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Exploring the New Zealand Child and Youth Profile as a collaborative tool to support educational planning for children with fetal alcohol spectrum disorder

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“Kaua e rangiruatia te hā o te hoe; e kore tō tātou waka e ū ki uta”
“Do not lift the paddle out of unison or our canoe will never reach the shore”

A Māori proverb quoted in Macfarlane, Blampied, & Macfarlane (2011) that highlights the importance of working collaboratively.

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Abstract

Research indicates that students with fetal alcohol spectrum disorder (FASD) are at increased risk of poor academic performance, however, educational planning for these students is difficult due to the complex nature of their educational profile. In order to improve educational outcomes, tools are required to support improved understanding of the student's profile along with enhancing a cross-disciplinary approach to educational planning. This study sought to investigate the use of the New Zealand Child and Youth Profile (NZCYP), a biopsychosocial framework designed to collect key information about a student from multiple perspectives, in order to facilitate cross-disciplinary educational collaboration and planning. A qualitative design was employed to explore the perceptions of two teams of participants using the NZCYP to support a student with FASD. Findings indicated several factors hindered the completion and application of the NZCYP (or Toolkit), which had a considerable impact on the teams' perceptions of the NZCYP. Overall, the teams perceived the NZCYP's ability to help improve understanding of the student's profile, to support teacher/classroom practice and planning, and to enhance collaborative practice was limited. This study highlighted the importance of providing tools which are easily understood, incorporate culturally relevant information and multiple perspectives, and provide suitable training to enable teams to utilise the information in a cross-disciplinary manner.

Table of Contents

Acknowledgements	ii
Abstract	iii
Table of Contents	iv
List of Figures and Tables	ix
Chapter 1: Introduction	1
1.1. Background to FASD	1
1.1.1. Epidemiology.	2
1.1.2. How does alcohol affect the fetus?	2
1.1.3. Secondary conditions.	3
1.1.4. How prevalent is FASD?	4
1.1.5. The financial burden of FASD.	6
1.1.6. School experience of children with FASD.	7
1.1.7. Supporting students with FASD.	9
1.1.8. Conclusion.	12
1.2. Research Aim and Questions	12
1.3. Glossary of Terms	13
1.3.1. Assessment	13
1.3.2. Collaboration	14
1.3.2.1. Collaborative educational teamwork.	14
1.3.3. Cross-Disciplinary Approach.	14
1.3.3.1. Multidisciplinary.	15
1.3.3.2. Interdisciplinary.	15
1.3.3.3. Transdisciplinary.	15
1.3.4. Educational Planning.	15
1.3.5. Perspectives.	16
1.4. Summary	16
Chapter 2: Literature Review	18
2.1. Barriers to Educational Planning for Children with FASD	18
2.1.1. Diagnosis.	19
2.1.2. Comorbidity and misdiagnosis.	20
2.1.3. Lack of knowledge by professionals.	23
2.1.4. Assessment.	25
2.1.5. Summary of barriers.	26
2.2. Learning Profile of Children with FASD	26

2.3. The Role of Parents and Family in Educational Planning	28
2.4. Cross-disciplinary Approach	32
2.4.1. Collaboration and educational planning.	34
2.4.2. Collaboration and FASD.	35
2.4.3. Barriers to collaboration.	36
2.4.4. Enhancing cross-disciplinary collaboration.	38
2.5. New Zealand Collaborative Assessment Approach	40
2.6. Perspectives	43
2.7. Disability Classification Systems for Collaborative Educational Planning	46
2.7.1. The ICF-CY.	48
2.7.2. The ICF-CY and Learning Support Needs.	51
2.7.3. The NZCYP.	55
2.8. Summary	57
Chapter 3: Methodology	59
3.1. Research Questions	59
3.2. Research Design	59
3.2.1. Focus group interviews.	60
3.3. Participants and environment.	61
3.3.1. Recruitment.	62
3.3.2. Participant detail.	63
3.3.3. Environment.	65
3.4. Training	66
3.4.3. The NZCYP.	66
3.4.2. Pilot training.	67
3.4.3. Training.	67
3.5. Data Collection	68
3.5.1. Interview guide development.	68
3.5.2. Procedures.	69
3.5.3. Moderator.	70
3.5.4. Digital recording and transcription.	71
3.6. Data Analysis	72
3.6.1. Data analysis framework.	72
3.6.2. Data analysis procedure.	73
3.7. Positionality	73
3.8. Ethical Considerations	76
3.8.1. Informed consent.	76

3.8.2. Confidentiality and privacy.	76
3.8.3. Cultural considerations.	77
3.8.4. Reciprocity.	78
3.9. Summary	78
Chapter 4: Results	79
4.1. Use of the NZCYP	79
4.2. Factors Impacting on the Completion and Application of the NZCYP	80
4.2.1. Complexity.	81
4.2.1.1. Language.	81
4.2.1.2. Clarity.	82
4.2.1.3. Time.	84
4.2.2. Relevance and fit.	85
4.2.2.1. Fit: Student.	86
4.2.2.2. Fit: School.	90
4.2.2.3. Fit: Community.	91
4.2.2.4. Fit: Culture.	92
4.2.3. The Focus of the NZCYP.	96
4.2.3.1. Overly negative focus.	96
4.2.3.2. Overly positive focus.	98
4.2.4. Knowledge about the Student.	99
4.2.4.1. Lack of Knowledge about the Student.	99
4.2.4.2. Transition.	100
4.3. Impact on Understanding the Student's Educational Profile	101
4.3.1. Change in awareness of student's profile.	101
4.3.2. Impact on understanding of educational profile of other students with FASD.	106
4.4. Impact of NZCYP on Teacher/Classroom Planning and Practice	109
4.4.1. Changes in teacher/classroom practice and planning.	109
4.5. Collaboration	113
4.5.1. Factors influencing the collaborative process.	113
4.5.1.1 Bringing the team together.	113
4.5.1.2. Generating discussion and sharing information.	114
4.5.1.3. Collaborative framework already in place.	115
4.5.1.4. Multiple perspectives.	116
4.5.1.5. Cultural misalignment.	118
4.6. Summary	119
Chapter 5: Discussion	120

5.1. Research Question One: What Factors Impacted on How Participants Used the NZCYP for Students with FASD?	121
5.1.1. Complexity.	121
5.1.1.1. Language.	122
5.1.1.2. Clarity.	123
5.1.1.3. Time.	124
5.1.1.4. Summary: Complexity	124
5.1.2. Relevance and fit.	125
5.1.2.1. Fit: Student.	125
5.1.2.2. Fit: School.	125
5.1.2.3. Fit: Community.	126
5.1.2.4. Cultural fit.	126
5.1.2.5. Summary: Relevance and fit.	129
5.1.3. Focus of NZCYP.	129
5.1.3.1. Overly negative focus.	129
5.1.3.2. Overly positive focus.	131
5.1.3.3. Summary: Focus of the NZCYP.	132
5.1.4. Lack of knowledge/transition.	132
5.1.4.1. Summary: Lack of knowledge/transition.	133
5.1.5. Summary of findings: Research question one.	133
5.2. Research Question Two: How is the NZCYP Perceived in Terms of Helping Teams to Understand the Educational Profile of Students with FASD?	135
5.2.1. Change in awareness of student profile.	135
5.2.2 Change in understanding of FASD profile for other students.	137
5.2.2.1. Misconceptions about FASD.	138
5.2.2.2. Misunderstanding about the purpose of the NZCYP.	139
5.2.3. Summary of findings: Research question two.	140
5.3. Research Question Three: How is the NZCYP Perceived in Terms of Supporting Teacher/Classroom Practice and Planning for Students with FASD?	141
5.3.1. Changes in teacher/classroom practice and planning for students with FASD.	141
5.3.2. Summary of findings: Research question three.	143
5.4. Research Question Four: How is the NZCYP Perceived in Terms of Supporting Collaborative Practice for Students with FASD?	144
5.4.1. Generating discussion/coming together as a team.	145
5.4.2. Collaborative framework already in place.	146
5.4.3. Multiple perspectives of the student.	147

5.4.4. Impact of different paradigms of disability on collaboration	148
5.4.5. Cultural misalignment.	149
5.4.6. Summary of findings: Research question four.	151
5.5. Summary	152
Chapter 6: Conclusion	155
6.1. Purpose and Rationale	155
6.2. Challenges/Limitations	156
6.3. Key Implications	159
6.3.1. Complexity.	159
6.3.2. Relevance and fit.	160
6.3.3. Focus of the NZCYP.	162
6.3.4. Misconceptions about FASD	162
6.3.5. Lack of knowledge.	163
6.3.6. Collaboration.	163
6.3.7. Training.	164
6.4. Future Research	165
6.5. Summary	166
Appendices	167
Appendix 1: Parent/Caregiver Letter of Invitation	167
Appendix 2: Participant Information Sheet	169
Appendix 3: Parent/Caregiver Consent Form	172
Appendix 4: Principal Information Sheet	173
Appendix 5: Principal Consent Form	175
Appendix 6: Participant Consent Form	176
Appendix 7: Demographic Questionnaire	177
Appendix 8: NZCYP	178
Appendix 9: Focus Group Ground Rules and Questions	193
Appendix 10: Codebook	196
Appendix 11: Journal Excerpts	199
Appendix 12: Low Risk Notification	201
References	203

List of Figures and Tables

Figures

Figure 1. Developmental Profile of 18 Year Old with FASD..... 9

Figure 2. Framework for NZCYP 56

Tables

Table 1. Demographic Information 65

Table 2. Global Themes, Organising Themes and Codes 80

Chapter 1: Introduction

Prenatal alcohol exposure represents the leading cause of preventable birth defects, intellectual disabilities, and adverse neurodevelopmental effects worldwide (Hoyme et al., 2016). The effect of fetal alcohol spectrum disorder (FASD) impacts not only the child, but their families and society at large (Gibbs & Sherwood, 2017). Without adequate support, educational outcomes for children with FASD can be poor, exacerbating the potential negative long-term outcomes of the disorder (Boys et al., 2016). However, educational planning for this population is difficult due to their uneven and complex learning profiles and challenging behaviours (Carpenter, 2011). This research aims to explore educational team members perceptions of the use of the New Zealand Child and Youth Profile (NZCYP) developed by McLaughlin, Budd and Clendon (2017) to support educational planning for children with FASD. This chapter will include background information on FASD, together with the research questions, and an outline of the chapters in the thesis.

1.1. Background to FASD

This section will provide a background to the study. It will outline the epidemiology of FASD, followed by a discussion on the impact of alcohol on the developing fetus and subsequent secondary conditions that can occur. The prevalence rate and financial burden of the disorder will then be discussed. Next, the educational experience of children with FASD will be considered along with how to support them.

1.1.1. Epidemiology.

FASD was originally used as an umbrella term covering a range of brain-based disabilities and craniofacial anomalies occurring as the result of prenatal alcohol exposure (PAE) (Kingdon, Cardoso, & McGrath, 2015; Rutman, 2016). Due to the range and severity of symptoms, four diagnostic categories were developed: fetal alcohol syndrome (FAS), partial fetal alcohol syndrome (pFAS), alcohol-related birth defects (ARBD), and alcohol-related neurodevelopmental disorder (ARND) (Hoyme et al., 2016). Recently these categories have been revised and redefined as two diagnostic categories: individuals with sentinel facial findings, which incorporates FAS, and those without sentinel facial findings, which incorporates pFAS, ARBD and ARND (Chudley, 2017; Cook et al., 2016). The timing, level, and frequency of alcohol exposure, along with maternal health, body mass, age, and nutrition; genetics, epigenetics, and fetal vulnerability factors determine the degree of fetal damage (Lussier, Weinberg, & Kobor, 2017; May & Gossage, 2011; Price, Cook, Norgate, & Mukherjee, 2017; Ungerer, Knezovich, & Ramsay, 2013). As there is no clear indication of a safe amount of alcohol to consume during pregnancy, the American Academy of Paediatrics currently advise that no alcohol is safe to consume during any stage of pregnancy (Williams, Smith, & the Committee on Substance Abuse, 2015).

1.1.2. How does alcohol affect the fetus?

Alcohol is a teratogen that can easily pass across the placental barrier, damaging the brain and other developing organs and systems of the fetus (Mattson, Crocker, & Nguyen, 2011; Popova, Lange, Probst, Gmel, & Rehm, 2017), including, for example neuroendocrine and immune function systems (Zhang, Sliwowska, &

Weinberg, 2005). Accordingly, children with FASD may experience a wide range of congenital abnormalities, along with physical, cognitive, behavioural, emotional, and adaptive functioning difficulties. These deficits are known as primary impairments. The impact of these impairments are likely to be lifelong (Connor & Streissguth, 1996; Pei, Denys, Hughes, & Rasmussen, 2011). There is no current pharmaceutical treatment for FASD (Dörrie, Föcker, Freunsch, & Hebebrand, 2014); however, Thomas, Warren and Hewitt (2010) point to the ability of a PAE exposed brain to be moulded and shaped when given early and appropriate interventions. For children affected by PAE, early diagnosis and intervention are vital in improving long-term outcomes (Kodituwakku & Kodituwakku, 2011; Parsonson, 2015; Streissguth et al., 2004). Critically, when FASD goes undiagnosed at an early age, and either no intervention, or inappropriate interventions and punishments are put in place, these children often develop complex secondary conditions (Petrenko, Tahir, Mahoney, & Chin, 2014a).

1.1.3. Secondary conditions.

Popova, Lange, Burd, and Rehm (2015) note that secondary disabilities in FASD are thought to occur through the interaction between primary FASD deficits and environmental factors. These secondary conditions can be severe and lifelong and include an increased rate of mental health issues (Pei et al., 2011), inappropriate sexual behaviour (Coriale et al., 2013), poverty and homelessness (Rutman, & Van Bibber, 2010; Streissguth, 1997), suicidality and mental health disorders (Baldwin, 2007; Weyrauch, Schwartz, Hart, Klug & Burd, 2017), and delinquency (Lynch, Coles, Corley & Falek, 2003). In a national register-based study of individuals diagnosed with FAS, Rangmar et al. (2015) found those with FAS had much higher

rates of receiving special education compared to the comparison group that was matched on age, gender and place of birth (25% to 2%). These findings support numerous studies that have demonstrated poor educational outcomes for individuals with FASD, including poor academic performance and increased rates of suspensions, expulsions, and drop-outs. (Alati et al., 2013; O’Leary, Taylor, Zubrick, Kurinczuk, & Bower, 2013; Sayal et al., 2014). Further, Rangmar et al. (2015) found higher rates of unemployment (51% to 15%), hospital admission for psychiatric disorders (33% to 5%), and alcohol abuse (9% to 2%). However, contrary to a wide body of research suggesting increased rates of criminality in individuals with FASD (e.g., Burd, Selfridge, Klug, & Bakko, 2004; Lynch et al., 2003, Popova, Lange, Bekmuradov, Mihic, & Rehm, 2011), Rangmar et al. (2015) found similar rates of criminality between the control group and the group with FAS. The authors suggest that receiving a diagnosis of FAS, and receiving it early, may have acted as a protective factor against the development of criminal behaviour in later life. Importantly, Boys et al. (2016) assert that many secondary disabilities are exacerbated by poor community service delivery and the failure to develop and adopt an individualized education or treatment plan.

1.1.4. How prevalent is FASD?

Prevalence rates for FASD are difficult to calculate due to imprecise measures, which may underestimate the occurrence of the disorder (Flannigan et al., 2018; May et al., 2014; Roozen et al., 2016). A recent global review of the prevalence of alcohol consumption during pregnancy was estimated at 9.8%, which equates to an estimated prevalence of FASD in the general population of 14.6 per 10,000 people (Popova et al., 2017). These results have been challenged, however,

by Strandberg-Larsen, Andersen, and Kesmodel (2017) who assert surveillance rates suggest numbers are much lower than those indicated by Popova and colleagues (2017). Research suggests incidence rates are considerably higher in some populations (Lange et al., 2017), such as groups with low socioeconomic status (SES), children in care (such as orphanages), and populations with high alcohol consumption (Barry, 2009; May et al., 2014; Meurk, Lucke, & Hall, 2014). For example, Lange, Shield, Rehm, and Popova (2013) found prevalence rates of FASD for children in care, such as child welfare settings, of 16.3% and May et al. (2014) found prevalence rates of FASD as high as 1 in 20 in populations with high alcohol consumption.

New Zealand rates of FASD are thought to reflect international rates, although there is limited New Zealand specific data on FASD, including prevalence rates, available (FASD Working Group, 2016). Current rates of FASD are based on international data and are estimated at 1% of live births (Easton, Burd, Rehm, & Popova, 2016). However, New Zealand has high levels of unplanned pregnancies (Mallard, Conner, & Houghton, 2013; Mallard, Gray, & Houghton, 2011), and a high rate of heavy episodic drinking in both men and women (Mallard et al., 2013; Ministry of Health, 2009) suggesting rates of FASD may be higher. For example, in a longitudinal study of methamphetamine users who were pregnant, Wouldes et al. (2013) found the rate of alcohol consumption by the New Zealand cohort of women was four times higher than that of matched cohorts in the United States of America. Findings by the Ministry of Health (2015) indicate that alcohol exposure may have occurred in more than 50% of all pregnancies in this country, which Gibbs and Sherwood (2017) equate to more than 570 babies born annually with FASD in New Zealand. No data

is available for FASD prevalence rates in New Zealand schools, but international research suggests it may be as high as 6.3% of school-aged children (May, 2009; Millar et al., 2017).

1.1.5. The financial burden of FASD.

The cost of FASD to society both economically and in human suffering is high (Hoyme et al., 2016). For example, Canadian research by Popova, Lange, Burd, Nam, and Rehm (2016) assessed the financial cost of special education services received by children with FASD in 2011-2012 at 53.3 million dollars. This figure represented 6,520 children with FASD aged 5 to 14 years receiving special education. In New Zealand, research suggests the financial burden of FASD is as high as 690 million dollars annually, including services and support, whilst lost productivity has been estimated at 200 million dollars annually (Easton et al., 2016; Ministry of Health, 2015). Furthermore, Gibbs and Sherwood (2017) argue that when the hidden social, health, and financial costs to families and individuals dealing with FASD is considered, this increases the burden of FASD further. Importantly, early diagnosis and appropriate interventions can help improve the outcome of children with FASD, thus reducing its impact (Kodituwakku & Kodituwakku, 2011; Parsonson, 2015). Indeed, given the right environment, research suggests that children with FASD can complete high school (Duquette, Stodel, Fullarton, & Hagglund, 2006a) and lead rewarding lives (Green, 2007; Ryan, & Ferguson, 2006a).

1.1.6. School experience of children with FASD.

Schooling for children and adolescents with FASD can be challenging, not just for the student, but also teachers, caregivers, and allied professionals, as neurodevelopmental damage caused by PAE impacts on cognitive and behavioural functioning (Poth, Pei, Job, & Wyper, 2014). There is a high degree of variability in intellectual ability ranging from severe intellectual impairment to high average cognitive capabilities in children with FASD (Chokroborty-Hoque, Alberry, & Singh, 2014). Further, many children with FASD will experience emotional and behavioural challenges, which can hinder their academic and social development. For example, children with FASD can show deficits in social skills and emotional maturity (Blackburn, Carpenter, & Egerton, 2012), leading to problems creating and maintaining positive peer and teacher relationships (Kalberg & Buckley, 2007). Negative peer relationships can lead to peer rejection and victimisation (Herrick, Hudson, & Burd, 2011), whilst poor teacher student relationships can lead to poor academic outcomes (Kully-Martens, Denys, Treit, Tamana, & Rasmussen, 2012). Deficits in both academic and behavioural functioning mean appropriate educational planning is critical in working with the child's unique developmental profile.

Children with FASD show an uneven and inconsistent pattern of development, which can make them difficult to accommodate within the general curriculum (Blackburn et al., 2012). For example, children with FASD may show expressive language skills in advance of their chronological age, reading skills can be appropriate for their age, whereas social skills and emotional maturity may be at the level of a child half their age. Also, these children frequently show particular difficulties with mathematical and numerical concepts (Blackburn et al., 2012;

Carpenter, 2015). Figure 1 illustrates how a child with FASD's chronological age and developmental age can be drastically different at any given time. Children who have been prenatally exposed to alcohol also have difficulty grasping and using strategies. For example, studies of children with PAE compared with control participants showed a greater tendency to persevere with incorrect strategies, more rule violations, and less time spent on planning strategies to complete a task (Aragon et al., 2008; Green et al., 2009). Whilst McGee, Schonfeld, Roebuck-Spencer, Riley, and Mattson (2008) compared concept formation (a component of executive functioning) in children with FASD to control group participants and found they had deficits in both generating and verbalizing concepts, which the researchers theorise could impact on problem solving skills and adaptive functioning. The impact of FASD for children in the classroom is highlighted by Millar et al. (2017) and Millians (2015) who contend that difficulties with attention can make daily classroom activities and tasks, such as listening, following instructions, and learning new concepts, difficult which can negatively impact academic progress.

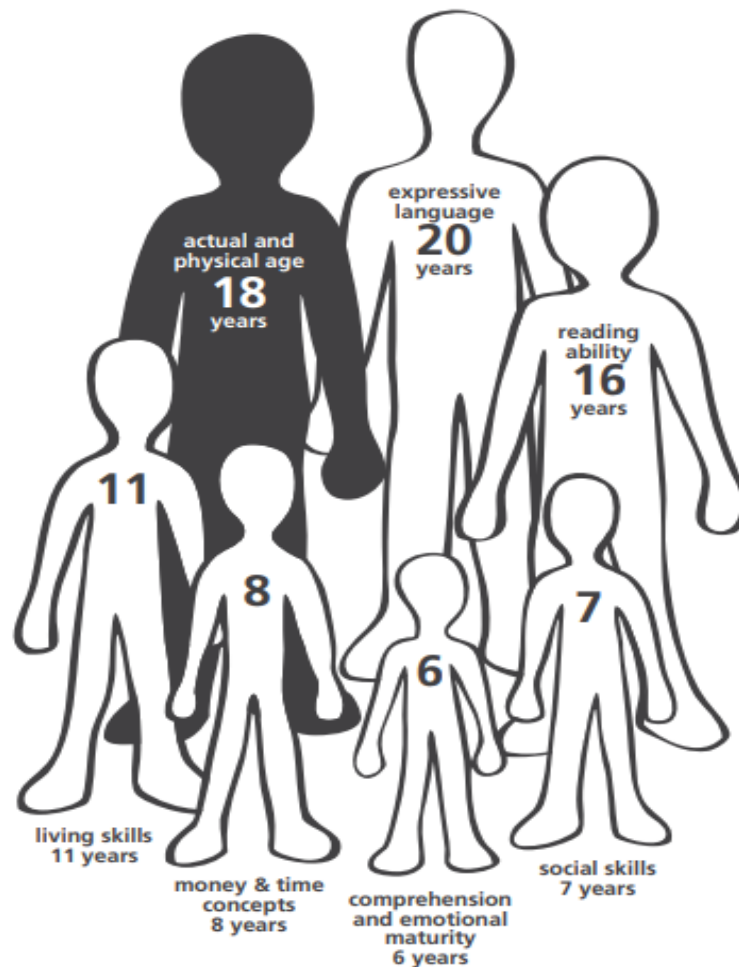


Figure 1. Developmental profile of an 18-year-old with FASD (Source: Jodee Kulp <http://www.betterendings.org> used with permission).

1.1.7. Supporting students with FASD.

Whilst FASD represents one of the leading causes of preventable learning disabilities worldwide, there is relatively little research into how FASD can be identified and supported in educational settings (Carpenter, 2011; Mukhurjee, 2015; Streissguth & O'Malley, 2000). Due to the complex nature of the disorder, traditional approaches to learning and behavioural issues by teachers and caregivers are often unsuccessful (Devries & Waller, 2004; Malbin, 2005). Further, the student's atypical style of learning and significant behavioural challenges means many teachers feel out of their depth (Carpenter, 2011). Also, many students with

FASD find it difficult to adhere to conventional learning strategies (Duquette et al., 2006a; Kalberg & Buckley, 2007), which Edmonds and Crichton (2008) suggests, requires a highly flexible approach. In order to meet the complex needs of the student, a comprehensive assessment of the student's learning, and developmental profile needs to be carried out and appropriate planning put in place (Blackburn, 2010). Further, a collaborative cross-disciplinary approach is viewed as vital in supporting students with FASD (Blackburn et al., 2012).

Currently there is limited research on educational planning for children with FASD (Bohjanen, Humphrey, & Ryan, 2009). In a recent review of the literature, Dudley, Reibel, Bower, and Fitzpatrick (2015) identified the need for comprehensive general planning that includes the student with FASD, and their families, and is developed through multiple agencies of care. The focus of the planning should be on encouraging participation by the child, as well as a focus on seeing the child as a whole and considering the home and community contexts. Further, planning should involve key partnerships between the parents, school, and other professionals. In another review of the literature by Parsonson (2015) for the New Zealand Ministry of Education, the author asserts that it is crucial that educational planning for children with FASD involves recognising and developing the child's strengths and identifying and adopting classroom instruction and behaviour management strategies that will help minimise the child's deficits. Finally, educational planning should also provide for effective transitioning into new classes and schools (Blackburn, 2017; Duquette, Stodel, Fullarton, & Hagglund, 2007).

Commentators argue that for educational planning to be successful for students with FASD there is an urgent need for research into the development of appropriate tools for assessment and cross-disciplinary collaboration (Blackburn et al., 2012; Brown, Harr, & Helmstetter, 2018). Brown and colleagues claim that better assessment tools would enable the identification of specific deficits, symptoms, and needs for students. They argue that to improve educational outcomes for students with FASD educational planning needs to be individualized to account for the student's unique developmental profile and take a functional approach, emphasising non-academic behaviours such as social skills and behavioural regulation. This approach is recommended by Kalberg and Buckley (2007) who assert that assessment should include how the child performs in diverse settings and under specific environmental conditions in order to gain insight into problems that may occur in different settings. As Kalberg and Buckley note, a thorough assessment process enables the team supporting a child with FASD to develop an understanding of the conditions required for the child's optimal performance, and those that may disrupt that performance. Data gathered can be used to create a specific learning profile of the student, which can then inform educational planning for the child.

In order to develop a holistic profile of a student with FASD, a framework is needed to enable multiple perspectives of the child to be considered, along with the complex interactions between the child and their environment. One such model is the NZCYP (McLaughlin et al., 2017), a tool based on the International Classification of Functioning, Disability, and Health for Children and Youth (ICF-CY). The ICF-CY utilises a biopsychosocial framework, designed to create a holistic profile of the child by considering the influence of biological, psychological and social factors that

impact on the child's development (Simeonsson, et al., 2014). Also, the framework allows the gathering of information on the child from multiple sources suggesting it would be helpful in supporting collaborative educational planning for students with FASD.

1.1.8. Conclusion.

Children with FASD present a complex challenge to educationalists and families in supporting their social, cognitive, and emotional development (Blackburn et al., 2012). The ability to identify and understand the learning profile of a student is an important step in developing educational plans that can support these students effectively. Educational plans need to build on the identified strengths and interests of the child, be at an appropriate developmental level, and contain realistic expectations, which consider the child's complex issues (Blackburn et al., 2012). A collaborative cross-disciplinary approach, which includes parents and family is considered essential in providing appropriate educational planning for children with FASD (Dudley et al., 2015). Identifying tools that can support the cross-disciplinary development of a holistic learning profile is vital in supporting children with FASD (Brown et al., 2018), therefore this research will focus on the NZCYP, a tool based on the biopsychosocial framework of the ICF-CYP.

1.2. Research Aim and Questions

The aim of this study is to explore The New Zealand Child and Youth Profile (NZCYP) as a tool that offers the opportunity for professionals (and parents) working with students who have FASD to work collaboratively on the development of appropriate educational plans. This project will consider the NZCYP in relation to

teams working with students who have FASD and will explore the following research questions:

1. What factors impacted on how the NZCYP was used by teams supporting a student with FASD?
2. How is the NZCYP perceived in terms of helping teams to understand the educational profile of students with FASD?
3. How is the NZCYP perceived in terms of supporting teacher/classroom practice and planning for students with FASD?
4. How is the NZCYP perceived in terms of supporting collaborative practice for students with FASD?

1.3. Glossary of Terms

The following section will describe a number of terms and define their usage for the purposes of this thesis.

1.3.1. Assessment

Assessment is undertaken to identify a student's strengths and weaknesses to inform decision making, and to support a student to reach their full potential. A key feature of assessment in educational settings is to reduce barriers to a student's learning. Assessment, therefore, offers information to assist educational planning (Australian Psychological Society & Speech Pathology Australia, 2014) and can directly inform the development of goals and objectives for the individualised education plan (IEP) (Kalbeg & Buckley, 2007).

1.3.2. Collaboration

Collaboration is defined as a reciprocal, dynamic, and harmonious process amongst individuals. Whilst conflict is not excluded from the process, the aim of collaboration is to reach consensus through a common frame of reference and develop a mutual understanding of the object of interest. This understanding may lead to a shared mental model of the object, mutual decision making regarding agreed upon goals and solutions, and the development of a collective identity by the team (Budd, 2014; Cowan, Swearer Napolitano, & Sheridan, 2004).

1.3.2.1. Collaborative educational teamwork.

Collaborative teamwork is a dynamic process where general and special education staff, allied professionals, the student and their family, work collectively, contributing their diverse understanding and expertise to identify the student's needs, in order to plan, instigate, and assess ways to help the student to succeed to their maximum capabilities (Dettmer, Knackendoffel & Thurston, 2013). Collaboration between the school, parents, and related professionals is considered essential in meeting the educational needs of students with learning support needs (LSN) (Cramer, 2006; Leyser & Kirk, 2011; Ryndak, Orlando, Storch, Denney, & Huffman, 2011).

1.3.3. Cross-Disciplinary Approach.

The term cross-disciplinary is an overarching term that encompasses multidisciplinary, interdisciplinary and transdisciplinary approaches and refers to the presence of more than one discipline (Wall & Shankar, 2008) and will be used in this sense in this thesis.

1.3.3.1. Multidisciplinary.

In a multidisciplinary team, individuals are assumed to have constant roles in line with their discipline (Hillier, Civetta, & Pridham, 2010). For example, Gargiulo and Kilgo (2014) argue that stakeholders operating under a multidisciplinary approach work independently of each other in both the carrying out of assessment and the writing up of reports. This then leads to discipline specific goals and there is little intercommunicative exchange between parties (Klein, 2010).

1.3.3.2. Interdisciplinary.

Characterised by greater interaction between team members to develop common goals for the student and co-ordinate service provision (Fitzmaurice & Richmond, 2017). In this model, there is a blurring of the roles, for example the role of the teacher may overlap with the role of the occupational therapist (Hillier et al., 2010).

1.3.3.3. Transdisciplinary.

In contrast to the multidisciplinary and the interdisciplinary approach, Russell, Wickson, and Care (2008) posit that a transdisciplinary approach transcends disciplinary boundaries providing a collaborative and responsive problem-solving method and encourages a whole-child approach.

1.3.4. Educational Planning.

Educational planning is a process where informal and formal decisions are made on behalf of students with LSN to enable access to general education content

and settings (Ruppar, Allcock, & Gonsier-Gerdin, 2017). Educational planning usually involves adapting the curriculum and modifying the learning environment to ensure students are achieving specific goals (Guardino & Fullerton, 2010; Rangvid, 2018; Shaddock, MacDonald, Hook, Giorcelli, & Arthur-Kelly, 2009).

1.3.5. Perspectives.

Individual team members perspectives will be influenced by multiple sources such as culture, ethnicity, religion, gender and life experiences, and provide a frame of reference from which they will interpret their experiences within the team (Annan, Bowler, Mentis, & Phillipson, 2008; Banks & McGee, 2013).

1.4. Summary

This chapter has provided a background to FASD, highlighting the prevalence and impact of the disorder on the student, their family, and society. The importance of improving educational outcomes for students with FASD was also underscored, as was the need for tools to support collaborative educational planning. This chapter has also outlined the study's aim and research questions and defined the usage of terms. The remainder of the thesis is structured into four chapters. The next chapter will review the relevant literature on educational planning, including barriers, learning profiles of students with FASD, and the role of parents in educational planning. Further, cross-disciplinary collaboration in relation to students with FASD will also be discussed. Also, in this chapter, frameworks and tools that provide cross-disciplinary methods of categorising and profiling children with disabilities will be considered in relation to their ability to support educational planning for this population. Chapter Three describes the method and methodology of the current

research, including ethical considerations. Chapter Four presents the findings from the focus group interviews. Chapter five discusses the research findings in relation to the literature. Finally, Chapter six provides a summary of the purpose and rationale of the study, discusses limitations and key implications of the research and makes recommendations for future research.

Chapter 2: Literature Review

“I sometimes think of him like a changeling, a very nice, very beautiful changeling but someone who is also like a jigsaw, so many different pieces and nobody seems to have the time to put the picture together and see the whole child!” (Parent of a child with an FASD, Carpenter, Blackburn, & Egerton, 2013: xxiv)

This chapter will consider the literature around barriers to educational planning, and the need for comprehensive educational profiles and cross-disciplinary collaborative approaches for teams supporting children with FASD. This chapter will also explore international and New Zealand research regarding tools that may enhance the development of learning profiles and cross-disciplinary collaboration in educational planning for children with FASD.

