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## Chapter 1 – Introduction

Chapter overview: The voices of individuals with significant disability have not been heard within their own transitions and in research on the subject. Furthermore, transition outcomes are dismal. The silences of individuals with significant disability in multiple contexts have made them the “ultimate lost voices” (Atkinson & Walmsley, 1999, p. 203). In this chapter, these concerns are explored within the wider context of transition out of school into adult life most specifically in Aotearoa New Zealand.

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Imagine someone who uses a wheelchair. The fact that the wheelchair is used for mobility is not in and of itself a problem, until the wheelchair-using individual comes to a building and there is no ramp to navigate the front stairs. Or maybe the building has been entered, and then the elevator broke, so the desired floor became inaccessible. Now replace the single building with the entire community students enter after leaving school. And replace the wheelchair with significant disability: significant cognitive impairment, coupled with varying degrees of autism-spectrum conditions<sup>1</sup> (Baron-Cohen et al., 2009). Include also non-verbal communication, vision impairment, incontinence, illiteracy, and antisocial behaviours. Because significant disability is far more complex than using a wheelchair, the issue of denied access goes beyond inadequate physical accommodations. For individuals with significant disability, historical segregation and marginalisation throughout most of the 20th century (Albrecht, 1973) has barred social access and meaningful community engagement.

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<sup>1</sup> The authors favour use of this term because they feel it is less stigmatising, and it reflects that such individuals have not only disabilities which require a medical diagnosis, but also areas of cognitive strength. Furthermore, there is no clear demarcation between multiple conditions.

## **Transition**

The simplest definition of a successful transition from school is that, “the day after graduation should look no different than the day before for the individual exiting the school system” (Certo et al., 2008, p. 89). Yet the complexity of that seemingly simple task cuts across multiple domains (e.g., academic, vocational, interpersonal relationships, health), contexts (e.g., classrooms, workplaces, residential homes), time points (e.g., in-school and post-school), and support systems (e.g., schools, adult agencies, families, community supports; Carter, Brock & Trainor, 2014). For students with, and without disability, transition involves taking on new roles and adapting or changing existing roles (Osgood, Foster, Flanagan, & Ruth, 2005). Transition is more than an administrative procedure, biological life stage, or public policy issue. Transition implies a change in status, both in how we see ourselves and how others perceive us (Dee, 2006).

Graduation is often synonymous with transition. Such a time can be marked by ending school, as well as a beginning of “active citizenship” (Smith, 2013, p. 415) that emphasises community agency, individual autonomy, self-determination, and the right to participate in the social and economic life of the community. Community participation, then, is not only a goal, it is also a “process by which other goals are achieved” (Emerson, 1985, cited in Myers, Ager Kerr, & Myles, 1998, p. 390).

Research literature on transition from school for students with disability is vast. Considered as a whole much is known, and there are two consistent themes. First, transition is typically researched by its outcomes. Outcomes include secondary school completion/dropout rates, inclusion status while in school, and post-school activities, such as enrolment and completion of post-secondary education and training, employment, and moving out from the family home (Certo et al., 2008; Grigal, Hart, & Migliore, 2011; Test et al., 2009; Wagner & Blackbory, 1996). Internationally, transition outcomes for individuals

with significant disability are dismal when compared to their mainstream peers (Rusch, Hughes, Agran, Martin, & Johnson, 2009). Over 70% of youth with disability are unemployed after they finish school, and over 90% live with their parents, mostly in poverty. Likewise, less than 1% of the entire population of persons with severe disability are enrolled in post-secondary education or educational alternatives. When work is found, sub-minimum wages and sheltered employment remain the predominant options (Carter, 2012). Growing waiting lists for entry into support services add further strain to the situation. Many students with the more specific disability label of autism-spectrum conditions, receive intensive instruction in schools, yet this does not appear to translate into success in adulthood (Wehman et al., 2014). The culmination of these challenges and the difficulty to access support, leads to largely unsuccessful transitions (Wagner, Newman, Cameto, & Levine, 2005) and limits opportunities for full participation in adult life (Stewart, 2006).

To address the bleak post-school trajectory that many individuals with disability face, the second noted theme is that researchers have broken down the enormity of transition into discrete chunks. Researchers examine particular aspects of transition, such as the aforementioned transition outcomes. Or researchers hypothesise solutions to improve sub-standard transition outcomes emphasising, for example, quality of life (Halpern, 1985), self-determination (Wehmeyer, 1995), person-centred planning (e.g., Hagner et al., 2012; Holburn, Jacobson, Vietze, Schwartz, & Sersen, 2000; O'Brien & Lovett, 1992), or vocational training (e.g., Butterworth, Hagner, Helm, & Whelley, 2000; Carter, Austin, & Trainor, 2012; Luecking, & Fabian, 2000; Wehman, Brooke, Green, Hewett, & Tipton, 2008). Often the fractured research pieces, whether focused on problems or solutions, are conducted in disregard of putting transition back together as a whole.

While graduation, or the exit from compulsory schooling, can be seen as a momentous achievement for some, for others, such as individuals with significant disability,



the exit from school is more of a process of “aging out” (Osgood et al., 2005). The term “aging out” typically refers to youth exiting childhood into adult services, such as within medical, judicial, or foster care systems. Aging out applies to students who are not graduating school because of merit, completion of standards, or even due to days of attendance. Some students are undergoing the critical life stage of exiting school for no reason other than their age. For this group of students, the process of transition is often overshadowed by low expectations (Holwerda et al., 2015; Hughes, 2008).

### **Silences of Significant Disability**

Research with individuals with significant disability involves fundamental silences. Historically, the silence reflected the marginalisation of individuals with significant disability. This group was considered to have nothing to say and, as such, no one listened (Bogdan & Taylor, 1987). May, Noonan-Walsh, and Simpson (2000) concur that those with disability used to be seen as one dimensional, one sided, with simple life experiences and basic understanding of critical life stages. Booth and Booth (1996) claimed that those most in need of having their stories told may be the least able to tell them. Individuals with significant disability have been considered “ultimate lost voices” (Atkinson & Walmsley, 1999, p. 203).

Silence exists within transition when students’ perspectives are undervalued throughout the process. Thirteen students with disability who were engaged in transition expressed in interviews that they were rarely invited to transition planning meetings (Hetherington et al., 2010). When they were invited, students reported not understanding how to effectively contribute to the planning process. The few students who managed to contribute felt that the transition goals did not match their personal life objectives. Parents described dissatisfaction within planning collaborations. In particular, parents noted that assumptions were made about individuals that led to generalised transition programs rather than

consideration of their child's personal priorities. Thoma, Rogan, and Baker (2001) reported similar results in their in-depth qualitative study of the transition planning of eight students with a range of mild-to-severe disability. Opportunities offered to students in transition were often mediated by the personal judgments of teachers and transition coordinators (Mitchell, 1999).

Amongst some with significant disability, silence is literal. Newman (2007) found that 13% of transitioning students with autism in the US considered communication no trouble at all, 31% had a little trouble conversing, and 38% had a lot of trouble. Eighteen percent were unable to communicate verbally at all. Dennis' (2012) exploratory study to include "non-verbal narratives" in narrative research, found that values and experiences of practitioners pervaded the communications of those with significant disability, with whom they worked.

Even within disability research, participation is often denied to those with more profound impairments. Silence from exclusion of individuals with significant disability from research is often footnoted deep within an article so as to be easily missed. The following is an illustration of a section in which participants were described as quoted,

The reasons the other 154 adults with Intellectual Disability (ID) did not participate included the following: (a) their guardians did not return the consent forms (64 cases, 42%); (b) they were not at work on the days of the interviews (28 cases, 18%); (c) *they did not show an understanding of the consent form, and therefore, their responses were considered invalid (16 cases, 10%)* (d) they no longer attended the workshops (16 cases, 10%); (e) they were mistakenly selected from among people attending non-work day programs (10 cases, 7%); (f) *they were non-verbal (8 cases, 5%)*; (g) there was no explanation made available (5 cases, 3%); (h) they declined to participate (4 cases, 2%), or (i) they had a job as a secondary activity (2 cases, 1%);

and (j) there was a mistake in the selection process (One person; 1%). (Emphasis added, Migliore, Mank, Grossi, & Rogan, 2007, p. 9)

Individuals with significant disability are considered silent as well as actively silenced within society, education, research and their own transitions. “Because of cognitive and communication limitations of young adults with severe intellectual disability, much of our understanding of their transition experiences depends on parent perspectives and contributions” (Neece, Kraemer, & Blacher, 2009, p. 32). Therefore, disability researchers must be willing and able to address all forms of silence.

### **Identity Statement**

My personal experiences as a transition teacher have prompted this research. Prior to my doctoral studies, I worked in special education transition for over 10 years in both Aotearoa New Zealand and the United States. Seven of those years involved working in one of the schools where my fieldwork began, though I had not worked at the school for two years prior to the start of my study. The emphasis of my teaching was focused on community. I attempted to transform the classroom into the very community students would enter after they left school. This was achieved through transition-aged students learning in community spaces (e.g., office blocks and store fronts) instead of traditional classrooms, and utilising community resources (e.g., public transportation, libraries) instead of school buses and school-based resources.

I considered transition to be “successful” when the goals set forth in each students’ transition plans were achieved. Despite the community-based orientation of my teaching, I was concerned with outcomes. I wanted to know the students would end up “somewhere” after they finished school.

I was trained as a special education teacher, and I have predominantly worked in

segregated special schools and self-contained classrooms. By their existence these separate environments reinforce a perceived need for parallel education systems, due to a presumption of inherent difficulties and undesirability of the students therein (Lalvani, 2012).

Thus while we advocate that special education teachers understand the disability studies perspective, they are still employed as agents of an oppressive system of institutionalized ableism where even the laws intended to support their disabled students mire them in non-supportive classifications and labels (Mutua & Smith, 2006, p. 129).

As Slee (2008) stated, the continuation of “irregular schooling” (p. 100) should hold everyone accountable for their personal actions and values that continue to promote segregation. Despite these concerns, I had teaching experiences that put me in contact with a range of students. This made me an insider in a social world that very few know much about (MacArthur, Kelly, & Higgins, 2005).

### **Significant Disability and Aotearoa New Zealand**

In order to define disability, I return to the introductory metaphor of the wheelchair-using individual and the multi-storey building. Looking at this metaphor from a social definition or the *social model* of disability, the steps in the metaphor are the disabling barrier. They restrict both physical and social access, thus disabling the individual. Within a social model line of thinking, a more inclusive society would reduce disability or impediments to disablement, such as by creating buildings with only ramps, or ramps and stairs (Oliver, 1983). The former conception of disability, the *medical model*, still holds significant influence, wherein disability is an inherent and individualised flaw in the person in need of fixing (Albrecht, Seelman, & Bury, 2001). The medical model of disability emphasises the individual's limitations and focuses on ways to reduce those impairments in order “cure, care, and remediate” (Ware, 2001, p. 109). A friction between the two models highlights the need to

focus on factors causing environmental and social exclusion, and envision ways to make Aotearoa New Zealand (Gasson, 2008), as well as all societies (Vehmas & Watson, 2014) more accessible.

Significant disability is synonymous with the classification of low-incidence disabilities, which are considered extremely rare disabilities that occur in less than 1% of the general population. Due to their rarity, each disability has special considerations, modifications, and accommodations (Hallahan, Kauffman, & Pullen, 2009). To pinpoint a specific definition of significant disability, I could use medically based nomenclature found in *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; DSM–5; American Psychiatric Association, 2013). The New Zealand Disability Strategy (2001), however, promotes a social conception, that “disability is not something individuals have. What individuals have, are impairments. They may be physical, sensory, neurological, psychiatric, intellectual or other impairments” (p. 3). Rather, “disability is the process which happens when one group of people creates barriers by designing a world only for their way of living, taking no account of the impairments other people have” (p. 3).

Within the education setting in Aotearoa New Zealand, students with significant disability are not required to have a specific disability label in order to receive special education services (Ministry of Health, 2001). Rather, students externally assessed as being within the highest 1% of significant special need within the general student population have access to funding through the Ongoing Resource Scheme (ORS; Ministry of Education, 2016). Transition programmes for students with access to ORS funding are currently undergoing pilot testing (Office of Disability Issues, 2013).

A central feature of pilot transition programmes is that the ORS-funded student receives one calendar year of facilitated support from a support person subcontracted by the

Ministry of Social Development (MSD). Also called transition coordinator, provider, independent facilitator, or navigator, the support person assists ORS-funded students and their families with major decisions related to transition into the community in the final year of school. Decisions may be about paid or voluntary work, further education, residential living, or community participation. Transition providers are employed by local disability agencies and then subcontracted and paid on a per student basis by the MSD for their services. Transition planning involves setting goals, and developing skills and experiences in order to lay the groundwork for life after leaving high school. Because the transition experience is unique for each student, goals are individualised and transition planning is a team process. Some typical areas of planning include: career planning, supported employment, life skills, further education, cultural support, access to community services (and necessary reassessments for funding), leisure and recreation activities, relationship building, and community access via transportation (Office for Disability Issues, 2016).

I admit to knowing little about Aotearoa New Zealand when I first arrived in the country in 2001. I will err on the side that readers may require a brief overview of what community life might look like beyond the stereotypes of; green rolling hills with sheep (or hobbits) running down them, rugby and the All Blacks, and kiwi, birds that can't fly. Or maybe those a bit more politically inclined might know that Aotearoa New Zealand was the first country to give women the right to vote, and that the most recent female Prime Minister, Helen Clark, is now the Administrator of the United Nations Development Programme.

Aotearoa New Zealand is made up of two main islands in the South Pacific, with a combined physical size similar to the US State of California. The country has a population (at the time of writing in late 2015) of 4.471 million and growing, edging towards the population of Ireland, for example. Aotearoa New Zealand is considered both bi-cultural and multi-cultural. Bi-cultural populations are those of European descent (69% identify as Pākehā, a

Māori term for New Zealand European) and indigenous Māori (14.6 percent). The largest multi-cultural components of the population include Asians, who make up 9.2%, and non-Māori Pacific Islanders 6.9% (Statistics New Zealand, 2013). English, Māori, and New Zealand Sign Language are the three official languages. English is predominant, though Māori language is often incorporated into popular culture, such as music, as well as place names; therefore, Māori terms and names will be used throughout the thesis unless describing a specific document or agency.

Aotearoa New Zealand is a developed country with a market economy. Chief exports are dairy, meat, wine, and tourism. The country ranks highly in international comparisons of economy, freedoms, peace, and quality of life, and has a solid reputation for health care and education. The country operates under a democratically elected parliamentary system with executive power held by the Cabinet led by the Prime Minister, currently John Key<sup>2</sup>, a National (conservative party) member.

### **Possibility-based study**

A first reading of the title, “Transition with Dignity,” may suggest that this thesis will be about positive, successful, and dignified transition outcomes for individuals with significant disability. This is not the case. Life experiences are rarely so clear cut, and the young men’s experiences were no exception. As will be described in detail in the forthcoming chapters, the aim of this study was to walk alongside ordinary transitions; transitions that were not selected for being exemplary in any sense. Use of the term *dignity* first and foremost signals the importance of the theoretical framework of the study, the capability approach, which will be further described in the literature review chapter.

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<sup>2</sup> As of 12 December 2016, Bill English serves as Prime Minister since John Key surprisingly stepped down.

The intention of term dignity is not to refute the young men's experiences. The title has an aspirational purpose. A transition with dignity is the goal, dream, and aspiration of this research, and while it was not always the experience lived by the young men in this study, it is argued that dignity remains a viable opportunity for future transitions. Essentially, the title is an acknowledgement of possibility. As such, the dignified language marks a "...shift from language as description to language as action" (Gaffney & Anderton, 2000, p. 76). The possibilities of what transition *can be* are brought to the fore, given much needed exploration and consideration. In doing so, this study is positioned not as problems-based research (e.g., Ellis & Levy, 2008) but as *possibility-based* (Gaffney, 2013).

### **Thesis Synopsis**

Transition for individuals with significant disability be explored through multiple perspectives. The specific objective was to understand transition from the perspective of those living the experience. The varied silences inherent in significant disability means that little is known about *lived* perspectives, particularly on critical matters such as transition and significant life changes.

A second key aspect was the urgent need to address transition as more than dismal outcomes. In order to reframe the topic, a capability framework, novel to the study of transition was applied to the setting of Aotearoa New Zealand. A country known for meeting and often exceeding human rights standards, and for its contribution to the development of international human rights treaties and covenants (Kearney, 2016), yet with minimal empirical studies of transition for students with severe disability.

Data for this study was collected over 6 months, three months bestriding either side of the progression from in-school to post-school life. The lived experiences of three young men transitioning from school guided ethnographic fieldwork. Specific methodological



adaptations were made to collect, understand, and interpret their voices and perspectives. Deductive analysis framed by the capability approach (Nussbaum, 2000; Sen, 1999) involved noticing and naming young men's personal capabilities, then reviewing the way they informed each transition. Through a further analysis using an inductive approach, two themes emerged that impacted the three transitions: *trailing* post-school options, and a lack of collaboration between transition partners referred to as *silos*.

If a society is able to think through and successfully confront issues of disability, doing so will make it more compassionate, more secure in its sense of community, and more understanding both of human vulnerability and dependence and of human nature and potential (Wolff, 2009, p. 148).

This study introduces the Aotearoa New Zealand context to the extensive international body of transition literature through amplifying unheard voices. In doing so, personal perspectives can strengthen far more than individual transitions. Working together with each young man to investigate transition holds possibility for advancing research methodology, theoretical frameworks, social policy, and our society.

## Chapter 2 – Literature Review

Chapter overview: The counter-narrative of transition, alternative and lesser considered conceptions of the topic, can best be appreciated in light of the master narrative, commonly held values, beliefs, and perspectives. The master narrative of transition is portrayed in the United States, where transition has been federally mandated for over 30 years, including internationally influential frameworks, interventions, and large-scale, longitudinal research. Then, three domains are positioned for their ability to conceive transition differently: (a) studies on students' perspectives about their own transition; (b) the capability approach, a novel framework through which transition is viewed; (c) Aotearoa New Zealand as country where transition is seen less as procedural steps for the exit from school, and more about a person's future within an inclusive society. Research questions are aligned with the argument arising from the reviewed literature, and culminate in a counter-narrative of transition.

### **Master Narrative and Counter-narrative**

Master narratives or dominant discourses (Mishler, 1995) frame individual and societal beliefs, experiences, and values. For example, the master narrative of disability being understood as different from 'normal' functioning, essentially the medical conceptualisation of disability, has led to physical and social exclusion of many with significant disabilities (Harter, Scott, Novak, Leeman, & Morris, 2006). Silences of disability, as previously articulated, have been the historical master narrative of disability.

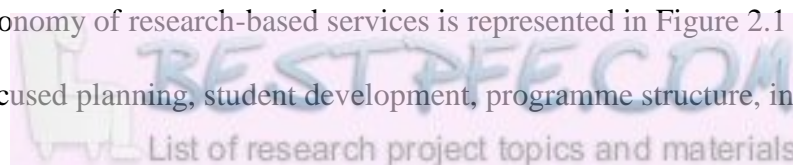
The counter-narrative is an argument that disputes commonly held beliefs or truths. Counter-narratives do not erase historical master narratives. Rather, counter-narratives give voice to those who otherwise are not commonly heard, and additionally, share novel points of view not often considered (Lindemann-Nelson, 2001). Essentially, counter-narratives can offer a new way of thinking about topics, such as transition.

Counter-narratives of transition can best be appreciated, however, in light of a master narrative. Therefore, a master narrative of transition will be articulated by way of the United States (US) where transition has been federally mandated for over 30 years through Individuals with Disability Education Act (IDEA) and prior, by the Education for All Handicapped Children Act. During this time, seminal frameworks to conceptualise transition have been brought forward, such as Quality of Life (Halpern, 1994) and Kohler's transition taxonomy (1996). Additionally, widely researched transition interventions of person-centred planning (Holburn et al., 2000) and self-determination (Wehmeyer, 1995) have dominated transition practices. Nicely bookending these frameworks and interventions are two waves of the largest scale study of transition for individuals with disability, the National Longitudinal Transition Study (NLTS and NLTS-2).

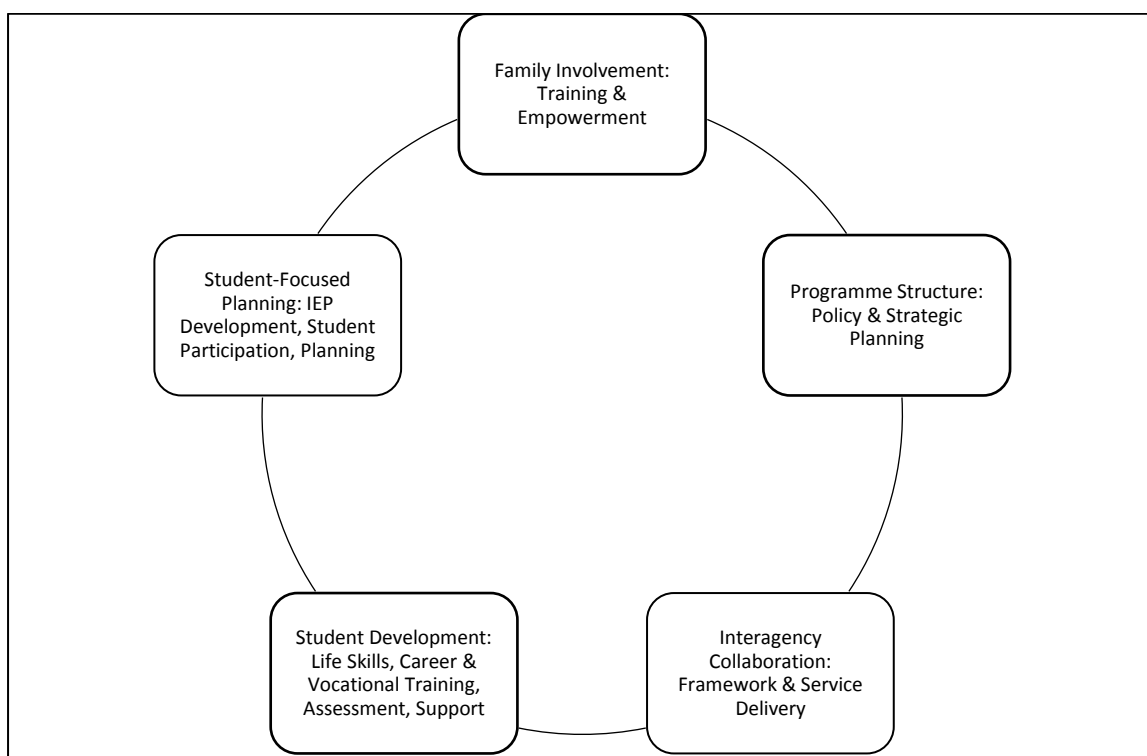
### **Constructing a Master Narratives of Transition**

In order to collect and critically analyse the vast body of transition research from the US, a systematic review was conducted guided by Kohler's transition taxonomy (1996; Kohler, Gothberg, Fowler, & Coyle, 2016). In identifying relevant work to include for review, care was taken not to prioritise one transition outcome over another (e.g., employment, post-secondary education). Multiple resources were searched, including articles referenced by Kohler et al. (2016), and Google Scholar searches on five primary-practice taxonomy categories (Kohler, 1996). Where relevant, empirical research is described alongside nationally representative outcomes data by way of findings from the NLTS and NLTS-2. The first wave, NLTS, tracked 10,369 youths in 1985 who were, at the time, between the ages of 13 to 16 years old. The second wave, NLTS-2, focused on a sample of 11,276 students exiting school in 2000. Each study followed students for 10 years.

Kohler's taxonomy of research-based services is represented in Figure 2.1 and includes: student-focused planning, student development, programme structure, interagency



collaboration, and family involvement. The five interconnected areas encompassed all aspects of education, and included a basis for planning, evaluating, and promoting transition effectiveness. Kohler viewed transition planning not as a part of transition, but as a required foundation. Since it has been found that post-school outcomes improve when students with disabilities, educators, families, community members, and organisations, all work together to implement a broad perspective of transition planning (Kohler et al., 2016), Kohler's five primary-practice categories frame this review of transition literature.



*Figure 2.1.* Taxonomy for transition planning.

Adapted from *Taxonomy for Transition Programming: Linking Research and Practice* (p. 3), by P. D. Kohler, 1996, Champaign: University of Illinois.

### **Student-focused planning.**

Student-focused planning involves individualised education plan (IEP) development, planning, and student participation, and was considered the centrepiece of Kohler's taxonomy (Cobb & Alwell, 2009). Cobb and Alwell (2009) conducted a systematic review of 31 studies involving 859 youths with a wide variety of disabilities using Kohler's transition taxonomy.

Findings showed student involvement in their own transitions improved transition outcomes for youth with disabilities. Student involvement, however, is challenging to achieve in practice. Challenges, similar to the difficulties of centralising students within their own transition planning (Hetherington et al., 2010), have also been found within IEP meetings (Martin et al., 2006). Across 764 IEP team members within 130 middle- and high-school transition IEP meetings, it was found that “without specific IEP meeting instruction, students attending their meetings do not know what to do, do not understand the purpose or what is said, and feel as if none of the adult participants listen to them when they do talk” (p. 300).

Grigal, Test, Beattie, and Wood (1997) evaluated the transition components of IEPs for 94 students between the ages of 18 to 21 years with mild-to-moderate mental retardation and emotional/behavioural disorders. The authors compared the documents with policy mandates, such as IDEA. Although the majority of transition components complied with policy, they lacked elements reflective of best practice. More specifically, transition plans stated goals in major outcome areas (education, training, employment, recreation, and residential), however the quality of the plans in those areas was ranked only adequate to minimal. Most included vague transition plan goals, such as “will explore jobs” or “will think about the best place to live.” Overall, the goals did not provide the transition team with specific process steps to facilitate students’ successful entrance into their adult life.

In another study, an analysis of transition plans for students with disabilities was conducted across 24 school divisions in the state of Virginia for 84 public school students, ages 14 to 21 with significant disabilities (Getzel & deFur, 1997). Findings showed 15% of students with significant disability were involved in the development of their plans, though only a third of the total sample were present at their own IEP meeting. Such participation rates were found to be significantly lower than for students with mild or moderate disabilities.

Taken together, studies on IEPs show that participation and attendance of students with significant disability at meetings is rare and the planning for transition is vague.

### **Student development.**

Student development involves the following domain areas: assessment; academic skills; life, social, and emotional skills; employment and occupation skills; student supports; and instructional context. Data on these domains come from NLTS presented in numerous formats: (a) for the collective group of students with disability, (b) for a range of disability classifications that culminate in a close approximation of significant disability, and (c) comparisons between NLTS and NLTS-2 to demonstrate changes over time.

*Assessment and academic skills.* NLTS-2 used two indicators to assess the academic performance of students with disabilities: course grades, and the perceptions of general-education teachers in academic classes of how well students with disabilities “kept up” with their whole class. Overall, good grades were common for many students with disabilities. Almost one-third (30%) of students with disabilities received grades considered “mostly As and Bs.” In contrast, 8% of students with disabilities received “mostly Ds and Fs.” Thus, the majority of students progressed in a satisfactory manner while in school. Failure to meet academic standards was uncommon. According to their teachers, virtually all students with disabilities who took academic courses in general-education academic classes were expected to keep up with the assignments and grading expectations of the class. In reality, almost three-fourths of students with disability were perceived by teachers as successful in keeping up, with 26% of students with disabilities failing to meet teachers’ expectations in general-education academic classes. These findings, however, varied significantly by disability category. For example, students with mental retardation, autism, traumatic brain injury, or multiple disabilities, had significantly lower grades than peers with learning disabilities.

***Life, social, and emotional skills.*** Focusing on students classified in NLTS-2 with autism, self-report data on their personal transition experiences revealed a sombre picture. Youth with autism agreed less than any other disability category with the statement “you can handle most things that come your way,” with only 39% feeling this was “very much like me” as opposed to highest category, 73% of those with visual impairment. Enjoyment of life for students with autism was also the lowest of all disability categories: 43% stated “most of the time,” as compared with those with traumatic brain injury ranking highest with 66%. Youth with autism reported they could get school staff to listen to them only 56% of the time, as opposed to 73% (highest) of deaf-blind students. Autonomy scores in the domains of personal autonomy, autonomy in career planning, self-realisation, and psychological empowerment were all ranked the lowest by youth with autism. Agreement with the statement “you can make friends easily” was thought to be “not at all like me” by 20% of youth with autism, the lowest score, compared to only 3% of those with learning disabilities. Perceptions of feeling cared for by their parents (76%) and friends (38%) was lowest for youth with autism. Finally, youth with autism had the lowest self-expectations of paid employment and financial independence, yet their actual employment outcomes were in the middle of the other disability categories, though they earned the lowest hourly wage.

***Employment and occupational skills.*** In the post-school phase of transition, data taken four years after completing school was compared between the two NLTS studies for all disability classifications. The number of students with disability attending post-secondary education increased in the NLTS-2 study (26% in 1990 vs. 46% in 2005). Completion rates, however, for those post-secondary education courses remained low and had not increased (17% completion in 1990 vs. 18% completion in 2005). Further, dishearteningly, little improvement over time was demonstrated in relation to employment for individuals with disability. Figures compared between 1990 and 2005 include: employment status (62% vs.

56%), job duration (15 months vs. 13 months), average wage (\$9.10 vs. \$9.00 adjusted for inflation), and health insurance received (52% vs. 33%). Essentially, despite an increase in enrolment into post-secondary education, education has not led to an increase in employment. If anything, the situation has worsened.

Again, occupational-skills outcomes differ dependent upon disability label. NLTS-2 tracked two disability categories it considered to be low incidence (i.e., affecting less than 1% of the population): traumatic brain injury and deaf-blindness. Data were combined with statistical information obtained from Social Security Administration and U.S. Department of Labor (University of Northern Colorado, 2006). In school, students with low-incidence disabilities were educated outside the general classroom for at least part of their day. Less than 50% graduated with a diploma and less than 20% received a certificate of attendance. Despite these findings, students with low-incidence disabilities were found to go on to post-secondary education, but at a lower rate than other disability classifications. Related to employment, between ages 18-24, 30.9% of those with low-incidence disability were employed, compared to 84.7% without disabilities. This group accounted for 36.7% of those receiving Supplemental Security Income at an average amount of \$384 per month. Between 13.1% and 44.5% of youth with low-incidence disabilities participated in one or more community groups. More than 75% of those out of school lived with a parent or guardian.

***Student supports.*** Returning to students with autism, more than 70% of secondary students received a variety of related services as part of their special-education programmes. Common services included: speech-language therapy (received by 67% of those with autism), specialised transportation services (54%), adaptive physical education (51%), behavioural interventions (35%), occupational therapy (24%), communication services, psychological or mental-health counselling, social-work services (22%), health services (14%), and physical therapy (6%). The related services and supports provided to students with autism were



coordinated and integrated into a student's overall educational program. To facilitate this coordination and integration of services, a case manager was assigned to almost half (45%) of secondary students with autism.

***Instructional context.*** Continuing the focus on secondary students with the disability label autism, 62% took at least one general-education course in any given semester, whereas 86% took at least one course in a special-education setting. Over three-quarters of students with autism attended at least one course in self-contained classrooms. Self-contained classrooms had low student-to-staff teaching ratios with, on average, three students per adult, compared with 10 to 22 students per adult in general-education academic classes.

In summarising the student development taxonomy category, and subsection of assessment; academic skills; life, social, and emotional skills; employment and occupation skills; student supports; and instructional context, NLTS data has demonstrated that despite the significant support and the relative success of those supports within school, post-school adult life is often bleak for those with significant disability. Additionally, for some students, such as those with the disability label of autism, many hold concerns over their post-school life. A reoccurring theme across NLTS data and other literature, is the existence of a vital disconnect from in-school to post-school.

#### **Interagency collaboration.**

In a review of literature identifying recommended transition practices, collaborative planning and formally sharing resources was considered one of four critical elements for improving outcomes for youths with disabilities (Morningstar, Kleinhammer-Tramill, & Lattin, 1999). Interagency collaboration requires a collaborative framework for those involved in transition planning and service deliveries (i.e., student, parents, educators, service providers, community agencies, post-secondary institutions, employers, and relevant stakeholders).

Devlieger and Trach (1999) found that the factors of interagency collaboration and support for individual students in transition and their families were very important. With sufficient support, transition goals were achieved, however insufficient support impedes goals.

Noonan, Morningstar, and Erickson (2008) held telephone focus groups with transition coordinators in 29 high-performing districts in the US. Three barriers to collaboration were identified: disagreement between transition planning team members, lack of understanding about each of the roles within the transition planning team, and dominance of particular members. Effective interagency collaboration, was considered to occur when practitioner, administrative, and state levels were all involved.

Further exploration of the first barrier to effective collaboration, disagreement within transition teams, found each transition team contributor prioritised different aspects of transition, and compiled different information about students' abilities and support needs (Meadows, Davies, & Beamish, 2014). The second barrier, lack of understanding about each of the roles, was addressed by Noonan et al. (2008) who found that transition coordinators were a critical contributor to transition, but no clear distinction existed between that role and the role of secondary special educators. Finally, the third barrier to interagency collaboration was explored by Cooney (2002), who examined nine transition cases of students with significant disability across the perspectives of the students, parents, and school professionals. Findings revealed that although both parents and professionals worked in the best interests of young adults' outcomes, their overall inability to collaborate across diverse perspectives hindered the quality of the transition process. Additionally, Carter et al. (2014) found distinct divergence between parents and teachers with regard to transition-related strengths and the needs of transitioning students.

Interagency collaboration remains a fundamental challenge for educators in the US (Noonan, et al., 2008). In IEP meetings of transition-aged students, teachers have been found to dominate. Martin et al. (2006) used momentary time sampling within 109 IEP team meetings and found special-education teachers spoke the most, during 51% of the sampled intervals. Also using the sampling approach, earlier research by Vacc, Vallecorsa, Parker, and Bonner (1985) found teachers and parents spoke for a similar amount of time. Of note, 33% of parents' contributions were considered to be passive, considerably different from teachers' contributions, considered passive for only 3% of the time. Likewise, Ruppert and Gaffney (2011) analysed an IEP meeting with a focus on decision-making processes and outcomes for a 5-year-old boy on his transition to school. School professionals strongly dominated the meeting, though the special-education teacher only spoke for 4.3% of the analysed time intervals. In this study, the teachers' influence was found to be more informal, for instance, in communication leading up to meetings that impacted tacitly-held beliefs, and, in turn, educational decisions.

Effective interagency collaboration often eludes the transitions of those with significant disability. This is of concern, because the collaboration of those who come together to guide transition is essential. Fragmented teamwork and individualised processes impede effective transition planning towards successful post-school goals.

### **Family engagement.**

Family engagement in transition is intended to ensure their involvement, empowerment, and preparation, yet the evidence suggests that it more commonly evokes considerable stress. In a study by Mellon, Wilgosh, McDonald, and Baine (1993), 12 parents of transitioning individuals with significant disability participated in in-depth interviews qualitative interviews in order to identify the types of stresses they experienced. Six themes emerged related to: uncertainty about the future, transition to new services, lack of services or options,

advocacy, physical maturity, and individual vulnerability. The authors linked effective, transition services with family satisfaction.

Neece et al. (2009) also examined parents' perspectives of transition for 128 young adults with severe intellectual disability, and suggested that transition satisfaction was related to young adult, family, and environmental characteristics, with environmental characteristics (a broad range of variables related to school programming and service quality, such as young adult work experience while in school and development of a transition plan) being the strongest predictors of transition satisfaction. Transition marked an especially stressful time for the families of these young adults, who often experience a sudden change, or decrease, in services. Considerable family stress and anxiety was found to loom over the processes of transition for their child.

#### **Programme structure.**

Programme domains include: programme characteristics, evaluations, strategic planning, policies and procedures, resource development and allocation, and school climate. Returning to NLTS data, comparisons over time between the two NLTS studies showed that students within the most recent cohort were more likely to take general-education courses in general-education settings. In the NLTS-2 study, seven in 10 secondary school students with disabilities took at least one academic course in a general-education class. Mainstream students focused more heavily on academic courses, compared with students with disabilities (16.1 academic credits vs. 12.7). Students with disabilities earned more vocational and non-academic credits than did students in the general population, but only by a minimal 1% difference. Ninety-six percent of students with disability took a vocational course, and 100% of those with disability took a non-academic course (e.g., life-skills). With a diminished number of vocational-skills course offerings found between NLTS and NLTS-2, divergent

student experiences predominantly focus on academic or non-academic courses with little in-between.

Another shift between the two NLTS studies was decreased student participation in special schools. The drop in special-school attendance went from more than 6% to about 2.5%; however, the numbers of students in special units or self-contained classrooms within mainstream schools increased. Correspondingly, a 3% increase was found in students with disability who attended mainstream secondary schools. Importantly, schools attended by NLTS-2 students with disabilities were much more likely to have self-contained special-education classrooms as a placement option than had been true for the first cohort of NLTS students. Thus, there is a trend for more students with disability to be prepared for transition from special classrooms within mainstream schools.

Taken together, the contemporary picture of transition as framed by Kohler's taxonomy (1996) is complex. The changes between NLTS and NLTS-2 demonstrated some improvements over time (e.g., the number of students with disability attending post-secondary education increased 20% between the two NLTS studies), yet those changes applied to some youth more than others. Overall, the NLTS studies indicated that there is just as much diversity within disability categories, for example between autism and the low-incidence disabilities of traumatic brain injury and deaf-blindness, than between those with and without disability. The complexity is further compounded by what those involved bring to transition planning, the emotions of family, and the challenges in interagency collaboration found for teachers. In summary, a fundamental problem exists in struggle to transfer in-school successes to post-school, but the picture thus far reveals little in the way of solutions.

### **Seminal transition interventions.**

A review of transition would be incomplete without describing the two seminal transition interventions of person-centred planning and self-determination. Each comes with a legacy of supported evidence and proven effectiveness in supporting students with disability in transition. The field of transition, on the whole, has been greatly influenced by each.

Person-centred planning has been used since the 1980s as an important tool for the planning and delivery of transition services for individuals with disability (Holburn et al., 2000). This “family of approaches” (O'Brien & Lovett, 1992, p. 5) has focused on interdependent planning and delivery of transition services to young adults with significant disability (Kim & Turnbull, 2004). While the aim of person-centred approaches is to respect the uniqueness of every student in transition, only family participation in planning meetings has been found to improve, with student participation remaining limited and unvalued by professionals (Hagner, Helm, & Butterworth, 1996). More recently, however, person-centred approaches have been found to promote awareness and communication of student transition preferences (Hagner et al., 2012). With a mixed picture of effectiveness, some have argued there has been an overreliance on person-centred planning, as organising day-to-day activities, but neglect of the importance of finding ways for individuals with disability to hold more distinguished, valued roles within society (Kendrick, 2003).

Switching the emphasis to promotion of agency within the individual, self-determination is a,

dispositional characteristic manifested as acting as the causal agent in one's life. Self-determined people (i.e., causal agents) act in service to freely chosen goals. Self-determined actions function to enable a person to be the causal agent in his or her life. (Shogren et al., 2015, p. 582)

Wehmeyer (2015) asserted, “We have as strong an evidence base for the importance of self-determination to successful school and post-school outcomes as we have for any ‘transition’-related practice” (p. 21). Yet, promotion of self-determination within schools remains as a “fringe activity,” not prioritised within wider curriculum (p. 21). Wehmeyer reasoned this may be due to continued emphasis upon what students cannot do, over what they can. This concern comes long after Wehmeyer’s (1998) clarification of self-determination for individuals with significant disability where he stated that historical misinterpretations of self-determination have led to unfortunate outcomes such as teachers’ insistence upon independent performance, absolute control, and unwavering success from students.

Taken together, person-centred planning and self-determination are individualistic interventions structured with an assumption that their use contains the answers to what people need. However, an idea for post-school life does not exist within a vacuum, and does not infer support through resources, services, or society. Furthermore, the premise of each intervention is to build upon what individuals have experienced and are known to enjoy, on the supposition that previous experiences have been fully explored.

Each intervention has been advocated for decades, with long and rich histories in research and informing practice. Combined with Halpern’s (1992) conception of quality of life in transition, and Kohler’s taxonomy (1996), each approach to transition existed concurrently with the two waves of NLTS studies in the US. Collectively, the various transition conceptions and interventions hold a substantial legacy within research and continue to influence transition practice. Yet, Rusch et al. (2009) stated:

Despite efforts over the past two decades to improve post-high school outcomes among youth with disabilities, these youth continue to experience dismal outcomes, including high rates of unemployment, incarceration, and financial dependence,

concurrent with low rates of enrollment in college or other post-secondary education alternatives. In short, youth with disabilities continue to face an uncertain future as they exit high school in spite of 25 years of transition-related legislation directed at improving post-high school outcomes for this population. (p. 53)

### **Transition research.**

Lastly, there is a noted incongruity between the complexity inherent in transition and the master narrative of predominantly quantitative methods used to research the topic; methods known to be limited in their ability to embrace and reflect such intricacies. A literature review conducted in Canada of 500 published articles from 2000 to 2008 established transition as a “complex phenomenon leading researchers to study interactions of person and environment, as well as dynamic processes, opportunities, and other complexities” (Stewart et al., 2010, Conclusion para. 1). In 2013, two literature syntheses evaluated 581 articles, published in 76 issues from 1978 to 2012, of the transition-related journal *Career Development and Transition for Exceptional Individuals* (CDTEI) for type of research methodology and topic focus. Methodological trends in transition research over the last 35 years indicated that 80% of studies were categorised quantitative and descriptive (Carter et al., 2013). Furthermore, the history of the CDTEI journal revealed an evolution from an early focus on career development for young adults, which expanded to wider foci on transition-related topics, but with a corresponding dearth in certain areas such as career development and post-school settings (e.g., post-secondary education; Madaus et al., 2013).

A systematic literature review of journals outside of CDTEI since 1990 confirmed gaps in transition literature (Cushing, Athamanah, Parker-Katz, Walte, & Posey, 2016). Challenges to the conduct of quantitative research within naturalistic settings have led to some transition topics being researched more than others. For instance, the authors reasoned they found many more studies on transition planning and self-determination because those



domains were studied in classrooms where conditions were relatively easy to manipulate. Less common were studies that focused on family and community because they involved interconnected dynamics difficult to tease apart. Furthermore, little research attention was given to other topics considered pivotal to transition, (e.g., interagency collaboration and student involvement). Even when successful transition factors were established, it was not clear which combination of elements made the most difference (Stewart et al., 2010).

### **Exploring Counter-narratives of Transition**

The counter-narrative of transition unearths lesser considered notions of transition through review of three bodies of literature. First, transition is understood through the perspectives of students living the experiences themselves. Next, the capability approach (Sen, 1980; Nussbaum, 2000) is described as a novel theoretical framing of transition. Lastly, transition practices are examined in the setting of Aotearoa New Zealand. Research questions are provided to directly align to the arguments arising from the reviewed literature.

To begin the pursuit of a counter-narrative of transition two definitions juxtapose current understanding. First, a comprehensive definition of transition adopted by the Council for Exceptional Children's Division of Career Development and Transition in the US. In this definition, a sequence of processes leads up to school leaving, and beginning of post-school life.

