takes to do and "people see it as another job" was also raised as an obstacle.

Person	Group	Quotes
Daisy	Support Worker	Complexities / the amount of different people doing it / really complex
Lily	Support Worker	Buy in / time / paperwork.
Violet	Support Worker	People see it as another job to do / attract IT difficulties /

Medical Professional – Barriers:

One medical professional declared that the Barriers will be within their own sector and that the medical sector are very "wary of change" with the challenge of convincing "them (medical professionals) that this is a good idea". Having the opportunity to show that this is going to be useful" and that "once you get it up and running it will save time in the long run" was also shared as a possible solution to the obstacle.

Person	Group	Quotes
Dorothy	Medical Prof	People are very busy / stay as clear as you presented it / logical / prompt to say what is available.
Rose	Medical Prof	To show how it can be used.
Blanch	Medical Prof	Challenge will come with professionals / wary of change / convince them this is a good idea / best person to sell it will be the person themselves.
Sophia	Medical Prof	Showing that it is going to be useful / everyone has to buy in / once you have it up and running it will save you time in the long run.

4.19 Discussion - Barriers

There were numerous barriers mentioned across all groups however the main area of concern was getting buy in from the relevant parties. Each group alluded to this in different guises, but the messaging was similar. Getting the buy in from an already busy sector was going to present an obstacle. Several obstacles spoken to were also aligned with a potential solution such as “it will save time in the long run” and “the best person to sell it will be the person themselves”.

There were also some valid points in remaining passionate for the concept as such a task can take many years to complete as well as bringing people around to the idea of using something different.

The barriers that were presented across all user groups did not seem insurmountable. If the product was built with the recommendations made by the participants groups, then several the obstacles would resolve themselves. The suggestion by one parent of “get people who own it to help drive it” would help alleviate several of the obstacles. For people to understand the importance of this information sharing and storing site and the benefits it will bring to the individual at the center are best explained by the individual themselves.

4.20 Summary of Findings

In summarising the findings of this research, there is clearly not only a concern for the current situation but also a willingness to look for a different approach. Although there were five different participant groups the overall messaging was that things could improve. Each group had different areas that were important or relevant to them however the overall messaging was similar in that the across sector the storing and sharing of information using a collaborative approach is lacking.

Throughout the findings reference is made numerous times to the benefits of being able to share and store information and how this would improve the lives of people with high and complex support needs. The sense of empowerment is also highlighted across all participant groups and seen as something that would work in favor of the individual. The absence of any references by the participants to a resource that would encourage the sharing and storing of information did not go unnoticed. The void in mentioning such a platform was noted across all participant groups.

Accessibility and the user-friendliness of a potential site gained many suggestions on how this could be achieved. Simplicity of both imagery and accessibility have come through as key considerations.

Security of personal information was emphasised particularly from both the individuals and the parents. The main area of concern was in the personal information falling into the wrong hands which is a significant concern. Security was also discussed through the other user groups although this was in relation to having the ability to share information when government systems are so locked down. This finding has been valuable and will now help in giving guidance in how information is shared, if the idea is developed further, across support organisations.

Organisational buy-in featured as a barrier in moving this concept to a phase where both individuals and organisations engaged with it. Changing the way systems are used is difficult and this was acknowledged. Unless a concept reduces workload rather than increases work load it would be hard to convince parties to use it.

5 CHAPTER FIVE:

5.1 Evaluation of Study

In gaining an appreciation of the complexities across all spheres of the research I can see that there is room for improvement in the way we share information and how decisions are made for or on behalf of an individual. There are clear benefits in having a high functioning collaborative approach across a person's support network. In looking at both the tangible and intangible threads within this research there is a commonality in that all parties are looking to find meaningful ways to support people with high and complex needs to the best of their ability. The technology industry is making positive gains in high end individually tailored assistive technology that can be controlled through a variety of methods. Stakeholders are working in an environment where expectations are adjusted to fit the fiscal constraints while still bringing hope to a situation. A solution focus approach has been adopted.

The concept of a storing and sharing platform is sound. The research findings and supporting evidence have identified there is a place for such a platform. However, it would be naïve to think that such an idea would be easy to implement. The strains on an already saturated care and education industry are stretched. For such a concept to be implemented several factors would need to be considered. These factors have come from the research findings and include the simplicity of the platform as a key consideration as well as the security of personal information. The current concept I believe is too complicated. As one person has said to me who wasn't part of the research group "I'd need to be able to use it while standing in line at the supermarket". I do not believe the current concept is pitched at this level.

I believe this research has served the purpose of testing the concept of a storing and sharing platform as well as assisting in giving context to the larger question of how we have arrived at our current destination. In understanding the context and knowing that there is systemic confusion in the inclusive education space brings the challenge of building collaborative conversations, regardless of the method, into perspective. I believe this research has shown that there is the opportunity to create a resource that information could possibly be stored. Do I believe this concept will bring clarity to inclusive practice on a nationwide scale – no I don't! That was never the intention. Has this research help build a picture of what I am up against – yes it has! Do I believe such a resource could help a small portion of the population share information that is relevant to them having a meaningful opportunity – yes I do!

In order to take this concept to the next phase more research needs to be carried out with a smaller targeted group with less questions. The research question I presented had two parts to it which I think blurred the research for me as a new researcher. I was focused for a long time on the 'who' would benefit from the concept as opposed to the actual concept itself. I don't believe anything has been lost apart from my own time, however a huge amount has been gained in terms of my own learnings and the importance of keeping things extremely focused.

5.2 Recommendations

With the evidence gained through my research project, my recommendation is to continue into a development phase by building a prototype that could be tested in a controlled type situation. The original concept would be required to be pegged back somewhat to a simpler version with the overriding thought and example given that individuals and their advocates need to be able to use it while standing in line at the checkout. This is how simple it needs to be.

There are going to be some financial constraints on moving the concept to the next phase which needs to be explored. There are several startups programmes that could be investigated. There is also a company in Dunedin that may consider the project *pro bono.*

Ideally, an end user group needs to be formed to give guidance to the project. This was recommended in the findings.

In terms of the functionality of the concept my recommendation is that all information that is potentially shared is put through an authorization type process where the owner of the site can check the information being shared before it is made live. This recommendation comes after considering the feedback from the participants. In suggesting this it would also create a more streamline way of seeking permission and remove the hoops that would be fought if an organisation tried to share information.

A final recommendation would be to share these research findings with the Ministry of Education – Learning Support, Inclusive Education Action Group and the Complex Carers' Network which may generate some thoughts and discussions on how things could be done differently. From the research findings the evidence shows that the current situation is not meeting the needs of our most vulnerable students. Learning Support has received a significant increase in funding for students with additional support needs, therefore there may be an opportunity to leverage this concept further. The Well-Being budget (Labour, 2019) may also support an initiative to trial a pilot programme whereby the concept could also be tested.

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7 APPENDICES:

7.1 Information for Research Participants

Project title:

Researching the concept of an individualised website for people with high and complex support needs.

Dear Participant,

My name is Bridget Meyer and I am a Master of Professional practice student at the Otago Polytechnic. I work as a lead adviser for a national disability sport organisation that promotes opportunities for people living with physical impairments.

I am inviting you to be a participant in my Master of Professional practice.

General Introduction:

The overall goal of my Master of Professional practice is to research and demonstrate the concept/idea of a website that encourages the sharing and storing of information for individuals with high and complex support needs at their discretion.

I will gather feedback from the five participant groups about the concept/idea.

3 individuals with high and complex support needs and/or their parents/caregivers.
3 primary school teachers.
3 teacher aides.
3 health professionals.
3 personal carers

This research will explore ways we can preserve and future proof the nature of our collective work for those who are unable to advocate for themselves. The research will be a catalyst in conversations on how to support the micro world of people with high and complex needs and the use of technology with appropriate information being housed in one place and accessed easily at the discretion of the individual or their advocate.

Through this process I will look for solutions on how the rich information that is used to create meaningful opportunities can be preserved for future reference and shared if and when appropriate.

My objective for the research is to analysis how intuitive and user-friendly, if at all, a website concept needs to be for people to populate it with information. I will demonstrate the concept of using a web based platform with various individuals and stakeholder organisations within the sector.

Through this research I will learn whether a person centred website with secure portals would be feasible.

Table 4: Ethics application information

This project will be used as a way to initiate conversations with the wider community on the

benefits of incorporating technology and interprofessional collaborative practice for people with high and complex support needs.

What is the aim of the project?

To research the concept of an online system that could be used to ensure information was stored and shared securely with the appropriate parties at the discretion of an individual with high and complex needs.

How will potential participants be identified and accessed?

Individuals and their support networks will be invited to participate in the research through an independent organisation. Once the participant has expressed an interest they will contact me directly and I will begin the process of making a time to meet and carry out the interview questions. I will not approach anyone directly.

Who will be the participants?

I will carry out fifteen interviews. These will be a combination of

Three individuals with high and complex support needs and/or their advocates.

Three primary school teachers.

Three teacher aides.

Three medical professionals.

Three personal carers.

What will my participation involve?

Should you agree to take part in this research you will be asked to meet for a one hour interview at a location of your choosing.

The interview will be a discussion around the concept of using a website to store and share information that is tailored specifically for a person who has high and complex support needs.

With your permission I will record the session using an audio recorder.

How will confidentiality and/or anonymity be protected? - see Otago Polytechnic Research Guidelines to determine whether you can promise these conditions.

All transcripts will be anonymous and no two participants will come into contact with each other. Names will be removed from transcripts and you will be given a number to code all correspondence. I will be the only person with knowledge of your transcript. Your transcript will be stored securely at Sport Otago's office.