2.1. Barriers to Educational Planning for Children with FASD

Research highlights several barriers to educational planning for children with FASD. These barriers include a lack or delay of formal diagnosis of FASD (Petrenko, Tahir, Mahoney, & Chin, 2014b), and high rates of comorbidity and misdiagnosis with other disorders (Boyes et al., 2016; Popova, Lange, Shield et al., 2016), meaning educational planning can be hindered by the complex and diverse neurocognitive profile (Poth et al., 2014). Also, many teachers and allied professionals lack knowledge in identifying and supporting children with FASD and may not fully comprehend the type and degree of impairment (Paley & O’Conner, 2009), consequently teachers may focus on behavioural characteristics instead of the underlying aetiology of the child (Boyes et al., 2016; Scheepers, 2009). Finally, poor

assessment practice and lack of appropriate assessment tools create a barrier to appropriate educational planning for children with FASD. This section will review the literature regarding these barriers.

2.1.1. Diagnosis.

Obtaining an accurate diagnosis is critical in supporting the educational development of children with FASD. For example, Olsen and colleagues (2007) argue that understanding a child with FASD's neurological profile can radically change people's perceptions of the child's behaviour and how they approach them. Also, early identification of FASD can improve long term outcomes (Streissguth et al., 2004). Yet acquiring an accurate diagnosis can be difficult (FASD Working Group, 2016; Petrenko et al., 2014a), and delay in obtaining a diagnosis increases the risk that individuals with FASD are under-recognised and undertreated (Paley & O'Conner, 2011). Further, a delay in diagnosis increases the risk of secondary issues developing, including emotional and behavioural problems, and poor educational outcomes (Streissguth et al., 2004).

Research highlights the importance of obtaining an accurate diagnosis, however, a scarcity of diagnostic and treatment services can lead to difficulties and delays for the families and individuals with FASD (Glass & Mattson, 2016; Murawski, Moore, Thomas, & Riley, 2015). These difficulties were underscored in a qualitative study by Petrenko and colleagues (2014a) who used semi-structured interviews and focus groups to explore system level barriers to support with 25 parents of children with FASD and 18 providers (including educational psychologists and teachers). Parents reported delays in diagnosis, in one case not until the child was 13, whilst others

experienced misdiagnosis of their child with other disorders. Teachers indicated delay in diagnosis and assessment prevented access to education support services. Petrenko et al. (2014a) also found a lack of awareness of the disorder by parents and professionals meant that a diagnosis of FASD could be overlooked. The researchers concluded individuals supporting children with FASD need to understand how the behaviour of a child with FASD's is impacted on by their neuropsychological strengths and deficits. Without accurate diagnosis, a child with FASD is unlikely to receive appropriate assessment, interventions, and support. This study highlights the need for tools that can support diagnosis and assessment processes.

2.1.2. Comorbidity and misdiagnosis.

As indicated by Petrenko et al. (2014a), another barrier to effective educational planning is the high rate of comorbidity and misdiagnosis with other disorders, which complicates obtaining an accurate diagnosis or assessment. For example, a recent review of 127 studies by Popova, Lange, and Shield et al. (2016), found 428 comorbid conditions co-occurring with individuals with FASD. Amongst some of the commonly co-occurring conditions were attention deficit hyperactivity disorder (ADHD), autism spectrum disorder (ASD), conduct disorder (CD), attachment disorders and sensory integration disorder (SID). ADHD is the most commonly occurring comorbid disorder with FASD (Rasmussen et al., 2010), yet Peadon and Elliot (2010) argue that current research has yet to clearly define the relationship between FASD and ADHD. Similarly, children with FASD are often underdiagnosed with FASD, or misdiagnosed with ASD, ADHD, social and emotional disorders, conduct disorder, and obsessive-compulsive disorder (Boyes et al., 2016; Carpenter et al., 2013; Edmonds & Crichton, 2008; Ryan & Ferguson,

2006b). The facial anomalies seen in some cases of FASD mean that some children can be misdiagnosed with genetic conditions like Williams Syndrome, Noonan Syndrome and de Lange Syndrome, yet prevalence rates for FASD are estimated to be five to 10 times higher than these disorders (Warren & Stein, 2011). Olsen et al. (2007) argue that an accurate diagnosis of a child with FASD is critical in accessing appropriate interventions.

The difficulty in getting an accurate diagnosis was highlighted by Chasnoff, Wells, and King (2015). This study identified high rates of missed diagnosis and misdiagnosis of FASD in children who were in foster care or adopted in Illinois, America. Of 547 children who had been referred for diagnosis, 156 children and adolescents met the criteria for a diagnosis within the fetal alcohol spectrum. Of the 156 children, 125 (80.1%) had never received a diagnosis of FASD. Thirty-five children had been recognised as having PAE, but of those children, 10 diagnoses were changed within the spectrum indicating they had been misdiagnosed. This study underscores the difficulty of getting an appropriate FASD diagnosis and raises questions regarding the impact of misdiagnosis on the type of support and interventions that children with FASD will receive.

Other studies highlight how misdiagnosis of FASD can lead to inappropriate interventions that add to the burden of the disorder. For example, interventions utilised in ADHD management have been found to be unsuccessful when applied to children with FASD due to underlying differences in information processing between the two groups (Coles, 2011; Westrup, 2013). These underlying differences were highlighted by Malisza et al. (2012) who carried out functional magnetic

resonance imaging (fMRI) of working memory of 63 children, aged 10 to 14, diagnosed with alcohol related neurocognitive deficits (ARND) and ADHD, along with a control group of typically developing children. The researchers found that the children with ARND demonstrated increases in frontal and parietal activity that was significantly higher compared to the other two groups. This elevated activity was linked with decreased accuracy and increased response time variability. Malisza and colleagues suggested that the participants with ARND needed to exert more effort than the other groups to manage short-term memory load, indicating the cognitive activity behind the behaviour is different between children with ARND and ADHD. In another study, Frankel, Paley, Marquardt, and O'Connor (2006) explored the different nature of FASD and ADHD. A friendship training programme was implemented with 77 children, aged 5 to 12 years, diagnosed with FASD. The children were in four subgroups who were prescribed either stimulant or neuroleptic medication, both types of medication and no medication. Parent and teacher reported social outcomes of the four subgroups were then compared. Results indicated that the children who received stimulant medication (commonly used in the treatment of ADHD (Conrad & Bergey, 2014)) showed no improvement or poorer results than children not receiving the stimulant medication. This study underscores the need for accurate diagnosis and appropriate interventions.

However, contrary to the Frankel et al. (2006) findings, a retrospective study by Doig, McLennan, and Gibbard (2008) found that symptoms of ADHD in children with FASD were improved with standard ADHD medication interventions. In Doig et al. (2008), 27 children diagnosed with FASD aged between 5 and 14 years who had been referred for ADHD medication took part in 41 medication trials. Stimulant

medication was found to improve hyperactivity and impulsivity scores, although the researchers found that inattention appeared to be less responsive to ADHD medication. In response, Kodituwakku and Kodituwakku (2011) emphasize that the considerable variability of participant responses to medication found across research findings highlights the heterogenous nature of the group, supporting the call for accurate diagnosis to inform care of children with FASD (Kalberg & Buckley, 2007).

These studies highlight that misdiagnosis can create a barrier to receiving appropriate supports and interventions and point to the lack of understanding around the disorder. The next section will consider the literature regarding professionals and their lack of knowledge about FASD, and how this can impact on teacher practice and educational planning for children with FASD.

2.1.3. Lack of knowledge by professionals.

Many professionals lack awareness of the nature and the impact of the disorder on the child with FASD and their families (Blackburn & Whitehurst, 2010; Paley & O'Conner, 2009). For example, a literature review by Olson, Jirikowic, Kartin, and Astley (2009) found low rates of awareness, understanding, and referral of children with FASD among early intervention providers. A more recent study by Mukherjee, Wray, Curfs, and Hollins (2015) used focus groups to ascertain the level of knowledge of FASD across various professional teams including, paediatrics, midwifery, nursing, social work, and mental health. The researchers found limited awareness of the full spectrum of disorders within FASD suggesting a need for

improved education and awareness among professionals working with individuals with FASD.

In education settings there is considerable evidence that many teachers lack knowledge about both the impact of FASD on the learner, and effective strategies to support them (Carpenter, 2011; Petrenko, 2014a; Poth et al., 2014). For example, in a Canadian study, Pei Job, Poth, O'Brien-Langer, and Tang, (2015) surveyed 77 preservice teachers and found limited awareness of the types of learning issues faced by children with FASD. Of primary school teachers, 55.9% reported only having a basic knowledge of FASD compared to 47.5% of secondary school teachers. Furthermore, only 26.5% of primary school teachers and 25% of secondary school teachers could accurately describe underlying difficulties such as cognitive and learning deficits in FASD. Lack of awareness rates were even higher in a UK study by Blackburn (2009). In this study, 78% of the 161 early years teachers and staff who were surveyed indicated they had low-level knowledge of FASD even though 40% of the participants worked in education facilities with children who displayed FASD symptomology. The respondents also revealed that a lack of knowledge about the disorder would detrimentally impact their ability to provide appropriate educational support. Blackburn (2009) concluded that the current lack of understanding and awareness by educational staff would make planning for children with FASD difficult as the staff did not have the training to support them. Likewise, Pei and colleagues (2015) suggest this lack of awareness means teachers make misinformed assumptions about the impact of FASD.

Another Canadian study by Job et al. (2013) found that 31 teachers who indicated having a degree of expertise in special education and some knowledge of FASD still struggled to translate their knowledge of FASD into clearly articulated and appropriate interventions for these children. Whilst teachers acknowledged the importance of adapting educational programming to meet the child's needs, the participants were 'vague' in their descriptions of what constituted effective strategies and practices for children with FASD. For example, teachers listed general teaching techniques, instead of FASD specific techniques, suggesting teachers may be using inappropriate interventions and strategies that do not address the fundamental needs of the child. These studies highlight the need, not only for improved understanding of the disorder, but also for tools to aid in appropriate assessment and planning for children with FASD.

2.1.4. Assessment.

Whilst diagnosis identifies and labels the disorder, assessment enables the individual needs of the child to be identified and appropriate supports and interventions put in place (Gargiulo & Kilgo, 2014; Kalberg & Buckley, 2007). However, several issues with assessment in FASD are evident. For example, Coles (2011) argues that a lack of understanding about the disorder increases the risk that children with FASD will be evaluated based solely on academic assessments and be mislabelled, misidentified, or overlooked entirely. Boyes et al. (2016) argue that to improve educational outcomes, schools must consider the overall neurocognitive profile of children with FASD and develop an appropriate educational plan to inform teacher practice, and to enable the student to experience success at school. Kalberg and Buckley (2006) also identify issues with assessment practices at schools,

suggesting that many move straight from eligibility evaluations of children with FASD based on a diagnosis to individual education plans (IEPs) without carrying out a full assessment of the child's current capabilities and specific needs in various settings. Kalberg and Buckley (2007) argue that the initial step in developing an educational programme for a child with FASD is to clearly define the child's unique learning profile by evaluating their academic and functional capabilities.

2.1.5. Summary of barriers.

In summary, the literature reveals several barriers that hinder access to, and the development of, suitable educational plans. These studies highlight the importance of accurate diagnosis and assessment, and improved knowledge by professionals around FASD. Further, the research points to the need for developing an individual learning profile to support appropriate educational planning for children with FASD.

2.2. Learning Profile of Children with FASD

Research has consistently underscored the importance of developing a comprehensive learning profile to ensure support is tailored and beneficial to children with FASD (Blackburn et al., 2012; Hall et al., 2010; Job et al., 2013; Pei, Job, Poth, & Atkinson, 2013). For example, in a literature review by Dudley et al. (2015), the authors assert that developing a learning profile specific to the child is critical in educational planning given the heterogenous nature of FASD, a finding supported by international studies. For example, an American study by Petrenko et al. (2014b) mentioned earlier (2.1) found that parents want a greater understanding of their child by all parties involved, citing the need for an individualised, clear,

holistic view of the child to help co-ordinate and support planning. This view was echoed by providers, who stressed the need for everyone to be on the same page.

Similar findings were reported in a Canadian study by Edmonds and Crichton (2008). In this study, a qualitative interpretative methodology was employed to investigate the experiences of six children with FASD, aged between 16 and 20, who participated in an educational programme designed for individuals with FASD. During the study, the researchers found the student's diverse needs became difficult to address. Researchers noted the need for thoughtful planning around the student's unique needs and decided to adjust and individualise the programme to meet these needs. They noted that considering the unique profile of the child led to successful outcomes as defined by learning objectives being met. Edmonds and Crichton (2008) concluded that a crucial first step in creating effective learning programmes for children with FASD is to gather an in-depth profile on their health conditions, past experiences, academic and social skill level, learning needs, interests, and life goals. Although it should be noted that developing such a profile takes time, and additional paperwork required to complete them can be viewed negatively by professionals (Frankl, 2005; Shaddock, 2002).

Similar to the findings of Edmonds and Crichton (2008), a Canadian study by Pei et al. (2013) identified two crucial themes in supporting children with FASD, responsive assessment processes, and the need to focus on the whole child. Interviews were conducted with 60 participants, consisting of teachers, caregivers, and allied professionals, working with children with FASD to examine their experiences of assessment practices. Participants noted information gathering must

be sufficiently comprehensive to encompass the complex needs of children with FASD. The critical need to collate information from multiple sources to improve understanding of the student's capabilities and weaknesses across settings was also identified. Further, a deficit focus was highlighted as an issue with current assessment practice, with a need to provide a more balanced view of the child, including their strengths and capabilities. All participants agreed that including strengths in a profile enhances programming and achievement success.

These studies underscore the importance of developing comprehensive learning profiles to support educational planning for children with FASD and point to the need to involve multiple sources. The next section will look at the critical role parents play in educational planning for children with FASD and the barriers to participation they encounter.

2.3. The Role of Parents and Family in Educational Planning

Research supports the need for parents of children with LSN (including those with FASD) to be involved in the educational planning process (Bredberg, 2011; Nochajski, 2002) as they provide a unique perspective on the child (Mengoni & Oates, 2014), leading to improved assessments (Illum, Bonderup, & Gradel, 2018), enhanced student engagement, improved academic outcomes, and children staying longer in school (Henderson & Mapp, 2002). For example, Ruppert and Gaffney (2011) carried out an instrumental case study of a five-year-old child with significant LSN in America. The 12-member team supporting the child reported parental involvement helped them make better informed decisions during planning meetings. In another study, Yaffe (2015) investigated the effect of parental involvement in

constructing children's IEPs, with 116 parents of children with LSN, and found that parental involvement was positively correlated with mathematic performance.

Contrary to these findings, in a study of 1364 elementary school children, El Nokali, Bachman, and Votruba-Drzal (2010) found no association between parental involvement and improved academic outcomes, although improvements were noted in problem behaviours and social skills. These studies suggest that a number of factors can influence the nature and impact of parental involvement.

Despite the differences in these studies, in New Zealand, parental involvement is considered critical in educational planning. For example, in a review of early intervention services carried out by the Ministry of Education, a key finding was the need for shared responsibility for a child's programme between parents and professionals (Ministry of Education, 2007). More recently, a 2014 report identified improving parent and family involvement as a key priority (Ministry of Education, 2014), and a 2015 report indicated that placing parents and families, along with educators, at the centre of educational decision making would have a positive impact on parent engagement and would allow them to share the wealth of information they have about their child (Ministry of Education, 2015).

Research on FASD also highlights the importance of parental involvement and advocacy. For example, Duquette, Stodel, Fullarton, and Hagglund (2006b) utilised qualitative methods to interview eight Canadian and American high school children with FASD and their parents. They found a key factor in the children's persistence at school was the involvement and advocacy of parents. One parent highlighted the constant need to ensure her daughter's programme was modified to meet her

changing requirements. This study underlined the value of parents acting as advocates. Likewise, a recent Canadian study by Coons, Watson, Schinke, and Yantzi (2016) also found that the role of advocacy by parents was important in educational outcomes. This study explored the experiences of 84 parents/caregivers of children with FASD and found that they took on the role of advocates for their children, educating others on the disorder, to ensure appropriate educational support and resources were received. However, Ryan and Ferguson (2006b) found issues with the role of parent advocacy in a qualitative study that investigated the experiences of families and professionals supporting five Alaskan children with FASD. The researchers found parents reported high levels of frustration at having to educate teachers and school staff about the effect of FASD on their child's learning at the start of each year.

Whilst parental involvement is considered vital in supporting children with FASD (Cleversey, Brown, & Kapasi, 2017), there are several factors that can hinder their involvement. For example, Brown and Bednar (2004) used concept mapping to gather 19 Canadian parents' experiences of raising a child with FASD. Parents responses indicated a lack of collaboration and a lack of being heard by professionals regarding their children were considerable challenges encountered. These findings reflect studies of parents' experiences of children with LSN. For example, Blackwell and Rossetti (2014) found family members often feel they are passive participants in the process. Whilst Fish (2008) found that decision making is largely influenced by educational assessments as opposed to anecdotal information provided by parents. Fish's (2008) findings were supported in a recent American study of parent and teacher perspectives of IEP meetings by Cavendish and Connor (2018) who noted

that parents maintained a passive role during meetings, with one parent noting that when she did speak she felt her input was ignored by other team members.

Yet another American study highlighting the disparity of control in the planning process was conducted by Childre and Chambers (2005) who found professional viewpoints were prioritised over those of the student and family. The researchers employed qualitative methods to gather six American families' (with children with LSN) perceptions of educational planning meetings. Parents reported that their perspectives were not heard or taken seriously, and educational plans did not consider life outside of the school environment. The researchers assert that failure to elicit family input and guidance in planning means the focus remains on school and lacks insight from home and community perspectives. Childre and Chambers (2005) concluded that educational planning that does not include a wider focus will not provide a broad base of goals from which wider skills that will help the student beyond the school environment can be targeted.

Reflecting these overseas findings, a New Zealand study by Salmon (2008) revealed that parents feel their voices are not heard. In a qualitative study of eight biological mothers of children with FASD, Salmon (2008) utilised purposeful sampling and analysis of open-ended interview data to explore the lived experiences of the woman from middle to high SES in New Zealand. Although the sample was small, Salmon's findings indicated that mothers felt there was a lack of support from the educational system. The mothers all reported that they felt their children had suffered at school due to a lack of understanding by teachers and staff of their child's unique needs, a failure by school staff to listen, and the use of incorrect or poor programmes and

facilities, leading to a disrupted educational experience. One mother noted the failure to teach to her child's educational needs explaining the teacher failed to note that her child's cognitive ability was lower than their chronological age and set schoolwork in keeping with her educational age as opposed to her ability. These findings support the need for parents to be involved in educational planning to ensure suitable programming and interventions are developed.

In summary, parents of children with FASD often feel excluded or not heard in educational planning. These experiences underscore the issues that teams supporting children with FASD can encounter and highlight the need for an inclusive team approach. The next section will consider cross-disciplinary approaches by teams supporting children with FASD.

2.4. Cross-disciplinary Approach

A cross-disciplinary approach is considered vital in supporting children with disabilities (Ritzema, Sladeczek, Ghosh, Karagiannakis, & Manay-Quian, 2014), leading to improved collaborative and responsive problem-solving and encouraging a whole-child approach (Care, 2008). Research also suggests this approach enhances teams' abilities to develop common goals for children and co-ordinate service provision (Fitzmaurice & Richmond, 2017). For example, an American study by Hong and Reynolds-Keefer (2013) used an exploratory methodology to examine professionals working in a transdisciplinary playgroup for children with LSN. Findings from the study indicated the transdisciplinary approach led to an improved ability to co-ordinate services, developed long-term professional relationships

between professionals and families, and enhanced outcomes for the child through a focus on larger team goals.

A cross-disciplinary approach is also regarded as crucial in educational planning and support for children with FASD (Blackburn et al., 2012). However, studies suggest that there is limited cross-disciplinary support for this cohort. For example, Blackburn et al. (2012) argue that one of the most pressing needs is for educators and allied professionals to increase their capacity to act collaboratively to promote the needs of the student with FASD. The need for cross-disciplinary collaboration was also highlighted in the previously mentioned study by Pei et al. (2013) where participants identified active collaboration as essential in establishing the strengths and needs of the student to ensure effective strategies could be planned and implemented. However, a disconnect was reported between the focus on compiling a report, collaborating, and including all relevant parties in the processes. The findings of this study suggest that more work needs to be done to develop cross-disciplinary practice among teams supporting children with FASD. Similarly, Ryan and Ferguson's (2006b) study, previously discussed, also found issues with teams' ability to work in a cross-disciplinary manner. Their research found divergent and incompatible views between educators and diagnostic teams. Teachers reported that they were rarely involved in diagnostic team meetings, and seldom received reports as they went direct to parents. Teachers expressed frustration at the generic nature of report recommendations, with one teacher observing she could not use any of the recommendations because they had not observed the child in the classroom.

In summary, these studies identify the need for co-ordinated, cross-disciplinary services to enhance collaborative teamwork for children with FASD and the barriers that can prevent such practice. The next section will consider the impact of collaborative practice on educational planning for children with FASD, along with barriers to collaboration, and methods to enhance cross-disciplinary collaboration.

2.4.1. Collaboration and educational planning.

A collaborative approach to educational planning for a child with LSN is seen as a key practice, as gathering information from multiple viewpoints enables greater understanding of the diverse and complex nature of the child's needs, provides information on the settings in which the needs occur (Dettmer et al., 2013), and improves goal setting (Malone & Gallagher, 2010). Clark (2000) asserts that successful collaboration involves the team committing to mutual problem solving, and child centred decision making, based on the student's skills and abilities. Further, the team's aim is focused on creating and implementing an educational plan, which will be instructionally meaningful and responsive to both the child's needs and the curriculum.

In New Zealand, The Ministry of Education (2011) asserts that collaboration is at the heart of educational planning for children with LSN and is an important feature of this country's inclusive education approach. In a New Zealand review on the education of children with LSN, Mitchell (2010) concluded that collaboration can create synergy, so that the whole is greater than the sum of the parts, offering individuals the opportunity to learn new methods of dealing with barriers to learning, and increasing the co-ordination of services for children with LSN. Mitchell's (2010)

findings reflect international research that suggests inclusive practice is more likely to occur when there is a collaborative approach (Argyropoulos & Nikolarazi, 2009; Waitoller & Artiles, 2013). Indeed, Odom, Buysse, and Soukakou (2011) contend that successful inclusion of children with LSN relates more to the nature of the collaborative relationship of the team supporting the child than the child's characteristics.

2.4.2. Collaboration and FASD.

A collaborative approach is considered vital in supporting children with FASD (Blackburn et al, 2012). For example, in a qualitative study by Boyes et al. (2016), teachers and school practitioners of children with FASD completed anonymous surveys about their experiences of an interagency collaboration programme. A total of 232 surveys were collected over four years with findings suggesting that the collaborative interagency method led to changes in how children with FASD are managed. Also, the children received more comprehensive and inclusive supports as interagency collaboration raised awareness of the need for thorough assessment to effectively meet the needs of the child. Further, this collaborative approach led to a greater understanding of comorbid symptoms, and how they impact on the child, with teachers reporting they were able to create more effective classroom ecologies. Finally, the study found that working with an interagency team led to greater awareness of a child's FASD profile by teachers, meaning they were more likely to focus on underlying neurocognitive difficulties as opposed to the presenting behavioural issues.

Research also indicates that collaboration may improve the relationship between the caregiver and a child with FASD. For example, in a study using grounded theory, Swart, Hall, McKee, and Ford (2014) explored how 17 Canadian parents and caregivers managed their children with FASD's schooling. Interview, document analysis, and observations were carried out to explore key strategies that parents employed to enhance their child's school experiences. Findings indicated that open communication and collaboration were not only beneficial for the child with FASD but also helped support the wellbeing of the parent/caregivers and benefited the caregiver/child relationship as well.

2.4.3. Barriers to collaboration.

Whilst collaboration is important, several barriers can hinder the collaborative process (Ritzema et al., 2014). These barriers include power relations (Budd, 2014; Choi & Pak, 2007; McDonald, Jayasuriya, & Harris, 2012), parochialism/imperialism (Budd, 2014), trust issues (McDonald et al., 2012), and language and cultural difficulties (Choi & Pak, 2007; Vangen, 2017), which can lead to fragmented care (Ritzema et al., 2014). For example, early research by Buysse, Wesley and Keyes (1998) highlighted issues with power relations and found parents had limited opportunity to be involved in educational planning, leading to poor collaboration between parents and professionals. Current research indicates that little has changed. For example, issues with power relations were highlighted in a review of the literature for the New Zealand Ministry of Education. In this review, Mitchell, Morton, and Hornby et al. (2010) found little evidence of interagency collaboration and asserted that schools are in the dominant position from the outset. A recent study by Nilsen (2017) found a lack of co-ordination and co-operation created barriers to

effective collaboration on educational planning. Participants, consisting of educational professionals, reported that without coordinated and cooperative action, team members had operated in parallel to each other leading to separate educational plans being instigated. The authors concluded that a lack of collaborative practice in curriculum planning reduces the child's opportunities, impacting on learning processes and outcomes. These findings support Buysse and colleagues' (1998) earlier claims that a lack of collaboration in educational planning creates a "monumental barrier to service co-ordination" (p. 181) and suggests more needs to be done to improve collaborative educational planning.

Collaboration has been identified as crucial in successful educational planning for children with FASD, however, collaboration is not always achieved (Bredberg, 2011, Blackburn & Whitehurst, 2010). Issues with collaboration in supporting children with FASD include differences in expectations, cultural and social issues (Bredberg, 2011), lack of support between systems (Massotti et al., 2015) and, as previously mentioned, parents' voice being overlooked by professionals (Brown & Bednar, 2004). Indeed, Blackburn et al. (2012) suggest that finding ways for stakeholders to effectively work as a collaborative team around a child with FASD is a pressing problem.

Two Canadian studies have explored the lack of effective collaboration for children with FASD. One qualitative study by Poth et al. (2014) carried out an inductive analysis of 11 focus groups and three interviews to explore the multiple perspective of 60 participants working with children with FASD. The participants comprised 31 teachers, seven administrators, 16 allied professionals, and six caregivers.

Participants identified gaps in services provided for children with FASD and argued for more effective collaboration between different service providers to increase access to appropriate assessments. In the second study, Cleversey et al. (2017) used concept mapping to study the experiences of 16 caregivers of children with FASD. The study found a lack of understanding around cultural issues, and a lack of open and clear communication from schools hindered the relationship between the caregivers and the school.

Similarly, a lack of open communication was found as a barrier to collaboration by Job et al. (2013) with parents feeling they could not bring their concerns to the school as they would be seen to be “making a mountain out of a molehill” and this impacted on their ability to work together as an effective team (p. 49). Further, parents reported that a barrier to effective teamwork was the negative judgements the school held about themselves and their children. Educating staff on the impact of FASD was recommended to develop more candid and collaborative practices.

The studies reviewed in this section have highlighted considerable barriers to cross-disciplinary collaboration in educational planning. In light of research identifying the importance of cross-disciplinary collaboration in successful outcomes for children with FASD, the need for tools that can enhance cross-disciplinary collaboration is evident.

2.4.4. Enhancing cross-disciplinary collaboration.

As discussed, cross-disciplinary collaboration plays a crucial role in successful educational outcomes for children with LSN (Hedegaard-Soerensen, Riis

Jensen, & Børghlum Tofteng, 2018), leading to improved communication, co-ordination, and support from professionals (Bricker, 2000). Likewise, the ability for teams to take a cross-disciplinary approach is considered vital in educational planning for children with FASD (Millians, 2015). Effective cross-disciplinary collaboration occurs where there is shared understanding between multiple stakeholders and they can co-ordinate their actions and behaviours to achieve their common goals and objectives (Bittner & Leimeister, 2014). Without a co-ordinated cross-disciplinary approach, confusion, duplication of roles, and competing interests occur, which place families of children with LSN under undue stress (Chen, Klein, & Minor, 2009).

Research suggests that tools are vital in enhancing cross-disciplinary collaboration. For example, Job et al. (2013), previously mentioned, stressed the need for tools to help integrate the knowledge and understanding of teams supporting children with FASD in meaningful ways to reach a shared understanding and improve collaboration. Whereas, a study by Chen et al. (2009) focused on exploring tools to develop cross-disciplinary collaboration. This study recruited 110 early intervention service providers, supporting children with multiple disabilities, to take part in an online course that focused on enhancing interdisciplinary practice. The course provided information about each profession's roles, responsibilities, and practices, and identified ways service providers could share perspectives and learn from each other. The results indicated participants reported increased knowledge of interdisciplinary practice, improvement in coordinating with other disciplines, and more effective collaboration with families. These studies highlight the importance of

tools that can enhance cross-disciplinary collaboration by encouraging understanding of each team members' different perspectives, and support integrating services.

The next section will review cross-disciplinary support services currently available in New Zealand for children with FASD. Consideration will be given to limitations within these services, which will be discussed in light of international findings on cross-disciplinary educational approaches.

2.5. New Zealand Collaborative Assessment Approach

New Zealand currently has only three teams providing diagnostic services and supports to children with FASD (Rogan & Crawford, 2014). These services resulted from a project undertaken by a cross-disciplinary team who established that a collaborative integrated approach to FASD diagnosis and support was urgently required (Rogan, 2010). One example of this approach is the Hawkes' Bay District Health Board who provides the FASD Developmental Assessment Pathway (DAP). This model employs a cross-disciplinary team, including paediatricians, psychologists, occupational therapists, social workers, and speech language therapists, that assess children with complex behavioural and developmental needs for FASD. A key feature of the programme is its collaborative approach with families, teachers and other allied professionals. Information is gathered by each discipline across multiple settings (including home, school, and clinic) and shared with family, school, and community agencies in a comprehensive report (Rogan & Crawford, 2014).

An evaluation of the DAP service carried out by Parsonage and the Health Promotion Agency (2015) gathered information by interviewing 22 stakeholders, including paediatricians, Resource Teachers: Learning and Behaviour (RTLB), a psychologist, and a parent of a child with FASD, and through documentation review. Findings from the evaluation indicated that the DAP service successfully identified children with FASD, promoted strong relationships between different services and engaged families from lower socio-economic backgrounds as well as many Māori families. Other successful factors identified included cross-disciplinary approach, shared vision and values, and the team approach; all considered essential in the delivery of the successful service model (Adams, 2016; Parsonage & Health Promotion Agency, 2015).

However, a number of issues were identified by the review regarding the provision, implementation, and practicality of the DAP model. For example, this service is currently only provided in Hawke's Bay (although implementation of programmes is planned in other regions), children cannot be assessed until they are eight years, and the waiting list can be long (Parsonage & Health Promotion Agency, 2015). The complexity of the report has also been highlighted as a problem. Parents and schools reported finding it lengthy and hard to understand, resulting in some schools not reading or applying the report. Another issue raised is the disconnect between health and education approaches. Stakeholders reported a mismatch between the diagnoses centred nature of the report and the functional based focus of educational reports (Parsonage & Health Promotion Agency, 2015; Rogan & Crawford, 2014).

The issues found with the DAP framework echo similar concerns with cross-disciplinary approaches already raised previously in this review. For example, Miltenienė and Mauricienė (2010) conducted interviews with 117 teachers in Lithuania who suggested that the separate focus of different professionals may mean the child is not seen as a whole. Further, the study found contradictory statements around how a cross-disciplinary approach is put in practice suggesting a disconnect between services. Similarly, Suc, Bukovec, and Karpljuk (2017) looked at cross-disciplinary teams in inclusive education in Slovenia and found a lack of communication and information sharing, as well as limited implementation of recommendations and a failure to take a holistic approach. Creating a more collaborative approach through training and ongoing support was recommended to enhance cross-disciplinary teamwork. To counter the mismatch and duplication of information between medical and educational fields in the New Zealand DAP model, it was recommended that reports be co-authored by both disciplines (Adams, 2016; Parsonage & Health Promotion Agency, 2015).

The DAP programme and the other studies highlight the importance of a cross-disciplinary diagnostic and assessment framework for children with FASD. They also underscore the need to develop a comprehensive, user-friendly profile for cross-disciplinary teams to utilise in supporting children with FASD. However, the need to resolve the mismatch between medical and health perspectives remains a key area of focus to enhance cross-disciplinary collaboration. The next section will consider the role of perspectives in peoples' conceptions of disability and how this may influence the development of educational plans for children with FASD.

2.6. Perspectives

Understanding individual's perspectives is important in effective collaborative teamwork (Budd, 2016). Individual's perspectives are influenced by multiple sources such as culture, ethnicity, religion, gender, and life experiences (Annan, Bowler, Mentis, & Phillipson, 2008; Banks & McGee, 2013), and provide different explanatory frameworks with which to interpret experiences within the team (Frost & Robinson, 2007). These multiple different lenses can be valuable, enabling teams to deal with complex cases and problems (Yoo & Kanawattanachai, 2001), and are a resource for generating new meaning (Akkerman, 2006). Importantly, how a person views disability will shape how they define disability, apportion causes of disability, and will influence the services and resources they will consider accessing for the disability (Kearney & Pryor, 2004). For example, Annan et al. (2008) note that in education, team members' perspectives influence their views on the cause and location of problems and what they consider suitable solutions. These different frameworks can be a source of tension and can also influence team members' expectations on how well an intervention will work for the child's learning and behavioural needs (Annan et al., 2008). However, these tensions if resolved can lead to creative solutions to the child's needs (Mortier, Hunt, Leroy, van de Putte, & van Hove, 2010).

Whilst different perspectives are important, they can create barriers to effective teamwork hindering shared understanding and learning (Marks, Sabell, Burke, & Zaccaro, 2002). For example, in a study by Carter, Prater, Jackson, and Marchant (2009), six pairs of general classroom teachers and special education teachers were trained in, and then had to use, a collaborative process for curricula planning for

children with LSN. After completing the process together, the participants were interviewed separately. The researchers found that teams who were unsuccessful in resolving differing perspectives on disability during the experiment failed to define and co-operatively address a problem-based task. For example, in one pair, one participant viewed the child's difficulty as being the result of her inability to concentrate and felt the other participant was failing to understand what was going on in the child's brain, whereas the other participant felt the problem was simply the child's unwillingness to focus and learn the desired behaviour. Overall, the researchers concluded that collaborative planning processes are most effective when teams share common philosophies about the education of children with LSN. Findings from this study highlight how individuals can hold different views of disability, which if unresolved can hinder effective collaboration, pointing to the need for tools to integrate these views.