Transition refers to a change in status from behaving primarily as a student to assuming emergent adult roles in the community. These roles include employment, participating in post-secondary education, maintaining a home, becoming appropriately involved in the community, and experiencing satisfactory personal and social relationships. The process of enhancing transition involves the participation and coordination of school programs, adult service agencies, and natural supports within the community. The foundations of transition should be laid during the elementary

and middle school years, guided by the broad concept of career development. Transition planning should begin no later than age 14, and students should be encouraged, to the full extent of their capabilities, to assume a maximum amount of responsibility for such planning. (Halpern, 1994, p. 117)

In the second definition, transition is seen as a critical life stage, which isolates students with disabilities from society through a progression of failures.

In the natural course of their lives, as people with disabilities migrate from one service industry landscape to another — for example, from education systems to community service systems — they are said by professionals to engage in a process of transition. Like other social service and educational industry processes, the transition from special-education services to supports received in community settings has been commodified and reified, a process controlled by educational and human service professionals, meeting the needs of the industries that they represent, guarded and surrounded by the boundaries of normative landscapes, and serving to keep people with disabilities isolated within social geographies characterized by segregation, institutionalization, and poverty (Smith, 1999a). (Smith & Routel, 2010, para. 3)

Transition implies a change in status, both in how we see ourselves and how others perceive us (Dee, 2006). Thus, a transition deemed to be successful encompasses many life domains. Halpern (1985) argued that employment alone was too restrictive to be the sole outcome of transition, and studies of transition should encompass all appropriate dimensions of adult adjustment and involvement in the community. He refocused emphasis on making transition work in the community, which he defined as “a period of floundering that occurs for at least the first several years after leaving school as adolescents attempt to assume a variety of adult roles in their communities” (Halpern, 1992, p. 203). Floundering was seen as necessary step, encompassing all the highs and lows of establishing a path towards adulthood.

Through his focus on the multidimensional nature of transition, he offered quality of life as a way of evaluating transition through three basic domains: personal fulfilment, physical and material wellbeing, and performance of adult roles.

### **Student Perspectives of Transition**

There has been little examination of the perspectives of individuals with disability about their transition experiences. The experiences of a group of 20 young people were collected during their transitions (MacIntyre, 2014). Findings illustrated that young people did not lack the motivation or work ethic to participate in employment, but they faced structural barriers. For instance, in a currently unstable economic climate, MacIntyre suggested that citizenship be seen as more than economic contributions and financial independence.

Another finding from focus-group data in the US on students' perspectives of their own transition, revealed that students reported the IEP process to be irrelevant to supporting their transitions (Morningstar, Turnbull, & Turnbull, 1995). Students indicated that school-based vocational training was not as important to them as family influence. Students reported that families supported and influenced their choices in areas such as career and lifestyle. Additionally, students reported they wanted to live close to their families. Yet, planning for such priorities was not evident.

On the community side of the transition progression, 28 adult, Aotearoa New Zealand vocational-service users collaborated in a participatory action-research project to develop shared understandings of community participation. Findings were that transition towards an integrated community required two-way interactions. Yet, participants more often experienced social inclusion considered "unidirectional" (Hornby & Witte, 2008, p. 60). Those with disabilities felt they made an effort to journey into mainstream contexts, but

failed to see reciprocal efforts by community members, “without any expectation that non-disabled people need to make the return journey” (p. 60).

A relatively small number of studies are focused on the experiences of transition from the perspective of those living the experience. Collectively, the extant studies report that the most vital voice of transition is often the least heard. Additionally, attempts at societal inclusion are perceived as one-sided, with the bulk of the effort made on the part of those with disability and reciprocal effort from non-disabled community members lacking. In light of these silenced voices, the first research question asks,

What are the perceptions and meanings of transition experiences for individuals with significant disability?

Undergirding this question is the foremost assumption that individuals with significant disability have a story to tell, that they have the capability to tell it, and that we as researchers, citizens, and human beings, have the capacity and need to hear it. Aligned with this assumption, a range of qualitative data-collection tools were reviewed and considered, as well as the epistemological positioning of inclusive research typically guiding such research approaches.

### **Inclusive research.**

The umbrella term used to collect and describe disability perspectives is inclusive research, with subtypes known as participatory research and, specific to disability studies, emancipatory research (Walmsley, 2001). The emancipatory paradigm and emancipatory research is aimed at addressing address the imbalanced power relationships between researchers and participants in disability research.

Emancipatory research is about the systematic demystification of the structures and processes which create disability and the establishment of a workable ‘dialogue’

between the research community and disabled people in order to facilitate the latter's empowerment. To do this, researchers must learn how to put their knowledge and skills at the disposal of disabled people. (Barnes, 1992, p. 122.)

Critical questions to evaluate whether research is emancipatory include:

Who controls the research? How have individuals with disability been included in the research process? What opportunities exist for individuals with disability to be critical and influence the research's future directions? What happens to the products of the research? (Zarb, 1992, p. 128).

One of the key challenges in emancipatory research is the notion that individuals with disability have central control over the research, from construction and consent to funding and dissemination of results (Zarb, 1992). Furthermore, Shakespeare (1996b) believed there is a difference between accountability to one's research subjects, and accountability to the disability movement or specific organisations within it. He noted predominance of disability advocacy connected to emancipatory research. Staying as closely aligned to emancipatory aims as possible, Roger (1999) conducted a pilot study in order to address Zarb's concerns of consultations with individuals with disability in research design and evaluation. For example, she arranged a seminar to relay key findings from the research on women's health, such as menopause, and invited consideration of how her findings related to personal experiences with those advising her research.

### **Qualitative toolbox.**

The implication of Rodger's (1999) emancipatory research was an acknowledgement that some approaches worked better than others. There was no one all-encompassing way to include individuals with disability in research. Disability researchers have used the metaphor of a toolbox or toolkit to describe approaches for collecting data from individuals with disability. Kidney and McDonald (2014) worked with two research advisors with intellectual

and developmental disabilities to develop a qualitative study toolkit that emphasised “accessibility, flexibility, variety, and responsiveness” (p. 1013); using tools for recruitment, consent, interview locations and questions, breaks, and incentives the researchers attempted to ensure the research advisors understood all aspects of the research process. Owens (2007) argued that narrative methods can assist in liberating the voices and stories of people who would ordinarily remain silent and, in doing so, gained access to “lives and worlds of people who have traditionally remained uninvolved in many aspects of their care and support, including their healthcare” (p. 299).

One example of toolbox-style adaptations was Preece and Jordan’s (2010) use of extended interviews to collect the views of children and young people (10 boys and four girls aged 7 to 18 years) with autism-spectrum conditions about their experience of daily life and social-care supports in England. In this study, the traditional qualitative interview process was extended through the following steps. First, introductions were made, not only to the researcher, but also to audio-recording equipment, which many participants found intriguing. Second, broad-reaching questions were discussed in order to allow for the participants to take discussion in directions they saw fit. Next, the researchers offered the participants the option to draw their perspectives, to appeal to the visual nature of autism-spectrum conditions, though none accepted. Finally, in eight of the cases, visual supports were used. Visual supports were based upon principles of structured teaching, such as work stations, whereby participants could sort pictures into “I like” and “I don’t like” piles. In two cases, short observations were done in the home where the interviews were taking place. Analysis involved a “template approach” (p. 38) whereby N-Vivo qualitative data analysis software (Version 2.0) was used to parse provisional thematic codes, then condensed into matrices shared with the participants of the study as well as externally audited for triangulation through supporting data sources.

The mere existence of a toolbox cannot be assumed to remove all research challenges. Despite the extensive adaptations to qualitative interviewing, Preece and Jordan (2010) reported a number of concerns related to data collection. The researchers perceived occasional discomfort on the part of the participants in social interactions and communication. They described challenges with participants' use of language, for example, in speech patterns such as echolalia, whereby participants would simply answer back what was just stated to them. The researchers also noted poor personal memory and over-selectivity of participants, who might get narrowly focused in one area of discussion and disregard other aspects. They expressed concerns about parents overshadowing their child's answers or stepping in to clarify or change the intention of their answers to questions. Finally, the created visual supports became confusing to participants. Such challenges align with research by Booth and Booth (1996) who highlighted four particular concerns of "inarticulateness, unresponsiveness, lacking a concrete frame of reference (unable to generalize from experience and think in abstract terms), and problems with time (ordering of events)" (p. 56). The authors, however, warn of the temptation to blame the limitations of participants over the limitations of the method, which can be overcome by seeing capability over barriers that impede participation.

Tools that are more broadly seen as inclusive include a growing use of *visual methodologies* (e.g., Denzin & Lincoln, 2013), with emphasis upon the inclusion of images in qualitative research (e.g., Burles & Thomas, 2014; Rose, 2012). For example, *photo-voice* (e.g., Wang & Burris, 1997) involves collection of images from particular aspects of an individual's personal life as a way to invite personal voices and perspectives. Several distinctive contributions of the photo-voice technique are: recording personal or community strengths and concerns, promoting critical dialogue related to the collected images, and as visual representations for target audiences, such as policymakers.

In a study focused on parental perspectives, the experiences of seven mothers of young adults with Down syndrome who transitioned, in one case from a mainstream classroom, and in six other cases from special units within mainstream schools, were described using collected images (Wills, Chenoweth, & Ellem, 2016). The study used photo-voice to collect the perspectives of mothers and their experiences of their child's transition. Another study that applied participatory photographic research methods (Aldridge, 2007) involved participants' use of a disposable camera to take a collection of photographs. Collected photographs offered direct entry into personal points of view, facilitating participants to show rather than tell their perspectives. Expanding beyond single, still-frame images, *visual ethnography* (Pink, 2001) combines visual images, technology, and text within the research processes. Using audio-visual media throughout processes of research, analysis, and representation, visual ethnography is inevitably collaborative, reflexive, and participatory, in order to explore other people's experiences.

Other inclusive tools are narratively based, for instance, life-history narration (e.g., Angrosino, 1992) and life-story books (e.g., Hewitt, 2000). Each has been used with individuals with significant disability in order to gain their perspectives on issues such as deinstitutionalisation and community living residences by way of a larger investigation into their identities, personalities, and unique ways of seeing the world. For example, co-creation of autobiographical accounts between the researcher, individuals with disability, and those who supported them, included pictures, drawings, and interview dialogue. Discourse analysis was used by Hewitt (2000) because it allowed examination of issues made relevant by the participants, rather than the researcher "imposing structure" on the analysis (p. 93). Perspectives of proxy informants providing information on behalf of those with disability filtered into and affected the data. While family, teachers, support workers, and other typical proxies may be better able to communicate and respond to the researcher, it was impossible



for them to divorce their knowledge of the participant from their own way of seeing the world.

One way to avoid domination of proxy-informant data is through the use of structured or focused observation. While not a study particular to individuals with significant disability, Mauthner (1997) joined children at school meal-times and was able to analyse the differences in students' understanding of healthy eating, for example, in the contrast between what students said about how they preferred to cook and eat, and their actual eating preferences. With adherence to naturalistic design over an extended timeframe, Mauthner had access to observe how issues such as autonomy and control played out (e.g., when students did or did not pack their own food, were or were not being watched by an authority, in school lunch-room versus home dining-room settings).

Another inclusive tool was the adaption of interviews. For example, semi-structured interviews were conducted with nine young people with high-functioning autism who provided a verbal account of their perceptions of autism and diagnosis experiences (Huws & Jones, 2008). Interpretative phenomenological analysis was used to explore the complexity between what participants thought and felt. Huws and Jones (2008) suggested the use of broad, exploratory, open-ended questions to encourage participants to talk about their perceptions of autism, rather than what the researcher perceived to be relevant. Additionally, they suggested reviewing back what had been discussed, so that participants could ask questions and clarify points. Similarly, another form of adapted interview was a project about four students who left a residential special school to attend a mainstream school in Aotearoa New Zealand (Gasson, Sanderson, Burnett, & van der Meer, 2015). They employed a poetic transcription approach, in order to highlight the perceived gap in literature inclusive of those with severe and complex behavioural needs, by asking students to write poems about experiences such as friendship.

The inherent challenge within the tools of the toolbox is that no one formula works. For example, the open-ended interview style utilised by Hews and Jones (2008) contrasted starkly with Owens (2007) who suggested the intentional use of closed questioning. Closed questioning, which he acknowledged may be less fruitful, can assist in confirming the accuracy of responses, akin to a member check. Likewise, Cameron (2005) offered strategies to individualise interview sessions, such as asking initial questions already known to the researcher and participants to serve as a warm up, encouraging free narrative for the participants to talk about any chosen subject, and keeping the researcher mindful of non-verbal cues, eye-contact, and number of questions asked. Such examples are used to illustrate that the tools in the toolbox must be applied through getting to know the research participants, and working with them, rather than strictly adhering to some formula or methodological prescription.

### **Research partnerships.**

Stemming from the disability advocacy notion of “nothing about us without us” (Charlton, 1998, title), Dennis (2002) examined the perspectives of practitioners who were considered successful listeners and interpreters for people with severe intellectual disabilities. “Perhaps of most interest is the need to make more explicit the impact of the practitioner’s attitude, behaviour, and demeanour on the communicative overtures of an individual with severe intellectual disability” (p. 248).

An increasingly common practice is to include individuals with disability as research partners. In one example, Turk et al. (2012) employed people with intellectual disability, and their carers, as paid researchers in a randomised controlled trial evaluation of a health intervention. In another instance, Ham et al. (2004) worked collaboratively on the process of seeking, and obtaining, ethical committee approval. Researchers of one study established “communities of practice” to include participation in research from inception to

dissemination in a national study (O'Brien, McConkey, & García-Iriarte, 2014). They suggested that the presence of five individuals with disability, three support workers, and 15 additional co-researchers, kept the four researchers “rooted in reality” (p. 73) with more nuanced appreciation of the daily lives of those with whom they researched. Initial thematic analysis was conducted by university staff prior to co-researchers distinguishing core themes they felt would enhance their life. Co-researchers also assisted with the dissemination of results in an accessible DVD format.

### **Personal perspectives.**

After an examination of the qualitative tools that contribute to inclusive research, and inclusion of research partnerships that guided such projects, what sorts of findings are gained? The work of Preece and Jordan (2010) is one example of participatory research that can be classified as personal-perspective research promoting autism advocacy. Essentially, autism advocacy encourages a counterpoint to the “neurotypical” perspectives of those who do not have autism-spectrum conditions. Previous autism-advocacy research established that expertise on autism was not solely held by professional and practitioners in the field, but by those who had autism-spectrum conditions themselves (Hurlbutt & Chalmers, 2002).

At a conference, Hurlbutt and Chalmers (2002) befriended three high-functioning adults with autism and conducted a qualitative research study with them over a 9-month period. The purpose was to depict personal perceptions of particular life experiences. Methods included: initial visits and interviews, conducting follow-up interviews, and reading published and unpublished material written by the participants. While individuals with autism-spectrum conditions held many of the same life desires as those without the disability label, for example, the desire for gainful employment, the assumption that they wanted to be positioned as similar to everyone else was overly simplistic. Autism advocacy meant pride in their unique attributes, building upon capacities often characterised as deficits.

Participatory methods can be used to interpret the personal experiences of critical life stages, such as death and dying, or more complex cultural topics, such as racism. Adults with intellectual disability were found to have a significantly poorer understanding of the concept of death. They knew much less and were less self-determined about end-of-life planning and reported greater fear-of-death, relative to those who provided their care (Stancliffe, Wiese, Read, Jeltos, & Clayton, 2016). Using survey data, the researchers compared what 39 individuals with intellectual disability knew about death as compared with 40 disability-care staff. Through systematic use of statistical data, researchers established what participants didn't know, yet failed to include what was understood.

Cancer experiences of 13 people with moderate to severe learning disability were shaped by their previous experience of life, which included deprivation, loneliness, and a lack of autonomy and power (Tuffrey-Wijne, Bernal, Hubert, Butler, & Hollins, 2009). An ethnographic investigation consisted of 250 hours of participant observation over a median timeframe of 7 months. Participants were visited at home and in inpatient settings, and sometimes accompanied to general practitioner and outpatient doctor appointments. Relatives, social-care staff, and medical staff were also accessed, and case reviews were attended with case notes studied. The majority of data consisted of extensive field notes, written by the researcher immediately after each observation session. Analysis followed a grounded-theory approach whereby data collection and analysis occurred concurrently. Emergent themes were fed back into the field and, in some instances, discussed with participants and their carers. Additionally, recruitment of new participants continued until saturation of the data was reached. No new themes were revealed with the last three participants.

Those with a learning disability who received a cancer diagnosis depended on others to negotiate contact with the outside world, including the healthcare system. This could lead

to delayed cancer diagnosis and a lack of treatment options being offered. Most participants were not helped to understand their illness and its implications. Doctors did not make an assessment of capacity, but relied on carers' opinions. Though an in-depth study, the researchers did not invite participants to guide the observation times or venues, and neither accessed nor validated their perceptions, or to validate the interpretations made from the observations.

Goff, Martin, and Thomas (2007) used phenomenological data collection to examine and understand the perceptions and meaning of students' experiences regarding the "burden of acting white" (p. 134). The researchers sought an emic perspective of 6 seventh- and eighth-grade students with disability about on racism in their US school. The research began with interviews with the principal and teachers to confirm the existence of institutionalised racism within and outside the school. School principals identified students who they felt needed to posture or perform a dominant, privileged position in order to advance themselves within school, and then mask their academic abilities in order to fit in better in their home community. Students felt alienated when they were not successful in doing so. The students, who had no knowledge of the phrase, were given disposable cameras and asked to photograph anything that influenced the way they felt about school. Photographs were used as the bases of interviews conducted for 20 minutes with each student, as well as a 45-minute focus group. Five steps of analysis included: initial coding, identification of relationships, member checks within the schools, development of initial themes, and comparison of themes against the data corpus and existing literature. Two researchers conducted analysis procedures, and one further researcher served as an auditor. Overall, this research enabled students to share their perspectives in order to actively bring about change in the issues which concerned them.

Ellis (2016) suggested, “the decision regarding which method to use when researching ... is a methodological, ethical and political issue” (p. 11). Personal perspectives have been unlocked from the normative expectations of silence for individuals with disability. In the shift away from those with disability being considered to have nothing to say (Bogdan & Taylor, 1987), a counter-narrative begins to unfold.

Returning to the first research question about personal experiences of transition, were it be the only question asked, findings may well be forecasted to align to the already known master narrative of exclusion and dismal transition outcomes (e.g., Rusch et al., 2009). To consider alternative possibilities a second interrelated research question asked,

How can understanding the perspective of individuals with significant disability impact a transition with dignity?

The use of the term *dignity* is purposefully used to reflect the capability approach as the theoretical framework of the study.

### **Theoretical Framework: Capability**

The capability approach was developed by Amartya Sen (1980) as a radically underspecified, normative framework for welfare economics. He looked to developing nations and found that large-scale measures of economic progress, such as socio-economic status or gross domestic product (GDP), did not accurately portray how individuals were faring in their day-to-day lives. A rise in GDP did not always correlate to the average citizen’s wellbeing reciprocally increasing. Essentially, Sen called into question aggregate measurements as suitable representations of individual experiences.

Sen shifted the unit of concern to every human being in his or her own right. “Human beings are not merely a means of production, but also the end of the exercise” (Sen, 1999, p. 296). Individual improvements were measured not in outcomes, but rather in opportunities to

achieve personal capabilities. Sen used a simple, yet poignant distinction of the difference between a starving person and a fasting person to illustrate his case. Both people have the same shared outcome of hunger, but for two very different reasons. The starving individual experiences hunger because of restricted access and opportunity to acquire nutrients and food, whereas the fasting person chooses to be hungry.

Sen's conception of the capability approach focused on the freedom to choose between personal capabilities in order to establish a life of personal value. Central distinctions of capability approach are: (a) capability, what a person can do, be, and find personally meaningful; (b) freedom, a person's "actual freedoms" (p. 7) to select from personally relevant opportunities that form an individual's capability set; and (c) functionings, the "beings and doings" (p.6), the realised choices of a person's life (Sen, 1993). The interplay of those variables is demonstrated in Figure 2.2. The figure shows that goods, services, or resources provide a means to achieve, or enable functioning (e.g., job, wage, vehicle, qualifications), but are a mere starting point. Crucial to the process are personal conversion factors (e.g., age, gender, ability), as well as social (e.g., norms, public policies, legal rules) and environmental (e.g., societal, climate, physical surroundings, infrastructure) conversion factors that need sufficient attention. The approach requires thorough investigation to ensure the extent to which people have genuine access to all of the capabilities in their capability set, rather than that set being contrived or prioritised by those other than the individual themselves (e.g., family and community).

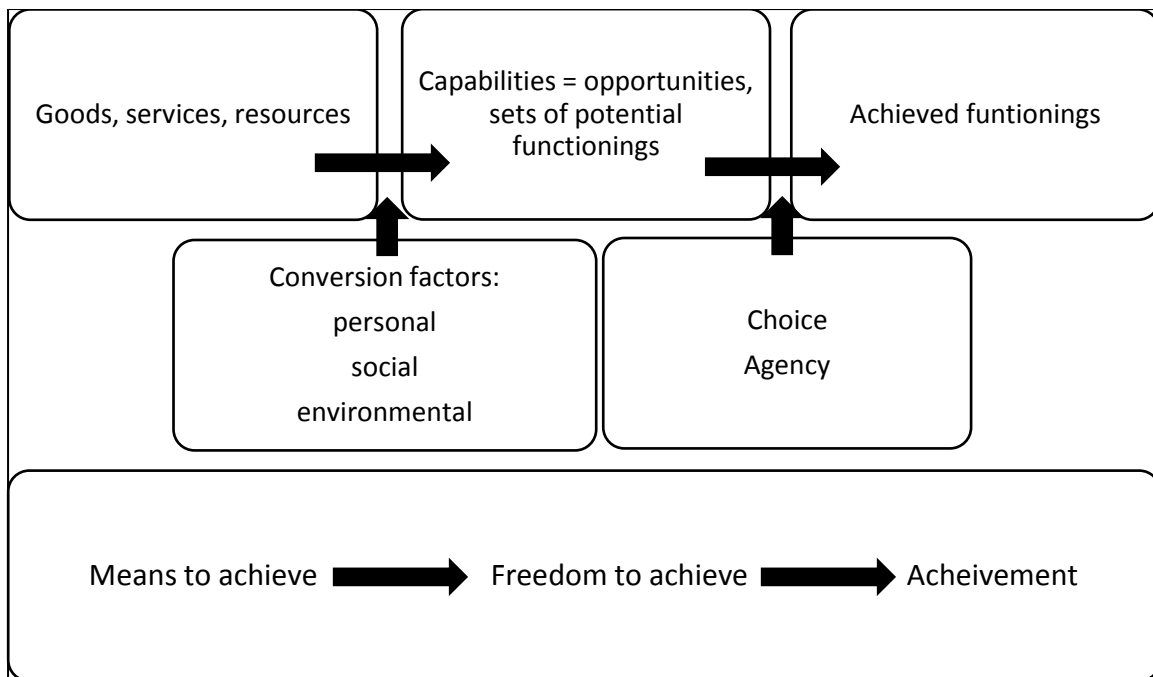


Figure 2.2. A schematic representation of capability approach. Adapted with permission from “Putting Skill in its Place,” by J. Bryson, 2015, *Journal of Education and Work*, 28(5), p. 557.

Sen (2009) acknowledged the unique experience of people with disabilities as not only among the most disadvantaged in the world, but also among the most neglected. As Sen noted, 600 million people with disabilities should not be considered disadvantaged solely by low income and, in many cases, abject poverty; “their freedom to lead a good life is blighted in many different ways, which act individually and together, to place these people in jeopardy” (Sen, cited in Terzi, 2013, p. 26).

Sen (2009) offered a poignant economic example of the same bundles of commodities being given to two individuals, one with and the other without disability. Sen suggested the likelihood that someone with disability will require more than the individual without disability in order to achieve the same level of functioning. This rationale, which is the same for distinguishing the difference between equality and equity, has been used to justify, for example, the extra expenditures of special-education services for students with disability (Reindal, 2009; Terzi, 2005).



Philosopher and legal scholar, Nussbaum (2000) worked from the same basic tenets of capability as Sen, but emphasised distribution of wealth, opportunities, and privileges within a society: all notions of social justice. Nussbaum used 10 capabilities to universalise fundamental human rights and principles that allowed for the greatest good for all human beings.

The capability approach operates with a list that is the same for all citizens, and it uses the notion of a threshold level of each of the capabilities, which is taken to be a minimum beneath which a decently *dignified* [emphasis added] life for citizens is not available. (Nussbaum, 2006, p. 179)

For her, the 10 central human capabilities ensure all human beings are entitled to live not only a mere life, but to live a flourishing life. These are:

1. *Life*. Being able to live to the end of a human life of normal length; not dying prematurely, or before one's life is so reduced as to be not worth living.
2. *Bodily Health*. Being able to have good health, including reproductive health; to be adequately nourished; to have adequate shelter.
3. *Bodily Integrity*. Being able to move freely from place to place; to be secure against violent assault, including sexual assault and domestic violence; having opportunities for sexual satisfaction and for choice in matters of reproduction.
4. *Senses, Imagination, and Thought*. Being able to use the senses, to imagine, think, and reason—and to do these things in a ‘truly human’ way, a way informed and cultivated by an adequate education, including, but by no means limited to, literacy and basic mathematical and scientific training. Being able to use imagination and thought in connection with experiencing and producing works and events of one's own choice, religious, literary, musical, and so forth. Being able to use one's mind in ways protected by guarantees of freedom of expression

with respect to both political and artistic speech, and freedom of religious exercise. Being able to have pleasurable experiences and to avoid non-beneficial pain.

5. *Emotions*. Being able to have attachments to things and people outside ourselves; to love those who love and care for us, to grieve at their absence; in general, to love, to grieve, to experience longing, gratitude, and justified anger. Not having one's emotional development blighted by fear and anxiety. (Supporting this capability means supporting forms of human association that can be shown to be crucial in their development.)
6. *Practical Reason*. Being able to form a conception of the good and to engage in critical reflection about the planning of one's life. (This entails protection for the liberty of conscience and religious observance.)
7. *Affiliation*. Being able to live with and towards others, to recognise and show concern for other humans, to engage in various forms of social interaction; to be able to imagine the situation of another. (Protecting this capability means protecting institutions that constitute and nourish such forms of affiliation, and also protecting the freedom of assembly and political speech). Having the social bases of self-respect and non-humiliation; being able to be treated as a dignified being whose worth is equal to that of others. This entails provisions of non-discrimination on the basis of race, sex, sexual orientation, ethnicity, caste, religion, national origin and species.
8. *Other Species*. Being able to live with concern for and in relation to animals, plants, and the world of nature.
9. *Play*. Being able to laugh, to play, to enjoy recreational activities.

*10. Control Over One's Environment: Political.* Being able to participate effectively in political choices that govern one's life; having the right of political participation, protections of free speech and association. *Material.* Being able to hold property (both land and movable goods), and having property rights on an equal basis with others; having the right to seek employment on an equal basis with others; having the freedom from unwarranted search and seizure. In work, being able to work as a human, exercising practical reason and entering into meaningful relationships of mutual recognition with other workers. (Nussbaum, 2000, p.78)

The articulation of 10 central human capabilities, is where Sen and Nussbaum differ. Sen preferred the framework to be radically underspecified in order to have the broadest applications. Nussbaum (2006) believed that each of the 10 human capabilities must be met to a sufficient level—anything less was not a life as a “truly human being” (p. 78). Furthermore, dignity means not exchanging or replacing any of the 10 capabilities. Dignity is interactional, between the individual’s freedom to choose from a personally meaningful capability set, and societal contexts that promote such freedoms. Even when an individual has no meaningful sense of the capabilities in question, Nussbaum argued society must strive to offer as many of the capabilities as possible, directly or through a suitable alternative arrangement.

Before her work on disability, Nussbaum (2000) first put the 10 central human capabilities into practice by studying women in India. From her investigation, three pivotal social arrangements were articulated: adaptive preferences, unequal distribution of resources, and understanding private social spheres. First, the personal preferences of women were found to have been largely shaped by unjust background conditions, known as *adaptive*

*preferences*. For example, women in India had grown so accustomed to their demoted social status they didn't question it, and almost preferred it, at times, as a feature of their femininity. Thus, it was insufficient to measure their preferences and satisfaction with their social status as a means to bring about social change. Second, response to historically unequal conditions called for an *unequal distribution of resources* in favour of the more marginalised groups. One basic and universal example is a nursing mother requiring more food and nutrients than a woman who is not nursing. Third, to fully appreciate features of dignity, private social spheres must be examined as fully as public experiences. Nussbaum's investigation sought to highlight personal experiences of gender inequality inside the family. These entailed inequalities in opportunities, educational deprivations, failure to work outside the home, and insults to bodily integrity.

Nussbaum's work has been a catalyst for a range of studies. For example, capability has been used to consider gender inequality related to capability in education practices (Robeyns, 2006), evaluation of development projects (Alkire, 2002), democratic citizenship (Anderson, 1999), and contemporary policy reviews to detect inequality (Burchardt, 2008). Capability has also begun to emerge as a framework for disability research. Most recently, a case has been made to operationalise capability into a useful guide for evaluating social policy and practices related to quality of life (Brown, Hatton, & Emerson, 2013). While no empirical applications have yet emerged, the argument has been established to add capability to current subjective and objective indicators of quality of life.

In summary, capability is understood as a *genuine opportunity*. Most simply stated, people have a genuine opportunity when they can actually and realistically choose a given function or life option. For example, a woman may choose to live off her husband's income, but if, for some reason, she is unable to work outside the family home, then her genuine

opportunities are restricted. These restrictions may occur at individual, social, or structural levels, thus all must be addressed in order for genuine opportunities to exist.

### **Transition in Aotearoa New Zealand**

Lastly, the transition practices and related research of a relatively novel research setting of Aotearoa New Zealand are described. As the New Zealand transition guidelines state,

We make many transitions in our lives but one of the most critical is our move from school into adulthood. For some students, particularly those with significant learning and social needs, the transition from school is probably the most crucial process for determining how the rest of their lives will unfold. (Ministry of Education, 2015, p. 2)

Disability policy in Aotearoa New Zealand stems from the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), ratified by Aotearoa New Zealand on 30 March 2007. Signatories to the UNCRPD agreed “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, para. 1).

The Ministerial Committee on Disability Issues in Aotearoa New Zealand provides leadership, coordination, and accountability for implementing UNCRPD. The New Zealand Disability Strategy is the central document for enacting the principles and obligations set forth in the UNCRPD.

The New Zealand Disability Strategy's vision is of a society that highly values the lives and continually enhances the full participation of disabled people. It provides a framework to guide government agencies making policy and services impacting on disabled people. In taking the lead, the government will do everything possible to influence the attitudes and behaviour of society as a whole. By all New Zealanders

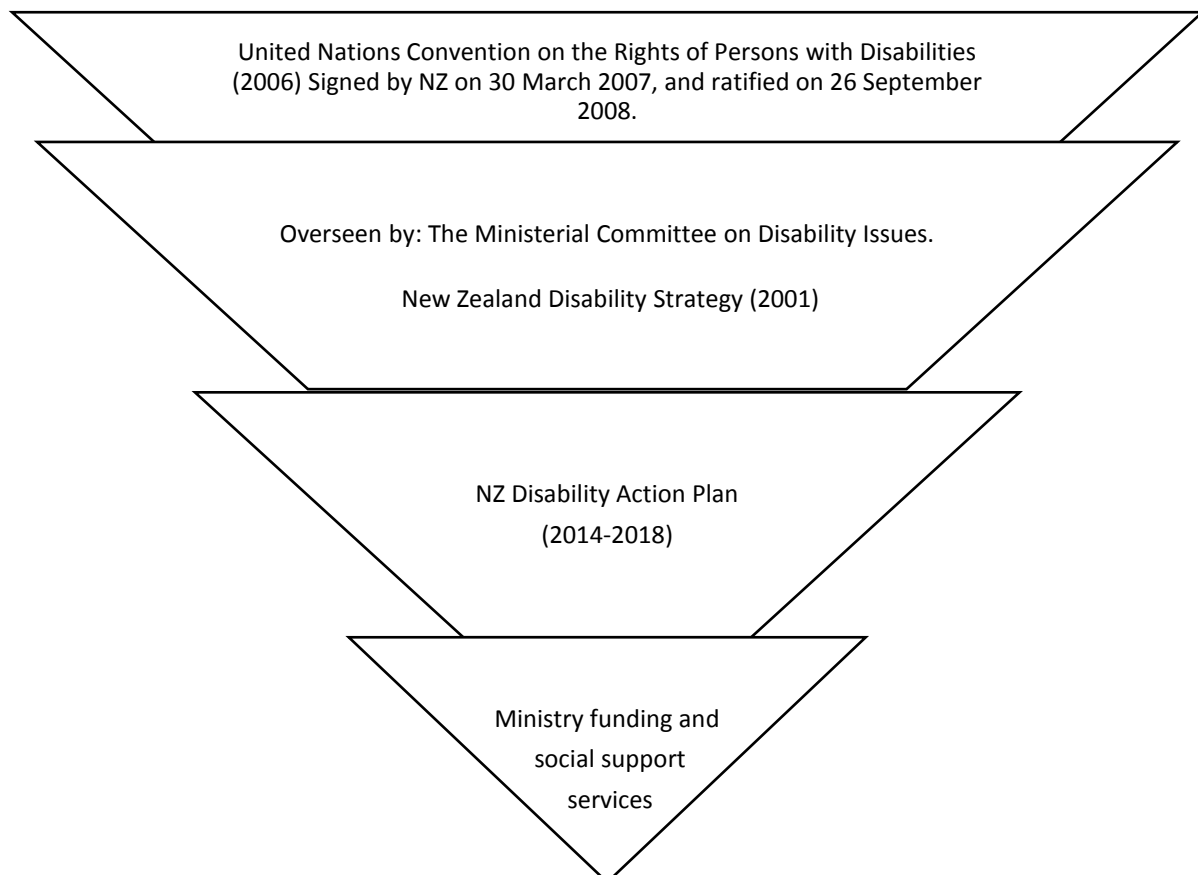
considering issues facing people with disabilities and their aspirations, New Zealand can become a fully inclusive society. (Office for Disability Issues, 2015)

The New Zealand Disability Action Plan establishes strategic steps for implementation. The plan is updated regularly through public consultation, cross-governmental agencies' input, and from perspectives of individuals with disabilities. The guiding aim is for "all New Zealanders to experience equal rights of citizenship" (Office for Disability Issues, 2015, p. 11). In the current 2014-2018 plan, actions include: increased employment and economic opportunities, ensured personal safety, modifications to the disability support system, and promotion of access in the community.

Many social supports are available to individuals with disabilities. For example, the Supported Living Payment and Disability Allowance (Ministry of Social Development) is for individuals with permanent, hospital, or residential care significance of need, and covers ongoing expenses related to their disability. Needs Assessment and Service Coordination (Ministry of Health) allocate provisions such as Disability Support Services, Carer Support, and Home and Community Support Services, for ongoing personal care and community engagement. Prior to leaving school, students with significant disabilities, and their family, will have already accessed and been supported by these social services. Exit from school marks a time when the need for social services will be reassessed in order to match the significant change in life circumstances. Most notably, as students age out of the services that come under the Ministry of Education (e.g., ORS funding), the other ministries become increasingly involved.

While many countries offer social supports comparable with those in Aotearoa New Zealand, the notable difference is that transition in Aotearoa New Zealand is seen less as a procedural exit from school, and more as a social process. The end-game of this process is

inclusion within society. Stated another way, transition is seen as one aspect over the longer course of a successful and integrated life for individuals with disability. Figure 2.3 is a schematic representation of the government departments and documents that have been described as relevant to this process.



*Figure 2.3.* Schematic of Aotearoa New Zealand disability policy.

As of 2016, the only legislation guiding these aims is the wide-reaching principles of UNCRPD. Best-practice suggestions for teachers (New Zealand National Transition Guidelines, 2011) and a transition fact sheet for parents (Ministry of Education, 2011) are available, but no policies set standards for practice. For example, there are no age requirements for schools by which to begin transition, nor is there any legislation requiring IEPs to incorporate, or be replaced by, transition plans.

One study that captured the novel aspects of transition in Aotearoa New Zealand and the flexibility of the social supports therein was conducted by Janson et al. (2013). Through

four years of observation, the pathway of one young artist with significant autism was demonstrated as he built a prominent career in the arts. The young man's mother and sister collaborated with researchers using narrative storytelling techniques to portray a "different challenge than implementing goals such as finding a flat or taking up a hobby" (p. 14). Over the course of the young man's transition, he transferred his career to France and, in doing so, "grew to become a role model to his peers" (p. 19). However, the authors consider the young man's story a unique outcome.

Three other studies about students with disability portray a different understanding of transition in Aotearoa New Zealand. Hornby and Witte (2008) interviewed 29 former students and their parents or caregivers 10-14 years after leaving a residential special school for students with emotional and behavioural difficulties. Interviews focused on educational achievement, employment records, and community adjustment. Their findings indicated low levels of achievement on educational qualifications and employment records, high rates of involvement with the criminal justice system, and, in turn, tenuous engagement with wider community life. Implications suggested more extensive focus on the transition from school was needed, including better training for teachers and ongoing support for former students.

A collaborative research project comprised of researchers with and without disability concluded that policy does not match practice in Aotearoa New Zealand (Dever, Gladstone, & Quick, 2012). Findings from the transition project called *My Life When I Leave School* was presented to the Minister for Disability Issues. In the study, three focus groups were held for 12 school students aged 16-20 years, and two focus groups were conducted for 15 young people who left school in the past five years. Questionnaires were sent to 57 additional currently-enrolled students, and 24 former students who had left school. The large majority reported they wanted to work, and, to a lesser degree, wanted to experience tertiary education and flatting outside the family home. However, participants also reported very little, if any,



work or paid employment or tertiary opportunities were available. Furthermore, most reported they had few friends and social networks, and were facing the reality of living at home for many more years to come.

Additionally, mothers expressed feelings of isolation and anger regarding their child's transition (Wills, et al, 2016). They likened the advocacy required during transition in Aotearoa New Zealand as akin to a battle. The authors called for political reform and change to address the life-span needs of family members.

In a contemporary commentary on transition, Gladstone (2014) contrasted policy rhetoric of outcomes such as having “an ordinary life” and the more recent, “everyday life in everyday places” (Minister for Disability Issues, 2011, p. 17) with experiences more akin to “supported loitering” (p. 230), which he considered to be the unrealised goals and aspirations of those with disability. Gladstone found no valid data on employment or tertiary study rates for young people with learning disabilities in Aotearoa New Zealand, and suggested this was because such individuals were commonly lost within the generic disability group. What was clear, however, was that young people with disability were the least likely of any marginalised group to be tertiary educated or employed, and this problem worsened the more severe the impairment (Statistics New Zealand, 2008). With transition in Aotearoa New Zealand described, one further aspect to consider is the education system from which students exit.

***Special schools in Aotearoa New Zealand.*** Aotearoa New Zealand considers itself a world leader in providing inclusive education, with only 0.4% of children in special-education settings separate from regular schools, as compared with other Organisation for Economic Co-operation and Development (OECD) countries, which range from 0.5% to 6% (Ministry of Education, 2015). Since the enactment of Special Education 2000, Aotearoa

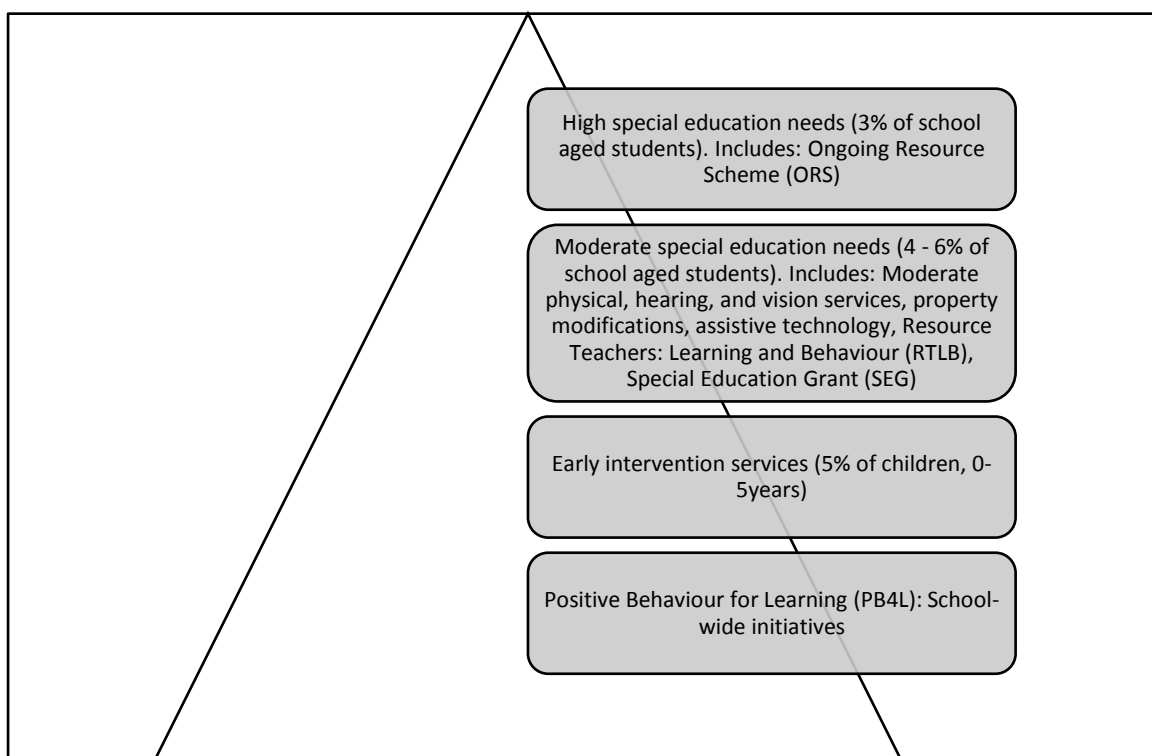
New Zealand has had a strategy for a “world class inclusive education system that will provide learning opportunities of equal quality to all students” (Ministry of Education, 1996, para. 1). Benchmarks used to assess a school’s inclusivity focus on professional learning and development, teacher-aide strategies, and collaborative team approaches to student learning. By those benchmarks, 77% of the country’s primary schools were found to be inclusive of students with significant disability (Education Review Office, 2013).

Students with disabilities are supported in a number of ways to learn alongside their peers in mainstream schools. Supports include:

1. Special Education Grant issued to all schools as part of their general operations. The grant is intended to enable schools to use the money creatively to best meet the needs of their students.
2. Students and their teachers can access support from a Resource Teacher of Learning and Behaviour (RTLb). These RTLbs are specialist, itinerant teachers who provide learning and behaviour support to a number of schools within a geographical region or cluster. In their roles, RTLbs may support classroom and teaching strategies, introduce class or school-wide programs, and work directly with a student or small groups of students.
3. Eighty percent of schools have been found to have a role for Special Education Needs Coordinator (SENCo). SENCo’s are teachers already employed by the school who, in addition to their full time position, help assess and monitor student progress, create IEPs, coordinate staff, liaise with specialists and families, oversee teacher-aide support, and attend related meetings.