Table 5: Ethics application information.

What data or information will be collected and how will it be used?

The data will be collected through a series of interview questions (attached). There will be 7 questions in total and you can choose not to answer any question if you wish.

Results of this project may be published but the data included will not be linked to any specific participant.

You may request a copy of the results of the research and it will be available on request. This information will be available 10 months after the interviews.

Data Storage

The data collected will be stored in such a way that only I as the researcher will have access to it. At the end of the project any personal information will be destroyed. The data will only be used for this project.

Can participants change their minds and withdraw from the project?

You can decline to participate without any disadvantage to yourself of any kind. If you choose to participate, you may withdraw from the project up to 48 hours post interview, without giving reasons for your withdrawal. You can also withdraw any information that has already been supplied until the stage agreed on the consent form. You can also refuse to answer any particular question, and ask for the audio to be turned off at any stage.

Additional support

Should you require additional support at any stage during this process this will be provided to you at no cost to yourself. This may cover both sign language and language interpreters as well as counselling support if required.

You are also welcome to have whanau support accompany you.

What if you have any questions?

If you have any questions about the project, either now or in the future, please feel free to contact

Bridget Meyer
meyerbt1@student.op.ac.nz
027 6977177

Table 6: Ethics application information.

Dr Jo Kirkwood
Jo.kirkwood@op.ac.nz
021 1310 686

Any additional information given or conditions agreed to will be noted on the consent form which will be a separate form with the title of the research on it.

I know that:

My participation in the project is entirely voluntary.

I am free to withdraw at any time without any disadvantage.

The data (including audio) will be retained in secure storage for five years after which time it will be destroyed.

The participation in this project is entirely voluntary, there will be no remuneration or compensation provided.

The information gathered will be coded and anonymised replacing names with four digit numbers. The data collected will only be used in this research.

I agree to take part in this project under the conditions set out in the Information Sheet.

signature of participant

date

signature of researcher

This project has been reviewed and approved by the Otago Polytechnic Research Ethics Committee.

Send a copy of the whole file to your manager to read, and the electronic copy signed by your Manager/HoS needs to be sent out to the Ethics Committee Administrator

(ethicsadmin@op.ac.nz).

Table 7: Ethics application information.

7.2 Ethics template to monitor changes

ISSUE: Research purpose and merit.	ADDRESSED BY:	Refer to page:	FEEDBACK FROM ETHICS COMMITTEE:	ADDRESSED BY:	Refer to page:
It is not clear what the research hopes to achieve.	This project will test the creation of a demo website for people with high and complex support needs and their parents and caregivers. The action research project will give an insight into whether this medium of communication i.e the website is of value for people who are unable to advocate for themselves. The website will be tested with feedback on whether is it something to be pursued or not.	Pg 3/4	Thank you. The clearest explanation for the lay reader is in the information to research participants section (appendices) . The intention is clearest in the overall goal statement. Suggest that this wording is used through the document to provided further clarity as it currently "shifts around".	I have brought the information from the Information for Research Participants across to the Ethics application to create consistency of language. I've reiterated that I am researching the concept of a site.	Pg 3
It is not clear from the title.	The research question has been changed to 'Does the ability to access a portal of individualised information improve the life of a person with high and complex needs'.	Pg 3	Would suggest further refinement to the research question as you have set up a pilot. There also appears to be two distinct parts to the project. Having a title that encompasses both aspects, e.g., "Developing an interprofessional website for people with high and complex needs": and separating the content into using two research questions • One relating to the kind of information that would be helpful to a range of people (with vested interests) , and • the other, relating to the accessibility and usefulness of this information to the research groups might further clarify this project and enhance its findings. This would better convey the research intention and is supported by an action research approach.	I have now changed the research question to "Researching the concept of an individualised website for people with high and complex support needs"….could add - "and the type of information that could be stored".?? Not sure.	Pg 3
High and complex needs to be defined.	**What is a 'complex' disability?** The New Zealand Complex Carers organisation describes a complex disability as one that requires intensive support: • because the person has multiple disabilities, i.e physically disabled and has an intellectual disability • is disabled and has serious ongoing medical condition, i.e epilepsy • is disabled and has autism spectrum disorder or behavior	Pg 3	Thank you.	All good	Pg 3

Table 8: Ethics revision proof of changes.

	that requires a high level of support				
Define the need for this research.	This research will give an insight into the feasibility of taking this concept of an individualised website further. The demo site will enabled all parties to test the concept and to consider whether such a website with individualised portals will enhance the support they are providing people who require it.	Pg 4	OK, thanks for this.	All good	Pg 4
Is there a perceived gap?	Research has been carried out identifying the need for support services to work more collaboratively. The New Zealand Complex Carers organisation identified in a 2017 report drew attention to the isolation carers are working in and the challenges faced in bringing support services together. Through my own role I am also faced with the yearly duplication of questions as student's transition from one class to another.	Pg 4	OK, this is clear and should be stated as a rational for the research.	Yes, I have done this.	Pg 4
Why this type of resource?	The ease of storing information over a cumulative period which does not involve support staff wading through a paper based resource is attractive. The instant accessibility to records/ideas/photos as well as the across platform sharing of ideas makes a website the most appropriate platform.	Pg 5	OK	All good.	Pg 5
Is there literature on this topic to support the application?	I have found a number of articles on the importance of a collaborative approach but I haven't found a lot of how to achieve such as approach.	Pg 5	OK	All good.	Pg 5
Is there a pilot version of a website?	Yes, a demo version has been built. It has not been tested as yet.	Pg 5	OK	All good.	Pg 5
Or is the researcher asking what kind of website/information would these different groups find useful?	As the bones of a website has been built as a starting point I am interested to know what information would be useful for all groups.	Pg 5	Ok, this relates to the earlier point about having more than one research question.	I have changed the research question so it makes reference to 'researching the concept of a website'.	Pg 5
What is the level of access to computers or apps among these groups?	This will vary from household to household however I imagine most do have access to some form of device.	Pg 5	OK. You may need to take an iPad for the demo.	Yes, I will use my laptop.	Pg 5
Would there be legal or privacy issues to be considered in setting up such a sharing website?	As the individual and the parent/caregiver will be the owners of the information which is housed in the portal they will decide who they invite to view the	Pg 5	This needs further clarification, particularly when dealing with vulnerable people. This mechanism is unclear, potentially unsafe/subject to misuse and possibly	As this is only a conceptualised idea I am gathering research on I do not believe this to be a barrier at such an early stage.	Pg 5

	information. Within each portal you require permission to view the various vaults. An example of this is that the sports coach would not need to see the medical vault however the medical professional might be invited to see the sports/leisure/recreation vault. All of these settings are managed by the host.		breaches and individuals person or group's privacy. Generic information (.e.g. that which is available in the public domain) is OK, However, including information relating to an individual's medical or personal situation, or anything that could be liked to an individual by inference (particularly as this is a relatively small and local community) cannot be shared.	I have left an additional paragraph explaining permission settings.	
ISSUE: Recruitment					
The recruitment method is unclear and difficult to follow.	The recruitment of volunteers will be managed through CCS – Disability Action Otago.	Pg 6	The new information sheet is better but requires further editing and simplification.	I have made changes to the flyer. I'm unsure if this is the information sheet you mean.	Pg 6
How will recruitment be done to select people who meet the inclusion criteria?	Step One: Flyer - advertising through CCS – social media, newsletter and other relevant organisations. Step Two: Letter of endorsement from CCS and participant information letter. Step Three: Interview times made and carried out.	Pg 7	Ok	Ok	Pg 7
Please clarify the recruitment process as this impacts on the ethical aspects/process of interviewing.	The recruitment of volunteers is being supported by CCS. A flyer will be made in the first instance advertising for volunteers to participate. The breakdown of the groups will be listed on the flyer as well as the ages where applicable.	Pg 6/7	OK	Ok	Pg 6/7
Issues of vulnerable participants has been addressed but aspects of this need to be incorporated into the participant information and consent form.	These have now been included.	Pg 10	See previous comments, Still not clear.	Have added a statement in the participant information and consent form on where to get support.	Pg 10
ISSUE: Cultural/Language consideration:					
How have these been considered, especially in reaching different cultural groups (if relevant)?	I have elaborated on these.	Pg 8	Partially addressed.	I had made reference to the refugee programme and have added a comment of the access to an interpreter.	Pg 8
Please expand/reconsider this section in your application.	Have expanded.	Pg 8		Have added in language interpreter, sign language interpreter and whānau support.	Pg 8
Please consider the specific needs of the included groups throughout the revised application.	Have considered and revised.	Pg 8	Partially addressed.	Have added additional support options including counselling.	Pg 8

7.3 Letter of support from CCS - Disability Action:

You don’t have to thank me - I am delighted for us to be involved!

Mel Smith

General Manager - Southern

DDI (03)479 6882

Mobile 0272 309 932

On 7/06/2018, at 2:56 PM, Bridget Meyer <bridget@halberg.co.nz> wrote:

Wonderful. Do you know how happy that makes me? Thank you so much. Ill be back in touch once I hear from Glenys and Jo.