As discussed, the ability to integrate different perspectives on disability is critical in developing appropriate educational planning and intervention goals, and for facilitating cross-disciplinary teamwork. For example, an American study by Mortier, Hunt, Desimpel, and Van Hove (2009) found that educational supports for children with LSN were more easily implemented when participants were able to apply localised knowledge that had been developed from the integrated perspectives of the different team members. However, barriers such as not sharing common philosophies, the inability to communicate ideas, language differences, and facilitator influence can restrict the ability of individuals to discuss and amalgamate different perspectives (Budd, 2014; Carter et al., 2009; Price, 2014).

A study by Marzano et al. (2006) documented the experiences of cross-disciplinary research and pointed to language differences as barriers to the understanding and integration of perspectives. They noted that communication of ideas across disciplines could be daunting for some, particularly regarding technical language, which could impede the successful understanding, and therefore, integration of perspectives. Whereas, Ruppert and Gaffney (2011) conducted a case study of IEP team meetings and found that the facilitator's approach to the meeting could act as a barrier to the integration of perspectives. The researchers highlighted that having the team members engage in turn taking reduced the ability of teams to discuss, and draw on, the different ideas and knowledge from each team member. These studies point to the importance of models that can integrate different perspectives to facilitate collaborative teamwork.

One model that incorporates diverse views on disability is the biopsychosocial framework. This model combines both medical and social perspectives of disability and is seen as a comprehensive way of viewing disability (Peterson, 2005). The biopsychosocial model views disability as the result of interacting mechanisms on several levels including biological, interpersonal, and environmental. Considering a person's environment is considered essential in supporting the individual with a disability (Cameron, 2008; Fava & Sonino, 2008). In an international review of best practice for children with LSN, which looked at how to improve co-ordinated services, Cooper and Jacobs (2011) strongly recommended the biopsychosocial approach. The reviewers state that the approach provides a holistic means to understanding the complexities of children with LSN. Also, the framework acknowledges the equal value of different disciplines, thereby facilitating cross-

disciplinary collaboration. Cooper and Jacobs (2011) concluded that this approach underscores the importance of social welfare, education, and health disciplines working in harmony, combining their knowledge and effort to improve outcomes. However, tools are required that will support teams in drawing on and sharing their different perspectives to support collaborative outcomes (Budd, 2016).

This next section will consider current methods used to classify disability for educational planning. Consideration will be given to the ability of these methods to support and enhance collaborative educational planning.

2.7. Disability Classification Systems for Collaborative Educational Planning

The ability to gather information on a child with LSN from multiple sources is a crucial part of educational planning, therefore tools that can assist in this process are vital. McLaughlin et al. (2017) argue that well-developed tools enable access to services and improve understanding of a child within different environmental contexts.

A scheme currently used in New Zealand, as part of an educational planning process for children with LSN, is the Ongoing Resourcing Scheme (ORS). The framework classifies and categorises children with LSN and provides funding for appropriate educational support for high and very high needs children (Education Review Office, 2005). However, questions were raised regarding the medical or deficit focus of the application (Mitchell, 1999). Further the ability of the scheme to support collaborative educational planning has been questioned. For example, in a review of the scheme, Bartleet (2009) asserts that ORS encourages a negative deficit approach,

places an over reliance on specialists' opinions, and disempowers the voice of parents. Bartleet (2009) concluded a more strengths base approach is necessary, and assessment results should consider the child's needs, interests, and aspirations. This conclusion is supported by Purdue (2009) who argues a deficit approach to disability is common when dealing with children with LSN in education settings, focusing too much on the child and not enough on educational systems that may be restricting the student.

This deficit approach also impacts on students with FASD. For example, Cleversey et al. (2017) notes a deficit approach to resource allocation and support means that children with FASD must compete with other children for resources based on relative educational challenges and ignore the strengths and capacities of the child. The researchers found that caregivers wanted to emphasise their child's strengths, as this was important in promoting participation and positive feelings, but this would diminish their child's challenges resulting in reduced funding and support. As already discussed, a deficit focus by schools for children with FASD has been highlighted as an issue by Pei et al. (2013). Finally, Burke and Ruedel (2008) argue that classification systems can perpetuate negative views leading to lowered teacher and parent expectations. These studies highlight the need for tools that move away from the more traditional deficit-based model to a more strengths-based holistic approach to educational planning. Further, these studies reinforce the need for tools that support collaborative cross-disciplinary approaches.

As previously noted, tools that enable the categorisation and development of a comprehensive profile of a child with FASD are essential (Kalberg & Buckley,

2007). However, developing tools that teams, including teachers and parents, can use to support the construction of learning profiles for FASD can be difficult. For example, a qualitative study of 60 key stakeholders was carried out by Pei et al. (2013) in order to develop a model for assessment for children with FASD. The aim of the model was to move from a simple diagnosis of a child, to assessing all aspects of the child within their environment known as a whole child approach. Pei et al. (2013) found that teachers and parents developing the model found it difficult to comprehend technical aspects of assessment reports, they were often too general, and did not include the strengths of the child or recommendations for improving the child's functioning.

The findings of these studies underscore the need for a tool that can provide a more holistic view of the child, and use a common language easily understood by cross-disciplinary teams to support the development of educational plans for FASD. The next section will consider the previously mentioned International Classification of Functioning, Disability, and Health for Children and Youth (ICF-CY); a tool developed to provide an integrated holistic perspective of a child with a disability, and a framework to support collaborative educational planning.

2.7.1. The ICF-CY.

The ICF-CY (developed from the International Classification of Functioning, Disability, and Health (ICF) framework) provides a multidimensional holistic conceptual framework, which considers the influence of body functions and structures; activities and participation; and environmental factors on the individual to create a profile of the child's functioning, disability, and health across these domains

(Simeonsson, et al., 2014; World Health Organisation, 2007). Although contrary to these claims, Kristensen, Lund, Jones, and Ytterberg (2015) argue that the ICF framework places too much emphasis on health components to the exclusion of other contextual factors, which undermines the holistic approach. Also, Morris (2009) and Reindal (2009) question whether the ICF framework can adequately capture subjective and social dimensions of disability. Pless, Ibragimova, Adolfsson, Björck-Åkesson, and Granlund (2009) argue that acquiring the knowledge needed to understand and apply the ICF-CY takes time. Finally, Thomas (2004) has criticised the model for perpetuating the notion of impairment and disability as a restriction.

Whilst questions have been raised regarding the model, the framework has been found to be effective in a number of settings. Strengths of the ICF-CY include the lifespan approach, which considers that the child's environment and developmental capabilities will change over time (Simeonsson et al., 2003). Furthermore, the common language and terminology makes it suitable to use across disciplines, government sectors (Threats, 2010; WHO, 2007) and by parents (Illum & Gradel, 2017), although Wade and Hellegan (2003) argue that the ICF lacks positive terminology. The ICF-CY is considered a universal tool applicable to all children irrespective of their health or cultural background (WHO, 2007). The tool has been utilised in a number of countries including Taiwan (Hwang et al., 2015), Portugal (de Miranda-Correia, 2010), Kyrgyzstan (Zakirova-Enstrand & Granlund, 2009), England (Norwich, 2016), and Italy (Raggi et al., 2014), although researchers such as Ibragimova, Lillvist, Pless, and Granlund (2007), and Zakirova-Engstrand and Granlund (2009) acknowledge there is limited research on the cultural sensitivity of the model. Moreover, Conti-Becker (2009) and Ytterberg et al. (2015) argue the

ICF-CY does not address contextual factors such as culture. However, in a review of research on the ICF-CY, Björck-Åkesson et al. (2010) concluded that the tool is feasible and useful for establishing a common language and framework to support children with disabilities. These studies suggest the tool may be suitable for providing a holistic profile of the child, which can overcome communication barriers in cross-disciplinary practice.

The focus and approach of the ICF-CY model enables a child's functional ability across domains to be profiled (Simeonsson et al., 2003). The utility of the model has been studied for a wide range of disabilities including communication disorders (Cunningham et al., 2017), visual impairment (Rainey, van Nispen, & van Rens, 2014), speech sound disorder (McLeod, Daniel, & Barr, 2013), cerebral palsy (Schiariti et al., 2014), muscular dystrophy (Bendixen, Senesac, Lott, & Vandenborne, 2015), ASD (Mahdi et al., 2018), and ADHD (Bölte et al., 2014). Although little evidence could be found of the model's use for children with FASD, studies examining the model for ADHD found the broad ICF-CY domains enabled the functional ability and disability in ADHD to be considered across all aspects of life, providing a universally applicable and useful framework (de Schipper et al., 2015), suggesting the model may be useful for categorising functional ability and disability for children with FASD.

Similarly, the use of the ICF-CY framework for children with ASD indicates the model could be effective in capturing the heterogeneous profile of children with FASD. For example, Gan, Tung, Yeh, and Wang (2013) used the ICF-CY as the basis of an ASD assessment questionnaire designed to capture the developmental

diversity of the disorder. The tool was tested on 26 pre-school children with ASD to assess functional ability and data was collected by two physical therapists. The ICF-CY based tool was reviewed by three experts for its validity and was rated as having a moderate-to-high interrater reliability. Further, the tool was found to produce profiles of preschool children with ASD across body functions, activities, and participation domains, suggesting the questionnaire is suitable for use in evaluating a heterogeneous group of children with ASD. Further research with larger sample sizes is required in order to generalise these findings to a wider population.

Another study by Salghetti et al. (2009) also highlighted the usefulness of the ICF-CY in cross-disciplinary teams in a longitudinal follow-up study of a tertiary care referral for paediatric neurorehabilitation in Italy. The study comprised participants who were members of a rehabilitation team who were given the ICF-CY, to use as a team, for rehabilitation programming. The participants completed a questionnaire on their experiences of using the model. Findings revealed the ICF-CY lead to improved team cohesion, improved agreement with families, and increased inter-professional collaboration, suggesting the tool may be useful in supporting cross-disciplinary collaborative teamwork in other settings, such as education. Although Sanches-Ferreira, Silveira-Maia, Alves, and Simeonsson, (2018) argued that a collaborative mechanism needed to already be in place to support teams using the ICF-CY as a collaborative tool.

2.7.2. The ICF-CY and Learning Support Needs.

Research has considered the application of the ICF-CY in supporting education for children with SLN (Maxwell, Alves, & Granlund, 2012). For example,

Simeonsson, Simeonsson, and Hollenweger, (2008) assert that the ICF-CY is a useful framework for analysing education processes and systems. Critics argue, however, that the model requires a more developmental and educational perspective (Hollenweger, 2011a). Also, the lengthy amount of time required to understand and utilise the ICF-CY for educational purposes has been identified by Ellingsen, Karacul, Chen, and Simeonsson (2018) and Sanches-Ferreira, et al. (2018). There is also debate as to whether the participation component adequately reflects the construct (Perenboom & Chorus, 2003).

However, there is also research that supports the benefits of the ICF-CY in special education. For example, Sanches-Ferreira, Silveira-Maia, and Alves (2014) conducted a content analysis of 33 focus groups, composed of 192 educational professionals, to gather their opinions on the ICF-CY in educational settings. Findings from the study revealed the ICF-CY was viewed as helpful in developing a deeper understanding of a child's functioning and needs due to the focus on environmental influences on student participation. Similarly, Snyman, van Zyl, Müller, and Geldenhuys (2016) found the ICF-CY's use of a common language to conceptualise functioning and disability helped foster cross-disciplinary collaboration and enabled all members of the interprofessional team to contribute in order to clarify and interpret the data collected on the student.

Likewise, an Italian study by De Polo, Pradal, Bortolot, Buffoni, and Martinuzzi (2009) also noted the benefit of the ICF-CY in creating a cross-disciplinary approach and a common language. The researchers carried out focus groups with preschool, primary, and secondary school teachers and found using the ICF-CY reduced

barriers to children's access to the education system. The ICF-CY was found to provide a dynamic and complex profile of a child's functioning and to facilitate an understanding of how the environment influences that functioning. Further, it was suggested that a cross-disciplinary team approach to using the framework would greatly enhance the use of a common language. Similarly, earlier research by Florrian et al. (2006), which involved a synthesis of six articles on disability classification found the ICF-CY model offers an appropriate common language for special education. These findings are important, as already discussed in the perspectives section (2.4.), communication and language differences create barriers to the effective integration of perspectives hindering the collaborative development of suitable educational plans (Mortier et al., 2009). Further, Rogers (2002) notes that when incompatible or inconsistent language is used to describe a child with a disability in different settings it can lead to confusion for the child and parents. These studies emphasise the need for disability classification models to "reconcile the language of education with the language of disability" (Hollenweger, 2008, p.122).

Researchers have also applied the ICF-CY to individualised education plans. For example, Castro, Pinto, and Simeonsson (2014) analysed 33 IEPs for young children with ASD using the ICF-CY framework and taxonomy. A key finding was the absence of environmental factors in intervention plans, and very few considered in assessment reports. This suggests that the framework is currently not being used appropriately to inform educational planning, and that training for those using the framework is necessary. Therefore, it is important that future tools include adequate

training to ensure that all relevant components of the framework are being utilised appropriately.

Hollenweger (2011b) asserts that the ICF-CY can help teachers improve assessment practice by providing a framework to organise assessments from multiple disciplines into a coherent fashion. Further, the framework provides teachers with the opportunity to understand the overall functional profile of the child, whilst the common language can encourage teachers to ask relevant questions of specialists and integrate this information into their own understanding of the child. However, despite having the potential to be useful in special education settings, Hollenweger (2010) found that the ICF-CY model, is infrequently used in this regard, indicating further research in this area is warranted.

In summary, the findings from these studies highlight the potential benefit of employing the ICF-CY model in special education settings for children with FASD. The research suggests that the model could support effective educational planning by providing a framework that can facilitate enhanced cross-disciplinary teamwork, a common language to support collaboration between professionals and families, and the ability to create an in-depth profile to enhance understanding of the unique needs of a child with FASD. Importantly, in New Zealand, the New Zealand Child and Youth Profile (NZCYP) has been developed from the ICF-CY model (McLaughlin et al., 2017) suggesting it may provide a framework suitable for children with FASD in this country.

2.7.3. The NZCYP.

The NZCYP is a Toolkit inspired by the ICF-CY model, but updated for New Zealand settings (McLaughlin et al., 2017). The Toolkit was developed to collect information about a child's strengths and limitations; sensory function; participation in home, school, and community settings; and interests and preferences. The aim is to gather information from diverse settings, and multiple perspectives, in order to facilitate cross-disciplinary educational collaboration and planning as outlined in Figure 2 (McLaughlin et al., 2017). A pilot study of the NZCYP was carried out in four educational settings, with professionals supporting students with LSN, to gather their feedback on how the NZCYP was utilised, if it was useful for educational planning, and whether it was socially valid. Feedback from the participants indicated that the NZCYP had been useful for educational planning. For example, broadening their thinking and awareness of the child in different contexts, increasing their understanding of other disciplines, and revealing areas of importance about the student they had not been aware of before. Further, some participants noted the NZCYP would be beneficial for cross-disciplinary collaboration, although none used it in this way, leading McLaughlin et al. (2017) to suggest more research is required to explore why it was not used in this regard, and to include improved training. Areas of concern raised in the pilot of the NZCYP included that not all aspects of the forms were age appropriate, the cultural identity categories were not comprehensive enough, and the multiple forms may hinder meetings with parents. Modifications in light of these findings have been made to the Toolkit.

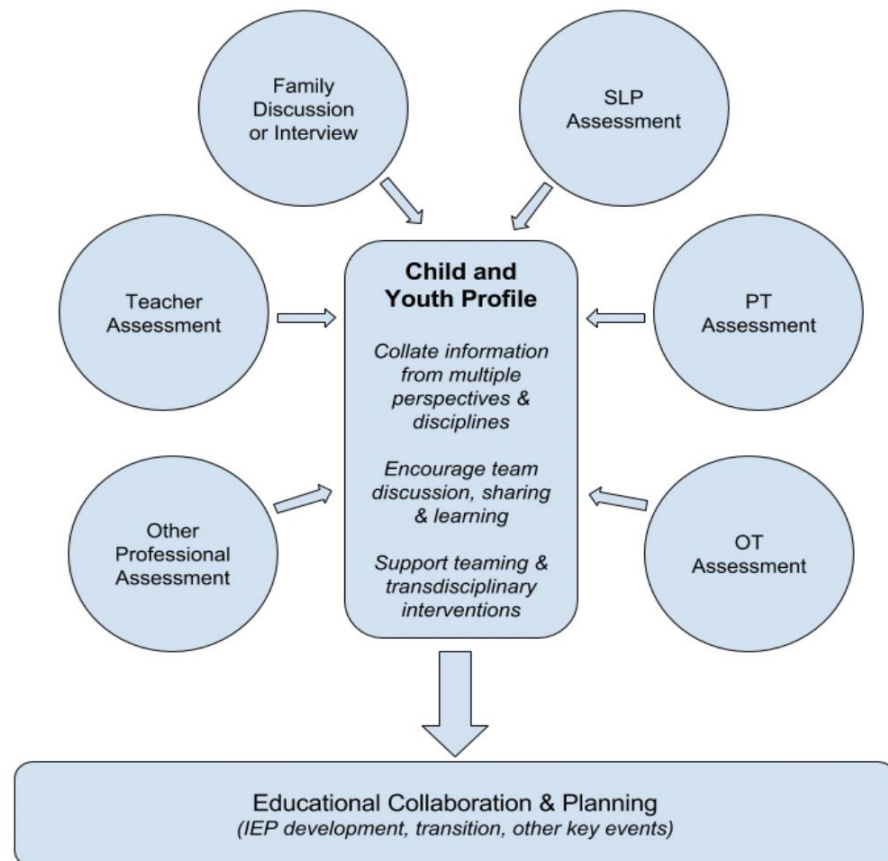


Figure 2. Framework for NZCYP. McLaughlin et al. (2017) used with permission.

In summary, the findings from the pilot of the NZCYP suggest it could provide a useful framework with which to collate key information on children with FASD to help teams with educational planning. Further, the Toolkit may enhance understanding of the unique needs of the student by providing a comprehensive learner profile and a common language. Also, the Toolkit’s ability to increase awareness and understanding of the child and the perspectives of other disciplines indicate it could be useful in integrating diverse views thereby enhancing cross-disciplinary teamwork and collaboration between professionals and families of children with FASD.

2.8. Summary

This literature review has highlighted a number of barriers in supporting students with FASD. Research suggests that current diagnosis and assessment practices for FASD, both internationally and in New Zealand, are inadequate meaning children with FASD may be misdiagnosed or remain undiagnosed. Further, research points to limited knowledge of FASD by medical, education, and allied professionals. The literature also indicates that without appropriate diagnosis or assessment to inform educational practice, many children with FASD will receive little, or inappropriate interventions, which can exacerbate the impact of the disorder. This literature review has also highlighted the need to develop a comprehensive learning profile of the student with FASD to inform educational planning and to involve parents and whānau in the development of educational plans. Research also points to a cross-disciplinary collaborative approach as the most effective means of assessing and supporting children with FASD. This approach allows for a comprehensive profile of the child to be developed utilizing multiple perspectives. However, a number of studies indicate parents and teachers experience barriers to collaborative practice, underscoring the need for tools to integrate perspectives and support cross-disciplinary collaboration.

This review then considered the literature on the ICF-CY as a framework for gathering and collating information on individuals with a wide range of disabilities and in a broad range of settings, including education. The NZCYP model, based on the ICF-CY biopsychosocial framework, offers a New Zealand tool to support the development of a collaborative cross-disciplinary approach to educational planning for children with FASD in this country. As a result, this study will explore what

factors impacted on how the NZCYP was used by teams supporting students with FASD, as well as how the NZCYP was perceived in terms of helping teams to understand the educational profile of a student with FASD, supporting teacher/classroom practice and planning for students with FASD, and supporting collaborative practice for students with FASD. The next chapter will outline the methodology, including research design, data collection methods, procedures, data analysis, positionality and ethical considerations.

Chapter 3: Methodology

This chapter outlines the methodological approach utilized in this research study. Firstly, the research questions are presented and then the rationale for employing a qualitative approach is discussed. Next, the design, participants and environment, training, and data collection are considered. Finally, the researcher's positionality along with cultural and ethical considerations are discussed.

3.1. Research Questions

This aim of this research was to explore educational team members perceptions of the use of the New Zealand Child and Youth Profile (NZCYP) regarding the following research questions:

1. What factors impacted on how the NZCYP was used by teams supporting a student with FASD?
2. How is the NZCYP perceived in terms of helping teams to understand the educational profile of students with FASD?
3. How is the NZCYP perceived in terms of supporting teacher/classroom practice and planning for students with FASD?
4. How is the NZCYP perceived in terms of supporting collaborative practice for students with FASD?

3.2. Research Design

This study utilized a qualitative methodological approach that Patton (2015) considers the most appropriate for conducting an in-depth inquiry into people's thoughts, feelings, and opinions on a topic or issue. As Yegidis and Weinbach (2002) explain "qualitative research designs seek to understand human experience

from the perspective of those who experience them” (p. 17). More specifically, this study is based on a phenomenological paradigm where knowledge is obtained through a close examination and interpretation of individuals’ lived experiences (Savin-Baden & Major, 2013). A phenomenological methodology was adopted for this study as this approach is considered suitable when seeking to gain deeper understanding of common or shared experiences of a phenomena by a group of people (Creswell & Poth, 2018).

The next sections will consider the focus group design of the study. The rationale for using focus group interviews will be outlined.

3.2.1. Focus group interviews.

A focus group design was employed as group discussion was anticipated to be more productive than individual interviews as the participants engaged in the same shared process of educational planning for a child with FASD. This is in line with Creswell and Poths’ (2018) assertion that focus groups can be highly valuable when team members share similarities and act co-operatively towards each other. Focus groups are also a widely used, cost and time effective method of exploring individual perspectives (Brinkmann & Kvale, 2015; Carey & Asbury, 2012). Focus groups support the goal of a phenomenological approach where the aim is to gain an insight into the phenomenon from the perspective of the participants, rather than imposing the viewpoint of the researcher onto the research (Vogt, King, & King, 2004). Focus groups are more than the sum of the individuals, as the interactions between each participant enables a more in-depth discussion on the phenomena than can be generated from individual interviews (Greenbaum, 1998). Finally, the use of

focus groups was employed in order to provide insight into team dynamics and to explore people's responses further (Krueger & Casey, 2015).

Focus groups exploit team interactions to gain insight by gathering multiple viewpoints including their differences and disagreement (Liamputtong, 2011; Wilson, 1997). For example, Stewart, Shamdasani, and Rook (2007) argue that the interaction between participants creates a 'synergistic effect' as team members build on the responses of each other. This team dynamic enables aspects of understanding to be accessed that would otherwise remain untapped using other methods such as questionnaires or individual interviews (Kitzinger, 1995; Kitzinger, 1994). Focus group interviews enable more detail to be gathered on a subject. This enables people's opinions, beliefs, and feelings to be placed in context leading to deeper understanding of the topic (Guichard et al. 2017; Patton, 2015; Ward, Bertrand, & Brown, 1991). Patton (2015) also asserts that focus groups enable diverse perspectives to be highlighted. This is salient for this project given the cross-disciplinary focus of the research and the importance of gaining multiple perspectives about the use of the Toolkit.

3.3. Participants and environment.

This section discusses participant recruitment methods and provides demographic details about them. Finally, consideration will be given to the environment in which the training and focus group interviews were held.

3.3.1. Recruitment.

Purposeful sampling is used in qualitative research to ensure the identification and selection of cases that will provide a rich source of data. Also, individuals can be selected who have a deep understanding of the topic or situation of interest (Creswell & Plano Clark, 2018; Yin, 2016). Purposeful sampling was used in this project as it enabled participants to be selected who had direct knowledge and experience in supporting children with FASD. As such, a homogenous sampling strategy was utilised enabling individuals to be selected based on similar defining characteristics in relation to their role in supporting, educating, and/or caring for a child who has FASD (Krueger & Casey, 2015; Savin-Badin & Major, 2013). However, each participant's individual background varied in terms of their roles and function in the team providing the opportunity to explore diverse perspectives (Kitzinger, 1995).

The participants were two teams of educational professionals, parents/caregivers, and other specialist professionals; each team working to support a child who has FASD. The two children with FASD were identified by a local member of the Tairāwhiti FASD Working Group who heard about the research and passed the researchers information on to the parents. Once the parents contacted the researcher, individual meetings were arranged with each family. As the families identified as Māori, a cultural advisor was enlisted and advised on the importance of considering the whakawhanaungatanga (relationship building) and mihi (introduction) process. This included the whānau selecting the place of meeting and who they wished to attend, initial face to face meeting with a mutually known support person to aid in appropriate introductions and relationship building, and the provision of kai (food)

by the researcher. The families were given a broad overview of the study and gave permission for the schools to be approached to see if they were interested in participating in the study. A Letter of Invitation (see Appendix 1), Information Sheet (Appendix 2), and Parent Consent Form (see Appendix 3) were then sent to request their consent to be participants in the study.

The researcher approached the contact person at each school provided by the parent/caregiver and arranged a meeting with the contact person. For one school (an intermediate school) the contact person forwarded the researcher straight to the Principal and a meeting was arranged with him. The second contact person was the Deputy Principal of a local high school. Both the Principal and the Deputy Principal were provided with a Principal Information Sheet (see Appendix 4), and Principal Consent Form (see Appendix 5) which requested approval for the research to take place in their school. The letter also asked the Principals to share the Information Sheet with their school Special Education Needs Coordinator (SENCO). The SENCO's were then asked to share the Participant Information Sheet (see Appendix 2), with the teams working with a student with FASD. The participants were asked to sign a consent form (see Appendix 6) indicating their willingness to participate in the project and return it to the SENCO. Participants could elect to take part in the training and use of the NZCYP but choose not to take part in the research study.

3.3.2. Participant detail.

There were two settings for this research. Setting A was an intermediate school and Setting B was a high school. Ten participants took part in the research project which comprised of two teams of participants. Setting A's team comprised

one general intermediate teacher, one SENCO, one caregiver, and the mother of the caregiver. Setting B's team comprised one homeroom teacher, one teacher aide, one SENCO, two RTLBs and the caregiver. Team A originally had a member from Child and Adolescent Mental Health Services, but due to unforeseen circumstances the participant had to pull out of the training and did not proceed with the research. One participant, the mother, in Team B pulled out of the research after the training due to personal reasons, whilst one of the RTLB's elected to do the training but declined to take part in the research.

Participants completed a survey to gather demographic information (relation to child, occupation, years of experience in field and other relevant qualifications and experiences) (see Appendix 7). This information was used to determine the level and amount of experience and the different professions that made up the teams. Table 1 details the role/occupation, qualifications and years in role of the participants and indicates, overall, considerable experience of participants in their respective roles.

Table 1. Demographic Information

Role/Occupation	Qualification	Years in Role
Parent/caregiver		
Parent/caregiver		
Grandparent		
Teacher (Team A)	Bachelor of Teaching	3 years
Teacher (Team B)	Diploma Teaching	18 years
SENCO (Team A)	Bachelor of Education, Post Graduate Certificate of Complex Education	1 year SENCO 15 years teaching
SENCO (Team B)	Bachelor of Arts (Hons), Diploma Teaching	23 years
RTLB (Team B)	Bachelor Education	1 Year RTLB 20 years teaching
RTLB (Team B)	Post Graduate Certificate in Learning and Behaviour, Post Graduate certificate Specialist ASD Endorsement	19 years
Teacher Aide (Team B)	-	15 years

3.3.3. Environment.

The environment is an important consideration in running a focus group. Brinkmann and Kvale (2015) recommend providing an environment that allows participants to feel at ease, with minimal disruptions. This encourages individuals to feel comfortable to share personal, contrasting, and conflicting points of views.

The training and focus group interview for Team A took place in the Learning Needs block at the school. The room was private, well-lit and comfortable. Water, and light refreshments were provided. Participants were seated at a round table, as spatial arrangements that allow for participants to easily see each other can help encourage discussion, which Stewart and Shamdasani (2015) belief reduces dominant behaviour. Parents can often feel they have less voice in education meetings (Fish, 2008), so ideally a more neutral site would have been beneficial. However, as the

mother and grandmother were already familiar with the school, and it was convenient and acceptable for everyone to meet at this site, it was considered adequate.

The training for Team B took place in the school's computer suite, whilst the focus group interview took place in a conference room off the library. Both rooms were quiet and well lit. Water and light refreshments were provided. One member of Team B was unable to attend the training with the team, so an alternative day was arranged, and the researcher carried out the training at a place nominated by the participant.

3.4. Training

The next section will give a brief description of the NZCYP. Then pilot training of the NZCYP and participant training will be discussed.

3.4.3. The NZCYP.

The 2018 updated version of the NZCYP was used in this study, comprising of a collection of profiles, questionnaires and planning forms. The NZCYP evaluates a variety of different areas, for example, children's sensory abilities, their communication skills and their interests and preferences. The profile also contains Priority Planning Pages (PPP) to enable the integration of the information gathered from the NZCYP to inform planning and interventions.

3.4.2. Pilot training.

Two pilot training sessions were carried out using Microsoft PowerPoint and a paper copy of the NZCYP (see Appendix 8). The first pilot training consisted of two primary school teachers and the second pilot training consisted of one clinical psychologist. The purpose of the pilot training was to enable the researcher to practice running through the training and to seek feedback on any areas of the training that could be improved. Adjustments to the delivery of the training were made based on this feedback. All parties expressed concern regarding the complex terminology of the NZCYP, in particular the Functional Ability Profile page (FAP), therefore, the researcher simplified the training instructions of the FAP and provided an every-day example. Further, the researcher sought clarification from one of the Toolkit developers around the FAP to ensure updated training was accurate.

3.4.3. Training.

All participants took part in semi-structured training on how to use the NZCYP. Training took approximately one hour. A PowerPoint presentation was provided to the participants supplying background information and an overview of the NZCYP, along with details and requirements of the study. Participants were guided through the Toolkit which consisted of ten forms. At the end of each session, participants were invited to share any thoughts or to ask any questions. The participants were directed to complete the NZCYP individually and then to come together as a team for the purposes of educational planning. The researcher was contactable during this phase of the study to clarify or answer any questions, although none of the participants did.

3.5. Data Collection

The data collection phase was carried out using two separate semi-structured focus group interviews. The rationale for the interview procedure and descriptions of data collection and analysis procedures are discussed next.

3.5.1. Interview guide development.

An interview guide was developed to assist the moderator in facilitating a guided discussion around the research questions (see Appendix 9) and to act as a discussion prompt to ensure conversation focused on the research questions. The interview guide contained several semi-structured questions. Morgan (2012) argues that interview questions can have a powerful effect on the shape of the discussion. Therefore, the development of the content of the questions is an important consideration in focus group design. Merriam and Tisdell (2016) stress the need to provide brief, clear, and easily understood questions that provide participants with a clear understanding of the focus of the research and set the tone for the interview. The opening question plays an important role in establishing this tone. Morgan (2012) maintains the first question should serve as a discussion starter, be easy to answer, and interest the participants in what the other team members have to say. Key questions that follow from the opening question need to be well-crafted to encourage diverse responses (Hennink, 2014). Key questions such as “Please describe your experience of using the Toolkit for team educational planning for your student with FASD” and “how has your understanding of FASD and its impact on a child’s learning and behaviour changed since using the Toolkit?” were then used to generate detailed responses and to probe for further information.

Semi-structured questions were used to keep the focus of the discussion around the research questions but provide flexibility. This flexibility allows participants to build on, and discuss others' responses, and permits the researcher to include questions in response to unexpected comments or issues (Krueger & Casey, 2015; Lodico, Spaulding, & Voegtle, 2010). Semi-structured questions were selected to create a more conversational style of interview, which can help put participants at ease, increasing information sharing and in-depth responses (Patton, 2015). Whilst the semi-structured questions are useful for increasing information sharing, it was important for this study to keep the conversation focused around the use of the NZCYP. Morgan (2012) recommends defining the situation clearly, which gives the moderator more control over the discussion and enables participants to be brought more easily back onto task. For the focus group interviews, the discussion was broken into four sections: opening questions, educational profile, educational planning, and collaboration. Before each section the participants were given a brief statement of the next area to be discussed to focus their attention and conversation on the area of interest. For example, *"Part of my research is to see whether the Toolkit helps improve understanding of a student with FASD's educational profile. I would like us to focus on this aspect now"*.

3.5.2. Procedures.

Participants were invited to join the project as outlined in the recruitment section 3.2.4. Two focus groups were carried out. Team A's focus group meeting was in the same space as their training, whilst Team B's focus group interviews took place in a spacious conference room at the school. Participants were advised that focus group interviews would take between 45-60 minutes. The content and

procedure of the interview, and ground rules were also discussed. During Team A's focus group interview, it was necessary to shift the focus of the questions due to some participants not completing/using the form. Questions were adjusted to explore factors that impacted on their decision not to use/complete the form. For example, "What were the things that stood out for you that you didn't understand?"

On the day of Team B's focus group interview, one participant was unable to attend, however, as he arrived at the conclusion of the interview a semi-structured individual interview was carried out with him then. The questions from the focus group interviews were utilised.