In contrast with supports for inclusive schooling noted in the preceding paragraph, this thesis pertains to students who have access to ORS funding, individually targeted funding. In order to access individually targeted ORS funding, an application must be made

for external assessment of a student. ORS funding provides support for students with the highest 3%<sup>3</sup> level of need for special education within the school population. There are two levels of ORS, high and very high, which denote the significance of ongoing or extreme difficulties in the areas of learning, hearing, vision, physical disability, and/or language use and social communication. ORS funding provides support for individual students to access specialists (e.g., speech-language therapists, physiotherapists), additional teaching supports (e.g., teacher aides), and consumable resources (e.g., technology software, Braille machines; Ministry of Education, 2016). ORS is the funding that enables students to enter special schools. Figure 2.4 puts each of these supports in a continuum of the inclusive education system.



*Figure 2.4. Inclusive New Zealand education system: Continuum of supports. Adapted from *Success for All: Special Education Briefing to Incoming Minister* (p. 16) by Ministry of Education, 2014, Wellington, New Zealand.*

<sup>3</sup> At the time of writing, ORS has recently been set at 3% of those students with the highest level of need within the mainstream school population, but historically it has been set at 1%.

A great deal of funding is allocated to special-education support services. The 2014-2015 budget for ORS funding was \$152 million. Closest budget comparisons for the same year were \$75 million for RTLBs, \$37 million for school special-education grants, \$36 million for school transportation assistance, and \$40 million for early intervention services.

Attending special school is a choice for students with ORS funding, not mandatory. Many students use the funding towards employing teacher-aide support or making structural adaptations within their mainstream school. In order for students to attend a special school, they and their families sign a Section 9 agreement with the special school. Section 9 refers to the part of the Education Act (1989) that deals with special-education services (Ministry of Education, 2015). The agreement ensures access to supports beyond those of typical students, such as transportation to and from school each day, and continued access to education from 18 to 21 years old in order to focus on transition.

The 28 special schools in Aotearoa New Zealand are outliers within an otherwise entirely inclusive education system. The total student roll for those attending special schools in 2015 was 3,141 (0.4%) out of a total of 776,815 students (Ministry of Education, 2009). Teachers working in special schools do not receive explicit training in special education, and are registered (i.e., certified) as any other mainstream primary or secondary teacher. In the past, there have been indications that special schools may be closed (Ministry of Education, 2010), but that has not happened, and, to the contrary, student numbers in special schools have grown. In 2014, over half the ORS funded students aged 19 through 21 exited from special schools (Ministry of Education, 2015).

The trend in increasing numbers of students attending special schools has been noted internationally (Kelly, Devitt, O'Keefe, & Donovan, 2014). For example, reports from survey data in Ireland indicated a “failure of mainstream schools to meet their academic,

social, emotional, behavioural, and access-to-health resource needs” (p. 68). Within mainstream schools in the US, where least restrictive environment is a legal requirement, Kurth, Morningstar, and Kozleski (2014) found the percentage of students with disabilities placed in self-contained classrooms (i.e., units) unchanged over the last decade, and those classrooms disproportionately comprised of students with significant disability. The authors suggested that states have not set rigorous improvement goals to reduce restrictive placements, thus segregated educational experiences continue for many students with disabilities.

Seen from a different perspective, within an Aotearoa New Zealand context, Gasson (2008) examined the perspective of 17 families of students from one special school and found two central justifications for their child’s enrolment. First, students who were classified as medically fragile stated they needed appropriate care facilities that were found in special schools. Second, those students not classified as medically fragile reported that they had sought school enrolment after feeling excluded from other educational settings. In either case, once students had enrolled in special school, the majority of families reported strong support for the special school. They reported their child was happy, engaged in appropriate learning, and accepted. Parents could see that non-disabled peers in inclusive schools might benefit from their child’s attendance, but did not see the benefit as reciprocal for their own child.

The growing friction between Aotearoa New Zealand’s commitment to the development of international human rights and lack of measurable human rights achievement, is of growing concern (Kearney, 2016). Emblematic of these concerns, school students with disability are regarded as being “in, out, or somewhere in between” (Rutherford, 2012). Through an analysis of legislation and policy documents, Higgins, MacArthur, and Morton (2008) argued that the rise in students attending special schools is like the “the clock is being wound back” (p. 145) with no clear path towards inclusive education for students with

disabilities. Clear discrepancies exist between the educational experiences of those with and without disability in Aotearoa New Zealand, but what remains unclear is to what extent.

Yet, despite concerns the spirit of counter-narrative can be understood in comments such as Kearney and Kane (2006),

New Zealand, like many other countries in the world is at the beginning of the journey, however, our walk is laboured as we try to carry with us the beliefs, values and assumptions based on exclusionary paradigms. These will wear us down and slow our passage unless they are recognized for what they are, challenged, and replaced by more inclusionary paradigms (p. 216).

An examination of transition practices in Aotearoa New Zealand is timely in light of the transition programme currently being piloted. Furthermore, examining the practices of a country outside the areas of dominant research production presents another way to gain a different perspective on transition. It could be tempting to dismiss the practices of a small, geographically isolated country; to do so would be to overlook the country's strong social-welfare and social-justice practices. Research conducted in Aotearoa New Zealand might be one such way of literally seeing the issues of transition from upside down.

## **Conclusion**

Since disability has typically been studied from a deficit model, “we are deficient in language to describe it any other way than as a problem” (Linton, 1998, p. 141). Or put another way, “today’s descriptions are packaged in yesterday’s language” (Graue & Walsh, 1998, p. 33).

The counter-narrative will not rewrite history. The counter-narrative will, however, privilege the centrality of personal experiences in the construction of knowledge. Creation of a counter-narrative that links the views and experience of students to the notion of a transition with dignity has powerful potential. Results represented in this manner can reshape individual students’ identities to a place of dignity within their community. “If we change the stories we

live by we quite possibly transform and change our lives and society too” (Smith & Sparks, 2008, p. 19).

In one example of looking at transition in a new way, Lichtenstein (1993) collected case studies of four individuals with disabilities, over a two-year period, who had dropped out of school. Emergent themes showed their disengagement within their IEP, and with vocational adult services. Instead of seeing the four individuals as failures, however, the research demonstrated the ways their education and social support systems failed each of them. Shortfalls were apparent in the system, rather than within the individuals.

Another example of an article written from a counter-narrative position, though not on transition, was a literature review about choice-making for individuals with disability who live in residential care (Bannerman, Sheldon, Sherman, & Harchik, 1990). The authors argued that all people should be allowed to exercise as much choice over their lives as their abilities allow, from expression of a simple preference, to complex decision making. Individuals’ access to choice between viable options reduced problem behaviours, for example, self-injury in individuals with autism-spectrum conditions. The authors concluded that while outcomes, such as ill health from eating too many donuts and then taking a nap, may be unfortunate, so long as healthier options remain available, being forced away from doing such unhealthy activities is equally unfortunate, if not socially unjust and undignified.

As the novel conceptions of transition – inclusive research, the capability approach, a small isolated country - are synthesised, they can form a counter-narrative. “Narrative life interweaves social forces, market patterns, institutional practices of individuals that intertwine to form the social milieu in which social performances unfold” (Harter, et al., 2006, p. 5). Counter-narratives seek to “disrupt stories of domination and dismantle hegemonic discourses” and replace them with “histories, fragments, and other anecdotes” to

give rise to social change (p. 6). The counter-narrative is “a story that resists an oppressive identity and attempts to replace it with one that commands respect” (Lindemann-Nelson, 2001, p. 6).

In conclusion, many ways exist to break transition down into more manageable pieces that facilitate understanding. Also conceivable, however, is that new ways exist to understand transition. With a paucity of research on personal perspectives of those with significant disability about their own transition, the case can be made that this silenced perspective must not only be heard, but amplified.

In order to gain the personal perspective of those with significant disability, methodological flexibility is required. Additionally, a new way of talking about transition must be used to frame discussions. Personal perspectives of transition can keep the holism and naturalism of transition intact, in order to counteract fragmentation. Personal perspectives of transition can avoid empirically confirming and repackaging the well-known dismal transition outcomes, and, in doing so, address new ways to conceptualise transition away from its problems. As a first step, Swenson (2015) encouraged, “We are not seeking a unified theory of life and disability . . . we are seeking some answers and some new ideas” (p. 412). “Honour our past, our leaders, the men and women whose research and assertions brought us to where we are. Then get over it. That is the real outcome of research: Not certainty, but progress” (p. 413).



## Chapter 3 – Methods and Procedures

Chapter overview: Ethnography is introduced as the guiding methodology to collect data on the two articulated research questions. This chapter describes the recruitment of participants with critical attention to consent and assent processes, and to emancipatory partnerships between the researcher and participants. Fieldwork settings and the study timeframe are outlined. Comprehensive descriptions of data collection are provided where novel techniques were adapted to the communication preferences and capabilities of central case participants with significant disability. Multiple waves of inductive and deductive analysis are described. The chapter concludes with reflections upon disciplined inquiry and credibility of the data.

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The epistemological position of this project was that knowledge about individuals with significant disability must be gained through their active participation and inclusion in the research process. In doing so, understanding of transition can be gained and applied to research, praxis, and wider society.

Conceptual tools that truly take account of impairments, and do not treat them as special cases, abnormalities, or exceptions deserving of care, compassion or pity, can broaden our notions of what it is to be human. In fully satisfying the existing, practical needs of disabled people, strategic interests will also be served, not just for disabled people, but in creating a broader and more inclusive vision of what it is to be human, and to enjoy human development and full human rights. (Baylies, 2002, p. 737)

Pursuant with these aims, two qualitative research questions guided this 6-month ethnography on transition out of special school into the early stages of adult life in Aotearoa New Zealand.

While the research questions have initially been raised in light of the reviewed literature, each will now be directly linked to the methods and procedures used in the study.

### **Research Questions**

The first research question asked:

What are the perceptions and meanings of transition experiences for individuals with significant disability?

The challenge to address this question can be understood in light of a comment by the mother of one of the young men, Cobain, who told me in interview that she wished she could have five minutes in her own son's mind to know what he was thinking. Her 21-year old son who does not speak verbally, and whose mind was still a mystery to her!

The second research question focused on transition as explored from a capability standpoint. Lived experiences and understandings can be used to see transition in novel ways. To access this new way of seeing, innovative, adapted, or expanded research techniques are required. In doing so, exploration extends beyond the current state of affairs and into the realm of what can be. The second research question thus asked:

How can understanding the perspective of individuals with significant disability impact a transition with dignity?

### **Research Design**

Social science research in education is not a hard science, but the "hardest-to-do science" (Berliner, 2002, p. 18). Research in special education is considered even more difficult than in general education, due to the variability of participants, the range of educational settings, and the highly politicised nature of the field, rendering it "the hardest of the hardest-to-do sciences" (Odom et al., 2005, p. 139). To reintegrate the fragmented pieces of transition articulated in the literature review, I turned to naturalistic strategies.

The notion of naturalism in research involves capturing diversity and holism by studying the social world in its natural state, instead of a state contrived for research purposes (Punch, 2009). Naturalistic research design is considered an observational tool whereby the researcher takes care to be as unobtrusive to the processes being observed as possible. I claim two central justifications for utilising a naturalistic design. First, this was not, for example, a retrospective study, whereby participants were selected for having exemplary transitions in any positive or negative sense. Due to the cognitive and communication challenges of the potential research participants, the research strategy was to follow along with each transition case as it progressed, exploring transition in-situ. Secondly, preserving the holism of transition's complexity meant observing the cases within a constant state of transience. This study was not a study of one particular setting (e.g., classroom or particular community service). This study was akin to a research journey (Kvale & Brinkmann, 2009), following each of the cases as they naturalistically progressed. Ethnography was used to retain the naturalism of transition, as well address as many of the core constructs of emancipatory research as possible.

### **Ethnography.**

Ethnography is often defined as both a process and a product. Criteria for an ethnographic study, or the process of conducting an ethnography, include (a) study of the shared cultural meaning of a group; (b) researcher becoming part of the natural setting in order to (c) access an insider perspective sensitive to meanings, behaviours, events, and contexts; (d) an unfolding and evolving study, rather than a pre-structured one; (e) use of eclectic data collection techniques; and (f) engaging in prolonged and repetitive fieldwork (Wolcott, 1987). Figure 3.1 is used to demonstrate the link between the reviewed studies in the previous chapter, in particular literature from the subheading about student perspectives of transition, with essential features of ethnographic research design.

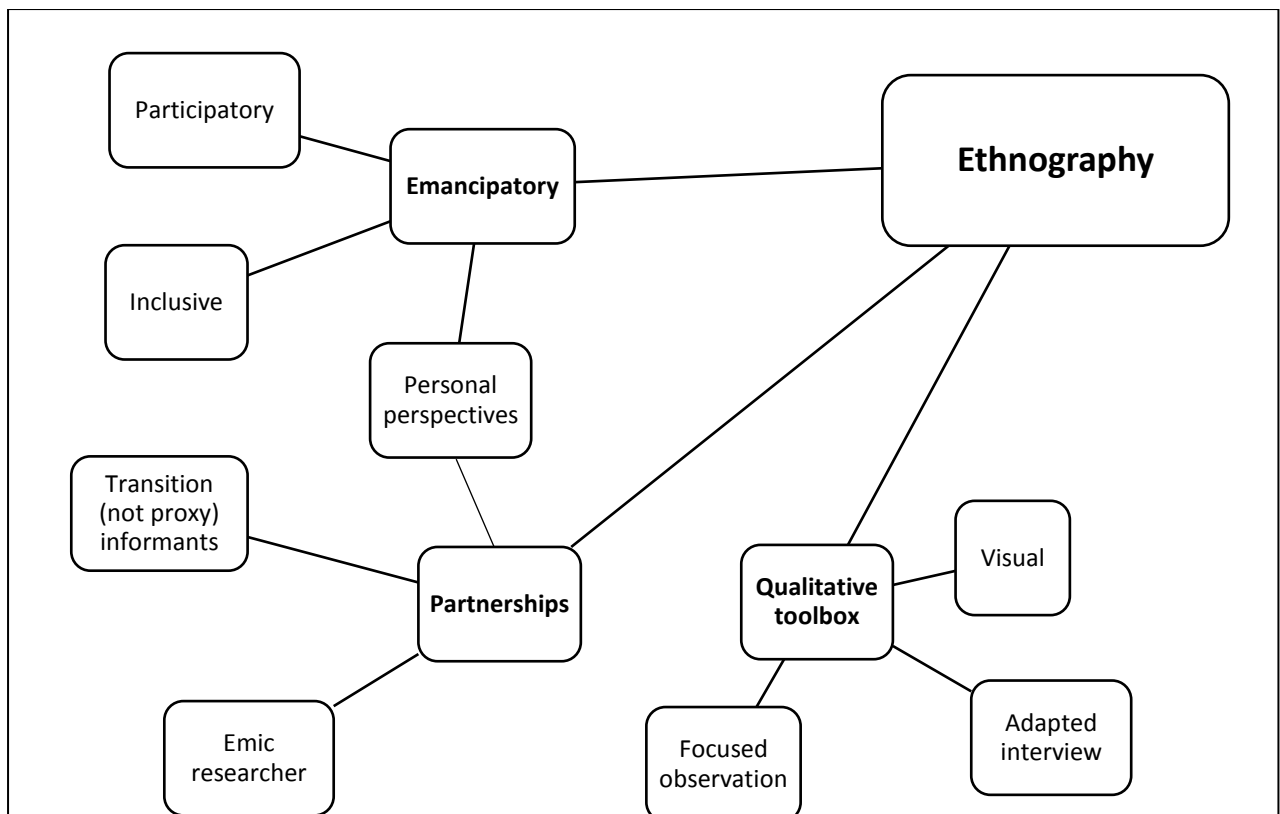


Figure 3.1. Links between reviewed literature and ethnographic research design

The essential message across the literature on student perspectives of transition (with subheadings on inclusive research, qualitative toolbox methods, research partnerships, and personal perspectives) was that no one single formula works to study personal perspectives of individuals with significant disability. Said another way, researchers in this area of study require flexibility of data collection techniques that are informed through an unfolding understanding of the field, and deepening insider perspectives and relationships. In Figure 3.1 these central priorities are underscored, and through their prioritisation, justify the use of ethnographic data collection methods for this study.

One might feel a project of this nature would be more accurately described as a “critical ethnography” (Wolcott, 1987), due to the inherent social justice implications of research with individuals with significant disability. Aligned with the theoretical framework used in this study, I prefer to think of it as a “capability” ethnography, building on what all of

us can do, rather than critiquing what we cannot. Individuals with significant disability were active participants at the heart of the transition research.

## **Recruitment**

### **Site-based strategy.**

A site-based sampling process was used to systematically locate, select, and recruit participants (Arcury & Quandt, 1999). Five steps were involved in participant selection:

1. pre-set the participant characteristics;
2. generate a list of potential sites;
3. meet “gatekeepers” of potential sites;
4. establish systematic invitation for participation; and
5. compare recruited participants to overall population of potential participants.

The first step in site-based sampling was to pre-set the characteristics of potential research participants. Typical characteristics include demographic characteristics (e.g., gender or age), sociocultural factors (e.g., ethnicity, education, or area of residence), or employment characteristics (e.g., working, retired, or unemployed; Arcury & Quandt, 1999). Due to the naturalistic emphasis of this project, such conditions were not prioritised. Yet, recruitment needed to begin somewhere. As described in Chapter 1, students in Aotearoa New Zealand do not require a disability label in order to receive special education services. In order to focus on students with the most significant disability, the characteristic I used to begin site-based sampling was access to ORS funding, denoting the student to be within the highest 1% of significant need within the general school population. Priority was given to those with the highest ORS disability category, Very High Needs.

The second step in site-based sampling was to generate a list of potential sites including places, organisations, or services. Special schools were prioritised for their contentious position in disability research, as well as in Aotearoa New Zealand’s (almost) entirely inclusive education system (as described in Chapter 2). A further reason for choosing

special schools was insider access. My position as a former special-school teacher aligned me with the special-school environment, rather than being an outsider in other transition programmes where my naivety to procedures, terminology, and policy would need to first be overcome.

Step three was to meet with the “gatekeepers” of potential sites (Arcury & Quandt, 1999, p. 129). Educators from two special schools became aware of the project through their involvement with the university, in unrelated capacities. Both school principals, an associate principal, and one chair of the board of trustees attended my research proposal presentation on 28 August, 2013. As a result of their attendance, a viable opportunity emerged for participant recruitment from within these two schools, as they had already had an in-depth briefing on specifics of the research design.

With two urban special-school sites in place, I began the participant recruitment process by meeting with the principal and associate principal (AP) in charge of transition at each school. In these meetings, we reviewed and discussed the participant information sheets (PIS), elaborating upon research design and involvement. Following an agreement for their schools to participate, consent forms (CF) were signed by the chair of the board of trustees and principals.

The fourth step was systematic invitation for participant recruitment. Senior management from the two schools and I decided that the APs, who had the closest relationship with school families involved in the transition process, would oversee this process. The APs began by extending invitations for research participation to families<sup>4</sup>. Interest in research participation was expressed by the mothers of three students, one from

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<sup>4</sup> Legal consent cannot be offered by those considered by the wider research community to be vulnerable participants. Central participants with significant disability therefore offered assent, and this process is described in the subsection on Human Participant Ethics.

Special School A, and two from Special School B (comprehensive descriptions of the schools is provided in the settings subsection). I made initial contact with each mother by phone or email. In two instances, I discussed the PIS over the telephone and sent the parents printed PIS and CF forms via their child's school teacher (see Appendix A for PIS/CF for parents). CFs were signed and returned in the same manner. Email exchange with one mother led to a face-to-face meeting to discuss the PIS directly with her and her son. The mother signed the CF after our discussions. Each mother gave consent for their child to take part in the research.

Finally, in step five, the three student participants volunteered by their mothers were compared with the rest of the potential population. Since no statistical comparisons exist between students with and without disability in Aotearoa New Zealand, Table 3.1 compares Haku, Cobain, and Faine (all names are pseudonyms; a description of each is provided in the subsection on central participants) within their special-school cohorts between the two respective schools. The statistical information provided within Table 3.1 is taken from the most recent Education Review Office (ERO) report available while each of the central student participants were attending their special school.

Table 3.1.  
*Comparison of Two Urban Special Schools and Central Participant Demographic Details*

	<b>Special School A</b>		<b>Special School B</b>	
<b>ERO report year</b>	2012		2010	
<b>School roll</b>	136		131	
<b>Gender</b>	78% male, 22% female		76% male, 24% female	
<b>Ethnicity</b>	NZ European/Pākehā 39%, Māori 25%, Samoan 8%, Indian 4%, Niuean 3%, Chinese 2%, Cook Island Māori 2%, Tongan 1%, other Asian 5%, other ethnicities 11%		NZ European/Pākehā 42%, Māori 15%, Samoan 8%, Chinese 5%, Indian 5%, Niuean 4%, Tongan 4%, African 2%, Middle Eastern 1%, South American 1%, other Asian 8%, other Pacific 3%, other European 2%	
<b># of school leavers 2013</b>	8		10	
<b>Class site for graduates</b>	5 at base school 3 in community-based satellite class		7 at base school 3 in community-based satellite class	
<b>Central participant</b>	<b>Faine</b>	<b>Haku</b>	<b>Cobain</b>	
<b>Gender</b>	Male	Male	Male	
<b>Age</b>	Aged 21	Aged 21	Aged 21	
<b>Disability</b>	Autism-spectrum conditions with intellectual disability (Not formally diagnosed)	Autism-spectrum conditions with intellectual disability	Autism-spectrum conditions, profound developmental delay, cortical blindness	
<b>Ethnicity</b>	Māori	Japanese	NZ European/Pākehā	
<b>Classroom</b>	Community-based satellite class	Community-based satellite class	Base school	

Next, I approached the teachers responsible for the students whose mothers had given consent. I delicately handled these meetings, individually, and in-person. Although school administration and parents had offered consent, the teachers were under no obligation to participate. As I invited each teacher to participate in the research, I underscored that their employer, the board of trustees, had agreed that whatever the teachers' decision was (to participate or not), would not affect their employment. I wanted to build trust because, should these informants consent, they would be assisting me to understand the transition process as it unfolded. The PIS and CF were reviewed and discussed, as I had done with the mothers.



Similar recruitment procedures continued for the duration of the study as transition continued to unfold. For example, transition support personnel, day service staff, and post-secondary programme advisors were all recruited in a similar manner. I had assumed that somewhere along the research process, consent would not be offered. Yet this never occurred.






Although the five stages of site-based sampling had been followed and consent had been offered by those involved in the transitions of three central cases, recruitment was not complete at this stage. This was a project designed to centralise the experiences of those with significant disability. Yet under university policy, individuals with significant disability were not authorised to offer consent, thus further attention was needed. Even at this early stage of research recruitment, the process of methodological adaptations had begun.

### **Human participant ethics.**

Approval was granted to conduct the outlined research procedures by the University of Auckland Human Participants Ethics Committee, reference number 9727. However, this study faced some challenging ethical issues somewhat unique to disability research.

Informed consent is the voluntary agreement of an individual (or authorised representative) with legal capacity and free power of choice, without coercion (Punch, 2009). To provide informed consent, knowledge and understanding of the nature of the proposed research are required, which includes weighting of anticipated risks and potential benefits, and ability to make an informed decision. Assent is a term used to express willingness to participate in research by persons who are considered unable to fully understand the proposed research and is, therefore, considered insufficient on its own (Punch, 2009). Disability researchers have begun to question the extent to which individuals with disability need protection. Such concerns have become overshadowed by the recognised value of first-hand insights into disability experiences that hold the potential to inform future services and treatment (Tuffrey-Wijne et al., 2009).

The central concern in the assent process for Haku, Cobain, and Faine was to distinguish research as a separate entity from, for example, school. Additionally, there was a need to highlight the contrast between myself, as the researcher, and the high rotation of individuals who interacted with each young man for care, education, and specialist services. In response to this concern, a visual assent form was created (see Figure 3.2). The form was submitted with the application to Human Participants Ethics Committee and was commended for sensitivity and consideration of the participants it engaged.

	<p>Hello, My name is Sarah. I used to work in schools just like yours. I worked with students like you who are leaving school. Now I am a researcher. That is someone who likes to learn about things.</p>
	<p>I want to learn about you. How you are getting ready for graduation and what you are doing when you leave school.</p>
	<p>If it's ok with you I'd like to:</p> <ul style="list-style-type: none"> <li>• Spend time with you in class.</li> <li>• Come with you on a few community visits.</li> </ul>
	<p>I will also take pictures and videos of our time together.</p>
	<p>If it's ok with you I'd also like to:</p> <ul style="list-style-type: none"> <li>• Talk to you</li> <li>• Talk to people like your teachers and parents.</li> </ul>



	<ul style="list-style-type: none"> <li>• Read papers written about you.</li> </ul>
	<p>Please write your name here if you feel this is OK:</p> <hr/>

Figure 3.2. Central Participants Information Sheet (PIS) and Assent Form

In actuality, the visual assent sheet was only useful in communication with one young man. Haku read through the adapted visual assent form with me, noting the text and illustration. He preferred visual communication over oral discussion. He showed his approval to take part in the research, as the visual assent form had been designed, by signing his name at the bottom.

Cobain, however, did not speak. He could not see the images on the assent form. Also, he could not confirm with any reliable certainty his comprehension of the details, were I to read the assent form to him. I decided, with the support of Cobain's transition team, that Cobain would demonstrate situational assent every time I engaged in fieldwork with him. I did this through a *sensory signature*.

A sensory signature is a recognisable pattern of sensory stimulation that is used as a greeting to alert someone with a sensory impairment to your presence, for example, when working with a blind person using a particular sequence of familiar sounds and/or physical contacts as an introductory greeting. (Firth & Barber, 2011, p. 144)

For every instance of data collection we had with one another, Cobain offered his situational assent. He did this by approaching me to hear my American accent, which stood

out from the rest of his teaching team, and touching a messenger bag (a preferred object of Cobain's), I kept on my person during fieldwork.

Since Faine was accustomed to making decisions collectively, we discussed his assent as part of a hui, the Māori term for a meeting or gathering, organised by his mother. Faine was present at the Hui, he and his mother together made their decisions to take part in the study. I read the assent form to Faine, because he could not read or write. I pointed to the images as I discussed them. Through our discussion about the research project, Faine verbally offered his assent.

Consent can be retracted at any time without reason; so too can assent be withdrawn. This potential process, however, is not straightforward and, therefore, assent required constant consideration and attention. Building trust and forging partnerships with those who supported the young men was part of this constant checking in with the research processes.

## **Participants**

### **Central participants.**

The three central case participants, Haku, Cobain, and Faine, were 21-year old males with varying manifestations of autism-spectrum conditions. Given that four out of five individuals with autism-spectrum condition are male (Jacquemont et al., 2014), the young men were representative of the dominant male presence found in special schools. Similarly, they were likely all the same age because of a policy in Aotearoa New Zealand that students with significant disability can remain in school through until their twenty-first year in order to focus on post-school transition.

Haku's mother immigrated to Aotearoa New Zealand from Japan before Haku was born. She raised Haku on her own. When Haku began school (at age 5 in Aotearoa New Zealand), his mother reported knowing nothing about special schools and, due to her son's

disabilities, was strongly encouraged by a disability support person (possibly a medical professional) that her son should attend such a school. His mother told me that Haku was only permitted to enrol at special school if she was a teacher aide in his class. This surprised me, but I didn't question it. It also surprised me that, as a child, Haku used to have loud, aggressive outbursts that were a struggle to bring under control. Throughout fieldwork I found him to be a mild mannered, sweet young man who spoke verbally, yet for whom actions spoke louder than words. His preference was to work visually to offer his opinions and more complex ideas. Haku's hobbies included video games, magazines about video games, and participating in drama and dance.

Cobain had lived in residential care support since his tenth birthday. His mother struggled with her son's living situation, but noted that the family, including Cobain's younger brother, felt Cobain's care needs were dominating their family life. In addition to autism-spectrum conditions, Cobain had significant cognitive impairment, so much so that he had not fully learned to toilet himself, and wore protection for adult incontinence. He also had vision impairment his mother described as like "seeing through Swiss cheese" (Interview transcript, Cobain's mother, T.7, in-school phase; see Appendix B for key to data source coding). Cobain did not speak verbally, and had occasional aggressive behaviours such as biting and pinching, which on the surface seemed to arise from nowhere. Cobain attended special school since age five. He was of Pākehā origins, a New Zealand Māori term for someone of white, European background. Cobain enjoyed music, food, and sensory stimulations such as shadows, the noise from a dehumidifier, and crumpled paper.

Faine lived with his older brother (age 27 at start of the study) and mother, and occasionally with foster children his mother supported. At the time of signing the PIS and CF, Faine's mother reported their household had recently gone down from 12 people to four. Faine was of indigenous Māori descent, and had a large whānau, an extended family with

very close-knit ties. Faine's educational history began in Kura Kaupapa Māori, an immersion Māori language class within mainstream school. The class ran until his intermediate years (around age 12). Faine had a few years uncustomary for secondary students, which are described in the findings chapters, then ended up enrolled in the special school he attended for three years. Until special school, Faine's mother had always been a teacher aide in his classes. Faine was a quiet and content young man, who loved to talk once he got to know you. His mother never sought a formal diagnosis of his disability label, but Faine's educational programmes indicated he had autism-spectrum conditions with related learning disabilities. Faine could not read and write, yet enjoyed using the computer to view pictures. He also enjoyed music, and was very artistic in media such as drawing, painting, sculpture, and clothing design.

Although the three young men were the central participants, I could not expect them to tell their stories independently (e.g., Angrosino, 1992; Hewitt, 2000). Many transition decisions and events were happening without their knowledge and were outside their control. To add to my understanding of the young men's transitions, I also collected data from transition informants.

### **Transition informants.**

An informant, or informant participant, is a term for the people I met during fieldwork who provided me with sources of information (Wolcott, 1987). Transition informants were individuals I spoke to or observed as part of fieldwork. Informants during the in-school context were, for example, family, teachers and teacher aides, and transition support personnel. In the post-school context, they were, for example, community support persons, residential care providers, funding agencies, and post-secondary education teachers.

Informants supplemented access to information and knowledge about each young man. I did not use informants to provide proxy information on *behalf* of the young men, as has traditionally been done in disability research (Carter et al., 2014). Rather, informants provided information on the transition processes, plans, and decisions being made that were often out of the young men's control.

In total, 60 informants informed the young men's cases. In order to focus my attention, I weighted each informant's influence on each young man's transition. The ranking process was done from my perspective. Criterion for each ranking were: high-influence transition informants were those with the most amount of hours observed in transition planning and significant authority for decision making; medium influence transition informants were defined as knowledge holders within the sphere of influence on transition planning; low influence informants were those who offered feedback on day-to-day aspects of transition related programmes with no decision making authority. The influence of each young man's informants was mapped onto concentric circles to illustrate ranking. Figure 3.3 demonstrates informant rankings for each young man.

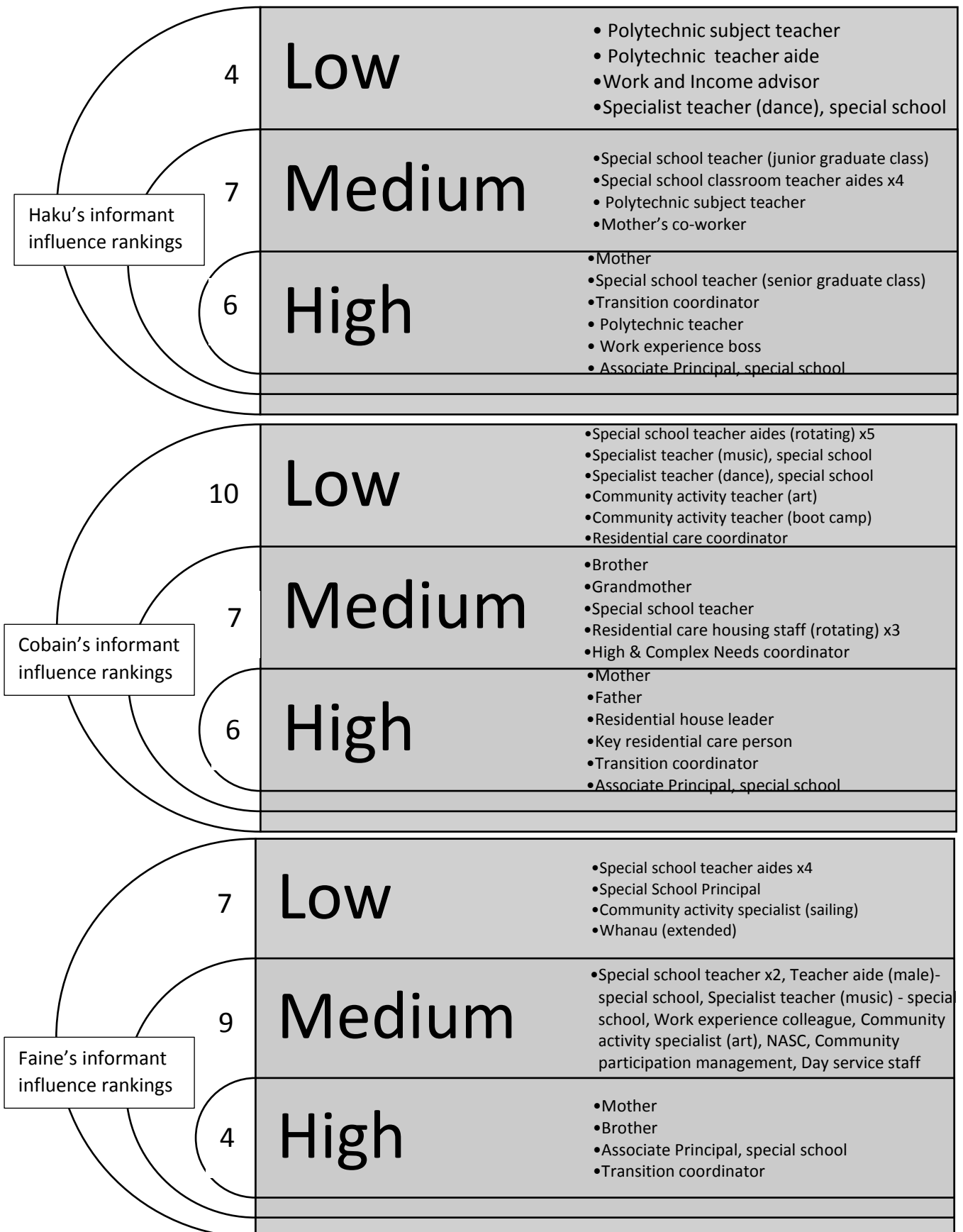


Figure 3.3 Informant rankings. Note. Numbers represent amount of informants in each category.



While all informants were essential in developing an understanding of transition and were observed interacting with the young men, moving the research forward, my focus was narrowed to interview only those considered as having high influence. For each young man, high-influence transition informants included mothers (and father for Cobain), special-school teachers, as well as APs responsible for transition, and transition providers. For Haku, who had 17 total transition informants, highest influence informants (41% of total informants) also included his boss at work experience and lead teacher at polytechnic. Cobain had 23 total transition informants, with six in the high-influence group (26% of total informants), which included also his residential care house leader. Faine had 20 transition informants, 4 considered high influence (20% of total informants), including his brother.

### **Emancipatory partnerships.**

Qualitative researchers often position themselves as the research instrument. Researcher reflexivity, then, is the process of examining both oneself as a researcher, and research relationships (Punch, 2009). Self-searching involves examining one's assumptions and preconceptions, and how these affect research decisions. While some challenge such practices, Brantlinger (1997) celebrated the fact that a phenomenon can be studied through a particular positional lens, and believed one's scholarly gaze is enhanced by moral grounding. Okely (1994) described ethnography as a constant reflexive process involving the reunderstanding of observations, eventually leading to representation of the interaction between the culture of the ethnographer and the cultures of those being studied.

Within the thesis, I have used the title *emancipatory partnerships* to refer to the relationships between myself as a researcher, the central participants, and the transition informants. The example of the distinction between consent and the assent processes for each of the young men was one example of how these partnerships played out. The assent example occurred early in the research, when partnerships were initially forming, and those

relationships evolved throughout the fieldwork. Emancipatory partnerships facilitated (and challenged) my access as an insider, and required reflexivity for me to maintain the research participants as the central focus of the study because, for example, transition informants “spoke louder” than the young men. This was because there were more informants, and their verbal and cognitive abilities meant they offered more detailed data. Thus I worked hard to facilitate the inclusion of the young men’s capabilities to work with me, and tell their stories. Evidence of the emancipatory partnerships is found throughout the thesis and particularly in the methodological adaptations detailed in this chapter, within the two findings chapters, and reflected upon within the discussion.

### **Settings**

Haku, Cobain, and Faine came from two special schools in city suburbs known for having high levels of diversity and mostly middle to low socio-economic-status residents.

Conducting the study in a suburban setting was representative of the majority of the country’s populace<sup>5</sup>. In Aotearoa New Zealand, a school’s decile ranking indicates the socio-economic status of the community in which the student lives and learns. Rankings range from 1 to 10, with one being the lowest socio-economic status, and 10 being the highest. In 2015, Special Schools A and B had decile rankings of 4.

The two schools had a network of facilities linked by a base school. In each case, the base school was the administrative centre of the school, and hosted therapy and specialist teaching services. Students with the highest needs within the school attended the base school in order to have better access to specialist services and associated adaptive equipment.

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<sup>5</sup> 2,654,850 New Zealanders lived in urban areas at the time of the 2001 census (with 71% of the population reporting) with anticipated urban growth of 20 percent between 2001 and 2021 (Statistics New Zealand, 2015).

These special schools also included satellite classes. In these settings, primary or secondary students received adapted curriculum with teachers employed by the special school, but within a mainstream educational environment. For transitioning students, both special schools also had unique community-based satellite classrooms. The aim of community-based classrooms was to learn in the very community students would be graduating into after leaving school. A storefront and an office block, respectively, had been adapted into classrooms in order for students to have easy access to public transportation and community services.

Haku and Faine both attended community-based, satellite classrooms. Their classmates were aged between 18 and 21 years old, all focused on their transitions from school. Haku would visit his base school for dance rehearsals. Faine visited his base school in his role as cultural supervisor to the school's cultural group. Cobain's classroom was situated at the base Special School B. He was one of four classmates leaving school at the end of the year, but other than these students, his classmates were younger than 18. The class focused more on sensory issues, since many of Cobain's classmates also had vision and communication impairments.

### **Procedures**

Aligned with ethnographic research design, I aimed for naturalistic inquiry, observing the three transitions from school to community without intervention. The study timeframe was the same for all three young men, three months bestriding either side of exiting school for a total of six months' fieldwork. The process of transition experienced by the young men, and those who supported them, began long before fieldwork. Likewise, transition continued long after I completed field work. For practical purposes, this project had a set fieldwork timeframe. The personal journey of Haku, Cobain, and Faine did not have such a distinct

beginning or end. Therefore, this research project chronicled a snapshot in time within a longer transition journey.

Importantly, the project was designed to promote active contributions from the central three young men. “The onus is on the receiver to listen, learn, and grasp what is being conveyed, a shift that entails extended observation, relationship, and concurrent recognition . . . as competent communicators” (Schormans, 2005, p. 112). Table 3.2 provides an overview data collection timeframe for in-school and post-school contexts. Each data source and method of recording data will be expanded upon within this section.

Table 3.2  
*Timeframe, Sources, and Methods of Data Collection*

<b>Timeline</b>	<b>Context</b>	<b>Data sources</b>	<b>Methods of data recording</b>
<b>Term 4 October – December, 2013</b>	In-school phase	<b>Observations</b> (one activity per week. Transition related events/meetings)	Field notes Photo / video
		<b>Document analysis</b> (e.g., transition plans, school reports, behaviour management plans)	Documentation
		<b>Interviews (adapted)</b> with central participants using collected photo/video <b>Interviews</b> (transition informants with high influence on transition – teacher and mother)	Audio and/or video recording with transcription  Audio recording and transcription
<b>School finished- End of December, 2013</b>			
<b>January – March, 2014</b>	Post-school school phase	<b>Observations</b> (one activity per week. Post-school related events/meetings)	Field notes Photo / video
		<b>Document analysis</b> (e.g., needs assessments, funding applications)	Documentation
		<b>Interviews</b> (transition informants with high influence on transition – transition provider)	Audio recording and transcription

### **Participant observations.**

Weekly participant observations lasted for the duration of the observed activity, typically between one to three hours per person. Observation settings and activities were suggested each week by high-influence transition informants. During the in-school research phase, settings were selected by family and teachers, and, in the post-school phase, observation settings were selected by family, transition providers, and staff from each young man's chosen post-school option.

Participant observation exists on a continuum ranging from mostly observation to mostly participation. Wolcott (1999) distinguished between active participant, privileged observer, and limited observer, each with their own consequences for ethnographic data collection. Due to my former role as a teacher, I could be most accurately described as a privileged observer. Overall, the ability to be unencumbered by the day-to-day processes of teaching (e.g., schedules, reports, meetings) enabled me to see transition, and those involved in it, in a whole new light. The number of hours of observation are broken down for each young man in Table 3.3. Planning meetings, interviews, and consent processes were classified separately from the number of hours logged in observation of in-school or post-school contexts.

Table 3.3.  
*Breakdown of Research Hours from October 2013 – March 2014*

	<b>Haku</b>	<b>Cobain</b>	<b>Faine</b>
<b>In-school context</b>	17	19	14
<b>Post-school context</b>	8	11	5
<b>Planning meetings</b>	4	6	3
<b>Interview (central participant and informants)</b>	3	2	3
<b>PIS/CF</b>	2	3	3
<b>Total</b>	34	41	28

**Field notes.**

Immediately following each participant observation, field notes were recorded. Field notes included time and place descriptions, as well as noting who was involved and the event, activity, or context being observed. A wide range of events were observed and rich details about what took place were recorded and are summarised in Table 3.4 for each young man across in-school and post-school contexts. A general description of the context was included in the field notes. I wrote down the setting as I saw it, described individuals involved and their relationships, and identified the activity occurring. Where appropriate, I recorded what Haku, Cobain, or Faine were saying and doing, and to whom or what. Likewise, I described what was happening to each young man, and with whom. In field notes, I also chronicled any photographs and videos taken or artefacts collected during the observation. The number of field notes recorded is listed in Table 3.4.

Table 3.4.  
*Research Settings and Corresponding Number Field Notes for Each Participant*

<b>Name</b>	<b>In-school</b>	<b>Post-school</b>	<b># Field Notes</b>
<b>Haku</b>	Classroom (community based), specialist programmes (dance), show-grounds (disability arts festival), polytechnic (application interview), school ball, community work experience, base special school (dance rehearsal), community gym, and graduation	Work and Income New Zealand (WINZ) – Ministry of Social Development, polytechnic (classrooms, teacher offices, break room, and library), and transition coordinator administrative offices	14
<b>Cobain</b>	Classroom (base school), community outings (mall, regional park), school specialist programmes (music, assembly), school ball, school report meeting, graduation, residential care home (transition planning meetings)	Community hall (sensory art), public walkway (walking group), disability day-service facility (music class), public park (boot camp), and community club (disco)	21
<b>Faine</b>	Classroom (community based), school specialist programmes (music), show-grounds (disability arts festival), base school (prize giving and graduation), community work experience, school ball, community art class, community market day, intermediate school (Faine's mother's employment)	Community participation day service, transition coordinator, administration offices, and Sail-ability	11

#### **Artefacts.**

Artefacts included documentation, photographs, and videos. Each served, at times, both as sources of data in and of themselves, as well as methods of data recording. Table 3.5 combines the number of artefacts collected across all three young men, and, for the sake of simplicity, breaks down each artefact by type, rather than purpose or use. Further description is provided to clarify or account for the varied uses of artefacts.