Bridget

Bridget Meyer

Lead Adviser

Halberg Disability Sport Foundation

E bridget@halberg.co.nz

C 027 6977177

L 03 474 6347

S bridget.halberg

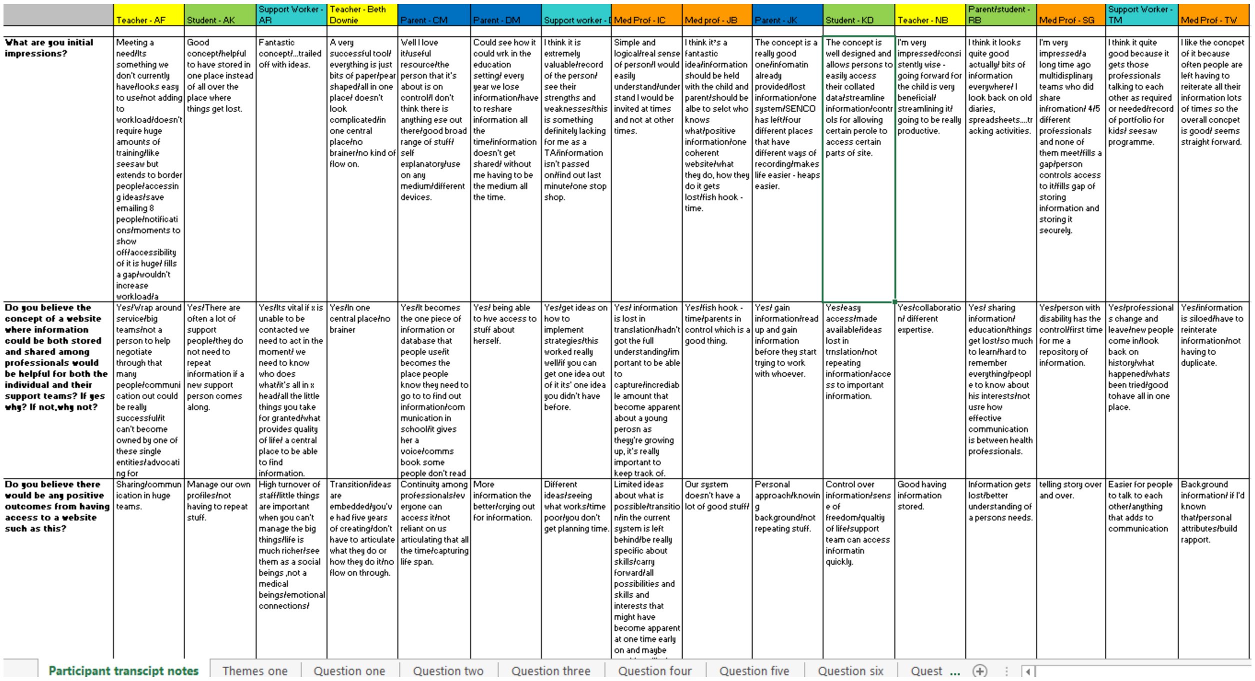
-------- Original message --------

7.4 Keeping track of required information

Document Title:	Action:	Other:	Notes:
Ethics application	Completed	Attached	Updated
Ethics revision table	Completed	Attached	Updated
Emailing from CCS confirming support.	Completed	Attached	No change
Draft flyer for research participants.	Completed	Attached	Updated
Interview questions	Completed	Attached	Updated
Letter of endorsement from CCS.	Completed	Attached	No change
Information for research participants	Completed	Attached	Updated

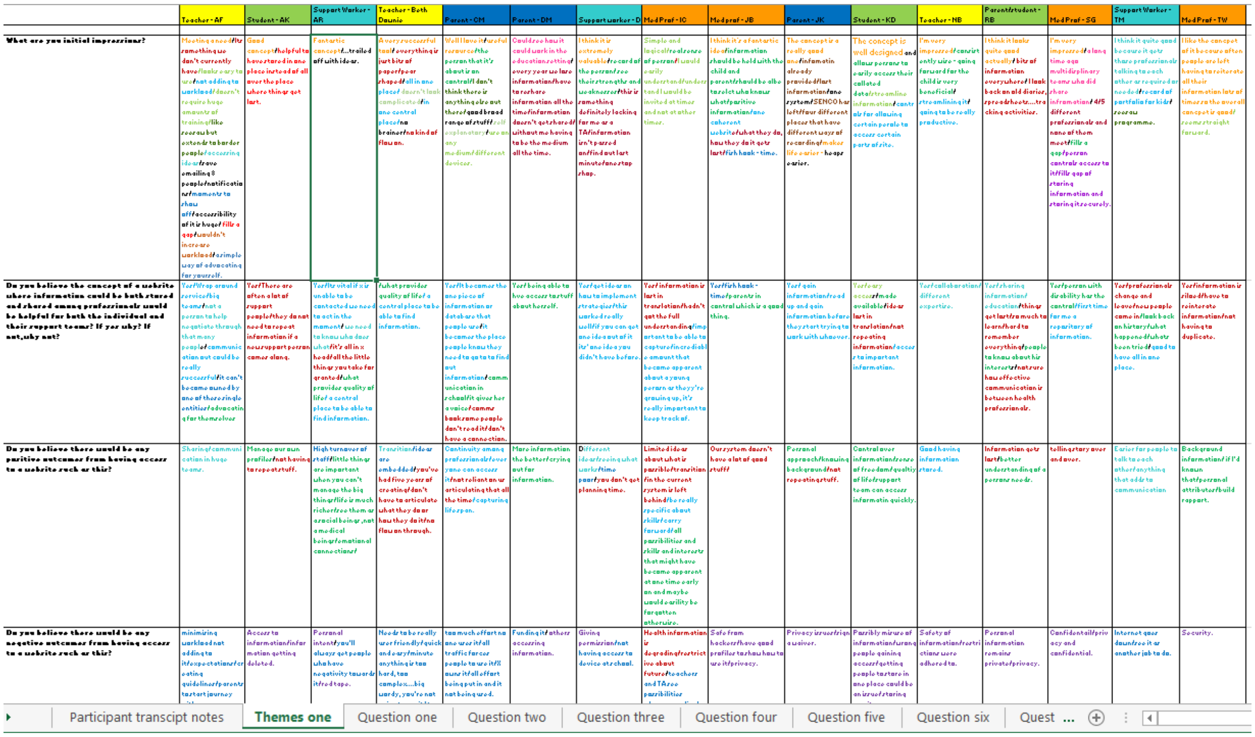
Table 9: Table to keep track of information required of journal entries