3.5.3. Moderator.

The role of moderator of the focus groups was carried out by the researcher for the purposes of this study. A number of skills are required by moderators when interviewing participants. Merriam and Tisdell (2016) recommend approaching participants in a non-judgemental, sensitive, and respectful manner. Also, the moderator should maintain a neutral approach to the content of participants' responses to ensure that the moderator's personal biases and opinions do not influence the interactions of the team. During the focus group, moderator intrusion was kept to a minimum, limited to seeking clarification, probing for a deeper exploration of an idea, and, where necessary, encouraging conversation when discussion had stalled or redirecting focus back to questions of interest.

During focus group interviews, the moderator needs to ensure that all participants feel included and able to have their say (Stewart & Shamdasani, 2015). With teams,

there is the possibility that one person will dominate, and others will not feel confident in sharing their views (Stewart & Shamdasani, 2015). This was salient in this study, as research suggests that parents of children with LSN struggle to speak up and can feel their voice is either not heard or not taken seriously in educational meetings (Blackwell & Rossetti, 2014; Fish, 2008; Mitchell, et al., 2010).

Therefore, it was important to employ strategies to ensure that all participants felt able to speak and were included in the conversation. Stewart and Shamdasani (2015) recommend ensuring at the outset of the meeting that everyone feels their presence is important and valued. The moderator should encourage all participants to speak, directing questions at reluctant to speak participants, and occasionally asking each member in turn to share their opinion.

To encourage full expression of opinions, at the start of the focus groups, the moderator established a set of ground rules (see Appendix 9). The ground rules encouraged participants to speak up if another team member's opinion did not match their own views and reassured participants that there were no right or wrong answers.

3.5.4. Digital recording and transcription.

Each focus group session was digitally recorded using an Apple i-phone S6. The device was placed in the centre of the table where the team were seated. Immediately after recording the file was emailed to the researchers email address as a precaution in case the recording was accidentally deleted, or the phone was lost or damaged before the file could be downloaded. The audio recordings were transcribed word for word by the researcher. Transcription occurred as soon as practical after the

completion of the focus groups. Minimising the delay in transcribing the data ensures the information remains fresh in the interviewer's mind, providing greater accuracy of transcription (Rubin & Rubin, 2012).

When transcription was undertaken modifications to the data were carried out, including adding in punctuation, including question marks, commas, and full stops. Verbal tics (such as um and ah) were removed. Laughter was indicated by [laughter] and long pauses by [pause]. Where the researcher could not understand/hear participants responses [inaudible] was noted (Creswell & Guetterman, 2019). Māori translations into English were placed in brackets using translations from Te Aka Dictionary (Moorfield, 2011), for example, tipuna [ancestors]. Finally, any data that identified a participant, student, or school, was redacted/changed to maintain confidentiality.

3.6. Data Analysis

The data analysis phase was carried out using both a deductive and inductive approach. The data was coded and then grouped into themes. The rationale and process used for data analysis are provided next.

3.6.1. Data analysis framework.

Data analysis took both a deductive and an inductive approach, which Fereday and Muir-Cochrane (2006) describe as a hybrid approach. Miles, Huberman and Saldana (2014) describe deductive coding as beginning with a 'provisional "start list" of codes' (p.81), which are developed from the initial investigations carried out by the researcher. These codes then guide the initial data analysis process. Inductive

analysis on the other hand is data-driven where a close reading of the data enables the discovery of patterns or themes that emerge from the data (DeCuir-Gunby, Marshall, & McCulloch, 2011). Qualitative data analysis is an iterative or cyclic process, whereby key phrases or themes are identified and coded, revised, modified or expanded upon and new codes/subcodes are added enabling interpreted meaning to be applied to the data (DeCuir-Gunby et al., 2011; Saldaña, 2016).

3.6.2. Data analysis procedure.

Raw data was configured into a single format, printed and saved into a raw data file for each interview. A preliminary exploratory analysis was carried out on the transcribed data for familiarisation of the text. Memos were made in the margin of any first impressions or thoughts, including noting contradictory information. Coding of the data occurred by segmenting text and assigning codes to each segment. A codebook was generated with a definition and an example of each code (see Appendix 10). Once the text had been coded these codes were categorised into organising and global themes that were developed from the data and from the research questions (Braun & Clarke, 2006; Creswell & Guetterman, 2019) (see Appendix 10). For example, the codes, language, clarity and time were grouped under an organising theme complexity. This theme was then placed under a global theme *Factors Impacting on the Completion and Application of NZCYP*.

3.7. Positionality

A researcher's positionality reflects their core beliefs and values about the world. It is important for a researcher to understand and articulate their personal stance in order to acknowledge how these views and beliefs can influence their research

(Savin-Badin & Major, 2013). Acknowledging a personal stance also enables preconceptions that can lead to bias to be investigated. This is done by the researcher taking a self-reflexive approach, continually examining and challenging their beliefs, values, perspective, and biases (Savin-Badin & Major, 2013). Positionality can be acknowledged by locating the researcher in relation to the subject, participants, and the context and process of the research (Savin-Badin & Major, 2013).

I identify as New Zealand Pākehā and Dutch. Whilst I have grown up in a bi-cultural extended whānau environment, placed within a wider bi-cultural community, it was not until adulthood that I began to appreciate the complexity and conflict inherent in New Zealand's history. Through my undergraduate study in psychology and education, I have developed an understanding of the privilege that I am afforded as a Pākehā and of the impact of colonisation on Māori wellbeing. I need to be culturally aware and responsive in my research approach so as not to perpetuate discrimination and marginalisation that can be inherent in mainstream education, health, and research settings (Durie, 1994; Penetito, 2011; Tuhiwai-Smith, 2012).

My four children's individual journeys through the education system, and my work as a teacher aide, have developed my interest in understanding and supporting children with LSN and their families. I believe that every child has the right to an education that meets their social, cultural, and cognitive needs and helps them reach their full potential (UNESCO, 2005), but I am very aware that not all children in New Zealand experience the same level of equality as others. My aim is to help these children, and those who endeavour to support and improve developmental outcomes for them, to find voice to enable their stories and experiences to be heard. This

stance has shaped the focus of my research, influencing the research questions and the methodology I have used.

My stance will influence my analysis and interpretation of the data, which can lead to biases. I sought to reduce this bias in the choice of semi-structured focus groups, which as previously discussed, enables the participants to give voice to their own perceptions and experiences (Liamputtong, 2011). Bias may also be reduced by exploring my stance and clearly identifying and stating my own values, and assumptions, which may enable readers to identify bias as it occurs within my research (Atkins & Wallace, 2012). Savin-Badin and Major (2013) assert that researchers should consider their influence throughout the process of the research. A reflexive journal was kept for the duration of the research project to reflect on my values and biases and how they may be affecting the outcomes of this project (Roller & Lavrakas, 2015). An example from the journal that highlights these reflections is:

“So, in going forward my focus will be on acknowledging the position and perspective that influences my writing. I am a woman of European descent, from a working class upbringing. I have a high level of education and enjoy a “middle class” lifestyle. My culture affords me the privilege of inheriting Eurocentric government, healthcare and education systems that were designed for, and benefit me. I have family and friends who do not enjoy the same privileges as I do. This makes me uncomfortable as it feels wrong that I should benefit through no actions of my own while they do not. I view this as an injustice and strive to keep that knowledge of my own privilege at the forefront when dealing with people who have not experienced

the same privilege. It is easier to judge someone and victim blame if you ignore your own privilege.”

Further excerpts from the journal are provided in Appendix 11.

3.8. Ethical Considerations

Key ethical considerations for this study were identified and analysed with assistance from the researcher’s supervisors. The study was determined to be low-risk and a low-risk ethics notification was submitted to the Massey University Human Ethics Committee and approval was granted from them (See Appendix 12). The key considerations were those of informed consent, confidentiality and privacy, cultural considerations, and reciprocity.

3.8.1. Informed consent.

Informed consent was ensured through participants being provided with a detailed Information Sheet (see Appendix 6) and a Participant Consent Form (see Appendix 7) prior to commencing the research project. Participation was voluntary, and participants were given the opportunity to ask questions and to withdraw from the study at any stage should they have wished to.

3.8.2. Confidentiality and privacy.

Confidentiality in focus groups is difficult and raises unique ethical issues. For example, Tolich (2009) argues that it is difficult to ensure confidentiality as the researcher is limited in ability to restrict the actions of the focus group participants. Tolich (2009) suggests that the researcher can only guarantee external confidentiality, i.e. confidentiality can only be assured in relation to what the

researcher can control, that is, the researcher will not reveal any information that may enable the identification of participants. However, internal confidentiality, relies on the individual participant's willingness not to reveal information shared in the group.

To protect external confidentiality of data on this research project, all names were removed from transcriptions and replaced with pseudonyms. Additionally, the names of the participants and schools involved in the research were not used in written reports about this project. All data collected was secured in a locked cupboard or on password protected computers. At the end of the research, all recordings were deleted.

To promote internal confidentiality, participants were advised on the Information Sheet (see Appendix 6) of limitations to confidentiality and anonymity within the focus group. Expectations of maintaining group confidentiality and the limitations of confidentiality and anonymity were also set out in the Participant Consent Form (see Appendix 7). Expectations and limitations were reiterated at the start of the focus group establishing the need to maintain confidentiality and anonymity of information and participants within the group (Carey & Asbury, 2012).

3.8.3. Cultural considerations.

An important consideration for this study was the need to ensure research was carried out in a respectful, ethical, sympathetic and useful manner with different cultural groups (Tuhiwai-Smith, 2012). The researcher read and considered the Te Ara Tika Guidelines for Māori Research Ethics (Hudson, Milne, Reynolds, Russell,

& Smith, 2010), and aimed to ensure the principles of the Treaty of Waitangi, including the values of partnership, participation, and protection were included in the research approach. Further, a Māori clinical psychologist, with an interest in Māori and indigenous models of health and wellbeing, was consulted during each stage of the research project to ensure the researcher was appropriately considering cultural knowledge and processes.

3.8.4. Reciprocity.

Participants were not reimbursed for their involvement in the study. However, a small gift was provided at the end of the focus group and a summary of the research was provided at the end of the project.

3.9. Summary

This chapter has outlined the methodological design and approach employed to explore individuals' perceptions of the NZCYP. Firstly, the rationale for using a qualitative phenomenology methodology was discussed. Research design was then considered, including an exploration of focus group interviews. Next, participants and environment were discussed, along with training. Data collection methods, procedures, and analysis were outlined, followed by a statement of the researcher's positionality. Finally, ethical considerations, including informed consent, confidentiality and privacy, and cultural considerations were detailed. Results of the data analysis are presented in the following chapter.

Chapter 4: Results

This chapter describes the results from an analysis of focus and individual interview data. Key themes from the interviews are outlined and used to explore how the teams used the NZCYP and their perceptions of it.

4.1. Use of the NZCYP

Qualitative data was used to explore both teams' experiences of using the NZCYP. It was anticipated that all participants would complete the NZCYP, however, the participants in Team A reported several issues with the NZCYP that meant they either did not fill out the forms, or only partially completed them. Two of the four team members (the teacher and the SENCO) did not complete any of the NZCYP, whilst the other two members (the mother and grandmother) reported that they filled out some of the forms together but did not complete all of it. Despite this, the participants reported using the partially completed forms, plus additional information written on the back of two of the pages of the NZCYP during the team planning phase of the research. The participants in Team B who took part in the focus group interview all reported filling out the NZCYP. The results from both teams indicated several factors may have impacted on both the completion and application of the NZCYP. Similar themes from both teams were also identified around understanding the profile of the student, educational planning and collaboration. Table 2 outlines the global and organising themes identified in the data along with codes. Colour coding has been used to highlight the themes and codes evident in both teams' data, as well as the themes and codes unique to either team.

Table 2. Global Themes, Organising Themes and Codes

Global Theme	Organising Theme	Code
Factors Impacting on the Completion and Application of NZCYP	Complexity	Language
		Clarity
		Time
	Relevance and Fit	Fit: Student
		Fit: School
		Fit: Community
		Fit: Culture
	The Focus of the NZCYP	Overly Negative Focus
		Overly Positive Focus
	Knowledge about the Student	Lack of Knowledge about Student
		Transition
	Student Profile	Impact of NZCYP on Understanding the Student's Educational Profile
Impact on understanding of educational profile of other students with FASD.		
Educational Planning	Impact of NZCYP on Teacher/Classroom Planning and Practice	Change in Teacher/Classroom Practice and Planning
Collaboration	Factors Impacting on Collaborative Practice	Generating Discussion and Sharing Information
		Bringing the Team Together
		Framework in Place
		Multiple Perspectives
		Cultural Misalignment

Note: ■ Shared Results ■ Team A only ■ Team B only

4.2. Factors Impacting on the Completion and Application of the NZCYP

A number of factors that impacted on the completion and application of the NZCYP were identified. As noted in Table 2, there were four themes that were revealed from both teams' data: Complexity, Relevance and Fit, the Focus of the NZCYP, and Knowledge about the Student. Whilst these themes were evident in both teams' data there were some differences in their experiences. For example, both teams highlighted the complexity of the NZCYP, and there was agreement that the

language and time taken to complete the NZCYP impacted on the use of it. However, only Team B raised concerns regarding the clarity of the document.

4.2.1. Complexity.

Both teams identified the complexity of the NZCYP as a factor that impacted on their ability to complete and apply it. Indeed, complexity was identified as a major factor affecting Team A's decision to either partially complete the NZCYP, or not complete it at all. The parent from Team A commented "*As a mum I got absolutely overwhelmed the moment I looked at it.*" Whilst the grandmother believed that the NZCYP "*was far too complicated to actually be able to put down or answer some of the questions.*" She suggested that "*the average mum, who hasn't had a lot of life experience [...] will really struggle with this.*" Team A's mother also reported feeling "*overwhelmed*" by the NZCYP, whilst Team A's teacher commented "*I took that form away from here and I felt lost aye.*" The SENCO from Team B also felt the complexity of the NZCYP would deter people from using it, commenting "*We try and make things too complex in education sometimes and you don't get purchase on things that are too complex.*"

4.2.1.1. Language.

Concerns with the complexity of the NZCYP also centred around the use of complicated language. When asked about the terminology of the NZCYP, the SENCO from Team A pointed to the need as teachers to be aware of the "*lingo*" and to not "*spout it out thinking everyone understands*" and suggested that the lingo was "*too much*" and "*too complicated.*" The mother from Team A agreed, stating the language was "*too advanced*" commenting, "*You know aided low aided [...] non*

symbolic communication. Vocalises body movements, gestures, happiness. Well what does that mean?" The mother also felt that the NZCYP was *"jargon-filled and not parent friendly and not teacher friendly."*

The technical language clearly impacted on both teams' understanding of the NZCYP. For example, the mother from Team A commented *"We had to try and figure out what they were meaning in this"* and as a result this hindered their ability to understand it. For example, the mother commented, *"I think [...] some of it was lost in translation. [...] Some of it we didn't understand."* A similar view was reported by Team A's teacher who responded that with *"the lingo and that, I was still a little bit lost within some of the jargon that was written there."* Further, the teacher expressed frustration at the language stating *"I am trying to figure out how to understand it. I just looked through and I thought how's this going to help me help X____? That's all I was looking for."* The concerns about the complexity of the language expressed by Team A were reinforced by the RTLB from Team B who suggested that for schools, the NZCYP needed to be *"in layman's terms"* to improve understanding.

4.2.1.2. Clarity.

Clarity was a factor that impacted Team B's use of the NZCYP. For example, it was clear that the SENCO thought the NZCYP lacked clarity,

"I think it's good for T____ [RTLb] [RTLb: It is. It is] but that's his specialist area. For us we want to be concise and clear and deal with things that are realistic. So, for us...we want it clear. We want it critical three, not 30 colourful pages of bullshit [teacher: where you are not just

confining us to ticking boxes]. You know this was good. And it's a good visual summary and I prefer that, [...]and when you have done a couple too and know where they sit, they would get easier. But I think that we just want clear and concise and something that is manageable and useable and if you are dealing with a kid in high school across a number of staff it would need to be simple clear, critical few rather than 50 colourful pages of bullshit that people aren't going to read to be honest aye.”

Although, of note from this discussion was the notion expressed by the SENCO that practice with the document would improve understanding.

The SENCO from Team B also identified that the lack of clarity with the NZCYP would be an issue for the student as well, for example,

“It's not helpful for the kid either. Because you access all of this stuff. That's great we know where the kid sits. But at the end of the day you've got to transfer that, along with the goal setting and looking at the kid's individual learning needs, to terms that he can understand as well. And in our case, it's a boys' school. You've got to stick that in the form, and he can get some measure on and understand where he is at and where he needs to go. And it's got to be simple. And if it's all simple like a critical few factors then everybody knows where we are, and we work on those this term, and then we work on something else next term.”

Regarding clarity, the teacher from Team B suggested that they wanted information that was straight to the point. For example, *“That's what teachers want to know aye, is just boom, what's wrong with the kid”*, likewise the SENCO from Team B replied, *“yeah they want to know that. They want to know where we are going”*, and further,

“The reality is - concise and clear is better for teachers.” However, when the RTLB from Team B suggested that schools needed things in *“layman’s terms”* the SENCO disagreed arguing, *“Not necessarily layman's terms. It's just the clarity. You have got 30 kids in your classroom [teacher: yeah and you have to read through all those].”*

4.2.1.3. Time.

The complexity of the NZCYP also impacted on the time taken to complete it, with participants from both teams viewing the amount of time required to fill out the NZCYP as a problem. For example, the mother from Team A noted *“It was just overwhelming for me, I don’t have four hours to sit and fill out paperwork like this.”* The same participant also felt that teachers would find the time factor an issue, commenting:

“When I went through the form [pause] as soon as I started going through it, I thought there's not going to be any teacher that, even if they only have 20 to 30 students, they are not going to have the time to fill that out. I'd be surprised if Y___ [teacher] even has time to even go through the first few pages because it was just for us. We're sitting there, we know the kid so well and it was a struggle for us.”

This point of view was supported by the teachers from both teams. The teacher from Team A commented *“The time, time factor too. We're pretty full on here at kura [school].”* Whilst the teacher in Team B commented, *“Someone will have to summarise that, [SENCO: Yeah, just in all honesty that's a hell of a lot of reading]. Yep it was. [RTLB: It was].”* The teacher also said, *“It took me a while to fill this out, with a little bit of discussion between myself and teacher aide. Time was an issue. Factor in that.”* The SENCO from Team B also supported the teachers’ views,

for example, *“You know staff are going, I've got 30 kids in this classroom, I haven't got time for this.”* He also indicated that time was an issue for him, commenting, *“Mine's time. Mine's time. [...] And again, I'm specifically dealing with his behaviour too. So, time and relevance probably.”*

Whilst the RTLB from Team B agreed that time for the teachers was an issue, he also indicated that he felt the schools should persevere with completing the document. For example,

“It was huge. It is really. I mean I would ask the teacher or the school to be very patient cos it's going to take [pause] it's not going to happen over a week or two weeks. It's going to take some time.”

4.2.2. Relevance and fit.

The relevance and fit of the NZCYP was a theme raised in relation to the student, school, community, as well as culture. Both teams mentioned the relevance and fit of the NZCYP for the student as well as the cultural fit. Team B also raised the relevance and fit of the NZCYP for the school and community. The following opening comment from Team B's SENCO captures some of the concerns raised by both teams

“I just think there are a couple of things here. One is the type of kid, so Q_____ is a bit different to a lot of boys with FASD that we see. And also, there are large parts of the form that just aren't that relevant probably in the secondary setting and they are not that relevant to, you know [...] the type of boy. He doesn't have those issues. There were just parts I guess, large parts, that we didn't feel were relevant.”

4.2.2.1. Fit: Student.

The fit of the NZCYP for the student was raised by both teams. It was evident that several participants had concerns regarding the fit of the NZCYP, although some held views contrary to this. Team A indicated that it was difficult to fit the complexity of the student's needs into the NZCYP. For example, the mother commented, *"I suppose because fetal alcohol syndrome is so broad that some of the things are like oh yeah sort of like that. But sort of not like that"*, suggesting the mother felt the NZCYP did not adequately cover features of her son's condition. In explaining the difficulty she was having, the mother commented further:

"Because I sort of thought mmmmm do you know what I don't know how to say it. I sort of felt like I'm sitting there - yes, he can communicate but there's nowhere to explain what I'm going mmmmm about. So, the explanation oh yeah somewhat he understands, but he understands what he is trying to communicate to you. And he will understand if you say go and get your pen, and now I want you to do your maths equation and come back to me. Now you [pause] do you know what I mean? If he is coming back to the base person, he is always going to understand if you are giving him one or two instructions at the most. But again, where do I fill that out?"

Both the mother and the grandmother felt the Toolkit *"boxed"* the student, whilst the SENCO thought the NZCYP did not provide *"the whole picture."* This view was supported by the mother who felt that the NZCYP lost sight of her son and *"it just became about what his problem was or how to not deal with him."*

Like Team A, the SENCO and the teacher of Team B found it difficult to fit the student's situation and needs into the NZCYP because *"he has different issues"*

which were “*off the scale.*” It was clear for both participants that they attributed the poor fit of the NZCYP to, firstly, the inability to record the student’s ongoing behavioural issues and secondly, the focus of the NZCYP on learning needs rather than behavioural needs. For example, “*It is elected behaviour, it’s behaviour, not learning*” and that issues were “*around behaviour and oppositional behaviour and just attitude and behavioural stuff rather [...] than learning needs*”. Both the teacher and SENCO felt that “*there didn’t seem really to be a place to write about or tick those things*”, further the SENCO remarked:

“I think with Q____, it's all about his behaviour. We can't do anything until we get the behaviour right and if we were able to manage that, and that's what this sheet doesn't give us. The sheet expects us to have a pliant student, who is in class 100 percent of the time”,

This suggests that the SENCO did not feel that the NZCYP covered salient aspects of this student’s profile.

The issue of fit was also raised by the *RTL*B from Team B who commented:

“Basically, you have the general outline there that we have when we do our assessments anyway. We cover all that. I think it's got enough there. It's the fit that sort of worries me. When I had a look through, I went mmmmm man you know.”

When asked by the researcher if he meant the fit for this student or for FASD, he replied, “*yeah FASD and the individual student. It's quite comprehensive though.*”

The lack of a behavioural needs focus was raised several times by Team B's SENCO and teacher and appeared to lead to difficulties in completing the NZCYP. For example:

SENCO: "Yeah so none of that is on here and [...] for a guy like this it's not so much the sensory stuff, or not in terms of his learning behaviour, it's how he chooses to react to things and that's something that we have sort of indicated. But these sorts of things aye, and I thought this would be really good, but I really struggled [teacher: yeah, I struggled too] he is able to, he chooses not to."

and again, when the SENCO commented *"He is actually fairly high functioning in terms of the things that are noted in this worksheet. He can do those things [...] but he is choosing not to."*

The inability to fit the student into the NZCYP led to issues for some participants in completing some of the profile pages. For example, when completing the Functional Ability Profile (FAP), the teacher and SENCO from Team B noted that they were scoring him "low" in some areas but felt that this was not an accurate reflection of the student due to his behaviour. Both the SENCO and the teacher felt that this aspect of the NZCYP made it "a hard scale" to complete. Although the SENCO did note *"I reckon that's a good page and a good sheet, but it doesn't work for this kid because he chooses or elects not to."* Also, in relation to the Sensory Modality form, the SENCO commented: *"they are not really relevant to [pause] you know the sensory stuff is neat, but with the type of boy he doesn't have those issues."*

However, contrary to the SENCO and teachers' concerns that the NZCYP did not cover behavioural aspects of the student, The RTLB from Team B, when asked by the researcher if he agreed that the behavioural focus was lacking, disagreed commenting,

"I mean it's very comprehensive and it does cover a lot of ground. I quite like this page here, the functional ability areas. I mean when you are doing a functional assessment of academic behaviour or just behaviour these things all fit in there anyway and that's what I specialise in, is functional assessment. You know – why, where, and how?"

These remarks suggest that he felt that the student's behaviours could be documented in the NZCYP. However, Team B's SENCO disagreed with the RTLB's view and argued,

"That's the bit I thought would be really useful [FAP]. I looked at it initially [...] but when we go through it and think about Q____, this individual and his behaviours, there wasn't anywhere that he actually really fitted on the scale and it was a struggle. So that's more about the individual."

Whilst the SENCO thought the student's behaviour did not fit many of the questions on the FAP, the RTLB from Team B countered that the template could be adjusted by placing *"your own functional abilities, and just insert it in here using that as a guideline – so how does he, or does he? No? Why?"* Although, the RTLB did acknowledge the difficult profile of the student commenting:

"He is a different beast really to the other fulla that I had in the homeroom. He was placid. [teacher: That's what they are usually like aren't they?] Yeah. [...] So, you have got two different views, but Q____ has obviously got that side to him",

suggesting he understood the difficulty the SENCO and teacher were having with the student and the complexity of the FASD profile.

The following discussion, between Team B's SENCO and teacher, again highlights the issues they had in completing some of the profile pages,

SENCO: "We started writing notes on that Interests and Preferences page, but it was just miles off.

Teacher: "I only wrote one note on that."

SENCO: "Really the simple thing is he doesn't fit the scale."

Teacher: "Doesn't fit anything"

SENCO: "Doesn't fit the criteria and even though it says examples are merely suggestive they are so far off, and they are really only focused on that learning."

The poor fit of the Interests and Preferences Profile (IPP) was further discussed by the SENCO and the teacher, from Team B, where they noted that the student's interests and preferences would be to do with "*Gang stuff aye. [...] And you know that's the sphere that he's sort of orbiting aye. So, these [indicating IPP] you know I've got a really happy teenager at home and this fits my girl [Teacher: Books and stories aye.] But it doesn't fit Q_____ [Teacher: No way].*"

4.2.2.2. Fit: School.

The relevance of the document in a secondary school setting was also raised by the SENCO, teacher, and teacher aide from Team B. For example, the SENCO commented: "*There are large parts of the form that just aren't relevant probably in the secondary setting.*" In support of the SENCO's views, the teacher felt that the

NZCYP did not provide questions relevant to high school students, suggesting questions needed to focus on the social aspects of student's lives, for example,

“Well I think you should elaborate a little more on those [pause] like activities and games. What type of activities are you looking at that these students are doing outside of the school times? Are they socialising? So, more the socialising. What are they doing when they socialise?”

Both the teacher and the teacher aide felt that the NZCYP was more appropriate for younger students, primary school or lower. For example, the teacher commented it was “babyish” and the teacher aide noted “*There were some aspects in this, throughout this whole documentation where I thought it was just not relevant for him. Cos, I picked up straight away some of the stuff was at primary level.*” Whilst the SENCO agreed that it was “*a bit bright eyed and bushy tailed*” he disagreed that it was better suited to primary school, commenting, “*I don't think it's even primary, I think it's just, it's not our socio-economy.*”

4.2.2.3. Fit: Community.

The relevance and fit of the NZCYP for the community were raised by some participants in Team B. For example, both the SENCO and the teacher felt that the NZCYP did not adequately reflect the social or economic background of the community, as explained by the SENCO here:

“To be honest, to be quite frank, a lot of the kids with FASD are not in a happy place where unicorns are running around [...]and they are eating candyfloss clouds and things like that. So, I think maybe for the form looking at the background, looking at societal influence,

is probably important. Because you know where you have got that in terms of background and this [indicating form] like that, that's high school musical, and that's not our kids. And it's nice too [the NZCYP]. It's hard, you can't just throw them a form that says which gang members have you been hanging out with?"

Both the teacher and the SENCO felt the NZCYP did not reflect their “socio-economy.” For example, the SENCO commented “Well how many FASD kids are from a white middle class background? And I think you have to look at the balance of that and say no they are not, [teacher: No] and the reality is, that’s not our community.” Whilst the teacher suggested the NZCYP needed to “have better key areas” to capture the student’s background and where they come from.

The idea that the NZCYP did not adequately capture the reality of the students social and economic backgrounds were further raised by the SENCO who noted,

“It's background stuff aye. It's when he is away from his parents. When he is in with his mates. You know food and drink looks like whatever they have managed to steal from the bottle store and smoking dope so that the food and drink sort of stuff. So perhaps naive about the reality for a lot of the kids.”

4.2.2.4. Fit: Culture.

The cultural fit of the NZCYP was raised by members of Team A and by the teacher aide in Team B. Participants raised concerns that the NZCYP lacked a te ao Māori (the Māori world) focus and was, therefore, a poor fit for the student. Both

teams suggested that having this cultural information in the NZCYP would be invaluable in supporting the student.

In Team A, the teacher, along with both the mother and grandmother, mentioned the lack of a cultural component to the NZCYP which “boxed” the student. For example, the teacher remarked:

“So, I looked through the form having looked at X_____ and his background, especially his whakapapa [genealogy], these are the things within te ao Māori, the tools and the taonga [treasures] which our kids just naturally [mother: gravitate] yeah. And so, within this document I couldn't see anything of that nature. Where is the Māori compartment? I just think it's boxing X_____ inside a box.”

This view was echoed by the mother referring to the background information page, *“It's not just English you know, and I know that we can write slash Māori but it's very [grandmother: Boxed]”*, again reinforcing the poor cultural fit of the NZCYP for the student.

In Team B, only the teacher aide voiced concerns around the lack of a Māori cultural component, although, as noted earlier, the fit for the school community was raised by the SENCO and teacher. Initially the teacher aide commented that *“It's a real thorough document... Well all the pages are. There are some that are in here that I thought was missing. I thought that there were some things that weren't covered”*

When asked to elaborate on what was missing, the teacher aide identified a number of cultural aspects, for example,

“What’s missing? The connection with his wider family is missing. It is a cultural component. I kept going through it many times to see if it was in there, but no it was all, do all the planning we can do, but I know outside of all that we have had success with the cultural side of it. Because his family is very staunch in their Māoritanga [Māori culture, practices and beliefs] I know. So, it was lacking.”

Further, the teacher aide observed,

“It's not holistic enough. Wairua [spirituality]. It is missing that. That's what it's missing all right. Because I know for a fact that that works, not just across FASD guys, it works across the board. Yeah for autism and all that.”

When asked what the NZCYP needed in terms of the Māori perspective, the teacher aide suggested the NZCYP needed to look at:

“The spiritual side of things. To cover it in here. It works in the identity yeah. It's all rolled up in that ball. How they are emotionally, physically and everything is rolled into that and whānau [family group] too is rolled into all that because it's them you know”,

suggesting that without a cultural perspective, the NZCYP does not provide a complete profile of the student.

Both the teacher aide from Team B and the mother from Team A pointed to the value of providing Māori cultural information in the NZCYP. For example, the mother from Team A commented,

“This bit [background information sheet] needs to be a couple of pages so that we can share info because there is that connection...there is that Māori connection if we are talking about children and I'm not... I don't

want to stereotype. But we know that it's a lot of Māori children and that could be really an important tool especially from caregivers who don't know it. It would be cool if we could give more information."

This notion was supported by the teacher aide in Team B, for example,

"His whakapapa wasn't flagged right at the start. You know cos normally I try and look for something that they can [pause] you know I look at all their pros and cons, but I try and look at something outside of academic stuff because to try to grab onto [pause] because I know that helps ground them a bit."

It was clear the teacher aide from Team B felt having a Māori component in the NZCYP was important for Māori students, including students with FASD. For example, *"Yes. I would definitely say 'main' Māori, because I am Māori myself and I know that's been successful with other students. With one other guy I had with the same condition we had tremendous success with him."* Here the teacher aide is acknowledging past success with students with FASD when cultural information is utilised, pointing to the importance of including this information to improve the cultural fit of the NZCYP.

The value of including cultural aspects in the NZCYP was further reinforced by the teacher aide who suggested that having information on the student's Māori culture and background would allow him to get *"to the nuts and bolts of what drives him ahead to find that gear that pushes him."* The teacher aide also commented,

"I do a lot of work with these guys. There is something magic that grounds them. It can be a person or a thing [...] and that's just enough"

to just bite in a little bit, to hold them. Because I am looking for what is going to drive them.”

4.2.3. The Focus of the NZCYP.

Both teams engaged in considerable discussion around the focus of the NZCYP. Team A generally felt there was an overly negative focus, although at times this was contradicted by some of the team. Whereas, Team B generally felt the NZCYP had an overly positive focus and did not allow for negative information to be recorded.

4.2.3.1. Overly negative focus.

Team A expressed concern at the overly negative focus of the NZCYP which they felt limited their ability to record positive information about the student. This was particularly evident from the grandmother and mother. For example, the grandmother noted *“This Toolkit focuses on the negatives and not on the positives that are there.”* Whilst the mother commented that the NZCYP *“Only wanted the negatives of what was my son's condition. It didn't want the positives”*, and appeared discouraged by the negative focus stating:

“I found it quite disheartening because I couldn't say the positive things about him [pause] it sort of tended to lean towards how to deal with the negatives of him, but he's not all negative. Some of his behaviours are, but there is some really good if you can get to it.”

Further, the mother remarked:

“We already know that FASD is a negative thing. But I hate talking about that. And I think you'll find any mum doesn't want to tell you all the bad things about their children and that's what I found.”

The mother's view that the NZCYP was overly negative focused was echoed by the SENCO from Team A who commented, *“It blows my mind for education when we are trying to be so strength[s]-based and then we don't start things out like this.”*

The lack of a positive focus was also noted by the SENCO,

“Yeah those little insights that weren't actually in there and I find that you talk to lots of people who fill in things like this and it's the same message everything is so negative. I don't want to know what my child can't do. What my child finds hard”

The mother and grandmother from Team A, who partially completed the form, noted that when they *“couldn't say the positive things about him...we started filling out our own part of the form.”* This was done by writing on the back of the pages where the information was relevant. This information was rated as invaluable by both the SENCO and the teacher from Team A. For example, the SENCO commented:

“When they [the student] come to us to start with they are a piece of paper aren't they. So, having all this information and where you can make those connections and start to build those relationships. Invaluable.” The teacher also viewed the extra information provided by the family as helpful as it *“helps us to align and plan.”*

While the team felt that the NZCYP had a mainly negative focus, they did note more positive aspects. For example, the mother commented *“The interests and preferences page wasn't all negative.”*

Whilst overall the negative focus of the NZCYP was seen as a problem by Team A, at times they contradicted this view. For example, where the mother expressed that *“what we really wanted them to know was what we were up against and the triggers”* suggesting this ‘negative’ information was viewed as important. Also, of note, the triggers which the mother is referring to were on the separate hand-written page. In another example, the SENCO commented, *“Yeah I think like because I barely know X____. Like I think all of this is useful information isn't it?”* Again, suggesting that the negative information had value.