Table 3.5.  
*Artefacts per Central Participant*

	<b>Total artefacts</b>	<b>Documentation</b>	<b>Photographs</b>	<b>Videos</b>
<b>Haku</b>	74	9	49	16
<b>Cobain</b>	87	19	53	15
<b>Faine</b>	65	7	50	8
<b>Total</b>	226	35	152	39

Context-specific documentation was used as a source of data and was collected throughout fieldwork. For example, during the in-school context, documentation included school reports, IEP's, teaching programmes, and behaviour profiles. In the post-school context, documentation included funding applications, residential planning files, and post-secondary school plans.

Documentation that served as a method of data recording was what I consider to be more “modern” or “non-traditional” forms of documentary data, including emails, Facebook posts, text messages, and PowerPoints. Of these non-traditional forms of documentation, some, such as emails and text messages, were composed for me as their intended audience, while others were written for wider audiences. For example, Facebook posts were composed for many to see and share. PowerPoints were used as ways to compose school reports and educational and transition portfolios.

Photographs and video recordings similarly served a range of purposes. First, photos and videos were taken to supplement field notes during participant observation. For instance, in order to describe what I was observing (e.g., a student's expression or interaction) I took photographs or a 30-second video clip. Photographs used in adapted interviews were either taken by myself or by the young men themselves.






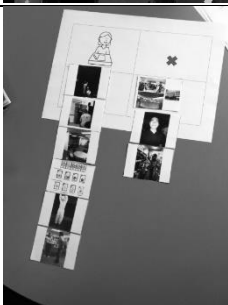

### Adapted interviews.



Table 3.6 outlines the types and numbers of adapted interviews conducted with each young man throughout the course of field work. Adapted interviews were informed by the participatory research reviewed in Chapter 2. Adapted interviews were further individualised to each young man's communication preferences and capabilities through information gained by way of emancipatory partnerships. Interviews were audio-recorded, where appropriate, and transcribed. Where interviews were silent, photographs and video were used to record responses.

Table 3.6.  
*Number of Interviews by Type and Participant*

	Number of adapted interviews	Types of adapted interview
Haku	4	- Participatory photographic (adapted) - Object interview - Context interview - Visual symbol exchange interview
Cobain	3	- Show me interview - Object exchange interview x 2
Faine	6	- Participatory photographic (adapted) - Context interview - Visual symbol exchange interview - Informal chat x 3
Total	13	

Figure 3.4 is used to describe and provide visual samples of each adapted interview type for each young man. In adapting Haku's interviews, preference was given to his ability to show, more than tell, his perspective. Variation best suited Haku's communication style. Cobain required the most significant adaptations from traditional qualitative interviewing. He embodied the data he shared through physical gesture or exchange of objects. With Faine, I used the same variety of adapted interviews as I had with Haku. The most productive style of interview for Faine, however, was having informal chats.

Adapted Interview Type	Visual Sample	Description
<p>Participatory photographic (adapted) interview.</p> <p>Conducted with Haku and Faine.</p>	 <p>* Photograph of weekly goal setting taken by Faine</p>	<p>In response to my request to be shown (a place), photographs were taken by the young man. Discussion was held during and after the collection of the images.</p>
<p>Object interview</p> <p>Conducted with Haku.</p>	 <p>*Photograph taken by Sarah of the contents of Haku's backpack</p>	<p>Key transition artefacts were described by the young man.</p>
<p>Context interview</p> <p>Conducted with Haku and Faine.</p>		<p>Photographs were taken within transition environments deemed to be important. Photographs were discussed in the environment where the photographs were collected.</p>
<p>Visual symbol-exchange interview</p> <p>Conducted with Haku and Faine.</p>		<p>Elements from the other interviews were brought together as the young men interacted and manoeuvred printed images in order to sort and rank preferences (See Appendix C for questions and sample responses from Faine).</p>
<p>Show me interview</p> <p>Conducted with Cobain.</p>	 <p>* Photograph taken by Sarah of the olive grove.</p>	<p>In response to my request to be shown (a place), I was guided (i.e., holding my arm and taking me somewhere).</p>

<p>Object exchange interview</p> <p>Conducted with Cobain.</p>		<p>Objects were presented and physically exchanged (note, further description is found in Cobain's case narrative).</p>
<p>Informal chats</p> <p>Conducted with Faine.</p>		<p>Unstructured conversations, important issues were raised, rather predetermined by pre-structured questions and conversation probes.</p>

*Figure 3.4. Samples of Adapted Interviews and Responses*

### **Informant interviews.**

Interviews were conducted with transition informants considered to be of high influence. The majority of the interviews followed a semi-structured interview format. The questions differed slightly, depending on the interviewee. Sample interview questions are provided in Appendix D. Overall, the intention of the questions was to differentiate the informants' own perspectives from what each young man was feeling about his own transition. All interviews were audio-recorded and transcribed.

There were six informant interviews about Haku. Interviews with Haku's mother, school teacher, and transition coordinator all followed a semi-structured format. The interviews with his work experience boss, special school Associate Principle, and lead polytechnic teacher were unstructured. Questions probed for setting descriptions, and gained a general sense of how Haku fit in within the related interviewee's environment.

Six informant interviews for Cobain followed a range of structures. Two semi-structured interviews were conducted with Cobain's mother (his father was unable to attend) and transition provider. The rest of the interviews were unstructured. Two interviews were

conducted and recorded with Cobain's school teacher, and one with a school specialist music teacher and special school Associate Principle. The final two were more situational, open-ended interviews with the residential house leader and key residential care provider regarding Cobain's individualised community program. Interviews were not audio-recorded, but documented within field notes.

Four transition informant interviews were also conducted with Faine's high-influence informants. Interviews with his mother, two school teachers, and transition coordinator followed the same semi-structured questions that were used with the other informants. Another interview with Faine's day-service manager was unstructured and followed a format of describing the community day-service culture and how Faine was fitting into it.

### **Data Analysis**

Analysis was conducted in multiple, deductive and inductive, waves. Deductive analysis framed by the capability approach (Nussbaum, 2011; Sen, 1999) involved noticing and naming the young men's personal capabilities, then reviewing the way they informed each transition. Using an inductive approach, two themes emerged that impacted the three transitions.

By the end of fieldwork, I had collected a great deal of multifaceted data. While data analysis procedures are explained linearly, the process was, in reality, recursive, going back and forth between various steps and stages. Thematic analysis was used to provide a flexible and useful framework to manage the complex, qualitative data corpus (Braun & Clarke, 2006). Themes were pinpointed and examined, and patterns were recorded in order to answer each research question.

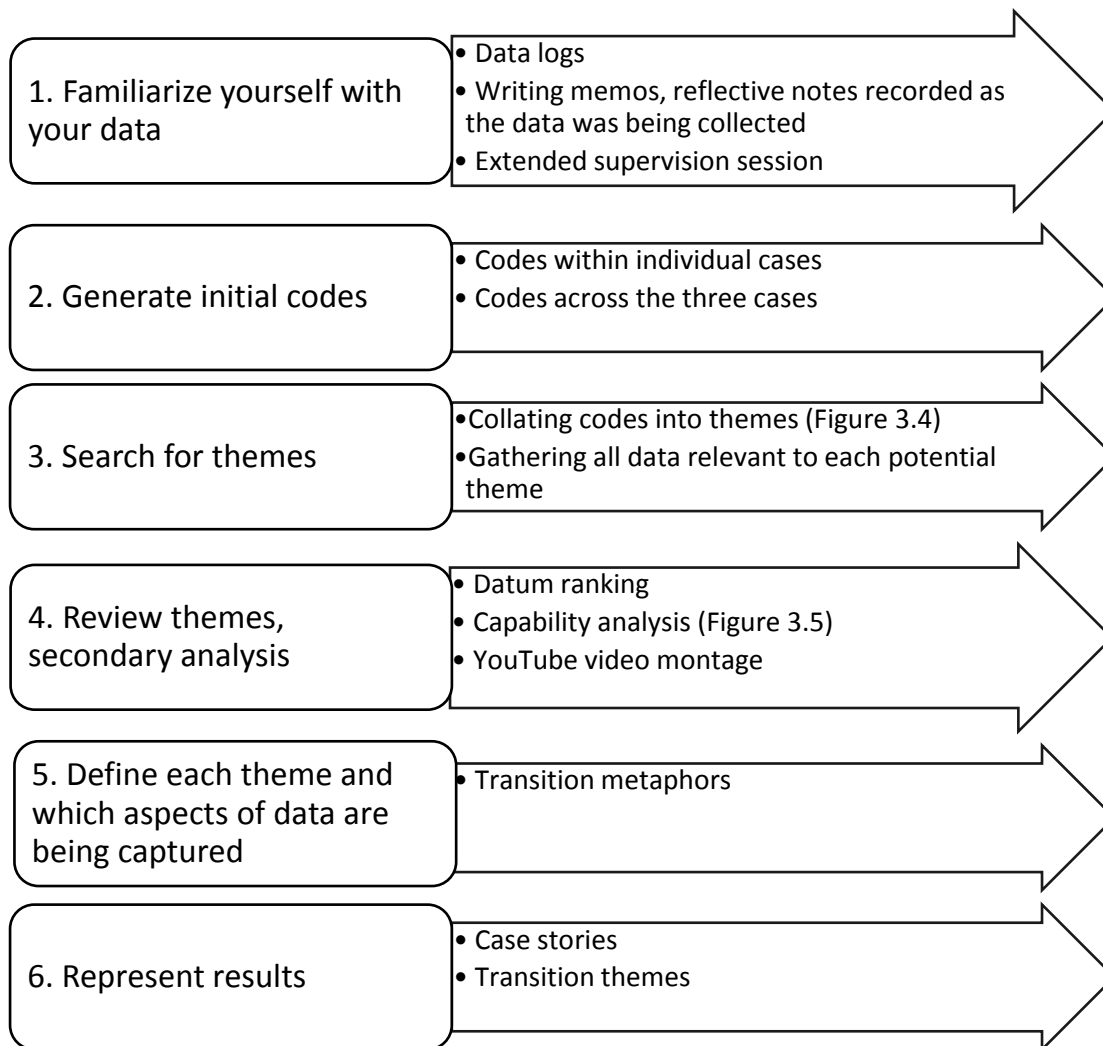


Figure 3.5. Thematic analysis model. Adapted from “Using thematic analysis in psychology,” by V. Braun and V. Clarke, 2006, *Qualitative Research in Psychology*, 3(2), p. 87.

Figure 3.5 provides an overview of the analysis procedures. Stage 1 was to re-familiarise myself with the data. I did this in three ways. First, I revisited the data logs for each young man. Data logs were records of observation details (time, place, and people), plus chronicling artefacts collected during the observation, including any visual artefacts collected. Data logs provided a sequence for each transition. Second, I reviewed memos I had made during data collection. Memos were inserted as comments made within documents or datum. For example, using the comment feature in Word, notations were made about a previous observation or whether two different informants spoke about the same topic. Also, throughout fieldwork I collected further thoughts, questions, ideas, and notes in a separate

word document. Finally, in an extended supervision session, I presented my supervisors with exemplars of each data source and methods of data recording for each of the young men. Each were discussed in collaboration.

Stage 2 was to generate initial codes by combining interesting features of the data in a systematic fashion across the entire data set, and collating data relevant to each code. N-Vivo qualitative data analysis software (Version 10) was used at this stage. Initial nodes were made for each young man, including an “interesting” node for data that fell outside of recognisable patterns. A fourth node was created for a secondary listing of data that overlapped between the young men. Therefore, some data excerpts were listed twice, once within nodes related to the individual, and a second time within shared nodes.

Stage 3 was to search for themes by collating the N-Vivo nodes. Each potential theme was reviewed by looking across all data. This process was completed for every overlapping theme across the three young men’s cases. Table 3.7 outlines the two central themes with definitions, along with the nodes that informed the collated themes. In particular, nodes reflect a combination of direct quotes used by transition informants, and labels or tags placed on chunks of data. Each theme has two applications, as described.

Table 3.7.  
*Nodes, Themes, and Descriptions Derived from Cross-Case Analysis*

<b>Nodes</b>	<b>Theme</b>	<b>Description of Theme</b>
<ul style="list-style-type: none"> <li>• "Factories" (safe spaces)</li> <li>• "Cherished for what he has to offer" (belonging)</li> <li>• "No man's land" (community acceptance)</li> </ul>	Trialling (Brokerage)	"Doing, looking, and working it all out" of post-school community options (Interview transcript, transition provider, T.8 (t), post-school phase).
<ul style="list-style-type: none"> <li>• "Making sure the pathway is clear" (transition planning)</li> <li>• "Clicking time over" (involvement)</li> <li>• "Flicking a light switch" (transition handover)</li> </ul>	Trialling (Outcomes)	(1) For students to familiarise themselves with the post-school environments they will be transitioning into, and (2) to let the relevant new staff and student get to know one another.
<ul style="list-style-type: none"> <li>• Pilot transition programme</li> <li>• Ministries</li> <li>• Residential care service</li> <li>• Funding "purse"</li> </ul>	Silos (Structural)	Break down between agencies and systems involved in transition, and individual implications.
<ul style="list-style-type: none"> <li>• "Grieving process all over again" (family emotions)</li> <li>• Transition coordinators</li> <li>• Special-school teachers</li> </ul>	Silos (Interpersonal)	Fractures in interpersonal collaborations between those who supported each transition.

Stage 4 of thematic analysis was a pause to review themes, checking if the themes worked in relation to the coded extracts and the entire data set. Within this fourth stage, I realised my analyses were incomplete. Important inductive themes related to transition had been explored, but in order to understand personal perspectives of transition, and transition with dignity, analysis required theoretical positioning.

Thematic analysis paused on this fourth stage, in order to construct and conduct deductive analysis theoretically framed by the capability approach. This strategy allowed me to refocus and centralise the young men's perspectives, access latent themes, examine

underlying ideas, assumptions, and conceptualisations. There were three steps to this capability analysis. First, as demonstrated in Table 3.8, each datum was ranked for its relevance to answering each research questions across the three young men.

Next, the personal capabilities of each young man were more closely examined by noticing (and listing who noticed), naming, and describing each capability demonstrated over the course of fieldwork. This process included listing the function of the capability for the young man, and the potential applications the capability held. Note, an example is provided for Cobain in Table 3.9, but each step of capability analysis was conducted for each young man.

Table 3.8.  
*Capability Analysis Step 1 Excerpt (Cobain)*

Datum	Type	In-school	Post-school	Ranking	Description
A.1	Bridging programme plan	X		T, C	Timetable, transition trialling, friendships
A.2	Timetable	X		0	No details
A.3	Mid-year report	X		T, C	Extending ability and maintaining skills
A.4	Graduate photos	X		T	One of the very few of him smiling

Data ranking: T (transition), C (capability), 0 (neither)



Table 3.9.  
*Capability Analysis Step 2 Excerpt (Cobain)*

Forbearance - He can sit contently himself or next to someone for an extended length of time (A.2 and A.3)			
Noticing	Naming	Informant interpretation (what is)	Capability interpretation (what can be)
Specialist teacher (music)	A. 8 standing next to piano in music lesson.	Passing time. Staying content without changing location.	Enjoyment
Teacher aide	FN. 2 Once in the car park, [teacher aide] got a text saying another student was out of adult diapers. [Teacher aide] apologised to Cobain and said we needed to make a stop off before his individualised community programme. Cobain seemed happy, compliant, content during 45 minutes of diversions (Cobain rocked, sat, and stayed close to [teacher aide]). He happily got back into the car and we made it back to the beach.	Accepts change, even from leaving preferred activity of beach walk. Cobain must <i>trust</i> teacher aid will return to preferred activity?	Trust and caring for others.
Sarah	FN. 17 He lay on his bed (P.38 & P.39), finger picked/chewed a piano keyboard floor mat (P.40), finger picked/chewed his blanket (P.41), and played with his shadows (P.42 & 43 & 44).	House staff were packing lunches and preparing for next activity, and Cobain was helpful by not interfering.	Hobbies
Sarah and school teacher aide	P.1 & P.2 Cobain playing with his shadow on community outing on sunny day.	Behaving	Enjoyment, hobby

In the third aspect of theoretical, capability analysis, each young man's personal capabilities were cross-referenced across the entire data corpus. This process culminated in the creation of a 2-3 minute video montage for each young man. The videos named and demonstrated the young men's personal capabilities across documentary, text-based data, combined with moving and still images, and was set to music of personal preference.

Sharing the constructed videos publically was beyond the consented ethical permission. Thus, after the completion of the capability analysis sub-steps, Stage 5 involved assigning a single, still image metaphor representative of each video. Metaphors were personally selected by combining the capability themes of each young man's video montage with central components of capability theory (e.g., capabilities, functionings, adaptive preferences). Metaphors have a noteworthy history in their contribution to scholarly endeavours (e.g., Lakoff & Johnson, 1980). Metaphors were selected for their ability to anchor typically unheard transition journeys, and provide understanding of personal strength and capabilities.

Finally, Stage 6, was the production of the final report, or in this case, the findings reported in this thesis. There are two chapters that report these findings. The first research question is addressed by way of three case narratives linked by the common transition artefact of a timetable. Each narrative concludes with a transition metaphor. In the second findings chapter, I address issues that impacted the transition of all three young men. Each chapter provides thick description in order for the reader to draw their own conclusions and applications, while also remaining transparent in the processes I used to report the results.

### **Disciplined Inquiry**

“Good research is a disciplined form of inquiry” (Cronbach & Suppes, 1969, quoted in Punch, 2009, p. 306) or “systematic self-critical inquiry” (Stenhouse, 1981, p. 103).

Disciplined inquiry is distinguished “from all sources of opinion and belief . . . and is conducted and reported in such a way that the argument can be painstakingly examined”

(Cronbach & Suppes, 1969, quoted in Punch, 2009, p. 306). Cronbach and Suppes continued,

Disciplined inquiry does not necessarily follow well established, formal procedures.

Some of the most excellent inquiry is free-ranging and speculative in the initial stages,

trying what might seem to be bizarre combinations of ideas and procedures, or restless casting about for ideas. (Quoted in Punch, 2009, p. 307)

This empirical project can be evaluated by the discipline used in addressing theoretical commitments, and by the transparency of procedures regarding contributions to qualitative methodology, emancipatory research, capability theory, and transition practices.

Qualitative research is not done for the purposes of generalization but rather to produce evidence based on the exploration of specific contexts and particular individuals. It is expected that readers will see similarities to their situations and judge the relevance of the information produced to their own circumstances. (Brantlinger et al., 2005, p. 203)

My aim is to provide transparent detail in order that future researchers can make informed decisions about the applicability to their own personal interests and practices.

### **Credibility.**

As this is a doctoral research project, credibility of the findings presented are underscored foremost by the processes of doctoral supervision. All aspects of the project, from conception, design, and execution, to analysis, proceeded in consultation. This form of “investigator triangulation” (Brantlinger et al., 2005, p. 199) ensured research design and interpretations were not idiosyncratic to my personal perspectives. Additionally, the extensive description of data collection measures culminates in a record of prolonged and substantive field engagement. All data collection measures were recorded to create an audit trail, which documented the chronology and the amount of time spent at each stage of fieldwork.

This chapter described the ways methods were open and flexible enough to collect data from individuals with significant disability. In doing so, a precedent is set, whereby it will be insufficient for future research to exclude marginalised groups for being too difficult to collect data from. The methods outlined here are by no means exhaustive. Instead, they

open opportunities for participation, and are an initial contribution to a “qualitative toolbox” (Owens, 2007, p. 300). After opening the toolbox, partnerships are needed with those who take part in the research to choose and adapt the tools to best suit the communication preferences of their research participants. In this sense, the qualitative tools can be seen as limitless and ever-expanding.

Through theoretical positioning of the capability approach, this project can be evaluated for the way it emphasises diversity as beneficial for a richer and fuller society. More specifically, for the space created for students with disabilities to make a contribution towards improving transition practices, instead of simply being the recipient of transition services. The methods described in this chapter would not have been possible without belief in human capability, that every human being, by virtue of their humanity, has a story - or data - to share. In this sense, there is no better way to evaluate this work than to judge its ability to be “informative” as well as “transformative” (Barton, 2005, p. 318).

## Chapter 4 - Findings: Case Narratives

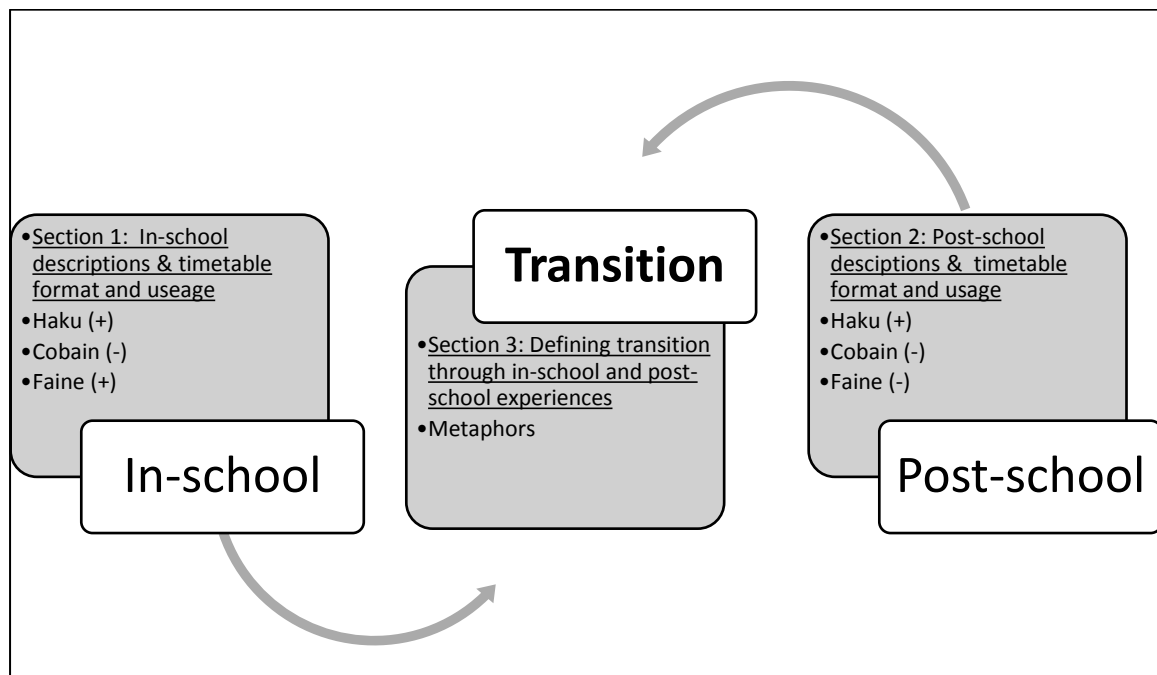
Chapter overview: This chapter addresses the first research question regarding the young men's perspectives of their own transitions. Rich descriptions of in-school and post-school environments are used to convey an understanding about transition, as well as to reveal the many significant personal capabilities of each young man. This chapter frames in-school and post-school descriptions through a central transition artefact. The use (or lack thereof) of a personal timetable, or calendar organiser, frames the evaluation of Haku, Cobain, and Faine's transitions. Each case narrative concludes with a representative transition metaphor discussed in light of an aspect of capability theory.

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This chapter addresses the first research question: What are the perceptions and meanings of transition experiences for individuals with significant disability? Across the three young men, no singular, all-encompassing transition experience existed. Case narratives are used to present each young man holistically, his transition contexts and journeys, prior to breaking down each experience by way of inductively analysed themes in the next chapter. The use of case narratives is aligned with Denzin's (2001) challenge to "experiment with alternate ways of presenting information" (p. 153). Findings presented in this manner support Denzin's claim that there is no single, interpretive truth, only storied or narrative accounts.

Transition is viewed as the amalgamation of in-school and post-school experiences. Figure 4.1 is an organising framework that illustrates the way in which each case narrative is described. Within the figure, details provided from in-school and post-school experiences culminate in understanding students' personal perspectives of their own transition. The

positive (+) or negative (-) notations next to each name refer to whether or not a consistent and meaningful transition timetable artefact was used during the particular transition stage.



*Figure 4.1.* Structure of each case narrative. Note: Symbols denote use (+), or lack thereof (-), of timetables in each setting for each young man.

A timetable is meant here as a schedule, diary, organiser, or calendar; a way of organising and structuring within and between days and activities, which was individually designed for the student using it. Each young man's timetable looked different and was used (or not used) in idiosyncratic ways. These timetables served as a pragmatic, tangible lens through which each young man represented and understood his own transition. Description of transition-related activities show, on the surface activities each young man enjoyed, and the nature and frequency with which he engaged in those activities. On a deeper level, theoretically framed by capability, timetables showed potential functionings. They enabled each young man to communicate his knowledge, and apply his understanding towards his post-school future. Timetables in and of themselves may seem a small, limited item, but the implications of timetables are far reaching.

Each case narrative concludes with a metaphor. Metaphors have a noteworthy history in their contribution to scholarly endeavours (e.g., Lakoff & Johnson, 1980). The metaphors in this chapter were chosen as a way to represent what I came to know about each young man's process of understanding his own transition. These metaphors are a culmination of all of my fieldwork. Text is supplemented by a visual image because, with the exception of Cobain, visual formats were meaningful to each young man.

Each metaphor concludes with discussion related to capability theory. Details are provided to explore the interconnection between each young man's personal capabilities and socio-political contexts that either supported or obstructed his ability to convert valued capabilities into life functionings. In doing so, the "assessment" of "quality" of each transition is not measured by personal satisfaction with transition outcomes, or the way things turned out, but rather in the genuine opportunities that continued once school had finished.

### **Haku**

Haku moved from strength to strength in his transition. Evidence in this section demonstrates positive experiences in both the in-school and post-school contexts. Correspondingly, the timetable Haku used successfully in both environments will be described.



*Figure 4.2 .Haku cleaning the power tools at his work experience at the building supply store*

### **Section 1: In-school: Special school and Haku's capability.**

Haku had attended special school since age 5. In an interview, he shared the following views of his special-school experiences:

Haku: [B. School] means to be special school. And we get some to the to the *special people and autistic and artistic.*

Sarah: Interesting! What are special people?

Haku: It's getting, wandering around people and also maybe...

Sarah: This is very good, Haku. Please tell me more.

Haku: [B] special school is the special needs and she's gonna help us, teacher aides and teachers. *[B] special school helps us and special needs and teachers and teacher aides.* (Interview transcript, Haku, T.2, in-school phase, emphasis added)

In this extract, key words are italicised in order to show how Haku expressed his personal understanding of special school. He unpacked central features of special-school life: help and support from teachers and teacher aides, and students who have both disability and capability, "autistic and artistic." Haku was unable to verbally describe the differences between his class and the classes at his base school. Through a photographic interview, however, he identified some features that made his class unique from a typical classroom. For example, unlike a typical classroom, his classroom contained such things as a video game console with corresponding flat screen TV and couches. This 'senior learning environment' was more akin to an office breakroom, with kitchenette, computers, and work desks included.

Haku's community-based classroom was a safe, familiar space. In the adapted interview I asked Haku to show me his classroom by taking photographs using the camera feature on my smart phone. He photographed cupboards and described from memory objects that were found in each. Through photographs, he drew attention to the wall displays that highlighted some of his achievements over the school year. His photos were taken during his



solo dance performance in the disability arts show, community gym, and work experience. In this manner, he drew my attention to the features of the class curriculum that were important to him. The activities did not appear to be out of the ordinary in relation to his class's curriculum. After getting to know Haku within his school, what stood out, however, were Haku's competencies in the activities he highlighted; he appeared to have a far higher level of mastery than his peers in the examples that he chose to portray.

One of my first observations of Haku was at a 3-day disability arts festival. Haku's class was performing a dance routine and he enjoyed a central role, as a principal solo dancer. I found it exciting to see Haku present himself so creatively and competently at the start of my fieldwork. He performed his solo with accuracy and precision in front of all his teachers, school administrators, his mother, and transition provider. Haku was also part of a second performance at an evening community group he attended after school.

I observed another of Haku's skills in the community gym. Haku and a male classmate independently managed everything related to the gym. They walked to the gym from their community-based classroom, used a gym tag to sign in, put their gym bags away in the locker room, then stretched and used weight and cardio training machines. Both young men used a visual booklet with photographs made by their special-school teachers to guide their gym routine. Haku referred to his dutifully, while his classmate followed Haku's lead. In my opinion, the teacher aide accompanying them to the gym appeared unnecessary.

Another photo featured on his classroom wall, to which Haku drew my attention, was of his work experience. Haku worked unpaid, three hours per week at a building supply store. Staff from school dropped him off and picked him up in a school-owned car used for transporting students engaged in work experience. In the past, staff had to support Haku at

the employment site. He had been doing the job for two years at the time of my observation, so now he worked independently with only the supervision of his boss.

Haku's work experience was fun, even for me as an observer. Haku had a set work routine, to dust and wipe down the display case at the front of the store, that he had memorised, and he later described to me in our context-led adapted interview. "There's over \$200,000 worth of products he's handling on those shelves," his boss told me (Quote transcript, field notes, FN.3, in-school phase). While Haku worked on his cleaning routine, his boss sat at the front checkout counter greeting and joking with customers. When Haku's boss needed him for an extra errand he yelled loudly, "Captain!" Responding to his nickname, Haku would stop what he was doing, briskly walk up to the checkout counter, and occasionally even salute his boss in a joking fashion, replying, "Yes, Chief!" Haku's one-off tasks included passing messages across the various store departments, and assisting in unloading vending machines.

Haku's boss was like a proud father, and bragged about Haku's accomplishments as he worked. "He's strong," his boss observed as he showed me boxes of nail packaging Haku stacked for them. Haku chimed in, "that's because I go to the gym." Then I was told about how Haku assisted in the annual store stocktake. "Nothing wrong with his counting at all! Haku's counts go straight to the head office," his boss told me. When Haku first started the job, he wouldn't talk, his boss recalled. "He's come a long way" (Field notes, FN.3, in-school phase).

When I asked Haku, in our context based interview, how long he had worked at the building supply store, he didn't know. He wanted to have an answer, so first he told me he went to work every day, then that he'd only been working at the building supply store for one month. What he did know, with perfect accuracy, was all of his work colleagues' names. He

greeted each of them as they walked into the break room. Likewise, he knew all the power tool names and manufacturers.

**Timetables.** At the beginning of my fieldwork observation with Haku, I found him writing in his timetable. Haku used an A4-sized hardbound, daily diary to plan, structure, and review each day. Once a week, he glued in a weekly calendar to give an overview of his activities and note any changes in his weekly routines. I described my first observation of Haku writing in his diary in the following field notes.

I walked into Haku's senior side of the classroom where I found Haku working on his timetable. I sat next to him and watched as he filled in his weekly calendar with neat and steady penmanship. He knew the procedure well: fill in a blank printout timetable, cut it to fit the diary size, and paste it in on the page. He knew the content of the timetable and activities from memory. One of the teaching assistants came over to let him know about some of the changes for the upcoming week that he noted on the timetable. (Field notes, FN. 1, in-school phase)

In his end-of-year school report, Haku's special-school teacher commented,

Haku continues to write in his diary when he is at school. He uses his timetable to manage his school week and it was lovely to hear of Haku preparing and planning ahead for various school activities without Mum even knowing it was happening. Super management Haku, your weekly timetable is so busy that I am sure you are the only one who knows what is happening each day. Well done! (End-of-Year report, Artefact A.5, in-school phase).

## **Section 2: Post-school: Polytechnic.**

Haku transitioned from school into a polytechnic programme akin to a trade school, in a course specifically designed for students with disability, to learn pre-employment skills. As a

prerequisite, he had attended a one-day-a-week course during the final semester at special school, which will be discussed further in the next chapter. The polytechnic curriculum was geared towards students who held few or no credits<sup>6</sup> from secondary school. The polytechnic course was popular. Approximately 50 new students enrolled each year, coming from suburbs across the city.

In one of the two transition planning meetings I attended with Haku, related to his forthcoming attendance at polytechnic, the transition team discussed the full-time nature of the polytechnic programme: from 9:00 am to 3:00 pm, five days a week. During the meeting, Haku chimed in and requested a return to work experience at the building supply store. There had been an assumption he would finish his work experience in order to attend polytechnic full time. The team scrambled and paused to consider how they might be able to accommodate Haku's request.

Following the meeting, and again in a Facebook post, Haku's mother expressed surprise at her son's assertiveness in the meeting. She knew if her son expressed an interest in getting back to work experience, it was important to him, and she called upon his transition coordinator to make this happen for her son. Haku's boss was happy that he continue, and the polytechnic programme teachers agreed that Haku could miss one morning a week in order to work.

I observed Haku's first day in the polytechnic. The day was as stereotypical as any first day I could imagine: taking a campus tour, and being issued a student ID. Reflecting upon my observations, what stood out in my mind was how this was likely one of the most inclusive days of Haku's polytechnic experience. All other days that I observed were held on

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<sup>6</sup> New Zealand's National Certificate of Educational Achievement (NCEA) is the national qualification for senior secondary school students. NCEA and the related national certificates are used as benchmarks for selection into university, polytechnics, and employment.

a segregated part of campus in classrooms designated only for students in his pre-employment programme. The only opportunities for inclusion within mainstream campus activity were at lunch times when students had the option to eat at one of the campus cafes. I never observed Haku choose this option. He preferred to eat lunch in the polytechnic programme's staff room, an option available to, and commonly used by, many students in his programme.

Once the polytechnic programme was underway, I observed Haku during a mathematics lesson. The class of 56 was broken into small groups. Each group was responsible for transferring an image from paper on to the sidewalk, by following a grid pattern. Haku was very good at it and did most of the sidewalk chalk drawing. Two of Haku's peers photographed him and the other groups working. The two students photographing had physical disabilities that prevented them from being able to get down on the ground. They joined me, I assumed because I, too, was not directly contributing to a group, rather simply observing the lesson.

After the mathematics lesson, I met with the lead polytechnic teacher. The lead teacher said she often found students from special schools to be very well prepared for the pre-employment programme at polytechnic, yet there were not many of them. Haku was one of only two students in the polytechnic programme from a special school. We agreed he was quite resilient in coming to polytechnic with no social connections when he arrived. The lead teacher mentioned his coping skills: "In computing class, he knows to sit next to two students who *have it* and he can watch and follow them" (Quote transcription, field notes, FN.12, post-school phase).

The teacher then described students who more commonly enrol at polytechnic. She pointed out one young woman who had come from a fully inclusive secondary school

experience. The young woman struggled to adjust to the disability-specific polytechnic programme because she had never realised until now that she, in fact, had a disability. The teacher then indicated another student, a young man who had Down Syndrome, with the best reading comprehension this teacher had ever taught. The teacher pointed out there were no other places for him to go after secondary school. He had skills beyond his peers in the pre-employment course, but not enough credits to enrol in other tertiary programmes. The lead teacher said she constantly grappled with how segregated her students were from the rest of the polytechnic campus, however she could see no other alternatives.

**Timetable.** On the first day at polytechnic, a free orientation tote bag was issued to each student. Amongst other items in the bag was a diary in the same format as the one Haku had used in special school. Students were directed by the lead teacher to put their name and contact details inside and while they had a pen handy to also sign their ID card. They were told to look after the diaries, as they would be used in important ways all year long.

On my next polytechnic observation, Haku's class had a free half hour that they used to finish a previous assignment-worksheet activity. I observed them cutting the worksheet to fit into their "visual diary" and listing the activity on their contents page at the front of the book. As described in my field notes:

The procedure of writing in his visual diary had now become second nature to Haku. The teacher handed out a slip of paper asking the students to describe the lesson in one word. She collected the words anonymously and comments included, 'fun and happy.' 'Good-ish,' was Haku's word. The student next to Haku asked for help on spelling *excited* and mistook *d for b*. Another student used a dictionary to spell her word. (Field notes, FN.11, post-school phase)

When assessed by the consistent timetable format, Haku's movement into polytechnic went seamlessly. Through diary use in in-school and post-school contexts, Haku could set out his week, note any changes to schedule, plan for upcoming activities (e.g., budget, list items to bring), as well as use the diary to debrief on how activities went, as described in the field notes from polytechnic. Haku transitioned from what was acknowledged to be masterful use of his timetable in special school, to having the same confidence in using his timetable at polytechnic.

Interestingly, this consistency in timetable use was serendipitous, not planned. Since every polytechnic student (institution-wide, not solely the students in the disability-specific pre-employment course) was issued a diary, it was purely coincidence that Haku used the same timetable structure in both school and post-secondary environments. Timetables were personally meaningful, individualised, and served as a daily anchor that provided consistency and stability during a challenging time of life.

### **Section 3: Transition.**

Haku's polytechnic course was funded by a government-provided training incentive allowance (TIA). The funds were accessed through Work and Income New Zealand (WINZ), one of the service delivery clusters within the Ministry of Social Development. WINZ describes the rationale for TIA funding on their website,

Clients at risk of long-term benefit dependency and with specific deficiencies in employment skills may be able to have their course fees paid for. Depending on your circumstances, up to a maximum of \$4,240.80 in total may be paid for course fees, transport, books, stationery and any additional caring costs you may have" (WINZ, 2014)

Haku was fortunate to have funds available to him, though a question lurked in my mind, posed by Haku's special-school teacher in our interview during the in-school phase of fieldwork: What will be left to support Haku after polytechnic finishes?

*Metaphor.* Figure 4.3 visually represents a transition metaphor for Haku's transition: a transportation map. More specifically, it represents the freedoms and opportunities that open up when one is capable of using maps and timetables, in this case to access public transportation. In urban Aotearoa New Zealand, school students do not commonly have access to school bus transportation to and from school. In primary school years, students typically walk or are driven to school by their parents. In secondary school years, students may walk or use public transportation. This is not the case for students attending special school, however. As part of their ORS funding package, students have taxi transportation from their home to school, and back again. Figure 4.3 is representative of the locations I knew of Haku to go during the course of fieldwork. When he was reliant upon external transportation supports, such as a taxi and his mother, he went to places in an approximately 16-kilometre radius from his home.



Figure 4.3. Haku's transition metaphor: Transportation



Even though Haku's polytechnic programme was for students with disability, he and his peers were expected to arrange their own transportation to and from the polytechnic each day. Due to the aforementioned transportation support, prior to attending polytechnic, Haku had never had the need or opportunity to use public transportation. Despite this, Haku's transition team supported him in learning to use a very complicated urban public transportation system<sup>7</sup>. Strikingly, not only did Haku learn to use transportation to get himself to and from his course each day, he also began using transportation for leisure. During the course of fieldwork Haku was known to have explored on his own initiative, places such as the beach, the mall, and new suburbs he had never been to before. His travel expanded to an approximately 42-kilometre radius from his home.

The metaphor of Haku's transportation map represents the differences between the taxi, with a predetermined route not necessarily set by Haku, and the freedom public transportation afforded him. In this metaphor, Haku's transition success can be understood not solely in terms of personal achievement (i.e., increase of 26 kilometre distance) but in opportunities that opened up to him after having learned to use public transportation. Haku's transition, thus, meant expanded opportunities for his future.

### **Capability discussion.**

Through the in-school to post-school transition, Haku moved from strength to strength. He demonstrated personal capabilities almost no one could ignore. This was represented by the pictures on the walls of his special-school classroom, in taking agency to continue in his work place, in his skills at his workplace, in lessons at polytechnic, and in successfully learning to use public transportation. Imagine what might be in store for Haku's future. In light of so many successes, I wondered at times what Haku was doing in a special school. How might

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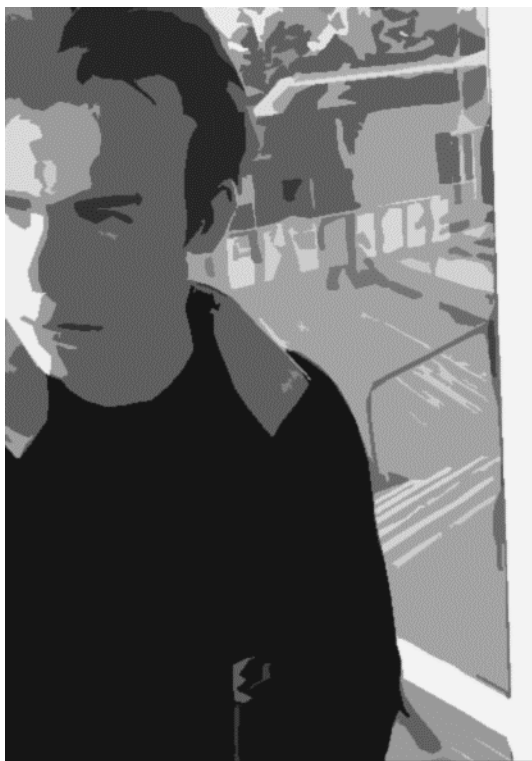
<sup>7</sup> The process of how Haku learned to access public transportation is described in the next chapter.

his experiences have been different were he to have transitioned from a mainstream school? Might he, for example, have been able to break out of disability-specific contexts as he had demonstrated in the examples of transportation and work experience? Maybe he could have enrolled at a polytechnic in a mainstream programme, instead of a course only for students with disability? Given what I learned about Haku's polytechnic classmates, sadly, I am inclined to think Haku would still have ended up with this transition outcome. Procedural barriers, such as National Certificate of Educational Achievement (NCEA) standards, and entry criteria, restricted the potential for inclusive post-secondary education options to students who had received sufficient credits while attending secondary school.

In conclusion, recall that Haku extended his skills by himself. For example, no one told Haku to use transportation for leisure. In the same manner, Haku led his transition team to enable him to remain at work experience during his tertiary education. Furthermore, it was only by chance, not by design, that the format of timetable diaries between in-school and post-school contexts was similar. An important question arises at this stage, one that will be addressed again in later chapters: How much of Haku's transition was by luck, chance, or most strikingly, through his personal skills, interest, and determination, rather than planned by his transition team?

### **Cobain**

Cobain's is a hard story to tell. He experienced obstacles in both in-school and post-school environments. Cobain had timetables, or ideas of timetables, in both contexts, but I never observed him use them.



*Figure 4.4.* Cobain with his reflection at the front door of special school

### **Section 1: In-school: Cobain at special school.**

When asked to show me around his base school, Cobain took me to hiding places away from the action of school. I photographed him under picnic tables, behind couches, and at the front door. (I'll come back to the door.) One of the calmest places he showed me was the olive grove. I had worked at the school for years prior to undertaking this study but was unaware of the olive grove. I videoed Cobain as he guided me to sit beside olive trees, by joining me at the arm, without the use of his white cane walking stick for support. I took pictures of him relaxing, lying on his back. When I asked teaching staff how often he went down to the olive grove, they commented he enjoyed the shadows made by the trees, though he only went there sometimes. The weather was not particularly sunny when we visited the olive grove. He seemed to be intentional in showing me something special.

On the same day as the olive grove observation, Cobain's teacher aide told me a story about a music lesson from earlier in the week. Cobain took an interest in playing the piano,

but, according to the teacher aide, the music teacher closed the lid to the piano to stop him from playing. The following week, I wanted to see him at music for myself.