7.5 Sample of steps taken to analyse transcripts



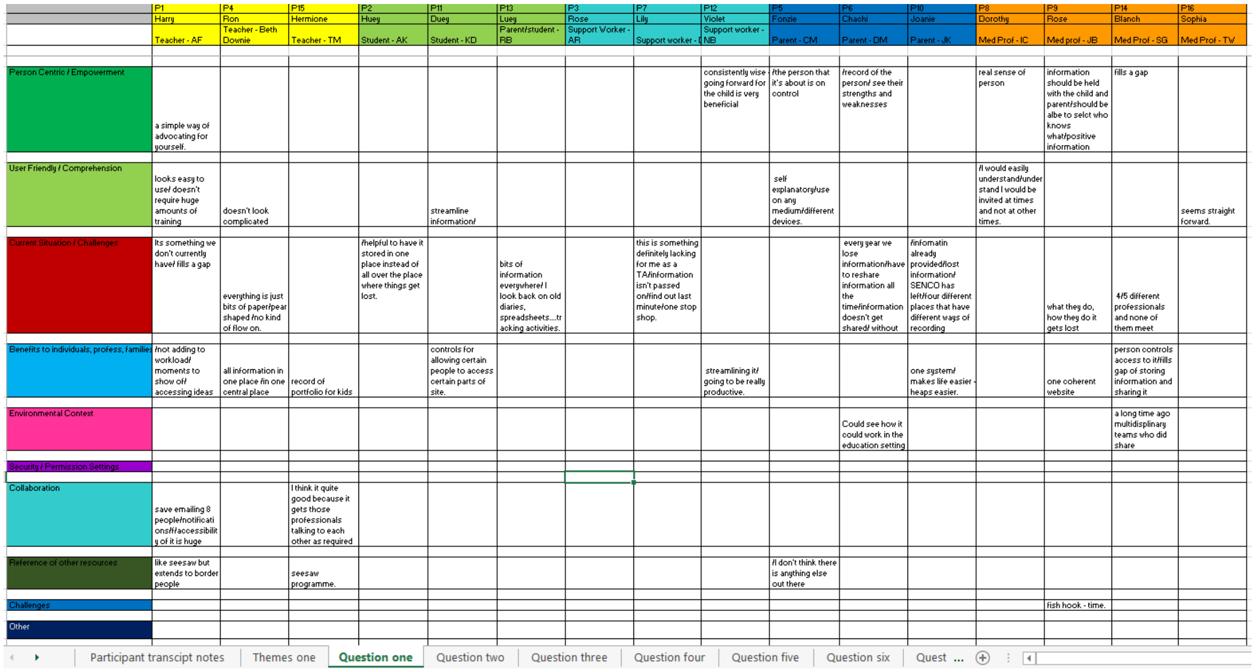
	Teacher - AF	Student - AK	Support Worker - AR	Teacher - Beth Downie	Parent - CM	Parent - DM	Support worker - D	Med Prof - IC	Med prof - JB	Parent - JK	Student - KD	Teacher - NB	Parent/student - RB	Med Prof - SG	Support Worker - TM	Med Prof - TW
What are you initial impressions?	Meeting a need/Its something we don't currently have/looks easy to use/not adding to workload/doesn't require huge amounts of training/like seesaw but extends to border people/accessing ideas/save emailing 8 people/notifications/moments to show off/accessibility of it is huge/ fills a gap/wouldn't increase workload/a	Good concept/helpful to have stored in one place instead of all over the place where things get lost.	Fantastic concept/...trailed off with ideas.	A very successful tool/ everything is just bits of paper/pear shaped/all in one place/ doesn't look complicated/in one central place/no brainer/no kind of flow on.	Well I love it/useful resource/the person that it's about is on control/I don't think there is anything ese out there/good broad range of stuff/ self explanatory/use on any medium/different devices.	Could see how it could wrk in the education setting/ every year we lose information/have to reshare information all the time/information doesn't get shared/ without me having to be the medium all the time.	I think it is extremely valuable/record of the person/ see their strengths and weaknesses/this is something definitely lacking for me as a TA/information isn't passed on/find out last minute/one stop shop.	Simple and logical/real sense of person/I would easily understand/understand I would be invited at times and not at other times.	I think it's a fantastic idea/information should be held with the child and parent/should be albe to selct who knows what/positive information/one coherent website/what they do, how they do it gets lost/fish hook - time.	The concept is a really good one/infomatin already provided/lost information/one system/SENCO has left/four different places that have different ways of recording/makes life easier - heaps easier.	The concept is well designed and allows persons to easily access their collated data/streamline information/controls for allowing certain perole to access certain parts of site.	I'm very impressed/consistently wise - going forward for the child is very beneficial/ streamlining it/ going to be really productive.	I think it looks quite good actually/ bits of information everywhere/ I look back on old diaries, spreadsheets....tracking activities.	I'm very impressed/a long time ago multidisplinary teams who did share infromation/ 4/5 different professionals and none of them meet/fills a gap/person controls access to it/fills gap of storing information and storing it securely.	I think it quite good because it gets those professionals talking to each other as required or needed/record of portfolio for kids/ seesaw programme.	I like the concpet of it because often people are left having to reiterate all their information lots of times so the overall concpet is good/ seems straight forward.
Do you believe the concept of a website where information could be both stored and shared among professionals would be helpful for both the individual and their support teams? If yes why? If not,why not?	Yes/Wrap around service/big teams/not a person to help negotiate through that many people/communication out could be really successful/it can't become owned by one of these single entities/advocating for	Yes/There are often a lot of support people/they do not need to repeat information if a new support person comes along.	Yes/Its vital if x is unable to be contacted we need to act in the moment/ we need to know who does what/it's all in x head/all the little things you take for granted/what provides quality of life/ a central place to be able to find information.	Yes/In one central place/no brainer	Yes/It becomes the one piece of information or database that people use/it becomes the place people know they need to go to to find out information/communication in school/it gives her a voice/comms book some people don't read	Yes/ being able to hve access to stuff about herself.	Yes/get ideas on how to implement strategies/this worked really well/if you can get one idea out of it its' one idea you didn't have before.	Yes/ information is lost in translation/hadn't got the full understanding/important to be able to capture/incrediable amount that become apparent about a young perosn as theyy're growing up, it's really important to keep track of.	Yes/fish hook - time/parents in control which is a good thing.	Yes/ gain information/read up and gain information before they start trying to work with whoever.	Yes/easy access/made available/ideas lost in trnslation/not repeating information/access to important information.	Yes/collaboration/ different expertise.	Yes/ sharing information/ education/things get lost/so much to learn/hard to remember everything/people to know about his interests/not usre how effective communication is between health professionals.	Yes/person with disability has the control/first time for me a repository of information.	Yes/professionals change and leave/new people come in/look back on history/what happened/whats been tried/good tohave all in one place.	Yes/information is siloed/have to reinterate information/not having to duplicate.
Do you believe there would be any positive outcomes from having access to a website such as this?	Sharing/communication in huge teams.	Manage our own profiles/not having to repeat stuff.	High turnover of staff/little things are important when you can't manage the big things/life is much richer/see them as a social beings ,not a medical beings/emotional connections/	Transition/ideas are embedded/you've had five years of creating/don't have to articulate what they do or how they do it/no flow on through.	Continuity among professionals/everyone can access it/not reliant on us articulating that all the time/capturing life span.	More information the better/crying out for information.	Different ideas/seeing what works/time poor/you don't get planning time.	Limited ideas about what is possible/transition/in the current system is left behind/be really specific about skills/carry forward/all possibilities and skills and interests that might have become apparent at one time early on and maybe	Our system doesn't have a lot of good stuff/	Personal approach/knowing background/not repeating stuff.	Control over information/sense of freedom/qualtiy of life/support team can access informatin quickly.	Good having information stored.	Information gets lost/better understanding of a persons needs.	telling story over and over.	Easier for people to talk to each other/anything that adds to communication	Background information/ if I'd known that/personal attributes/build rapport.

Participant transcipt notes | Themes one | Question one | Question two | Question three | Question four | Question five | Question six | Quest ...



	Teacher - AF	Student - AK	Support Worker - AR	Teacher - Beth Downie	Parent - CM	Parent - DM	Support worker - D	Med Prof - IC	Med prof - JB	Parent - JK	Student - KD	Teacher - NB	Parent/student - RB	Med Prof - SG	Support Worker - TM	Med Prof - TW
Do you believe there would be any negative outcomes from having access to a website such as this?	minimising workload not adding to it/expectations/creating guidelines/parents to start journey	Access to information/information getting deleted.	Personal intent/you'll always get people who have negativity towards it/red tape.	Needs to be really user friendly/quick and easy/minute anything is too hard, too complex...big wordy, you're not	too much effort no one uses it/all traffic forces people to use it/X owns it/all effort being put in and it not being used.	Funding it/ others accessing information.	Giving permission/not having access to device at school.	Health information is degrading/restrictive about future/teachers and TAs see possibilities	Safe from hackers/have good profiles to show how to use it/privacy.	Privacy issues/sign a waiver.	Possibly misuse of information/wrong people gaining access/getting people to store in one place could be an issue/storing	Safety of information/restrictions were adhered to.	Personal information remains private/privacy.	Confidentail/privacy and confidential.	Internet goes down/see it as another job to do.	Security.

Participant transcipt notes | Themes one | Question one | Question two | Question three | Question four | Question five | Question six | Quest ...



	P1	P4	P15	P2	P11	P13	P3	P7	P12	P5	P6	P10	P8	P9	P14	P16
	Harry	Ron	Hermione	Huey	Duey	Luey	Rose	Lily	Violet	Fonzie	Chachi	Joanie	Dorothy	Rose	Blanch	Sophia
	Teacher - AF	Teacher - Beth Downie	Teacher - TM	Student - AK	Student - KD	Parent/student - RB	Support Worker - AR	Support worker - [	Support worker - NB	Parent - CM	Parent - DM	Parent - JK	Med Prof - IC	Med prof - JB	Med Prof - SG	Med Prof - TW
Person Centric / Empowerment	a simple way of advocating for yourself.								consistently wise - going forward for the child is very beneficial	/the person that it's about is on control	/record of the person/ see their strengths and weaknesses		real sense of person	information should be held with the child and parent/should be albe to selct who knows what/positive information	fills a gap	
User Friendly / Comprehension	looks easy to use/ doesn't require huge amounts of training	doesn't look complicated			streamline information/					self explanatory/use on any medium/different devices.			/I would easily understand/understand I would be invited at times and not at other times.			seems straight forward.
Current Situation / Challenges	Its something we don't currently have/ fills a gap	everything is just bits of paper/pear shaped /no kind of flow on.		/helpful to have it stored in one place instead of all over the place where things get lost.		bits of information everywhere/ I look back on old diaries, spreadsheets....tracking activities.		this is something definitely lacking for me as a TA/information isn't passed on/find out last minute/one stop shop.			every year we lose information/have to reshare information all the time/information doesn't get shared/ without	/infomatin already provided/lost information/ SENCO has left/four different places that have different ways of recording		what they do, how they do it gets lost	4/5 different professionals and none of them meet	
Benefits to individuals, profess, families	/not adding to workload/ moments to show off/ accessing ideas	all information in one place /in one central place	record of portfolio for kids		controls for allowing certain people to access certain parts of site.				streamlining it/ going to be really productive.			one system/ makes life easier - heaps easier.		one coherent website	person controls access to it/fills gap of storing information and sharing it	
Environmental Context											Could see how it could work in the education setting				a long time ago multidisplinary teams who did share	
Security / Permission Settings																
Collaboration	save emailing 8 people/notifications/f/accessibility of it is huge		I think it quite good because it gets those professionals talking to each other as required													
Reference of other resources	like seesaw but extends to border people		seesaw programme.							/I don't think there is anything else out there						
Challenges														fish hook - time.		
Other																

Table 10: Example of steps taken to analyse transcripts

7.6 Curriculum Vitae

Bridget Tracey Meyer

1032 Mount Cargill Road

RD2

WAITATI 9085

03 482 1019 hm

027 69 77177 cell

Employment Pathway:

Qualifications: **Bachelor of Social Services (Distinction)**

Current Masters Candidate

Topic – Researching the concept of a storing and sharing website for individuals with high and complex support needs.

Employer: **Halberg Foundation**

Date: August 2005 – Present

Position Held: Lead Adviser

, Otago, Southland and Central Otago

Key Performance Areas:

- Establish an extensive communication network with individuals in allied organisations both regionally and nationally within the social service sector.
- Effectively promote the Foundation’s vision and mission in all presentations, newsletters and personal interactions
- Lead the Foundation’s training courses and advisory services with knowledge, clarity and passion
- Advocate for young people with disabilities and ensure opportunities are created within the sport, recreation and leisure sector in an inclusive manner.
- Promote the work of the Halberg Disability Sport Foundation.
- Research, consult and analyse local community needs.
- Identify projects that are sustainable and coordinate the implementation of them.

Employer:	Adventure Development and Counselling.
Date:	January 2004 – August 2005.
Position Held:	Operations/Administration Manager.