4.2.3.2. Overly positive focus.

Team B suggested that the focus of the NZCYP was overly positive and as a result needed more space to record negative aspects. For example, as noted earlier in 4.2.2.3, the SENCO suggested the NZCYP was *“high school musical”* and that the reality was not *“a happy place where unicorns are running around [...]and they are eating candyfloss clouds”* indicating he found the focus of the NZCYP was too positive. The teacher commented *“I think they needed a little bit more negative stuff on there as well that would have been [SENCO: Yeah, yeah] easier.”* The lack of places to record negative behavioural information was seen as a considerable problem by Team B’s SENCO and teacher. For example, several times during the interview, the SENCO and teacher detailed a number of the student’s behavioural issues and then the SENCO noted: *“you can’t record that anywhere”, “those real negative social aspects aren’t there to record”* and *“he is more extreme than most kids you are going to deal with. There's nothing there that's recordable on this.”* Although this view was contradicted by the RTLB who, when asked about the need for more space for behavioural aspects commented, *“I mean you can add things in*

here like looking at the functional abilities. I mean that's a guideline so what you do is you expand on these things and in your functional assessment process you expand. I found that very helpful."

The lack of places to write negative information was seen by Team B's teacher as providing an incomplete picture of the student, for example, "*unless there was somewhere there for us to write that, you could read that differently than with us ticking those boxes. It's just saying yes he can do that [...] you are only getting a smaller picture.*" The teacher suggested the NZCYP needed to be "*asking a little bit more, elaborating.*" This view was supported by Team B's SENCO who responded, "*I reckon there probably needs to be a separate section for behaviour...for extreme behaviour and that will make it more relevant for Q____. I think we are dealing here with some pretty gentler [sic] FASD students.*"

4.2.4. Knowledge about the Student.

Knowledge about the student was raised by both teams as a factor in completing and applying the NZCYP. For Team A's SENCO and teacher, having limited knowledge about the student was a hindrance in completing the NZCYP. Whilst all of Team A, and the teacher aide in Team B, viewed the ability of the NZCYP to assist in gathering more knowledge about the student as being valuable for transition.

4.2.4.1. Lack of Knowledge about the Student.

Both the SENCO and the teacher in Team A suggested a contributing factor in not completing the NZCYP was their lack of knowledge about the student. Both

felt filling out the NZCYP at the start of the year had no value as they did not yet know the student. For example, the SENCO reported that she felt she was “*plucking information out of thin air*” and therefore, filling out the NZCYP had “*no point whatsoever.*”

4.2.4.2. Transition.

Whilst the SENCO and teacher felt they could not fill out the NZCYP due to a lack of knowledge about the student, all Team A participants agreed that receiving a document, such as the NZCYP, already completed from the previous year’s teacher would be beneficial. For example, “*getting the information a bit earlier, I didn’t start implementing things with X_____ until around week six or seven. And you know that’s six weeks too late*”, was a comment made by Team A’s teacher, suggesting the NZCYP may be valuable for transition.

The idea of using the NZCYP for transition was also raised by Team A’s SENCO who commented that transition was something she felt the school “*could improve upon*” and that the information provided from the parents had been “*invaluable.*” All agreed that starting the document earlier, perhaps “*preschool*” and adding to the document as the child progressed through school would be beneficial. Similarly, the teacher aide from Team B felt that the information provided by the NZCYP would be invaluable in transition settings to help staff get to know the student better. For example, “*Sharing the document before they come to us. Definitely at intermediate level. [Researcher: So that transition?] Yes, transition definitely.*” Further, the teacher aide suggested that receiving transition information from the previous school would be valuable for planning.

“It gives an origin point for you [for] putting a good plan together for him as well. [...] Then we can look at it before they get to us and say shit this is what's worked in the past. This is like this guy here, so we've got generic things that go on with these guys, but when we start watering it down to some real nuts and bolts then boom. That's where this will definitely work in terms of knowledge for the next education provider.”

4.3. Impact on Understanding the Student's Educational Profile

This section will consider the impact of the NZCYP on the participants' understanding of the student's educational profile. Firstly, changes in awareness of the student's educational profile will be discussed, followed by how the NZCYP was perceived for educational planning for other students with FASD.

4.3.1. Change in awareness of student's profile.

Participants in both teams indicated a change in awareness of the student's profile after using the NZCYP. It was evident that Team A's SENCO and teacher, along with other staff members within the learning hub, had developed a greater understanding of the student's profile. For example, the teacher commented:

“So yeah my kind of things that which I put in my head was to ease up because you know like I can be quite hard on these kids. ‘Why aren't you doing your work? Get into it’ type of thing. But actually, when you see, which I see X_____ having those moments... [SENCO: It's not actually his fault aye]. Nah aye you know some kids do tend to do bugger all, piss around, whereas with X_____, I understand that things work differently for him.”

Another example of a change in awareness of the student's profile was expressed in a conversation between Team A's teacher and SENCO where they discussed the impact of FASD on the student's brain:

Teacher: "So like there was this korero [talk] about his mind can be like a block of cheese at times, like it's got holes and stuff in there. So, when you are doing maths in the morning, and he's saying that he can't comprehend, and he can't kind of work it out, when actually for the whole week he's been doing it and he's been mastering it and you know it's gone."

SENCO: "The file aye. It's gone. The files gone."

It was also apparent that changes in awareness had led to improved understanding on how to support the student, for example, the teacher commented:

"What I didn't know was how he can flip out and kind of leave his body and all that kind of thing. And woah that's next level." [...]. My awareness, if that was to occur then I would know alright let's put him into a small space and to sit with him and to let him ride it out and not freak out at him and not march him off to the principal's office."

Whilst the teacher and SENCO from Team A articulated an increased awareness of the student's profile, both indicated they felt they still had limitations in their understanding of FASD after using the NZCYP. For example, when asked if the NZCYP had improved their understanding of FASD, the SENCO commented, *"I'd say it has improved a little bit, but this kind of thing for one student. Like that approach isn't going to work for all students. But invaluable."* Similarly, the teacher noted, *"I wouldn't say about FASD, just X_____ and how he rolls."*

Team B had mixed results regarding the impact of the NZCYP on awareness of the student's educational profile. For example, the SENCO and the teacher both responded respectively, "No" and "No not for Q____" when asked if it helped them understand the student's educational profile. However, the RTLB suggested that the NZCYP would also make identifying and sharing information about the student's profile with teachers easier, which would increase their awareness and understanding, for example,

"It would give us the alternatives and the conditions of where that persons at. Of where the child's at. And it just builds, it makes it a little bit easier to actually say to teachers (share with teachers, I should say) that hey look, this is what's happening are you aware of these things? And often very often, more often they aren't really they don't have the faintest idea. But once they see something [...], once they see sharing this with teachers there would be a better understanding of where that child was coming from and what they could do. The possibilities, but there are also the restrictions of what anybody can do."

The teacher aide also found using the NZCYP to compare the student's profile with another student with FASD helpful in improving his understanding of the student, for example,

"When I compared this with the other guy that I had, there were definitely difference[s]. Yep there were definitely differences. [...] So, it was about getting those [pause] these building blocks in place. These very simple basic things and this document here was perfect for that"

It was also evident that the teacher aide felt the NZCYP was helpful in supporting a broad understanding of the student's educational profile. For example,

“When I looked at his communication profile and looked at his educational history and then when all the others fell in behind that, I could really see the minefield for him. I could see all the landmines just coming up out of the ground. Reading through this and also just looking for any kind of corrective measures more than what we were doing. And it was huge.”

Further, the teacher aide commented,

“It just made me look at some areas where especially when it's profiled from early childhood to now. It gave me a huge scope to see where he had come from plus the other resources I had. It's just comparing everything across the board from when he started school. The education background I was mainly examining, and all these other things were basically add-ons that came into the equation and I was trying to work this guy out. You know when you link all the documents together to form a profile.”

When asked how he had used the profile to build up a picture of the student the teacher aide commented,

“To build it up like a jigsaw. I was putting all the jigsaws together and basically lining all the ducks in a row. Just building that profile first so all these components on every one of these pages scattered out with him in the middle and look at all these supporting documents, educational timeline, strengths and weaknesses, and then link them into, some overlapped, they were very similar, but all contributed. So, it was a huge, a huge shuffle of cards to do just to get a sense of where his, you know his life, and where he has come from”

When asked if it was a useful shuffle of cards, the teacher aide replied, “*yeah, it’s about tomorrow. I was trying to see which plan was working, and where to now from the present with this guy. To put a better plan in place and the right plan in place*”, indicating that the NZCYP had led to improved awareness of the student’s profile and this was valuable in supporting educational planning for the student.

It was also evident that the multiple perspectives had impacted on Team B’s understanding of the student. For example, the SENCO commented:

“So, it takes away the personal. Well you know if you have been abused by the kid it certainly gets [teacher: it’s pretty hard] a bit negative. You know, reality. The reality is that, you know, we are all professionals and we isolate that out and we don’t take it personally. But you know if somebody had abused you in that way it’s pretty hard to see any positives in some. I think the alignment helps us re-centre and that’s what V_____ [teacher] referred to. We had slightly different pictures of where he was at with different things. These guys [teachers] had different pictures to me because I am not responsible for his learning. I don’t look at his learning. So, V_____’s got that, [pause] the capture on that, that I haven’t got. She’s all over that and I guess it’s just alignment.”

Team B also indicated that the different perspectives helped provide a more complete picture of the student. For example, the teacher commented, “*The perspectives were aye? When you are coming in without knowing the child. [SENCO: and I know when he comes in, he’s different for me] than he is for me [SENCO: than he is in his classroom environment].*” These comments suggesting

that the different perspectives provided by the NZCYP helped the team create a more complete and objective view of the student.

The teacher aide from Team B found sharing the different perspectives with some of the student's teachers enabled him to show different sides of the student, thereby broadening their understanding of the student. For example, *I can pour a lot of this stuff into staff and say have a look at it from this angle. Have a look at it from this angle and walk away and have a look at this profile again.*” The teacher aide also commented, *“I shared this with our Te Reo [Māori language] teachers as well because he is taking Te Reo and it opened their eyes as well just to see those different components of him in this format.”*

4.3.2. Impact on understanding of educational profile of other students with FASD.

All of Team B felt the NZCYP could be useful in improving their understanding of the educational profile of other students with FASD. For example, the teacher commented *“I was going to say that that would be useful for other FASD students in my class. Totally different kids.”* In fact, three of the team identified another student with FASD, currently at the school, which the NZCYP would be suitable for. For example, the SENCO remarked,

“If you put W_____ [another student with FASD] into that [teacher: Yeah probably he would meet those criteria] he'd probably fit things and you would be able to work him up and down the scale because he is more learning based I guess [teacher: yeah] learning based needs. He's a lovely boy, and pliant, and socially pretty cool and tries pretty hard. He's got learning needs, so he'd probably be a better guy if we were to

sit down and do this again maybe with him [teacher: Yeah, I would do it on W_____] probably easier. You know if we could choose at the start of the year based on what we have seen out of the sheet W_____ would be the one. Because Q_____ doesn't fit any of this."

The RTLB indicated that the NZCYP had been utilised by other RTLBs who had found it helpful working with students with FASD, for example,

"I have shared this with a couple of the staff and they said it was very helpful, because part of our job, every time we get an individual referral, is that we have to build up a case and this stuff here they see as a very good guideline into actually looking at the conditions of FAS [fetal alcohol syndrome] and then moving on from there. Because part of the process is completing a hypothesis of why and where and what to do and they see it as a very functional document for them in our line of work anyway."

The RTLB further commented,

"I am also in a working party on FASD [which] is very interested in this form and some of the staff have mentioned that they would like to be able to utilise it with students that are suspected of FASD."

These comments suggest the NZCYP was perceived as being useful for other students who have FASD, although they also highlight that it was too focused on learning-based issues and therefore, not helpful in developing a clearer understanding of this student's profile.

Overall, the team appeared to think the NZCYP would be useful for other students with FASD as it had helped them gain a general understanding of FASD, and its

impact on other students. Although at times these views were contradicted by the SENCO when he commented that the NZCYP was not an accurate fit for “*the kinds of kids*” they were dealing with. And, in another example, he appeared to contradict his assertion that the NZCYP helped clarify the team’s understanding of the educational profile of students with FASD,

SENCO: “If you a talking about standardised high end behaviour then that fits but we are talking about a guy here, particularly the boys who are coming in with fetal alcohol into this, we are talking about guys who are learning at level two of the curriculum. They have been eight years in education and that is where they are at you know. So, there are issues, but they are hard to diagnose, and I think they are in the pretty basic primary area.”

Researcher: “So the Toolkit helped clarify for you where they were sitting?”

SENCO: “Yeah where some of those guys are and possibly for Q_____ as well, but we can't see past the behaviour, we can't see past the behaviour and again there were a lot of negative behaviour there like V [teacher] says. If that's standardised secondary, then we are not really talking about that for fetal alcohol kids I wouldn't think.”

Here the SENCO from Team B seems to be implying that the NZCYP would not be suitable for students with FASD. The comments also suggest they may have misunderstood the nature of the NZCYP and viewed it as FASD specific. For example, when the SENCO commented “*It helped us develop our understanding of what other FASD kids are like*”, he was asked to expand on this comment and replied,

“Honestly just reading through and looking [RTL: yeah] at the

developmental issues that other kids are having, particularly the younger kids I suppose, it opened our eyes to that I suppose, but didn't really relate to Q_____ that clearly",

suggesting that he thought the NZCYP was specific to students with FASD.

Another example of this is when the SENCO commented,

"I don't think it has hurt though to go through and have a look at the profile and go ok - you know in terms of informing us about FASD kids what that looks like. What the condition looks like. What we have got in front of us has been good for learning I suppose. [teacher: yeah what an FASD student looks like.] Yeah because we're not experts [teacher: yeah, cos I didn't know]."

The contradictions and assumptions made by participants regarding the usefulness of the NZCYP regarding students with FASD may indicate a general lack of understanding around the disorder, and/or a lack of understanding about the purpose and use of the NZCYP.

4.4. Impact of NZCYP on Teacher/Classroom Planning and Practice

This section will explore the impact of the NZCYP on teacher/classroom planning and practice. Changes in planning and practice by both the participants and other staff members will be discussed.

4.4.1. Changes in teacher/classroom practice and planning.

It was apparent that that the information gained from the NZCYP had impacted on teacher/classroom practice and planning for both teams. For example, the teacher from Team A commented:

“So, another thing is he can't take instructions so being in a classroom with about 120 max [maximum students] we do give out lots of instructions so what I have come up with is just to keep an eye on him and make sure that when we release the kids to go and get on to their task and that is to just check in with him and providing that hey C are you good, yeah I'm good Matua [Uncle] and he's away and if he's not then come over here and we will move forward.”

In another example, it was evident that Team A's teacher had made changes to the student's classroom environment based on information that was shared on the back of one of the pages of the NZCYP. For example,

Mother: “we also put if you put X_____ with a mongrel mob kid he's going to become a mongrel mob kid. If you put X_____ with a higher achiever, he's going to strive to be like that child because he wants to be the same.”

As a result of this information, the teacher reported:

“I have set him up a tuakana teina [older brother, younger brother] which is pretty much the Māori version of a big buddy system. So, there are some year sevens and eights in our class, there's some real cool boys, which you know the younger boys look up to, so I just grabbed one of them and went ‘oye can you buddy up with our man to make sure he is all right’. So, he just checks in with him. So that's going back to what works. It's from this korero, from this page here [indicating handwritten page].”

Team A's results also indicated that other teachers in the student's learning hub had adapted their practice. For example, the grandmother referred to a meeting she had

with one of the teachers in the student's collaborative classroom and the effect a change of awareness had had on the teacher. In this excerpt, the grandmother is relaying the teacher's comments:

"I talked to Matua P_____ [Collaborative teacher] and he said to me 'I gave all the kids instructions for the bombing competition' and he [the teacher] said 'I got really wild at X_____ because he went down the other end of the pool instead of staying and then he said, now I realise I gave him too many instructions. I have to change so that he can get them'. And I thought – that's huge."

However, it appeared the changes in Team A's classroom practice may have resulted from either the handwritten comments and/or the information the mother and grandmother had shared. It is, therefore, unclear whether these changes occurred as a result of using the NZCYP or because of the team's own discussions that resulted from them taking part in the research. For the most part, the team appeared to attribute their increased understanding, and changes in practice, to the extra notes written by the caregivers and the chance to talk as opposed to the NZCYP itself. For example, when questioned whether it was the NZCYP or the talks that were useful the grandmother noted *"the talks were really profitable"*, and the SENCO noted that *"without a doubt the talking"* although she advised the NZCYP was invaluable as *"it started the conversation"* and *"just bringing us together."*

It was apparent from Team B's interview data that the NZCYP had initiated an evaluation of current educational plans and classroom practice. For example, the teacher commented,

“So, they asked the questions at the bottom of what plan have you got in place? This one here. Is the child currently receiving support? So, I looked at the supports that I had in the class because I’ve got the teacher aide [...]. But having a look at what programmes I had, and how they were being used in the class, and how it was being catered for all of the students in the class, whether they had FASD or not. So, it made me look at that. So, it was useful.”

It was also evident that this focus led to changes in planning and practice. For example, the teacher commented, *“Yeah, it made me look at the planning I had. So, I changed a couple of things in the classroom, so they are more visible now based on having gone through those.”* Although the teacher reported that it had not been helpful with educational planning for the individual student stressing *“yeah, but that’s for my whole class”* The SENCO supported this view commenting, *“for the whole class and I think that’s it and we are trying to think a little bit big picture, but if we are talking specifically about Q_____ it hasn’t been that useful.”*

In contrast to the teacher and SENCO in Team B, who did not consider the NZCYP helpful for educational planning for the student, it appeared that the RTLB and teacher aide rated the NZCYP as useful in this regard. Whilst the RTLB agreed that the student’s behaviour was in a *“special bracket”*, when asked if the NZCYP enabled him to record enough information to make recommendations regarding educational planning, the RTLB replied, *“Oh yeah quite easily, if I have made my observations and come to my findings.”* The teacher aide, likewise, felt the NZCYP was useful for educational planning as it enabled him to consider different areas affecting the student. For example, *“Yeah all the information. It’s filtering all this*

out. It's all these different components here overlapping and filtering stuff out here and shifting around and seeing what works in every environment, social, home.”

4.5. Collaboration

Both teams reported effective collaborative teamwork, although a number of participants did not feel that this was due to the NZCYP. There appeared to be several factors that impacted on the team’s ability to work collaboratively, which in turn influenced their perceptions of the NZCYP.

4.5.1. Factors influencing the collaborative process.

This section will outline factors that may have influenced the teams’ collaborative practice. These factors included bringing the team together, generating discussion and sharing information, collaborative frameworks already in place, the impact of multiple perspectives and finally cultural misalignment.

4.5.1.1 Bringing the team together.

Team A unanimously agreed they had worked well as a team; however, they largely attributed this success to the research “*just bringing us together*” and having the opportunity to talk about the student, as opposed to the NZCYP itself. For example, the grandmother commented,

“The talks that we had with the four of us, when we had the one with the four and then we were invited into the classroom to have a talk to the other three teachers it was really profitable.”

The value of the face to face meeting referred to by the grandmother was confirmed by the teacher,

“What I did get out of this process, which was priceless, was the face to face korero. So in between our last hui [meeting] when you came, when we actually had mum and nan come along with our team and sit down and share those things that work well with our man and triggers that kind of to be wary of too.”

This view was also supported by the SENCO who said, *“I guess the benefit for me is listening and learning”* suggesting the opportunity to share information about the student was important. When asked about the usefulness of the NZCYP for collaboration, the SENCO commented *“but then having these discussions is even more beneficial. Face to face is always going to win isn't it?”* indicating that the opportunity to meet with the family and simply talk about the student enhanced collaborative teamwork more than using the NZCYP.

4.5.1.2. Generating discussion and sharing information.

Whilst Team A did not perceive the NZCYP as helpful in collaborative practice, it appeared to have generated discussion and enabled information to be shared which had enhanced the collaborative process. Participants from Team A, all reported a strong sense of team collaboration and a feeling of being *“on the same page.”* Here the NZCYP was attributed by the teacher as supporting collaboration by *“getting us together, and it started the conversation that we need to address this. So, all that stuff came up from having to do it.”* It was evident that the NZCYP generated ideas that the team could discuss, for example, the mother commented, *“Yeah we sort of went through it together and then went through each page and was able to ... [SENCO: pull things out aye”].* The NZCYP also appeared to act as a prompt to include information, for example, the grandmother stated *“I think of one*

thing though. It caused Z_____ [mother] and I to put down what we could and when we got with the teachers and talked about it and I think that way we didn't leave stuff out. We were able to actually share."

The RTLB from Team B expressed that the NZCYP could be useful in team meetings, as a starting point for sharing information, for example,

"Well the RTLB staff that I have shared it with would actually look at it as a way of adjusting things to suit any of their cases. They see what's in here is a good lead into the entry meetings and the observations that basically it covers a lot of ground and they would make use of it by adapting to their own personal needs as far as individual cases go."

4.5.1.3. Collaborative framework already in place.

Team B's participants all felt they already worked well collaboratively. The team attributed this to the current collaborative framework already in place within the school. Both the teacher and SENCO did not feel the NZCYP had added anything extra to this process. For example, the SENCO responded,

"To be honest I've probably been to the room...we are pretty regularly in contact around the room and student anyway. And a good triangle with mum as well. We work hard to communicate, to be honest, with him, and you are dealing with his behaviour anyway. I think we have been pretty efficient in what we [...] how we deal with it, and it hasn't changed that or the behaviours."

It should be noted that the SENCO from Team B elected not to involve the mother in the planning meeting due to “*the current situation*” with the student and not wanting to put her under any more pressure.

The teacher from Team B supported the SENCO’s view that there was already a robust collaborative process in place, commenting, “*Yep, so that was already in place so if I needed some assistance I would text or ring you anyway.*” The teacher aide also indicated that there was a strong collaborative focus commenting “*I have a really good relationship with staff. [...] Everyone is in the communication circle.*” Further, when asked about whether the NZCYP supported collaborative teamwork with the other members of the team, the SENCO commented, “*We have a strong relationship anyway*” which the RTLB confirmed, noting,

“It’s already here because I get feedback from what’s going on after R_____ [newly appointed RTLB to student’s case] comes over to the student support meetings and she is in that role and she feeds back to me. But normally S_____ [SENCO] and V_____ [teacher] will just give me a call anyway and say, ‘hey let’s move on this’ [teacher: yeah if I don’t see him, I get an email or a phone call].”

These comments suggest Team B’s participants did not feel the NZCYP added anything to the collaborative process they already had in place.

4.5.1.4. Multiple perspectives.

It was evident that the opportunity for Team B to consider multiple perspectives generated by the NZCYP had been useful for collaborative practice as it

helped initiate discussion and enhance consensus. For example, Team B's teacher commented,

"The other thing was clarification of some of those as well. So, sort of doing the comparing with another person and saying, 'oh why have you given a plus and whereas I have given a negative?' But then it's our perception of that student."

Further, these discussions had helped the team reach consensus. For example, in this conversation between Team B's SENCO and the researcher,

SENCO: "I think we were fairly well aligned but there were the odd bits here and there where there were differences",

Researcher: "How did you negotiate those different pictures?"

SENCO: "Well we just put them together aye and we just took the middle... You know we found the middle ground."

The ability to provide different perspectives was considered valuable by Team B's RTLB for collaborative teamwork, for example,

"Because I haven't had much to do with Q_____ I had to rely very much on S_____ [SENCO] and V_____ [teacher] on what they have given me and shared with me, but the whole thing fits into the interdisciplinary model and we rely on that very much and this also fits in there so it's the sharing and the backwards and forwards about the information that's coming. I mean I have learnt quite a lot about this young fellow already in this session. Yeah that makes it much easier to understand where this is going."

These comments suggest that the NZCYP supported collaborative practice as it enabled multiple perspectives to be gathered and shared.

4.5.1.5. Cultural misalignment.

A cultural misalignment between the more informal collaborative processes of the Māori focused classroom hub with that of the more structured and formal approach of the NZCYP may have hindered the collaborative process in Team A. This was indicated by the teacher who commented,

“Our language was a[n] oral language not really a written language so when we need to sort things out it wasn't send an email. It wasn't send a message. It was hey come and have a chat. And that way you can't read the wrong way into messages [...]. And sort of read that and 'Oh I am a little bit lost' it is probably best just to have a korero”,

suggesting that he felt the NZCYP unnecessarily complicated the collaborative process.

As already discussed, the results supported the notion that Team A felt that the most successful part of the process in terms of collaboration was the opportunity for face to face discussions. It was also clear that this face to face approach was more culturally aligned with Māori collaborative practices as highlighted by the teacher's comment,

“The other tool that has been really massive in these hui has been the kanohi ke te kanohi [face to face] which is pretty much that face to face dialogue which is another tool which our tīpuna [ancestors] used.”

These results suggest that the formality of the written format of the NZCYP may have conflicted with the more informal Māori collaborative approach of the classroom and that this may have hindered collaborative teamwork. Further, it

appeared that the more informal based face to face approach was considered more valuable.

4.6. Summary

This chapter has outlined the results of focus group and individual interviews from both Teams. Four key themes were identified from the data which impacted on how the NZCYP was used and participants perceptions of it. Firstly, a number of factors were identified that impacted upon the completion and application of the NZCYP. These factors included the complexity of the NZCYP, the relevance and fit, the focus of the NZCYP and knowledge about the student. A second theme identified was the impact of the NZCYP on understanding the student's profile, with a change in awareness around the student's educational profile. A third theme identified was the impact of the NCYP on teacher/classroom practice, with results indicating that the NZCYP had helped facilitate changes in planning and practice in teaching and the classroom. The final theme identified was collaboration and the factors that influenced collaborative practice. The next chapter will discuss the findings of this research.

Chapter 5: Discussion

FASD is a complex heterogenous disorder resulting in atypical learning styles and behavioural challenges that can make educational planning difficult (Blackburn et al., 2012). Research suggests that there is limited awareness of FASD by professionals supporting students with the disorder (Pei et al., 2015). Moreover, current diagnosis and assessment practices are inadequate meaning students with FASD may receive little, or inappropriate, support and interventions exacerbating the impact of the disorder (Coles, 2011; Murawski et al., 2015). There is limited research on how best to support students with FASD (Carpenter, 2011; Mukhurjee, 2015; Streissguth & O'Malley, 2000), in particular educational and instructional assessment and planning (Bohjanen et al., 2009; Brown et al., 2018), which Brown et al. (2018) asserts requires urgent research to find tools to help support students in this regard. A cross-disciplinary approach to educational planning is viewed as the most effective means to both assess and support students with FASD as it allows for a comprehensive profile of the child to be developed utilizing multiple perspectives (Dudley et al., 2015). However, there is limited research on tools which can support the development of cross-disciplinary collaborative educational planning for students with FASD.

The NZCYP is a New Zealand tool, based on the ICF-CY's biopsychosocial framework for gathering and collating information on individuals with disabilities (WHO, 2007), and is considered appropriate for educational settings (McLaughlin et al., 2017). This study sought to explore how two teams working with students with FASD used the NZCYP to support cross-disciplinary collaborative educational planning in regard to four research questions. Firstly, what factors impacted on how

the NZCYP was used by teams supporting a student with FASD? Secondly, how is the NZCYP perceived in terms of helping teams to understand the educational profile of students with FASD? Thirdly, how is the NZCYP perceived in terms of supporting teacher/classroom practice and planning for students with FASD? Finally, how is the NZCYP perceived in terms of supporting collaborative practice for students with FASD?

The results suggested several factors impacted how the participants used the NZCYP and their perceptions of it. These factors have been broadly grouped into key themes including factors that influenced the completion and application of the NZCYP, factors that influenced the participants' ability to understand the student's profile, factors that impacted on educational planning, and finally, factors that impacted on collaborative practice. This chapter will explore these key themes and how they relate to the participants' perceptions of the NZCYP in relation to the research questions.

5.1. Research Question One: What Factors Impacted on How Participants Used the NZCYP for Students with FASD?

Several factors affected the participants' ability and willingness to fully engage with the NZCYP, which hindered it being utilised to its full extent. These included the complexity of the NZCYP, the relevance of the NZCYP, the focus of the NZCYP and a lack of knowledge about the student.

5.1.1. Complexity.

The complexity of the NZCYP was a major issue for both teams and this clearly impacted on their willingness to complete and apply the Toolkit, which in

turn impacted on their perceptions of it. Issues with complexity centred on the complex language and terminology used, lack of clarity, as well as the time required to complete it. This section will consider how the findings surrounding complexity compare with findings from other studies.

5.1.1.1. Language.

The participants from both teams (except for the RTLB in Team B) perceived the language and terminology of the NZCYP as complex and confusing, which impacted on their willingness to complete and use it. This finding is consistent with McLaughlin et al.'s (2017) research on the NZCYP where participants reported feeling overwhelmed by the terms or unsure about the concepts. This finding also corresponds with research suggesting that overly complex, technical or jargon laden documents are a common issue in education (Marzano et al., 2006) and a challenge faced by teams working with students with FASD (Pei et al., 2013; Ryan & Ferguson, 2006b). Further, the findings from this study are in keeping with Rogers (2002) who found that parents can become confused when incompatible or inconsistent language is used to describe disability in different settings.

The findings from this study differ from research that found the ICF-CY, on which the NZCYP is modelled, is suitable for cross-disciplinary teamwork because of the common language and terminology used (Illum & Gradel, 2017; Threats, 2010; WHO, 2007). Only one participant, the RTLB from Team B, found the terminology appropriate for his role. However, he acknowledged that the language was an issue for the rest of his team, suggesting that it was incompatible across home and school settings. This finding is consistent with Rogan and Crawford (2014) who noted that a

disconnect between the language of different disciplines in relation to FASD can be an issue for parents and schools.

The results indicate that the language of the NZCYP led to confusion, impacting on the team's motivation to complete it, which may have influenced their perceptions of it in relation to the other three research questions. New Zealand research suggests that ensuring language is clear and easily understood is vital in supporting students with LSN. For example, Bevan-Brown (2011) asserts that jargon-free and user-friendly communication in education is critical for families and service providers and Macfarlane (2005) states that professionals need to ensure respectful interactions with whānau by, amongst other things, avoiding the use of jargon. The findings from this study reinforce the need for tools that support children with FASD to use language and terminology that is common across disciplines, consistent with family language use, and is accessible and easily understood by all.

5.1.1.2. Clarity.

The SENCO and teacher from Team B indicated that the clarity of the document was an issue. For example, when the SENCO commented, "*for us we want to be concise and clear and deal with things that are realistic. So, for us...we want it clear. We want it critical three, not 30 colourful pages of bullshit.*" The two participants suggested that the lack of clarity was confusing for staff using it and would be difficult to share with students. Further, the SENCO compared the NZCYP to another collaborative framework that the school had in place, which he argued was clearer and more concise. The perception that the NZCYP lacked clarity appeared to be due to the complex terminology, unclear instructions, and the

perceived lengthiness of it. These results correspond to McLaughlin et al.'s (2017) study where participants found that some of the definitions in the NZCYP needed more clarity.

5.1.1.3. Time.

The time taken to complete the NZCYP was also an issue which impacted on both teams' perceptions. This related not only to the complexity of the Toolkit, but the number of forms contained within it. This confirms previous research carried out by the developers of the NZCYP (McLaughlin et al., 2017) who identified that the multiple forms may be a hinderance in meetings with parents and that the time taken to complete them was an issue. It was evident that all of Team A's participants and Team B's teacher and SENCO felt the amount of time required to complete the Toolkit was excessive, which negatively impacted on their perceptions of it. Time is an important factor for teams. Frankl (2005) and Shaddock (2002) found that SENCOs reported being time poor, that paperwork in the role can be excessive, and that additional paperwork is perceived as limiting their ability to carry out their role effectively. The teams' negative perceptions of the amount of paperwork and the time taken to complete the forms also corresponds with research by Ellingsen et al. (2018) who noted that professionals using the ICF-CY identified the lengthy amount of time to learn and use it as challenging.

5.1.1.4. Summary: Complexity

In summary, participants found the complexity of the NZCYP a barrier to using and applying it. The complex language, lack of clarity, and time required to complete the

NZCYP were identified as issues that may have impacted on the team's perceptions of its usefulness.

5.1.2. Relevance and fit.

This section will discuss the participants' perceptions of the relevance and fit of the NZCYP and how this impacted on their ability to complete and use it.

Participants raised concerns regarding the relevance and fit of the document for the student, school, and community as well as the cultural fit of the NZCYP.

5.1.2.1. Fit: Student.

The results indicated that many of the participants felt the NZCYP was a poor fit for their student and failed to capture the reality of the student's situation. Further, both teams maintained there was no space or place to record relevant information. These findings correspond to research by Ryan and Ferguson (2006b) where teachers supporting students with FASD viewed the generic nature of reports for IEP meetings as being of little value for the individual student. The findings are also consistent with McLaughlin et al.'s (2017) findings that participants using the NZCYP wanted to be able to personalise it to suit individual settings as well as strongly recommending increasing the space for notes and comments.