Music sessions were structured in two half-hour blocks, once per week. The class was split into the “quiet” students, who had a relaxing music session, and the “loud” students, who played the drums and more active music. Cobain was in the former group. I interviewed his music teacher after the session, who reported she felt Cobain was not his usual self during my observation, possibly, she suggested, because of the loud noise of the lawn mower outside. The music teacher believed that I had seen elements of how Cobain displayed his enjoyment of music (i.e., finger tapping to the beat and following the harmonica as the teacher moved around the room making music).

I never got to the bottom of Cobain not being permitted to play the piano, but what I observed was a structured programme that engaged Cobain’s interest. In music, he was considered capable and was expected to contribute to the music session in his own way. Music was, however, atypical in terms of the experiences I observed at the special school. His teacher described to me on my first observation,

[Cobain] doesn’t quite belong to the class. He can get up and go whenever he wants. He can join. He doesn’t have to join. He doesn’t have to sit at the table if he doesn’t want to.... He does not like being part of a group. So when they [his transition team] start, that’s going to be fun to watch. (Interview transcript, T.1, in-school phase)

This statement was one of the first things Cobain’s teacher said to me, and the comment made a significant impression. In it, I felt she was expressing three important points. First and most strikingly, it was the final term in Cobain’s final year at school, and his teacher hadn’t yet considered his transition to have begun. Second, the teacher’s use of the word “they” in her quote implied she didn’t feel she was a part of his transition. Third, she had already moved on from Cobain being her student. She had taught Cobain for years. Some

of those years, she later described, were very good, but at this final stage of his education, she had no expectations for him. He didn't "quite belong to the class."

In contrast to the music lesson, most of my observations of Cobain at special school resembled my visit a week before graduation. That week I came to Special School B and likened my entry to walking into a land mine. Cobain's female classmate was throwing her body into the front doors, yelling and crying "ooh myyy goooooo!" I watched, waiting for about five minutes before senior management of the school permitted me to go past the front door. I waited with the senior management team of the school, who were together staring at the young lady through the reinforced glass doors, and trying to decide whether or not to call in her parents to take her home. "What if she brightens up by the time she is collected? Do her parents work?" (Quote transcript, field notes, FN.8, in-school phase), they asked one another.

All classroom doors at the base school were locked to reduce the possibility that the female student would aggressively target a vulnerable student. When I was let into Cobain's classroom, a male classmate was yelling loudly and rocking. Over the course of my observation time in class I saw this student strip naked twice, and fail at attempts to strip on another two occasions, due to quick staff intervention. The first thing Cobain's teacher said to me, in front of the whole class, was that she wanted to quit. The second thing she said, more discreetly to me, was that the male classmate kept taking his clothes off because he had successfully learned how to pleasure himself. Another schoolmate, a young man who had emotional disabilities and was prone to violent outbreaks, was moving around outside Cobain's locked classroom. The day before, I was informed, the school had been in lockdown because of him. Like Cobain, all of these students were leaving school. Their behaviours leading up to the end of the school year were degenerating, like falling dominos.

Amongst all the chaos surrounding him, I found Cobain in a pleasant mood. I could see no set curricular activity for the afternoon. Staff were doing their best to entertain students, distracting them from the misbehaviours of their peers, but certainly the antisocial student behaviours distracted the attention of staff from teaching the set curriculum. I used the time with Cobain to hold the second of two object-exchange interviews, which requires a brief background description.

Previously, I had used the cues in Cobain's object-cue timetable as adapted interview probes. The idea behind the object-cue timetable was that the object-cues served as prompts, representative of the upcoming activity. So, for example, in the case of the previously described music lesson, were the timetable used, Cobain would have felt a small maraca on a wooden shelf, taken it, and used the maraca as part of the music session (see Figure 4.5). When Cobain returned to the classroom after music he could then feel an empty shelf where the music maraca had formerly been placed, then feel the next shelf down to find the next activity. In this instance, a spoon to indicate it was time for lunch, the activity following music. In the first adapted interview, I had the impression Cobain was unsure of the novel interview format, and possibly distracted by the sensory stimulation of the sun reflecting on the metal spoon object-cue.



*Figure 4.5.* Cobain's sample object-cues and timetable shelves

Even though I had not observed Cobain's use of his timetable, I took the object-cues from his timetable and presented them to him a second time. I described in my field notes, I joined Cobain on the bean bags – the same place I had interviewed him last week. I again brought him three cues from his object timetable. A small scrap of cloth (I did not know what it symbolised), a spoon (lunch), and measuring cup (cooking). I rustled the three objects in a box in front of Cobain and after a short time he pulled out the cloth with a huge smile on his face (photograph recorded, P. 24, see Figure 4.6). Cobain began moving around and he lost the cloth. So I laid all the objects out on the floor. I rustled the cloth to make a quiet noise and tapped the spoon and measuring cup against the floor, so that they all made noise. He grabbed the cloth again and began to rustle it in the same way I had. (Field notes, FN.10, in-school phase)

From Cobain's physical reaction of happiness, I wanted to learn more about the object he had chosen. So I asked teaching support staff if they knew what the cloth symbolised.

A regular reliever teacher aide told me it was the sensory room object-cue. The same teacher aide described that she was assigned to take Cobain to the sensory room earlier that morning. She had taken him to his object-cue timetable and given him the small piece of cloth to indicate to him what activity was about to occur. As soon as he arrived at the sensory room door, he tugged her away and gestured towards the bathroom. His shorts were wet. By the time he was changed, he seemed hungry, so they instead went back to class for an early morning tea. She told me she was also in charge of taking him to the sensory room last week, and he had really enjoyed himself. He particularly liked the light reflected on a hanging, white bed sheet and strings that hung down from the ceiling and lit interchanging different colours. But Cobain hadn't made it to the sensory room today. Cobain became so overjoyed with the conversation I had with his teachers' aide that he laid back on the floor with the

cloth still in his hand (Photograph recorded, P. 25) and kicked his feet back and forth.

(Field notes, FN.10, in-school phase)



*Figure 4.6. Cobain's reaction: Physically overjoyed (P. 24 & P. 25)*

Underlying Cobain's final days in special school was the assertion by Cobain's mother that Cobain and his family would not attend his special-school graduation ceremony. Cobain had a scheduling conflict, with a Christmas party at his residential care house on the same day as graduation. While the scheduling conflict was a simple explanation for not attending, Cobain's mother further discussed her emotions surrounding her son's graduation in our interview, and again in one transition planning meeting, and finally in Cobain's end-of-year report meeting.

When I walked in to observe graduation at the school, I was surprised that one of the first people I noticed was Cobain's mother. Rather than explain to me her rationale for changing her mind, she stated she didn't want Cobain to know she was there. I believe her reasoning was that if he were to sit with her, he wouldn't take part in the graduation ceremony, preferring to be by her side instead. Or perhaps another interpretation was she already felt exceedingly stressed and didn't want her son's knowing she was there to increase the tension. Cobain arrived at graduation, with residential care-support staff, about 45



minutes late, and struggled to stay in his specially allocated graduation seat on the stage.

When he began to walk around on the stage, another graduate's family invited him to sit next to them. Later, in the graduation ceremony, Cobain's father announced they had bought the school an award cup to be named in their son's honour. He made a speech through a teary voice.

This gives me great pleasure giving this award, it's for my special son. Cobain, love him to death. And I'd like to take this opportunity to thank the school. All the caregivers, all the teachers who have helped Cobain over the years. And anyone else who has helped him grow, and made him who he is. Excuse me [as he cried]. (Quote transcript, field notes, FN.21, in-school phase)

On Cobain's last day of school, the base school was sparsely furnished. The teachers had packed up all the furniture, so students had to sit on the floor or on the few permanent picnic benches outside. Cobain spent his last day at the front door. He didn't try to push, or pinch, or run away. He just stood at the door and waited to leave. A teacher aide told me he'd been there all week. Not long after being dropped off at school, he'd turn around and wait to go home. "He's over it, he's finished [with school]," Cobain's teacher aide reported (Field notes, FN.12, in-school phase).

Since there were four graduants in Cobain's class, the board of trustees' chairperson came to the class to give one final round of congratulations to them. Cobain was in the classroom at that moment, and moved to sit closer to the chairperson. After a few minutes of sitting near her, he got up and gave her a hug. She gave him a kiss on the cheek and congratulated him. He smiled and she gave him another kiss. He tensed a bit to pull her hand, gesturing to pull her somewhere, but then looked as though he thought better of it. He let go of her hand and went back to the front door.

Unfortunately, Cobain's was one of the last taxis to come on the last day of school. His teacher cried when she said goodbye to most of her graduates. No tears fell for Cobain. The members of the senior management team and the board of trustees' chair were at the front door of the school to send off all base-school students at the end of the school year. I didn't see anyone give Cobain a farewell. I might have missed it, but that would have only been because such a gesture was so brief.

*Timetables.* Through my object-exchange interviews with Cobain, using cues from his timetable, he conveyed that he understood his object-cues as meaningful and representative of the activities of his day-to-day school life. Since I never observed the timetable used, I further clarified his understanding by re-examining six occasions where I observed him demonstrating what I called a *calendric capability*. I defined the ability as instances when he exhibited not only knowledge of the upcoming activity, but more accurately had an internal clock to know what time the activity would begin. For example,

It was time for the afternoon "cuppa," cup of tea to end the day. A few students stopped by the table, but Cobain was already sitting at the table before the teapot was even set down. (Field notes, FN.10, in-school phase)

Not only did Cobain have the ability to know his day-to-day scheduled activities, he also had an internal understanding of days of the week and even weeks in a month. This was reported by many who knew him, and comments were sometimes offered as part of other discussions. Many of the conversations were about Cobain's favourite activity, going home to visit his parents.

Cobain's teacher aide suggested his aggravated behaviour at school might be in excited anticipation of going home to his parents' house this evening. She mentioned that they often have difficulties getting him to settle on Mondays for this reason. (Field notes, FN.5, in-school phase)

Cobain is happy, residential staff told me, because he spent the evening at his parents. He showed his joy with a bounce in his step, repeating a “Ha” sound, and occasionally bumping his head into [residential staff’s] shoulder or his own hand. All were video recorded. (Field notes, FN.17, post-school phase)

He knows his routine. He knows what day he comes home. And if I don’t have him home for one reason or another, and it has to be something I can’t get out of, something major, he’ll be shitty the next time he comes home. (Interview transcript, Cobain’s mother, T.7, in-school phase)

These examples provide evidence that Cobain knew his routine, and knowing his routine was important to him. Even though he had a timetable, I never observed his timetable used in special school. Nor did I ever hear Cobain’s calendric abilities discussed in connection with transition planning or processes.

### **Section 2: Post-school: Individualised community-based programme.**

Following his transition out of school, Cobain continued to live in a community-care setting with carers and four other young men of similar ages with special needs. His mother was involved in his care through regular meetings, at which planning for Cobain’s activities in life were discussed and planned. I observed three planning meetings that occurred at Cobain’s residential care home (akin to group home).

As an introduction to Cobain’s post-school experiences, I first report and reflect upon the third and final planning meeting, which occurred at the same time as he exited school. On this occasion, Cobain’s mother was 20 minutes late. Cobain’s transition coordinator and residential house leader used the time to talk about how plans for the central feature of his transition programme, horseback riding, were still uncertain. Various combinations of Cobain and his teaching team, his mother, and his residential house staff had been, at different times, to visit a horse, and reports were that typically these visits did not go well. Cobain pulled to

return to the car instead of being interested in the horse. They agreed it was not too late for Cobain to enrol at a community day service, at least a few days a week, instead of focusing on horse riding. They also agreed that Cobain's mother was not yet emotionally ready to handle this decision (for reasons to be revealed in the next chapter).

After Cobain's mother arrived, Cobain's transition team explained that this meeting had been called by the transition coordinator with the intention that this meeting served as the completion of the transition from school service. Cobain's transition coordinator raised her concerns to the group, for example about Cobain having a limited peer group and limited opportunities for a social life after school. Her concerns did not gain traction, as conversations fairly quickly went back to tactical decisions about how to make horseback riding work.

After the conclusion of the final planning meeting, I exited Cobain's residential care house with the transition provider. As we walked to our cars, she told me about a recent workshop she had attended. "More to life than services," was the phrase she used to describe situations when custodial concerns, such as the routines of Cobain's life in residential care, dominated and suppressed a person's ability to develop and grow. She was saddened by Cobain's transition. Even with the extensive services available to someone with very high needs, she expressed that certain areas of his life were left unaddressed. Cobain had "no room to move" from within the large residential service (Quote transcript, FN.13, post-school phase).

In the weeks after school had finished, Cobain's mother reported that her son was depressed. He had been crying, banging himself on the head, and not sleeping well. It was hard to get a clear picture of the accuracy of these claims, because the comments were made by Cobain's mother and the administrator of the care service. Cobain's house leader, who

was involved with his day-to-day care, remained carefully ambiguous about any concerns, if she held them. With four other housemates to attend to, the house manager had day-to-day planning of the housemates and the care staff distracting her attention.

I observed four of Cobain's individualised community-based programme sessions. I will describe one observation that revealed many of the common features across all of my observations. I arrived at Cobain's residential care house in time to go with the group to an adapted arts programme held in a community hall. His "individualised programme" was undertaken with two other housemates. Cobain spent 40 minutes waiting outside for his housemates to be ready to leave in the house van. While waiting, Cobain's key support worker told me about the constant juggle with transportation. There were five young men living in the house, each with individualised programmes, and they all needed to share one van. Riding public transportation was a prioritised goal for Cobain, but he refused to get on the bus when it came to the bus stop. While another of his housemates might have been more suited to accessing public transportation, he was "a runner," and therefore behavioural issues of absconding made using public transportation too risky (Quote transcript, FN.15, post-school phase). In fact, challenges associated with the housemate's absconding behaviour loomed over much of the residential care house. For example, a very loud siren went off every time the front gate was opened to let someone in or out of the house.

I drove in my own car to the art lesson, following the house van. The house leader said this was for safety reasons. I missed Cobain's initial entrance to art lessons while I parked my car. Once at the class, I observed that Cobain engaged for only three minutes of the hour-long art session. One of those minutes was a finger painting he made with hand-over-hand support from his house leader, who dipped Cobain's hands into paints and manually spread them on to the paper. The next minute of engagement was bubble paints, where art attendees were meant to blow bubbles mixed with soap and food colouring through

a straw on to a page of paper. Cobain drank the bubble mixture. In his final minute of engagement, Cobain was given clean straws to stack and construct with, but he tried to eat them instead.

Cobain spent the remaining 57 minutes of the lesson lying on the floor and standing at the exit door. His house leader pulled a large white board in front of the glass doors that led into the common area of the community hall because Cobain kept tapping at the door handle as if to gesturally indicate his interest in leaving. After one door was blocked, Cobain switched to pass time at the fire exit door. Some of the other housemates were more engaged in the art lesson than Cobain. So even though this was his individualised programme, Cobain needed to wait for everyone to be finished.

The class was led by a staff member from another residential care house. All the art class participants had disabilities and lived in various residential care homes. Thus, this was not a public class with a diverse range of people with and without disability. In order to attend, participants had to pay art supply fees for the term. Cobain's housemate's family paid for the rental of the community hall space. The art class physically took place in a community hall, yet all other aspects of the experience were segregated for only individuals with disability within the residential care service.

***Timetable.*** Awareness of Cobain's calendric capabilities were known to his transition team, as highlighted in the prior quotations, and described in examples of his special-school timetables. Cobain's house leader also demonstrated her awareness of his calendric capabilities following a visit with the Foundation for the Blind, which I described in my field notes.

Cobain's house leader proudly showed me some of Cobain's recent paperwork. His weekly timetable, arranged by his residential staff (Artefact, A.19, day programme,

post-school phase) was briefly discussed. Cobain's house leader was most excited about her developments with the Foundation for the Blind. Cobain had two visits from a representative from the organisation. His house leader showed me a picture of an alarm clock that can announce scheduled activities when set to the specified activity time. She told me that staff will just need to remember to shut the clock off, otherwise the clock will keep repeating (Field notes, FN.14, post-school phase).

By the end of my fieldwork, I had neither seen the alarm clock, nor heard any further discussions about it. This is not to assume the alarm clock idea did not happen at some future stage. Rather, I point out that even if Cobain did get an audio alarm clock, it would have been a new timetable format, one which would require a whole range of new learning. Some such learning might be incompatible to his capability set, as alluded to in the comment about staff having to shut the alarm off for Cobain. Having to learn a new system seemed in my mind unnecessary, and disruptive to a familiar, though inconsistently used, timetable routine that had already been established.

Many disconnects were apparent when applying Cobain's timetable experiences to his transition. First, he had an object-cue timetable procedure that he knew and understood, even though evidence led me to assume it was inconsistently, if hardly ever, used during the latter stage of his time in school. Second, transition might have been a time to revisit his existing timetable system and use it to assist Cobain's move between the in-school and post-school environments. This was not done, nor even discussed as an option. Third, an entirely new timetable system was excitedly discussed in a fashion akin to a fun, new gadget, wanting to keep up with technology, but with little regard to Cobain's actual ability to potentially use the timetable independently. The only consistency, sadly, was that despite Cobain's calendric capability and the observed importance of time to him, timetables were not consistently used in his transition.

### **Section 3: Transition.**

Cobain had access to Very High Needs ORS funding while in school. Upon completion of special school, his funding halved and could be used for individualised post-school services. If Cobain and his family had chosen for him to attend a community day programme, for example, this funding would have been enough for him to attend approximately three full days per week with intensive or one-to-one staffing, depending on the service.

Cobain and his family chose to put the funding towards an individualised programme. Typically, individualised programmes are allocated funding for 15 hours per week of one-to-one staffing at a pay rate of nearly minimum wage, \$16.50 per hour<sup>8</sup>, to support access to community activities (Ministry of Health, 2010). Since, in Cobain's case, one-to-one support staff were provided from the residential care service (and I assume, on a higher pay rate and requiring more administrative costs), Cobain had a reduced amount of hours available, a maximum of 10 hours of individualised programmes per week. Those 10 hours were exchangeable for funding to pay for community activities. Since Cobain's individualised programme hinged upon the central activity of therapeutic horseback riding, an expensive activity, the decision was made for him to receive 8 hours of one-to-one support per week with a supplemental activity fee provided by the disability and residential care service to pay for the costs associated with the horse riding. Transportation to and from horse riding counted as part of the eight total hours. Eight hours could be stretched if Cobain shared staff with other housemates and those in the residential service. For example, if he had a two-to-one staffing for most of his week, his hours would then double.

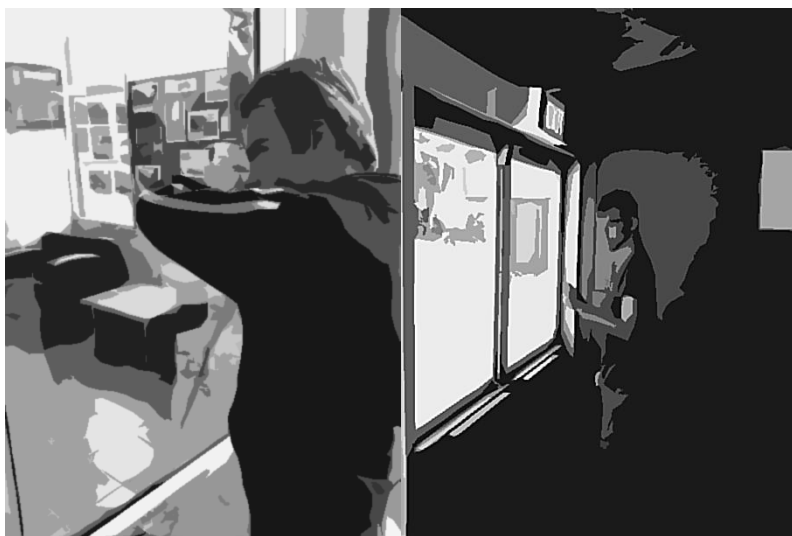
***Metaphor.*** (Un)locked doors signified Cobain's transition. As portrayed in the transition details above, Cobain's transition involved emotions, tensions, and stress for those

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<sup>8</sup> At the time of the study, minimum wage in Aotearoa New Zealand was NZ\$14.25, and moved to NZ\$14.75 in April, 2016.



around him. He spent great lengths of time at the front door of the special school watching bursts of sunlight and reflections in the glass that appealed to him, given his visual impairment. This was one of his spaces of calm. I observed him spending a far longer time at the glass door than engaged in scheduled curriculum, with classmates, or participating in class activities. Stories were shared amongst staff members about times when a new person, such as a relief staff member, would join the class. Cobain would demonstrate his knowledge of the door's purpose when he would pull the new person to the door with an encouraging gesture for them to open it (Field notes, FN. 3, in-school phase). Nevertheless, I never observed him try the door knob himself. He knew special-school doors were locked.



*Figure 4.7.* Cobain's transition metaphor: (Un)locked doors

The locked doors of the school extended beyond a physical symbol. Cobain had been locked into a student profile of disengagement. In his final months at school, no one had expectations for him to be interested in people or curriculum in his current setting. He didn't "belong to the class." This sentiment permeated engagements with his entire teaching staff, relegating him to time alone with his reflection in the door.

After leaving school, Cobain's individualised programmes were held in community spaces where doors were not typically locked. When not engaged in the activity at hand,

which was still quite often, Cobain again spent his time by the door. In contrast with special school, now doors held the possibility of being used for their intended purpose. Cobain knew doors within community spaces were typically unlocked, and in every community setting he was observed trying to open the doors. As a consequence, support staff found ways to block or obscure the door handle.

Through this subtle gesture of trying to open doors, Cobain demonstrated his knowledge about his own transition. He knew what doors were for and how they were used. In the special school he didn't bother trying to open the door handle, for he knew they were locked. Yet in community, there was now the opportunity to try.

In my opinion, the knowledge Cobain held about his own transition was remarkable, and made even more so by the fact that I never observed one instance in my fieldwork when someone explained to Cobain that he was finishing school. One could challenge my premise, by pointing out, for example, that he attended graduation. Nonetheless, if the event is examined from Cobain's perspective, to someone who has low vision and significant cognitive and sensory impairment, graduation may have been another confusing event for which he was late and spent the majority of his time sitting amongst the audience next to someone else's family. No one explained, in a manner meaningful to Cobain, that school was over. Special-school administration staff did not farewell him on his final day of school. It was like any other day. Cobain figured out school was over on his own, and demonstrated this knowledge subtly through one of his preferred activities, standing by the front door.

(Un)locked doors are an apt metaphor for potential and opportunity. In a sense, the unlocked doors represented Cobain's potential for freedom, no longer restricted behind the locked doors of special school. A door that is not locked could almost be seen as an invitation

for future community integration. Cobain had the potential to walk through an unlocked door as much as anyone else in his community might.

### **Capability discussion.**

I argue that Cobain's transition team attempted to block or even re-lock the doors to Cobain's transition. Cobain had become absorbed, consumed, monopolised by his residential care service when special school and the transition from school service finished supporting his transition. All of his individualised community activities were filtered through his residential care services. The scene for these activities may have been set in the community, but programmes were run by, and specifically catered only for, those within the disability care service.

Another important point about Cobain's transition metaphor is that I appeared to be the only one who noticed it. Others may have noticed him standing at the door for years and not thought anything of the subtle difference in his attempt at using the door handle. Alternatively, even if others had noticed, they may not have seen this subtle act of Cobain's as a demonstration of profound understanding. So this metaphor will remain a story, unverified, not triangulated, but from the amount of time I spent with Cobain, I believe it was of substantial significance.

Through the portrayal of Cobain's in-school and post-school challenges, a central question came to my mind: Did Cobain's personal capabilities such as his personal understanding of transition, go unnoticed or were they noticed and simply ignored? I do not have an answer to this question. I suggest it might have been too painful for his mother and others close to Cobain to acknowledge his capabilities, and then see how restricted his transition and future opportunities had become.

This line of thought sheds light on Cobain's mother's comment about "transition being the grieving process all over again" (Quote transcription, field notes, FN.1, in-school phase). I always took the comment to mean the emotional equivalent of first getting a disability diagnosis for your child. Perhaps emotions ran even deeper, beyond the family. It is plausible there was a societal aspect to the "grieving process," of fitting in and finding places of acceptance and support within the community. Cobain and his family had found a sense of belonging in special school. Attending school behind locked doors meant safety. Literal safety for students like "the runner", and symbolic safety, an emotional safety net, amongst peers and families who shared similar experiences, needs, and concerns. Transition meant severing the support network of the special school as the (un)locked doors open directly into the heart of community life—raw, unsheltered, unsupported, and, in many instances, not accepting. This might be why Cobain's mother positioned her son within the residential care service, so he could regain some amount of shelter and to essentially lock Cobain's doors once again.

### **Faine**

The broad strokes of Faine's transition were straightforward. He had previously been home-schooled, then, through the serendipitous meeting with an outreach itinerant teacher from Special School A, he was able to enrol full time for three years before he turned 21. Even though fieldwork enabled me to observe Faine's transition events first-hand as they unfolded, certain details were never fully clarified. For example, the importance of the teacher was abundantly clear, as described in the next sub-section, though how the teacher and Faine met remained unclear. In a similar sense, stories about Faine occasionally took on an exaggerated or even folk tale-like status. For example, everyone from school, to family, to community members knew Faine had personal capabilities. Yet, for some, Faine's capabilities were so strong they were more like powers beyond typical human ability.



*Figure 4.8.* Faine preparing for special-school ball

### **Section 1: In-school: Faine's short time at special school.**

Understanding Faine's educational history is important to his story. Unlike Haku and Cobain, he's the only young man in this study who had not attended special school for his entire educational career. He had only attended special school for three years prior to graduation and would have preferred to stay longer. Faine's mother explained her son's educational history in this way,

Faine's mother: What happened was, oh this is a whole story about special ed, but he was in total immersion, Kura, where they just spoke Māori. But the age group stopped at intermediate, about 10 years old at the latest. He came out of three years [in intermediate school] and no one would take him. . . . He'd just done three years with a group of kids [in intermediate school] and they all knew him. And [the secondary school up the road] wouldn't take him.

Sarah: Was this back in the days when Faine had big antisocial behaviours?

Faine's mother: No, well yeah, but nothing major.

Sarah: So why wouldn't they take him?

Faine's mother: Out of zone, any excuse you can use. Anyway, they choose their students. So we went to [a different secondary school] and couldn't get him in there. He was just horrified. He wanted to stay at the Kura, that's where he wanted to be. So we got an extension for him to go to the Kura and stay there. Which was another hard road. And then [an outreach itinerant teacher from Special School A] started coming. Faine formed a relationship with [the outreach teacher] and he'd say 'come and see my school.' And they'd go out for like half a day or something. Then it got a bit longer, then whole day, to a week. Faine loved [the outreach teacher] and really trusted him. Probably the first person he trusted outside the family. And that's how he got into Special School A .... He was such a great advocate for Faine. Otherwise we never would have found Special School A.

Sarah: So you never thought of a special school sort of route?

Faine's mother: No. I never ever knew they existed. Cause we struggled with mainstream. All by myself. We went on without support [financial or caregiving]. And we kept struggling through. And every time it was time for him to go through schools, I moved a year ahead of him. So when he was at primary I was there all the time. Not with him, but teaching at the school... So that was our first separation, when he started going to Special School A. We've been together 24-7 and the 2 years he's been at Special School A is the only time we've been separated.

Sarah: It's amazing to me that you work in the school system and yet felt like you didn't know your options.

Faine's mother: I went through all that with no support. I mean he could have had a laptop to work on. Did I know that? No. Now I found out all these things that I never knew that he can't use because he's leaving school. Too old. So I've made it my thing, if there are any others coming through school that they know that special schools are out there. And other schools like that. And becoming aware of all the resources there are. (Faine's mother, interview transcript, T.3, in-school phase)

From this passage comes the understandable impression that Faine and his family began his experience at special school hesitantly, feeling unsupported by community and social services, so much so his mother never even knew special schools existed. Faine had a long history of schools rejecting him<sup>9</sup>. Faine's reticence in beginning school was also because, at 18 years old, this marked the first time he attended a school separate from where his mother was teaching.

By the time I met Faine he was ending his time at special school. No longer timid and shy, he was described by the school Associate Principal in these words, "I have seen you grow and develop into a wonderful confident young man who has good direction for his future" (End-of-year summary, Associate Principal's comment, A.5, in-school phase). Faine's school reports had a long list of accomplishments, such as giving a speech at the opening of his community classroom, being the lead singer in the school band, and holding the role of the school's senior supervisor for their kapa haka cultural group. "From shy Faine to leader Faine in a couple of years . . . You have helped shape the work and culture of the school" (End-of-year summary, Principal's comment, A.5, in-school phase).

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<sup>9</sup> From my understanding, turning down a student from their local school would be illegal, but this is what happened, from Faine's mother's perspective. Enrolment in senior schools was not the focus of my study, so I did not press the issue for further detail.

Faine's final IEP had goals around leadership and communicating with unfamiliar people. Evidence of his achievements in these areas includes, for example, his responsibility for giving the Māori blessing when visitors joined for shared meals at school, and his roles as senior Māori supervisor when new students enrolled. His opportunities to meet and communicate with new people came from social-skills curricular sessions, work experience, visiting the public gym, and community visits to places such as the grocery store.

When I walked into Faine's community-based classroom for my first observation of his work experience, he looked a little tired. His teacher prompted him to get ready for work, and then he got a jolt of energy. He brushed his hair, packed his morning tea, and put on his uniform t-shirt for the chain store where he worked. As I walked to work with him, a classmate, and a teacher aide, Faine cracked jokes about his job. He knew where to walk to get to work, and how to clock in once he got there. On this occasion, he was working in the garden department. During his work in the garden department, I noticed Faine needed help from his teacher aide, which was offered very patiently and supportively, although no independent work skills were being taught. I asked the teacher aide if there were jobs at the department store Faine could do independently and he couldn't think of any. Faine was calm, patient, and focused throughout my observation of his work experience, but showed no signs this would be a job he could do independently in the future. Nor did I get a sense from anyone else that they ever expected he could. Yet, they were willing to let him try.

At morning tea time, Faine spoke with other employees about the new staff t-shirts soon to be issued. "What do you think they'll do with the old ones?" he inquired. Overall, Faine was comfortable and familiar in the work environment, having worked there for the school year in various departments across the large store.



When I got back to Faine's classroom, I noted on the class schedule that many of Faine's classmates went to the same department store for work experience on other days of the week. Faine's classmates did not have individualised, customised work experiences. Rather, classmates who were interested and able went collectively to one work site.

In my next observation with Faine, he and half his classmates were preparing for the upcoming school ball (akin to a senior school prom) by cooking some simple finger foods. Faine helped in the group making savoury Danish and worked with a group of four. I commented in my field notes,

Faine was clearly the least capable of his group of male classmates. He struggled with fine motor coordination to use the knife and to spread the filling onto pastry and roll it. He seemed aware of his inadequacies and would cover it up by joking with comments like, 'My eyes are stinging from onions!' I observed the teachers sticking with him and refusing to let him fail. There were no opportunities to give up, just to finish in his way and time. For example, they were okay that his onions were cut to different sizes, and the Danish was rolled in a style unlike the classmates. They didn't care that the final product might have not looked as 'polished' as his classmates. For this, he remained in good spirits and happily volunteered to help with the dishes. (Field notes, FN.4, in-school phase).

I noted how adaptations made by teaching staff supported Faine's opportunities to try new things. Faine could feel this support as well, which he demonstrated by not getting discouraged or frustrated. In doing so, he experienced accomplishments throughout school.

Another observation was held at an art studio, another instance of a physically integrated setting exclusively attended by those with disability. I arrived when he was sitting next to two classmates, the teacher aide who supported his work experience, and a young

woman not from his school. They were the most talkative of the group of 20 or so artists who sat at long art benches skirting the art room. They laughed and joked about topics only adolescents would find funny, like times they injured themselves. Upon further listening I realised the conversation topics were mostly made up. For instance, they spoke of when they were joining in professional wrestling matches, or playing games in their private swimming pool. They also had an amazing repertoire of jokes. For example, Faine knew many pirate jokes: What's a pirate's favourite singer? Rrrrrr Kelly! The most factual conversation they shared was about music and musician gossip. The conversations at times fell into fiction, when they took turns listing all the concerts they had attended and the musicians they met afterwards. Both Faine and his female classmate demonstrated a good running knowledge of musician's top hits and upcoming concerts (Field notes, FN.5, in-school phase).

Faine's mother was outside after art class. She worked at a school nearby, and took a short break in order to take her son, his peers, and the teacher aide back to school on rainy days. Faine had borrowed her digital camera so he could photograph his and his friends' artwork from the class. He excitedly showed his mother the photos he had taken. Faine's mother shared a story with me about one of Faine's art projects that sold at an art auction fund raiser. He was sent a check for half the value of the sale, the other half went back to the studio. Faine was so proud he wanted to frame the check, but his mother compromised by photocopying the check for him.

The list of Faine's capabilities continued to unfold during my observations at special school. For example, at senior prize giving he was given an award for his leadership in the school's kapa haka cultural group. As part of the school's literacy focus, he printed and bound a book he wrote and illustrated with the support of his teachers. Crafts he had made throughout the year, as part of a business enterprise group, were proudly offered for sale at a

market day in the local shopping mall. Faine did not come to school that day to see his work being sold. I was told there were family issues at home.

Two of the most defining moments I observed of Faine's school success were as stereotypical as I'd imagine any other students' transition: the school ball (prom), and graduation. The ball was a joint effort between Special Schools A and B and was held at the community satellite classroom at Faine's school. Overall, the ball had a pleasant, happy vibe. Everyone was well dressed. Four tables were filled with food, mostly prepared by students or brought in by family as a shared plate. The plentiful amount of food at the ball served, in my mind, as a demonstration of the abundance of collective love for the schools and one another. The more able students were helping those less able, for example, pushing their wheelchairs in order to dance together. Or together doing activities like karaoke, as any of their mainstream peers might do, though some of the students holding the microphone were non-verbal. The most noticeable thing was actually an absence of antisocial behaviours from any of the students in attendance.

Faine was dressed up as his favourite singer. He had fake tattoos on his hand and neck. During the ball, he performed with his band. The school principal even joined the band for the evening. Soon after, the king and queen of the ball were announced. The queen was a young woman in a wheelchair dressed in an elegant Indian sari. Faine won king of the ball. He was so hot from all his singing and dancing, the sweat could almost be mistaken for tears of joy. There was, however, no mistaking his beaming, proud smile.

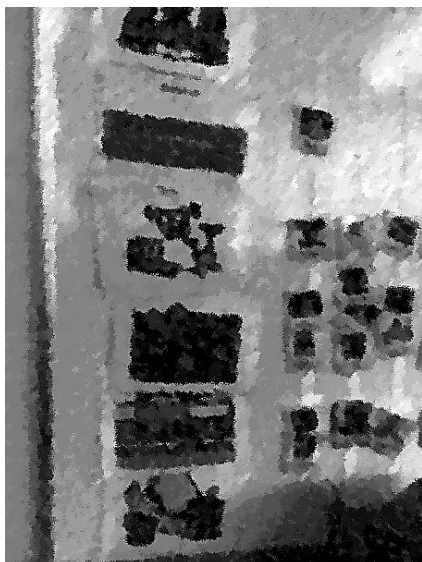
Graduation was held at the base school. Families and guests of the school were asked to wait outside so they could be formally welcomed through a powhiri, a Māori welcoming ceremony to greet visitors. I felt of two worlds, both an insider and outsider of the school. In the end I decided to be welcomed as a visitor to the school, because I had brought my

daughter, who was in fact visiting for the first time. Personally, the most salient memory I have from Faine's graduation was of where to sit.

The powhiri was led by Faine's mother and members of his whānau. In between graduation speeches from the school community, principal, and teachers, waiata, Māori language songs, were sung by most in attendance. The school principal introduced the graduation ceremony, stating to the students "we have learned far more from you than you've ever learned from us" (Quote transcript, field notes, FN.8, in-school phase). Each graduate was introduced by a photographic slide show of family photos of them as a child and school photos leading up to graduation, all set to music; each song was unique to each student. Teachers then shared more specific comments about their students. The principal gave each graduate a gift, mostly Māori carvings in greenstone.

Faine's turn to graduate came near the end of the presentations. He sobbed, crying throughout his whole slideshow. His family cried, too. His family again sang for him in Māori. Then the school's cultural group led a haka (a traditional, ancestral, postured, rhythmic group dance) in his honour. In this final moment, it was clear how integral Faine and his family had become to the school. Faine's contribution to the school had almost been larger than life and he would be sincerely missed.

***Timetable.*** As part of Faine's participatory photographic adapted interview, I asked him to take photographs of his classroom. Figure 4.9 demonstrates one photo he took on his own initiative of his classroom timetable. The image has been blurred to declassify place names (larger symbols on left of the image) and classmates' pictures and names (smaller symbols on the right side of the image). Faine's comments about the photo in our discussion were literal and straightforward.



*Figure 4.9.* Faine's photograph of his timetable.

Sarah: What's this next one?

Faine: Morning circle, [work experience department store], gym, and bocce.

Sarah: Is this your class timetable?

Faine: Yeah, class timetable and what we are doing. Lunch.

Sarah: That's how you know what you're doing for the day. (Interview transcript,

Faine, T.2, in-school phase)

Faine demonstrated with this quote that he understood the component elements that made up his classroom timetable. The use of picture communication symbols (PCS) supplemented the text and enabled him to “read” his timetable. Furthermore, he could distinguish between his own daily activities and those of his peers by way of student photographs. In a photographic interview, Faine conveyed that timetables held personal relevance. I did not raise this question with him, he raised the topic of timetables himself.

## **Section 2: Post-school: Community day programme.**

While still at special school, Faine made a few visits to the community participation day service he was to attend after he left school. He was only able to go a few times because the

schedules between the school and the day service conflicted. He was supported by a teacher aide at his special school. His teacher described,

I do have a few concerns just from what [the teacher aide] has said. They take a long time to set up and organise staffing. Mind you, they don't have Faine in the first session, he's there for the second session. They get there [to the day service] and they have their morning tea, then its 11:00 and it takes them a while to set up, so she [the teacher aide] has to go, and she doesn't want to take Faine away but her school day finishes. (Faine's two teachers interview transcript, T.2, in-school phase)

With the increase in visits to the post-school day service, Faine's stress began to rise. His mother commented that his elevated stress meant an increase in Faine's antisocial behaviours at home. I wasn't seeing such behaviours in my observations at school, but then some days I would come for an observation, and Faine wouldn't be there. Faine's mother commented to me that he associated his fears about the new day programme with not wanting to go to school at all. His mother raised the issue of his stress worsening in our interview,

Faine's mother: He's pretty anxious at the moment. I'm pretty anxious at the moment. It's like the unknown, really. I think we're going to hit a few behaviours, maybe.

Sarah: What do his behaviours look like? Anxiety?

Faine's mother: Yeah. He hasn't had any violent episodes, but occasionally he will and you know it's a big overload, so I just stop everything. And wait for him to get back on [track]. And he's teary for a few days.

Sarah: Oh, because he was absent the other day, when I was supposed to see him.

Faine's mother: He turned into this really horrible child.

Sarah: I couldn't imagine!

Faine's mother: Verbal like a wolverine. And physical and everything. And you point your finger and then he comes here and dumps it all on the ground. And it's always been focused at me. But his brother is the one to be stern with him, to say that's enough, and go to bed. Or go to your room or something. And then the next day he just feels absolutely horrified at what he's done. So then we have two to three days of feeling like, oh my god why did I do that? I've hurt feelings and upset people. He gets anxious over that too.

Sarah: He's so sensitive, that's what I've found.

Faine's mother: So we just go through that process.

Sarah: He doesn't do that at school, does he? Just for you?

Faine's mother: Ah, no, he stopped doing any of that when we went to Special School A. He was really, really bad up until then. My main focus was get on with people and social skills, and the rest I didn't care about. That's what we needed to work on. And so he's come a long way. (Faine's mother, interview transcript, T.3, in-school phase)

Faine's community day service was located in an industrial park. A mechanic and boat supply warehouse were on either side of the day service's building. On my first visit, I walked inside and from the corner of my eye saw Faine lying on the couch with his shoes off, feet up, and an icepack on his forehead. Before I could approach him, however, I ran into three of my own former students. After I caught up with each of them, and quickly explained to staff working who I was, we all sat next to Faine on the couch. He complained of heat stroke after a walk outside. The day was sunny, though cool in comparison to the previous days of high humidity. He was sweating, so I offered to get his drink bottle from his backpack.

Initially he was quiet and unenthusiastic, but then perked up when he began to talk about special school. He told me he had been invited back to his former special school to attend a 21<sup>st</sup> birthday party for one of his peers. At that moment, one of his fellow graduates walked past us. He was non-verbal and communicated by jumping and making noises like, “ha!” I asked Faine if he was happy to have a former classmate from special school attending day service with him. His attitude again became sombre as he told me he couldn’t remember the young man’s name. I looked around and saw that most of Faine’s potential peers at the day service were similar in non-verbal or semi-verbal communication. My conversation with Faine continued like this for about an hour. When he brought up special school, he was happy. When I brought up current life at the day service, his attitude dulled.

Following my time with Faine, I visited the programme coordinator. The day programme was one aspect of a wider collection of disability services including residential, educational, and horticultural. I asked the programme coordinator about Faine’s adjustment to the new service, and she said his progress may have seemed small, but improvements were noticeable and goals achievable when set to his pace. She gave examples like taking initiative in getting himself a drink.

We discussed upcoming activities and she mentioned an adapted sailing programme for individuals with disability. Faine had begun this activity the previous week and begrudgingly approached sailing with his hoody on, a stance he took when he was unsure. By the end of the day, the programme coordinator reported Faine was overjoyed by learning a new skill and overcoming his fear of a new activity. She reported the new experience gave him a big confidence boost, so I was invited to attend the next session (Field notes, FN.9, post-school phase). When I came the following week, Faine was away, and no one had heard from him or his mother. I called his mother and sent her emails, and continued to keep in



touch with the day service in case they heard anything. I received the following email a week later,

Hi Sarah

Thank you so much. It has been a sad time for our extended family and I appreciate your offer of help. I am sad to hear that our time together will soon come to an end, but am happy you have nearly completed your research.

It has not been a very smooth transition for Faine from the [his community satellite class at Special School A] and we have all had a lot of emotional challenges and hurdles to work through. [Associate Principal] and our whānau Special School A and the [community-based satellite] have given so much, helped bring out the best qualities in Faine, and always made him part of the decisions and choices he needed to make to take his life on a pathway that made him happy and that was good for him. Challenge, laughter, independence, learning, and love was what Faine received and gave every day. Unfortunately, he is missing these very important things during this transition and is finding it very hard. It is hard when all your child wants is to be included when making choices in his daily activities and all he wants is to have a day when his life is filled with so much laughter that your sides hurt and you are still smiling hours after. We will continue to keep striving for those things. Thank you for everything. We will see each other again soon.

Faine & his mother (Email transcript, T.7, post-school phase)

It transpired that Faine had gone with his family to a tangi, a ceremonial Māori funeral, which typically lasts about a week. I tried to get in touch, but never saw Faine or his mother again.

***Timetable.*** In the post-school phase, I noticed a timetable on the wall of the day service above where Faine was sitting. The observation was described in my field notes,

I mention the timetable I see on the wall behind Faine. He says he can't read the timetable, and suggests the one at special school was better. The one at the day service is written in small, printed lettering for the whole week (rather than daily as it was at his special school) and with no symbols. I ask what activity is coming up after lunch. Faine offers a few suggestions, but none prove to be correct (Field notes, FN.9, post-school phase).