Key Performance Areas:

- To provide support and information on all programmes administered by Adventure Development and Counselling.
- Programming and planning of outdoor residential course.
- Market and promote this service to the wider community.
- Work in partnership with other at risk youth service providers.

Employer:	CCS Disability Action – Otago.
Date:	October 2000 – December 2004.
Position Held:	Recreation and Volunteer Coordinator.

Key Performance Areas:

- Recruit, support, orientate and train volunteers to meet the responsibilities of their positions in supporting people with disabilities.

- Ensure volunteers are equipped with the necessary skills to undertake appointed tasks. Support volunteers, provide feedback on performance. Provide a job description that outlines the roles and responsibilities of the volunteer position. Coordinate volunteers to ensure outcomes are achieved.
- Develop and coordinate recreational/leisure activities.
- Network and liaise with relevant agencies.
- Monitor and address changing requirements of clients.
- Access and apply for grants through community funding organisations.
- Manage training and volunteer budget.

Employer: **CONNECT – Development Training and Corporate Events.**

Date: January 1999 – November 2003.

Position Held: Self Employed/ Company Director.

Employer: **Otago Youth Wellness Centre.**

Date: January 1998 – August 1998.

Position Held: Operations/Administration Manager.

Employer: **Roxburgh Children's Health Camp.**

Date: January 1992 – November 1997.

Position Held: Fieldworker – Otago/ Southland

Employer: **Roxburgh Children's Health Camp.**

Date: January 1991 – January 1992.

Position Held:	Residential Child Care Worker.

Employer:	**Cobham Outward Bound School.**
Date:	February 1989 – January 1990
Position Held:	Catering / general Gopher

Voluntary Positions:

2012 – Present	Koru Care Otago
2012 – Present	National Disability Snowsport Foundation
2011 – Present	Chairperson of the Otago Family Network.
2007 – Present	Blueskin Bay Youth Group coordinator.
2002 - 2003	CCS – Recreation support person for the Boccia team.
1990 – 1997	CanTeen – Otago/southland Coordinator. CanTeen – National Executive.

Achievements/Highlights:

Wednesday Sport Programme (2005 – present)

- An interschool sports initiative working with 8 secondary schools throughout Dunedin – an introduction to inclusive sports practice

Spike Swim Squad (2005 – present)

- A demand for young people with disabilities to have swimming lessons saw these classes piloted and then begin in an inclusive environment alongside able-bodied swimmers. These classes are now administered through the Swimsation swimming class programme and run three times a week.

Jolt Dance (2007 – present)

- This initiative was created after a dance 'taster' at the Wednesday sport programme. The opportunity for creative rather than structured dance classes sees this programme running two classes a week.

Mustangs soccer team (2006 – present)

- The Mustangs soccer team is a mixed ability soccer team which plays throughout the season in the Unipol (University/Polytech) social grade competition. Supported by Physical Education Students.

Wildcatz Basketball (2006 – present)

- The Wildcatz Basketball team is a mixed ability basketball team which plays in Otago Basketball social league competition. It is now organised by PE students.

Otago Adaptive Snowsports (2007 – present)

- Collaboration between University of Otago and Halberg Disability Sport Foundation to create a sustainable pathway for athletes with disabilities within the snow sport arena.

Adaptive Outdoor Education (2008 – present)

- Collaboration between University of Otago, Halberg Disability Sport Foundation and Wild Earth Adventures to provide an outdoor experience for young people with disabilities as well as a learning opportunity for the Physical Education students who are supporting them.

Adaptive Sport Mentoring (2008 – present)

- Collaborative partnership between Regional Sports organisations, University of Otago and the Halberg Sport Opportunity Programme to create a sustainable pathway in inclusive sports for young people with disabilities.

Equipment Pool

- An equipment pool has been established to allow families/schools/community groups to borrow adaptive equipment on a short term loan basis. Purchase of two 'Trailriders' imported from Canada have also been secured.

USA – sabbatical

- Visited a number of disability sport and recreation providers including University of Arizona disability sport programme – Tucson, Arizona, SPLORE (Special Population Learning Outdoor Recreation) Salt Lake City, Utah, Wounded Warriors Programme, Salt Lake City, Utah.

'Attitude' programme on Central Otago Rail Trail

- Coordinate logistics for the filming of 'Attitude TV" Central Otago Rail Trail programme.

http://www.youtube.com/watch?v=kGy58BFo15I&feature=relmfu

Conference presentations – ISAPA (2011)
Everybody In (2011)

The opportunity to present the concept of Adaptive Sport Mentoring at the International Symposium Adaptive Physical Activity (ISAPA) in Paris, France 2011

Outward Bound / Halberg Disability Sport Foundation

- A collaborative partnership between the Cobham Outward Bound School and the Halberg Disability Sport Foundation has been established with a pilot course being held in June 2014 for 10 physically disabled young people from throughout New Zealand.

Mango Tree Centre – Tonga

- A personal initiative to work alongside the Mango Tree Centre to create a disability sports programme and to introduce inclusive practices into primary schools on the island of Tongatapu.

Personal Interests:

Personal Statement:	I am a firm believer in the philosophy 'it takes a village to raise a child'. I believe if you are in a position to support and advocate for others it is an honour and privilege to do so.
Family:	Partner and 2 sons (19 yrs and 20 yrs).
Interests:	Tramping Snow Boarding Gardening Sailing
Personal:	Warm, friendly, confident and enjoy working with people in a wide range of spheres. Reliable and trustworthy. Team player. Adaptable and patient. Organised, creative, with a can-do attitude. Have empathy for others and can participate in and/or lead situations that require diplomacy.

7.7 Review of Learning – Course one

Introduction:

I wanted my introduction into my Review of Learning to be filled with profound reflections, newly created coined phases and penny dropping epiphanies, however I have so many thoughts and questions racing around in my head it is difficult to know where to begin.

One thing I do have a lot of clarity on since finishing my Bachelor of Social Services however is that I want more! I want to learn more and I want to be more! I have many questions around my personal competencies as a productive member of my family and community and so many more questions around my profession, my current work place and the social inclusion space.

To link what I have learnt in the past to what my future aspirations are, I believe I need to firstly understand and gain more evidence in why I think the way I do when it comes to social inclusion -

not an easy task! I need to gain some perspective as to whether there is a space for what I believe is the right way forward or am I completely dreaming. I need to unravel and settle the neurons that are currently firing off in all directions and begin by having some conversations with individuals who are the recipients of the decision makers on what they believe is in fact social inclusion.

Professional:

If I look back to where I was at the beginning of my professional practice (30 years ago) there has been expediential growth. From being a reactionary fire fighter in my early days in the social service arena to what I believe now is a more strategic practitioner with a much greater understanding of the landscape in which I operate.

I am currently in the position of Lead Adviser for the Halberg Disability Sport Foundation. A position in which I lead a cluster of advisers from throughout the country. I also lead the recreation strategy at a national level which includes managing various projects with national stakeholders. These include Outward Bound and the Department of Conservation.

In completing my BSS my interest and curiosity into the space of social inclusion has created a brain explosion where currently I have more questions than answers! I believe by exploring this theme further I will be able find a place where my own philosophies will be challenged and hopefully reconciled. Upon the completion of this 'adventure', ie my Masters, I am looking to align myself with an organisation that has their compass set in the right direction - if there is a ‘right’ direction.

Personal/Education:

My personal journey and development to date has been quite a ride. In beginning my studies in 2016 and finishing them mid-way through 2017 was a cathartic experience and one, upon reflection, I am so thankful I was able to take. To be able to step outside of myself and be gifted the time and head space to create a timeline of 'happenings' and write about these in detail was truly decadent. To be given the support and encouragement to learn about ones hotspot and triggers and more importantly to then be supplied (actually, we paid a lot of money) with the tools to manage these, has I believe, set me up to take make some major changes in my professional life.

Gaining a formal qualification that recognises and brings balance to both hemispheres of my brain has created a shift in my thinking and possibly ‘a don't mess with me’ attitude. I sometimes worry about the strength of my convictions around the inclusion model and would like to explore this more through my Masters. I have had over many years the opportunity to observe many different forms of best practice and have attended and organised many forums and conferences both nationally and internationally that touch on this topic.

Community/Volunteer:

My volunteering and community work has always been focused around my work. I have never explored or thought about why this is so up until now. I think perhaps we tend to be attracted to people who believe in the same as us therefore are drawn to similar social movements - whatever they may be. My take on volunteering is that if you can support others who are in need then this is what you ought to do. For the most part the giver will get more out of the act of giving than the receiver (unless you are doing periodic detention!).

I have also managed a lot of volunteers over the years and this too can come with its challenges. I have no doubt there is research on managing volunteers, but I don’t think it is rocket science in working out how to do this well. My theory is that we form relationships with others/groups it is because we want to receive something back. Whether that is the sense of contributing to cause, a letter of reference, credits towards a degree, somebody makes you laugh or you have a social conscience that needs a top up. If we can provide an incentive for others to engage then the volunteering opportunity is usually a success.

My current volunteering is through an organisation called The Mango Tree Centre which is based in Tonga. (I have a social conscience that needs a top up and I have access to a lot of sports equipment that I can’t stand to see be put in the landfill).

I have stepped down from chairing a number of groups over the last two years as I need to focus on other things including my personal and professional development.

Skills, Knowledge and Attributes:

My biggest strength or skill is also my Achilles heel! I am extremely solution focused which works superbly well for those I am advocating for but can be challenging to manage. I am fully aware of this trait and make a very conscious effort to pick my battle wisely. My knowledge and networks in the sector are vast and due to my solution focused approach to my practice if I don't know the answer to something I will find someone who does. I believe in surrounding myself with a scaffolding of knowledge.