5.1.2.2. Fit: School.

Results from this study indicated that Team B felt the NZCYP was not relevant for a high school setting and was more suitable for younger children. This corresponds with earlier findings by McLaughlin et al. (2017) who found that participants felt that not all the forms of the NZCYP were age appropriate. Although

in McLaughlin et al.'s research, participants felt that the indicators on the Participation and Access Scale were not relevant for early childhood education settings.

5.1.2.3. Fit: Community.

It was evident that Team B's teacher and SENCO felt that the NZCYP was not reflective of their community and did not consider the impact of socio-economic factors such as poverty, gangs, and drugs. It was clear that these participants felt this information was necessary to understand the student's profile. This is similar to concerns raised about the ICF by Wade and Halligan (2003) and Ytterberg et al. (2015) who suggest that too much emphasis is placed on health components whilst contextual factors, such as local culture, are missing from the framework, which limits its ability to provide a comprehensive picture of the individual. The findings from this study also reflect Conti-Becker's (2009) argument that the ICF does not address the influence of more contextual personal factors and the impact of socio-economic factors

5.1.2.4. Cultural fit.

A major finding from this research was the perceived lack of cultural fit of the NZCYP with the student's cultural background. The participants in Team A, and the teacher aide from Team B, identified that the NZCYP lacked a cultural component meaning that Māori cultural information could not be recorded. This finding is concerning as Macfarlane (2005) suggests Māori are failing in mainstream and special education settings because there is a failure to understand and incorporate Māori cultural practices and values in education. Further, Kingi and Bray

(2000) argue that when Māori identity, culture, and views on disability are ignored, this further disables the individual. These studies point to the vital importance of the NZCYP including Māori cultural information to enable a complete picture of the student to be developed to inform educational planning. Although participants from McLaughlin et al.'s (2017) research reported that the cultural identity categories in the NZCYP were not comprehensive enough, the findings from this research indicate a more serious failure of the NZCYP to account for culturally diverse students within the framework. The importance of providing culturally relevant services to Māori with disabilities is highlighted by Ratima et al. (1995) who argue "there is an added onus on providers of services to Māori, that not only shall clients be equipped to participate in mainstream New Zealand society, but they should have the opportunity to participate in Māori society, to belong to Māori institutions, and importantly, remain Māori. The costs of disability are high; they should not include cultural alienation" (p. 48).

It was evident from the results that both teams identified several cultural dimensions that they felt were missing from the NZCYP. These dimensions included genealogy (whakapapa), tribal affiliation (iwi), family (whānau) as well as a spiritual dimension (wairua). The features identified as missing can be seen in several Māori models of health that have a holistic focus and stress the importance of cultural connectedness for wellbeing, such as 'Te Whare Tapa Wha' (Durie, 1994), and 'Te Wheke' (Pere, 1991). Participants from Team A and the teacher aide from Team B viewed the missing cultural information as vital in helping them to make cultural connections with the student. These views are supported by Gilchrist (2017) who identified meaningful connections as an important contributor to the health and wellbeing of

Māori. Furthermore, Wirihana and Smith (2019) found practices that enable the exploration of genealogy aided in the healthy expression of feelings and emotions and finally, Miahere (2015) suggests that strengthening Māori cultural identity connections offers a means to “positively influence attitudes and behaviour” (p. 161).

Participants from both teams indicated that they felt the inclusion of Māori cultural information would have improved the ability of the NZCYP to assist them to understand the educational profile of their student and inform educational planning. The value of including relevant cultural information into planning practice is supported by research that found including Māori content and adherence to tikanga Māori in schools’ special education programmes was ranked as one of the top five culturally appropriate and effective strategies in special education (Massey University, 1999, 2001a, 2001b). Similarly, Gay (2002) argues that in order to effectively teach students of different cultures you need to draw on their cultural experiences, viewpoints, and characteristics. Alton-Lee (2003), Bishop and Berryman (2010), and Ford (2013) assert that being aware of, and utilising, a student’s cultural background are important in supporting the education needs of Māori students. Higgins et al. (2010) found that students reported positive school experiences when an effort was made to consider the whole child, including accommodating the student’s cultural identity as well as their learning support needs. In this current study, the participants felt the NZCYP was a poor cultural fit for the student, suggesting without this cultural component, participants felt they were ‘fitting’ the student to the profile, imposing a set of norms or criteria that did not

meet the needs of the student. This is an issue which Penetito (2011), and Durie (1994) argue is entrenched in New Zealand's education and health systems.

5.1.2.5. Summary: Relevance and fit.

Findings from this research revealed that participants felt the relevance and the fit of the NZCYP was not suitable for the student, the school, and the community. The research also revealed participants felt the NZCYP was a poor cultural fit for their student. These findings suggest that the Toolkit was not flexible enough to accommodate relevant information across these different settings.

5.1.3. Focus of NZCYP.

It was evident from the results that both teams found the focus of the NZCYP a factor that hindered the completion and application of the Toolkit. Issues with focus included an overly negative focus, an overly positive focus, and not providing areas to record important information.

5.1.3.1. Overly negative focus.

Team A perceived the focus of the NZCYP as overly negative. The mother and grandmother felt using the Toolkit was a disheartening experience, whilst the SENCO viewed the deficit approach as contrary to the strength-based focus of education. These findings are similar to parents' responses to completing ORS applications where they felt emphasis was placed on negative aspects of the student and more positive information could not be shared (Bartlett, 2009). These findings also reflect research by Pei et al. (2013) where parents and teachers felt reports on students with FASD were too general and did not include the child's strengths. Team

A's perceptions of the NZCYP also correspond with Wade and Hellegan's (2003) findings that the ICF lacks positive terminology and Reindal (2009) who argues the ICF-CY does not allow for focus on goals and empowerment making it unsuitable for special education purposes. The results from this study are also in keeping with Thomas (2004) and Burke and Ruedel's (2008) criticism that the ICF perpetuates negative views including the notion of disability as a restriction. This is an important consideration as negative views of disability can lead to lowered teacher and parent expectations (Burke & Ruedel, 2008) and negative attitudes towards the student with a disability (Corbett, 2001).

Team A's reported concerns with the negative focus of the NZCYP were at times in contradiction to their own views, where it was apparent that the perceived negative information had been rated as valuable by the SENCO, teacher, and other teaching staff they had shared the information with. It was also clear that the information had led to a change in awareness of the student's educational profile and changes in teacher practice and planning. This supports research by Illum et al. (2018) who suggest that when parents share not only positive information, such as their hopes for their child with a disability, but express their concerns as well, this may support improved co-operation between parties, facilitate ongoing dialogue, and improve assessments. The complexity of the NZCYP may have contributed to the contradictory views of it as many of the forms such as the Participation and Access Profile (PAP), FAP, and the IPP make provision for recording strengths, interests and preferences of the child.

5.1.3.2. *Overly positive focus.*

In contrast to Team A, who felt the focus of the NZCYP was too negative, Team B's SENCO and teacher clearly felt the focus was overly positive given the student, school, and community, and as a result wanted more space to record negative aspects about the student. This view was highlighted by the SENCO commenting that the NZCYP was "*high school musical*" and that they did not have students with FASD who "*are in a happy place where unicorns are running around [...]and they are eating candyfloss clouds.*" Once again, this reinforces findings on the ICF-CY that it fails to account for contextual factors (Conti-Becker, 2009; Wade and Halligan; 2003; Ytterberg et al., 2015). The SENCO and the teacher also indicated the overly positive focus meant there was limited space to record negative information about the student's behavioural issues, leading to perceptions that the NZCYP was "boxing" the student and not providing a complete picture. These findings again reinforce McLaughlin et al.'s (2017) finding that participants wanted more space to provide relevant information about the student as well.

Team B's results also align with the findings from Team A that negatively perceived information can be useful for teams. This is also consistent with research by Kalberg and Buckley (2007) who suggest that a comprehensive awareness of the child's profile enables teams to understand those conditions needed for optimal performance, and those that may disrupt the student's performance, suggesting the value of including both positive and negatively perceived information. The contradictory results from the participants may indicate the NZCYP is too generic and not flexible enough to capture all aspects of the student's profile. Although, once again, the complexity of the Toolkit may have meant participants did not understand

where they could record relevant information. However, another possible explanation for the results is that the two teams held different views of disability that may account for their conflicting perceptions on the focus of the NZCYP.

5.1.3.3. Summary: Focus of the NZCYP.

Findings from this study revealed conflicting opinions on the focus of the NZCYP, with Team A viewing the focus of the NZCYP as far too negative, whilst Team B felt the focus was overly positive for the student's background and did not allow them to record negative aspects of the student's profile.

5.1.4. Lack of knowledge/transition.

The results indicated that the SENCO and teacher from Team A felt that they had insufficient knowledge about the student to fill out the NZCYP and this was one of the reasons why they did not complete it. All of Team A and the teacher aide from Team B suggested that it would be more appropriate to complete the NZCYP before the student transitions to the team next year, or to a new school. Transition was highlighted as an important area for schools with participants from both teams suggesting that providing information for future teams working with the student as invaluable. The SENCO from Team A also reported that schools were currently not effective in transitioning students. These findings are consistent with research by Duquette et al. (2007) who found that parents of students with FASD reported their children had not received transition plans or transition plans were ineffective. The findings from this study also support research by Job et al. (2013) who found school administrators felt there was a lack of transition support for students with FASD coming into new schools.

5.1.4.1. Summary: Lack of knowledge/transition.

The findings from the study indicated Team A's SENCO and teacher did not feel they had enough knowledge about the student to complete the NZCYP and was a reason why they did not fill out the forms. All participants from Team A and the teacher aide from Team B felt the document needed to be completed at the end of the year and used for transition to the next year's class or school.

5.1.5. Summary of findings: Research question one.

The findings from this research indicated a number of factors affected the participants' ability and willingness to fully engage with the NZCYP, which hindered it being utilised to its full extent. These factors also impacted on the participants' perceptions of it, which, were overall, quite negative. The complexity of the NZCYP, including the overly technical language, lack of clarity, and lengthy amount of time required to complete it were considerable barriers to the completion and application of the Toolkit. his finding was consistent with findings of the NZCYP from McLaughlin et al. (2017), and also reflects wider concerns regarding the complexity of educational tools and reports (Ellingsen et al., 2018; Marzano et al., 2006; Rogers, 2002; Pei et al., 2013), which research suggests can impact on professionals' perceptions of their ability to work effectively (Frankl, 2005; Shaddock, 2002).

This research also found perceptions of poor relevance and fit of the NZCYP for the student, school and community, as well as poor cultural fit. This finding was consistent with McLaughlin et al.'s (2017) research where participants indicated there was not enough room to provide relevant information about the student, that it

was not age appropriate for their student, and cultural features were not comprehensive enough in the NZCYP. These findings also correspond with research that LSN reports used to support students with FASD are too generic (Ryan & Ferguson, 2006b), as well as research that found that the ICF-CY does not take into account contextual factors such as gender, race and cultural background (Conti-Becker, 2009; Wade & Halligan, 2003; Ytterberg et al., 2015). The findings from this research regarding the poor cultural fit of the NZCYP are also consistent with a wider lack of culturally responsive frameworks for Māori within New Zealand's education and health systems (Durie, 1994; Kingi & Bray, 2000; Macfarlane, 2005; Penetito, 2011; Ratima et al. 1995) and the vital need to draw on the cultural background of students in order to improve outcomes for them (Gay, 2002; Bishop & Berryman, 2010; Ford, 2013; Gilchrist, 2017; Higgins et al., 2010; Miahare, 2015; Wirihana & Smith, 2019).

The focus of the NZCYP also hindered its use. Findings indicated that Team A found the focus of the NZCYP was overly negative whilst Team B perceived the focus as being too overly positive for the student's background and as a result did not allow for negative information to be recorded. The findings from Team A were consistent with research by Bartlett (2009) and Pei et al. (2013) that found too much focus was placed on the limitations and deficits of students. The findings also support research that suggests the ICF-CY remains deficit focused rather than strengths focused, perpetuating negative views of disability (Burke & Ruedel, 2008; Reindal, 2009; Thomas, 2004; Wade & Hellegan, 2003). Of note, the negative information provided by Team A was utilised by the participants and provided insight into the student, consistent with findings by Illum et al. (2018).

In contrast, Team B's view suggested the NZCYP had an overly positive focus which did not suit their student, and as a result did not provide space to record negative information. These findings again align with findings on the ICF-CY that it fails to account for contextual factors such as local culture (Wade & Halligan, 2003; Ytterberg et al., 2015) as well as McLaughlin et al. (2017) regarding the need for more space to record information, and support Kalberg and Buckley's (2007) assertion that both positive and negative information is required to develop a comprehensive profile of students with FASD.

Whilst a lack of knowledge around the student was also viewed by some participants as a hindrance to completing the NZCYP, many of the participants felt it could be used successfully for transition planning. With Team A suggesting transition planning is currently not done well, corresponding with research by Duquette (2007), but vital in supporting students with LSN in line with Job et al.'s (2013) research on transition planning for FASD.

5.2. Research Question Two: How is the NZCYP Perceived in Terms of Helping Teams to Understand the Educational Profile of Students with FASD?

Some participants from each team reported that the NZCYP had facilitated a change in understanding of the educational profile of the target student. Team B participants felt it had led to an improved understanding of FASD and may be helpful to enhance their understanding of the educational profile of other students with FASD.

5.2.1. Change in awareness of student profile.

FASD is a complex heterogeneous disorder, so understanding the learner's profile is vital for educational planning and improved social and educational

outcomes (Blackburn et al., 2012; Brown et al., 2018). It appeared that the NZCYP had facilitated a change in understanding of the student's educational profile by both teams, although not all participants agreed. The overall findings from this study correspond to research by Mclaughlin et al. (2017) where teams reported that the NZCYP had improved gaps in their understanding of the student. However, whilst it was clear that participants had experienced a change in awareness of the student's profile and of FASD, this was at times in conflict with some of the participants' own perceptions. For example, in Team A, the SENCO articulated a clear change in understanding about the student's educational profile, however, she did not rate the NZCYP as valuable in this regard, *"I'd say it has improved a little bit, but this kind of thing for one student. Like that approach isn't going to work for all students."* Similarly, whilst the teacher reported an improved understanding about the student, he did not believe it had helped him understand FASD, for example, *"I wouldn't say about FASD, just X_____ and how he rolls."* This view reflects issues many educators have in understanding the complex and heterogenous nature of FASD and supports research by Carpenter (2011) that the atypical style of learning and diverse LSN of students with FASD can be challenging for teachers.

Two potential explanations for these contradictory results are that the complexity and time taken to complete the NZCYP influenced the perceptions of the team regarding its usefulness, or that the informal discussions that took place as a result of coming together for the research impacted on the participants' understanding of the student's profile but were not attributed to the NZCYP.

Not all the participants viewed the NZCYP as unhelpful in developing a better understanding of the student's profile. Both the RTLB and the teacher aide from Team B indicated positive perceptions of the Toolkit in this regard. The RTLB felt the NZCYP would make sharing information about a student's profile with teachers and parents easier as it allowed both the possibilities and the restrictions of the child's situation to be clarified. This suggests he believed the Toolkit had provided an in-depth profile of the student, consistent with claims by McLaughlin et al. (2017) that it is an effective tool for developing a multi-dimensional profile. These findings also correspond again to research by Kalberg and Buckley (2007) who argue that considering factors that can support students with FASD's performance along with factors that can disrupt their performance is crucial in supporting students with FASD. The teacher aide viewed the NZCYP as providing an in-depth profile of the student, which he rated as invaluable in supporting the student and making planning decisions. This finding is also similar to findings by Sanches-Ferreira et al. (2014) who found the ICF-CY was perceived as useful in developing a deeper understanding of a student's educational profile and also supports research by Edmonds and Crichton (2008) who found developing an in-depth profile was a critical first step in providing appropriate educational support for students with FASD.

5.2.2 Change in understanding of FASD profile for other students.

All of Team B felt the NZCYP could be useful in improving their understanding of the educational profile of other students with FASD. For example, when the SENCO commented "*It helped us develop our understanding of what other FASD kids are like.*" The results also indicated that Team B felt the Toolkit would be

useful as a tool for educational planning for other students with FASD for example, the RTLB commented, “...*some of the staff have mentioned that they would like to be able to utilise it with students that are suspected of FASD.*” Team B’s belief that the Toolkit would be useful to use with other students with FASD supports Mclaughlin et al.’s (2017) assertion that the NZCYP may be effective in improving team understanding of a student.

5.2.2.1. Misconceptions about FASD.

The participants from Team B reported that the NZCYP had been useful in improving their understanding of other students with FASD. Whilst this is a positive outcome, as research clearly supports the need for teachers and professionals working with students with FASD to be more informed and knowledgeable about the disorder (Boyes et al., 2016; Job et al., 2013; Pei et al., 2015), it did appear that some of the participants may have had misconceptions about FASD. This misunderstanding is seen in comments by the SENCO and teacher that suggested they believed the student was atypical of students with FASD as he appeared to function reasonably well on learning tasks. These views suggest the participants lacked awareness about the heterogenous nature of the disorder as there is considerable variability in intellectual functioning which can range from severe intellectual impairment to high average cognitive capabilities (Chokroborty-Hoque et al., 2014).

Another example of the teams’ apparent misconception was evident in the following conversation between the RTLB and the teacher, “*He is a different beast really to the other fulla that I had in the homeroom. He was placid. [teacher: That’s what*

they are usually like aren't they?] Yeah.” The belief expressed by these participants that students with FASD are usually placid is concerning as research highlights that students with FASD are at increased risk of experiencing behavioural, emotional, and social issues (Mattson et al., 2011; Weyrauch, et al., 2017), moreover, a failure by the participants to understand the characteristics of FASD could place the student at greater risk of receiving inappropriate supports and interventions (Job et al., 2013; Pei et al., 2015).

The findings from this study support studies that found professionals lack knowledge about FASD (Mukherjee et al., 2015; Paley & O’Conner, 2009). As already discussed, the SENCO and teacher in Team B both raised the student’s behaviour as being the most significant issue for the student but did not appear to attribute this to the disorder. These results suggest that whilst Team B perceived the NZCYP as helpful in improving their understanding of FASD in other students, they still appeared to misunderstand the disorder. Once again, these findings reflect the considerable difficulty student’s with FASD face in receiving appropriate educational support.

5.2.2.2. Misunderstanding about the purpose of the NZCYP.

At times the results suggested that some of the participants from Team B had misunderstood the nature and purpose of the NZCYP. In one of the comments made by the SENCO, it appeared that he had misunderstood the FAP example sheet and further had perceived the NZCYP as being a FASD specific framework. For example,

“Honestly just reading through and looking [RTL B: yeah] at the developmental issues that other kids are having, particularly the younger kids I suppose, it opened our eyes to that I suppose, but it didn't really relate to Q_____ that clearly”,

The complexity of the document, and the perceived lack of clarity with the forms, may have contributed to the misunderstanding regarding the use of the NZCYP leading participants to believe it was FASD specific, reinforcing the need for effective training on its nature and use.

5.2.3. Summary of findings: Research question two.

Some participants perceived the NZCYP had been useful in improving their understanding of the educational profile of their student with FASD and would be useful as a tool to use for other students with FASD. This is consistent with findings by McLaughlin et al. (2017) that the Toolkit is effective for developing a student profile to support teams with educational planning. Whilst Team B reported they felt they had an improved understanding of FASD in other students, it appeared they still had little understanding around the nature and symptomology of FASD, a finding consistent with several studies that found professionals lack knowledge about FASD (Job et al., 2013; Mukherjee et al., 2015; Paley & O'Conner., 2009; Pei et al., 2015). Findings also indicated that some participants in Team B thought the NZCYP was FASD specific and that this may have added to confusion about the use of it, as well as impacting on the teams' perceptions of how helpful it was.

5.3. Research Question Three: How is the NZCYP Perceived in Terms of Supporting Teacher/Classroom Practice and Planning for Students with FASD?

The results indicated that both teams reported making changes to their teacher/classroom practice and planning because of using the NZCYP. However, most of the participants perceived the ability of the NZCYP to inform educational practice as limited, or attributed changes in practice and planning to factors, other than the Toolkit.

5.3.1. Changes in teacher/classroom practice and planning for students with FASD.

The results showed that Team A had experienced a change in understanding of the student's profile and that this had led to changes in teacher practice. However, rather than attribute this to the NZCYP participants put it down to the face to face meetings, and the information provided by the family that was separate to the NZCYP. It was clear that the information provided by the family had led to considerable changes in planning and practice, which had been shared with other teachers in the learning hub. For example, the teacher had recognised the need to limit instructions, and to monitor the student once instructions had been given. Further, the student had been set up with an older classmate to support the student and to act as a role model. These findings suggest the anecdotal information provided by the family was invaluable, which is in line with research by Illum et al. (2018) and Ruppert and Gaffney (2011) that information shared by parents is useful in informing educational planning and leads to improved outcomes (Yaffe, 2015). These findings also suggest more space is needed for information to be recorded, corresponding with McLaughlin et al. (2017) whose participants indicated that the NZCYP needed to provide more space to write notes.

The SENCO and teacher from Team B indicated that they felt the NZCYP had led to changes in their classroom or planning practice, however, they noted that changes had not been made specifically for the student, but for the class in general. For example, the teacher commented,

So, I looked at the supports that I had in the class because I've got the teacher aide [...]. But having a look at what programmes I had, and how they were being used in the class, and how it was being catered for all the students in the class, whether they had FASD or not. So, it made me look at that. So, it was useful."

Indeed, these two participants perceived the NZCYP as having limited benefit for educational planning for their student. It was evident throughout the interview that Team B had become very focused on the student's behavioural issues, believing the student was simply choosing not to behave appropriately, which impacted on his learning. This finding corresponds with several studies, including Paley and O'Conner (2009) who found many teachers and allied professionals do not fully understand the nature and extent of students' needs; Boyes et al. (2016) who found teachers focus on behavioural characteristics of students with FASD rather than the underlying causes of the behaviour; and Scheepers (2009) who found teachers consider students with FASD to be lazy, rude, and defiant, and often blame the parents and the child's upbringing for this behaviour. Team B's views may have impacted on the team's ability to understand the educational profile of their student and, therefore, their perceptions of the NZCYP's effectiveness for planning and practice.

Whilst most of Team B did not appear to realise that behavioural issues are a symptom of FASD, as previously discussed, research very clearly indicates that behavioural issues are a common consequence of the disorder (Mattson et al., 2011; Weyrauch, et al., 2017). It was evident that Team B had limited understanding of the disorder, and how it could impact on the student, and as already discussed, this may have influenced their perceptions of the NZCYP. The findings of this study correspond with research that highlights a widespread lack of knowledge and understanding around FASD (Carpenter, 2011; Paley & O’Conner, 2009; Petrenko et al., 2014a; Poth et al., 2014), and the detrimental impact this can have on student outcomes. For example, research by Blackburn (2009) found that a lack of knowledge about FASD could negatively impact on a teacher’s ability to provide educational support, suggesting that there is a critical need for teachers and other professionals to be educated around the impact of FASD. Further, Job et al. (2013) found that a lack of awareness of FASD can hinder the ability of teams to collaborate.

As previously noted, some participants in Team B appeared to think the NZCYP was FASD specific, and this misunderstanding may have influenced their perceptions of its usefulness for teacher/classroom practice and planning. Once again, the issues the team had with the complexity of the NZCYP may have contributed to this misunderstanding.

5.3.2. Summary of findings: Research question three.

It was clear that the NZCYP had led to changes in teacher/classroom practice and planning in both teams. However, it was apparent that both teams perceived the

ability of the NZCYP to facilitate change as limited. Team A attributed changes in teacher and classroom practice to the informal meetings held with the family, along with anecdotal information that the mother and grandmother had provided separately to the NZCYP. These findings support research that found information provided by parents was valuable for teams supporting students with LSN (Illum et al., 2018; Ruppert & Gaffney, 2011, Yaffe, 2015). Further, some participants had perceived it as unhelpful for practice and planning as it did not allow them to record behavioural aspects of their student. Once again, these findings supported the finding from McLaughlin et al. (2017) that the NZCYP needs more space to record information. The results from question three also reinforced the finding that some of Team B's participants may have held misconceptions about the nature of FASD, consistent with research on FASD by Boyes et al. (2016), Paley and O'Conner (2009) and Scheepers (2009). Also, some participants from Team B may have thought the NZCYP was FASD specific impacting on their perceptions of its usefulness in teacher/classroom practice and planning.

5.4. Research Question Four: How is the NZCYP Perceived in Terms of Supporting Collaborative Practice for Students with FASD?

Overall, it was evident that the NZCYP was not perceived by many of the participants as useful for collaborative practice, although at times it was clear aspects of the Toolkit had supported teamwork and enabled the consideration of multiple perspectives of the student. Factors that impacted on the teams' perceptions of how the NZCYP supported collaboration were generating discussion/coming together as a team, a collaborative framework already in place, multiple perspectives, and cultural misalignment.

5.4.1. Generating discussion/coming together as a team.

Team A did not feel the NZCYP had facilitated collaborative practice, although they all expressed that it had generated discussion and provided them with the opportunity to come together as a team and share information, which was viewed as invaluable. It was evident that Team A had worked well together and that the openness, honesty, and willingness of the family to provide information had improved the other participants' understanding of the student's educational profile and had enhanced the collaborative process. This finding corresponds to Malone and Gallagher's (2010) findings where special education teachers identified open and honest communication between all team members, including parents, as a cornerstone of successful teamwork, and that the inclusion of multiple perspectives improved problem solving and led to an improved sense of efficacy by the team. It was also clear, from this current research, that the SENCO and the teacher had demonstrated a strong desire to include the family in the classroom environment, which had led to an effective collaborative partnership between the school and the family. This supports research by Job et al. (2013) who argues that building strong partnerships with the parents is a vital collaborative practice for students with FASD.

The RTLB from Team B also felt the NZCYP was useful for sharing information and suggested it would be beneficial as a starting point for team meetings indicating he perceived the NZCYP as useful for supporting collaborative practice. This participant also reported that the Toolkit would be effective for working in a cross-disciplinary manner which corresponds with research by De Polo et al. (2009) who found the framework of the ICF-CY useful in supporting cross-disciplinary approaches.

5.4.2. Collaborative framework already in place.

Like Team A, most participants from Team B did not perceive the NZCYP as effective in supporting collaborative practice and attributed successful teamwork to a collaborative framework already in place. As the parent in Team B did not attend the focus group interview, and subsequently was not able to be contacted, it was not possible to ascertain her perspective of the school's current collaborative process or that of the NZCYP. This was unfortunate as parents often report negative experiences when dealing with schools (Blackwell & Rossetti, 2014), and often feel excluded from educational planning processes (Childre & Chambers, 2005), so having the parent's perspective on the school's current collaborative process would have been valuable. What was evident from the results, however, was that the SENCO held strong views on the effectiveness of the school's current collaborative framework, which he argued was clear and concise. His view of the school's current approach was in stark contrast to his view on the NZCYP as a collaborative tool. It was clear that the SENCO felt the Toolkit was too complex and lacked clarity and this had impacted on his willingness to engage with it in a collaborative sense. This finding corresponds with research by Mortier et al. (2009) that complex and technical language can act as a barrier to collaborative practice in educational planning.

Whilst the SENCO's strong views may have impacted on his willingness to engage with the NZCYP they may also have influenced other team members' perceptions and, therefore, their responses during the focus group interview. This factor may also account for why the teacher aide, who was not present for the focus group interview, and was interviewed separately, reported more positive attitudes overall towards the

NZCYP. These findings correspond with research that suggests power relations can be a barrier to collaborative practice (McDonald et al., 2012). Moreover, when strong views are expressed by a person in a position of authority, this can influence the views of others, a phenomenon known as ‘group think’ used to describe collective conformity to group values and beliefs (Janis, 1972). Basadar (2004) suggests that in ‘group think’, subordinate team members may take on the values and beliefs of those viewed as higher up the hierarchy giving the illusion of collaborative practice. Group think can occur when participants are afraid to show their ignorance or to ask questions when other team members seem to know or accept the information. Bénabou (2012) cautions, however, against overlooking the more positive phenomenon of ‘group morale’ (where team members function cohesively and are accepting of different members opinions) as an explanation for agreement and should be considered in this research as an alternative explanation for the team’s views. Improved training on the use of the NZCYP to enable individuals to feel more confident in the use of it may mitigate some of the effects of ‘group think’ if present.

5.4.3. Multiple perspectives of the student.

Whilst this study found the NZCYP was not perceived as useful in supporting collaborative practice, Team B indicated the ability to consider multiple perspectives of the student had led to useful team discussion and improved understanding of the student, particularly when dealing with interpersonal issues that arose between the student and staff. This reflects research findings from Mclaughlin et al. (2017) where team members found the different perspectives of the participants led to constructive conversations about the student. The findings from this current research also correspond with research by Akkerman (2006) who found that multiple

perspectives are useful for generating new understanding of situations, as well as Yoo and Kanawattanachai, (2001) who found different perspectives can assist teams in dealing with complex issues. Finally, these findings also reflect research by Mortier et al. (2009) who found that implementation of educational supports for children with LSN was more easily accomplished when participants were able to utilise localised knowledge provided by different participants' perspectives of the child.

5.4.4. Impact of different paradigms of disability on collaboration

Budd (2014) suggests that different paradigms of disability can impact on the capacity of cross-disciplinary teams to work collaboratively, particularly when dominant views on disability are held by some. In this research, some participants from Team B, appeared to hold strong and, at times, singular views of the student's disability, which may have influenced their perceptions of the NZCYP as a collaborative tool, and other team members' views. Team B's SENCO and teacher, appeared to have a deficit perspective that placed the focus of disability within the child (Rouse et al., 2008). At times, this perspective dominated the discourse of Team B, suggesting that the NZCYP itself was not sufficient in combining these viewpoints cohesively, which may have impacted on the team's ability to understand the student's profile, apply this information to educational planning, and to work cohesively as a team. These findings correspond with earlier research that suggests that unless team members can successfully negotiate their different perspectives, this can hinder teams working with children with disabilities (Carter et al., 2009), and raises questions regarding claims that the NZCYP's biopsychosocial focus enables the integration of multiple perspectives of disability (McLaughlin et al., 2017).

The deficit view of disability displayed by the SENCO and teacher from Team B is consistent with research by Purdue (2009) who found a negative view of disability is common in education settings and places the problem with the child and overlooks barriers within the education system. The findings from this research are also in keeping with research by Pei et al. (2013) who found many educational professionals hold a deficit focus and negative view about students with FASD and, as previously mentioned, these views can negatively impact on collaboration (Job et al., 2013). The contrasting views on disability held by participants may have impacted on their perceptions of the NZCYP and hindered their ability to work collaboratively suggesting that the NZCYP was unsuccessful in supporting collaborative practice.

5.4.5. Cultural misalignment.

An unexpected finding from the research was that the formality and complexity of the NZCYP appeared to be culturally misaligned with the more relationship centred and informal collaborative approach of the Māori focused classroom hub in Team A. This misalignment may have contributed to the perception that the NZCYP was not helpful in supporting collaborative teamwork. All participants from Team A agreed that the opportunity for face to face interaction had been the most beneficial part of the research. Further, team members appeared to value the informal approach, for example, the opportunity to just get together have a cup of tea and discuss the student. This supports Pere's (1991) assertion that Māori expect "'eyeball to eyeball' communication" where the individual does not "hide behind a system" (p. 36) and Bevan-Brown's (2015) comments that educational meetings for Māori children with LSN should be more informal and allow time for small talk.

The value of the Māori focused learning hub's more informal approach is supported by Mckinley (2000) who notes clear communication and an informal approach is the most successful approach for encouraging active participation of Māori families, findings supported by Henderson (2013) who notes developing an open and effective reciprocal process between whānau and educators is crucial for effective educational outcomes for Māori. The importance of the NZCYP being culturally aligned with Māori students' backgrounds is also highlighted by research by Higgins, Phillips, Cowan, Wakefield, and Tikao (2010) who note that Māori students struggle with a cultural mismatch between home and school contexts. Further, the need for culturally aligned frameworks for students with FASD is evident in research by Cleaversey et al. (2017) who found a lack of understanding of cultural issues, and a lack of open and clear communication was a barrier to successful collaboration between parents and schools.

The apparent cultural misalignment found in this research may also reflect different cultural conceptions of disability between the NZCYP and Māori views of disability which may have impacted participants perceptions of the Toolkit in terms of supporting collaborative practice. This is supported by Vangen (2017) who found cultural differences in perspectives can negatively impact on collaborative practice when these differences cannot be integrated or reconciled. As previously noted, participants felt the NZCYP failed to incorporate te ao Māori, suggesting the NZCYP reflects a more western view of disability. Hickey (2015) asserts that Māori concepts of disability differ from the western conceptualisation of disability in that the role of the whānau is paramount over that of the individual. The western individual focus contrasts with Māori views of health that are more holistic and

interdependent, placing the child within the context of whānau. A Māori view of disability also recognises cultural and spiritual components of health, and the interconnectedness between these components (MacFarlane, 2012), which the NZCYP does not currently incorporate into its framework.

The results from this research suggest that the cultural misalignment impacted on the participants' willingness to engage with the NZCYP and had a negative impact on their perceptions of its ability to support collaborative practice. This finding is important as research indicates a person's perspective on disability will influence their views on how to approach the needs of the student and what services and resources they will consider using (Annan et al., 2008; Kearney & Pryor, 2004). If the developers of the NZCYP do not enhance the ability of the Toolkit to account for Māori cultural dimensions and viewpoints of disability, it may not be utilised for or by Māori students. The lack of cultural fit of the NZCYP for Māori students also raises the question of the value and use of the Toolkit in its current format for students who do not identify as Western/European.