At the special school, Faine had access to a timetable meaningful to him. He could understand and plan his days at school. Also important was Faine being able to know what his peers were doing, a way of demonstrating his care about his friends' well-being. In the post-school phase of the community day service Faine appeared lost. The timetable used in the community day service was likely most useful to the staff as a way to organise what was going on, where, and when. Faine had the capabilities to track the progression of his own day, as well as the ability to situate his day in relation to the activities of his peers. In the transition handover process between in-school and post-school, these skills were lost.

### **Section 3: Transition.**

When I first met Faine's mother, she told me she had always thought transition from school signalled a time when students with disability "disappear" (Field notes, FN.1, in-school phase). Faine's mother had literally planned to retire when her son finished school, in order to look after him. After three years of special-school experiences, she felt she and her son were "on a new journey." Faine's mother communicated her son's impression of special school as, "If he could stop time, it would be now. And that would be his ideal world, right now. Stop it right now" (Interview transcript, Faine's mother, T.3, in-school phase). Something as good as special school was difficult to replace. She expressed a feeling of being "cheated," having not known about special school for so long, and then Faine only having three years to enjoy it before having to move on.

Faine's transition was funded in a roundabout manner. After leaving school, High Needs ORS funding stops altogether. Essentially, no funding is provided for community participation day programs. Instead, funding came in a circuitous way through the Needs Assessment Service Coordinator (NASC) who assessed community support hours via the Ministry of Health. Through the process of needs re-assessment during transition, there was a re-allocation and re-distribution to supplement the number of hours needed per week towards personal care, home support, and community support. Those surplus hours were used to fund day services.

Faine was allocated enough funding to attend the day programme for three days each week. I understood this to be fairly common amongst his peers at the day service. He used *care and support* hours to continue attending the community art class he enjoyed during special school. One weekday per week he spent at home.

**Metaphor.** Faine's dynamo character (Figure 4.10) was drawn in his weekly community art class previously described. The male image embodied a developing maturity. In my mind, the image represented Faine's progression towards young adulthood, no longer a school boy, but without fully embracing manhood. Faine was unable to articulate those subtleties or the meaning of his word choice. Whether by chance or by design, Faine's artwork will be described as a metaphor encapsulating his educational experiences.



*Figure 4.10.* Faine’s transition metaphor: “Dynamo” drawing

As previously described, Faine’s family was sceptical of the public education system, and, in turn, Faine’s engagement with his wider community. In attempts to shelter Faine, he was, for a time, home-schooled. Faine’s mother was shaping her own life plans around preconceived unjust conditions in which her son would one day “disappear” from society altogether.

Once “found” by the special school he enjoyed a number of successes. His “dynamo” personality flourished. It was likely that his dynamo personality began to emerge in his prior mainstream education experiences. At age 18, it marked the first time Faine he had attended a school without his mother working there as well. His dynamo personality embodied independence and autonomy outside of his whānau/family. Faine demonstrated enormous potential personal capability and many interpersonal strengths in leadership.

### **Capability discussion.**

Understanding Faine's transition through his metaphor meant finding ways he could transfer his dynamo personality to new community contexts. Peers at the post-school day service had more significant, communication-based disabilities. The development of friendship with such a peer base was thus very challenging for Faine.

The progression of Faine's transition turned from unexpected and resounding positivity, akin to the successful use of his symbol timetable, to challenge, analogous to the hand-written weekly timetable that Faine could not understand. Faine's overwhelming success within school begs the question, what was so special about special school? What came together to create such a positive experience for Faine? Was it the context of special school itself, or was it that it was simply his time to blossom and mature into young adulthood?

Furthermore, might it have been that in transition, special school was too good to replace? Or maybe did Faine and his mother simply need more time to work through Faine's significant life challenges? But such questions may all be a moot point, as it was unclear whether Faine was going to get a chance to continue trying new contexts in which he could use his vibrant interpersonal skills. By the end of my fieldwork, Faine was spending more time at home. His whānau's answer to the stresses of transition appeared to be to return Faine, once again, into their protection. This may have been his whānau's way of coping with Faine's reaction to his post-school programme. His mother, more than anyone in Faine's family, saw how special school provided a place where Faine was "cherished for what he has to offer" (Interview transcript, T.3, in-school phase). Yet it may be that the community offers few places for such individuals, or maybe for anyone, to feel cherished.

## **Conclusion**

The three case narratives revealed three transition realities. For Haku, transition appeared successful, drawing on consistent supports and familiar artefacts such as his timetable in the in-school and post-school contexts. In contrast, Cobain experienced challenges in both environments, akin to how timetables (or ideas for timetables) existed but were never fully utilised. Finally, Faine moved from strength to post-school distress - the timetable he used successfully in-school was discontinued in the post-school context. Timetables were one useful way to consider the consistency, or the degree to which, each young man experienced a successful transition. Beyond the success or quality of the transition outcome, timetables also enabled consideration of how the young men got to each point of success or struggle.

The elements that constituted a timetable, the activities and priorities set within them, conveyed vital elements of personal priority. The chapter revealed how activities such as transportation, cooking, and kapa haka, for example, were important to these young men, and how an appropriately implemented timetable could scaffold dignified daily engagement. Timetables were personalised, and held information such as how long it was appropriate to expect each young man to be engaged in activities, or how often activities typically occurred. In turn, timetables also provided a communicative element by enabling each young man's ability to convey, share, assess, and structure their understanding of their own transition, as well as the transitions of their peers.

The significance of timetables was also salient when seen as emblematic of genuine opportunities. When used consistently and proactively, timetables held personal meaning to represent components of transition shared between in-school and post-school environments. In order for genuine opportunities to exist, individual, social, and structural domains must all be addressed.

Coupling timetables and metaphors within this chapter helps to demonstrate the significant personal capability of the three young men within their own transition. Each young man physically established his understanding of his own transition, and in doing so, brought to light many of the opportunities inherent within transition. Haku gained freedom and opportunities through unrestricted access to public transportation, enabling him to participate in work, education and leisure activities. Cobain's (un)locked doors demonstrated his personal awareness of alternatives, even though he was unable to access them. Faine's dynamo social abilities, enabled him to become a leader within his special school, and held potential for him to be engage in a range of peers in post-school settings.

With personal capabilities articulated for the three young men, my attention now turns to the social and structural forces which either helped or hindered their transitions, despite their personal capabilities. All of the positive aspects of Haku's transition were brought about either by his own actions or by chance, not by intentional design. Cobain's needs were overshadowed by the needs of those planning his transition. Faine fulfilled his mother's expectation of "disappearing" in post-school life. Each of these concerns extended beyond the young man himself, and moves into the institutional, socio-cultural, and family influences that either helped or hindered genuine opportunities for the future. The next chapter draws upon these personal experiences as the foundation for explaining procedural impasses to a transition with dignity.

## Chapter 5 - Findings: Trialling and Silos

Chapter overview: This chapter addresses the second research question through the examination of two emergent themes that impacted each young man's transition: trialling and silos. The trials of transition section provides details on the pilot transition programme, as well as the personal experiences of each young man's brokerage and outcomes trialling. The silos section uses evidence to demonstrate how the young men were alienated from selecting their post-school programmes at both the systems and interpersonal levels. This hindered their sense of belonging in life post-school. The challenge of transition-team collaborations also overshadowed the young men's ability to have input into their own transitions.

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This chapter addresses the second research question: How can understanding the perspective of individuals with significant disability impact a transition with dignity? To fully appreciate a transition with dignity, I must first articulate transition realities, in order to portray what the young men were up against. Concepts of trialling and silos are examined from an inductive analysis of the data. The significance of each theme emerged insofar as each theme impacted all three young men's transitions, and cut across organisational levels (i.e. interpersonal, social supports systems, policy). Furthermore, each theme was an "unanticipated insight" (Braun & Clarke, 2006, p. 97), not an anticipated focus of each transition.

Importantly, the findings presented in this chapter are not the personal perspectives of the young men themselves. I use Haku's, Cobain's, and Faine's experiences as a basis for description of how each young man's transition was affected by processes of trialling and of the silos that developed. Then, I move towards broader applications, namely, a consideration of how current procedural indignities may someday be repositioned so as to contribute to



wider transition practices of dignity. In doing so, conceptual shifts in the capability approach, from Sen (1999), based on the individual, to Nussbaum (2000), based on the interaction with an individual's context, are exemplified here.

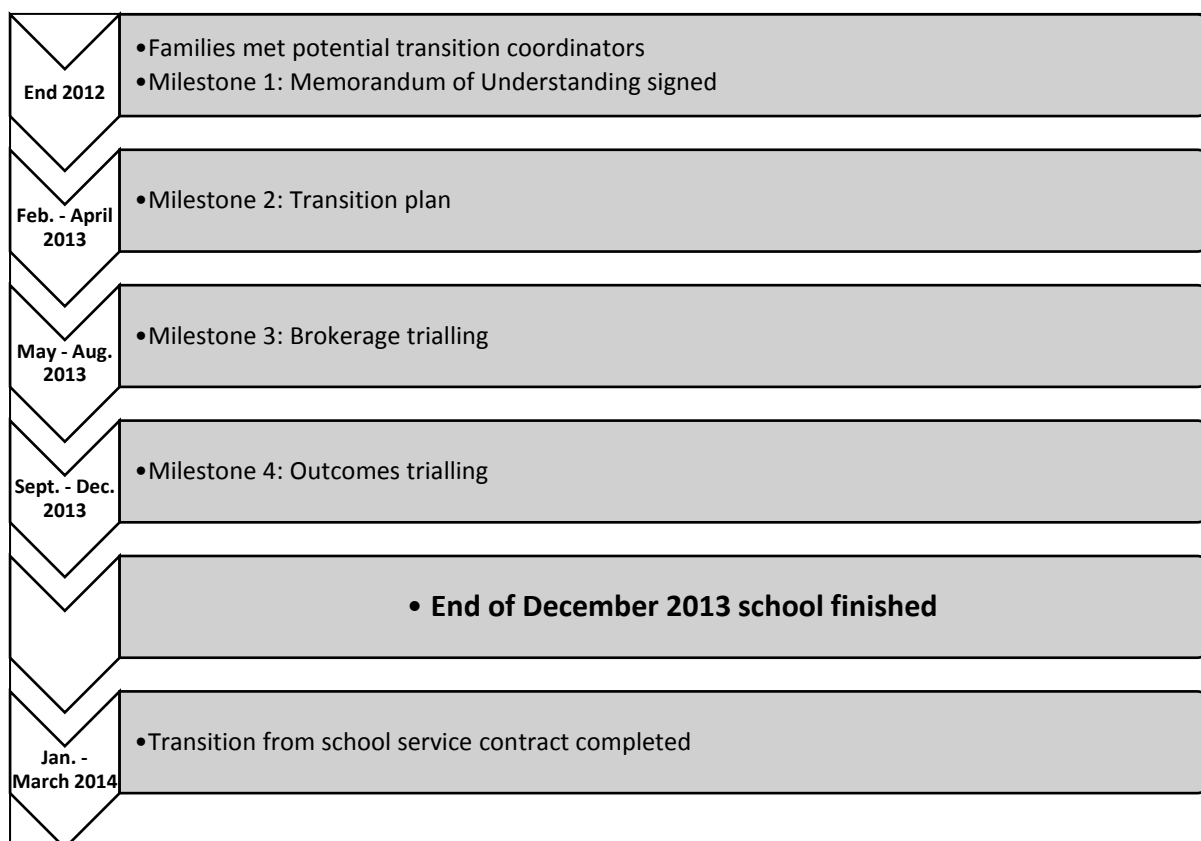
### **Trialling: The Trials of Transition**

Trialling was a term used by some participants within the study to describe trying out post-school options during each young man's transition. On analysis, I found the term used in a broad range of settings, and came to understand it as a constituent feature of transition. In spite of its widespread application to transition, I did not find the term explicitly used in the existing transition literature. To trial something is to test it for suitability. I describe the trialling experienced by each young man as a means towards an understanding of the term. Such understanding is then used as a framework to explore what dignified trialling practices might look like.

#### **Pilot transition programme: Transition coordinators.**

I looked to transition coordinators, from the transition from school service for language to frame the concept of trialling. Transition coordinators were accountable for four milestone stages of their service. The first milestone was for the student in transition, their family, and school to select a transition coordinator from the available community options. In the pilot transition programme I observed, each transition coordinator was subcontracted from local disability agencies that worked across the city. Each transition coordinator was meant to offer an individualised and comprehensive service, even though the disability support services they were employed by typically had a specific focus. For example, services targeted individuals of indigenous Māori descent, or of religious affiliations, or supported employment services. Transition coordinators raised awareness about their services, typically through community expos and by visiting individual schools for parent evenings. Senior management from the special school typically encouraged parents to begin meeting transition

coordinators prior to their child's last year of school. A signed memorandum of understanding was the first milestone, which marked an agreement that their service would begin at the start of the new school year. Figure 5.1 is an approximation of the chronology of transition from school services experienced by each young man and his family.



*Figure 5.1.* Chronology of transition from school service experienced by each young man

In the second milestone, the transition coordinator visited the school and family in order to construct a transition plan. The transition plan guided the services provided for students and their families. In Aotearoa New Zealand the school year begins in February, so completion of this second milestone was anticipated in the few months after school was underway. When I asked one transition coordinator what goes into the transition plan she replied, “What the young person wants to do, their dreams, their goals” (Interview transcript, transition coordinator, T.8 (t), post-school phase). When I asked how transition coordinators ascertain such information, she replied,

Well, talking to them and everyone that's involved in their life. Like I'm doing home visits at the moment. [Observing] IEP meetings at school. In certain situations, I've had to be involved with police safety teams or dual disability teams. All the variety of what's happening in a person's life. So as much as we can, we gather information. Especially from the person. But if they're non-verbal, very high and complex needs, it's trying to glean what's really them and what someone else thinks. (Interview transcript, transition coordinator, T.8 (t), post-school phase)

Trialling terminology entered the vernacular of the transition coordinators in the final two milestone stages. *Brokerage* trialling was the third milestone. This phase occurred prior to my fieldwork, so I did not directly observe it. In order to learn more, I coupled interview data (i.e., young men, and their mothers, teachers, and transition coordinators) with documentary artefacts (e.g., school reports, transition plans). Once transition options were selected, the fourth and final stage of *outcomes* trialling occurred. This stage occurred early in my fieldwork. To understand outcomes trialling, I analysed interview discussions, coupled with artefacts from outcomes trialling (e.g., schedules, plans, staff rosters), as well as observations of each young man.

### **Brokerage trialling.**

Brokerage trialling involved the “doing, looking, and working it all out” of post-school community options (Interview transcript, transition coordinator, T.8 (t), post-school phase). Notable for each young man were the types of options trialled, how and with whom such options were trialled, and the frameworks used to judge or assess each post-school option.

**Haku.** In essence, Haku did not have a brokerage trialling phase. He was shown only one post-school option, the polytechnic tertiary programme he then enrolled in. The fact that

he only explored one transition option appeared to have gone unquestioned by anyone in Haku's transition team, so I questioned it. I spoke with Haku's transition coordinator and her colleague from the supported employment agency they worked for and was told,

Transition coordinator: I knew he was going to get in [to polytechnic].

Sarah: But you never thought other options would be good for Haku?

Transition coordinator: Not for Haku. He's brighter, he's able to work.

Sarah: You got to know him and made that judgement?

Transition coordinator: But that's because I've been doing it for many years. You sort of know. I mean, you know when you go in there to a day programme, who's going to [tertiary] and who's not...

Colleague: And the other thing about day programmes is that a lot of them get very full very quickly. So in some ways we'd be wrong to take that place if the student we're working for is brighter, we should leave that place for someone who really needs it. (Interview transcript, Haku's transition coordinator, T.12, post-school phase)

When I questioned Haku's mother about only trialling one post-secondary option, she shared a similar sentiment,

[Haku's transition coordinator] knew. On the other hand, if it's the case that he's not happy about [polytechnic] or [polytechnic] didn't accept him, I thought still [transition coordinator and her supported employment agency] are very strong for finding employment opportunities anyway. So I was quite comfortable about it.

Whatever [Haku's transition coordinator] brings up is very cool. (Interview transcript, Haku's mother, T.8, in-school phase)

While on paper Haku's brokerage trialling was accomplished, in reality, he was not given an opportunity to experience or consider a range of post-school options. In addition, Haku's transition coordinator was trusted to know what post-secondary option suited him

best. In describing her focus for Haku's brokerage trialling, a tacit outcome of the transition from school service was revealed. Amongst finite post-school options and resources, spaces needed to remain available "for someone who really needs it."

**Cobain.** Cobain's brokerage trialling became synonymous with the post-secondary option his mother called "factories." The term was used to express her animosity towards day programmes for individuals with significant disability. Her opinions about factories were always emotionally evocative, and said with so much conviction; she often suggested she wanted to raise the issue with broadcast news sources. Her unremitting passion, reflected in almost every fieldwork conversation and observation, was akin to this comment,

I don't like those factories; I don't think our kids should be put in those factories. And with Cobain, I feel that he will be forgotten. He hasn't come 21 years of his life to end up in a bloody factory. I'm sorry. It's just not right. You wouldn't put your little kid into one of those places that they expect these guys to go to. Sorry, I'm getting emotional now. I understand that it's about the funding, but that's not where these guys should end up, in that setting. (Transition-planning meeting #2, transcript, T.3, in-school phase)

In her quote, Cobain's mother highlighted a range of concerns. First, she alluded to restricted funding after school finished. Post-school day programmes do not have the same level of funding for their services as special schools, as discussed previously in the literature review and within transition narratives. Another concern was safety. As Cobain's mother described,

"Those places aren't locked in. They have a buzzer on the door. Well what if they're too busy and Cobain gets out? That was a huge issue for me as well. Safety. He will go. A lot of them would". (Interview transcript, Cobain's mother, T.7, in-school phase)

Despite her concerns, factories were the only brokerage trialling option shown to Cobain's mother. Cobain himself was not shown anything. His transition options were explored without his presence, as his mother explained,

Sarah: What were initial stages like?

Cobain's mother: You go out, and [transition coordinator] makes appointments at different places... [One day programme] was really lovely, new, but still a factory.

Another two. And that's it. That's all there are.

Sarah: You did this in a day?

Cobain's mother: Over a few months.

Sarah: Did you bring Cobain?

Cobain's mother: No way. Me, [transition coordinator], and one time with Cobain's father. He hated it. (Interview transcript, Cobain's mother, T. 7, in-school phase)

Cobain's parents conducted brokerage trialling without their son, and assessed each day programme as a resounding failure. Cobain did not get any opportunity to provide input into his brokerage trialling. Brokerage trialling for Cobain's mother cast her son's transition into a dismal state of negativity. She often repeated phrases such as, "You wouldn't put a dog in one of those places". (Interview transcript, Cobain's mother, T. 7, in-school phase). The process of brokerage trialling seemed to reaffirm her son's marginalised place in society.

**Faine.** In an interview, Faine's mother described her son's initial brokerage trialling at the same polytechnic Haku enrolled in,

When we walked around, I didn't walk with him. I just wanted to see how he was and it was the first time I've seen him walk around and be confident. And go join in with people he didn't know. And he was saying, 'come on [peers], come on let's go,' and they didn't want to, they just hung back. And he was the one. He went around.

(Interview transcript, Faine's mother, T.3, in-school phase)

From this quotation, it was obvious that Faine was positive about this possibility for post-school life. His physical demonstration of optimism, and his mother's pride in her son's confidence and capabilities were obvious while trialling polytechnic as a post-secondary option. In this post-school option, Faine's mother saw an environment where her son could focus on an academic trajectory beyond social and life skills. However, Faine's mother also noted,

They didn't know that he can't read and he can't write, so they put a portfolio in front of him, and everyone else is turning the pages. So he's looking at everyone thinking I can't read this so I'm just going to watch the pictures. I knew he was doing that, and so he'd watch what someone else was doing when [the polytechnic teacher] was talking. She turned the pages, so ok, I'll turn the page. He was kinda faking that. He was going along with everybody. (Interview transcript, Faine's mother, T.3, in-school phase)

Faine's mother explained her assumption that her son's illiteracy would be an ongoing problem at polytechnic, an assumption she did not, however, discuss with anyone in the transition team. Instead, Faine's mother simply did not pursue the polytechnic option. Therefore, Faine's brokerage trialling preferences were not actioned in his transition.

Faine's brokerage trialling continued. Faine's mother described the process of post-school programme selection for her son in her interview,

[Transition coordinator] told me what places we could go visit and have a look at. And then she's pretty well connected with [the disability service she worked for], and [I visited on my own]. And then I came back and I wasn't happy. I thought no. The age group was too big. Faine needs his age group and the age group was huge, thirties and [older]. So that, plus I wasn't too sure about the place. I went with preconceived ideas anyway. So I was judging it on things, so I decided the next time we go I'm

going to take Faine's brother. So big brother came and so did Faine. They both went, which was really funny because Faine's initial reaction was no, this is not for me. And then we got home and Faine's brother and I talked, he said it had a few good qualities to it. He pointed out what he observed, and talked about what I was concerned about and put those things together. And what Faine was concerned about, and thought out of all of those places this is the best place for him to be for now. So I think if I hadn't taken the boys with me, both of them, I think Faine would have stayed home [and not done any post-school activity]. (Interview transcript, Faine's mother, T.3, in-school phase)

When I asked Faine's mother about her "preconceived ideas" she raised the concern, That they're put in these places to click time over. And I didn't want Faine to be part of that, just filling in time. I want him to be productive and for someone to see what he brings and what we can do with it. He could sit at home and click time over. He doesn't need to go to these places to do that. That's what I mean. If this place can't offer this for my son, then I don't want him there. More or less that was in my mind every time I went. (Interview transcript, Faine's mother, T.3, in-school phase)

Faine's mother overcame this challenge, with the day programme she eventually selected, because Faine's brother helped notice evidence of the values of the programme, [Faine's brother] saw good kinda things, he realised things that were in the place. Like a few spiritual things there, the rose quartz on the side, those sorts of things. And Himalayan writing and that. Things that were in the place. And yet those are all the things that are important to us as a family. It shows what kind of people they are. And what kind of things they believe in. That holistic side of his growth. (Interview transcript, Faine's mother, T.3, in-school phase)



The priority of Faine's brokerage trialling was to find a post-school option where he could do more than "click time over." The desire was for Faine to attend a post-school option where he could feel productive, as well as be acknowledged by others for his productivity. At polytechnic, Faine and his mother had found an option that fitted those criteria, but this preference was not pursued due to Faine's illiteracy. Second choices were less desirable, with positive aspects having to be searched for, rather than weighted, compared, and considered. Faine's mother expressed that her two sons' presence during brokerage trialling assisted her to find what she felt or, maybe more accurately, hoped, would serve as a viable post-school option for her son.

**Conclusion: Brokerage trialling.**

In sum, the "doing, looking, and working it all out" of brokerage trialling involved three considerations: the types of options trialled, how and with whom such options were trialled, and the frameworks used to judge or assess each post-school option. While each of the three considerations inferred an inherent decision-making process within them, in actual fact, none of the brokerage trialling experiences provided viable choices at all. Haku only pursued one post-school option. Cobain's mother was so upset by day-service factories, the only options she saw, that her reaction was to create an individualised programme for her son. Additionally, Cobain never experienced any brokerage trialling. Faine's trialling preference was not pursued, and, therefore, Faine's mother searched amongst undesirable options for a second-best fit.

The experiences of brokerage trialling can be best understood as missed opportunities. Each young man missed the chance to learn more about his post-school options during the critical life stage of transition. In turn, he missed the opportunity to be agentic in constructing his future and setting his priorities for a productive life after school finished.

### **Outcomes trialling.**

After brokerage trialling came the final milestone of the transition from school service, outcomes trialling.

The idea around the [outcomes] trial is when a student has been to school and then they're going to attend a [post-school] community participation programme, the school supports them to be there, and the staff at the community participation programme gets to know them. And that's the trial situation. (Interview transcript, Haku's transition coordinator, T.12, post-school phase)

Outcomes trialling occurred near to the end of school and had two purposes. First, for students to familiarise themselves with the post-school environments they would be attending once school finished. Second, for the new community-support staff and student get to know one another. Descriptions are provided on how each young man's outcomes trial worked differently.

Haku had a structured outcomes-trialling process. During his final semester at special school, Haku spent one day per week attending a short course at polytechnic. Attendance at the short course enabled Haku to familiarise himself with the campus and teaching staff. Initially, he attended the short course with support from special-school teacher aides. Their support tapered off over time. For instance, it was during outcomes trialling that Haku learned to ride public transportation. Initially, this learning required significant staff support, but, as he gained confidence, the need for such support lessened.

During the short course, polytechnic teaching staff conducted assessments of Haku's scholastic skills, held meetings with Haku and his mother, and worked on class projects where they got to know Haku's level of academic, social, and personal functioning. I observed, for instance, his completion ceremony, or graduation from the short course, when

Haku and his classmates made speeches about a hand drawn map highlighting their favourite spots on campus. The audience was comprised of polytechnic teaching staff and family members (Haku's mother attended). Through such activities, Haku got to know some of the students and staff he would be on campus with after leaving school, and reciprocally, they got to know him.

On another occasion, I observed a transition-planning meeting towards the end of his short course (and thus, when he had nearly finished special school). An excerpt from my field notes described Haku's challenges in participating in his own planning meeting,

Overall, Haku had a difficult time answering [lead polytechnic teacher's] questions. [Lead polytechnic teacher] checked with Haku's mother regularly to see if what he was reporting was accurate. But I often observed Haku's mother rolling her eyes and silently laughing as if Haku was giving answers he thought were correct rather than ones that were the actual truth. The questions seemed to be thorough, very relevant to attending post-secondary schooling, but I don't feel confident they were effective in getting to know Haku. (Field notes, FN.2, in-school phase)

Even after Haku's regular and structured visits to polytechnic, supported by teaching staff from the special school and polytechnic, challenges in getting to know him were apparent.

Cobain's outcomes trialling involved adapted horseback riding, an activity he had enjoyed years before at special school, but had discontinued in recent years. By this stage, a dark shadow of "factories" was cast over Cobain's transition. There was a palpable sense that horseback riding would not need to be pursued had there been suitable day-service options for Cobain. Furthermore, Cobain's transition team was still putting together an individualised plan. Horseback riding was set as the central feature of his post-school week, yet his transition team wasn't entirely sure if he still liked the activity.

In order to assess Cobain's preference, his transition coordinator arranged with a friend for Cobain to visit her personal horse. As Cobain's special-school teacher noted, "If you want [our students] to do things that you want them to do, you need plenty of time to introduce them" (Interview transcript, Cobain's teacher, T.5, in-school phase). Cobain's mother, teacher, teacher aides, house leader, and residential-care coordinators, all had turns visiting this horse with Cobain. This is despite the fact that the horse was not in the place where he would attend lessons, and not with horses he'd likely ride in the future; the visits were simply for Cobain to be in proximity to a horse. As can be recalled from Cobain's case narrative, this did not go well. He typically pulled to be taken back to the car, or he demonstrated antisocial behaviours, which would, in turn, upset his mother.

Cobain's outcomes trialling took up a lot of time and resources. His teacher made the comment about the outcomes trialling of one of Cobain's classmates,

Another problem with trialling is that it encroaches on what I'm doing here [in my classroom curriculum]. So like Friday, for some reason I need to take [Cobain's classmate] swimming. Which he doesn't need practice to do, because he does it every week and he loves it and we know he loves it. (Interview transcript, Cobain's teacher, T.5, in-school phase)

In the teacher's example, the student she referenced had already established his enjoyment of an activity to be continued post-school. Thus, there was an inherent repetition in the outcomes-trialling processes for this student. More concerning from the quote, however, was how the teacher did not see herself as an important part of outcomes-trialling procedures.

Cobain's teacher diminished her role in the outcomes-trialling process, and so too did his transition coordinator. Cobain's transition coordinator described it as a challenge of transition for someone with very high needs. She described in interview,

Yes, I set [horse farm visits] up, but I didn't have enough of a relationship with Cobain to be able to [trial visits] with him. Someone with high and complex autism - there's no way I can step in like that. It needs to be the people that know him well. It's too short a timeframe for me. (Interview transcript, Cobain's transition coordinator, T.8 (t), post-school phase)

Cobain's outcomes trialling therefore was stuck at an impasse. His outcomes trialling failed to achieve either of its intentions; he did not get to know the new environment where he would take part in horseback riding, nor did new staff from the horse-riding programme get to know him. Cobain required a lot of support to achieve such aims, yet few people had the priority or ability to give it to him.

At best, Cobain's outcomes trialling could be understood as a cost-benefit ratio. Whether horseback riding activities was worth the expense and significant staffing hours was difficult to establish for Cobain's transition team. Six cumulative hours of transition-planning conversations seemed to always come back to whether or not the activity was worth the expense. Within those conversations, Cobain's transition got stuck on planning trialling, rather than moving through a trial to the construction of a personally relevant life plan.

Faine's mother succinctly summarised her son's outcomes trialling as, "He might be familiar with the surrounds, but we're going in blind" (Interview transcript, Faine's mother, T.3, in-school phase). The mounting stress Faine experienced, as a consequence of visits to the new day programme he would attend after he finished school, has been described in his case narrative. Faine had experienced the post-school day-service he would soon be attending, but not sufficiently to feel comfortable with the choice.

Faine's mother was the only one who offered an understanding of what outcomes trialling might look like from her son's perspective. She shared in her interview, "But he

can't do both at the same time. He wants to just finish [school] first and then go on to what else we've got to do. Like flicking a light switch" (Interview transcript, Faine's mother, T.3, in-school phase). Her comment holds profound implications for the process of outcomes trialling. The question of whether or not students desire to experience both in-school and post-school worlds at the same time suggests the format and timing of trialling may require individualisation as well as further systemic consideration.

In addition, Faine's teachers shared concerns about the handover of knowledge, from school to his new day programme, at the interpersonal and structural levels of outcomes trialling. I asked Faine's teachers,

Sarah: How do you pass on all the information you have about the students?

Teacher #2: We do a leaver's profile.

Teacher #1: But that's not the same as having a chat.

Teacher #2: Or going with him to see what he's doing.

Sarah: Do day-service support staff come here to chat with you guys?

Teacher #2: Has [Faine's day programme] come [to special school]? No.

Sarah: Did they sit in on any of your transition or report meetings?

Teacher #1: No. I've never met any of them. (Interview transcript, Faine's teachers, T.2, in-school phase)

Faine's special-school teachers had not met the day-service staff. Even without first-hand experience of the day programme or meeting their staff, there was an assumption by the teachers that the curriculum taught in special school would not be carried on after leaving school. During interview, Faine's teachers spoke emphatically about a book Faine had recently created as part of his special-school literacy curriculum. When I asked if there were plans in place for such creative projects to continue post-school his teachers replied,

Teacher #2: Well I hope so because I would hate to see him stifled. I think that's the hardest thing about teaching this level.

Teacher #1: [What will it look like] on the other side [post-school]?

Teacher #2: We put all this effort into teaching [students], encouraging them to be creative and independent and have great experiences and learn important skills and then we know there's not really that much going on in these community places?

...

Teacher #2: It's just, it's the first time Faine's ever done anything like this [book making]. So it's like, if he could do this, what more could he do? And I would love for him to be taken under someone else's wing who could bring out that side of him and get him to produce more. He could be, he could write children's books. I truly believe that.

Sarah: Is there any way that you can pass on information like this? Have you been involved in any meetings or handovers?

Teacher #1: We haven't met anyone.

Teacher #2: [Associate Principal of the special school] does all the meetings and we fill in information. But we didn't have the book at that time. We didn't see what it looked like. To see his creativity. His potential. I don't know that [the day programme] would take on that side. They are short staffed from what [our teacher aides who have visited] have said. (Interview transcript, Faine's teachers, T.2, in-school phase)

### **Conclusion: Outcomes trialling.**

In sum, the two objectives of outcomes trialling were: for students to familiarise themselves with the post-school environments they would be attending once school finished;

and for the new community-support staff and student to get to know one another. While some case experiences came closer than others to meeting those two objectives, in no instance were both criteria met. Haku came the closest. Through a weekly, structured short course, Haku learned about the organisations and systems of polytechnic. While presumably, during that same time, polytechnic staff had occasion to get to know Haku reciprocally, communication challenges within Haku's transition-planning meeting were evident. Haku's experiences demonstrate the challenges in getting to a confident stage of familiarity with someone with significant disability.

Cobain was the furthest from meeting both objectives of outcomes trialling. The constant cost-benefit ratio weighting of whether or not to pursue therapeutic horseback riding kept him stuck within the realm of trialling, so much so that, by the end of fieldwork, he had not yet begun actual lessons. Finally, Faine's outcomes trialling did more to raise his anxiety about leaving school, than it did to prepare him for his post-school life. His situation, more than any other, raises questions about what students require in order to trial. This is not to suggest Faine didn't want and need to get to know the routines of his post-school life, but to question whether the end of the year, a time filled with so much emotion and confusion, was the appropriate stage to take on such new information.

Moving away from individual experiences, outcomes trialling can be used to examine the interface between school and post-school services from a more systematic perspective. From Faine's teachers' interview data further questions are raised. For instance, what obligation do special schools have to mirror the realities their students may face in the community? Conversely stated, is it the responsibility of post-school options to do the best they can to continue school's curricular priorities? Furthermore, how ought such entities to coordinate?



Outcomes trialling, as it was experienced by each young man, held a range of challenges: timing of outcomes trialling at the end of the school year, difficulties in getting to know and communicate with students, and detachments between in-school and post-school activities. Lost within the various breakdowns and challenges were the students themselves. Their hopes, dreams, priorities, and skills, were eclipsed by ineffective outcomes-trialling processes. I suggest that, when such central life preferences and capabilities are lost at this stage, their likelihood for remaining viable options later into adult life diminishes.

### **Trials of transition: Discussion**

Overall, brokerage and outcomes trialling can collectively be understood as the processes of exploring and getting to know post-school options. Each young man experienced only disability-specific, pre-existing programmes and services. While the requirements of each component of trialling were met, they lacked two important elements.

First, the young men and their families did not fully explore what their choices were. In some instances, the young men themselves did not have any involvement at all in decision making. In other cases, the young men and their families were selecting from a restricted set of post-school options. Overall, selections of post-school options were made, but from a set of options so restricted, any choice and freedom inherent within those selections was highly compromised.

Secondly, there was little to no evidence to suggest that the young men were understood as unique and individual human beings. Evidence to support this claim came, for instance, came from struggles to communicate with Haku in transition-planning meetings after regular trialling visits to polytechnic, and continual questioning of Cobain's preference for horseback riding after regularly visiting a farm horse. As evidenced in their trialling

experiences, struggles to get to know the young men does not suggest this occurred from a lack of trying.

The difficulties in getting to know someone with significant disability cannot be diminished. However, it is fair to question whether or not it was considered necessary in these instances, or done effectively in each case. Transition options were finite. Therefore, the transition coordinators' role within trialling may more accurately be understood as screening students between disability-specific transition outcomes in order to prevent overcrowding in the more popular post-school options. By this logic, getting to know transitioning students would mean only needing to know enough to figure out what service they best fitted. This reality of trialling deviates from the stated intention of the process, finding and establishing personalised post-school plans. Further complicating the matter was the fact that, in actuality, the role of transition coordinators served less to advocate for students, and more to temper parents' emotions through a challenging life process for their sons.

The lived experiences of the three young men demonstrated trialling to constitute many missed opportunities. The capability of a person corresponds to the freedom that person has, to lead one kind of life or another, chosen from a range of options (Robeyns, 2005). Trialling emphasised only where the young men were going after they left school. Haku, Cobain, and Faine were funnelled into transition outcomes, with little consideration for the experiences they had in getting there.

### **Silos**

The term *silos* was first brought to my attention during an interview with a transition coordinator. The transition coordinator described the challenges of working between the various ministries that support transition:

There's a constant argument that [transition] should be [Ministry of Social Development] MSD funded. But MSD funding is appalling. And [Ministry of Health] funding is much better. And at the end of the day, it all comes from the same purse, so the *silo* aspect is really frustrating. (Interview transcript, transition coordinator, T.8 (t), post-school phase)

Collective tax payer dollars are the "purse" referenced in the quote.

A silo is a system, process, or department that operates in isolation from others (Oxford English Dictionary, 2014). This definition aligns with the experiences expressed by the transition coordinator. Based upon this understanding, I did not search for the term directly, but explored the dataset for instances of isolation or its opposite, collaboration.

In the first half of this section, silos are reviewed at the systems level; between individuals and the systems that are designed to support them. More specifically, I focus on two observations of interactions the young men had with ministry sub-services of Work and Income (WINZ; Ministry of Social Development) and Needs Assessment Service Coordination (NASC; Ministry of Health). The observations are contextualised by interview data from transition coordinators and parents. Secondly, I use the lens of silos to examine the interpersonal level, particularly in the collaborations between the individual roles that make up transition teams. More specifically, I analyse five transition-planning meetings I observed, supported by transcripts of informant interviews. Finally, taken together, I demonstrate how silos at both system and interpersonal levels isolated the transitioning student instead of centralising them within their own transition. Silos imply the need to address collaboration and advocate for student voice and preferences.

### **Systems silos.**

By design, transition programmes currently under pilot testing in Aotearoa New Zealand were meant to promote a partnership between government ministries and the disability sector. Therefore, the frustration expressed in the transition coordinator's quote about silos was initially surprising. But two observations of interactions between two of the young men and the social services drew my attention to the tensions between individuals and the support systems designed to facilitate out-of-school transitions. These situations, for Haku and then Faine, are reported next, followed by further analysis of system-level silos and their effects.

Polytechnic teaching staff strongly encouraged Haku and his mother to apply for discretionary funds for stationery and other school supplies. "It's a privilege and Haku is entitled to it" (Quote transcript, field notes, FN.2, in-school phase). Therefore, Haku's mother arranged to visit Work and Income New Zealand (WINZ), a branch of the Ministry of Social Development responsible for providing financial assistance and employment services. I described the application meeting in my field notes,

The woman conducting the interview had a trainee at her side. After waiting a half hour to begin the appointment, we sat down at our meeting, to learn from the WINZ officer that the meeting was booked too early, prior to the course starting. Haku's mother took this news politely. Her work colleague (whom Haku's mother had brought along for support) and I said nothing, but the frustration was palpable. Why could this "rule" not have been explained at the time of booking the appointment? And what kind of "rule" was it anyway? What was it trying to safeguard, other than increasing the likelihood that Haku and his mother would not return for another appointment? Of course, the rescheduled appointment had to be made over the phone,

and would occur when Haku's mother was back to work, so she would need to take time off for the appointment. (Field notes, FN.7, post-school phase)

The most obvious breakdown, in Haku's example, was the adherence to policies he and his mother had not been made aware of. Instead of WINZ working to understand and support Haku's needs, he was supposed to understand and adhere to the WINZ procedures. Furthermore, polytechnic teaching staff informed Haku's mother of this financial support and strongly encouraged her to apply, but without helping her to know the ground rules for application. While frustrating, Haku's example provides a preliminary understanding of the concerns related to silos.

My observation of Faine delves deeper into the notion of siloed experiences. I observed Faine's needs reassessment conducted by a Needs Assessment and Service Coordination services (NASC) assessor a subcontracted service of the Ministry of Health. The meeting was held at the Kura Kaupapa Māori-language immersion wing of the school where Faine's mother worked. Faine's mother, the transition coordinator, and the regional NASC assessor were present. Of note was that despite this being a reassessment of Faine's needs, he was not present. His absence signalled the ultimate marginalised silence, and surprisingly, was not questioned by the NASC assessor. Faine's mother did not want her son to be present, for reasons soon evidenced.

The process of reassessment involved Faine's mother answering pre-set questions that were recorded in by the needs assessor, by hand, in triplicate carbon copies. Questions pertained to support networks: formal (e.g. school, Special Olympics), informal (e.g. Faine's large whānau), and Faine's abilities in communication, mobility, and personal care. Questions arose about services to support Faine's lack of balance getting in and out of the shower, which had led to his mother needing to bathe him. Faine's mother rented their family

home, thus NASC services could not assist in adapting the bathroom facilities. At age 21, Faine and his mother continued a routine of indignity because they could not be supported with an alternative.

The comprehensive reassessment took two hours. After the NASC assessor finished her questions and departed, I describe in my field notes a conversation between Faine's mother and the transition coordinator,

Faine's mother says everyone in her family knows Faine is special but not because of his needs, rather because of his ability to talk with the angels. His mother said she feels really good when visiting Faine at his special school, because she is amongst his "special" peers. Special was a positive term she used to denote skill and respect.

Faine's mother felt the community has a lot to learn from individuals with special needs and their way of seeing things. At this point, she called into question individualised processes such as the needs assessment that just took place. "All this focus on the individual is so off from my way of thinking," said Faine's mother. "With my people, we move forward together. If one is held back, we are all held back." The overall tone was that the needs assessment and the individualist processes built into it could never take into account and appreciate the depth and complexity of Faine as a human being himself and his wider networks of support. Thus, for example, questions about his sleep were expressed by his broken patterns of staying awake for three days at a time about twice a month, because nowhere within this question was a space for his mother to tell the needs assessor about his time spent awake talking to angels or making spiritual visits. (Field notes, FN.2, in-school phase)

In order to receive Ministry of Health funding, individuals with significant disability must undergo assessment/reassessment processes such as the one experienced by Faine's mother. This glimpse into the needs-assessment process shows the regular indignity families

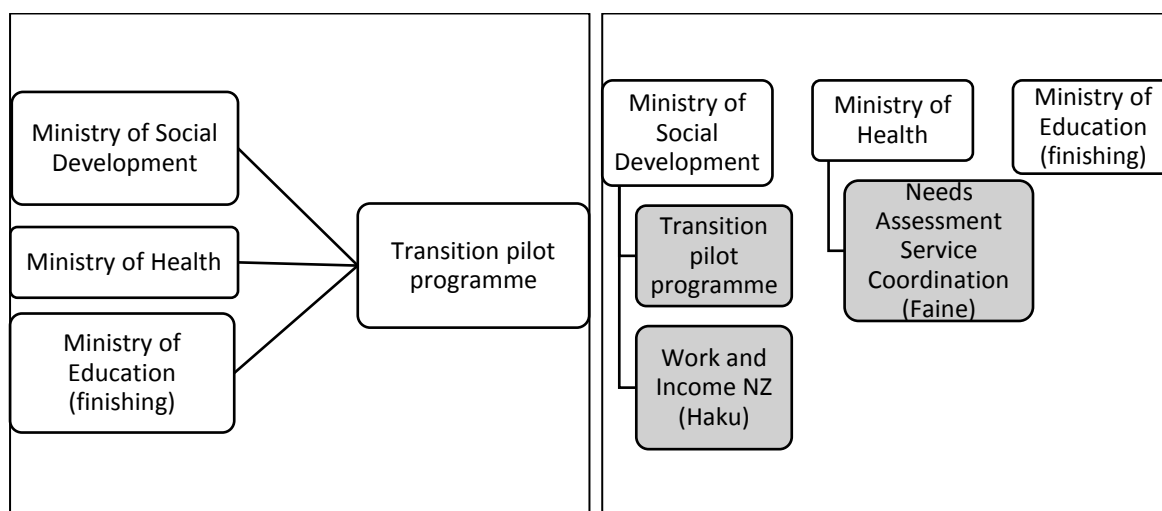
must endure in order to receive funding to support their child. Faine's mother was required to speak in a language uncomfortable to her, of pessimism and negativity. There was no space within this process for her to express her belief that it seemed the good of society comes before the welfare of the individual, as her son's identity became lost in problems and deficits, which led to increased funding. Faine's mother was aware needs reassessment would operate in this way, and therefore didn't want her son present to hear the negative things being said about him.