In leading my team I also have the skills and knowledge to encourage and support others in managing both internal and external conflict. I am very aware that being in a middle management position that I am often pulled in both directions which can create its own challenges. I have learnt and put in place a number of tools that I use daily to manage and dilute the hysteria that can sometimes arise within our organisation. I am a firm believer that someone else’s urgency is not mine and often find myself swiping left!

The attribute that has stood me in good stead and may seem a little out of place within the social service sector is I am creative with a relatively high level of detailed ingenuity. I can do both big picture thinking as well as detailed thinking which helps see projects and plans through from inception to completion. I am an ordered and visual thinker and use creative methods to remember various pieces of information. The challenging side to this within my own organisation is that it is very much disorganised with often the left hand not knowing what the right is doing. We receive mixed messages on a daily basis. I think when you are working with people as opposed to products you are going to get a melting pot of mixed messaging – this is the nature of the beast and rather than fighting it the best way forward is to put your own systems, whatever they may be, in place.

Future intentions on the MPP:

My past learnings and observations over the last five years is that my own organisation as well as many others including the Ministry of Education have lost their way on what social inclusion means. The Ministry of Education (Ministry of Education - Inclusive Education, Kāhore he rā) states that 'Inclusive Education' is whereby young people are "present, participating, learning and belonging". However, as time moves on we are becoming fully aware that some schools are not engaged in this value which means that students are moving away from their closest schools to attend schools where these values are upheld. This is creating a 'magnet school' model. The same is happening with the sport and club scene. Disability specific sport clubs are growing in popularity and the numbers that were once participating within a mainstream environment are dwindling. Through my studies I would like to understand why this is happening and look to do something to reverse this occurrence if possible.

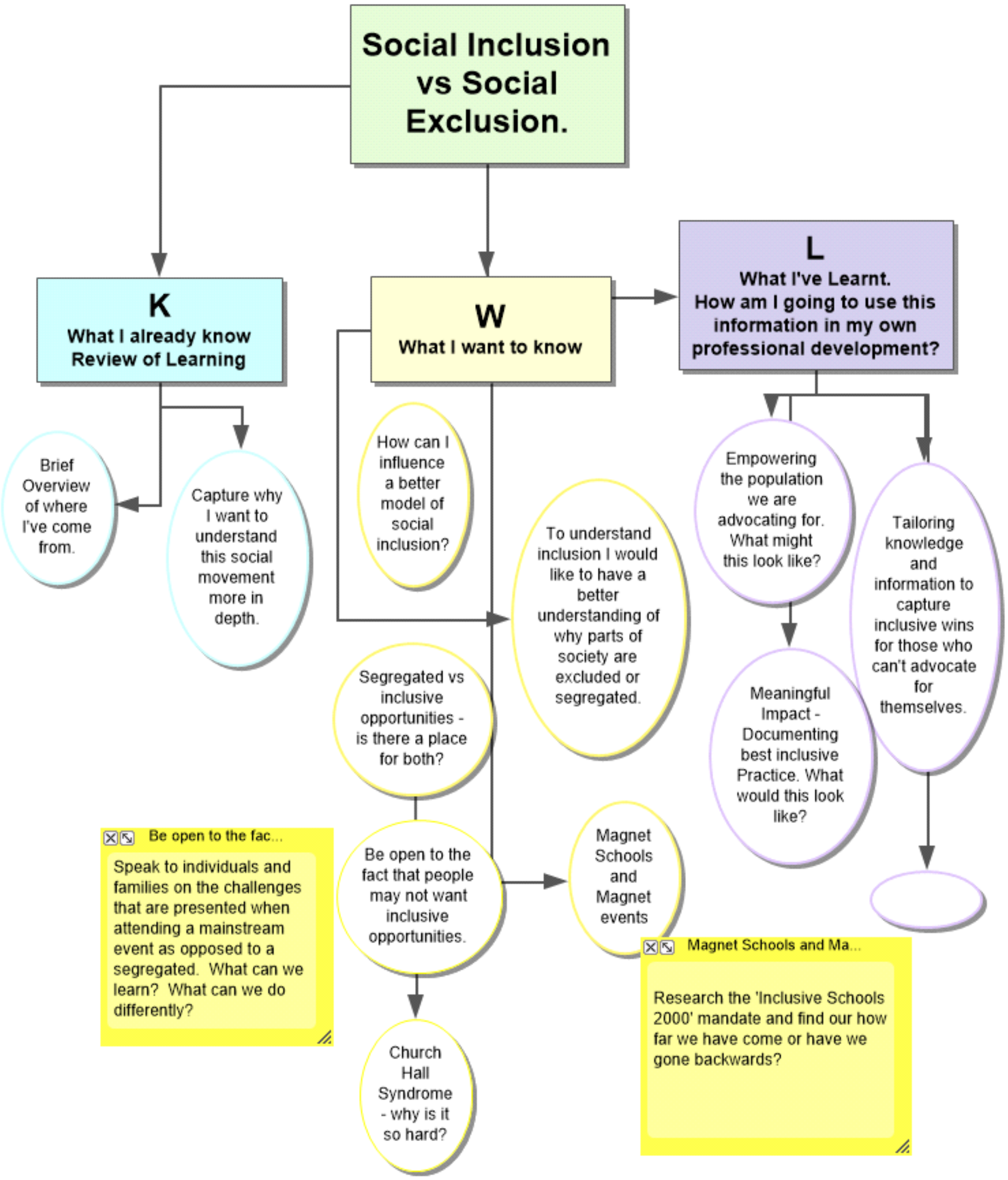
I would also like to gain a much clearer understanding of why the mighty dollar that is provided by our funders and sponsors is influencing where we as an organisation put our resources. We are returning to the model of what is easiest not necessarily what is right! We have moved away from working hard alongside well established community events where we looked to break down barriers and encourage inclusion for people of all abilities. Our main focus now I believe is in running segregated/exclusive 'Have A Go' carrot dangling events once a year for physically disabled young people, whereby we take a number of 'money shots' (photos of children who are impaired i.e amputation, wheelchair users, cerebral palsy etc) which are then used as propaganda in our marketing material to appease our sponsors and funders and in turn generate more income. I have learnt that there must be a budget line in everything we do. I understand that we need an income stream to do our work but I am very uncomfortable having the dollars for services so closely linked. An example of this is a workshop called No Exception Training that we use to deliver for free to schools and sports clubs we are now required to charge for this information. There are enough challenges for this particular sector without creating more barriers. This may be brutal but I we are currently using other people's misfortune in a very unpalatable way! I do not agree that this is the way we ought to be conducting ourselves. I feel a fraud as this is not what inclusion is in my mind or in the mind of many of the families I work alongside!

I think I waited a whole 6 days after completing my degree before I made an appointment to meet with my supervisor again. I wanted to learn more! I didn't want this process of learning to stop. I wanted my ideas and ideals challenged and I found myself craving robust discussions on my professional philosophies on inclusive practice. Inclusive Practice as stated in article 30 of the United Nation Convention on the Rights of a Person with Disabilities of which New Zealand is a member is outlined below –

> Participation in cultural life, recreation, leisure and sport:
>
> 1. States Parties recognize the right of persons with disabilities to take part on an equal basis with others in cultural life, and shall take all appropriate measures to ensure that persons with disabilities:
>
>   (c) To ensure that persons with disabilities have access to sporting, recreational and tourism venues;
>
>   (d) To ensure that children with disabilities have equal access with other children to participation in play, recreation and leisure and sporting activities, including those activities in the school system;
>
>   (e) To ensure that persons with disabilities have access to services from those involved
>
> (United Nations Convention - Right of Person with Disability, Kāhore he rā)

I grew an extra arm each time I held my own in various forums when I heard myself drawing upon theories, referring to research and articulating the latest findings in my area of interest. I can't help but think that my organisation is perpetuating social exclusion especially in that fact that our vision statement is 'An Inclusive New Zealand' - (Halberg Disability Sport Foundation, Kāhore he rā)

My future aspirations are to find the touch stone for what I stand for and find a space that I can practice this on/within. This process will be a positive and heathy platform that will allow me to sound out my theories, come up with a potential framework for practice and generate a personal guidebook that will give me direction for the future of my work practice.



Speak to individuals and families on the challenges that are presented when attending a mainstream event as opposed to a segregated. What can we learn? What can we do differently?

Research the 'Inclusive Schools 2000' mandate and find our how far we have come or have we gone backwards?

Figure 20: Mind Map of Potential Journey of MPP process

7.8 Learning Agreement – Course two

Master of Professional Practice

Learning Agreement:

This Learning Agreement is between a Master of Professional Practice learner – Bridget Meyer and the Otago Polytechnic. The purpose of the Learning Agreement is to help ensure projects are completed in line with student learning goals.

Name of Student:

Bridget Meyer

Facilitator:

Dr Glenys Forsyth

Academic Mentor:

Dr Jo Kirkwood

Title of Project:

'Research the concept of a storing and sharing website for people with high and complex support needs'.

Introduction:

1. Context and background:

I am currently employed as a Lead Adviser for the Halberg Disability Sport Foundation, a role I have been doing for the past 13 years. My core role for the Foundation is focused on breaking down barriers and creating opportunities to encourage people of all levels of ability to participate in sport and recreation in a meaningful way alongside their peers. The strengths I bring to this role are in being innovative as well as being persistent around ways in which we can turn what some people perceive as an obstacle into what I would describe as an opportunity.