5.4.6. Summary of findings: Research question four.

The findings from this research suggest that the NZCYP as a stand-alone document was insufficient in supporting collaborative practice for students with FASD. This finding is in line with Sanches-Ferreira et al. (2018) assertion that there is a need for teams to already have collaborative mechanisms in place to support the use of the ICF-CY. This suggests more needs to be done to support collaborative processes for teams working with children with FASD.

5.5. Summary

This chapter has explored the key factors which influenced the participants' use of the NZCYP and their perceptions of it in relation to the research questions. Overall, participants' responses to the NZCYP were mixed and at times contradictory. Some of the participants did not fill out the Toolkit, whilst others only partially completed it. Several factors were identified that impacted on the use of the NZCYP and it is likely that these will have influenced the participants' perceptions of the NZCYP in terms of the research questions. The complexity, relevance and fit, and focus of the NZCYP were amongst the factors identified that impacted on the participants' use and perceptions of the Toolkit, along with a lack of knowledge around the student. However, the Toolkit was identified as being potentially useful for transition planning.

In regard to the second research question "how is the NZCYP perceived in terms of helping teams to understand the educational profile of students with FASD?", it was apparent that although there had been an improvement by some team members in their understanding of the student's learning profile, generally participants did not perceive the Toolkit as helpful in this regard. Whilst some team members reported an improved understanding of FASD in other students, it was clear from their responses that they still held misconceptions about the nature and symptomology of FASD. Findings also indicated confusion over the nature of the NZCYP with some participants viewing it as FASD specific, which will have impacted on their overall perception of the Toolkit.

In regard to research question number three, “how is the NZCYP perceived in terms of supporting teacher/classroom practice and planning for students with FASD?”, although it was clear that the NZCYP had led to changes in teacher/classroom practice and planning in both teams, most participants perceived the NZCYP to be limited in its ability to facilitate change. Team A attributed changes in practice and planning to informal meetings with the family, and separate information supplied by the family as the reason for changes. Although the RTLB and the teacher aide from Team B indicated the NZCYP had been useful for teacher/classroom practice and planning, the teacher and SENCO perceived it as ineffective in capturing the extent of the behavioural issues of the student, which they viewed as limiting the usefulness of it. However, once again, the misconceptions about FASD, and the NZCYP being FASD specific, may have impacted on some participants’ perceptions of its usefulness in teacher/classroom practice and planning.

Finally, in response to the final research question “how is the NZCYP perceived in terms of supporting collaborative practice for students with FASD?”, participants overall indicated that the Toolkit had not been helpful in supporting collaborative teamwork. Team A felt the ability to meet and share information informally had been of more value, whilst Team B reported they already had a successful collaborative framework in place. The ability to consider the student from multiple perspectives, however, had clearly supported collaborative practice in some instances. Different perceptions of disability may also have contributed to negative perceptions about the ability of the NZCYP to support collaborative practice. Finally, a cultural misalignment between the formality of the NZCYP and the more informal Māori

learning hub may also have negatively impacted perceptions of the NZCYP as a collaborative framework.

The next chapter will discuss the purpose and rationale, challenges and limitations, and key implications of the research. Finally, future research will be discussed.

Chapter 6: Conclusion

This chapter summarises the purpose and rationale of the research along with challenges and limitations. Key implications are then discussed in relation to the research findings. Finally, future research directions are considered.

6.1. Purpose and Rationale

This project aimed to explore the perceptions of teams using the NZCYP to support a student with FASD in order to answer four research questions. It was anticipated that the NZCYP would offer a framework to provide a holistic profile of the student, as research suggests there is limited awareness by professionals about the nature and characteristics of FASD and how it impacts students (e.g. Brown et al., 2018).

Further, it was hoped the NZCYP would enhance educational planning for students with FASD as research also highlights the difficulty of providing appropriate supports and interventions (e.g. Job et al., 2013). Finally, it was hoped that the NZCYP would support cross-disciplinary collaboration as research indicates that whilst this is critical in supporting students with FASD, this can be difficult, and there is limited evidence to suggest this occurs (e.g. Dudley et al., 2015).

Prior to this study, there was limited research that explored tools that could support team educational planning for children with FASD. Further, the use of the NZCYP for students with FASD had also not been investigated. The developers of the Toolkit assert that the NZCYP provides a biopsychosocial framework for developing a holistic profile of a student for educational planning and a means to support cross-disciplinary collaboration (McLaughlin et al., 2017). However, the results from this research suggest that overall the NZCYP was not perceived by the participants as helpful in

developing an improved understanding of the student's educational profile or in supporting cross-disciplinary educational planning for their student with FASD. However, the findings from this study should be considered within the context of challenges and limitations that were encountered, which are discussed next.

6.2. Challenges/Limitations

Several challenges were encountered regarding carrying out the training and interviews. For instance, while a number of measures were taken to adhere to Māori protocol for meetings, including ensuring face to face (kanohi ki te kanohi) meetings, providing refreshments (kai), offering karakia at the start and end of focus group interviews, and providing a small gift (koha) after the focus group interviews, due to a delay in the arrival of some participants at the start of Team A's training, karakia was overlooked. An apology was made during the interview and karakia was offered from this point on. Whilst this was remedied as soon as possible, a failure to follow Māori protocols at the start of the meeting may have impacted on some of the participants' willingness to engage with the research and, therefore, their perceptions of the NZCYP.

Another issue that became apparent during the research was that the 45 minute training session was insufficient to adequately support the participants' understanding of how to complete and apply the NZCYP. Future research should look at extending and elaborating on the training and will be discussed later in this chapter.

Another possible limitation regarding the training was that it was provided at the start of term one. Both students were transitioning from a different educational setting, so the school staff had limited knowledge of the student, which impacted on their willingness to complete and use the NZCYP. From a methodological viewpoint, it would have been more suitable to have the participants carry out the training and apply the Toolkit later in the school year as they are more likely to complete and engage with it. However, due to the time constraints of completing this project, this was not possible.

The loss of the mother from Team B's focus group interviews removed an important voice from this research. Whilst efforts were made to contact the mother, the need to be sensitive to her situation meant that her viewpoint was not included. The mother's absence from the focus group interviews reduces the ability to draw conclusions about the overall findings, particularly regarding collaboration where her perspective of the NZCYP in this regard would have added a valuable point of view.

This research did not include the student as a participant as they were not the focus of the study. However, given the aim of the NZCYP is to support learning and participation for students with disabilities, including their perspective and voice in future research is important in order to draw conclusions regarding the effectiveness of the Toolkit for them.

The credibility of this research may have been reduced as member checking was not carried out due to time constraints. However, developing a detailed codebook and providing enough direct text from the data offers readers a chain of evidence with

which to evaluate interpretations and to “see for themselves” how interpretations were made (Mills, 2014, p. 118). Further, two supervisors reviewed the codebook and interpretation of data, which provided feedback on the consistency and accuracy of how the codes were being applied and how the data was being interpreted.

It is important to acknowledge that as the researcher, I do not have a teaching background placing me in the role of the ‘outsider’ within this research. Thorne (2016) suggests an ‘outsider’ can lack insider knowledge of roles, factions, and understanding of internal culture, and can be viewed as an intruder, which can impact on how participants respond. To help mitigate this problem, I worked as a teacher aide, which I believe improved my understanding of classroom practice and education settings and reduced the impact of my ‘outsider status’. Further, every effort was made to develop positive relationships with the participants, including ensuring that meetings were held at times and places that were convenient to them. Whilst there can be advantages to an outsider position, including a greater degree of objectivity (Thorne, 2016), a lack of knowledge and experience around educational matters may have impacted on the focus group interviews as well as interpretation of meaning of the data. This is also pertinent in my role as a cultural outsider as both students that the teams supported were Māori, and one student was in a Māori centred learning hub. Consulting with a cultural advisor will have gone some way to mitigating this situation, whilst keeping a reflexive journal helped to ensure that I considered the influence of my beliefs, values, perspective and biases on my approach to the study, and the interpretation of results (Savin-Badin & Major, 2013).

6.3. Key Implications

Overall it was clear that the participants had not perceived the NZCYP as helpful regarding team educational planning for their students with FASD. Several key findings were revealed that appeared to impact on the participants' willingness to engage with the Toolkit and their perceptions of it. These findings will be discussed next, along with recommendations to improve understanding and perceptions of the NZCYP.

6.3.1. Complexity.

A key finding from this research was that the NZCYP was perceived as complex, time consuming, and difficult to complete. This perception impacted on the participants' willingness to engage with the NZCYP and their thoughts on it. The findings suggest that more needs to be done to reduce the complexity of both the language, and the instructions for use, of the Toolkit. Updating the terminology to ensure the language is jargon free as well as providing training to enhance users' understanding of terms and instructions in the NZCYP may improve perceptions regarding its complexity and reduce the length of time required to complete it. However, careful consideration to training must be given as research by Sanches-Ferreira et al. (2018) on the ICF-CY found that professionals' perceptions of the ease and time taken to complete it did not alter after training on the framework. Findings from this current research suggests reducing the complexity of the document is paramount and indicates setting realistic expectations around the length of time to complete the NZCYP is recommended.

6.3.2. Relevance and fit.

Another key finding was the lack of fit of the NZCYP for the student, school, community and culture. Participants indicated the Toolkit was too generic and did not allow for important relevant information about the student, and their background to be recorded. This had a considerable impact on the teams' perceptions of the NZCYP in terms of helping them understand the educational profile of their student. Providing space to record extra relevant information to 'personalise' the profile is recommended. Further, enhancing the clarity of the Toolkit and improving training may go some way to mitigating these perceptions. However, a major finding from this research is the need to substantially improve the cultural fit of the NZCYP. The Toolkit in its current state, whilst offering a biopsychosocial framework of disability, is still grounded in western ideology where the focus remains firmly on the individual and overlooks Māori perspectives on disability. For Māori students with FASD, this represents not only a missed opportunity to account for, and utilise, important aspects of te ao Māori but also boxes them within narrow definitions of disability. By ignoring Māori culture and perspectives on disability, the NZCYP risks alienating Māori students with FASD, and their whānau, adding to the burden of the disorder. Several recommendations for improving the cultural fit of the Toolkit are suggested from the results.

It is recommended that consideration should be given to making cultural features of the NZCYP more clearly defined and explicit. Whilst the cultural features raised by the participants were not clearly mentioned in the NZCYP, a number of the profile pages could potentially accommodate such information. For example, as suggested by some of the participants, the Background Information Page could add a section on Māori whakapapa and whānau history. Further, both the PAP and the IPP pages note

that information can be recorded regarding the student's access to, and interest in, such things as family, cultural community and religious activities. It is also recommended that a te reo Māori version of the Toolkit be developed and offered. Finally, consideration should also be given to the NZCYP incorporating dimensions found in Māori models of health such as Te Whare Tapa Wha (Durie 1994) and Te Wheke (Pere, 1991). This is supported by research by McLachlan, Wirihana, and Huriwai (2017) who found that therapy models for Māori clients which incorporated dimensions of Te Whare Tapa Wha led to increased engagement and promoted the exploration of behaviours that supported health and wellbeing and the barriers that prevent it.

Updating the NZCYP to include a Māori cultural perspective is an important and necessary step in supporting Māori students with FASD. However, even with changes to the NZCYP, limited awareness by professionals of a Māori worldview (McFarlane et al., 2011) will impact on the ability of the NZCYP to be used in a culturally responsive manner. This suggests training on the NZCYP may also need to include a te ao Māori focus to ensure the Toolkit is being engaged with appropriately for Māori students. It is also important to note Durie's (2001) point that Māori culture is diverse and not all Māori share the same cultural background or experiences. Therefore, Durie argues, it should not be assumed that all Māori will wish to have cultural components included in assessments and supports whilst others may feel disadvantaged without the opportunity to access cultural frameworks. Accordingly, the NZCYP, and the training, needs to be flexible to accommodate the cultural preferences of those the Toolkit is being used to support.

6.3.3. Focus of the NZCYP.

A number of the concerns raised by the participants about the NZCYP were around the overly negative and overly positive focus of the Toolkit. However, many of the profiles did provide a place to record positive information, for example the IPP page, PAP page, and the FAP page, further, behavioural issues raised by Team B could be recorded in the FAP page. A lack of understanding on how to use the Toolkit clearly impacted on the participants' perceptions of its ability to record useful information. If the issues with the complexity of the language were rectified, directions made clearer and more concise, and training provided to support teams on how to complete the document, this may improve perceptions of the NZCYP's focus and relevance. Further, increasing room to record notes will also allow for anecdotal information to be recorded, which was clearly useful to Team A in helping them understand the profile of their student.

6.3.4. Misconceptions about FASD

It is disappointing, although not unexpected, that this research has corroborated findings from previous studies that professional's lack knowledge and awareness about the characteristics and impact of FASD on students. Also, this research has confirmed that professionals focus on behavioural characteristics rather than the underlying condition that causes the behaviour. It is likely that this lack of knowledge may have impacted on some participants' perceptions of the NZCYP. It is vital going forward that professionals are provided with appropriate training on how to support students with this complex disorder as without enough understanding of FASD tools, such as the NZCYP, will be ineffective. Long term, without adequate knowledge and awareness of FASD, students with the disorder will continue to

receive ineffective and inappropriate services and interventions, which exacerbates their risk of negative long term educational and social outcomes.

6.3.5. Lack of knowledge.

Participants indicated a lack of knowledge about the student had hindered their ability to complete the form suggesting the NZCYP should be completed at the end of the year and used as a transition document. These findings suggest follow-up research exploring the NZCYP's effectiveness in transition planning is warranted.

6.3.6. Collaboration.

Another key finding from this research is that the NZCYP in its current format was not perceived as useful for collaborative practice. This was in line with research on the ICF-CY that suggests collaborative mechanisms need to already be in place to support cross-disciplinary collaboration (Sanches-Ferreira et al., 2018). Further, the findings from this research suggests that multiple and differing perspectives of disability may have impacted on the participants' perceptions of the NZCYP as a collaborative framework. Consideration should be given to training the teams in collaborative practice prior to training them in the use of the NZCYP, including exploring different perspectives of disability, and FASD. Training to clarify how the NZCYP can be used and applied in a collaborative manner may improve perceptions of it in this regard. Further, providing a coach to support teams completing and using the NZCYP for the first time may improve the ability of teams to integrate and utilise multiple perspectives.

6.3.7. Training.

As clearly indicated throughout this chapter, a major recommendation from this research is the need for improved training on the completion and application of the NZCYP in educational settings. This finding is supported by Sanches-Ferreira et al.'s (2014) research into the IC-CYF which gathered professionals' perspectives on using the document for educational planning. The results indicated that participants identified the need for increased training for all team members working collaboratively for students with LSN. Further, Pless, et al. (2009) conducted research on providing training to professionals on the ICF and the ICF-CY and found that an initial 2 hour information session, a follow-up assignment, and then a two day training session was effective in increasing participants' knowledge and understanding of the frameworks. However, the researchers noted training had less impact on the application of the ICF or the ICF-CY. The authors also found that instructor-led training rather than self-directed learning is more beneficial and making the training relevant to the participants' everyday working contexts is important. Finally, when participants have limited pre-existing awareness of the frameworks, then knowledge and understanding takes time to acquire.

Considering the findings from previous research and the findings from this research it is evident that training on the NZCYP needs to be comprehensive, led by an 'expert' instructor, and focus specifically on improving understanding of the terminology and how to apply this to everyday settings of the student. Further, case studies could be included to demonstrate how the NZCYP can be utilised. It is also recommended that realistic expectations be set regarding the time required to gather an appropriate level of understanding and awareness on the use of the NZCYP.

Improving training and setting realistic time expectations for users of the NZCYP may result in increased understanding of the Toolkit and improve the likelihood it will be completed and applied more effectively by teams supporting students with FASD. Finally, as already discussed, for first time users of the NZCYP it is recommended that after the initial training is completed, a coach/support person remains to support teams in the completion and application of the NZCYP as this is likely to improve teams' understanding of how to complete and use the toolkit appropriately.

6.4. Future Research

A number of limitations and conclusions identified in the research suggest future research directions. These included the need for follow-up research on the impact of both enhanced training and ongoing coaching of the NZCYP on participants' use and perceptions of it; research on the impact of training to increase knowledge and understanding of FASD and collaborative practice on participants' use and perceptions of the NZCYP; and investigating the NZCYP as a transition tool for FASD. Finally, based on the current findings regarding the lack of a cultural fit and perspective in the NZCYP, along with previous research highlighting the importance of including such a viewpoint, it is vital that future research explores developing the NZCYP into a more culturally responsive framework and the perceived effectiveness of this. The lack of cultural fit of the NZCYP for Māori also raises questions regarding its suitability as a multicultural tool for educational planning, suggesting further research is required to investigate how teams supporting students of different cultures use and perceive the toolkit.

6.5. Summary

FASD is a complex disorder requiring an in-depth understanding of the learner's profile, and a cross-disciplinary approach to educational planning, to effectively support students with FASD. This research explored whether the NZCYP was perceived as useful for collaborative educational planning for students with FASD. Overall, most participants expressed negative perceptions of the NZCYP suggesting that, in its current form, it was not effective. The findings suggest that the complexity, and the lack of relevance and fit, of the NZCYP, in particular cultural fit, had a considerable impact on perceptions of it. Results suggest that improving the terminology, making provision for Māori cultural information and perspectives, as well as other anecdotal information about the student, and improving the training, to include a coach to support teams to use and apply the NZCYP would enhance the effectiveness of its implementation.

Of note, from this research, was the apparent lack of knowledge and understanding of FASD by many of the participants in educational roles, a situation prevalent in this field. Not only will this situation have impacted on the teams' ability to complete and use the NZCYP and therefore, their perceptions of it, it will also have impacted on the teams' capacity to provide appropriate educational planning and support for their students with FASD. Without a strong foundation of knowledge around FASD, including a comprehensive understanding of the impact on the student, and the teaching and learning strategies needed to support them documents such as the NZCYP are likely to be of limited value.

Appendices

Appendix 1: Parent/Caregiver Letter of Invitation



MASSEY UNIVERSITY
INSTITUTE OF EDUCATION
TE KURA O TE MATĀURANGA

Exploring the New Zealand Child and Youth Profile as a collaborative tool to support educational planning for children with fetal alcohol spectrum disorder

PARENT/CAREGIVER LETTER OF INVITATION

Tēnā koe (Parent/caregiver name)

It was great to meet with you and discuss your potential involvement in my research project, thank you for taking the time to see me. As discussed, I am a master's student in the Institute of Education at Massey University conducting a research project entitled: "Exploring the New Zealand Child and Youth Profile as a collaborative tool to support educational planning for children with fetal alcohol spectrum disorder."

The New Zealand Child and Youth Profile (NZCYP) is a Toolkit designed to support teachers, teacher aides, families, and specialists to reflect on and organize their understanding of a child's strengths and limitations; sensory function; participation at school, home, and in the community; and interests and preferences. The aim of this project is to explore how the NZCYP is perceived as helpful in understanding the educational profile of children with FASD, and how the NZCYP is perceived in terms of facilitating team educational planning for these children.

I would like to invite you to participate in my research project. I have attached an information sheet which provides more details about the project. Please note that (child's name) will not be participating in this project and I will not have access to any of the data collected in the NZCYP. Further, any information that may identify your child will be removed from the data.

If you grant approval to carry out this research project, then (SENCO's name) will approach other potential team members and invite them to join the project team.

If you are interested in participating in this project, please sign the attached consent form and contact me to arrange collection. Should you require any further information, please contact me. You can also contact my supervisors, Dr. Julia Budd on 06 356 9099 ext 84412 and Dr Sally Clendon on 09 414 0800 ext 43537

Ngā mihi

Joanne van Wyk
Postgraduate Student
Phone [REDACTED] [REDACTED]
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Appendix 2: Participant Information Sheet

Exploring the New Zealand Child and Youth Profile as a collaborative tool to support educational planning for children with fetal alcohol spectrum disorder

INFORMATION SHEET

Tēnā koe.

My name is Joanne van Wyk and I am a postgraduate student undertaking my Master of Arts (Education) in Massey University's Institute of Education. I am currently completing a research project exploring the use of the New Zealand Child and Youth Profile (NZCYP) (McLaughlin, Budd, & Clendon 2017) with children who have fetal alcohol spectrum disorder (FASD). The NZCYP is designed to support teachers, teacher aides, families, and specialists to reflect on and organize their understanding of a child's strengths and limitations; sensory function; participation at school, home, and in the community; and interests and preferences. The aim of this project is to explore how the NZCYP is perceived as helpful in understanding the educational profile of children with FASD, and how the NZCYP is perceived in terms of facilitating team educational planning for these children.

I have approached parents/caregivers who have children with FASD for permission to conduct my research project. I have then contacted school principals and asked their permission to recruit the teams (including teachers, and other specialists) working with these children. Your school has given permission; therefore, I am sharing this Information Sheet and Consent Form with you.

I invite you to participate in my research project. Specifically, I am seeking your participation as a team member in four key activities. Please note that team members can participate in Key Activities 1 and 2 but choose not to participate in the research study.

Key Activity 1: I will provide face to face team training and support to use the NZCYP. This will involve attending a training session to learn about the NZCYP and the different forms available. The training will take approximately one hour and will be scheduled at a time convenient to the team. The session will be semi-structured, and you will be provided with opportunities to ask questions.

Key Activity 2: Following the training, you will be asked to complete the NZCYP for the student individually. The team will then come together as a group to discuss and formulate an integrated educational plan based on your collective findings. I am available to the team should you have questions while using the NZCYP. I will not have access to the student's data that is collected.

Key Activity 3: If you choose to participate in the research study, I will collect basic demographic information from you regarding your profession and experience for summative descriptive purposes only.

Key Activity 4: I will also conduct a semi-structured focus group interview (and if necessary, follow-up individual interviews) with you and your team. I will determine whether individual interviews will be used based on feedback from the focus group. The focus group (and individual interviews) will gather your perspectives on how you found using the NZCYP. Focus groups are expected to take between 45-60 minutes per team. Individual interviews are expected to take between 20-30 minutes. To enable accurate recording of the focus group and any individual interviews, an audio recording will be used that will later be transcribed.

It is not expected that you will experience any harm or discomfort as a result of your participation in the project. Potential benefits may include learning about alternative methods for educational planning. Please note it will not be possible to withdraw your data from the focus group discussion.

All data gathered for this study will be kept in a secure and confidential manner and used for the purposes of this project and publications that arise from this work. It may not be possible to keep total anonymity as the team members will recognise one another in the study. The researcher will keep any information shared by members of the team confidential. All team members will be asked to maintain confidentiality regarding other team members' involvement and contribution to the project. However, there are limits on confidentiality as there are no formal sanctions on other group participants from disclosing your involvement, identity or what you say to others in the focus group.

Please note that you are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- decline to answer any question;
- withdraw from the project at any time prior to the beginning of each key activity;
- ask any questions about the project at any time during participation;
- provide information on the understanding that your name will not be used unless you give permission to the researcher; and
- be given access to a summary of the project findings when it is concluded.

If you participate in an individual interview, you also have the right to:

- ask for the recorder to be turned off at any time during the interview;
- amend the transcript sent to you following the interview if you do not feel it accurately represents what was said;

Should you wish to participate, please complete the attached consent form and return it to me. Please feel free to contact me or my supervisors at any time if you have any questions in relation to this project.

This project has been evaluated by peer review and judged to be low risk. Consequently, it has not been reviewed by one of the University's Human Ethics Committees. The researcher(s) named in this document are responsible for the ethical conduct of this research.

If you have any concerns about the conduct of this research that you want to raise with someone other than the researcher(s), please contact Associate Professor Tracy Riley, Acting Director - Ethics, telephone 06 3569099 ext 84408, email humanethics@massey.ac.nz.

Ngā mihi

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Postgraduate Student
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Appendix 3: Parent/Caregiver Consent Form



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Exploring the New Zealand Child and Youth Profile as a collaborative tool to support educational planning for children with fetal alcohol spectrum disorder

PARENT/CARGIVER CONSENT FORM

This consent form will be held for a period of five (5) years from the date of the study

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time. I understand that my child will not be participating in this research, that the researcher will not have access to any of my child's data collected in the New Zealand Child and Youth Profile and that any information that may identify my child's identity will be removed from the data.

I agree/do not agree to the study being conducted in relation to educational planning for my child.

Signature:

Date:

Full Name - printed

Exploring the New Zealand Child and Youth Profile as
a collaborative tool to support educational planning for
children with fetal alcohol spectrum disorder

PRINCIPAL INFORMATION SHEET

Tēnā koe

My name is Joanne van Wyk and I am a master's student in the Institute of Education at Massey University. I am writing to inform you about a research project that I am conducting entitled: "Exploring the New Zealand Child and Youth Profile as a collaborative tool to support educational planning for children with fetal alcohol spectrum disorder."

Children with fetal alcohol spectrum disorder (FASD) are at increased risk of poor educational outcomes due to the complex and often misunderstood nature of the disorder. Further, it can be a challenge identifying the developmental level of these children. A multidisciplinary collaborative approach to educational planning is considered critical in improving academic outcomes. The New Zealand Child and Youth Profile (NZCYP) is a Toolkit designed to support teachers, teacher aides, families, and specialists to reflect on and organize their understanding of a child's strengths and limitations; sensory function; participation at school, home, and in the community; and interests and preferences. The aim of this project is to explore how the NZCYP is perceived as helpful in understanding the educational profile of children with FASD, and how the NZCYP is perceived in terms of facilitating team educational planning for these children.

I am recruiting two teams supporting children who have been diagnosed with FASD. I have received consent to proceed with the project from the parent of a child with FASD who will be attending your school. I am writing to share the details of the project with you, and to request approval for the research to be carried out in your school.

The project will begin in Term 1, 2019 and staff commitment to it will be needed during this period. Initially, the team will receive training in the use of the NZCYP, which will take approximately 1 hour. Team members will then individually complete the profile for the child before coming together as a team to share their information in order to develop an integrated educational plan. I will not have access to children's data collected at any stage during the research.

Once the team has met and used the NZCYP, focus and, if necessary, follow-up individual interviews will be conducted at a time convenient to your staff and the parents/caregivers. Focus groups are expected to take between 45-60 minutes per team. Individual interviews are expected to take between 20-30 minutes per teacher.

Team members can attend the training and engage in the use of the NZCYP but can elect not to participate in the research.

If you grant approval to carry out this research in your school, I would like to request your assistance to facilitate the process by:

1. Sharing the attached Information Sheet with your school's SENCO.
2. Asking your school's SENCO to share the Information Sheet with the members of the child's team (e.g., teacher, other professionals/specialists).

If you have any questions relating to the project, please call my Supervisor Dr. Julia Budd on 06 356 9099 ext 84412.

This project has been evaluated by peer review and judged to be low risk. Consequently, it has not been reviewed by one of the University's Human Ethics Committees. The researcher(s) named in this document are responsible for the ethical conduct of this research.

If you have any concerns about the conduct of this research that you want to raise with someone other than the researcher(s), please contact Associate Professor Tracy Riley, Acting Director - Ethics, telephone 06 3569099 ext 84408, email humanethics@massey.ac.nz.

Thank you for considering this request for assistance. I would be most willing to meet with you to provide further information and explanation about the project.

Yours sincerely,

Joanne van Wyk
Postgraduate Student
Phone [REDACTED]

Joanne.Van_Wyk.1@uni.massey.ac.nz

Appendix 5: Principal Consent Form



Exploring the New Zealand Child and Youth Profile as a collaborative tool to support educational planning for children with fetal alcohol spectrum disorder

PRINCIPAL CONSENT FORM

This consent form will be held for a period of five (5) years from the date of the study

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree/do not agree to the study being conducted at

.....
(Name of school)

I agree to the participation of the staff members

.....
(Name of staff members)

Signature: _____ **Date:** _____

Full Name - printed _____

My Role _____

Exploring the New Zealand Child and Youth Profile as a collaborative tool to support educational planning for children with fetal alcohol spectrum disorder

PARTICIPANT CONSENT FORM

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I understand that I have an obligation to respect the privacy of the other members of the group by not disclosing any personal information that they share during our discussion.

I understand that all information I give will be kept confidential to the extent permitted by law, and the names of all people in the study will be kept confidential by the researcher.

Note: There are limits on confidentiality as there are no formal sanctions on other group participants from disclosing your involvement, identity or what you say to others in the focus group. There are risks in taking part in focus group research and taking part assumes that you are willing to assume those risks.

I agree/not agree to participate in the training under the conditions set out in the Information Sheet.

I agree/not agree to participate in the focus group under the conditions set out in the Information Sheet.

Signature:

Date:

Full Name - printed



Appendix 7: Demographic Questionnaire

Exploring the New Zealand Child and Youth Profile as
a collaborative tool to support educational planning for
children with fetal alcohol spectrum disorder

DEMOGRAPHIC QUESTIONNAIRE

Please complete the following short survey, answering those questions
that are relevant to you.

What is your role with the student? (e.g., parent, caregiver, teacher, SENCO)

.....

For teachers and other specialists:

What is your occupation?

.....

How many years of experience have you had working in this occupation?

.....

What qualifications do you hold?

.....

Please share any other professional learning and development, or experiences that
you feel are important in your role supporting the student?

.....

Appendix 8: NZCYP



Child and Youth Profile – New Zealand Toolkit

A toolkit to profile the characteristics of children and youth to support learning and participation in home, school, and community activities.

Julia Budd, Tara McLaughlin, and Sally Clendon
Massey University

The toolkit is designed to consider and document child characteristics, participation, and preferences. Tools allow teachers, families, and specialists to reflect on and organize their understanding of the child's functional strengths and limitations; sensory function; communication function, participation at school, home, and in the community; use of adaptations and specialised equipment to support participation, and interests and preferences. Information gained across the tools provides a holistic view of the child in context. The toolkit can help a team to identify priority areas for home, school, and community interventions. Priority learning areas can be documented on the priority planning page or other local-based planning forms and documents. We suggest teams identify which of the tools in the toolkit are most useful for their purposes. The toolkit is inclusive of all children and youth. The toolkit includes:

The **Background Information (BI)** is designed to provide information about a child's cultural identity, educational placement, On-going Resource Funding (ORS) the professionals who work with the child and family, family members, and family support services.

The **Sensory Modality Profile (SMP)** is designed to gather information about a child's current level of ability to perceive sensory information and use it to explore their world, discriminate between objects and use for specific tasks. This profile helps to identify the sensory modalities that a child uses to engage with the world.

The **Communication Profile (CP)** is designed to gather key information about the child/youth's communication system and record how the child/youth expresses different important communicative functions.

The **Participation and Access Profile (PAP)** is designed to ascertain a child's interest, availability, access and accommodation to a range of educational, recreation and sport, family, cultural community and religious activities and to consider if participation is acceptable to the child, family or others involved in the activity.

The **Functional Ability Profile (FAP)** is designed to gather information about a child's current level of ability across 11 functional ability areas. Functional abilities are viewed as the integrated skills that children can do to participate in the activities of life. The profile helps show areas of strength and weakness for the child/youth.

The **Adaptations and Specialised Equipment Profile (ASEP)** is designed to identify the types of adaptations, augmentative and alternative communication systems, assistive technology, or adaptive devices the child currently uses and/or which might be desirable for future use.

The **Interests and Preference Profile (IPP)** is designed to identify a child's areas of interest and preferences for items and activities so that they can be used as starting point to increase engagement and participation and/or act as potential rewards or reinforcers of desired behaviours and competencies. This includes an awareness of family preferences for the child.

The **Priority Planning Page (PPP)** is designed to integrate information from the toolkit to inform planning and interventions. Key information about the child and priority goals and interventions for home, school, and community can be documented.

The suite of tools is based on the International Classification of Functioning, Disability and Health-Children & Youth Version (ICF-CY; World Health Organization, 2007).



Name of child/youth: _____

Name of person completing form _____ In collaboration with: _____

Background Information (BI)

Directions: Provide information about a child/youth's cultural identity, living situation, educational placement, funding, supports and the professionals who work with them to provide a context for the educational planning and interventions.

Name of Learner:		DOB:	Age:	Gender:
Cultural Identity:	Home Language:	Living Situation:		
Educational Placement Past : <input type="checkbox"/> Early education environment <input type="checkbox"/> Mainstream without withdrawal <input type="checkbox"/> Mainstream with withdrawal <input type="checkbox"/> Special unit or school <input type="checkbox"/> Home school <input type="checkbox"/> Other (specify)	Educational Placement Now: <input type="checkbox"/> Early education environment <input type="checkbox"/> Mainstream without withdrawal <input type="checkbox"/> Mainstream with withdrawal <input type="checkbox"/> Special unit or school <input type="checkbox"/> Home school <input type="checkbox"/> Other (specify)	Services Provided Now: <input type="checkbox"/> None <input type="checkbox"/> Speech Language Therapist <input type="checkbox"/> Developmental O & M <input type="checkbox"/> Physiotherapist <input type="checkbox"/> Occupational Therapist <input type="checkbox"/> Educational Psychologist <input type="checkbox"/> Resource Teacher Learning and Behaviour <input type="checkbox"/> Resource Teacher Deaf <input type="checkbox"/> Early Intervention Teacher <input type="checkbox"/> Teacher aide or Education Support Worker <input type="checkbox"/> Other (specify)		
List Key Family Members/Whānau and Roles: (parents, siblings, grandparents, etc.)		Services Provided Past:		
<input type="checkbox"/> Respite care <input type="checkbox"/> In-home support <input type="checkbox"/> Parent support group <input type="checkbox"/> Parent training programs <input type="checkbox"/> Counselling services <input type="checkbox"/> Financial supports or grants <input type="checkbox"/> Specialised equipment for home <input type="checkbox"/> Other (specify)		<input type="checkbox"/> None <input type="checkbox"/> Speech Language Therapist <input type="checkbox"/> Developmental O & M <input type="checkbox"/> Physiotherapist <input type="checkbox"/> Occupational Therapist <input type="checkbox"/> Educational Psychologist <input type="checkbox"/> Resource Teacher Learning and Behaviour <input type="checkbox"/> Resource Teacher Deaf <input type="checkbox"/> Early Intervention Teacher <input type="checkbox"/> Teacher aide or Education Support Worker <input type="checkbox"/> Other Health Service Provider (specify)		
Family Supports Provided:		Names of Key Family Supports:		
Notes or Other Background Information:				



Name of child/youth: _____

Sensory Modality Profile (SMP)

Directions: Indicate with a tick if the child/youth can use the different sensory modalities to perceive objects, explore their world, discriminate between objects and/or undertake a task such as reading or mobility. Also indicate if there are any sensory integration issues. Use the notes section to specify any other information relating to sensory modalities that need to be considered in terms of educational planning not included elsewhere in the profile.

Sensory Modality	Perceive Objects	Explore their World	Discriminate between Objects	Undertake a Task (e.g. reading, mobility etc.)
Does the child/youth use their sense of sight to ...				
Does the child/youth use their sense of hearing to ...				
Does the child/youth use their sense of touch to ...				
Does the child/youth use their senses of taste and/or smell ...				
Does the child/youth use their sense of balance to ...				
Does the child/youth use their sense of knowing where their body is in space to ...				
Does the child/youth have sensory integration issues (if yes please describe)				
Notes:				



Name of child/youth: _____

Communication Profile (CP)

Directions: Respond to each of the questions related to key information about the child/youth's communication. Consider how the child/youth expresses different communicative functions and provide a brief description.

<p>Does the child/youth have a reliable and consistent communication system?</p>	<p><input type="checkbox"/> Yes – everyone can understand his/her communications <input type="checkbox"/> Somewhat – some people can understand his/her communications <input type="checkbox"/> No – everyone is taking a best guess at his/her communications</p>	<p>If somewhat, list the reliable communication partners for the child/youth:</p>
<p>How does the child/youth typically communicate?</p>	<p><input type="checkbox"/> Non-symbolic communication (e.g., vocalisations, body movements, gestures, or facial expressions) <input type="checkbox"/> Unaided Symbolic Communication (e.g., speech, Makaton, New Zealand sign language) <input type="checkbox"/> Aided: Low-Tech AAC (e.g., objects, choice boards, picture exchange, communication book, single message device) <input type="checkbox"/> Aided: High-Tech AAC (e.g., dedicated speech devices such as Dynavox, mobile speech device such as iPad with communication app)</p>	
<p>Does the child/youth have a consistent yes/no response?</p>	<p><input type="checkbox"/> Yes – specify method used _____ <input type="checkbox"/> No</p>	
<p>Notes or comments on child/youth's communication system:</p>		
<p>For each of the following areas provide a brief description</p>		
<p>How does the child/youth initiate communication?</p>	<p>How does the child/youth express wanting more?</p>	<p>How does the child/youth express wanting to stop?</p>
<p>How does the child/youth express wanting to do an activity?</p>	<p>How does the child/youth express wanting help or assistance?</p>	<p>How does the child/youth express feelings (e.g., happiness/joy, sadness, anger)?</p>
<p>Notes or comments on current strategies used to support communication:</p>		



Name of child/youth: _____

Participation and Access Profile (PAP)

Directions: There are two separate participation and access profiles. The first profile focuses on a child's participation in **early childhood, school or special school settings**. The second profile focuses on a child's participation in **home and community life**. Each profile lists activities typically associated with each setting. To complete each profile, determine whether the child (and family as appropriate) have an interest in pursuing the listed activities and determine if the activity is a priority. Skip items that are not applicable to the child and family. Consider and answer the questions relating to the participation of the child or youth.

Early Childhood, School or Special School setting activities relate to the child's participation in life of the school or education setting. Activities listed include: involvement in daily programs and activities; social interactions and school trips or special events. Other activities can be included that are relevant to the child/youth or setting using the rows provided.

Examples of **Home and Community Activities** are provided, however, the child and family should define what the activity area would involve for them. Home and family life activities should be inclusive of important cultural or religious/spiritual activities associated with family and community life. Team members should invite the family to describe what is important to them and their child for the different activities listed. As appropriate, the team should work with the child/youth directly to determine important activities and priority areas.

For activities that are priorities, discuss and note barriers to participation. Barriers may include physical environment, policies or regulations, resources or staffing, demands of activity, attitudes, or other areas that impede participation. Noting key barriers will be important for educational planning.



Name of child/youth: _____

**Early Childhood, School or Special School Setting
Participation and Access Profile (PAP)**

(The activity can be undertaken with or without adult support as age appropriate.)

Early Childhood, School or Special School Setting Activities	Is the activity a priority for the child/youth?	Does the child/youth have the opportunity to participate in the activity?	Can the child get to the activity?	Are adaptations made to help facilitate participation for the child/youth in the activity?	Is the child/youth actively involved in the activity?	Do others accept the child/youth while they are participating in the activity?
Daily program and activities						
Social interactions						
Special trips or special events						
Other: (use the following rows to add your own activities these may include things such as leisure activities during break, transitions between classes, school clubs, groups etc.)						
Notes:						



Name of child/youth: _____

Home and Community Participation and Access Profile (PAP)

(The activity can be undertaken with or without adult support as age appropriate.)

Home and Community Activities	Is the activity a priority for the child/youth and/or family?	Does the child/youth have the opportunity to participate in the activity?	Can the child get to the activity?	Are adaptations made to help facilitate participation for the child/youth in the activity?	Is the child/youth actively involved in the activity?	Do others accept the child/youth while they are participating in the activity?
Daily family activities such as involvement in family meals, household chores, family games evenings etc.						
Special family events or trips such as family reunions, weddings, vacations etc.						
Host guests or family friends for dinner, tea, BBQ or social gathering						
Play dates, friends' parties, or social gatherings with peers						
Recreation or leisure at home such as reading, watching television, or computer etc.						
Regular trips into the community such as grocery shopping, park visits, church, synagogue, temple etc.						
Special trips into the community, museums, zoos, cinema etc.						
Play sports or involvement in clubs or groups e.g. gymnastics, swimming, dance, singing group, kapa haka etc.						
Manage public transportation e.g. walking to bus stop, using bus or train or using taxi etc.						
Other (specify)						
Notes:						



Name of child/youth: _____

Functional Ability Profile (FAP)

Directions: Consider the children/youth's abilities on each of the 11 functional ability areas. Based on knowledge of the child, make an overarching judgement about the extent to which the child/youth experiences limitations in functioning that influences his/her participation in daily activities. Place a tick in the corresponding ability/participation box. For each ability area, read the general description of each area (next page) and refer to the age-specific guidance that corresponds with the child/youth's age to inform your ratings.

*Indicate whether the child/youth typically uses (circle the + symbol) or does not use (circle the - symbol) adaptations, augmentative and alternative communication systems, assistive technology, or adaptive devices on a regularly basis. Ratings should be based on child/youth's ability with these adaptations or devices present. In some cases, ratings focus on the extent to which the child/youth is able to use the ability serving the same function without reference to differences in the form of how the ability is performed (e.g., child who uses a wheelchair may move around the environment similar to same aged peers even though the form, using a wheelchair, is different than what same aged peers might do).

** Indicate yes or no to the whether the child is currently receiving supports or services to enhance this area. Based on the level of limitation consider whether new supports or services are needed. Use the notes section following the general descriptions as needed.

		Functional Abilities: Integration of Skills to Participate in the Activities of Life												
		Express Meaning to Others	Comprehend Meaning from Others	Learn New Things	Form and Apply Ideas	Focus Attention and Action	Regulate Emotion	Interact with Others	Daily Care of Oneself	Manipulate Materials	Move Around Environment	Orient Self in Space		
Current Ability	Enhances participation													
	Supports participation													
	Somewhat limits participation													
	Significantly limits participation													
	*Adaptations, AAC, assistive technology, or adaptive devices	+	-	+	-	+	-	+	-	+	-	+	-	+
	**Is the child currently receiving supports or services to enhance this area? Yes / No													



Name of child/youth: _____

Functional Ability Area Description and Age-Specific Guidance:

	Description	Age Specific Guidance				
		<i>Examples are merely suggestive of related age-expected behaviours for the functional areas.</i>				
		For infants and toddlers	For early childhood	For primary	For intermediate	For secondary
Express Meaning to Others	Use language or structured systems with increasing complexity to express ideas, make requests, or interact in verbal or written forms.	Babble, cry, point, emerging words, face expressions; make choices; scribbling	Use basic words, phrases, sign, AAC responses and sentences; gestures; drawing, scribbling; attempts "words"	Speak, sign, uses AAC or writes/types sentences with increasingly complex vocabulary and sentence structure	Develop coherent and comprehensive arguments to identify, form, and express ideas with confidence	Seeks feedback and input from others to make changes to oral and written expression to improve clarity, meaning, and effect
Comprehend Meaning from Others	Receive and understand the communications of others from verbal, gestural, sign, or written messages including literal and implied meanings.	Orient to sound, movement and faces; follow simple directions	Follow directions (words, signs, and symbols) with increasing complexity; ask questions to clarify (e.g., why)	Follow multi-step and complex directions; ask questions to gather more information or clarify	Use information from others to develop ideas, comment on or critique ideas	Make connections by interpreting and integrating ideas from multiple sources
Learn New Things	Acquire new knowledge and skills from observing, reading, listening, doing, and adapting.	Imitate actions- clap hands, grab objects, explore objects with mouth, hands etc. Look at books and pictures	Engage in increasingly complex play and interactions with people, materials, and resources; pretend read	Use a variety of sources to gain new information; identify strategies to gain information – read, videos, talk with others	Plans out how to approach learning based on preferences, skills, and strategies	Plans and evaluate learning; makes adjustments to strategies to increase learning
Form and Apply Ideas	Use knowledge and skills to shape, examine, and evaluate ideas, solve problems or make decisions, show mental flexibility and openness, and have creative or logical ideas.	Looks for hidden objects, plays repetition games	Knows basic facts such as names of animals, colours; tell stories or describes play ideas	Uses knowledge to solve problems and can try out different solutions	Conduct investigations, make predictions, and compare experimental results with expectations	Develop and carry out more complex investigations; use data to inform decisions
Focus Attention and Action	Control the attention, concentration, motivation, and persistence that is brought to tasks; carry out plans and manage time and energy.	Focus eye gaze; persist at making sounds or movements	Persist at a play activity or task; Complete a desired project	Block out distraction; complete self-selected or assigned tasks	Persist with complex assigned tasks; plan and manage time to complete tasks	Direct attention to priority tasks and manage multiple tasks at a time
Regulate Emotion	Understand and express a range of emotions in appropriate ways for setting, show empathy for the emotions of others, and handle stress and disappointment.	Shows a range of emotions with facial expressions and sounds; can be comforted with help of adult	Express what is liked and disliked; identifies emotions in others	Can regulate emotional response in most social situations; express a range of emotions shows kindness to others	Regulate emotions in social situations; manage stressful situations, show compassion to others	Regulate emotions during stress; identify ways to actively manage stress and emotions; show empathy to others
Interact with Others	Interact with others (adults, peers, family) using socially and culturally appropriate behaviours and show social awareness in diverse social situations.	Looks at others, reaches for others, engages in play songs and games	Plays with other children; works together with other children to accomplish goal or task	Can partner with a range of peers; understands rules for group games	Understand how groups make and implement rules and laws; consider the role of culture in interactions with others	Understand how to affect personal relationships with actions, beliefs, and decisions, have a sense of self-worth



Name of child/youth: _____

		For infants and toddlers	For early childhood	For primary	For intermediate	For secondary
Daily Care of Oneself	Carrying out daily routines to look after one's body (hygiene, nutrition, health) and day-to-day demands or duties (chores, homework, etc) and manage responsibilities.	Cries to show hungry, wet, or tired; follows care routines with support	Increasing interest in feeding, dressing, and toileting without help from adult	Completes self-care tasks; interest in food and exercise. Complete a few household chores with reminders	Manages time to complete homework, home routines, and chores	Manages time to complete homework, home tasks, and care for family members or begin employment
Manipulate Materials	Perform tasks with objects and materials including holding, picking up, throwing, catching, turning, twisting, etc.	Grasp objects, put object in and take out, bang objects together, use spoon or cup	Begins to use materials in intended ways – scissor to cut, pitcher to pour	Increasing accuracy with the movement of and use of materials such as scissor or writing utensil	Use movement skills to engage in challenging and tasks (painting, drawing, and sculpture)	Use movement skills to engage in challenging and tasks with refined skills
Movement	Coordinate movements, muscles, and body position to move between locations, on and off objects.	Crawl, roll, scoots Stands with support, first steps, increasing balance	Walk, run, climb, jumps on and off objects	Increasing endurance for running/walking greater distances; hopping, jumping climbing novel objects (tree)	Gaining agility, strength, endurance and coordination	Sustain movements and physical activities; regulate and adjust physical performance
Orient Self in Space	Understand body in space in relation to objects and surroundings.	Has body awareness; understands body parts and how the body fits together; understands how body parts move	Understands body planes e.g. front, back side; understands self to object relations	Understands object to object relations; can navigate in familiar environments	Understands how object to self relations change as we move; can use map to navigate unfamiliar areas	Understands compass directions and can use them to navigate in unfamiliar areas
Additional Notes about Functional Ability						



Name of child/youth: _____

Adaptations and Specialised Equipment Profile (ASEP)

(Adaptations, augmentative and alternative communication systems, assistive technology, or adaptive devices)

Directions: In the functional ability profile, teams indicated whether the child typically uses or does not use adaptations, augmentative and alternative communication systems, assistive technology, or adaptive devices on a regularly basis related to each of the functional domains. In this Profile you will record those which the child has previously used, currently uses and/or which might be desirable for future use. Adaptations and specialised equipment are grouped by general categories. The general categories are not intended to be mutually exclusive; nor are the lists exhaustive. Please describe other adaptations and equipment as needed.

Communication - Literacy	Previously Used	Currently Used	Possible Future Use	Orientation – Mobility - Positioning	Previously Used	Currently Used	Possible Future Use	Other	Previously Used	Currently Used	Possible Future Use
Large print				Pre-cane				Glasses			
Screen enlargement software				Cane				Hearing aides			
Screen reader				Walking frame				FM system			
Talking books				Standing frame				Hearing amplifier			
Daisy Reader (or audio books)				Lift				Timer			
Magnifiers or monoculars				Modified chair				Talking watch			
CCTV				Seat cushion				Talking calculators			
Reading guides				Wedges				Adapted utensils			
Adapted keyboard				Orthotic devices				Liquid level indicator			
Adapted mouse				Resonance Boards				Individualised schedule			
Touch screens				Maps				Adaptive switches			
Large handled writing devices				GPS software				Joysticks or trackballs			
Brallers				Models				Electronic pointing device			
iPad				Slope board				Audio recorders			
Computer				Wheelchair – describe:				PDA or Smart Phone			
Visuals – describe (e.g. visual timetables, visual stories)				(e.g., powered, self-propelled, attendant)				Specialised software - describe:			
Low-Tech AAC – describe system(s) & access mode:				Other:				Specialised app - describe:			
				Other:				Environmental control - describe:			
High-Tech AAC – describe system(s) & access mode:				Other:				Daily living equipment (e.g., toilet) – describe:			
				Other:				Other:			



Name of child/youth: _____

Adaptations and Specialised Equipment Profile (ASEP)

(Adaptations, augmentative and alternative communication systems, assistive technology, or adaptive devices)

Directions: In the functional ability profile, teams indicated whether the child typically uses or does not use adaptations, augmentative and alternative communication systems, assistive technology, or adaptive devices on a regularly basis related to each of the functional domains. In this Profile you will record those which the child has previously used, currently uses and/or which might be desirable for future use. Adaptations and specialised equipment are grouped by general categories. The general categories are not intended to be mutually exclusive; nor are the lists exhaustive. Please describe other adaptations and equipment as needed.

Communication - Literacy	Previously Used	Currently Used	Possible Future Use	Orientation – Mobility - Positioning	Previously Used	Currently Used	Possible Future Use	Other	Previously Used	Currently Used	Possible Future Use
Large print				Pre-cane				Glasses			
Screen enlargement software				Cane				Hearing aides			
Screen reader				Walking frame				FM system			
Talking books				Standing frame				Hearing amplifier			
Daisy Reader (or audio books)				Lift				Timer			
Magnifiers or monoculars				Modified chair				Talking watch			
CCTV				Seat cushion				Talking calculators			
Reading guides				Wedges				Adapted utensils			
Adapted keyboard				Orthotic devices				Liquid level indicator			
Adapted mouse				Resonance Boards				Individualised schedule			
Touch screens				Maps				Adaptive switches			
Large handled writing devices				GPS software				Joysticks or trackballs			
Braille				Models				Electronic pointing device			
iPad				Slope board				Audio recorders			
Computer				Wheelchair – describe: (e.g., powered, self-propelled, attendant)				PDA or Smart Phone			
Visuals – describe (e.g, visual timetables, visual stories)				Other:				Specialised software - describe:			
Low-Tech AAC – describe system(s) & access mode:				Other:				Specialised app - describe:			
				Other:				Environmental control - describe:			
High-Tech AAC – describe system(s) & access mode:				Other:				Daily living equipment (e.g., toilet) – describe:			
				Other:				Other:			



Name of child/youth: _____

Interests and Preferences

Directions: Consider the child/youth's likes and dislikes related to key areas indicated. Within the space provided, list things the child is known to avoid, show an interest in or has a favourite related to the key areas. Fill out information that is most relevant for the child/youth (i.e., not all spaces need to be completed).

Key areas	Avoids	Shows an Interest In	Has as a Favourite Thing or Activity
Clothes, toys & materials			
Activities or games			
Types of electronic or social media			
TV, Movie, other dramatic themes and characters			
Books or Stories			
Songs or Music			
People (<i>adults or peers</i>)			
Food & drinks			
Other (Specify)			
Are there any things the child/youth likes or dislikes that are inconsistent with family preferences, aspirations, or routines? (e.g., <i>child likes to use the computer but the family wants him to spend more time outside</i>)			Note how rapidly or slowly the child/youth's interests and preferences change.



Name of child/youth: _____

Priority Planning Page (PPP) – Information Summary

Directions: Record key information from sections of the toolkit (i.e., what the team learned about the child that is relevant for setting priority goals & designing interventions).

Record Key Information from Each Profile					
Sensory Modality Profile (SMP)	Communication Profile (CP)	Participation and Access Profile (PAP)	Functional Ability Profile (FAP)	Adaptations and Specialised Equipment Profile (ASEP)	Interests and Preference Profile (IPP)
List key sensory strengths:	Describe the child's method of communication:	List key activities currently actively participating in:	List key functional ability strengths:	List current adaptations and equipment in use:	List child preferences and interests:
List key sensory difficulties:	List the reliable communication partners:	List key activities to strengthen participation in:	List key functional ability difficulties:	List possible future adaptations and equipment:	List un-preferred or avoided items:
Other notes:	Describe how the child communicates key information:	Describe current barriers:	List adaptations or assistive technology used or desired:	Consider pathways to access new equipment:	Other notes:



Name of child/youth: _____

Priority Planning Page (PPP) – Educational Planning

Directions: Have the members of the educational team fill out the profile and jot ideas into the this form. Then engage in collaborative goal-setting and decision-making with children/youth and families based on an integrated view of the children/youths' needs in the home, school, and community.

Based on Information Gathered about the Child/Youth			
Setting:	Identify priority goals for learning and participation (<i>needs</i>):	Describe the planned supports and interventions (<i>building off strengths, interests and preferences</i>):	Indicate who will support the child/youth and when:
Home			
School			
Community			

Appendix 9: Focus Group Ground Rules and Questions

Focus Group Interview

Welcome

Kia ora and welcome to this focus group interview. Thanks for taking the time to be a part of this team looking at the New Zealand Child and Youth Profile.

Overview of the topic

The purpose of this interview is to gather your experiences and opinions as individuals who are supporting the education and development of a child with foetal alcohol spectrum disorder. I am seeking your views on how your educational team used the New Zealand Child and Youth Profile, how helpful it was in understanding the educational profile of your student, and how it facilitated team educational planning. To keep things brief, from here on in I will refer to the New Zealand Child and Youth Profile as “the Toolkit” and foetal alcohol spectrum disorder as FASD. At this point I would also like to reiterate that you have the right to decline to answer any question.

Ground Rules

I’ll be asking you a series of questions which I would like you to discuss. I’m interested in hearing lots of different experiences and opinions—as much as you can tell me about my questions. There are no wrong answers. I expect that you will have differing points of view. Please share your point of view even if it differs from what others have said. Don’t feel like you have to respond directly to me all the time. If you want to follow up on something that someone has said, you want to agree, or disagree, or give an example, feel free to do that. Feel free to have a conversation with one another about these questions. I am here to ask questions, listen, and make sure everyone has a chance to share. I am interested in hearing from each of you. So, if you are talking a lot, I may ask you to give others a chance. And if you aren’t saying much, I may call on you. I just want to make sure all of you have a chance to share your ideas.

I am recording the session because I don’t want to miss any of your comments. No names will be included in any research reports. Your comments are confidential. If you have a cell phone, please put it on the quiet mode, and if you need to take a call, please step out to do so. Feel free to get up and get more refreshments if you would like.

Opening questions

Let’s get started. Let’s find out more about each other by going around the table one at a time.

Please tell us your name, relationship to the student and your role in supporting them? What skill, talent, experience do you bring that you believe is important in helping your student/child?

It has been a few weeks since our last meeting, and you have had the change to fill out the profile individually, and then come together to use it as a group.

Please describe your experience of using the Toolkit for team educational planning for your student with FASD?

Part of my research is to see whether the Toolkit helps improve understanding of a student with FASD's educational profile. I would like us to focus on this aspect now.

Educational profile

In what ways did you find the Toolkit improved your understanding of the developmental profile of your child/student?

What were the strengths of the Toolkit in this regard? Weaknesses?

In what ways has the Toolkit changed your perceptions of the child's learning profile? i.e. Did it change or strengthen any of the ideas you had previously held about the student?

How has your understanding of FASD and its impact on a child's learning and behaviour changed since using the Toolkit? In what ways?

Now I would like to look at team educational planning.

Team Educational Planning

How did you find using the Toolkit in relation to educational planning for your student with FASD?

How did you use the Toolkit for educational planning?

What worked well?

What could be improved?

What problems or issues were encountered during the use of the Toolkit?

What were the strengths and weaknesses of the Toolkit in relation to educational planning?

What factors would be involved in your decision to use/not use the Toolkit in the future?

i.e. what are the reasons that would prevent you from using the Toolkit?

What would encourage you to use it more?

Collaboration

Part of my research is trying to see how the Toolkit aids in collaboration. I want to focus on your experience using the Toolkit as a team and what that was like.

In what ways did you perceive the Toolkit as contributing to successful collaboration?

In what ways did you perceive the Toolkit as hindering successful collaboration?

Did you feel like an equal member of the team? What made you feel that way?

How can the Toolkit be used to improve collaboration between team members in educational planning?

What steps might be used to enhance collaboration?

Final question

Is there anything else you would like to tell me about your experiences of using the Toolkit?

Thank you for coming together today to share your ideas and experiences with me. After listening to this recording, I may want to approach some of you individually to clarify some things and ask you more questions. Are you alright if I do this?

I just have a card of thanks and a small gift to give to you.

Prompts

Tell me more about...?

What do you mean when you say...?

Can you give me an example of...?

What was it like for you when...?

What did you do then...?

How is it...?

Why is it...?

How do you feel?

How does that affect...?

Note: Not all lead on and prompt question will be used. It will depend largely on the given responses of the participant

Appendix 10: Codebook

Code	Description	Example
Language	Participant indicates that the language of the NZCYP made it difficult to understand and/or complete	“I was still a little bit lost within some of the jargon that was written here.”
Clarity	Participant indicates the need for clarity in documents like the NZCYP.	“The reality is - concise and clear is better for teachers”.
Time	Participant indicates that the length of time to complete the NZCYP made it difficult to complete.	“I don’t have four hours to sit and fill out paperwork like this.”
Student	Participant indicates the NZCYP was not a good fit for the student.	“Really the simple thing is he doesn't fit the scale.”
School	Participant indicates the NZCYP was not a good fit for the school.	“There are large parts of the form that just aren't relevant probably in the secondary setting.”
Community	Participant indicates the NZCYP was not a good fit for their community.	“Because you know where you have got that in terms of background and this [indicating form] like that, that's high school musical, and that's not our kids.”
Cultural fit	Participant indicates the NZCYP was not a cultural fit for the student.	Mother: “It's not just English you know, and I know that we can write slash Māori but it's very [Grandmother: Boxed].”
Overly Negative	Participant indicates the negative focus of the NZCYP impacted on their completion and use of it.	“But I found it quite disheartening because I couldn’t say the positive things about him. It sort of tended to lean towards how to deal with the negatives of him”.
Overly Positive	Participant indicates profile was overly positive for their student.	“It’s not a happy place where unicorns are running around [...]and they are eating candyfloss clouds”
Impact of Lack of Knowledge	Participant indicates that their lack of knowledge about the student impacted	“I haven’t had very much to with him at all or anything and so for me filling out the form was no point whatsoever.”

	on their ability to complete and/or apply the NZCYP.	
Transition	Participant indicates that the information provided by NZCYP may be a valuable tool for transition.	“Sharing the document before they come to us. Definitely at intermediate level. [Researcher: So that transition?] Yes, transition definitely”.
Change in Awareness of Student’s Profile	Participant indicates a change in awareness around the profile of the student.	“What I didn't know was how he can flip out and kind of leave his body and all that kind of thing. And woah that's next level”.
Change in Teacher/Classroom practice/planning	Participant indicates a change in teaching practice and/or planning as a result of a change in awareness of the student’s profile.	“Yeah, it made me look at the planning I had. So, I changed a couple of things in the classroom, so they are more visible now based on having gone through those”.
Impact on Understanding of FASD Profile for Other Students	Participant indicates NZCYP impacted on their awareness of the profile of other students with FASD.	“It helped us develop our understanding of what other FASD kids are like”.
Generating Discussion, Sharing Information	Participant indicates the team had been able to generate discussion and share this information.	“It caused Z and I to put down what we could and when we got with the teachers and talked about it, I think that way we didn't leave stuff out. We were able to actually share”.
Bringing the Team Together	Participant indicates team collaboration was the result of bringing the team together and not the NZCYP.	“What I did get out of this process, which was priceless, was the face to face korero. So in between our last hui when you came, when we actually had mum and nan come along with our team and sit down and share those things that work well with our man and triggers that kind of to be wary of too.”
Collaborative Framework already in Place	Participant indicates the team already had an effective collaborative framework in place.	“To be honest I've probably been to the room...we are pretty regularly in contact around the room and student anyway. And a good triangle with mum as well. We work pretty hard to communicate, to be honest, with him, and you are dealing with his behaviour anyway.

Multiple Perspectives	Participant indicates that considering multiple perspectives helped support collaborative practice.	<p>I think we have been pretty efficient in what we...how we deal with it, and it hasn't changed that or the behaviours”.</p> <p>“The other thing was clarification of some of those as well. So, sort of doing the comparing with another person and saying, ‘oh why have you given a plus and whereas I have given a negative?’ But then it’s our perception of that student.”</p>
Cultural Misalignment	Participant indicates more informal cultural practice of the classroom better suited for collaboration than NZCYP.	<p>“Our language was a[n] oral language not really a written language so when we need to sort things out it wasn't send an email. It wasn't send a message. It was hey come and have a chat. And that way you can't read the wrong way into messages [...]. And sort of read that and ‘Oh I am a little bit lost’ it is probably best just to have a korero”.</p>

Appendix 11: Journal Excerpts

Reflexive Journal

May

I have been working my way through my methodology chapter and have included that I will keep a reflexive journal throughout this process. This is something new for me and I am not sure of the shape that it will take, or quite what things I need to be reflecting on during this process. When in doubt go to the library!

Thorne (2016) argues that before beginning research the researcher should acknowledge and record their ideas and beliefs on the phenomenon they are going to study as their perspectives, and experiences will influence their approach to, and their interpretation of, the study. Thorne (2016) recommends keeping a reflective journal which, whilst it may not form part of the data, it can be used later as a reference to support understanding of the reasons and consequences for the researcher's actions in regard to collecting and analysing data.

I am feeling quite daunted by this process and how I fit into it. Not sure my background is going to give me the experience and expertise to be confident and competent in the training. Most of the articles I have read around this suggest lots of practice at taking focus groups. Will have to think on how I can get that practice in.

June

Sally has posted an article on reflexivity by Creswell and Poth (2018). A quote that seemed pertinent was '*How we write is a reflection of our own interpretation based on the cultural, social, gender, class, and personal politics that we bring to research. All writing is "positioned" and with a stance. All researchers shape the writing that emerges, and qualitative researchers need to accept this interpretation and be open about it in their writings*' (p. 228). So in going forward my focus will be on acknowledging the position and perspective that influences my writing. I am a woman of European descent, from a working class upbringing. I have a high level of education and enjoy a "middle class" lifestyle. My culture affords me the privilege of inheriting Eurocentric government, healthcare and education systems that were designed for, and benefit me. I have family and friends who do not enjoy the same privileges as I do. This makes me uncomfortable as it feels wrong that I should benefit through no actions of my own while they do not. I view this as an injustice and strive to keep that knowledge of my own privilege at the forefront when dealing with people who have not experienced the same privilege. It is easier to judge someone and victim blame if you ignore your own privilege. I place great importance on my role as a mother, having four children of my own.

In coming to this research, I am already aware of the stigma that comes with FASD, both for the birth mother and the child. As I have carried out my research I am aware that there are multiple potential contributing factors, including the impact of poverty and colonisation, that can contribute to women consuming alcohol during pregnancy and the impact of this on the child. Further, I am also mindful that this issue is not a women's one and should not be targeted so.

August

Work has begun on the training PowerPoint. I am trying to put myself in the place of the people receiving the training to work out what information they will need versus what is irrelevant. Not sure all the information regarding the psychosocial model is necessary. These people are busy, do they really need to know this stuff? Feeling nervous about the training as it will put me way outside my comfort zone. Am concerned that as I am not a teacher and have no teaching experience on which to draw from, I may be at a disadvantage when completing training on the Toolkit for educational planning. In my role as teacher aide I have been asking a number of questions around educational planning for children with LSN. Have found there appears to be confusion by teachers regarding the function and purpose of educational planning, in particular who is responsible for what roles, and then how this is implemented and monitored. This suggests the Toolkit maybe useful in helping to clarify roles and responsibilities through its collaborative approach.

September

The trial of the training was held today. The teachers raised concerns regarding the ability of some parents to understand the complex language being used in the NZCYP. Indeed, they struggled with aspects themselves. This seems a realistic concern by the teachers, but I am also aware there is also the potential for bias or assumptions regarding the parents' abilities that may be attached to this concern. I.e. the notion that parents with children with LSN/ disabilities will be less educated and less able to understand the terminology. This may also support research that suggests that parents feel their voices are not heard and that there is an uneven balance of power, with schools and other professionals in the dominant position. If the teaching and allied professionals have a belief already that parents are going to struggle to understand the document, this may reinforce the unconscious or conscious assumption that teachers and schools are in a position of superiority. If so, is it possible that the NZCYP may perpetuate this dominance?

On the other hand, if the teachers raise a valid point, will the language of the Toolkit also perpetuate this perceived dominance by creating a situation where the parents feel 'foolish' because they do not understand the language, and therefore feel they need to acquiesce to the seemingly more knowledgeable professionals?

Appendix 12: Low Risk Notification



Date: 30 April 2018

Dear Joanne Van Wyk

Re: Ethics Notification - **4000019426 - Exploring the New Zealand Child and Youth Profile as a collaborative tool to support educational planning for children with fetal alcohol spectrum disorder.**

Thank you for your notification which you have assessed as Low Risk.

Your project has been recorded in our system which is reported in the Annual Report of the Massey University Human Ethics Committee.

The low risk notification for this project is valid for a maximum of three years.

If situations subsequently occur which cause you to reconsider your ethical analysis, please contact a Research Ethics Administrator.

Please note that travel undertaken by students must be approved by the supervisor and the relevant Pro Vice-Chancellor and be in accordance with the Policy and Procedures for Course-Related Student Travel Overseas. In addition, the supervisor must advise the University's Insurance Officer.

A reminder to include the following statement on all public documents:

"This project has been evaluated by peer review and judged to be low risk. Consequently, it has not been reviewed by one of the University's Human Ethics Committees. The researcher(s) named in this document are responsible for the ethical conduct of this research.

If you have any concerns about the conduct of this research that you want to raise with someone other than the researcher(s), please contact Associate Professor Tracy Riley, Acting Director - Ethics, telephone 06 3569099 ext 84408, email humanethics@massey.ac.nz."

Please note, if a sponsoring organisation, funding authority or a journal in which you wish to publish requires evidence of committee approval (with an approval number), you will have to complete the application form again, answering "yes" to the publication question to provide more information for one of the University's Human Ethics Committees. You should also note that such an approval can only be provided prior to the commencement of the research.

Yours sincerely

A handwritten signature in blue ink, appearing to read 'Tracy Riley'.

Research Ethics Office, Research and Enterprise
Human Ethics Low Risk notification

Associate Professor Tracy Riley, Dean Research
Acting Director (Research Ethics) Research Ethics Office, Research and Enterprise Massey
University, Private Bag 11 222, Palmerston North, 4442, New Zealand **T** 06 350 5573; 06
350 5575 **F** 06 355 7973 **E** humanethics@massey.ac.nz **W** <http://humanethics.massey.ac.nz>

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