Elaborating further on the process of needs assessment, it was noted that Faine's mother essentially underwent this process alone, and was hence yet another silo. Although Faine's transition coordinator was present, at this stage in the transition process his transition coordinator had met Faine only once or twice, and certainly did not have sufficient knowledge about him to support the reassessment process with anything more than moral support. I observed that no documentation was referenced during the meeting (e.g., teaching reports), nor did anyone discuss any formal evaluations that might contribute to Faine's reassessment. Without her son's presence, in essence, Faine's mother was the sole advocate of her son's needs and experiences. The isolation of her experience established an undesirable silo, whereby the reassessment process was her word, and her opinion of her son's level of functioning, against that of the need assessor who had never met her son.

In both ministry interactions that I observed, Haku and Faine's mothers had to acquiesce to funding-support systems that siloed them into procedures and process, rather than taking a holistic view of transition and personal needs across social services. In each instance, transitioning individuals and their families were made to comply and fit into a service, even if the service didn't fit in with them. Note, there is good reason I never had occasion to observe any interactions between Cobain and systems-level silos. Due to living in residential care, the disability-care coordinator acted as an intermediary between Cobain's

family and ministry support services. Cobain’s experiences in residential care could therefore be seen as another form of silos. As explained in Cobain’s case narrative, his transition coordinator, who was subcontracted from outside his care house, felt he had “no room to move” from within the disability-care service. Cobain’s access to activities outside those related to the disability-care service was isolated and restricted.

Figure 5.2 visually expresses the contrast between the intention of the Aotearoa New Zealand pilot transition programmes on the left side of the figure, and the reality Haku and Faine experienced, on the right hand side. If funding and resources were pooled, as intended and demonstrated on the left hand side of Figure 5.2, Haku and Faine could have spent more time establishing and executing their transition priorities, and less time complying with ministry protocols. In contrast, the right hand side of Figure 5.2 is used to demonstrate what Haku and Faine actually experienced, each having to work with discrete ministry sub-services in order to arrange for their transition. Each sub-service came with its own rules, requirements, and regulations to be followed.



*Figure 5.2.* Schematic of Pilot Transition Programme as Intended (Left), and as Observed (Right)



There is precedence for such collaboration within other social services. Take for example, High and Complex Needs (HCN) interagency strategy (HCN Governance Board, 2007). The programme serves young people who have substantial and unmet needs beyond those that regular health, education, and social services can offer. The collaborative services work to improve the wellbeing of children across a range of domains (e.g., physical health and mental wellbeing, social interaction, and educational foundations for lifelong learning). Accordingly, intersectional interventions work across Ministry of Education, Ministry of Health, Ministry of Social Development (including Child, Youth, and Family Services), and Ministry of Māori Development (HCN Unit, 2005).

In order to access HCN services, short-term, intensive interventions require the commitment of at least two ministries. To be accepted, involved ministries must offer a blueprint for how front-line staff will provide opportunities for the child to succeed through enhanced collaboration and coordination. However, HCN services are not available for students in transition, as the funding is intended for school-aged students.

HCN strategies can serve as a guide for other systems-level support strategies. Collaborative ministry services can offer social supports tailored to unique needs, priorities, and what each individual considers to be their valued wellbeing priorities. On this note, however, it is important to remember it is not systems themselves that promote positive and meaningful change, it is individuals who accomplish such procedural changes. Significant effort goes into the planning of the collaborative services, requiring interpersonal collaboration.

### **Interpersonal silos.**

Analysis of five transition-planning meetings, and interview transcripts of all informants related to transition planning, revealed that special-school teachers were not

invited to, did not directly or indirectly participate in, and thus were entirely absent from, transition planning for their students. Two planning meetings were related to Haku's transition, both held on the polytechnic campus at his pre-employment course classrooms. Each meeting lasted for an hour and a half. The first meeting, an enrolment interview, was held during the in-school phase. The second, a person-centred education plan, was held after Haku left special school. Haku was present at both meetings, as were his mother, lead polytechnic teacher, and subject polytechnic teacher (on one occasion). Three transition-planning meetings, related to Cobain's transition, were held at his residential-care home. All occurred during the in-school research phase, and each lasted two hours. In attendance were one residential-care administrator, Cobain's house leader, mother, and grandmother (on one occasion). Cobain never attended. After one meeting, I questioned within my field notes,

As the planning meeting unfolds, Cobain's adult life turns into a laundry list of things to try that no one is sure he'll like anything of. There's no central focus, no human capability he is working towards. How might this be different if the teacher were present? (Field notes, FN. 13, in-school phase)

Teachers' interview transcripts were used to supplement observational data. Faine's teachers expressed their hopes and dreams for his future. When asked if they had any way to pass along those aspirations to future support staff, the teachers replied they had not met any of them. Interview data provides an understanding of the teachers' feeling of absence, employing their own perspective.

(Teacher #1) It's really hard, I'm finding, from the teacher's point of view with transition, because you don't have any input. You don't have any say on how things go, even if you know that all sorts of things would be ideal for [transitioning students]. You don't have any input into it. (Interview transcript, Faine's teachers, T.2, in-school phase)

Haku's teacher expressed similar opinions in her interview. When asked if she was involved with any planning meetings her reply was "No". Likewise, when we discussed Haku's programmes following school she stated, "I don't know what their programme covers" (Interview transcript, Haku's teacher, T.7, in-school phase). Her lack of transition participation was described in this manner,

I don't feel like I've played a big part in his transition, except that we keep Haku up-to-date with what's happening, and we talk about it as part of the day. ... But really his mum and transition coordinator have done the work with him. (Interview transcript, Haku's teacher, T.7, in-school phase)

The three special-school teachers were all absent from transition planning, though for different underlying reasons that were discussed in teachers' interviews. Haku's transition coordinator dominated his small transition team. Since his mother had no immediate or extended family to support her, she was guided by Haku's transition coordinator, stating that "whatever [Haku's transition coordinator] brings up is cool. Without [Haku's transition coordinator] I have no idea what's going on" (Interview transcript, Haku's mother, T.8, in-school phase). Cobain's teacher felt her perspective was overshadowed by the relationship between Cobain's mother and his residential-care staff. His transition from school marked a time when connections with the school were being severed, while the scope of residential services was expanding. For Faine's teachers, a school policy restricted them to the classroom during school hours. Thus, they were unable to go for community visits, or attend transition-related planning meetings held within school hours. Paraprofessional teaching support staff, or teacher aides, supported students in community environments during the school day, and reported their observations back to Faine's teachers.

The special-school teachers expressed frustration and concern regarding their exclusion, yet, when describing their teaching role, each expressed the need to be supportive

and follow, rather than actively contribute, to the transition team. Essentially they acquiesced to their diminished status and accepted their passive positioning, as demonstrated in a quote from Faine's teachers:

Sarah: Where do you see yourselves in the bigger picture of Faine's transition?

What's your role?

[Teacher #1]: Because we don't get to see these places...

[Teacher #2]: We're just preparing him...

[Teacher #1]: We're preparing him. And supporting him in what he chooses to do.

Sarah: What do you mean when you say preparing?

[Teacher #2]: We're trying to give him as many skills as we can before he goes.

(Interview transcript, Faine's teachers, T.2, in-school phase)

In a further example, Haku's teacher describes:

Sarah: So basically what I hear you saying is that you provide a general transition curriculum and an individualised curriculum happens ...

Haku's teacher: More with the transition [coordinator] person. It's the only way we can do it. (Interview transcript, Haku's teacher, T.7, in-school phase)

In contrast to the side-lined experiences of the teachers, the significance of the transition coordinator increased as time went on. For example, when asked about the most helpful member of the transition team, each parent responded it was the transition coordinator. Faine and Cobain's mothers, however, both retracted their initial responses. Faine's mother later identified the support of Special School A.'s Associate Principal who was in charge of transition as the most supportive. Cobain's mother became saddened when answering this question and expressed she hadn't felt supported through the transition process.

Haku's transition coordinator described the communication between those involved in Haku's transition,

I just emailed them everything I was doing. And I think the school liked this.

Everything I was doing with Haku, I'd let the school and mum know. I'd CC them everything. They said to me often, oh so great that you let us know. I say, well that's how I work. That's the way I've been taught. Keep everyone on the same page. We're all communicating. (Interview transcript, Haku's transition coordinator, T.12, post-school phase)

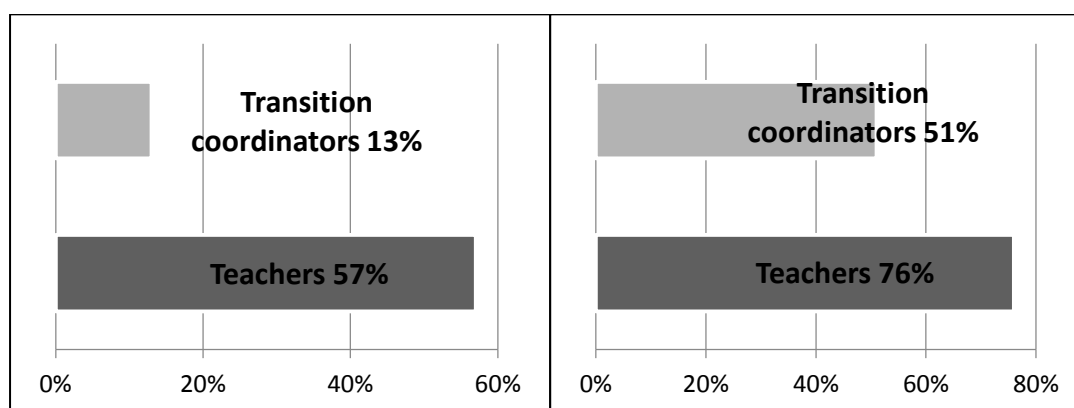
While Haku's transition coordinator communicated with all the roles listed in her transcribed quote, in actuality the communication only flowed in one direction, from the transition coordinator to the rest of the 'transition team'. Faine and Cobain's transition coordinator took a more collaborative approach, but similarly saw herself as the central figure. As she described in an interview:

And because there's so many strands, as a transition coordinator, you're really frustrated if people aren't engaged. Because you're really the one person holding everything. ... All the strands sitting around students and school, then the bridge, which is transition, and then the after-school life. At some point those strands are all being let go by school and all other aspects of the student's life and they need to be in place here. As they get let go, or things are changing, [I am] the one person holding this overview. (Interview transcript, Faine and Cobain's transition coordinator, T.8 post-school phase)

The transition coordinator held the strings of the transition team together. In doing so, she centralised herself, instead of the student, as the pivotal figure in the transition team. The transition coordinator acknowledged the importance of school in her statement, but saw the majority of the school's contribution to transition as being one of "letting go." Thus, each of

the transition coordinators said they communicated and wanted collaboration; however, their actions demonstrated siloed isolation.

Without the active contribution of the special-school teachers, transition-team collaborations lacked a valuable perspective. To assess just how *valuable* that perspective was, and how much was lacking in its absence, and, furthermore, how much was gained by the inclusion of the transition coordinators' presence, I returned to participant observation data. Figure 5.3 is a side-by-side graphic comparison between teachers and transition coordinators. I tallied all of my participant observation hours across the three young men. The left hand side of the figure shows the percentage of observations with teachers or transition coordinators out of my total number of participant observations. Teachers were present in 46% to 67% of fieldwork participant observations. In contrast, transition coordinators were present in .08% to 25% of fieldwork participant observations. Note, the timeframes for potential observations differed. All teacher observations occurred during only three months of in-school time points, while transition coordinators extended to a total of six months across in-school and post-school contexts. Therefore, the little time spent with the students by transition coordinators stood out even more significantly because their potential to be observed was over a longer period.



Number of settings observed with young men (left). Transition-team interactions observed (right).

Figure 5.3. Graphic comparison teachers vs. transition coordinators.

On the left hand side of Figure 5.3, teachers were observed with their students in integrated community settings (e.g., parks, shopping malls), as well as in disability-specific contexts (e.g., base special school, satellite classrooms). In contrast, transition coordinators were observed most often in disability-specific, segregated spaces (e.g., disability services and day-programme services). All of the special-school teachers had been teaching the young men for over three school years, whereas the transition coordinator service lasted for one calendar year.

The right hand side of Figure 5.3 demonstrates the amount of interactions observed between teacher or transition coordinator with other transition-team members. Percentages were averaged across three young men and calculated out of total number of participant observations. Despite their siloed position, teachers' contact was observed with 71% to 80% of their students' total support networks. In contrast, transition coordinators' contact was observed with 48% to 59% of student support networks. The settings of interactions for transition coordinators were formal (e.g., planning meetings), while interactions for teachers represented a mix of informal (e.g., student pick up/drop off, telephone calls) and formal (e.g., graduation, report meetings). Teachers might, therefore, be assumed, within the demonstrated contact times, to have ample opportunities to pass along information about their transitioning students. However, special-school teachers were not present at the vital planning meetings where options were considered and decisions were made.

### **Silos: Conclusion.**

The silos section of this chapter has detailed system silos and interpersonal silos. In both instances, the systems and interpersonal relationships, designed to work collaboratively, appeared fractured and isolating. Most worrying of all, within these breakdowns, the transitioning students were lost. A lack of systems-level collaboration was incompatible with the pilot transition programme design. These breakages in the system meant students and

their families had to navigate between discrete social services, and to acquiesce to policies and procedures that promoted adverse discourses about the transitioning student. A breakdown in interpersonal collaboration side-lined the special-school teachers from the transition planning for their students. The consequence of this was the loss of a valuable advocate and spokesperson for the student. While the transition coordinators knew a great deal about available options in the community, they knew far less than the teachers did about the students themselves.

Working from the premise that changes need to be made to transition, Cobain's mother poignantly posed the question of who was best situated to support her son's transition, accompany him to community options, and raise concerns about the appropriateness of the services available. She said in an interview,

And I said to the school, "You don't prepare us for what we are going to see" [in community options]. And I think it sucks. So [transition coordinator] said in a group transition meeting earlier in the year, [community day services] are not going to be what you expect or you're used to. (Crying). I'm sorry. Have you seen those places? You need to go. And have a look. ... You wouldn't put a dog in there, Sarah.

Sarah: You're raising a really good point. Teachers don't get to see these places.

Cobain's mother: When these guys leave [school]. I mean, think about it, when you leave school, that's it. The teacher doesn't go with you. But I think in this instance, they need to. ... And what can [the transition coordinator] do? She works for the government. So she can't say anything. (Interview transcript, Cobain's mother, T.7, in-school phase)

The findings in this chapter demonstrate the special-school teachers' diminishing impact during transition. Yet, when examined from a position of their importance to transition, their role should, in actual fact, be increasing. Parents have been shown to have



incomplete information about transition options, experiencing substantial emotional burdens, as well as fractured transition procedures. Furthermore, as Cobain's mother points out, transition coordinators may not feel at liberty to question the government systems they work within. In this sense, only the teachers have knowledge of the capabilities of their students, the experience of working with them over several years, and the expertise to be advocates for them in making life choices. As one of Faine's two teachers said in an interview:

Teacher #1: But I personally would like to have a bigger involvement...The places available in the day programmes, there isn't enough out there. And that's a big problem. There can be problems with what [students] can do with their days.

(Interview transcript, Faine's teachers, T.2, in-school phase)

## **Conclusion**

The current practice of trialling and the siloed nature of the transition processes do not support a transition with dignity. Rather, each exists as a hurdle to be overcome. The young men and their families struggled to find and make decisions about their post-school life and activities. Once post-school options were selected, it was questionable whether it was necessary for each young man to be known and understood on a personal level, because all of the post-school options were generic, group-managed activities. The young men fell in between the cracks of their fractured transition-support networks. Throughout the end of school phase of transition, each was on a speeding train racing towards what was supposed to be the exciting start to his adult life. Sadly, the post-school realities looked more like an inevitable end, like they were "falling off a cliff" (Stewart, Law, Rosenbaum, & Williams, 2002, p. 12). While the milestones of their transitions were achieved, there were many missed opportunities to promote choice and freedom to fulfil truly human capabilities.

## Chapter 6 - Discussion and Conclusion

Chapter overview: This chapter begins by discussing the overall findings. Findings are then interpreted in light of prior literature in order to construct a counter-narrative to the transition experiences of the three young men. Next, the emancipatory research partnerships as a unique aspect of this study are discussed in the methodological reflections section. Limitations and future research directions are then described in the critical evaluation. Following this, the research questions are addressed through the capability notion of genuine opportunity. The thesis concludes with practical and theoretical implications.

### Discussion

Genuine opportunity, or the conversion from capability into lived functions or outcomes, are the central focus of discussion. A visualisation of this process is provided in Appendix E, which contains four figures based upon Figure 2.2, the schematic flow of the capability approach (Bryson, 2015). In Figure E1 the central findings from this study were overlaid on top of the schematic. The left hand side of Figure E1, or the beginning of the capability process, noted that the means to achieve was in place for each of the three young men. Each young man had access to resources and social welfare typically associated with the internationally high standing of Aotearoa New Zealand.

Additionally, at the furthest right hand side of the schematic, the outcome or functions arising from capability processes, were considered suitable, preferable, or even desirable by the young men and their families. Professed satisfaction with unjust conditions has similarly been noted within capability theory, called adaptive preferences. Some adjust to their marginalised circumstances to the extent that they do not question them, or even find them preferable. This is why, for example, wellbeing is challenging to ascertain by subjective measures alone.

The theoretical notion of adaptive preferences, as well as the lived realities of the young men of this study, situate the area of concern within the central portion of the graphic, in the capabilities, opportunities, and freedom to achieve. The conversion factors assist to articulate where and how breakdowns occur. Personal capabilities were demonstrated by way of each young man's transition metaphor. Therein, each young man demonstrated his personal understanding, willingness, and readiness to engage in his transition. Yet, silos or interpersonal breakdowns in collaboration, impeded the participation of the young men and their teachers causing an isolation from transition processes and procedures. Interpersonal concerns were further impacted by the majority of the young men experiencing insufficient or incomplete trialling of post-school options. The impediments of silos and trialling limited each's set of potential post-school choices. With known opportunity restrictions, it was questionable how much, if any at all, freedom each young man experienced in his transition.

The next three figures in Appendix E illustrated individual implications. Figure E 2, highlights Haku's case, and demonstrates the central concern that even though he attended his own transition planning meetings, the transition team was challenged to understand and action his personal preferences. Many of Haku's transition achievements thus came about by self-advocacy and chance, rather than by design. Cobain's case represented in Figure E 3 highlighted the missed opportunities of Cobain's transition. He did not attend or contribute to his transition planning meetings, his personal capabilities went unnoticed, and his transition was overshadowed by emotions and shock at the perceived lack of available post-school services. Faine's case in Figure E 4 showed a progression from the unexpected success of his time in special school to a challenging start in post-school programmes. Many of the successes Faine experienced in school were discontinued after he finished. In all three cases, there were noted misunderstandings about the young men's personal preferences and

capabilities, which led to missed opportunities and challenged the freedom each young man had to transition with dignity.

### **Findings Interpreted**

After discussing the findings of this study within the context of capability, now each of the findings are understood individually. The findings chapters were presented in an order that best portrayed each young man's transition in a holistic way. A fuller appreciation of the circumstances surrounding each transition came with an understanding of each young man. In this chapter, discussions of the central findings are presented in a different order from that in which they were reported. This is done in order for each to be considered in light of the reviewed literature and to then culminate in the construction of counter-narratives to the collective transition experiences of Haku, Cobain, and Faine.

#### **Trialling.**

The second findings chapter investigated the socio-political systems of trialling and silos, and their failure to take into account each young man's potential and personal perspectives. The ineffective trialling processes restricted the young men's exploration and establishment of their post-school priorities. Prior to leaving school, a restricted range of post-school options were trialled. This represented a breakdown in the transition process that the providers called brokerage trialling. Despite a variety of examples of outcomes trialling, by the time they left school, none of the young men had had enough experience in post-school settings for them to consider each possibility, nor were their priorities well understood.

The two forms of trialling culminated in three concerns: insufficient exploration of post-school options, difficulties assessing those options, and complications in getting to know the student once their post-school choice had been selected. Insufficient exploration of post-

school options happened for a variety of reasons. For Haku, trialling involved only one option - the option to which his transition provider felt he was best suited. For Cobain, trialling was obstructed by his mother's contempt for the insufficient day services she called "factories." In Faine's case, his mother struggled to find a second-best fit after her son's initial preference was not actioned. All three cases were less about freedom of choice between viable post-school options, and more about making the best out of very restricted options.

Also, in all three cases, experiences of outcomes trialling revealed that getting to know the young men was difficult. The polytechnic struggled to understand Haku's priorities. Likewise, Cobain's transition team were unsure about his horseback-riding preferences. Faine's attendance at a day programme for individuals with more complex communicative challenges left him feeling isolated. At a time when each young man entered his earliest stage of adult, community life, the consequences of his incomplete trialling negatively impacted his ability to feel productive and included, and to have a sense of belonging.

The confusing mismatch between effort put in and questionable resulting outputs, make trialling akin to a black box of transition: a complex system whose internal workings are not readily understood, thus challenging to know what contributes to it. Transition-planning guidelines are understood, namely that more than employment and post-secondary education outcomes (Halpern, 1992) should be considered. The outcomes of transition are also broadly agreed upon. Individuals with disability should work towards establishing an "enviable life" (Turnbull & Turnbull, 1998), in all the same respects as their mainstream peers, even if desires and preferences between the two groups differ.

In order to address the exploration of post-school options, Miner (2013) suggested person-centred planning as a means to articulate things that do and do not work for the individual's future. For example, person-centred planning should consider natural supports,

community preferences, and preferred activities. In order to address the fact that not all life aspects carry the same weight or priority, Miner suggested community-presence maps as visual demonstrations of personal preferences. Detailed within were activity descriptors, such as how often activities should be expected to be done (e.g., five times per week or five times per year). The process of constructing community-presence maps led to more effective transition planning towards an individualised post-school programme.

The trouble with the sole use of person-centred transition planning is that individualised approaches address personal needs, but neglect or underemphasise the social context in which they occur. By their very definition, person-centred approaches are based upon what individuals prefer or have access to, but do not provide sufficient attention to the range of experiences that led to individual preferences. What happens if individuals have only experienced a restricted range of options? Addressing such questions by way of an enriched understanding of trialling may be one contribution of this study.

Despite the noted paucity in the literature, the capability approach is well suited to address the process of trialling. I suggest that trialling is similar to the process of conversion from capabilities, or opportunities, to lived functionings, or the beings and doings of life. Conversion factors that bring a person from capability to lived functionings include personal choice and agency, as well as social and environmental factors. Nussbaum (2000) argued that the 10 human capabilities set a standard, not for how life should turn out, but rather for what every individual should have access to, experiences that should be trialled for suitability.

Focusing on satisfaction of outcomes is insufficient, because, as demonstrated in this thesis and in Nussbaum's research, people become satisfied with unjust conditions, known as adaptive preferences. By this logic, the trialling experienced by the young men was, in the most pessimistic sense, a self-fulfilling prophecy. The young men's post-school options were

limited and restricted, because that was precisely what they were expected to be. A slightly more optimistic take on trialling, was that outcomes were generic. These findings match the findings of earlier studies in the US, where vague transition outcomes have been listed in IEPs (Grigal et al., 1997). In the current study, the young men were understood by transition coordinators just enough to know which disability-specific, pre-structured programme each suited. The trialling experienced by each young man was unjust because they did not actively contribute to the construction of their post-school life.

Capability can also be used to construct a counter-narrative of the young men's trialling experiences. Therein, the 10 human capabilities (Nussbaum, 2000) could replace the existing four milestones of transition-provider services in Aotearoa New Zealand. In this counter-narrative, the priority would shift away from blinding focus on post-school outcomes, and be replaced by exploration of the fundamental tenets of a good life. In this alternate version of trialling, a minimum level of each of the 10 capabilities would be addressed without exchanging one capability for another, or prioritising one person's capability over, or as dependent upon another's. Trialling practices should consider each and every human being, regardless of disability, in their own right. With a postulated counter-narrative of trialling, I now address how the capability approach might be implemented by way of timetables.

### **Timetables.**

In the first findings chapter, personal perspectives of the young men were tangible, pinned to artefacts, such as timetables. Timetables are most commonly thought of in classroom settings (Mesibov, Browder, & Kirkland, 2002). Benefits of timetable use include: communication of information; predictability and anticipation as a means of reducing challenging behaviour; consistency; memory aid; establishing relationships between events;

understanding; attention; motivation; independence; and control. Timetables can also address transient and abstract information, such as time concepts.

Despite their classroom benefits, the only references to timetables in transition literature denote procedural timelines. In this study, timetables served as a novel way to assess and assist transition by the consistency of their use from in-school to post-school contexts. More commonly, however, transition research is evaluated by outcomes, such as rates of employment, enrolment into post-secondary education, and moving out of the family home (e.g., Grigal et al., 2011; Grigal, Neubert, & Moon, 2002; Hart, Grigal, Weit, 2010; Test et al., 2009). As argued in the subsection on trialling, evaluation that focuses only on outcomes, without considering the opportunities which led to such outcomes, is insufficient.

Beyond an evaluation of transition, timetables had the receptive function of supporting young men's understanding and in-take of information. For instance, Haku benefited from regular monitoring of his timetable, in a coincidentally consistent diary format. In the pages of his diary, he pasted in weekly activity calendars, highlighted upcoming events, and noted changes in his routines. In contrast, Cobain formed his own understandings of his transition without consistent use of timetables. In the special school, Faine's classroom timetable served as personal daily anchor that informed him of his own routines, and his peers' schedules, both of which were unfortunately lost through the course of his transition. Timetables have been used to ease the transition between classroom activities (Mesibov et al., 2002), thus, it is reasonable to consider the same application in the transition from in-school to post-school life.

Timetables also held a communicative purpose. Adapted interview data was used to demonstrate that each young man had feedback to share on the course of his transition, which he either struggled to share, or others struggled to hear. For example, Haku's diary was a



space where he could collect his thoughts in writing, one of his preferred methods of communication. In another instance, Cobain, used his timetable object-cues to convey preferential activities. Through the shared classroom timetable, Faine checked up on his friends' routines as well as his own, and in doing so used the monitoring of his peer's timetable as an expression of care. Restricted access to personally meaningful timetables cut the young men off from receiving and contributing information about their transitions. These results support previous findings about the ways students are disconnected from their transition (Hetherington et al., 2010), and from making contributions to their IEP meetings (Martin et al., 2006), despite the fact that student involvement has been found to lead to better transition outcomes (Cobb & Alwell, 2009).

In a counter-narrative experience, every transitioning student would have consistent access to a timetable, or some such meaningful representation and communication tool about personal routines. All students can share in experiences similar to Haku's, of having access to personally relevant future-planning information and the ability to reflect upon preferences and priorities. Furthermore, the consistency between in-school and post-school should be intentional, not by chance, so that other transition artefacts of equal importance may one day be understood and serve to enhance transition processes. With constructed counter-narratives of trialling and timetables, namely the component parts of transition, I now examine the silos finding of this study about the processes of transition planning.

### **Silos.**

Silos, or their converse, collaboration and collaborative transition planning have substantial research backing. I return to Kohler's (1996) taxonomy to discuss the findings of the research related to silos in prior literature. Silos, in this study, occurred at two different levels: a systems level (e.g., social-service-level supports for transition); and an interpersonal

level (e.g., transition-planning teams' efforts to construct a post-school plan for each young man).

I first address the systems-level silos related to Kohler's taxonomy elements of programme structure and student development. The lack of systems-level collaboration found in this study was incompatible with the Aotearoa New Zealand pilot transition-programme design. These breakages in the system left students and their families to navigate between discrete social services, and to acquiesce to policies and procedures that promoted adverse discourses about the transitioning student. For example, the deficits brought forwards in Faine's needs-based NASC reassessment process was to the extent that his mother did not want her son to be present to hear what was said about him.

The most obvious structural influence in this study was the fact that the three young men transitioned into community life from special schools, rather than from inclusive environments in regular schools. Internationally, the prevalence of special schools is a mixed picture. Aotearoa New Zealand is considered one of the most inclusive nations in the OECD, yet special-school attendance has grown, with over half of students aged 18–21 with ORS funding undertaking their transitions from special schools (Ministry of Education, 2015). These findings are aligned with Kelly et al. (2014) who found that, internationally, numbers of students attending special schools have increased. Changes between the two NLTS studies in the US, however, show numbers of special schools halving, but with related increases in special units or self-contained classrooms within mainstream schools. Such findings can be understood in light of the concern articulated by Kurth et al. (2014), that rigorous standards have not been set to reduce restrictive placements, thus segregated educational experiences continue for many students with disabilities, particularly those with significant disability. As Higgins et al. (2008) suggested, students currently have no clear path towards inclusive

education. In contrast however, Gasson (2008) found that, no matter the process of enrolment, students and their family felt strong positive support for special schools.

One way to view special schools is to see them as a structural silo that isolates students in culturally and socially unique experiences. The experiences of the young men in this study, however, aligned with Gasson's view (2008). Each student (though Cobain to a lesser degree) and their families felt a sense of belonging within the special school that was challenging to match elsewhere. In the words of Faine's mother, special school was a place where her son was "cherished for what he had to offer", an experience she struggled to match in post-school life. One way to engage with the intersecting perspectives on special schools is to examine their existence from a capability perspective. Capability places emphasis on opportunities over outcomes, so with this understanding, special schools are only unjust when no other viable educational options are available. Applying this notion to the three young men: The concern about Haku and Cobain's special-school experience was that they had never tried any other form of schooling outside of special schools. The concern about Faine's educational experience, or at least how it was expressed by his mother, was that no other educational alternative (other than home-schooling) was viable. In each of the three cases, the existence of special school was not in and of itself unjust. Rather, the young men's experiences were restricted due to special schools being perceived as the only viable option.

Moving on to student development within school, students with disability have been found to do well in school and are well-prepared academically for their futures (Wagner et al., 2007). These findings are consistent in this research. The young men were well-prepared within the special-school environment. Each special school organised community-based classrooms, gym memberships and other community-based leisure programmes, and work experiences; all were component parts of the wider picture of transition. The struggle in both the NLTS studies and in this research was that in-school successes did not transfer into post-

school life. In the case of NLTS findings, in-school preparation did not lead to post-school employment, despite a noted increase in post-secondary education. Correspondingly, the skills of the three young men in special school did not transfer into their post-school lives. For instance, Faine's teachers lamented that his skills in writing and illustrating books did not continue in his post-school day programme. As Faine's mother commented about her son's successes in special school, "If he could stop time, it would be now. And that would be his ideal world, right now. Stop it right now" (Interview transcript, Faine's mother, T.3, in-school phase).

With structural silos discussed, I now turn to interpersonal silos, and discuss them through the remaining three components of Kohler's (1996) taxonomy: student supports, interagency collaboration, and family engagement. Students in transition have many people who support them (Morningstar, 2013). This study confirmed the existence of a large number of support people involved in each young man's transition (for example, see the transition-informant schematics in Methods chapter). The impact of interpersonal silos was found to restrict not the number of people supporting the young men, but rather the influence certain support people had upon transition planning and decision making. Essentially, student supports were available, though not always at the critical time when transition decisions were being made and planned.

Interagency collaboration is used to further explore the roles involved in planning teams, with an emphasis on more extensively supporting the young men's transitions. Interagency collaboration entails the following: networking (i.e., team members identify services available and make referrals with distributed and shared information), cooperation (i.e., team members assist in accessing services, identify individual and community needs and strategies), coordination (i.e., regular interaction, systems-level scheduling and planning), and collaboration (i.e., jointly developing mission, training, and evaluating services, flexible use

of funding and resources; Morningstar, 2013). Yet, difficulties in collaborative transition planning have been reported in prior research findings (Noonan et al., 2008). For instance, imbalances in special-education planning teams (e.g., IEP meetings) have occurred because of the dominance of special-education teachers and other special-education professionals (e.g., Martin et al., 2006; Ruppap & Gaffney, 2011; Vacc et al., 1985).

The findings of this study are in line with those of previous studies inasmuch as silos led to fractured collaboration. In contrast to prior research, where teachers tended to dominate transition (e.g., Martin et al., 2006; Ruppap & Gaffney, 2011; Vacc et al., 1985), however, special-school teachers in this study were side-lined from planning with their students. One possible explanation for this difference may be that transition planning differs from other forms of special-education planning because of the proximity to leaving school. However, the teachers' absence was demonstrated to be a significant loss. Teachers held knowledge about their students, knew them over extended periods of time and across a range of environments. Even though teachers talked about having opportunities to pass along information about their students, their absence from formal transition planning meant the loss of a valuable advocate and spokesperson for the student at vital times, when such information was needed.

Along with the absence of teachers, it may be possible that other roles were also siloed from collaborative transition planning. Within the transition-informant schematics provided in the Methods chapter, high-, medium-, and low-influence informants were noted. The differentiation between categories did not represent what was known about the student in transition, rather the influence each role held on the young man's transition. It may be that those who hold significant information about the student were most removed from transition planning, mirroring the experiences of the special-school teachers. In this study, low-influence informants who demonstrated significant knowledge were, for example, Cobain's

residential-care staff and teachers' aides, noted for their significant contribution to the education of students with special needs (Rutherford, 2012).

Returning to Kohler's final taxonomy domain, a family's involvement is key to transition planning. Transition is a stressful time for families, likened to "the second shock" (Hanley-Maxwell, Whitney-Thomas, & Pogoloff, 1995). For instance, the mothers in this study expressed feelings of isolation and anger regarding their children's transitions. They likened the advocacy required during transition in Aotearoa New Zealand as akin to a battle (Wills et al., 2016). Families also experienced stress due to a sudden change, or decrease, in services (Neece et al., 2009). No matter where the stress originated, a parent's satisfaction with transition outcomes can overshadow their child's preferences (Neece et al., 2009). The findings in this study corroborate prior research, in that parents overlaid their child's transition with their own concerns. Data on both trialling and silos demonstrated that while the young men were said to be the central concern of transition planning, the process often attended more to the parent's emotions. As Cobain's mother stated about transition, it was the "grieving process all over again" (Quote transcription, field notes, FN.1, in-school phase). While enlisting the involvement of family is integral to transition planning, one concern raised by both this study and prior research is the misallocation of priority in favour of the parent over their child.

Kohler's domains have been used to discuss the siloed breakdowns in transition-planning collaborations. Yet, other roles existed within this research, which require further attention, most notably, the transition coordinator. The role of the transition coordinator was a cornerstone feature of the pilot Aotearoa New Zealand transition programme: a role which presumably should have supported rich exploration of transition possibilities and encouraged collaboration in planning. However, this was not the case, as the young men experienced incomplete trialling and fractured transition communications, resulting in silos. Rather than

place blame on the transition coordinators, I contend they had a somewhat impossible task. They had only one year to complete four milestones. Therefore, one explanation for the findings of this study may be that the thorough exploration of options suffered as an unintended consequence (e.g., Merton, 1936) of the transition coordinator's promotion of efficient outcomes and expeditious decision making.

The reality of transition experiences for Haku, Cobain, and Faine demonstrated opportunities that were overshadowed by outcomes-oriented processes. Similarly, agencies and individuals worked in isolation towards individual aims and did not always join in partnership. At each stage, and at every organisational level, vital information about the student was lost. Lost perspectives and isolated understandings, meant that the student remained silent.

With an examination of what roles were present and absent from transition planning and why, a counter-narrative of collaboration can be envisioned. Central features of networking, cooperation, coordination, and flexible use of resources (Morningstar, 2013) combine into a gestalt. Gestalt is when the organised whole is greater than the sum of its parts. When gestalt is applied to collaboration, no one transition-team member's knowledge or concerns takes precedence over another's, rather they work in tandem. In this counter-narrative, perspectives become so intertwined they are perceived as one. This one, holistic perspective then encapsulates all aspects of the student in transition; their prior experience, and physical and social perceptions, all come together in a gestalt.

In a counter-narrative gestalt, the sum of the transition-team members coming together to create a whole greater than each of their parts means the voice of even those without literal voice becomes heard. Haku, Faine, and Cobain did not stand alone in their identities. Each stood in relation to others who represented, advocated, and supported their

identity. Imagine trialling as an exciting opportunity guided by 10 human capabilities (Nussbaum, 2000) with opportunities akin to structured internships, practica, and apprenticeships. Envision ministry agencies working collaboratively in a manner akin to High and Complex Needs (HCN) interagency strategy. Envisage there existed ways for more perspectives to be included in transition planning by exploring opportunities far before the final year of school. In the counter-narrative, the tugs and pulls of the relationships, the various hopes, dreams, aspirations, and plans, all mix together to create an understanding of transition and in turn, promote the human voice that is essential in a transition with dignity.

### **Methodological Reflections**

Accessing the perspectives of individuals with significant disability came from a commitment to methodological experimentation and innovation. With this belief in mind, the methodological reflections section will be used to discuss two interrelated topics of reflexivity, and its impact upon the newly coined phrase from this project, emancipatory partnerships. As qualitative researchers often bill themselves as the primary research instrument, as opposed to, for example, quantitative data management and processing software, these reflections are aimed to advance my own personal research abilities, as well contribute to future inquiry.

#### **Reflexivity.**

Reflexivity is the systematic attendance to the construction of knowledge. Researcher reflexivity, is the acknowledgment of researchers' roles within the research process with associated understanding and self-disclosure of personal assumptions, beliefs, and values (Brantlinger et al., 2005). I argue that in this study, the research design directly impacted my role and positioning as a researcher.



Due to the flexibility inherent in the naturalistic design of this ethnography, the young men were not selected for having exemplary transitions, as one might consider advantageous to investigate a transition with dignity. To do so, however, would have been to lose the input of individuals with significant disability, as it would not have been meaningful for them to reflect upon historical events.

Kvale and Brinkmann (2009) differentiate between the researcher's role in the collection of knowledge through the metaphors of the miner and the traveller. In the mining metaphor, knowledge is understood as buried minerals that the researcher seeks to unearth. In contrast, this study was more analogous to the traveller metaphor. This study was a journey. I wandered, was guided through transient landscapes, and asked questions of those I encountered. From the research journey, knowledge, or the research findings, came from involvement with all those encountered. Such a journey has significant impacts.

In terms of data collection, the naturalistic design of this study required constant flexibility. This has been exemplified in the use of the iPhone, where its multifaceted features enabled wide ranging data collection formats during fieldwork. Likewise, the field was an open-ended rather than confined space, often marked by transience to different activities and associated settings. Most importantly, while the emphasis in this thesis was the exploration of a counter-narrative, the findings from fieldwork, could not be promised to be anything other than what the young men experienced in the reality of their transitions. In actuality, the described findings chapters demonstrated, predominantly, a counter-narrative was not found.

Yet, commitment to the emancipatory paradigm (e.g., Oliver, 1992) reminded me that researchers must be called upon as servants of advocacy and change. Therefore, I positioned my research self to serve as a facilitator or translator to the young men's expertise of their own experiences. I use these terms facilitator and translator intentionally to denote the

inherent challenge of my task. As stated previously, when Haku expressed a personal preference his transition team was shocked, and Cobain's personal perspectives were a mystery to even his mother. I relied upon the theoretical framing of the project, capability, to advance my belief that that the young men had a voice (whether literal or gestural) and a perspective to share. The way I felt best to achieve access of this voice and perspective, was in partnership.

### **Emancipatory partnerships.**

As illustrated by the inclusive research literature review, many studies have been conducted from a similar premise of collaboration and partnership with individuals with disability. For example, "communities of practice" have been constructed to encourage research collaboration between those with and without disability (O'Brien et al., 2014). Yet, this study subtly differs from prior inclusive work, as illustrated by two examples: Consent and assent were described in the Methods chapter as an important methodological distinction, yet I did not collaboratively seek ethical-committee approval with the three young men of this study (Ham et al., 2004). In another example, I considered the young men to guide the study, yet would not have claimed they were advisors to the process of research (Kidney & McDonald, 2014).

I considered the young men research partners, and to do so required reflection on my conduct during the data collection, about how others invested in the partnership, as well as the tools used to collect their experiences. This process of coming to know the young men's perspectives and understanding their personal transition journeys did not occur in isolation. The emancipatory partnership, or the careful balance between myself, as the researcher, case participants, and transition informants, afforded access to the young men's perspectives about their transition experiences. Emancipatory partnerships were a process of coming to know the adaptations needed to "hear" each young man's story, and handling this research relationship

as ethically as possible. Emancipatory partnerships were one of the most valuable, as well as complex, methodological aspects. Partnerships privileged the three young men, and leveraged their capabilities, rather than focusing on disabilities, as now described by a few anecdotes from my field work.

What I anticipated to be a seemingly simple act of walking alongside the transition journeys of each young man was made more complex by the range of intimacy required. For example, Haku's mother invited me to be her friend on Facebook. I accepted the friendship offer because I thought the insult of not accepting could potentially hinder our research partnership. Delicate and person-specific considerations were often required in my fieldwork.

For example, during the exit-from-school phase (month 3 of 6), I was informed by teachers and transition providers that Faine's family was significantly stressed. I had a moment's pause before I contacted Faine's mother for an interview. I thought any decent person should give them space to deal with their struggles as a family. The researcher side of me overrode such thoughts; his mother had the ability to choose not to answer the phone or decline my interview invitation. So I called, and an important interview about the transition challenges of leaving school was conducted.

The interview with Faine's mother spurred my awareness of another important overall feature of my informant interviews. In my fieldwork preparations, I wrote pre-set interview questions in a tone I assumed researchers should have, semi-structured and objective. Yet, the formality and structure I prepared for quickly broke down in actuality. Semi-structured interview questions served more as discussion prompts, and shifted from interview style to free form in-depth discussions.

The interview example is used to demonstrate that in the course of fieldwork I got close to transition informants, or as close as they allowed me to get. Informants had the

cognitive and communicative ability to tell me “no,” if data-collection processes became overwhelming. I intentionally did not come as close to Haku, Cobain, and Faine. For example, Cobain demonstrated his preferences behaviourally. By that I mean, if Cobain wanted to do something, he smiled, and went ahead and did it. If he didn’t want to do something, he typically showed an antisocial behaviour such as biting, pinching, or grabbing. Occasionally he presented those behaviours during a participant observation. I made the assumption that his behaviours indicated that he did not desire to be observed at that time. Likely, my presence had little or nothing to do with Cobain’s behaviours, but since Cobain had no other consistent manner of confirming whether or not my observations prompted his antisocial behaviours, I felt it necessary to afford him the respect to assume he needed a break.

Reflecting upon the conclusion of fieldwork was also illustrative of the nuanced partnerships. I was struck by how the mothers of each young man were sad to see the research finish. Their compliments and expressions of enjoyment about taking part in the research project surprised me, because I felt that I wasn’t actually doing anything. Rather I was an observer who watched their transition journeys unfold. In these moments, I came to realise the power and support manifest in the simple act of walking alongside another at a stressful time in their life, and being there to ask questions of and as an ear to listen. In the process of trying to get as close and as deep to informants’ perspectives as possible, sometimes informants felt a mutual closeness to me.

My final observation of Cobain at a youth disco exemplified the opposite experience. At the disco there were a few of my former students whom I had previously supported in transition. Though I had helped them through the critical life stage of transition, not a single former student showed any indication of remembering me (e.g., smile, hug, or handshake). They walked right past me like a stranger. I didn’t take it personally. It confirmed my initial

assumption that individuals with significant disability are very accustomed to people coming and going in their lives, for various educational, care, or support services.

What I strove always to prioritise, was that no one knew their transition better than the young men themselves. The differentiation of relationships within the emancipatory partnerships was essentially an examination of what happened to the relationships of research when those who have rarely, if ever, held the position of expertise, become the authority. This position of expertise was subtly embodied, in one example, by Haku. In his polytechnic class, one of his peers asked me what I was doing there. He confused me for Haku's mother, wondering why I was following him around. I explained that I was a student, just like they were, and Haku was helping me with my studies. I could see a notable sense of pride Haku felt to be positioned in this manner.

Reflecting on the range of emancipatory partnerships I made through the course of my fieldwork, I became aware of my own "research armour" (personal communication, 20 March, 2014). I explored the boundaries between myself as a person, teacher, and researcher. I knew Haku, Cobain, and Faine did not have the ability to do the same. They could not hide under false pretences, or switch between identities. They would be themselves around me, because they had no social filter to do otherwise. I may have been in a position to probe more deeply, and to have delved more deeply in the data collection, but this would have possibly come at the cost of confusing or misleading the young men into thinking I was someone I was not.

Bringing notions of reflexivity and emancipatory partnerships together, this research relied upon a triadic partnership between myself, the young men, plus those who knew them best. Yet, this partnership was imbalanced due to the 60 transition informants that far outweighed myself and the three young men. Furthermore, the data from informants was

more articulate and emotionally evocative. In order to keep the young men at the central heart of the study, reflexive techniques were used, albeit sometimes subtly, like Haku, Cobain, and Faine, being the only names used for participants within this thesis.

Personally, reflexivity made me develop a qualitative imagination that I applied to a range of tools in the toolkit. Akin to my own personal experiences, I suggest all researchers focus on challenging themselves and their methods to be more inclusive of individuals with significant disability, rather than to focus their attention on the development of the skills of individuals with disability. Essentially, the ‘limitations’, if any, are not in those with significant disability, the limitations are within the methods. When qualitative tools can be applied more inclusively, this serves a wider outcome to acknowledge the diversity inherent within the disability community. There is not an inherent link between the experiences of those with differing disability labels (i.e., NLTS-2 results across disability categories). Nor can it be assumed that research with individuals with less significant disabilities can be applicable to those with more significant disability. Research and the capability approach upon which the research was designed, provide an opportunity to take part and celebrate the inclusion of diverse perspectives. The outcome is the amplification of marginalised, lesser known, minimally heard experiences, and thus the betterment of ourselves and our society.

### **Critical Evaluation**

Ethnography sustained over a six-month period afforded access to understand and observe the social process of transition for individuals with significant disability. Prolonged field engagement enabled the use of a range of data-collection techniques that were personalised by way of emancipatory partnerships. In doing so, the holism of transition was preserved.

One limitation to the study was that after spending time to understand and establish each young man’s communication preferences, no interviews were held with my central

participants after they left school. Finding time for interviews within post-school settings was challenging for several reasons. First, I didn't want to distract Haku from the start of his polytechnic course. As it was only the start of his post-school life, no other programmes were observed, and thus, no other opportunities were evident for holding interviews. With Cobain, once school had completed I no longer had access to the object-cue timetable that had facilitated our previous interactions. Finally, due to his abrupt departure for his family's tangi (funeral), I only saw Faine once after leaving school. In each instance, personal perspectives on how transition was going and the success of each transition was gained through documentation, observations, and anecdotal conversations with the young men, rather than through direct interviews.

A further challenge in the post-school phase, that I had not anticipated, was how long it would take for the post-school activities to start in the new year. This created an imbalance between lengths of time available to observe the post-school contexts in comparison with in-school phase. Allowing more time for programmes to get underway after an extended holiday break can address this second limitation.

While not a limitation of this study, future studies with emphasis on unheard voices may benefit from recruiting participants who use, for example, alternative augmentative communication devices in order to communicate. Those individuals might not have verbal ability, but will likely be more experienced (than for instance, Cobain) in communicating their opinions and preferences. Additionally, aligned with emancipatory aims, future iterations of similar studies might do more to include participants' reflection upon the collected data. For instance, if I had created the video montage clips (described in the Methods chapter in the subsection on analysis) prior to the completion of fieldwork, I might have invited Haku and Faine to view and give feedback on their videos as a form of member check. Consideration might also be given to ways for participants to assist with research

dissemination. For example, attending conferences, creating online or blog forums, or constructing visual displays of results (beyond the provided metaphors).

### **Research Questions Addressed**

The thesis began by asking, what are the perceptions and meanings of transition experiences for individuals with significant disability? Across the three young men in this study, there was no singular perspective or experience of transition. The three case narratives revealed three transition realities. Where they came together was in the fact that each young man knew he was in transition despite, in some instances, being given little indication that this was the case nor how he could participate. When asked, each demonstrated understanding of what transition meant to him personally, through images, gestures, and in transition artefacts. By expanding communication beyond verbal modality, it was possible for them to share their personal experiences and understandings. Sadly, this didn't happen for Cobain and could have been significantly enhanced for Faine and Haku.

To address the first line of questioning by way of personal preferences and satisfaction is too simplistic. The young men and their families became accustomed to, and even preferred, their segregated-schooling experiences. When it came time for transition, the young men and those who supported their transitions may have understandably preferred socially segregated post-school options. Thus, returning to capability as a means for framing transition, enrolment into disability-specific post-school options, whether they be tertiary, day programmes, or individualised, can only be seen as dignified if other socially integrated post-school options are equally viable and explored.

The second research question asked how understanding the perspectives of individuals with significant disability impacts a transition with dignity. Rather than structuring a transition based upon what they can do or be, the young men's transition



outcomes were adjusted to what was thought to be suitable and achievable for “someone like them.” Furthermore, the process of each young man’s transition was not dignified. Their trialling of post-school options was incomplete, they did not experience a range of post-school options, and at times they were left out of the decision making process altogether. Their transition decisions were not made in a collaborative way. Although Haku and Faine did have some trialling experiences, none were fully informed about possibilities, and they were not able to adequately express their preferences. But this does not mean there can be no hope for dignity in transition.

A transition with dignity can be the precursor to a thriving life where every all people, by virtue of their humanity, have access to sufficient human capabilities to build a flourishing life of personal relevance (Nussbaum, 2006). “Success” in adult life, just like success in the transition that preceded it, can be measured not solely in achievement but in access to opportunity. Opportunities must be available at the individual, social, and structural levels. Each young man demonstrated individual capabilities, and a willingness and understanding of his exit from school and forthcoming adult life. Future emphasis must be focused on the social and structural opportunities to support personal dignity, not simply on meeting milestones that place young people with disabilities in to programmes.

Within capability theory, the importance of opportunities overrides outcomes. As the simple example illustrated, both a starving and fasting person share the outcome of hunger, but their choice in the matter separates their experiences. The personal perspectives of the young men demonstrated so many capabilities, personal understandings, and unique experiences. For example, Haku took agency to ask for his work experience to continue, a fulfilling part of his life. What they simply required was the genuine opportunity to be heard.

## **Implications**

The central implication of this study is that opportunity serves dignity. In transition, this means the opportunity for each of Nussbaum's 10 Human Capabilities (2000) to remain viable from in-school to post-school life. This is not to say dignified outcomes must be an absolute outcome. As the title of the aptly named study reminds us, there is a balance in, "the rights of people with developmental disabilities to eat too many doughnuts and take a nap" (Bannerman et al., 1990). Freedom is the cornerstone of capability (Sen, 1988).

In research, opportunity to take part is a fundamental priority. More specifically, researchers must acknowledge the inherent diversity in disability perspectives. Research findings of individuals with less significant disability cannot be imposed upon those with more significant disability as though there is an inherent correlation. The diverse perspectives of those with significant disability need to be understood and amplified in a manner accessible to all. Rather than challenge the capabilities of those with significant disabilities to take part in research, the rigour of the methods used to capture such perspectives must be challenged. This thesis has argued one of the ways to begin this process is via emancipatory partnerships.

Lastly, the practices arising from the piloted transition policies in Aotearoa New Zealand must be re-examined for their alignment with their social justice intentions. Figures 6.1 and 6.2 illustrate important implications and applications from this study. Figures depict the study's current findings of trialling and silos, respectively, and then hypothesises each in a more dignified structure.

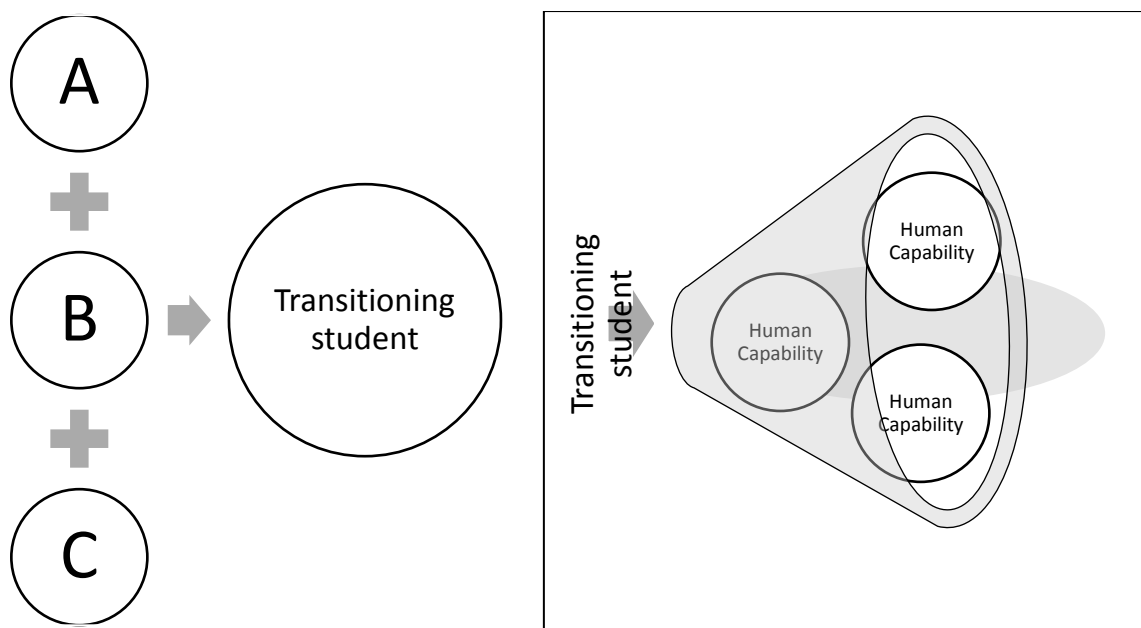
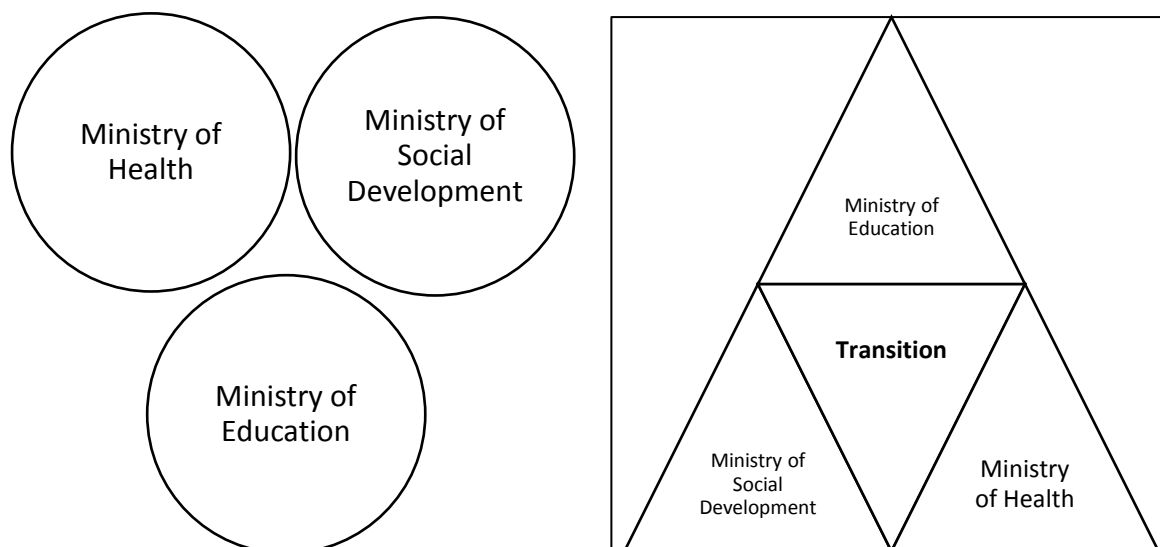


Figure 6.1. Undignified trialling (left) and trialling with dignity (right)

Thorough trials of post-school opportunities need to be provided to all in transition, in contrast to the expeditious selection of one or maybe two trials from pre-existing, disability specific programmes. On the left hand side of Figure 6.1, letters A, B, and C denote pre-existing transition options. As trialling was experienced by the young men in this study, transition coordinators screened each young man for enrolments between pre-existing services. Transition was essentially a process of four milestones, each ticked off as procedurally completed and was not the preface to a thriving post-school life.

In contrast, the restructured trialling with dignity on the right hand side of Figure 6.1 is informed by the 10 human capabilities (Nussbaum, 2000). In this conception of trialling, the transition coordinator's role is to expand an individual's capability set through a thorough exploration of viable opportunities. When suitable opportunities are not available, akin to Cobain's experience of "factories", the transition provider serves as an advocate demanding more community resources be put in place. Importantly, the processes of trialling with dignity must be done in collaboration, not isolation, leading to the next finding of silos.



*Figure 6.2.* Undignified silos (left) and collaboration with dignity (right)

Silos of isolation can be broken down into genuine collaboration and partnerships across Ministries and individuals. On the left hand side of Figure 6.2, the Ministries predominantly involved in transition for students with significant disability are shown to operate in siloed isolation, as was found in this study. The young men and their families had to adhere to separate programmes and policies in order to receive social supports. The re-envisioned collaboration with dignity on the right hand side of Figure 6.2 combines Ministry supports to promote individualised transition opportunities. Remembering that individual's action the policies of Ministry agencies, there is need to examine interpersonal collaboration also. Most notable, instead of a the diminished role teachers experienced in this study, special school teachers must be supported to regain their place as active participants within the transition processes of their students, and where necessary, transition advocates within their communities.

To action the changes suggested within the two figures may transform more than individual transition outcomes. A more inclusive society, one aligned to the envisioned purpose of transition in Aotearoa New Zealand can become a reality. Therein, a transition with dignity towards a thriving life may be a viable opportunity for all.

With these implications in mind, the lens of capability is used to reimagine the transitions of Haku, Cobain, and Faine. We see past the fragmented trialling of post-school options and isolated silos of planning. Threads of dignity are found within their experiences, and woven into a future with experiences every bit as exciting as their mainstream peers' future prospects. The gaps in the literature, the highlighted problems and concerns of transition, the things that individuals with significant disability are typically found not to know or understand, are the foundations of a counter-narrative. In the counter-narrative, however, not only are the young men's perspectives amplified, but their names are the only ones given.

Imagine the young men's experiences turned upside down: where Haku trialled many different options, maybe even various departments and faculties at the polytechnic. Within these options he used his "senses to imagine, think, and reason—and to do these things in a 'truly human' way, a way informed and cultivated by an adequate education" (Nussbaum, 2000, p. 78). Envision that Cobain's "factories" became places for him to "live with and toward others, to recognize and show concern for other humans, to engage in various forms of social interaction" (p. 78). Imagine that in Cobain's adult life he was "treated as a dignified being whose worth is equal to that of others" (p. 78). Picture Faine having control over his future, where his preferences for his post-school life were actioned, and he had "practical reason... to engage in critical reflection about the planning of [his] own life" (p. 78). Living these and the other 10 human capabilities are what should be expected from any decent, democratic society. A threshold level of each should be available to every human being, not only for 'tax-paying citizens' or people without disability.

## **Conclusion**

Recently, I've been listening to the second season of the Serial, a podcast that breaks down into twelve, one hour segments, the circumstances surrounding Sergeant Bowe Bergdahl's

five year prisoner-of-war capture. The journalist, Sarah Koenig (2016), described her initial intention, with the podcast project, to reveal a linear sequence of events supported by in-depth investigation. Instead, she explained, the story that emerged was more akin to the children's book, *Zoom* (Banyai, 1995). The story of *Zoom* begins with one simple image, for example, a red triangle, which then zooms out to reveal itself on the next page as part of a rooster's comb. The images throughout the book keep expanding; the rooster lives in a barn, the barn is on a large farm, the farm is in fact within a snow globe that a child is playing with in his classroom. On and on the zoom continues until the final images are as large as the universe. The book, just like the podcast, is dependent upon what layer is being brought forth for examination. Yet, each layer, in each story, is interrelated. It is not only stories as complex as Bergdahl's capture and military hearing, to which this notion of zoom applies. It is all stories. This complexity applies to all of us, and each vantage point, each telling, each layer of the zoom, and each member of a transition team, can appear different, while all relate to one another.

At the same time, I was also reading Oliver Sacks, simultaneous with his recent passing. His bestselling case histories, such as *The Man Who Mistook His Wife for a Hat*, written in 1985, describe his patients' neurological conditions. Sacks has been admired for humanising the experiences of difference that readers might never have even imagined. For example, he stated, "A neurologist's life is not systematic, like a scientist's, but it provides. . . novel and unexpected situations, which can become windows, peepholes, into the intricacy of nature – an intricacy that one might not anticipate from the ordinary course of life" (Sacks, 1995, p. 109). Following his death, I read praise for his work.

However, at the same time, I came across one scathing criticism by Tom Shakespeare, a disability scholar and advocate cited within my thesis. He felt Sacks had exploited his patients for personal gain, and dubbed Sacks "the man who mistook his patients for a literary

career" (Shakespeare, 1996a, p. 137), a title which was said to haunt Sacks for the rest of his career. I raise this issue to say, every story, just like the young men's transition stories, has a different angle, a different perspective. While those perspectives can be so different on the very same topic, they, like Zoom, are all interconnected, and they all need to be told, and heard.

In my years of being a doctoral candidate, I have talked a great deal about my project, across many different audiences, who may have been academic, non-academic, subject specific, or advocacy groups. I ask myself, what's in it for my audience? Why should they care? How can they relate to my project? Some people, for example, look to disability as a looming threat that one day will strike us all, due to either age, accident, or association. Others look to disability as an inspiration, either something along the lines of gratitude for not being afflicted with a similar disability, or motivation in their perseverance. I've also met a lot of people who approach disability with fascination. For example, such individuals may highlight the lack of social filters or disregard of social conventions, perceiving some sort of purity in their experiences of significant disability.

In fact, individuals with significant disability represent both optimism and pessimism. But when we boil it down to the everyday lives of the young men of this research and others like them, they are also none of these things. They don't see disability as good, bad, or anything other than reality. Their life. A life that is worthy of all of our thoughts and considerations, because they, like us, are human beings. They are loved and have love, and while their contribution to the wider society may look different, it is no less valuable than yours or mine. While I have been so focused, throughout the thesis, on providing opportunities to individuals with significant disability, perhaps the most beneficial contribution of this thesis is that, through the experiences of Haku, Cobain, and Faine, and

the transitions of many others, we have gained the opportunity to share in a small bit of humanity, what joins us together, rather than what separates us.



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## Appendix A: PIS/ CF Parents



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The University of Auckland  
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Auckland 1150, New Zealand

School of Learning, Development, and Professional Practice

### Participant Information Sheet (Parents/caregivers graduating students)

Project title: Transition with Dignity

Researcher: Sarah Hart

Hello,

My name is Sarah, and I am a PhD candidate in special education at the University of Auckland's Faculty of Education. I am studying under the supervision of Associate Professor Mary Hill and Professor Janet Gaffney. I am a fully registered teacher with many years of professional experience in special schools.

The focus of my research is to improve transition through emphasis on the personal experiences of the graduating students with special needs. The information gained from this research will allow your child to contribute to the overall improvement of transition practice throughout New Zealand.

I would greatly value the opportunity to conduct my research with your son/daughter. Graduating students will be the central focus of my research and I aim to understand their personal transition experience from their perspective. I am therefore inviting you to allow me to include your son/daughter in my research.

#### What participation in this study involves

It is important that I spend time getting to know your child, and their unique communication styles. Therefore, I would like your permission to observe for two days each month, for three hours a day, for the last three months of the 2013 school year. While using the school as a base, my aim is to see your child in his/her various community environments and within his/her transition experiences. I will schedule visits by your child's unique schedule, following recommendations of teachers. Please know that I will respect the routines and policies of the school, trying not to interrupt the teaching and learning interactions, as they are the very things I want to observe.

With your permission, I plan to photograph and video some of your son/daughter's interactions. This video will be used in discussion with your son/daughter to break down complex transition concepts. Images from one student will not be shown to another or to other teachers.

As a further aspect of my research, please note that I will also ask teachers to see documentation about your son/daughter. This will involve my making a photocopy of documents such as Individualised Education Plans (IEP), school reports, transition plans and portfolios.

If you agree to allow your son/daughter to participate, I will ask to interview you. This will be about your child's transition, as well as the ways they make and communicate their transition decisions. Our interview will be conducted at a time and place convenient to you and will last approximately one hour. I plan to audio tape and then transcribe this interview. You will have the right to ask the recording to be suspended at any time, and a transcript of your interview can be provided upon request. Please note, transcripts will only be provided to the interview participant, they will not be shared between third parties. Also note that similar interviews will be conducted with other members of your child's transition team. The purpose of these interviews will mostly be clarification of something I have observed or to enquire about communication strategies with your child. I assure you, only information already known will be discussed within these interviews. No new or private information will be passed along about your child.

### **Key student participants**

While this research will involve many transition facilitators, the priority is on students in their graduating year. I will make efforts to explain my presence to all students I come into contact with. Whenever I am in the presence of the students I will immediately suspend any research activities should any safety related issues become apparent. I will comply with the recommendations of teaching staff regarding any student behavioural or wellbeing concerns. I will not film, observe, or document students during personal care routines or if they are distressed. I will provide a visual symbol for students to indicate if they are feeling uncomfortable with me, and will remove myself conditionally as needed. I will take care to always have a member of teaching staff present when I am with students.

### **Benefits and risks**

My hope is that those involved in the transition of your son/daughter will feel they benefit from taking part in this research and the time for reflective discussions about transition. Initially they may feel embarrassed about the extra attention placed upon them. The extended observation times are for the teaching team and students to feel comfortable with my presence, and carry on their regularly scheduled curriculum. Should you or your son/daughter feel they need support with this process, I will discuss with them and you avenues for follow-up and support.

As an additional benefit, I will offer you and your child's teaching staff any photos or videos which may be used in some manner to benefit your child's transition (for example, transition plans).

### **Voluntary participation/withdrawal**

Participation in this research is entirely voluntary. You are under no obligation to allow me to conduct research with your son/daughter. You can withdraw from this study at any time and withdraw your data within two weeks following its collection. Likewise, senior management and BOT have given assurances that teaching staff are under no obligation to participate, and that their decision will not affect their employment status. Teachers, BOT and the senior management of the school have agreed that you are free to decide whether or not to allow your child/ren to participate, and that your decision will not impact on the care and education your child/ren receives.

### **Confidential identity**

My identity within this research will be kept confidential. In order to protect your privacy I will not disclose the identity of the school or your child. You may choose, or I will assign your child a name that will not reflect his/her real name in any way.

Please note, this also mean I will not discuss any of the interviews or observations with you or between the various third parties. I am happy to provide you with a link to the written study once it is finished.

I will use excerpts from the interviews and my observations in my PhD thesis and in subsequent publications and presentations.

### Use of the data

The data I gather will be analysed and then form the basis of my PhD thesis. I will also use the data in future publications in academic journals, or to support conference or teaching presentations. I will regain consent if I would like to use the video footage in any public presentations.

### Storage and destruction of data

Your signed consent form will be stored in a locked cabinet in my doctoral office at University of Auckland's Faculty of Education for six years. The data I collect will also be securely stored for six years. Electronic data will be stored in a password protected file on the University server. Paper data will be stored in a locked cupboard in my doctoral office. After six years, electronic data will be deleted and paper data will be securely destroyed.

Thank you for the time to read this letter. I hope that you will consider allowing me to carry out my research with your son/daughter. If you have any questions about this research or need any further information, please do not hesitate to contact me or my supervisors. Our contact details are below.

All the best,

Sarah Hart

<p>Sarah Hart University of Auckland Faculty of Education Gate 3, 74 Epsom Ave, Auckland shar934@aucklanduni.ac.nz 021 118 6141</p>	<p>Associate Professor Mary Hill University of Auckland Faculty of Education School of Learning, Development, and Professional Practice Gate 3, 74 Epsom Ave, Auckland mf.hill@auckland.ac.nz 623 8899 x 48630</p>	<p>Professor Janet Gaffney University of Auckland Faculty of Education School of Curriculum and Pedagogy Gate 3, 74 Epsom Ave, Auckland janet.gaffney@auckland.ac.nz 623 8899 x 48323</p>
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You may also contact the head of the School of Learning, Development, and Professional Practice, Associate **Professor Christine Margaret Rubie-Davies**, telephone 373- 7599 ext 82974, c.rubie@auckland.ac.nz

For any queries regarding ethical concerns, you may contact the Chair, The University of Auckland Human Participants Ethics Committee, The University of Auckland, Research Office, Private Bag 92019, Auckland 1142. Telephone 09 373 7599 ext. 87830/83761.

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE  
ON 29 July 2103 for three (3) years, reference number 9727

### Consent form (parents/caregivers)

This form will be held for a six year period

Project title: Transition with Dignity

Researcher: Sarah Hart

I have read the Participant Information Sheet. I understand the nature of the research and the reasons why I have been invited to participate. I have had the opportunity to ask questions.

Please indicate YES or NO as appropriate

I agree to allow my child to participate in this research: YES / NO

I agree to:

- Allow the researcher to observe my son/daughter while at school or in community transition: YES / NO
- Allow the researcher to audio record the interviews: YES / NO
- Allow the researcher to video my son/daughter: YES / NO
- Allow documentation to be collected and photocopied about my son/daughter's transition: YES / NO
- Allow the researcher to interview or discuss transition with my son/daughter: YES / NO
- Take part in individual interview: YES / NO

I understand (please tick):

- My child's school programme is not affected by participation in this research.
- Interviews will be conducted about my child with various transition professionals, though no new information will be shared about my child's transition case.
- I will also take part in an interview about my child.
- I can ask for the recording of my interview to be suspended at any time.
- I can ask for a transcript of my interview at any time.
- The interviews will be transcribed by the researcher.
- The researcher will make written observations of my child in class and in community transition.

- The researcher will never be in a one on one situation with my child. Teaching staff will always be present.
- The researcher will not film, observe, or document a student during personal care or when distressed.
- Research will be suspended should any safety issues become apparent.
- All video and audio content, transcripts, and footage will only be seen by the student and researcher. No information will be shared between individuals.
- I have the right to withdraw my child and any information I have provided without giving a reason.
- Data gathered during this study will be securely stored for a period of six years, after which they will be destroyed.
- The findings from this study will be used in a PhD thesis, and to support the researcher's future publications, teaching and conference presentations.
- I will not be identified by name in this study not will my child. The researcher will make every effort to conceal my identity and identifiers about their transition.
- Teachers, BOT and the senior management of the school have agreed that participation or non-participation will not impact on the care and education your child/ren receives.
- The researcher can discuss appropriate avenues for follow-up or support if requested

Name:

Signature:

Date:

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE  
ON 29 July 2103 for three (3) years, reference number 9727

## Appendix B: Data Source Coding

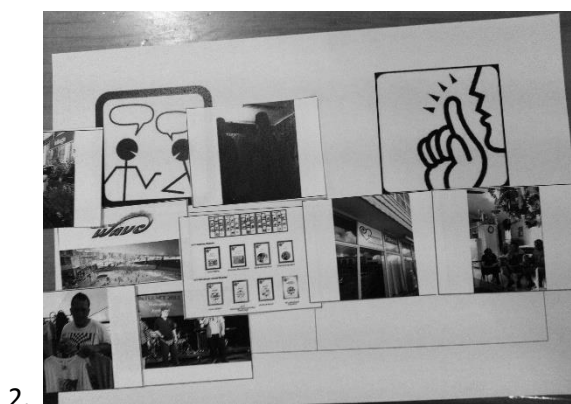
<b>Coding</b>	<b>Data source</b>	<b>In-school</b>	<b>Post-school</b>
A	Artefacts		
FN	Field notes		
P	Pictures		
T	Transcript		
V	Video		

## Appendix C: Visual-Symbol Exchange Interview

Questions:

Student question	Concepts and thoughts behind the question
1. Describe each picture. Are any pictures missing?	Open ended discussion about school, transition activities, events, celebrations, and my observations.
2. Where can you talk to other people and where are you quiet?	Opportunities for integration, interpersonal relationships, and expanding community.
3. Like movie ratings, can you rank which are your most, OK, and least favourites?	What is important at this stage? Shifting preferences next year?
4. Which activities would you like to do a lot of next year – like every day? Or sometimes – like once a week? Or not so much – like once a month? Which activities might not happen at all next year?	Double checking accuracy of previous question to see if there's a differentiated understanding between now and future. Transition chronology? How much access to preferred activities will they get next year?
5. In which pictures are you being a student and when are you not? Will you be a student next year?	Changes that occur as part of transition. How do students understand the life stage they are in?

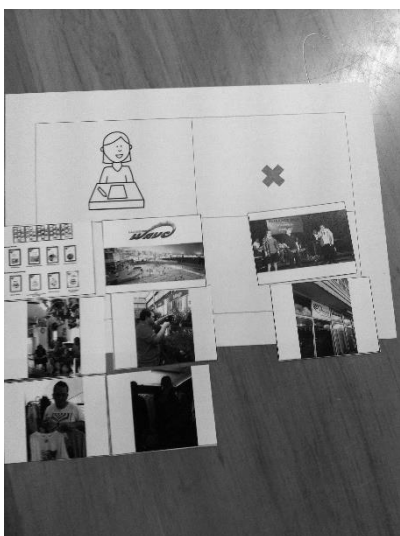
Sample answers from Faine:







4.



5.

## Appendix D: Interview Questions

Interview questions for parents and teachers:

Parent	Child (from parent perspective)	Theory/theme/thought
<p>Describe what you anticipate ...'s life will look like after he leaves school.</p> <ul style="list-style-type: none"> <li>• Living arrangements</li> <li>• Employment</li> <li>• Leisure and recreation</li> <li>• Social</li> <li>• Financial</li> </ul>	<p>What do you think ... will miss about school? What do you think he's looking forward to?</p>	<p>Do they link with 10 central human capabilities?</p>
<p>In your opinion, is ... ready for transition? How has he been prepared? How did this come about?</p>	<p>How does ... show that he knows he's graduating?</p>	<p>Concept of transition</p>
<p>Tell me about when you began to think about transition and what the process has looked like?</p>	<p>How do you think ... is feeling about leaving school?</p>	<p>Transition chronology</p>
<p>Who helped you the most in transition?</p>	<p>Who do you think has helped ... the most with his transition?</p>	<p>Shifting priorities, unobstructed engagement with community agencies.</p>
<p>How would you describe the relationship between the people involved in ...'s transition?</p>	<p>What's ... relationship like with the people involved in his transition?</p>	<p>Student involvement (Hetherington et al., 2010), behaviours to be aware of in observation.</p>
<p>What do you want most for ... is his adult life?</p>	<p>What do you think is most important to ... after he leaves school?</p>	<p>Life preferences</p>

Teacher	Student (from teacher perspective)	Theory/theme/thought
<p>Describe what you anticipate ...'s life will look like after he leaves school.</p> <ul style="list-style-type: none"> <li>• Living arrangements</li> <li>• Employment</li> <li>• Leisure and recreation</li> <li>• Social</li> </ul>	<p>What do you think ... is looking forward to next year?</p>	<p>Do they link with 10 central human capabilities?</p>
<p>In your opinion, is ... ready for transition?</p>	<p>How does ... show that he knows he's graduating?</p>	<p>Concept of transition (what informs transition decisions?)</p>
<p>How did you decide what to do for ...'s transition? (and when)</p>	<p>How do you think ... is feeling about leaving school?</p>	<p>Transition chronology</p>
<p>How do you describe your involvement with the key people in ...'s transition?</p>	<p>What's ...'s relationship like with the people involved in his transition?</p>	<p>Student involvement (Hetherington et al., 2010),</p>

		behaviours to be aware of in observation.
<b>What do you think are the most important aspects from school that ... should take with him after graduation?</b>	<b>What do you think ... will miss about school?</b>	Preferences. What gets followed on from school?

Appendix E: Capability Schematics of Findings

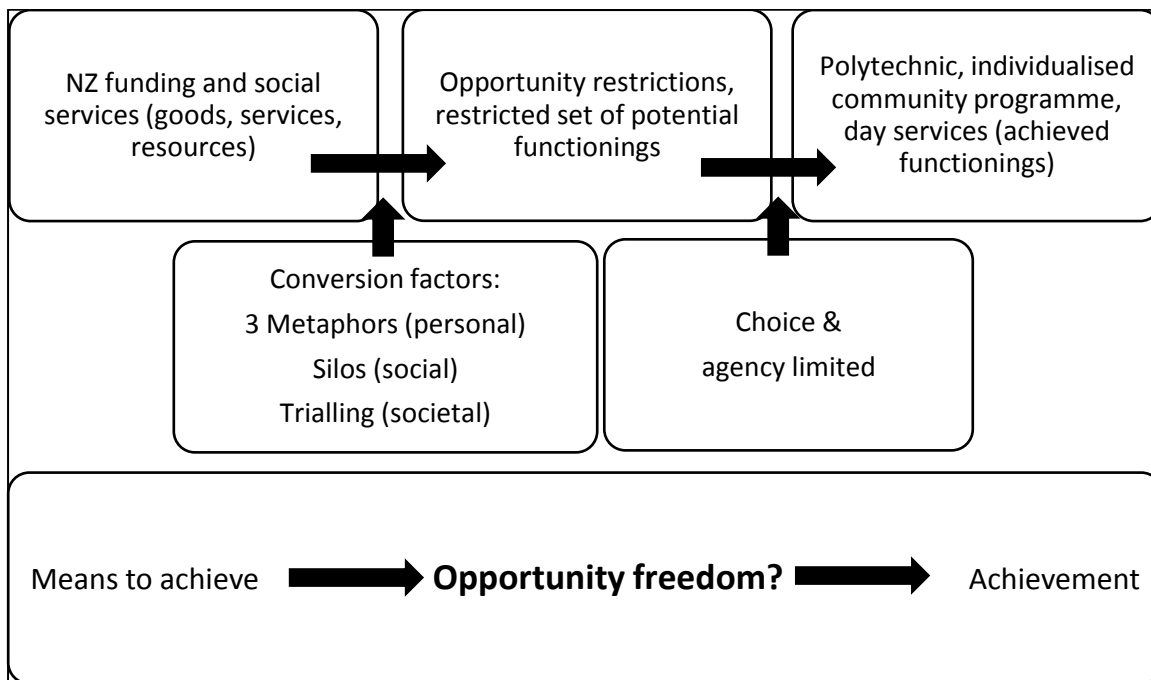


Figure E1. All research findings presented within schematic representation of capability approach.

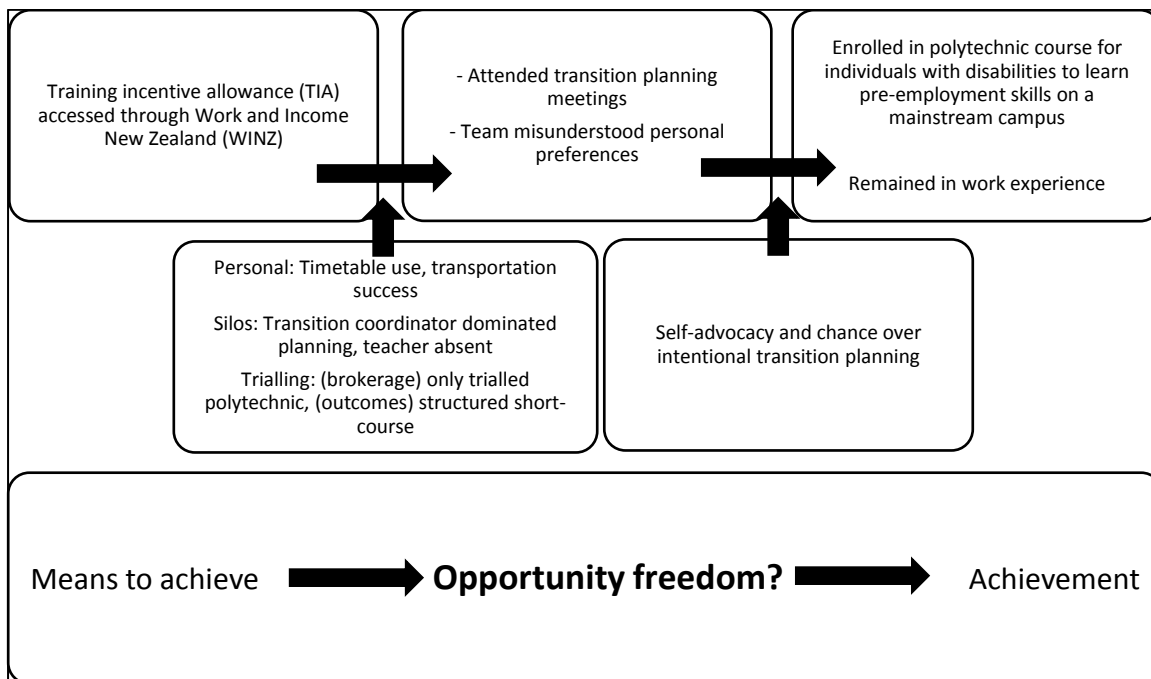


Figure E2. Haku's transition experiences within schematic representation of capability approach.

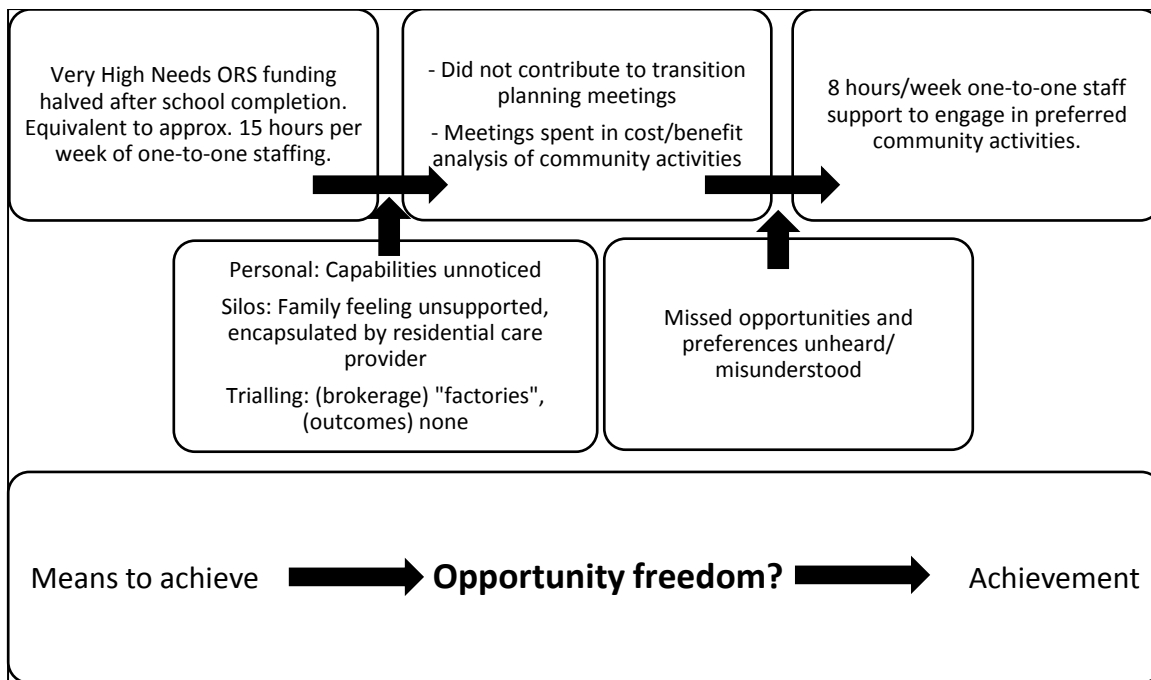


Figure E3. Cobain's transition experiences within schematic representation of capability approach.

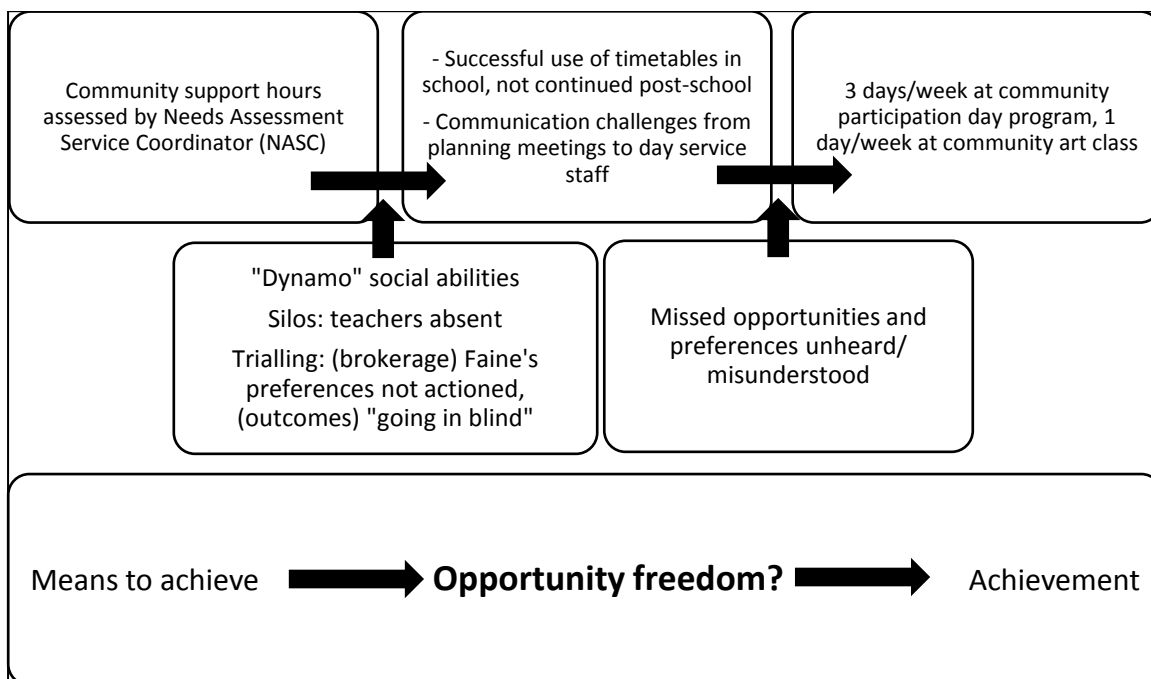


Figure E4. Faine's transition experiences within schematic representation of capability approach.