The context to which I am basing my Masters on has been formed over my career working within the social service industry and more recently within the disability sector. I have become more and more aware of the number of service organisations and personal that pass in and out of an individual's life each day, month and year. The personnel and organisations I am referring to are teachers, teacher aides, physiotherapist, occupational therapist, personal carers and for some individuals their friends and family.

As this particular project does not align with the core work of the Foundation I am doing it independently of my employer. However, to achieve the necessary outcomes and to ensure the project has support I will be working with CCS – Disability Action Otago with additional support from New Zealand Complex Carers Group.

The opportunity for me is to find a way of using technology through a website where we can capture and share information that is specific to individuals with high and complex needs.

The definition of high and complex needs has been described by the Complex Care Group NZ as:

- Multiple disabilities including sensory disabilities, physical disabilities, severe intellectual disability, or serious and ongoing medical conditions.
- Behaviours that may require a very high level of support.
- A lack of appropriate services or policies to meet their intensive support needs.
- Often unable to voice their needs in appropriate forums due to their severe intellectual and learning disabilities.

https://www.complexcaregroup.org.nz/voice/definintion-document/.

My interest in people with high and complex needs stems from conversations I have had with both individuals and their families, schools and community support organisations, on how information is stored and shared as a child transitions through their school years and post school. For individuals who are unable to advocate for themselves this information can be vital as they work towards creating a meaningful life experiences.

The situation that I have seen within my role revolves around the sourcing of ideas, and the planning and ability to implement these ideas. The time pressures to achieve certain tasks are challenging and things are often done in haste with few resources, training or guidance. The access to previous ideas in which a task may have been achieved with great success may have been archived in somebody's journal or are housed in the memory of a parent, support person, previous teacher or teacher aide. Many times people will think of a way to modify something, it will work well and then they will do nothing with that information. I also witness this regularly among my colleagues as I visit schools to work with young people with various levels of ability and discover the teacher aide working in a separate space from the rest of the class, having been given no information on what the class was about to engage in, few or no ques on what has worked the previous year. Therefore are unable to plan, modify or adapt in any meaningful engagement with the group. The sharing of this information that could potentially bring inclusive opportunities for an individual is often not shared as support staff continue to work in isolation.

The United Nations Convention on the Rights of Persons with Disabilities in article 30 talks about the need "to ensure that children with disabilities have equal access with other children to participation in play, recreation and leisure and sporting activities, including those activities in the school system". Article 30 UNCRPD.5d.

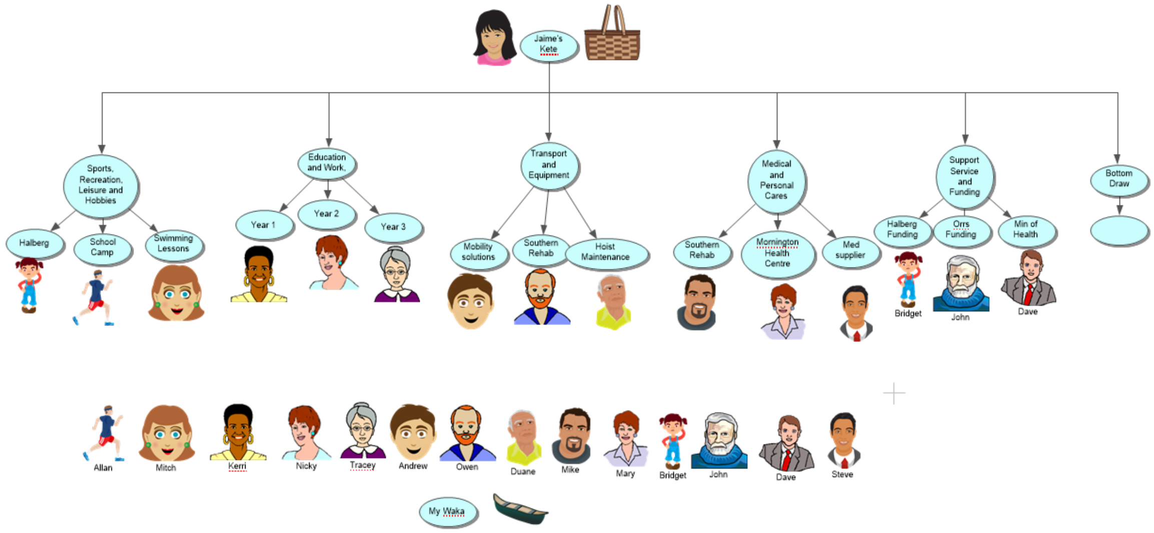
I was attracted to this project because of the repetitive enquiries I have received over my time with the Foundation about how an inclusive or workable opportunity has been created the previous season or year but then this information isn't easily retrievable for others to use.

A recent example of this was a school athlete's day for a young girl who has complex support needs. Rachel* is a young girl who gets a huge amount of pleasure from being included with her able bodied classmates at every opportunity she is given. Rachel is unable to communicate in the traditional sense although she can make her feelings known. Rachel also has limited mobility. I received a phone call from school to say that their athlete's day was coming up and could I join them to help support the teacher aide in ensuring that Rachel was included. In Rachel's first three years of school she had been taken to the school library while the rest of the school attended the athletics day which is held off site. I have received the same phone call for the past 2 years. It appears there are new teachers and teacher aides supporting her each time. Nowhere has it been recorded what modifications were made for Rachel to participate alongside her peers. I believe there is an opportunity here to make an impact within this space. Had Rachel's teacher had easy access to images and ideas from last year's athletics day she would have been able to go into the day with a higher level of confidence on how to deliver a meaningful experience, the correct equipment and perhaps even a goal of looking to beat last year's times/throws. The integrity of the day would have been aligned to all of the other students participating in the athletics day.

The following modifications were made for Rachel:
Whenever Rachel was required to jump or throw something we got her to use a small beanbag the size of her palm. For the long jump her teacher aide moved her chair to the end of the long jump pit and Rachel threw the beanbag into the pit from which the measurement was taken. We used the same idea with the high jump, the teacher aid moved her chair up to the bar and Rachel threw the beanbag over the bar. For the hurdles we lay them down flat and Rachel was able to step over them with support. Rachel experienced great success and a huge amount of encouragement from her classmates. To bring about any form of social change that is long lasting and to work towards building an inclusive community I believe we need to be able to access information easily. This information can often make or break an opportunity for an individual. Meanwhile children are being left behind while their classmates go on school camps, have swimming lessons, excursions to the beach, education outside the classroom modules among other things.

Below is a visual of how the website could potentially work.

- The site is person centered/controlled with different vaults of information housing different areas of a person's life.
- The person would decide the names of each vault.
- Professionals are invited by the person to be a part of the person's network or waka.
- Professionals are given permission to view different areas of a person's life.
- The professional uploads reports, photos, videos, pdf for others to view if permission is given.
- Nothing is shared without permission.
- A physio for example might be invited to view the sport, recreation, leisure and hobbies vault as there will be some relevant information in here, however the sports coach would not be given permission to view the health vault.
- This website would allow for all information to be stored on the one site.



2. Master of Professional Practice – Overall Goal:

Aspirational Professional Practice Statement:

My intention is *"to leave a legacy as someone who advocated and raised awareness of the importance of individual empowerment for people with disabilities"*.

The overall goal of my MPP is to introduce and test the concept of a website that encourages people to store and share information that is easily accessible to people with high and complex needs. In addition I will investigate whether the concept of a storing and sharing website is something that could be supported by the sector and gather feedback on this.

Through this process I will look for solutions on how the rich information that is used to create meaningful opportunities can be preserved for future reference and shared when appropriate.

My goal for the website is to analyse how innate and user-friendly it is to populate with information and administer. I will assess the concept of using a web based platform with various stakeholders within the sector. I am interested to know whether a person centred website would be feasible or whether the site would be required to sit with an organisation. The success of the website will be measured in how instinctive it is to engage with for both the individuals and their support team.

This project will be used to initiate conversations with the wider community on the importance of incorporating technology and encouraging interprofessional collaborative practice. I will research ways we can preserve and future proof the nature of professionals work for those who are unable to advocate for themselves. The project will be a catalyst towards supporting the micro world of people with high and complex needs by using technology with all relevant information being housed in one place and accessed easily at the discretion of the individual or their advocate.

The interprofessional collaboration model of practice within the education setting has been described by Golom and Schreck when "people from two or more professions learn about, from and with each other to enable effective collaboration and improve outcomes" 2017 pg 3. To be a catalyst towards social change I believe that sharing, storing and creating a legacy of meaningful information is important. For individuals who are unable to advocate for themselves the long term benefits of having future proofed ideas and resources through interprofessional collaboration will assist in the building of an inclusive society.

3. Learning Outcomes

1) To test the concept of an information storing and sharing website for people with high and complex needs.

2) Gather feedback and analyse.

3) To reflect upon my practice.

4. Main audience for my project:

There will be three main recipients who will benefit from this project.

1) The individuals with high and complex support requirements.

2) The family.

3) The professionals working alongside - teachers, teacher aids, physios, occupational therapist, sport coaches and personal caregivers.

5. Action Research:

In looking at a number of different research methods I believe this particular project incorporates the main tenets of an action research project. Action research is practitioner based, self-reflective and improvement focused.

Three key components to an action research project that have come to the fore are:

- See a problem that needs a solution.
- Work collaboratively with others to solve problem.
- Motivate to improve the situation.

My reading on research methods pointed most favourably towards action research. Action research involves the researcher and encourages self-reflection as well as delving more deeply into an individual's own practice. An example of the questions I may use are 'what leads me to do the things I do?', 'What shapes the way I practice?'

My plan going forward using the action research model will look like the following:

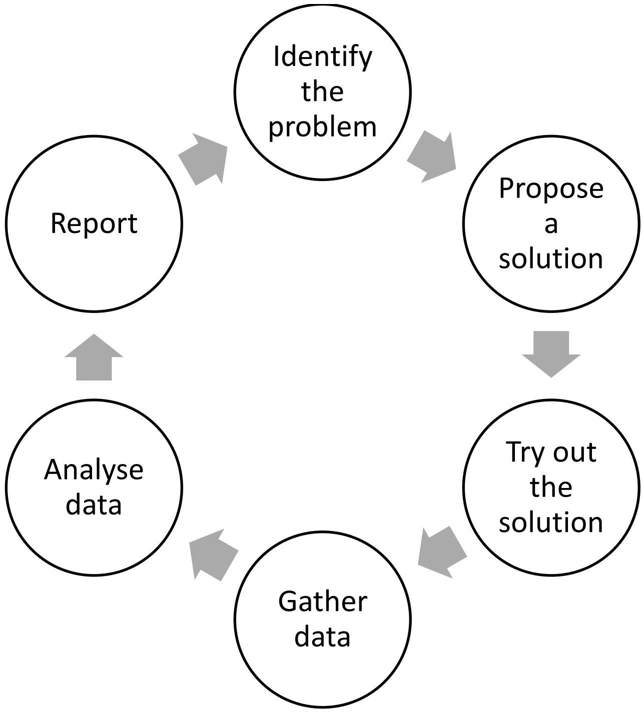


Figure 21: Action research model

1) IDENTIFY THE PROBLEM:

The challenge that I have identified in my years as a practioner is the loss of valuable information among an individual's support network. This problem has also been highlighted in a number of reports and surveys carried out by the New Zealand Complex Care Group.

2) PROPOSE A SOLUTION:

To build a website that allows information to be stored for future reference as well as shared easily among an individual's support network.

3) TRY OUT THE SOLUTION:

Test out the concept of the website with stakeholders.

4) GATHER DATA:

Gather qualitative data from the group and look for common themes.

5) ANALYSE DATA:

Analyse the data and make changes if necessary. Go back to 1.

6) REPORT:

Write up a report with findings.

As a reflective practioner I am looking for a solution that I can share with the sector that will guide and support us to enhance the lives of the people we work alongside.

Project Method:

The method I will use to collect data will be in a qualitative form. Qualitative research will allow me to capture information through a narrative story telling process.

1) I will conduct fifteen interviews. These will be a combination of three individuals with high and complex support needs and/or their advocates. Three primary school teachers. Three teacher aides. Three medical professionals and three personal carers.

2) A ten minute instructional webinar will be shown to the interview participants. Feedback on the webinar will be recorded. There will be set questions.

3) Participants will invited to use the website. Feedback will be recorded. There will be set questions.

4) The interview will be recorded. Each interview will be 1 hour in length.

5) The interviews will be carried out at a convenient time for the interviewee and at a location of their choice.

6) An independent organisation (CCS – Disability Action Otago) will recruit participants to be a part of the research.

7) The qualitative data will be transcribed and the findings and conclusion written up in a report and presented.

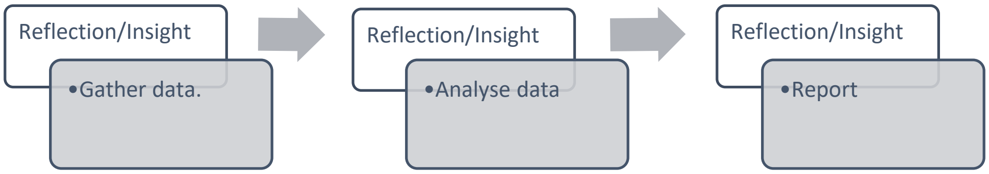
Project Methodology:

Action research methodology will allow me to be both researcher and reflective practioner throughout the project. The action research methodology will also allow me to work in a co-operative partnership with the research participants as well as my colleagues from the Foundation to look for solutions to the identified problems.

As a reflective practioner my awareness of my own biases will be front of mind. An example of bias are in the questions being asked, interpretation of feedback, how you ask questions, consistency in all the interviews.

Jean McNiff describes the action research methodology as "an enquiry conducted by self into the self. You, a practioner, think about your own life work, and this involves you asking why you do the things you do, and why you are the way you are".

I will keep a reflective journal that will shadow the more tangible results of the action research. At each stage of the project I will record my insights on why I thought or behaved in a certain way in conjunction with the steps being taken to carry out the project.



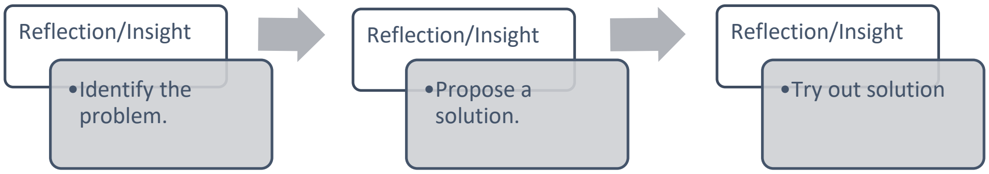


Figure 22: Example of parallel process

6. Ethical process:

My ethics application is being prepared for a category A application.

7. Māori Consultation:

My research does not target Māori specifically although will likely include Māori in the gathering of data. During my research I am also very interested to speak with the Ministry of Education regarding their Specialist Teaching programme called Māwhai. My understanding is that Māwhai is the Māori word web and net. This particular programme is a self-directed learning programme for specialist teachers to share the knowledge with one another in an educational setting only. I would like to gain an understanding of the protocols in regards to using Māori language as metaphors to describe scenarios and certain environments. I will make contact with the Māori adviser at the Otago Polytechnic.

Contact has been made – see below.

Tēnā koe Bridget,
Thank you for your Masters of Professional Practice Capable NZ research proposal. My name is Kelli Te Maihāroa and I will be overseeing your application through the Kaitohutohu Māori consultation process. This email acknowledges receipt of your research application within our office. We look forward to learning more about your research proposal and will be in touch with you soon.

Nāku noa
Nā Kelli Te Maihāroa

Tūmuaki Rakahau Māori Research
Otago Polytechnic
Kelli.temaiharoa@op.ac.nz
T: 021493355

8. Literature Summary:

Introduction:

The framework for this review had been divided into two parts. I had begun the summary review by looking to form an understanding of segregation, the pros and cons of inclusion and then inclusion from a school point of view. For the second part of the review I had begun to narrow in on what will form the foundations of my research project. However, after a reconfiguration on the scope of my project I have narrowed it down to focus on just the key elements and therefore have removed all of part one.

PART 1

1) Segregation and social groupings.
2) Pros and cons of inclusive education.
3) Inclusive education.

PART 2

4) Understanding Interprofessional Collaboration
5) Advocating for individuals with high and complex needs.
6) Lived Experience and empowerment.
7) Using technology in an unspoken world.
8) Transition of knowledge/ Storing and sharing sites.
9) Reflective practice.

Summary Literature Review.pdf

My summary literature review is in this format as I did the orginal review using the reference programme of Endnote and in doing course three I moved to Mendeley due to what was avaiable.

PART 2

9. Sustainable Practice:

My overarching goal or outcome for this project is to test a concept, to house a dossier of tailored information for an individual that they will be able to use over their life time. I will test the concept, listening to the sector and responding to their feedback. The sustainability of this project and my practice within it will be measured in people's response to the concept of the website and their use of it.

I am motivated in my practice to always be looking for sustainable solutions on how we can better serve the population we are privileged to be working alongside.

10. Reflection:

I have begun a journal to capture conversations, emails, readings, my own thoughts and anything else that is relevant to my Master in Professional Practice journey. The journal will be provided as evidence where and when required.

11. Reflective Critical Commentary:

Through my reflective critical commentary journey I am going to be able to describe in detail what I have learnt, how I have learnt, why it matters and how this will influence my practice in the future. I will be able to draw and reflect upon the challenges as they arise and explain the processes that I undertook to overcome these moments. I will be able to describe in detail where my own beliefs and bias have been challenged. My reflective critical commentary will be a method of self-enquiry.

Insight One:

As this is only the beginning of my journey I have only just begun to capture the insights that are occurring alongside the writing up of project II. Already there have been a number of significant moments, particularly as I unravel the many lines of thoughts and the angles I could take with my supervisor. An example of the type of reflection and insight that is currently unfolding is the lofty scope I was initially trying to encapsulate within this project. After much discussion and contemplative thought I was able to see the importance of keeping the focus narrower but going deeper in my line of enquiry and not moving too quickly towards what I want the end result to be. Upon reflection I also understand and believe now that in narrowing the focus will ensure there is clarity.

I will continue to capture my reflective commentary as I move through this process.

(I am keeping a hand written journal of my insights and will add in time).

Insight Two:

Changing Tack…

Insight Three:

Conversation with Shelley at the end of 2017….

Insight Four:

Conversation with Dr Jude MacArthur beginning of 2018 around including the website as part of my research….

Insight Five:

Conversation with Jo and feedback from reviewers –….

Insight Six:

Conversation with Shelley and making it a work based project…..

Insight Seven:

Frustration…Halberg not supportive…back to plan A.

Insight Eight:

Changing tack for the third time….

12. Main outputs from my study:

The main output from this project will be a Practitioner Thesis:

1) The researching of a website based platform concept that will allow information to be stored and shared when appropriate.

13. Key Milestones:

Learning agreement completed	June 2018
Reflective journal started	June 2018
Course three started	June 2018
Interviews	July 2018
Draft of oral presentation	February 2018
MPP oral presentation	March 2018

14. Employer/Professional representative: