Creating appreciation and community support for mothers caring for a child with an anxiety disorder

discovering our meaningful values,
doing meaningful work & activities together,
connecting, helping, & feeling happy for others,
having childhood trauma being acknowledged & supported
creating a secure future

Creating

Connection

Managing the Challenges of Ongoing Stress

Completing the stress cycle
Managing the stressors
Making Meaning

7 Connecting Habits to meet needs

caring,
trusting, listening,
supporting, negotiating,
befriending, and encouraging

5 Basic Human Needs

Survival
Love & Belonging
Power
Freedom
Fun

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Abstract

This project examined a unique approach to anxiety disorder, one of the most prevalent and growing mental health concerns internationally. It uncovered the mostly invisible and challenging experiences of mothers caring for a child with an anxiety disorder and the value of their reciprocal relationships with their children for both their health and wellbeing. In addition, it explored social identity in making meaningful connection using a generative action-oriented social approach to address anxiety in the community.

An Appreciative Inquiry, using social constructionist theory, and underpinned by elements of Kaupapa Māori values, was utilised to explore the research questions. The data was collected via paired interviews, focus groups and small questionnaires with three to four mothers, after which, thematic analysis was undertaken to identify important themes.

There were four key themes discovered in the findings. (1) The mothers' ongoing and challenging experiences of being silenced and isolated on the fringes, navigating the quagmire of social and institutional systems to help them help their children; (2) The mothers' learning to cope by creating calm in the home, the child, and in themselves, often requiring them to 'suspend' their lives until their children become more independent; (3) The mothers employing a 'Mother as Advocate' identity to face the challenges, and co-creating a 'Mother as Advocate' group identity to continue to face those challenges to design a collective initiative; and (4) The value of freedom that the mothers experienced participating in the appreciative inquiry process with other mothers facing similar challenges and sharing their stories.

This study demonstrates how appreciative inquiry is aligned with and supports the value of social identity theory and creating meaningful connections to help position and address anxiety disorder in the community. A key insight gained in this study is that our current social and institutional systems create disconnection in many facets of western life, which contribute to the generation and perpetuation of stigmatisation, isolation, and anxiety disorder. With a western capitalistic and individualistic culture, mental illness has become predominantly pathologized and medicated, positioning anxiety disorder within the child, and relegating the social dimension of the biopsychosocial approach as almost irrelevant. As mothers in this system spend valuable energy advocating for more support for their children, they put their own mental health at risk. There is no one solution; however, this study demonstrates that when mothers are supported through an appreciative inquiry process, strengthening their personal and social identities, health and wellbeing have the potential to increase for them, their children, and the community.

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Chapter One: Introduction

This project will focus on a unique perspective to anxiety disorders – the mother's experience caring for a child with an anxiety disorder, and a collective approach to address the social and community aspects of childhood anxiety disorders.

An anxiety disorder is not an isolated experience: both the child and their parent(s) need to directly and indirectly manage the disorder in every facet of their lives. Anxiety disorder behaviours may present as fear and avoidance of social situations (avoiding school, public places, public transportation, going outside the house), panic attacks, irritability, fatigue, and sleep problems while the child deals with excessive worrying, agitation, restlessness, difficulty concentrating, and irrational fears. When one or more of these symptoms are experienced on the majority of days for at least six months, it is considered an anxiety disorder (American Psychiatric Association, 2021; Healthline, 2018).

Anxiety disorders are prevalent and rising (Bowden et al., 2019). Moderate to severe anxiety disorders are the most common psychiatric illnesses affecting 1 in 4 children and adults in NZ over their lifetime or 14% in any one year (Anxiety NZ, 2020). For Māori, the lifetime prevalence of anxiety disorder is 31%, and often presents alongside other conditions such as substance abuse and mood disorder, all of which appear to be overrepresented in comparison to non-Māori (Kopua et al., 2020). With a total July 2018 population of 4,545,627 (Indexmundi, 2019), we can estimate that more than 630,000 families in NZ are experiencing anxiety in their homes each year.

Anxiety disorders are also cited as one of the most common mental health problems internationally. In Australia, anxiety disorders are affecting 14% [12 months prevalence] of all people aged 16-85 years (Australian Institute of Health and Welfare, 2021, para 3; Soo et al., 2011, p. 54), and in the United States, anxiety disorders have "the highest prevalence of any other group of disorders [31.1% lifetime prevalence], and have been called 'the single largest mental health problem in the [US]" (Moore Mayo et al., 2006, p. 119). Mental Health America (2021) cite that over 21% of adults (42.5 million) are affected by anxiety disorders each year (para 2). From a 2020 mental health condition screening of over 1.5 million people, loneliness and isolation were identified as one of the top three contributors to their mental health concerns (Mental Health America, 2021, para 14).

The most recommended treatments in NZ for anxiety disorders are individualised therapeutic sessions with a counsellor/psychologist/psychiatrist, and antidepressant medication (Bowden et al., 2019; Anxiety NZ, 2020; Healthline, 2020; Health Navigator NZ, 2020), despite the fact that "antidepressant medications, especially SSRI's (serotonin-specific reuptake inhibitors) have been shown to be [only] *modestly* beneficial for the treatment of anxiety and depression in children and young people" (Bowden et al. 2019, p. 56). Hari (2018) cited Harvard research

that concluded that "antidepressant effects are largely a placebo, but the side effects are mostly the result of the chemicals themselves, and they can be very severe" (p. 39).

This research will not specially engage with the therapeutic approaches that focus on treating the individual who has anxiety; rather, it will focus on a collective approach with the aim of addressing anxiety disorder at a community level. Hari (2018) concluded that there are two things that make anxiety and depression more likely:

> Having a severe negative event, and having long-term sources of stress and insecurity in your life. But the most startling result was what happened when these factors were added together. Your chances of becoming depressed didn't just combine: they exploded. For example – if you didn't have any friends, and you didn't have a supportive partner, your chances of developing depression when a severe negative life event came along were 75%. (p. 62)

> Years later, [Harris] used the same technique to carry out a study of anxiety – and found similar results. It wasn't just a problem caused by their brain going wrong. It was caused by life going wrong. (Hari, 2018, p. 65)

Hari (2018), Maté (2019), and Glasser (2002) argue that the social and psychological causes of depression and anxiety are all forms of disconnection. Hathaway (2017), Hari (2018), and Haslam et al. (2018) demonstrate that together we can move from despair to empowerment to create social change in response to a collective issue.

Using focus groups, in an appreciative inquiry, this research will uncover parents' lived experiences caring for a child with an anxiety disorder, and through this process, discover possibilities for creating community action to address the community component of anxiety disorder. My research posed these questions:
1. What are the stories of parents' lived experience caring for a child with an anxiety disorder; especially in relation to coping, stabilising factors, hopes for the future, and taking action?
2. What are the ideas for change that emerge from appreciative inquiry discussions and connection?
3. What kinds of actions can parents see themselves doing individually and/or collectively in the immediate future?

As the researcher, I come with a lived experience of caring for three children (one as a client I work with 2 to 3 days a week) with an anxiety disorder, each presenting different behaviours and needs. I am a trained Narrative Therapist, Group Facilitator (anti-bullying & sexual assault prevention), Community Coordinator, and Community Facilitator.

Chapter Two: Literature Review

"Never doubt that a small group of thoughtful committed citizens can change the world, indeed it is the only thing that ever has." Margaret Mead

(Ricketts, 2012, p. 20).

2.1 Introduction

This review will give a brief description of anxiety disorders and some of the current individualistic treatments for people with anxiety. It will describe parental distress caring for a child with an anxiety disorder or disability, and the prevalence of disconnection in relation to childhood anxiety and parental distress. This review will then report on different social approaches to create reconnection and improve mental health, with examples.

2.2 Anxiety Disorders

The 5th edition of the Diagnostic Statistical Manual of Mental Disorders (DSM 5) characterises anxiety disorders as having an excessive degree of anxiety and fear and related behavioural disturbances, and it no longer considers obsessive-compulsive disorder, acute stress disorder, and post-traumatic stress disorder as anxiety disorders (Medscape, 2019). An anxiety disorder can be distinguished as the feeling of fear where there is no obvious threat (as cited in McMurray, 2003, p. 2). Because the body's stress response system cannot turn off, people with an anxiety disorder are living in a state of emergency (Dispenza, 2014; Mayer, 2016; Kanji, 2019). Pai et al. (2017) explained that (post-traumatic stress disorder) PTSD used to be considered an anxiety disorder in the DSM-IV but was changed to a "Trauma and Stressor-related Disorder" (p. 2) in the DSM-5 due to more emotions being experienced with PTSD in addition to fear and anxiety. In this review I include PTSD as an anxiety disorder mainly because the treatments for PTSD are very similar to those for anxiety disorders.

As discussed in the introduction, anxiety disorders are found in people who have experienced trauma and/or ongoing distress, especially when they are without social support. Kanji (2019) cited Harvard research (Famularo et al., 1992) that demonstrated that "children who were maltreated were 300% more likely to experience mood disorders and 200% more likely to experience anxiety" (p. 23). Another study (Masuda et al., 2007) cited by Kanji (2019) concluded that "adverse childhood experiences, such as emotional abuse and an illness in the household, almost doubled the person's chance of stress related illness" (p. 25), and if a child is emotionally or physically bullied at school by peers or teachers, "the person's risk of stress related illness [increased] by 250%. The more factors a person experienced the higher their risk of stress related illness became" (p. 25). Bridgman et al. (2018) cited the OECD 2015 PISA International Survey where "at 18.5%, New Zealand has the second highest percentage of school children who are frequently bullied, double the OECD average" (p. 23). They also cited seven Ministry of Health studies to conclude that "our age-standardised rates of admissions

to mental health services for 10 to 14-year-olds have risen 63% from 2010 to 2016…and are rising faster than any other age group" (p. 23).

2.3 Treating Anxiety Disorders: Antidepressant Medication

In NZ, between 2007 and 2016, "the total number of annual antidepressant prescriptions dispensed to children and young people increased by 68%...and the rate of prescribing increased by 44%" (Bowden et al., 2019, p. 55). With the significant growth of antidepressant treatment for children and teens, it is important to understand if it is working.

A meta-analysis of 234 studies involving 37,333 participants (Bandelowa et al., 2015) compared the efficacy of antidepressant medication, therapeutic treatment and combined treatments for anxiety disorders (panic disorder, generalised disorder and social phobia) and determined that "medications [with some exceptions] were more effective than placebo and psychotherapies" (p. 183). However, they also warned that drugs "may have side effects, interactions and contraindications" (p. 191). A Lancet systemic review and network meta-analysis based on 89 trials and over 25000 patients (Slee et al., 2019) compared 22 different medications and placebo for generalised anxiety disorder (GAD). They concluded that the majority of the drugs were more efficacious than placebo, with varying tolerances and acceptability. Another meta-analysis (Carl et al., 2020), using 79 trials and 11,002 participants tested the efficacy of medications and psychotherapies for GAD. The results indicated a small effect size on GAD outcomes for medication.

Although the above meta-analysis and systemic reviews appear to indicate medication as good, or, the best option for treating anxiety, there is noteworthy research indicating different results. Kanji (2019) claims "medications can often help short term but often work poorly long term for insomnia, anxiety, and depression" (p. 29). In his book, *Lost Connections*, Hari (2018) cited Kirsch (2009) arguing that "25% of the effects of antidepressants were due to natural recovery, 50% were due to the story you had been told about them, and only 25% to the actual chemicals" (p. 27). Also, weak results from clinical trials have deliberately been hidden for purposes of profit over wellbeing (Hari, 2018) and a 2016 meta-analysis published in the Lancet (Cipriani et al., 2016) verified the lack of any "clear advantage" (p.881) of 14 major antidepressants given to teenagers.

Page et al. (2004), Hari (2018) and Bowden et al. (2019) all conclude that only about 30% of people have actually recovered using antidepressant medication alone. Haslam et al. (2018) similarly argue that the lack of evidence for effective treatment of chronic physical and mental health conditions by medication alone, suggests that "there is generally no simple biomedical fix that can be administered to restore health" (p. 4).

2.4 Treating Anxiety Disorders: Individualised Therapies

In NZ, most treatments for anxiety disorders involve prescription antidepressant medication and Cognitive Behavioural Therapy (CBT), one of the most researched and practiced clinical and mainstream treatments (McMurray, 2003; Haslam et al. 2016). A systematic review concluded that CBT is an effective treatment for anxiety disorders; however, the evidence is limited and inconclusive of whether it is more effective than other treatments (James et al., 2015). James et al. also found 16% of participants recover without treatment and that over 40% who were treated with CBT did not recover. Bandelowa et al. (2015) verified in their meta-analysis that CBT had a higher rate of efficacy when compared with waiting list and psychological and pill placebos, and although their analysis concluded that medication was better than CBT, they noted that the UK National Institute for Health and Clinical Excellence evaluated psychotherapy to have similar or better results than pharmaceuticals. Carpenter et al. (2018) conducted a meta-analysis on the efficacy of CBT for anxiety disorders using 41 studies and 2843 patients, and determined that CBT's efficacy rate is moderate when compared to placebo, and they further identified that PTSD requires more effective treatments. Also, in the same meta-analysis, CBT benefits are initially shown to be maintained longer after treatment compared with medication.

A 2018 network meta-analysis suggested that CBT delivered in a group format has better results for young people with acute anxiety and who have received individual CBT treatments (Zhou et al., 2018). In comparison, (Bandelowa et al., 2015) concluded that individualised CBT treatments are more effective than group CBT sessions. A possible reason for this variance could be the different ages and disorders used in this meta-analysis in comparison to focusing on youth with acute anxiety.

Individuals experiencing an anxiety disorder have also found individualised support outside of CBT in non-mainstream treatments and practices. Wahbeh et al.'s (2014) systematic review of 33 studies involving 1329 adults reported while many utilise complementary and alternative medicine for PTSD symptoms, they determined that "repetitive transcranial magnetic stimulation has the strongest evidence for benefit followed by acupuncture, hypnotherapy, meditation, and visualization" (p. 172). They determined that more research is needed for biofeedback, relaxation, Emotional Freedom and Thought Field therapies, yoga, and natural products in relation to PTSD. Further, a meta-analysis of 209 studies involving 12,145 participants (Khoury et al., 2013) and systematic review of 47 studies and 3,515 participants (Goyal et al., 2014) on mindfulness meditation showed that mindfulness-based therapy reduced anxiety and was more effective than psychological education, supportive therapy, relaxation procedure, and imagery or suppression techniques and that there were no significant differences in outcomes compared with CBT and medication.

Like meditation, Emotional Freedom Technique (EFT), a tapping therapy, also works to decrease stress and improve emotional wellbeing and is "considered an evidence-based therapy for anxiety, depression, phobias and post-traumatic stress disorder" (The Recovery Village, 2020, para. 2). Two small scale meta-analysis/systematic reviews (Clond, 2016 – 14 studies, Sebastion & Nelms, 2016 – 7 RCTs) showed that EFT produces significant and durable reductions in anxiety and PTSD at about the same level as CBT and eye movement desensitization and reprocessing therapy (EMDR). It also has the benefits of no adverse side effects and can be used as both a therapy and a personal practice.

Neuro-linguistic Programming (NLP) was shown to effectively reduce social anxiety in a small study of 30 participants (Abdivarmazan and Sylabkhori, 2016). In a small-scale meta-analysis involving 12 studies focused on NLP as a strategy for dealing with psycho-social problems, Zaharia et al. (2015), concluded that although positive outcomes are demonstrated, there is insufficient data to recommend it as a therapy.

The individualised psychological approach of Western psychiatry utilises medication and therapeutic sessions for treating children with anxiety. Concerns have been raised about the effectiveness of an individualised therapeutic approach and how a Western therapeutic approach positions the understanding of anxiety disorder as a problem of individual biology and way of thinking, and how community healing approaches are largely ignored (Haslam et al., 2016). Another concern, identified by Kopua et al. (2020), points to the issue of not integrating valuable local indigenous healing approaches that sit outside the practices of Western psychiatry.

2.5 Parental Distress Caring for a Child with an Anxiety Disorder

The individual's experience of mental illness, has been the primary focus of most of the research on anxiety disorders, however mental illness affects the whole family who are in relationship to the needs, behaviours and recovery journey of the child with an anxiety disorder. The young person may not be the only family member experiencing an anxiety disorder. Mental health researchers (Keeton et al., 2013; Franck et al., 2015; Pishva, 2017) agree with Leamy Case's (2009) assertion that "when a child is diagnosed with a significant health problem, they and their families are at increased risk of experiencing psychological distress and disorder" (p.1).

Parents face considerable challenges with anxiety disorder, an invisible disability, that presents with unpredictable behaviours that are ongoing. Charles & Butera-Prinzi (2008) described how these challenges influence parental coping, where parents often experience: "persistent heightened distress, hypervigilance, depression, anxiety, anger and physical ill health" (p. 64). Ennis et al. (2013) and Norup et al. (2013) note the importance of including the parents' health and wellbeing, as well as the overall functioning of the family, in the

child's recovery plans. Citing Chwalisz' (1996) *perceived stress model of caregiver burden*, Norup et al. (2013), demonstrated that if the injury [or illness] exceeded the "caregiver's available resources… [it] would lead to negative outcomes" (p. 143). Nagoski and Nagoski (2019) in *Burnout: The Secret to Unlocking the Stress Cycle*, argue similarly about caregiver burden exceeding capacity with the cultural expectations of "Human Giver Syndrome" that is put on women [and mothers] to be *self-less*, with any self-care being deemed *selfish*.

Norup et al. (2013) identified key strategies of coping that were helpful or detrimental to the family. Their long-term study demonstrated that positive reframing, acceptance and taking an active approach created better outcomes for parents. An active approach included facing problems as challenges with a sense of agency and calm. The approach that created poorer outcomes was denial with passivity. This approach included things like worry, isolation, self-blame, and substance use which lowered quality of life, family functioning and increased stress. Similarly, Nagoski and Nagoski (2019), contend that "wellness is a state of action" (p. 28), where practices like physical activity, mindful breathing, positive social interaction, laughter, affection, crying, and creative expression, release the stress chemicals in the body so they don't turn into burnout and illness. Nagoski and Nagoski (2019) also include the importance of "ongoing, mutual exchange of support [as] the essential action of wellness" (p. 214).

Parents face extra challenges in caring for a child with mental or physical chronic illness or injury. Several studies have demonstrated some support factors that help parents cope:
- a more accessible, and easy to navigate health system;
- targeted information and advice for parents (Williamson, et al., 2009; Keeton et al., 2013; Franck et al., 2015);
- opportunities for parents to gain new knowledge and skills (learn CBT for continuance of support at home),
- support from a therapist, and from other parents (Leamy Case, 2009; Pishva, 2017).

Keeton et al. (2013) and Norup et al. (2013) concluded that interventions that improve parental and family functioning also improve the wellbeing or functioning of the child. Helping one automatically helps the other. All benefits are experienced together, as the family is interconnected.

2.6 Disconnection as the Major Cause of Anxiety

Hari (2018) argues that "It is foolish to deny there is a real biological component to depression and anxiety (and there may be other biological contributions we haven't identified yet) – but it is equally foolish to say they are the only causes" (p. 184). Hari (2018), referencing four sources on neuroscience and neuroplasticity (Lewis, 2011 & 2015; Doidge, 2008; Costandi, 2016), argues that the distress of the outside world and the changes in the brain are in direct relationship with each other; the pain caused by life going wrong for a

long period can trigger the brain to stay in the fixed state of anxiety and depression, until something pushes the pain away.

Similarly, Kopua et al. (2020), argue that by isolating the experiences of "distress, addiction, madness, and dislocation" into biomedical approaches of "mental illness … the highly individualised idiom of psychiatry fails to capture the ways in which whole communities are struggling, and can serve to obscure the social, cultural, and economic dynamics that lead to such suffering" (p. 376).

Kanji (2019), Mayer (2016), Hari (2018) and Maté (2019) demonstrate that the development of anxiety stems from major events of disconnection – i.e. childhood trauma, abuse, family illness, bullying or physical violence, and significant and prolonged stress, even for a baby in utero. Hari (2018) concluded that disconnection is the major cause of anxiety and depression: disconnection from meaningful work/school/values, other people, childhood trauma, status and respect, nature, a hopeful or secure future, and biological changes.

2.6.1 Disconnection to Intrinsic Needs
2.6.1.1 Lack of Internal Control

Over the past decades, children spend more time at school and in structured activities, with less freedom, play, and opportunity to develop their internal locus of control (Bregman, 2020). Bregman cited (Rosen, 2014) that "in the US, working mothers spend more time with their kids today than stay-at-home mothers did in the 1970's" (p. 281) and cites psychologist Brian Sutton-Smith who said, "the opposite of play is depression" … to which Bregman concluded that "no freedom, no play, no intrinsic motivation – is fuelling an epidemic of depression" (p. 294). This lack of meaningful play translates in adulthood to a lack of meaningful work.

In a 2011/12 Gallup poll (Crabtree, 2013), millions of workers across 142 countries were studied to find that "only 13% of employees worldwide are engaged at work" (para. 1). Other global surveys say "nearly half of global employees are unhappy in jobs" (Harjani, 2013, para 1), and fully a quarter of respondents doubt the importance of their own work (Salisbury, 2018). Hari (2018) observes that disengagement and "disempowerment is at the heart of poor health – physical, mental, and emotional" (p. 83).

The current economic system is not set up for equality. Hari (2018) cited research from Messias et al. (2011) and Wilkinson & Pickett (2009) that concludes that, "the more unequal your society, the more prevalent all forms of mental illness are" (p. 147). Renowned trauma therapist Gabor Maté says

> The economy needs people that are going to meaningless jobs with drudgery
> or circumstances that are really intolerable, but they will put up with it. There
> is a confluence of the needs of the economy and the way we parent kids, and

the more disconnected kids are, the more they can fit into the economy that doesn't care about human feelings, it just cares about profitability and production. It's just a cycle that keeps going round (2019, 11.15min).

2.6.1.2 Lack of Meaningful Connection

McGonigal (2013) demonstrated that the oxytocin hormone is released in times of stress to motivate the body to experience human connection to mitigate distress. The problem that Hari (2018), Haslam (2018), and Maté (2019) point to is that loneliness makes it more challenging for oxytocin to do its job of connection. Loneliness is defined as "the sense that you're not sharing anything that matters with anyone else" (Hari, 2018, p. 101). Loneliness is a significant and growing cause of depression and anxiety in the western world where from 1985 to 1994 "active involvement in community organisations…fell by 45%" (p. 96). Maté (2019) states that we live in "a highly stressed and traumatising society … [with many losses] "of people's livelihood … of meaningful employment, … of secure employment, austerity, … of communion and communities" (5.19min). Social media cannot compensate us for the connection and community support we have lost (Hari, 2018).

Haslam et al. (2016) write about the many reasons for disconnection such as "social disadvantage, mental health problems, negative experiences of social exclusion and rejection (e.g., ostracism), and even in response to common life transitions (e.g., changing jobs, moving house, retiring)" (p.188). Glasser (2002) and Maté (2019) suggest that this disconnection is a disruption of the attachment bonds between parent and child and is the origin of "almost every mental health disorder" (Maté, 2019, 30 sec). Maté described the disconnection practice of not responding to children when they cry as embedding anxiety in the child. It is a form of external control psychology, a power-over "destructive psychology" (Glasser 2002, p.11), because when it is used in a relationship, "it almost always begins what I call the *disconnecting process… disengaged, separated, uncoupled, disassociated, and withdrawn*" (p. 11).

2.6.2 Disconnection: Stigma and Anxiety

When significant trauma, prolonged stress, and disconnection combine to reach a state of chronic anxiety, stigma will either be an initial part of that process or appear to exacerbate the disconnection and anxiety, for both the child and the parent(s). There are normative evaluations in society that create the opportunities to judge people as normal/acceptable/whole/usual or abnormal/unacceptable/tainted/discounted (Francis, 2012; Okiscova et al., 2013; Haslam et al., 2018). This judgement may be invisible to the people that fit the normal and don't experience it, but it is perceived, accepted and internalised by the people on the fringes who experience the stigma. This societal judgement creates stigmatisation mostly in the form of social distancing, where, when a person is discredited, that person "stops being its equal member" (Okiscova et al., 2013, p. 14) and is

shunned (Haslam et al., 2018), mostly in their personal and work relationships. Okiscova, (2013) summarises Prasko (2005):

> People experiencing anxiety can be especially sensitive about **"**the presence of the stereotypes in their social environment and might expect repeated rejection from the others in advance… might be too self-critical, feel shame and demoralization, and avoid social contacts…The negative self-concept can become a main factor of vulnerability (p. 14).

Okiscova et al. (2013), Busby Grant et al. (2016) and Haslam et al. (2018) all argue that stereotypes and stigma add to the already considerable psychological, physiological and economic burden of mental illness, in part, by making people reluctant to seek or commit to long term treatment.

Haslam et al. (2018) describe how stigma and discrimination have a negative impact on health. Stigma and discrimination cause stress in the body that exacerbates anxiety disorders which can be pervasive and prolonged and can provoke a chronic stress response - unhealthy behaviors and addictions - which in turn create a vicious spiral of more stigma and more stress. Through this power, stigma is able to create anxiety in its "unacceptable" targets, and exacerbate the anxiety more by creating barriers to help-seeking. This establishes an effect of distancing, which positions the 'unacceptable' people on the margins of society, and then this margin is further extended by the 'unacceptable' people who actively distance themselves further.

2.6.2.1 Understanding Stigma in relation to parents caring for a child with an anxiety disorder

One type of stigma is described as public, social or personal stigma, which is an attitude towards others who are "undesirable" (Ociskova, 2013; Busby Grant et al., 2016). Another type of stigma is defined as internalised stigma where a person, or a group, is on the receiving end of the public stigma. This happens in three stages: perception of the negative stigmatising attitudes of others, acceptance of these attitudes, and then internalisation and applying of these attitudes to the self. The social and internalised stigma affects not only the children experiencing an anxiety disorder: it also extends to their parents (Francis, 2012).

For parents who have children with invisible disabilities, like an anxiety disorder, the cause of the disorder or the abnormal behaviour determines the intensity of society's rejection. If the cause is considered a character flaw or weakness, the parents receive the blame, however, if the cause of the anxiety disorder is perceived as biomedical in nature, it can reduce the stigma of bad parenting (Francis, 2012; Okiscova 2013) and suggest a biomedical solution. This supports the use of medication to manage anxiety and other mental illnesses, and at the same time it individualises the problem within the child. It's not the fault of parents or society, because the fault rests with the child's biology.

Francis (2012) discovered that how and when the invisible disability started in the child, also helped determine the level of stigma and parent blame. Firstly, where children had well developed social relationships when they were small, parents were much less isolated by

stigma than "parents whose children developed problems as teenagers and young adults" (p. 938). Secondly, where young children had "invisible disabilities … [these] were re-narrated as problems of character [flaws, such as laziness] among teenaged and adult children" (p. 938). These older children were expected by society to be less vulnerable and have better self-control and their parents suffered the greatest degree of parent-blame.

2.6.2.2 Parental Stigma and Mother Blame

> Stigmatisation is shaped by gendered constructions of parenthood, assumptions about what constitutes a legitimate disability, and notions about children's innocence and fragility. These findings highlight how parental stigma is not a matter of children's discrediting attributes, but a matter of which parents, under what circumstances, are deemed worthy of blame, pity, or full acceptance in this era of medicalisation and anxious parenting (Francis, 2012, p. 927).

Benard and Correll (2010) established that "descriptive stereotypes … cultural beliefs about what men and women *can* do … [and] prescriptive stereotypes … cultural beliefs about what men and women *should* or *should not* do" (p. 619), led to discrimination that negatively affects mothers more than fathers in the workplace. The dichotomy of agency-communality is found in these stereotypes where "men are expected to be agentic (and not modest), and women are expected to be communal (and not assertive)" (p. 619). Nagoski and Nagoski (2019) identified these stereotypes through the lens of patriarchy and misogyny where males are "human beings" who have a duty to *express* their humanity, and females are "human givers" who have a duty to *give* their humanity to human beings (p. xiii). This human giver description highlights a cultural system that is rigged for stress, burnout and illness for women.

Francis (2012) established that not all parental stigma is equal. Feminist scholars argue that mothers experience the bulk of the blame attached to parenting because the prevailing cultural assumption is that the mother has the primary responsibility for their children's challenging behaviours. Consequently, mothers "experience blame more frequently and poignantly" (p. 928), and while fathers are stigmatised by association, they are not blamed. These differences are accentuated by Francis who asserts that "these assumptions are embedded in a gendered culture of anxious parenting that has developed in tandem with the widespread medicalisation of children's deviance" (p. 939).

Both the parent(s) and the child with the mental illness are very likely facing two challenges: the challenge of finding suitable treatment(s) that support their recovery and healing; and the challenge of isolation and discrimination from different forms of stigma.

2.7 Reconnection: The Social Approach to Health

There are many studies that show that anxiety is a collective issue, with a variety of connecting strategies for healing and social change (Glasser, 2002; Leamy et al., 2011; Haslam et al. 2016 & 2018; Jetten et al., 2017; Hari, 2018; Williams et al., 2020). Hari (2018) evidenced the need for reconnection to address anxiety and depression: reconnecting to our relationships; meaningful work; meaningful intrinsic values; community projects with others; sympathetic joy (meditation, compassion); overcoming childhood trauma; and restoring hope for the future. Glasser (2002), Hari (2018) and Haslam et al. (2018) argue for 'reconnection' alternatives to what they consider the over-prescribing of antidepressant medication. Hari (2018) claims we "are suffering from a social and spiritual imbalance in how we live. Much more than [we've] been told up to now, it's not serotonin; its society. It's not [our] brain, it's [our] pain" (p. 313).

With a focus on societal pain, Kopua, et al. (2020) developed an indigenous Māori framework, Mahi a Atua, as an adjunct and alternative to the individualised treatments found in western psychiatry. With knowledge of the effects of colonisation on indigenous cultures, they referred to a Canadian study (Kirmayer et al., 2001) that argued that "framing the problem purely in terms of mental health issues may deflect attention from the large scale, and, to some extent, continuing assault on the identity and continuity of whole peoples" (p. 376). Indigenous cultural and healing practices create more opportunities for connection, understanding and the development of "resilience and strength" (Kopua, et al., 2020, p. 377).

In his book, *Unhappy Teenagers: A way for parents and teenagers to reach them*, Glasser (2002) identified that humans have "five basic needs built into our genetic structure: survival, love and belonging, power, freedom, and fun" (p. 17), and to help meet those needs, there are seven connecting habits for strengthening satisfying relationships: "caring, trusting, listening, supporting, negotiating, befriending, and encouraging" (p. 14). Glasser (2002) illustrated that the strategies we use to meet our five human needs can sometimes be in conflict with another and that the effectiveness of the seven connecting habits works when we use them with the understanding of "internal control" instead of power-over "external control". For example,

> With you and your teen…when you disagree, the prime consideration should
> not be who's right and who's wrong. It should be whether what you are trying
> to do will preserve or harm the relationship between you and your
> child…Learning to respect what the other wants even though you may not
> agree will accomplish much more with your teen than having each
> disagreement escalate into a power struggle, even though you win (p. 8).

This social approach to health is relational, including our personal and professional relationships, and our relationships with the outside world -- the culture, systems, and

environmental contexts around us -- and examines whether those relationships are supporting our health and wellbeing.

2.7.1 Group Membership and Social Identity

Learning how to relate to each other to make meaningful connections in our families and social circles makes a significant difference to our health. Haslam et al. (2018) argue for a new approach that appreciates "the immense importance of people's psychology *as group members* for their health – the psychology of 'we' and 'us'" (p. 4). Jetten, et al. (2017) point out social identity's importance for health and wellbeing with over 400 publications on this topic, and from 2012 to 2017 "three (biennial) international conferences on social identity and health (ICSIH) [were] held in Europe, North America, and Australia" (p. 790).

Although the 'social' is included in the integrated bio-psycho-social (biological, psychological, social) approach, it is often not given value. Haslam et al. (2018) refer to Holt-Lunstad et al.'s (2010) meta-analysis which found that while social support and social integration were the key correlates of health, "the general public perceive these to be among the least important" (p. 3). Haslam et al. (2016) evidence 30 studies on social isolation and loneliness where group interventions were the most effective 90% of the time and conclude "that social group activity was a vital component in managing loneliness and isolation" (p. 189).

From previous research informed by a social identity approach to health, Jetten et al. (2017) describe four key resources that bolster social identity:

- **a sense of social connection** … the sense that one is psychologically close to, and entwined with, other members of one's ingroup;
- **a sense of common direction, meaning and purpose** … working towards particular collective outcomes [that] channels their attention and energy;
- **a sense of shared identity** …[which] lies at the heart of the provision and receipt of social support, [especially when recognised as] … one of us [with clear intentions and] ... being in a position to benefit; [and]
- a **sense of personal control** … [with being part of a group with] collective efficacy, agency and power" (p. 797-98).

Williams et al. (2020) confirm the findings that mental health recovery is significantly assisted by group memberships that provide meaning, support and agency to help create a positive sense of social identity. However, social support and social contact are not sufficient on their own. Using previous studies, Haslam et al. (2016), identify features of group life that go deeper and target social connectedness. These are:

- **multiple group memberships** … access to multiple identities increases the likelihood that a person can access useful forms of support when needed;
- **group compatibility** … ensures they are easier to manage and not a source of unwanted interference and stress;

- **group maintenance or continuity** … provides a sense of social identity-based self-continuity in the face of change and uncertainty;
- **new group acquisition** … where it is neither possible or desirable to retain old identities, such loss can be countered by acquiring new group memberships that afford opportunities to develop new social identities (p. 189-190)

In summary, positive group membership is a resource that strengthens a person's health and wellbeing and strengthens their ability to overcome significant challenges in their lives. Group membership is intrinsic to our health and wellbeing and it must be given precedence in the struggle to address disconnection, loneliness and isolation.

2.7.2 Social Identity Framework

From a large body of research, Haslam et al. (2018) identified two key frameworks that help shape people's social identity and health based on their social circumstances: *social capital* and *social determinants*. Social capital includes "the networks, norms of reciprocity, and trust among members of a neighbourhood or community that develop through social interaction and mutual cooperation" (p. 7). They cited Putnam's (2000) conclusion that "if you belong to no groups but decide to join one, you cut your risk of dying over the next year in half" (p. 7). Social determinants of health include things in our culture and environment that have influence over us, like our systems of education, economics, and governance. As determined in section 2.6.1.1, inequality is proven to be detrimental to mental health, and by understanding these adverse social determinants, there is more opportunity to counteract them.

An aspect of the perpetuation of inequality may be understood with ingroups and outgroups. Haslam et al., 2018 argue that

> phenomena like prejudice, discrimination, and hatred, as well as cooperation, solidarity, and trust, are more a reflection of people's social identities [in groups] than of their personal identities…how we understand, treat, and engage with other people depends very much on the degree to which we see them as sharing a social identity with us (p. 15).

People's social capital (the groups they have created and belong to), and the social determinants in their environments (how they are positioned for opportunities and connection or roadblocks and disconnection), make up a person's social identity, which largely influences their health and wellbeing. When a family member experiences an anxiety disorder, all the members of the family - and the family as a whole - are likely to be challenged in each of their group memberships. The quality of their shared social identity will have effects on the process and outcome of the recovery journey of the child and their family.

2.7.3 The Recovery Model and Social Identity

The recovery model advocates for an approach to mental illness that emphasises the journey of recovery rather than the hoped-for outcome of perfect wellness. This means that regardless of how chronic or severe their mental illness is, people should be able to experience positive social identity, hope, empowerment, wellbeing, social inclusion and a meaningful life (Leamy et al., 2011; Ellison et al., 2018). The Ministry of Health (2021) supports the recovery and wellbeing model as a guiding model for mental health services. Because recovery has to be a journey shared with others, western society's fear and stigma that has historically been attached to mental health issues is challenged (Beehler et al., 2014; Cruwys et al., 2014; Tew et al., 2012). This is, in part, through diverse group-based activity programmes (Williams et al., 2019), often facilitated by peer workers who have a lived experience of mental illness (Eisen et al., 2012; Cruwys et al., 2020).

Cruwys, et al. (2020) align the recovery and social identity models in resourcing people psychologically with support, meaning and purpose to provide more resilience when facing life's challenges. Cruwys et al. (2020) identified several studies where application of social identity model demonstrated powerful health benefits:
- better depression recovery (Cruwys et al., 2013)
- better quality of life following brain injury (Jones et al., 2011)
- fewer visits to primary care (Cruwys et al., 2018)
- Meta-analyses that suggest:
  - social relationships are more protective against premature death than regular exercise or quitting smoking (Holt-Lunstad et al., 2010)
  - interventions that increase social identification benefit both physical and mental health (Steffens et al., 2019) (p. 2)

Jetten, et al. (2017) have shown with people with autism, that "greater identification with others who have autism is … associated with a greater sense of worth as well as reduced anxiety and depression" (p. 798). The social identity approach provides a framework giving in-depth awareness of the qualities of group membership and their effects on our mental health, whether a person is in the in-group or the out-group.

2.7.4 Social Identity as Pathway to Social Cure or Social Curse

2.7.4.1 Social Cure

Williams, et al. (2020) have researched mental health, group membership, and social identity, and have shown that when new group memberships have meaningful and equitable values and norms that people can capably align with, being part of the group helps them overcome negative challenges on their personal and social identities. Cruwys et al. (2013) demonstrated the power of group memberships and social identity on mental health showing that "for people who have experienced a depressive episode, joining one new social group reduces the likelihood of depression relapse by 24% and joining three new groups reduces the risk of

relapse by 64% (p. 179). A key question Williams et al. (2020) have identified is "what type of identity is the group supporting" (p. 171), a recovery identity or an illness-based identity?

A group that follows a recovery identity approach, such as Alcoholics Anonymous (AA), supports meaningful goals that require social engagement and group empowered actions. Arts-based recovery groups provide "a way to restore a positive group identity … [that shifts] from mental illness and toward personal strengths" (Williams et al., 2020, p. 171). These studies generated five major themes: "belonging, support, self-efficacy, purpose, and positive emotions" (p. 173).

Social identity has the opportunity to work as a 'social cure' where people have the opportunity to move beyond the illness identity and identify with a recovery, strengths-based identity, and become something more meaningful as a group.

2.7.4.2 Social Curse and its mitigation

Not all group membership is positive. Multiple studies demonstrate a group "formed based on mental health diagnoses, values and norms may also support illness-related identities" (Williams et al., 2020, p. 171) and that it can be a social curse "when people belong to stigmatised groups, when groups promote toxic and unhealthy norms, or when people belong to groups that do not provide them with social support" (Jetten, et al., 2017, p. 790). The social identity and recovery approaches both work to mitigate the social curse by challenging stigma, social systems and processes, and supporting people into positive group membership that is strengths-based, meaningful and supportive of collective efficacy. Busby Grant et al. (2016) provide considerable evidence indicating the effectiveness of "stigma reduction campaigns that target improving knowledge of/contact with mental illness" (Busby Grant et al., 2016, p. 250).

Mother-professional partnerships are another avenue of mitigation of the social curse. In relation to mother blame, Kingston (2007) demonstrated that true partnerships between professionals and mothers hold an important key in supporting children with an invisible disability. She advocates serious listening and "a true partnership [that] entails mothers and professionals involved together, on equal terms, in planning and implementing services [which will require an examination of] our internalised notions of motherhood and mothering." (p. 169)

Social identity and the recovery model create opportunities to mitigate negative factors that lead to disempowerment, disconnection, loneliness and isolation, and to build life-enhancing social identities, social connection and a sense of meaning and purpose that creates social change.

2.8 Social Connection Interventions

There are a variety of interventions internationally and nationally that provide opportunities for people of different ages and ethnicities on their recovery journey to receive support, participate in support groups, increase awareness and skills, do creative and meaningful projects, and connect with the community in active and meaningful ways. The interventions listed in the table 2.1 below are colour coded into categories functions (by columns).

2.8.1 Intervention Examples: Addressing Collective Despair

Currently, there are no interventions available in NZ that address anxiety disorder in the community using a collective action approach that supports social change. There are only two groups I have found in NZ that are designed to support people who are experiencing the emotional challenges of supporting family in recovery and creating social change in a supportive, collective and action-oriented way: Al-Anon and Work that Reconnects (WTR). They also have a spiritual factor included in their programmes which connects people and the group to something bigger than them.

Table 2.1: Social Connection Interventions
Green: Addressing Collective Despair; Orange: Creating Connection and Social Identity; Grey: Group Therapeutic Support for mothers and their families. AI= Appreciative Inquiry, PDR=priority driven research.

Intervention Strategy	Inter-national service	NZ service	Youth Focus	Adult Focus	Carer Focus	Mental Health Focus	Arts, Enviro Focus	Spirit Factor	Community Partnership & Service	Indig-enous Focus	Total
Alcoholics Anonymous	Y	Y		Y	Y	Y		Y	Y		7
Al-Anon	Y	Y	Y	Y	Y	Y		Y	Y		8
Project Self Discovery	Y		Y	Y	Y	Y	Y		Y		7
Drugs, Hopes and Dreams (AI)	Y		Y	Y	Y	Y			Y		6
The Work That Reconnects	Y	Y		Y			Y	Y	Y		6
Mahi a Atua - A Māori Approach		Y	Y	Y		Y		Y		Y	6
PDR - Empowering Partnerships	Y			Y					Y	Y	4
Social identity & recovery models	Y			Y		Y	Y				4
Groups 4 Health (Social Identity)	Y			Y		Y	Y		Y		5
Arts based Groups	Y	Y		Y		Y	Y				5
Mapura Studios (art)		Y	Y	Y		Y	Y		Y		6
Green Room (music)		Y	Y			Y	Y				4
Making Change Happen	Y			Y			Y		Y		4
Chicago Freedom School	Y		Y						Y		3
Anxiety NZ Support Groups		Y	Y	Y	Y	Y					5
Parent Help		Y			Y	Y					3
Parent to Parent		Y			Y	Y					3
Skylight		Y			Y	Y					3
Healthy Mothers, Healthy Families	Y				Y	Y					3
Yellow Brick Road		Y			Y	Y					3
Strengthening Families		Y			Y	Y					3
Total	12	11	6	10	9	15	5	4	10	2	

Alcoholics Anonymous (AA) provides a similar model of support to sufferers and has over decades proven to have a success rate at least as good as cognitive behavioural and motivational enhancement therapies, the two most effective psychotherapies for addictions

(Vaillant, 2005). Its effectiveness as a social cure is based on four factors: "frequency of AA attendance, with having a sponsor, with engaging in Twelve-Step work, and with chairing meetings" (p. 433). AA was also very effective in tandem with psychotherapy, with the more AA meetings attended the better the outcome. In NZ, there are more than 500 meeting groups available every day of the year, making this programme very accessible (Alcoholics Anonymous NZ, 2021).

Al-Anon Family Groups provide recovery support to families and friends of alcoholics who learn to practice the 12 Steps (personal recovery) and 12 Traditions (unity and fellowship) of Alcoholics Anonymous with a vital purpose of service and action. They interpret alcoholism as a family illness and work to support changed attitudes within the family to aid recovery. Currently there are 28,000 Al-Anon groups in 133 countries, with more than 80 NZ groups (Al-Anon Family Groups, 2021).

Project Self Discovery is an Icelandic national youth stress, addiction and substance use programme that has spread to 35 municipalities across 17 countries. The results from those countries have shown lowered drug, alcohol, mental illness and crime amongst youth (Young, 2017). The project increased youth recreational and social opportunities for more meaningful connections with families and friends, plus it provided training in relational and skill development (Volteface, 2020).

The South African *Drugs, Hopes and Dreams* programme - appreciative inquiry with marginalized young people using drugs and alcohol – also builds community partnerships and focuses on working together to address a communal concern using a recovery approach that builds positive social identity. A small community used a two-day collaborative strengths and value-based Appreciative Inquiry to help and support 120 young people with anti-social behaviour and drug and alcohol misuse. They focused on being present for the participants, hearing "stories of competence and success …[appreciating] their abilities and skills, believing in their potential through dreaming with them … [creating] space for them to move into new identities, [and treating them] … as competent and trustworthy" (McAdam & Mirza, 2009, p. 188). This was a community witnessing of the transformation that was happening.

The Work That Reconnects (WTR) is a workshop process used for creating change related to environmental and climate-change issues. It addresses the accompanying collective despair by building trusting relationships to contribute to creative solutions. WTR has been operating for over three decades and, like Project Self-Discovery and *Drugs, Hopes and Dreams,* focuses on meaning-making, strengthening relationships with one another, and developing collective efficacy.

2.8.2 Intervention Examples: Creating Connection and Social Identity

Mahi a Atua (tracing ancestral footsteps - Kopua et al., 2020) is a Māori approach to mental health that uses a *wananga* group approach involving meeting, discussing, learning, and the passing on of wisdom and connection not only with living present but also to something

bigger than oneself – whanau, iwi, ancestors, community and colonisation. Social identity is strengthened culturally and intergenerationally. This is done "through learning about and engaging with pūrākau [myths/legends]. Regardless of which pūrākau are shared, the basic feature is that each participant can create a shift in awareness both within themselves and within others" (p. 378). This is similar to the community witnessing alluded to in the *Drugs, Hopes and Dreams* project

Three Queensland mental health focussed programmes emphasise social identity through collaboration and partnerships. The *Priority Driven Research Project (PDR) for Empowering Community Partnerships* (Haswell-Elkins, M., et al., 2009) was an indigenous community action research project which aimed at bringing the collaborating groups into partnership with primary healthcare practices. Cruwys, et al. (2020) researched three different types of recovery-oriented support groups from Footprints, a community mental health service in Australia. They linked reductions in psychological distress and better recovery outcomes to group-based empowerment which broke down isolation through shared experiences and collective action. Some of the best outcomes for the social identity/recovery models come from Haslam et al. (2016) research on the *Groups 4 Health Intervention Improving Social Identity.* This manualised programme supports people to grow their social identity through creating multiple group memberships that are compatible and meaningful for them and has been found to significantly improve mental health, wellbeing, and social connectedness on all measures, both on programme completion and 6-month follow-up. In line with social identity theorizing, analysis also showed improvements in depression, anxiety, stress, loneliness, and life satisfaction.

Art therapies have a built-in ability for self-expression and collaborative practice which are both powerful enablers for social identity. Therapies can range from participation in choirs and creative writing groups (Williams, et al, 2020), film and television work, theatre, quilting, art, music and dance (Sonke, et al., 2021 – a 9 study systematic review focused on suicide prevention). These studies demonstrated improvements in self-efficacy, self-image, awareness and prevention strategies, and reductions in risk-taking and self-harming behavior.

There are many arts-based groups in NZ that carers/mothers can join for their personal wellbeing; however, I haven't discovered any that have a specific focus of supporting mothers caring for a child with an anxiety disorder or mental illness. There are arts-based programmes in Auckland, like the Green Room (Eliette's Music Academy, 2021) (music for teens with anxiety) and Mapura Studios (2021, art for people with visible and invisible disabilities), which use the arts to support young people directly, which supports the mothers indirectly.

The art/creativity theme is present in a parent focused programme *Making Change Happen Leadership Academy for Empowering Leaders in the Community* (Generate Health, n.d.)

where parents are asked to take photos of what they want to change in their communities, learn leadership skills, and develop strategies for community change. The crux of community change, particularly in communities where stigma and discrimination prevail, is not just engagement in the social-emotional learning underpinning positive social identity formation, but also, as McKay-Jackson (2014) explains in her analysis of the *Chicago Freedom School: 2008- 2009 Freedom Fellowship*, an engagement with socio-political learning and a goal of liberation. A focus on community change, rather than individual change, focuses on a collective response to systemic oppression.

2.8.3 Group Therapeutic Support for mothers and their families.

NZ has a variety of individualised support interventions to address anxiety disorder that include helplines, information provision, advocacy, one-on-one therapy, and medication. The support groups in NZ promote themselves to be therapeutically-focused on the individuals giving and receiving support to each other to reduce isolation, share strategies to improve their coping and wellbeing, and providing opportunities for self-development. These support groups include:

- Anxiety NZ (2021) Support Services provides information, peer support groups and resilience courses and a number of helplines including links to other support services offering group and family support.
- Parent Help (2018): Provides a helpline, counselling, and courses for all parenting matters
- Parent to Parent (2021): Provides volunteer parent support for parents caring for a child with a similar disability, as well as support group meet ups and information
- Skylight (2021): Provides parent support groups, including Bereaved Parents Support Group (suicide)
- Yellow Brick Road (2020): Provides information, advocacy, wellbeing webinars, group support/support person, self-development programmes.
- Emerge Aotearoa (2021): Provides social services to strengthen families/whanau so communities can thrive, including: Mind and Body for-peer-by-peer support (initiatives, programmes and advocacy and Rethink's nationwide Like Minds, Like Mine programme that seeks to tackle stigma and discrimination)
- Strengthening Families (2021): Provides a networking approach in connecting and supporting families with family support services and government agencies

2.9 Summary

Anxiety disorder is one of the most significant mental health concerns internationally and is most commonly managed with the Western biomedical model approach using antidepressants and individualised therapies. Although there are mixed reports on the level of efficacy of antidepressants, they are a culturally accepted treatment that is significantly escalating in use for young people. Antidepressants are often paired with individualised

therapies like CBT for treating anxiety disorder. CBT is the most researched and commonly used treatment modality and shows as having the highest rate of efficacy at 58%. There are many other individualised treatments that have been shown to be beneficial for managing anxiety disorder, as well as personal practices such as mindfulness, meditation, and yoga.

There is a lack of literature on the parental experience of caring for a child with an anxiety disorder. Most research in this area comes from studies of parents of young people with brain injuries and anxiety, physical disease or disability, and young people with ADHD, autism disorder, and Downs syndrome. Parents, particularly mothers, of children with invisible disabilities have a more challenging time facing more stigma and judgement due to ongoing, in public, unpredictable behaviour associated with anxiety disorder. Parents also have to navigate the challenge of finding the right treatment and practitioner for their often-avoidant child. The research indicates the importance of including the parents in the treatment plans, as the child and the parent(s) lives are intertwined in life and in the recovery journey.

Disconnection is one of the leading causes of anxiety disorder and stems from childhood trauma and/or chronic stress. When a person is without supportive friendships and family, their chances of getting anxiety disorder increase by 75%. Disconnection is primarily felt as a result of trying to cope with challenging family relationships (i.e., abuse, judgement, external control, serious illness or changing situations), and social relationships (trying to keep safe from real and perceived dangers i.e., stigma, physical/mental/emotional bullying or harm). Disconnection also happens when a lack of meaningful values and meaningful work/school opportunities reduce hope for the future and a sense of place in the world.

Social identity and the recovery models address the loneliness, isolation, and disconnection that is found with people with anxiety disorders. This is also true for the parents caring for the child with an anxiety disorder, as their lives are interconnected. Having multiple, positive, and compatible social identities are valuable resources that create a sense of social connection, common direction meaning and purpose, shared identity, and personal control on a person's journey of recovery. This strengths-based approach creates more opportunities for a person to see and experience themselves beyond their mental illness or family challenges, with a sense of self and collective efficacy. They can discover they are more than the challenges they face. A variety of group processes and programmes support social identity and recovery approaches where people are present and connected together for something meaningful and empowering.

When the anxiety disorder presents in someone in a family who experiences disconnection, and disconnection is created as a way to cope, whether the disconnection began within or outside the family, research suggests that the recovery journey needs to focus on the interwoven experience of disconnection between the parent(s) and the child.

Chapter 3 Methodology/Method

3.1 Introduction

The aim of this research is to uncover parent's lived experience of caring for a child with an anxiety disorder and discover possibilities for creating collective action and social reconnection through the use of focus group work.

3.2 Methodological and axiological issues

3.2.1 Appreciative Inquiry

An Appreciative Inquiry (AI) methodology, using social constructionist theory and underpinned by elements of Kaupapa Māori values, has been chosen for this research. The AI approach is well positioned to work with focus group methods and with issues where the desire is to create change collectively. With a strengths-based, 'life-centric' view, "appreciative inquiry assumes [communities] are centres of vital connections and life-giving potentials: relationships, partnerships, alliances and ever-expanding webs of ideas, knowledge and action that are capable of harnessing the power of combinations of strengths" (Fry, 2014, p. 44).

Appreciative Inquiry, developed by David Cooperrider and Suresh Srivastva in 1987 (Zandee, 2014), is a proven, researched, and purposeful form of generative action research (Fry, 2014), that Kelm (2011) and Stavros & Torres (2018) identify as being well-grounded in positive psychology, sociology, medical studies and neuroscience. "The mindset of AI, an approach that values all voices, seeks to inspire generative theories and possibility thinking, opens our world to new possibilities, challenges assumptions of the status quo, and serves to inspire new options for better living" (Stavros & Torres, 2018, p. 22). Jackson et al. (2014) used AI in their community engagement research "to prevent individuals from feeling helpless by energising them through a focus on available assets [strengths], possibilities, and their potential influences in co-creating their desired futures" (p. 1788). Kelm (2011) differentiates between our normative strategies of trying to solve a problem by restoring the status quo and AI, which seeks to generate new possibilities. AI aims to solve a problem in a strengths-based way that opens the focus group up to possibilities, challenges the status quo, and inspires new options for better living and a preferred future (Stavros & Torres, 2018; Msukwa et al., 2003; Coghlan & Brydon-Miller, 2014; Zandee, 2014).

The strength of this type of inquiry is the experience of being part of a focus group or series of focus groups that follows a 4-D process (Fry, 2014; Stavros & Torres, 2018; Zandee, 2014; Msukwa et al 2003). This is, once the topic is defined (sometimes called the 5th D) (Moore, 2021), the process involves the following:

- Discovery: where participants look for the best elements of their lives in relation to the topic. Their successes, goals achieved and strengths discovered.
- Dream: where participants dream about the future they would like. What would change, who would change, what possibilities would emerge?
- Design: participants co-create from their collective dreams the strategies needed to bring their vision of the future into being.
- Destiny or Delivery: participants commit to putting their strategies into action, adapting them as they get feedback on their effectiveness.

Appreciative inquiry is useful in a variety of settings: for participatory research and policy-making in relation to international community development and change management in business (Aldred, 2009); for therapeutic coaching (Subirana, 2016); and for facilitating social change workshops (McAdam and Mirza, 2009). The benefits of using Appreciative Inquiry are that people participating in the process experience personal and collective power which they are able to activate for the good of the whole (Whitney & Trosten-Bloom, 2010).

Underpinning all research is an axiology or set of values. I have chosen the principles of Kaupapa Maori research (Smith, 1999) to define the process of participant engagement in recognition of the comprehensive nature of these principles and their ability to relate to a wide range of cultural circumstances. In doing so, I concur with Love & Tilley (2014) who argue that Kaupapa Maori principles and values should be considered in all public engagement in NZ. Cram (2010) describes the AI process as one of "transformational change … compatible with Kaupapa Māori concerns that whānau strengths be recognised and built upon" (p.1)

In my research, I will pay particular attention to: Ata: Principle of Growing Respectful Relationships (key understandings that build healthy relationships and wellbeing); Kaupapa: Principle of Collective Philosophy (the collective vision and hopes in the community, and how knowledge and action contribute to that); Whanau: Principle of Extended Family Structure (acknowledges ALL relationships, their connections and responsibilities), and Tino Rangatiratanga: Principle of Self-Determination (personal rights to determine your own culture, aspirations and destiny) (Smith, 1999, Pohatu, 2013).

3.2.2 Constructionist Principle
Underlying Appreciative Inquiry are the principles of social construction which is "based on the theoretical assumption that reality is socially constructed and mediated through language" (Milioni, 2001, p.12). Milioni argues that "it is of paramount importance that theoretical 'truths' are acknowledged for being metaphors for the many ways it is possible to view [reality], rather than 'the truth,' as a reflection of an objective, knowable reality" (p.13). Using language through metaphors and discourse, social construction brings into focus three significant relationships: "the researcher's relationships with the subjects of research, with the audience, and with society more generally" (Gergen & Gergen, 2012, p. 1).

Our words, and how we use them in our languaging and our stories, create multiple perceptions and realities in our world, affecting our behaviours and beliefs (Stavros & Torres, 2018; Subriana, 2016; Millioni, 2001). "If the way we talk together influences understanding, personal dynamics, and teams, it makes sense to hold our beliefs lightly, ask questions, [and] make room for new knowledge and new meaning" (Stavros & Torres, 2018, p. 62).

The Constructionist Principle and Kaupapa Māori values both concur in identifying and challenging social and cultural norms and becoming more aware of how power is shared or not shared. Love & Tilley (2014) argue that "for non-Māori working with Māori, thinking about one's own values, motivations and identity is therefore crucial. So too is taking a critical approach to Western influence, and especially one's own influence" (p. 40). The Whanau: Principle of Extended Family Structure recognises the close and extended relationships we all have with each other and the world around us and within these relationships are the responsibilities to hold and nurture them (Smith, 1999). Both Smith (1999) and Gergen & Gergen (2012) acknowledge the fundamental connection between the researcher, the researched, and the research.

3.2.3 Simultaneity Principle
"Inquiry is intervention" (Stavros & Torres, 2018, p. 74; Subirana, 2016, p. 85). Kelm (2011) and Stavros & Torres (2018) posit that the moment a question is asked or a statement is made, change happens, and that that change will be influenced by the tone and direction of the conversation. Subirana (2016) argues that culturally we focus on the negative, and we need to "redirect the conversation…so that little by little they start to focus on discovering their positive core and what they want." (Subirana, 2016, p. 87). Ata, the Principle of Growing Respectful Relationships, will help guide conversations to build relationships in the group and for each other's children and families, and hold a focus on a hopeful future.

3.2.4 Poetic Principle
This principle heeds the multiple perspectives and realities of social constructionism, which allows for genuine curiosity in understanding and appreciating the variety of meanings and interpretations of life experiences and beliefs (Stavros & Torres, 2018; Subirana, 2016). This awareness affects our positioning in discourse, or in our reality, as "whatever we focus on expands" (Kelm, 2011, 6.29min; Subirana, 2016, p. 88).

The Kaupapa: Principle of Collective Philosophy upholds this principle by responding to the unique realities held by communities and how their visions for the future are based on those realities (Smith, 1999). With this awareness, we can ask ourselves what we are paying attention to, individually and collectively, that we are experiencing, creating, and therefore expanding in our lives.

3.2.5 Anticipatory Principle
What we anticipate or imagine is likely going to be what we see and hear. Stavros & Torres (2018) iterate it "makes sense to stay open, anticipate the best from others, and expect to

be pleasantly surprised" (p. 63). This principle tells us to be aware of what we are anticipating and how we go about it. The Principle of Tino Rangitiratanga (Self-determination), while upholding the primacy of culture, asks us to also consider power sharing and spatial politics (Smith, 1999). Using these principles together, we ensure and anticipate that the culture of each participant in the research process is acknowledged and has equal power, and that co-creative processes can occur in a meaningful way from start to finish.

3.2.6 Positive Principle

> AI doesn't dig into problems, it acknowledges them, appreciates them and works with them if they arise, but it doesn't inquire into their causes. Rather, it enquires into what gave someone strength to get out of similar situations that might serve as guidelines to connecting to those inner strengths and capacities in the present. That is, we always inquire into the positive core, which is life-giving, reinvigorating people to go forward with greater power and lightness, and less heaviness. (Subirana, 2016, p. 93)

Subirana (2016) and Stavros & Torres (2018), iterate the importance of creating positive images that give direction to conversation and new realities in the future. Through this process, the focus is on resilience and empowerment instead of on victimhood and helplessness. As the focus group defines its 'positive core' using the Positive Principle, the values of Kaupapa, the Principle of Collective Philosophy, assists the group in placing the collective purpose over individual agendas (Smith, 1999). In this way, multiple aspirations will be brainstormed into a collective dream and plan while being held strongly by the group's positive core, its foundation of strengths.

3.3 Methods

Focus groups are central to appreciative inquiry. They generate the group's experiences, reflections, and ideas in the communal space to understand their shared life experience as a collective phenomenon, and they can create a strengths-based group identity for designing meaningful initiative(s) that address that phenomenon. Kamerelis and Dimitriadis (2013) positioned Friere's argument as central to focus group work, in that "we must acknowledge the ways in which we, as human beings, are fundamentally charged with producing and transforming reality together" (p.20). The focus group method provides a unique opportunity to research an individualised and stigmatised problem collectively, where the synergy of the group is positioned to explore "the relations among 'self,' 'other,' and 'context' [that] can help us answer Foucault's most fundamental question: why is reality organised as it is and not some other way?" (Kamberelis and Dimitriadis, 2013, p. 6).

My AI process also involves semi-structured interviews, commonly used in qualitative research (Holloway & Galvin, 2016). This method was selected for the paired interviews that began the appreciative inquiry. This facilitated a way of gathering more in-depth experiential information (Kvale, 2003), providing more opportunity to build relationship and

trust between participants and the researcher (Liamputtong, 2007), and allowing for conversational asides that have the potential to provide unexpected narratives to the inquiry (Taylor & Francis, 2013).

As well, a small questionnaire was used in this inquiry. Its purpose was to provide quantitative data that could confirm (or not) the impressions gathered from the qualitative methods. This was a small claim in the direction of an integrative mixed methods approach to data collection and analysis (Plano Clark & Ivankova, 2016, p. 4).

Gergen and Gergen (2012) posit that "for the [social practice] researcher, the pressing concerns of the society may be prime stimulators of inquiry, and the methods may be tailored to achieve social change" (p. 7). This research is not challenging the current medical model that emphasises diagnostic categories of mental illness based on individual pathology (Milioni, 2001); it is exploring, through AI, more of a recovery model that emphasises the creation of an empowering community focusing on wellness, strength and resilience (Clossey et al., 2011).

3.4 Selection

Interested parents made contact with me by phone or email to determine whether they met the three criteria. When they did, our conversation began regarding the research aims and design, and how their participation may bring value to them and the community. Once they indicated they wanted to participate in the study, they were sent an email (see appendix B) that contained:

1. Confirmation they met the five criteria above.
2. An invitation letter and information sheet (see appendix C and D) with a few questions that would help me in setting up the paired interviews.
    a. Basic demographic questions: culture, age, gender, occupation, married/single, children in full or shared care
    b.   What do they hope to get out of participating in this focus group research?
    c.   What is their interest level in being part of any collective action that comes out of the focus group meetings?
3. A Consent & Confidentiality Form (see appendix I) to sign and return to me
4.   Upon receiving the Consent & Confidentiality Form and their answers, paired interviews and focus group sessions were organised. (See appendix F for paired interview and focus group guide)
5. Post-session Support Hand-out (appendix H)

3.5 Identification and Recruitment of Participants

For this study, purposeful sampling for relative homogeneity (Palinkas, et al., 2015) was chosen with clear criteria for creating a small group of four to six participants from the same

suburban locality who have lived experience of being a parent of a child with an anxiety disorder. Peek & Fothergill (2009) both concluded that "focus groups that included between three to five participants ran more smoothly than the larger group interviews that [they] conducted" (p. 37).

There is a large pool of potential participants. Bowden et al. (2019) reports that by age 15 "between 10% and 12% of young people have a diagnosable anxiety disorder" (p. 56). The criteria for inclusion in the appreciative inquiry are:

1. Participants need to be a parent of an intermediate or high school student who has experienced an anxiety disorder for a year or more.
2. The child is/has been, within the current year, demonstrating avoidant behaviour such as refusing to go outside or to school, and/or is experiencing panic attacks.
3. The parent has, as a result, experienced distress, both directly, and in the process of finding treatment and support for their child with an anxiety disorder.
4. The parent and child are not in crisis at this time.
5. All participants live in the same Auckland suburb.

These criteria were chosen to ensure that the participants had a length and breadth of experience navigating support for their child who is of similar ages to other children in the group and that parents are as local as possible to create opportunity for community action and support.

I approached a number of organisations by phone and email with the advertisement and shortened invitation letter (see appendix E) that they could distribute to or display for potential participants. These included Te Kura Correspondence School, four local intermediate level and secondary schools and 10 NGOs with connection to anxiety issues. As the topic of this research is sensitive, and participants potentially hard to access, I also used a snowballing recruitment method (Cohen et al., 2007), enlisting the help of my informal contacts to find participants for the research.

The timing of the recruitment was challenged by coinciding with the end of a school term and severely challenged by the first Covid lockdown which made it difficult to access and promote the study using the school-based contacts. Lynda Wharton, from the Wholistic Women's Health Facebook page offered to interview me to help with recruitment[1]. I got some leads from there; however, all of my participants came from sharing the advertisement poster in the local community Facebook group pages. It took me six weeks of promoting to get six people committed, with some pulling out along the way due to lack of time to commit and because some children's ages fell outside the desired age criteria. Four participants came from Facebook community posts and two from Strengthening Families.

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[1] https://drive.google.com/file/d/10re0y-o1DcihtSGYehKi0dn7yDlRdKjd/view

3.6 Data Collection

This study used the 4-D process described in s3.2.1 in a series of paired interviews, focus groups, and questionnaires covering five different appreciative inquiry sessions over two and a half months (see table 3.1 and for a full description of the process, see appendix F). One or two days prior to each session the participants received an information sheet that gave them an overview of what to expect for that session, together with the questions that were going to be asked. Each of the sessions were recorded using both Zoom and a back-up recording device. Each of the sessions were initially transcribed using the Otter app (Otter.ai, 2021), and then reviewed for accuracy by me. The participants received each transcript and were given the opportunity to read and comment if they wanted any changes made.

Table 3.1: Information given and data collection - Appreciative Inquiry Timeline	
When	**What happened**
Week 1	Recruitment: Advertisement, Invitation letter and Information sheet Selection Questions & Answers. Consent & Confidentiality forms signed
Week 7	**Pre-Questionnaire** sent and responses received
14 Aug	**Information Sheet** sent *Before* Paired Interviews
15-16 Aug	**Discovery:** Paired Interviews x 2
16-28 Aug	*After* Paired Interviews: Thank you email with check-in & **Support Sheet**, Transcript sent *Personal Identity symbols & words, and main themes:* received and shared with participants
28 Aug	Information Sheet sent *Before* First Focus Group
30 Aug	**Dream:** First Focus Group
2 Sept	*After* First Focus Group: Thank you email with consolidated notes from brainstorm. Check-in, in case some parents were having challenges with children. Transcript sent.
7 Sept	Received permission to use Kinsley's narrative
2-13 Sept	Positive Core Identity symbols and words: received and shared with participants
13 Sept	Information Sheet sent *Before* Second Focus Group, with Personal Strengths and Group Strengths consolidated
13 Sept	**Design: Second Focus Group**
14 Sept 7 Oct	*After* Second Focus Group: Thank you email with consolidated notes from the brainstorm. Check in, in case some parents were having challenges with children. Transcript sent.
26 Oct	Information Sheet sent *Before* Third Focus Group
28 Oct	**Destiny:** Third Focus Group
28 Oct	Post- questionnaire Participation Feedback Questions
	After Third Focus Group: Thank you email. Check in, in case some parents having challenges with children. Transcript sent.
29 Oct	School Interview Notes received
22-30 April	Post-script Questionnaires

Each of the sessions were organised in coordination with the participants for times that best suited them. Due to the Covid lockdown restrictions, the participants started the paired interviews and the first focus group session using Zoom, and April[2], one of the participants,

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[2] A pseudonym

offered her home for the last two focus group sessions as she didn't have childcare for her children. This situation worked well for all participants.

Beside the narrative that was collected in the group sessions, there were two questionnaires that asked the same questions before and after the research process in order to discover any difference the appreciative inquiry may have made. There were also feedback questions at the end of the inquiry that provided more narrative opportunity of the mothers' experience of participating in the inquiry (see appendix J and N).

3.7 Data Analysis

The transcriptions, questionnaires and participants' symbols and words were collected together in a single file for data analysis. Thematic analysis was used with a social constructionist lens, with an awareness of not 'one truth', but stories and metaphors depicting multiple perspectives and realities. Inherent in social constructionism is the theory that "individuals cannot be separated and studied independently of the social fabric that constitutes their environment…They are constantly engaged in a dialectical process with their environments, which is mediated through language or discourse" (Milioni, 2001, p. 12).

Through the multiple perspectives and realities, I specifically looked for areas of parental agency in regard to the coping/stabilisers/hoping stories while using a latent/emergent approach to bring theory and meaning from the features of the stories. With this framework and social construction theory in mind, I followed Braun & Clarke's (2006) helpful guidelines and steps for conducting thematic analysis, which are: familiarising yourself with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing a report.

The coding process began by putting all transcribed narratives from each focus group session into one document. This overall transcript was read to identify key ideas (codes) and themes. Keywords were identified for themes and the transcripts searched for all possible examples of themes using these keywords. This is to ensure that the position of each participant can be described in relation to each theme. The draft themes were checked for consistency by myself and my supervisor.

Theme pages were created, with quotes placed into each pertinent category. Some themes were created around the responses to specific questions or specific phases of the AI, but there were also overarching themes that emerged from many different contexts in the inquiry. In this process, I sought to understand the themes within the participant narratives: the similarities and differences, and the presence or absence and range within themes, and consolidated the information into a reflections and outcomes chart.

3.8 Ethical Considerations

To ensure that this study was conducted within the ethical guidelines of the Unitec Research Ethics Committee (UREC), an application was submitted and approved for research involving human participants that involves, or may involve, potential for sensitive issues. See appendix A for a full discussion of the ethical issues involved in this research. This research was not about delving deeply into trauma; rather, it was focusing on a strengths-based appreciative inquiry. It was not anticipated that this inquiry would cause direct harm to the participants; however, possible discomfort could not be excluded. Therefore, the researcher provided verbally and in written form the information needed to ensure participant safety (see Invitation letter, Information sheet, and a Participant Consent and Confidentiality Agreement, Post-session Support Hand-out – appendices C, D, I, H). In addition to this, participants received an information sheet before every session to help them be prepared (see Appendix K, L. M, N).

Check-ins were done after each session to ensure that participants were not distressed. At all points during the research process, participants were able to contact me directly. The researcher did not select participants who were clients, ex-clients, or friends. In order to mitigate conflict of interest, all participants were made aware during their first phone consultation that the researcher was a parent of a child with an anxiety disorder, and this position was acknowledged during the inquiry. Reeves (2007) argues that where participants are set up as collaborators and the researcher is facilitator and witness, "the subjectivity, life history and agency of the researcher invariably influences the interview, ultimately affecting the content and analysis of the data" (p. 264). To ensure the safety of everyone, the researcher kept a journal for reflection and talked about any concerns with her supervisor who reviewed the focus group questions and design and provided support on any issues, concerns and challenges that occurred during the focus groups or emerged in the data analysis.

Chapter Four: Research Findings

4.1 Introduction

A four-phased appreciative inquiry was used to collect raw data with a group of mothers. Due to the Covid lockdowns, some sessions were online using Zoom, others were face to face (F2F), and one mother needed to leave after the paired interview:

- Discovery (Zoom):   2 x paired interviews 2 x 2 mothers
- Dream (Zoom):   focus group   3 mothers
- Design (F2F):   focus group   3 mothers
- Destiny (F2F):   focus group   3 mothers

Four main themes have been identified as a result of the thematic analysis. The first theme illustrated the mothers' challenges of being on the fringes and navigating the quagmire of support around them - including the mental health professionals, friends and family, and their children's schools. The second theme demonstrated that the mothers learn to cope by creating calm in the home, in the child and in themselves. The third theme reflects on the strengths-based personal and collective identity of the mother as advocate that developed the group's positive core statement. The fourth theme described the mothers' experiences in their freedom of sharing within an appreciative inquiry. Pseudonyms were used in this study.

4.1.1 Study Participants

The focus of the research was on parents, with five mothers and one father registered to participate. Just before the paired interviews, one mother needed to pull out due to her son being in crisis. Then, before the first focus group, the married couple needed to pull out with the extra responsibilities of the second Covid lockdown in their businesses. With the father gone, I decided to focus the research on mothers, and Kinsley has given me permission to use her narrative from the paired interview.

Table 4.1 presents some of the demographic features of the mothers who participated in the research and their families. All of the mothers have at least one teenager with a clear and debilitating anxiety disorder that has lasted longer than a year. The list of strengths and challenges in this table is by no means complete; however, they position the mothers as struggling with significant issues of stress beyond the care of a teenager without mental illness.

4.2 Theme 1: On the Fringes, Navigating the Quagmire of Support

In each of the three sections on this theme I am exploring the challenge that parents experience in trying to get support for their children and themselves. Support means being able to have a relationship of trust and shared responsibility with another person.

Table 4.1: Some demographic features of the participant mothers and their families				
Feature	Sienna	Grace	April	Kinsley
Ethnicity	Pakeha	NZ European	European	South African European
Age	30-40	40-50	30-40	30-40
Occupation	Kindergarten Teacher (FT)	Managing Director (FT)	Childcare (PT)	Business Manager (FT)
Marital status	Married. Māori man	Single	Single	Married, Euro Man
Care of Children	3 Children: Full care	1 Child: 11 nights a fortnight	2 Children: Full care	3 Children: Full care + 1 overseas
Family Situation (as well as child with anxiety shown below)	Living with husband *1st son*, 15yrs: Learning difficulties + dyspraxia *2nd son*, 10yrs: Anxiety, OCD, ticks, Asperger's	Left abusive marriage, single.	Left abusive marriage, single. *2nd Daughter*, 8yrs	Left abusive 1st marriage, married. *2nd son* has anxiety, and self-harms *2nd marriage*, living with husband's daughter too
Self-Care	Citalopram. No therapy this year , "but I need to talk with someone" Talk with counsellors before and after sessions, giving great advice and support. No time for support group	Citalopram. No therapy this year – "I should have someone". Talk with counsellors before and after sessions, giving great advice and support. Member of ADHD organisation, online groups -, share frustrations, tips, daily – "makes me feel I'm not alone!"	Citalopram. Counselling (once a week. Yoga, Mindfulness, Church	N/A
Child with Anxiety	Zoe: 14yrs old High Anxiety (selective mutism as child)	Axl: 13yrs old ADHD + High Anxiety (discovered at 8yrs old)	Dianna: 14yrs old High & Social Anxiety	Tyler: 19yrs old ADHD + High Anxiety (discovered at 8yrs old)
Specific features	Avoiding school and going outside. Panic attacks. Upset by noise, listening to people eat, crowds, making small talk, getting things wrong, what people think of her. Trouble sleeping	Avoidance. Withdrawal - (sleeps a lot). Self-harm (cutting) Odd panic attack	Noise, others present or looking at her, Withdrawal, Panic attacks, Self-harm, Runs away/hides, Needs a lot of sleep	Dyslexia at 13yrs old
Strengths	Some netball Good friends	Plays basketball Good friends	Classed by Mensa for high intelligence	Played rugby
Treatments	Fluoxetine, Sleeping tea + magnesium Family dog Not talking much with counselling and nurse at Marinoto	Citalopram (2yrs) Still anxious, but less so. Private counselling (variety, and responding well to CBT & someone he trusts) Peer mentor	Refused counselling Lemon balm and yoga Only church has helped – handing it over to God Extra help at school	Marinoto, counselling, medication, RTLB learning support

4.2.1 The Mental Health Professionals

The mothers described the level of trust, relationship, and accessibility required for both mothers and their children to have good professional help experiences. Grace and Kinsley ("when [she] had the finances"), were two mothers who chose private counselling and found it useful for their children when they found the right therapist, agreeing that "the main thing is that [their children] find someone that they can relate to talk to". However, when children refuse to talk with counsellors, it's extra challenging. April has found "only church has helped" where her daughter is open to "hand it over to God".

Marinoto, Auckland's Child and Youth Mental Health Service, was the organisation the mothers felt most challenged by. Due to her 'bad experience" at Marinoto, Grace had a "general mistrust of public systems to help our kids". Sienna "always just rubbished [Marinoto]" due to the "bad experience" with her sons. Kinsley's younger son "hates going there". However, it wasn't all bad news: two mothers shared their good experiences with their other children at Marinoto as well. Kinsley took her son there 11 years ago and they were able to help Tyler "a lot", and Sienna has recently found with Zoe, that "they've gone over backwards [for her] …it's almost like they've got a whole new culture". Grace reflected that she thinks part of her issue with Marinoto was "I didn't know the people… I didn't have that trust". In an interview later with Grace, her school DP also shared her thoughts about Marinoto, and public health in general, being "underfunded and very stretched".

The mothers generally appreciated their GPs as someone who "has your best interest at heart" (Sienna). However, Kinsley's trust in her GP in a crisis situation left her traumatised and isolated:

> I was really sick and I took Tyler to the doctor because he was having a really bad anxiety patch and he needed some extra support. He had a meltdown at the doctor's rooms. That panic attack was like something I've never seen before. He ran outside and was trying to run into the traffic. I had to hold him and I was… aching, and … holding him, like for 45 minutes before the police came to help me. The doctors just left me outside with him, and he ripped all his clothes off… he was [in}… another state … all I could do was just hold him, and he's 19, he's so much stronger than me, taller than me … [after the Police helped,] I phoned my husband. I said, 'Can you meet me at the mental health unit' and he just came and sat with me, and just him being there… is helpful for me, just knowing he's there. But apart from that, I just felt utterly alone. …
> [The doctor had] came out and he looked at him and he went, he was like, 'I'm busy'. You could see it in his face. He went inside, he phoned the police, and he just stayed inside … Afterwards I was just like, shaking…I just didn't tell anyone about it.

The professional therapeutic situations were individual sessions with the child, not a collective or family recovery experience. For Sienna and Grace, the counsellor only included the mother a little bit before and/or after the sessions, offering advice and support.

4.2.2 Friends, Family and Community: Navigating Stigma and Acceptance for Support

This section demonstrates the very strong sense of isolation the mothers experienced in their community of friends and family, even when there may be some support around them.

4.2.2.1 Being isolated while having high support needs

Getting support from 'family and friends' was one of the most difficult tasks for mothers. Their stories reflect unspoken agreements between friends and family that when you are in need, you will ask for help, and that when you ask for help, support will be there. However, the support is often not present and so asking for help becomes difficult and leads to a sense of isolation for the mothers. When Grace initially shared with her friends, she discovered that "they just didn't know how to cope with it … [they didn't] know what to say … [or] how to help me". So, she decided she wouldn't "talk to them about that sort of stuff, they're different sorts of friends". April also expected her friends would be there for her, as "that's what we're all in here for is to support each other", but they decided, "'actually, this is just getting too hard for me, I can't cope with that … people just piss off". The result, as Kinsley explains, is that

> I do feel isolated because a lot of the time when the show does go on, I do shut down and I don't share with anyone what I'm going through … sometimes I feel completely alone, even though my husband will be there.

That sense of aloneness grows with Grace, asking herself, "am I the only one going through this?"

April voiced the mothers' experience of a lack of understanding and negative judgement that they experienced from the people around them.

> The judgment from other people on us as mums, and … on our children… is ill-informed. People don't know what happens behind closed doors … [the kids] wait till they get home and they only express their emotions at home … other people might think they're this perfect child.

Even when she could talk to friends, Sienna felt "unless they have teenagers going through the same thing, they don't understand … it's just hard to find support".

4.2.2.2 Mothers' strategies for dealing with judgement and isolation

Some of the mothers shared their strategies. These were having discernment about what you can share; having an acceptance of the limitations of support and understanding from friends and family, and a silencing of the experience of judgment, knowing that those who judge have

no understanding of your situation; Grace explains how discernment leads to acceptance – "I was quite open with a lot of my friends in the beginning, and like I said, they just didn't know how to cope with it, so we don't really talk about it". The last step is silencing – "they say, 'how's Axl going?' [I say] 'Oh, he's good, he's good'". She still found it difficult to accept "the lack of understanding of it in places like schools, where I would expect it to be not a stigma." Kinsley, in response, shared a silencing strategy, creating an armour of rejection of outsider views in the face of their judgements.

> I haven't experienced too much stigma, mainly I think because I don't really care if people don't understand… I know what I'm going through, and what our children are going through is real… I'm not really looking for validation from them.

Grace eased the discussion back to discernment - "I tend to overshare, and I've learned that there's only a few people I can actually share with". Grace and Kinsley developed their own strategies to navigate what they saw wouldn't change - their friends' judgements, lack of understanding and their inability to cope. April found the idea of acceptance difficult, and held both need and hope that she could mend friendships and create more support - "it's nearly been a year since I've spoken to some of my friends because of their lack of empathy, and I was thinking of reaching out and talking to them…via a friend [who] is a mediator".

This is what April would like to say to them to create understanding:

> Do you know what happens behind closed doors? Are you in a position to make a judgment on something you aren't living? And for me, I don't judge people. I don't make a comment on their life… I just listen. I don't tell them what to do. Because I don't know what happens behind closed doors. I don't know why children feel the way they do. Sometimes a parent doesn't know why the children don't feel the way they do. But whatever there is, there is a reason, and you need to respect that person's feeling, and don't judge them. And it's the learning journey. And that's what I want to say to them.

April needs affirmation of her experience, but it may be a challenge for her friends to give it.

4.2.2.3 Pre-research questionnaire

Table 4.2 shares how the mothers rated their experiences of support, isolation, stigma around mental illness, and their levels of confidence in their abilities to support or find support for their child. The table shows that the mothers, although moderately confident in being able to source help and support, don't appear to be getting much support and are experiencing "a lot" to "huge" isolation. Kinsley appears to experience more support on average and no stigma at all compared with the other mothers, but this is possibly because she shuts herself away from potentially stigmatising interactions. With April, who experiences, on average, the least support, matches Kinsley's experiences of a huge amount of isolation.

Table 4.2: Participant ratings of support. For q1-3: *Not at All* =0, *A Little* =1 *Moderate*=2, *A Lot*=3, *Huge Amount*=4. For q4 and q5, there is reverse scoring so that *Not at all*=4 and *Huge amount*=0.				
As a parent caring for a child with an anxiety disorder, to what extent	Sienna	Grace	April	Kinsley
1. Are you experiencing support currently?	1	1	0	2
2. Are you feeling confident in your abilities to personally help & support your child?	1	2	2	1
3. Are you feeling confident in your abilities to source help & support for your child?	2	2	1	2
4. Do you experience isolation?	1	1	0	0
5. Do you experience social stigma around mental illness?	2	1	0	4
Average support experienced	1.4	1.4	0.6	1.8

4.2.2.4 Where Support is Found

The mothers identified that there were four types of people who will take the time and care to understand and provide support: a key family member or friend, people who are in a similar situation, key work colleagues, and staff and volunteers from a local community church and family service (see table 4.3 – I was only able to get partial data for Kinsley).

Table 4.3: Where support is found				
	Sienna	Grace	April	Kinsley
Family	Sister Husband Mum (a little)	Sister (New York) Mum (a little)	None	Husband Father
Friends	Yes, limited	Yes, limited	Yes, limited	Yes
Friends in similar situation	None	3 to 4 people	None	N/A
Work colleagues	Yes	Yes	None	Yes
Online support groups	None	Yes – several, use daily	None	N/A
Face to face groups	None	None	Church & Community Family Service	N/A
Other	Family dog			

The narratives show that work colleagues are one of the best sources of support for the mothers. Grace revealed that "work is more supportive than a lot of [her] friends … I don't feel at work I have to hide anything … maybe it's because I'm the boss". Kinsley feels

"lucky" at work too. As the manager, she supports some of her staff who also "have anxiety issues" and has helped create an environment where they "all get on like family". Sienna has some teacher friends who have older daughters and understand "that kind of thing," and there is a "common goal of everyday trying to work together doing fun, fun things". "It's a good group to belong to" says Sienna.

Key family members also provide valuable support. Grace's sister is her "kind of rock" … "despite being so far away", and Sienna's sister is "really good" too. Both Sienna and Grace limit what they share with their elderly mothers because they don't want to "worry" them. Both Sienna and Kinsley find support with their husbands, while for Grace and April who left abusive marriages, that's not the case with their ex-husbands. Kinsley's father in South Africa shares "lots of insights" that help her.

April, with "no family" and "no support," and even though she's "never been religious," she became involved in the local church, a "nice, safe environment," which she considers as part of her "support network". Grace has also taken the initiative to extend her support network, by developing a couple of friendships with mothers who are in "a similar situation," and joining several online support groups which she checks on daily for "tips, ideas, and suggestions".

Kinsley is "very lucky" with her friends, especially her best friend from school who lives down the road and works for Lifeline. "She's a wealth of information and she's just so level headed … she's always there. She's amazing." As a family who has experienced "limited social options", April treasures time visiting friends as "one of the most precious gifts". Sienna talked more about her puppy than her friends, as her daughter "calls it her therapy puppy".

In summary, the mothers struggled finding support with the majority of people they might have expected to support them: their friends and family. They have had to navigate how to participate in their relationships with friends and family in the face of potentially stigmatising interactions – what to share, who to share it with, and how to cope and manage it all.

4.2.3 Schools: Advocating for Support is On-Going

Each of the mothers experienced the on-going struggle of trying to get support at school for their child, the worry for their child's wellbeing and their future, and the determination to not stop fighting for them. The advocating was challenging a school system that isn't set up for the needs of children with high anxiety, to collaborate with mothers, so that both mothers and educators can help each other help the children.

4.2.3.1 Pushing, advocating, fighting for more support in schools

All the mothers had to fight to get help for their child with special needs in schools. Grace said,

> I naively thought that that's what a school does … they know each kid and they have a plan for each kid… [but] if you're not there pushing, advocating… my son's been suspended twice this year… and I fear that he'll be expelled… I try everything I can to make sure that doesn't happen, but only because I'm in the position, not because the school does the right thing.

Kinsley reinforced this perspective:

> You have to constantly stand up to people… You absolutely do the right thing by pushing… with my younger son, … I've had to fight so much harder for him, because people don't realize that he's going through [anxiety]… [It's] very distressing when they cut themselves and trying to get the school to understand… I expect more from schools.

April shared the frustration, "You have to fight with your schools to get the help".

4.2.3.2 The advocacy is ongoing

Even where the school seems supportive, you never know when that support will be removed. Sienna, who received extra care for her child after fighting for her in primary school, discovered "when [she] got to intermediate that things kind of changed … it's like they don't care once they pass the little kid ages … like the problem should be solved… and you don't need any help anymore!".

With three children with special needs, Sienna says she has "spent pretty much my entire parenthood… advocating for them, trying to find support… I have no qualms about talking to whoever I need to…ringing up ministries… having arguments with principals at high schools, I'm quite good at that now". Normally "a quieter" person, Sienna sees "being strong" and "standing up for what's important" as a "learned thing" that she did for both her children's special needs and for "their culture", as her husband is Māori.   She doesn't care about "being seen as trouble or annoying", because she is proud the advocacy has produced results - "I've done that!". Grace reflects on the need for constant advocacy, "that's when you realize, even when you're exhausted and mentally drained, just how much strength you really do have".

April describes a similar long-term progression of having to fight for good resources at each level of the education system, starting at "primary school, even from the age of five". The years and intensity of advocating have shown a positive academic outcome for Dianna, and required a lot strength from April.

> I didn't let the three of them [Principal, Deputy Principal, teacher] intimidate me… They got busy and she went up in leaps and bounds and now at… high school, she's one of the top readers … and she's doing well at Maths…but [once again] they weren't teaching [her properly]. I went to occupational therapists - I went to everything known to mankind… I've always shared the way that she needed to be taught for her to learn, and they just ignored it.

The gains that are made are so fragile that significant shifts in the external environment, such as the Covid-19 enforced lockdown, can easily disrupt them. So, although school was going well, April's daughter in lockdown "now thinks she's living the dream because all she's ever wanted to do is do home-schooling…and she said, 'I'm quite happy to stay here and do schooling over the internet with you because I learn more at home". Sienna is wondering if her "daughter will go back [to school] **…** she stopped going every fortnight for two days a week since we went back from the last lockdown…it became a massive thing and so there's no point for us. I can't force it".

4.2.3.3 Facing stigma and an education system not set up for them

You always need to be "up for the fight" in schools, where you "wouldn't expect stigma to be" says Grace, "its constant". For Kinsley this stigma makes her frightened to ask for help as it "is one of the most scary and difficult things… it doesn't come naturally. I just always back away from it, but when it comes to your kids, you'll put yourself forward even though it's not your comfort zone". Not fighting, not being "in their corner the whole time" (Grace) just adds to the stigma – "people would just see him as being naughty… the teachers shun them, their friends sometimes shun them" (Kinsley) and the outcome of being put in a "special small school where he's made to feel more different" (Grace) hangs in the background. "What would happen to him" asks Kinsley if she wasn't there? She feels "so desperate, … [she's] always there, no matter what". Grace agrees, "that's what we do as mum's right?", "100%" confirms Kinsley.

Both the parents and the children with high anxiety are trying to deal with an education system that isn't set up for them. Each child "expresses it differently" (Grace) and at present, schools seem to be "treating [students] as a mass" instead of "as an individual" (Grace and April), which hasn't helped their children. Grace and April suggest "a mindset change for the educational system" where educators and mothers work as a team in supporting their children with special needs. This teamwork has been challenged in the past with situations where the mothers experience being:

- "ignored" when trying to help educators help their children (Grace & April)
- "outnumbered" (Grace & April) and given "such a hard time" (April) in meetings
- condescended to with statements like, "Don't be so silly, 'mum'", or "It's all right dear" which can exacerbate the situation into, "It's not fucking all right, my son cuts himself at school!" (Grace)

- Stressed with high expectations on their children in and out of the classroom (April & Sienna) where "the rooms are overcrowded" (April) and there is too much homework (all mothers). The children "do enough at school and especially if they have to work extra hard to figure it out" (Sienna). April said to her school that all this homework is making Dianna "distraught" and "anxious" and she "doesn't want to go to school. You are making our lives hell".

This advocacy process is about trying to create a change in the system. Grace reports her son's DP saying that "the mainstream schools can't deal with our kids now, that's the problem." Grace acknowledges this, noting that each classroom has "30 kids, and probably 10 of them are neurodiverse … [the government should be] putting the money into education, so that we can have more teachers. We need bigger schools".

4.2.3.4 What positive differences look like in schools

One theme that stands out in this research, largely by its absence, is the amount of influence one positive person can make in a child and their parent's lives, simply by recognising that the child "can be more than… the challenges [they] face". Without any pressure from Grace, her son was offered a leadership role on his basketball team to be "a bit of a mentor for the other kids" by his coach. This was "pretty exciting and very rare with my son to be… chosen for a leadership role".

Strong relationships are really important in creating the wrap-around support that is effective. The Dean in Kinsley's son's school, supported him from Year 9 to Year 12. Tyler could "leave the class if he needed to", and go and talk with the Dean throughout all those years. Through Marinoto, Tyler also had the support of an "RTLB teacher in class", and counselling and medication. "Honestly", Kinsley said, "without the support of those extra people and me pushing it quite hard, that would have been almost impossible for me to get through that school with him".

Still requiring pushing on Grace's part, a "wellness plan" was created and a "[peer] mentor" was arranged for Axl at his school. "But I had to do that, you know… it was me at my best, sitting down and being calm with them and just reminding them of his challenges" … "so there is something concrete that [makes the school accountable]" especially "when he cuts himself in school". Sienna feels when there was a plan and support (through her advocacy) in place, there were better results. For children who are noise or crowd sensitive, the school environment can be a challenging place. April was pleased to discover Dianna's new high school has "a separate room … they do their exams separately from everyone else… there's about 10 kids, and it's just silent. And that's where [Dianna's] happiest".

In summary, the mothers experienced the on-going struggle of advocating for more support for their child in schools, often a place of stigma attached to both their child's challenges,

and to them as a mother advocating. The mothers also shared some positive initiatives that made a difference with things like: recognising the child as more than their challenges, having wrap-around support, and creating tailored plans and special spaces that take into account children's special needs.

The narratives relating to this first theme *On the Fringes, Navigating the Quagmire of Support* demonstrate that caring for a child with an anxiety disorder places the mothers on the fringes of what we could expect to be the key sources of support provided by mental health professionals, family and friends, their children's schools, and the community. While advocating for more support, they discovered key people they could place their trust with, and they also realised more about their strength and determination, especially in the face of ongoing judgement, feelings and experiences of isolation, and for most, carrying the sole responsibility for the care of their child.

4.3 Theme 2: Learning to Cope

As part of the appreciative inquiry, the mothers reflected upon the coping mechanisms they had heard each other use. For brevity I have just used initials for the names of the mothers below.

Putting your child's needs first: "You're doing an amazing job … make sure you give yourself a break and look after yourself" (S), "you put his safety and his wishes and his needs in front of how you might be feeling about it" (G), "Extraordinary of you to work so hard [to keep the house for the girls] … and realise how important that is" (A), "you really value your daughter so much" (A), "standing back and letting your daughter deal with the situation" (A), "Putting your [children's] needs first" (K).

Understanding and kindness: "you love her" (S) "getting them to understand he needs help in a certain way" (G), "to really understand [your child]" (A), "you've obviously recognised that and its different things for different kids, but you have to advocate differently" (K), "Sense of kindness [towards the children]" (K).

Strength and Self-belief: ""It's really a lot that you went through [for your degree], which was great" (S), Empowering yourself" (G), "you had a strength that you didn't know you had" (G), "Belief in self" (G, K) "self-confidence" (G, K), "Admitting that you need help" (G), "that takes a lot of strength…a lot of time and effort" (A), "Inner strength" (K),

Resilience: "Its commendable, and you must have worked so hard to do that" (S), "your focus has been on educating people…pushing the kid's school to understand where he's coming from" (G),   "you'll carry on regardless because you know that it's the right thing to do" (G) "your ultimate goal to survive" (A), "you get up every day and carry on" (A), "you are finding…outward things for support" (A), "Up for the fight" (K), "you've succeeded…screw everyone else, you've done it" (K)

Calmness: "time to demonstrate love, and just wanting to be together, and just be calm" (S), "Kids want to spend time with you" (S), "stay calm" (G), "you've thought of some coping strategies… the usefulness of yoga and… mindfulness" (A), "you created a calm, calm space for your children" (K).

The feedback the participants gave reflected the elements of appreciation they noticed in each other. The sequence above reflects a process of the mothers' decisions to put their child's needs above their own, the understanding that underpins those decisions, the strength and resilience that's required to implement them and ultimately a sense of calm that comes from knowing that they've done what was necessary. Those most isolated, April and Kinsley, are the most affirming, perhaps appreciating what they are learning from Sienna and Grace.

The sub-theme that emerged was shifting from a power-under position in the face of stigma and ignorance (learning to cope), to a power-within position to create calm in order to cope. This theme had three parts: creating calm in the home, in their child, and in themselves. The mothers' shared experiences in this appreciative inquiry included a journey from learning to cope, to appreciating their learning.

4.3.1 Creating Calm in the Home:

The home is stereotypically seen as the place where the mother has the greatest influence to create a calm, nurturing environment for her family. Three of the four mothers didn't start out in environments that supported that influence, but have been working to create it ever since. Those mothers experienced the challenges of standing up to, and separating from, abusive husbands. Kinsley shared that her ex-husband was "a raging psychopath"; she "never knew what animal [she] was getting home to". There was "quite a lot of abuse and some violence" in April's marriage, and Grace had to stand up to her "very angry narcissist" ex-husband, who was "[her] bully basically".

When the mothers stood up for their child(ren)'s safety, they also learned to stand up for themselves. They were proud of themselves for being "level-headed" (Kinsley), "strong enough to fight" (April), and "doing what was right for my son's mental health" (Grace). April was able to "navigate [her] way around the system to keep [their] home" and make sure there was "no change" for the kids. Kinsley worked to make her and her kids' lives "normal" which "help[ed] the kids be quite calm" and Grace has been standing up to her "bully" husband "ever since".

The three mothers were able to take themselves and their children out of the chaos and into more calm. In Sienna's situation, with three young children with special needs, the external struggle to find the inner power and calm came differently. She was doing her degree when she learned her youngest son "has an extra chromosome." Sienna says she "almost gave up [her degree] … but I didn't, and carried on." For 3 ½ years "it was hard work" that showed her children that "even though we all go through tough times… things can be completed and we can push on".

4.3.2 Creating Calm in the Child:

To help create calm in their children, the mothers spent a lot of energy noticing, de-escalating, and modifying the triggers in their child's external environment that would activate anxiety, as well as building a sense of trust, acceptance, and constant support to maintain their relationships. This huge amount of energy with the unpredictable and ongoing nature of anxiety and the environment leaves the mothers exhausted and at the same time continually searching for new strategies to help them help their child.

4.3.2.1 Each Mother's Experience

Kinsley said, "I don't think {being a mother] comes naturally to me at all. It's been hard work right from day one". With the very high needs of her son with high anxiety and ADHD, together with her lack of confidence in her abilities to support him (table 4.2), Kinsley put her confidence in the external supports she located to help keep her son calm. This included the wrap-around support at Tyler's school; counselling; medication - when "the only real peace came"; and the Police who "were just amazing" helping out with "very serious escalations" that Kinsley could not deal with on her own. A personal de-escalation strategy that Kinsley felt confident about was "talking about [detailed plans] earlier" so that Tyler could build himself up to "go into [situations]".

Grace, who was "moderately" confident in herself supporting her son with high anxiety and ADHD (table 4.2) felt a lack of trust in the external support for her son. Most of Axl's "anxiety is generated firstly by his dad" who he sees "three nights a fortnight" and "secondly by school". Both of those environments have a difficult track record of not listening or being on the same page as Grace in their management of the anxiety Axl experiences. Grace has been proactive in standing up to both those main triggers for Axl, especially at school, "you can't just sit back and assume that others will do it". Through all Grace's advocating, Axl has a wellness plan and peer mentoring in place at school; he is doing private counselling, through which Grace also learns "how to handle things"; he is taking Citalopram, which just makes him "less anxious"; and he is playing basketball competitively. Grace provides reassurance to Axl with things like, "it will be alright", however, when Axl is particularly anxious he will "self-medicate" with "drugs and alcohol" to "help calm him and deal with the pain". Grace manages this by meeting the families of Axl's friends, "you have to know the family to know the kid!".

Sienna rated herself as "a little" confident in her abilities to help her daughter Zoe (table 4.2). As Sienna has been advocating for her children in schools and getting some good results, she experiences more support around her that she can trust. However, Sienna's struggle is that Zoe needs to want the support, and currently, "Zoe doesn't want a bridge to the rest of the world". The anxiety causes Zoe to: physically isolate and not communicate with others, including family; avoid school, crowds, "listening to people eat, making small talk"; and have a fear of "getting things wrong" and being judged. Sienna has learned to

support Zoe by "backing right off", "being quiet", and not letting the anxiety escalate. To maintain connection, Sienna tries to do what Zoe is able to manage, and so far, that is "watching movies in bed" and "taking care of their puppy". Zoe has recently started on fluoxetine and doing talk therapy, but "she doesn't talk much to them" so it has "been a struggle".

April felt "moderately" confident in supporting her daughter (table 4.2), and relies on herself a lot as she, like Grace, has been let down by conflict with her ex-husband and Dianna's schools. Dianna is highly anxious and is "classed as Mensa for her [high] intelligence". April and Dianna "work on self-managing things" because Dianna "struggles socially", finding situations difficult "when there is noise or others present or looking at her". April needs to be continually aware of Dianna as the panic attacks will make her want to run away, hide silently, and in some situations, self-harm. Some panic attacks last for "nearly two hours" where April will hold her and calm her down. Through April's advocacy, Dianna is: supported to achieve more at school, "she is like a military operation"; and receiving support at church where she is told "to release it and hand it over to God and that she isn't responsible". "Only church has helped really", as Dianna "shut[s] down all counselling," she will, however, "munch on" lemon balm "when needing to calm down" and April and Dianna "do yoga" together. April "won't medicate her".

4.3.2.2 From external control to learning internal control

The mothers shared stories of external control strategies where if the child didn't do something the parent wanted them to do, then the parent would take something the child values away from them, like, "just [turning] off the WIFI" (Sienna). The mothers agreed this didn't work, they found that the anxiety created a stronger need in the child, than the need for whatever they thought the child valued, and for April, Dianna "wanted to be with me more" than she wanted her favourite toys. Sienna recounted the time when Zoe said, "I wish I wasn't so quiet" and they talked for a bit, with Sienna beginning to feel hopeful, and then Zoe said, "that's enough talking" … "she [wanted] to be able to do it, but she just can't".

The mothers' strategies of creating reassurance, comfort, safety, and connection, even if they seemed tenuous at the time, appeared to have more positive outcomes. For Sienna, her ability to connect with Zoe is severely challenged, "she doesn't talk to me and I'm not even allowed to kiss her, hug her, tell her I love her". Sienna can go the "whole day without talking or seeing her", and tries to keep the reassuring, safe connection with "movies or something in my bed" or even giving her "sleeping tea" and "magnesium" when she can't sleep. April helps Dianna go to sleep by going into her room "every five minutes, give her a kiss on the head and a pat …until she feels comfortable and safe [to sleep]". For Grace and Kinsley, there is the knowing of "when I need to stay and either stand up to him, or comfort him, [and] when I need to walk away" (Grace). "That is 100% right," Kinsley agrees.

The mothers recognise the struggle and hardship their children experience of facing the anxiety on a daily basis, "because it's too much for [them]" (Sienna). Sienna, like the other mothers, feels the struggle and hardship, "it's exhausting", like "walking on eggshells". Grace and Kinsley share that the children need to learn how to de-escalate themselves and manage their situations because "at the end of the day, you can't be with them 24/7… and other people are always going to deal with it differently to what you would" (Kinsley). The mothers, in their main caregiver support roles, are mirroring so much of what their children are going through by learning to manage the high emotions of their children and themselves, while trying to live their own lives in a healthy and well-connected way.

4.3.3 Creating Calm in Themselves

A common experience for the mothers in dealing with the anxiety of their children was the self-sacrifice, or internal disconnection, that happened in order to cope. This was found when they put their kids first and shut themselves down. Another common experience that showed up in the narratives was the mothers creating connection to self for better coping. This presented in mothers taking personal time-outs to deal with their emotions to become better able to cope. After the sharing, feedback, and reflections of the appreciative inquiry, the mothers were able to acknowledge and value their coping and their learning.

4.3.3.1 Self-sacrifice/Internal disconnection in order to cope

The effects of the mothers coping by "putting their child's needs first," translates to the mother's needs becoming secondary, if they are met at all. The anxiety works directly on the child, and indirectly on the mothers, potentially keeping them disconnected to their emotions and/or their external environment in order to cope in the world.

Kinsley said, "What I've done over the years is just shut myself down. I don't have feelings. I don't have reactions… I always try to squash what I'm feeling and deal with what they feel… I haven't really dealt with it myself". Grace empathised with Kinsley, "possibly also, as you say, you're not actually dealing with your shit, but whatever, I stay calm…I don't react…I'm empty". This way of coping works for Grace, allowing her to put aside her "own [stressful] issues", because "sometimes I do lose the plot with him and I know when I do that, it really makes things worse and he spirals downward". For Sienna, "It's as hard as" … "my boundaries have…become more flexible…just to avoid the screaming matches".

There appeared to be a deep self-sacrifice when April said,

> I do accept that … I've done my life. And now all I have is … to look after the girls. I will never have another relationship … because I don't think that anyone could cope with my kids and their sensitivities, and they would probably never accept anyone.

Grace added, "my son's the same".

The internal disconnection in order to cope was seen in the workplace as well. Three of the four mothers continued to work full time while caring for the high needs of their child(ren) with an anxiety disorder, one of them as a single mother. A common denominator to each of the three mother's working environment appears to be how supportive their colleagues and work culture is (table 4.3: Where Support is Found). "I don't let [the challenges with my son] stop me doing my job," Kinsley says. She has learned to "just block it out" and "carry on with work". Grace has also continued to work full time, sharing that she doesn't "know if I have a coping strategy to be honest". As a single mother, with minimal family support physically around her, Grace says, "you just have to get on with it". Unlike Grace and Kinsley, who overrode their emotions, Sienna became more entrenched in the challenging emotions by "taking everything so big". She was an "emotional wreck" and at work, she became "just withdrawn" and disconnected to the children and projects she did in a teaching job she greatly valued.

April was not in employment due to a brain injury, however, she created part time work doing after school care in her home that included her children. Not having any family in support and being a single parent, this helped financially support her and her children while also giving her valuable time to connect with herself to better cope (counselling and mindful practices, see below).

4.3.3.2 Creating connection to Self for coping:
While the mothers' personal needs are perceived as secondary, they still need to be able to cope. The strategies the mothers have used to find their calm are all different to each other, however the one common ground is they are all on the same medication.

"You've gotta be really strong" says Grace, "which is why it's so important that I am on something like the citalopram because I can be stronger, not so much ditch down". Each of the mothers, to their surprise, had all independently chosen to take citalopram to help themselves cope. Grace believes that "it takes a lot of strength to [take medication]" as "there is a lot of judgement". April agrees, she feels like she has to "hide things" to "protect the kids and [her]self". She hasn't been able to work the last few years with her "stress levels" being "so high", and she has been going to weekly counselling. Grace has had "therapy over the years", and has "been thinking I should have someone". Similarly, Sienna shared, "it's almost too hard to tell other people about it", and that she also needs "to talk to someone".

Another way the mothers talked about coping, was taking time out to release the emotional stressors and reconnect with themselves so "I can think clearer" and "just deal with it better" (Sienna), and "I can release some tension" and "get it out of my system" (April). "If [Zoe and I] have these [difficult] moments" in the evening, Sienna gets "a glass of wine and I go to my room, and I put on Netflix" which takes her "completely out of the situation, or the

rage", and, "if it's in the day, I might go for a walk". Sometimes when things are "really bad", April says "I might have to go and lock myself in the car and turn the music … really loud… and just scream and cry". Sienna has done a lot of crying too, "I actually don't have any more tears that are left in my body". Grace is able to keep herself "empty of stresses for Axl" by talking "every day" to her sister who lives overseas and "takes it all on!".

April has had more time to reconnect with herself in active ways while she is not working, with things like yoga and mindfulness, which she considers are "good" for her, "I'm doing a little bit less screaming lately". Also, with the Covid lockdown, April and her daughters have been doing free Les Mills on demand classes, saying "it's actually been quite bonding". For Sienna, who is both working and studying with three kids, "I can't commit to anything else I'm doing" … "I can't have anything else in my brain", it has "reached capacity of thinking of where I need to be". However, Sienna's dog has been "the best thing", and describes her dog as "the therapy dog", and if she didn't have her this year, she "wouldn't have coped as well".

4.3.3.3 Post-research questionnaire

Table 4.4: participant ratings of support. For q1-3: *Not at All* =0, *A Little* =1 *Moderate*=2, *A Lot*=3, *Huge amount*=4. For q4 and q5, there is reverse scoring so that *Not at all*=4 and *Huge amount*=0. The first rating is before the research, and the second rating is at the end of the final focus group session. Kinsley withdrew after the first focus group session.

As a parent caring for a child with an anxiety disorder, to what extent	Sienna	Grace	April	Kinsley
1. Are you experiencing support currently?	1, 3	1, 3	0, 1	2
2. Are you feeling confident in your abilities to personally help & support your child?	1, 3	2, 4	2, 2	1
3. Are you feeling confident in your abilities to source help & support for your child?	2, 3	2, 3	1, 2	2
4. Do you experience isolation?	1, 3	1, 4	0, 0	0
5. Do you experience social stigma around mental illness?	2, 3	1, 2	0, 0	4
Average support experienced Pre-questionnaire	1.4	1.4	0.6	1.8
Average support experienced Post-questionnaire	3	3	1	n/a

Table 4.4 shows that at the end of the four phases of the AI, through the act of sharing and reflecting on each other's experiences in an appreciative way, the three mothers who did both questionnaires showed a doubling of *average* support. Grace and Sienna showed a marked improvement from *a little* to *a lot* or a *huge amount* in relation to their *current level of support*, their *confidence in their abilities to help their child* and a lowered level of the *experience of isolation.* They had smaller improvements for *less stigma around mental*

illness and *confidence about getting help and support for their child*. April had only a small improvement in this last area and in her *current level of support.*

In summary, the theme of Learning to Cope describes the mothers' journeys through the chaos of stigma and ignorance to find the calm to cope, moving from a power-under to a power-within position by creating calm in the home, creating calm in their child, and creating calm in themselves. This was exhausting, because they all put their child first, which also meant that their lives were "suspended" and not given priority. The pre and post questionnaire comparison showed the mothers had felt an improvement, large for two, in support and connection.

4.4 Theme 3: Mother as Advocate – Personal Identity and Collective Identity

The theme of mother as advocate rode strongly through each phase of the AI process. In this pre-Dream phase, the mothers were tasked with creating a symbol and a few words that exemplify their strengths and values that represent their personal strengths-based identity. These images and words spoke strongly to mother as advocate, and the theme continued into the first focus group dream phase where the mothers shared more stories about their values, group values and hopes for the future to create the first draft of their 'positive core' statement. The mothers then created a symbol and words about their collective identity and came together in the second focus group, to finalise their positive core statement before brainstorming their initiative. The initiative was also about advocating for their children and will be discussed further in the 4th theme section.

4.4.1 Personal Strengths-based Identity (Discovery Phase)

Sienna: The words Sienna used to describe herself were: "Strength, Love, Responsibility, and Commitment". Sienna created a picture that was a collage of different images, one being a **Mother Bear**, "I will do anything for my children"; a Heart, "I love my life that I've created"; Children on arms, "I hold each of my children's issues on my shoulders"; and an iceberg half-submerged, "What people see is the outside of me, but inside, I have a whole lot going on to stay afloat".

Some noticing:

When Sienna is a "Mother Bear" her face is front on with both eyes making contact and focused, ears up and listening, at the ready and strong.

When Sienna holds the children on her arms, she is faceless, almost a generic mother figure, thin as a stick standing still, almost without moving.

The iceberg identifies a significant amount of herself that is hidden from others, with only the top portion able to view. If you think of water as emotions, this could signify emotions that are now solid, frozen in place where no one can see or touch them.

The size of the heart and almost centre placement shows a strong value of love that is central to life.

Overall, there is a tension between both containing and wielding power, and a 'holding things together' with love holding centre ground.

Grace:

Grace used the words "Integrity, Fairness, Courage, and Positivity" to describe herself. She created an image of a **Mother Duma** (cheetah) who is "Fragile but Fierce"
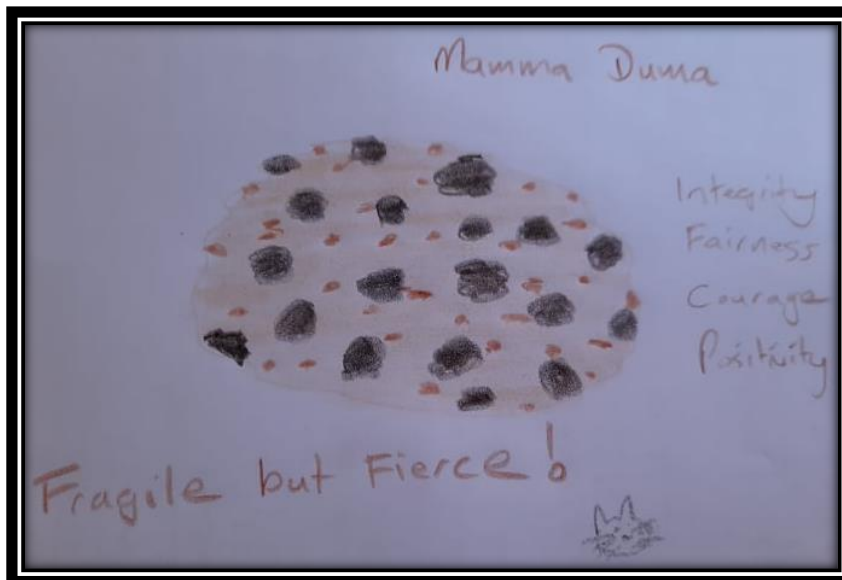
Some noticing:

When Grace places her symbol strongly centre, with 'Fragile but Fierce!' it signifies how central and important to her life this identity is. It comes from her experiences in Kenya watching a mother cheetah protect her babies from hyenas. This is how she protects her son from external forces.

There is a sense of movement, with flexible boundaries, and a sense of playfulness, reassuring us with the friendly cat face. The black spots could signify she means what she says, but there is also a soft side with the little orange dots and soft orange background. Being a symbol, Grace has chosen to show us the fur and the face of the cheetah, what we can't see are the legs to stand on, or the main body.

April:

The words April used to describe herself were, "Advocacy, Supportive, Stability, Encouraging, and Tough". She created an image of a mother "ninja - I am constantly trying to find the strength to keep fighting for those I love".

Some noticing:

When April uses the image of a ninja as her symbol, there is a sense of a trained and skilled warrior, able and ready to take on anything as it comes at her. It is always ready for action at the slightest sign, there is no let-up.

April's ninja appears faceless and male, or androgynous, with no signs of weakness or vulnerability, or a playfulness.

Overall, there is a sense that the strength comes from the doing and the fighting, rather than from any words or softness. It is like this need to be strong all the time overrides anything else that life has to offer.

The mothers reflected on each other's symbols and words before the first focus group session in order to identify key themes that give life to themselves as a group:

Grace: Resilience, Advocacy, Commitment
April: Supportive, Lots of love, Courageous
Sienna: Love and Strength

4.4.2 Collective Identity – the Creation of their Positive Core (Dream Phase)

Table 4.5: Group Culture and Shared Values	
Group Culture	Shared Values
Positive experience	Integrity
Common worthwhile purpose to help each other	Self-belief
Respect and listen to each other	Advocacy
Kindness, No judgement	Fairness
Confidentiality	Everyone' voice is important
Trust	Giving others self-worth
Responsibility and flexibility	Honesty
	Transparency

Table 4.5 shows statements of group culture and values that arose from sharing stories of their values of being in a group and their hopes for the future about being in a group.

4.4.2.1 Group Culture Brainstorm

The mothers shared stories of positive group experiences they have had to draw out the key elements they want to have in their group. April was on a work team "full of camaraderie and team support" where "everybody got along" and there was "no nastiness". Supporting her son's basketball team with a group of parents, Grace recounted, "we had this common

goal, which was get them as far as we could, but make it really positive no matter what happened". Sienna's team experience also included, "working together" for a "common goal" where she is currently part of a "really renowned, well-organised kindergarten … run by incredibly intelligent and charismatic women … doing fun, fun things".

The group culture list shows the mothers' strong sense of purpose and fairness to create a safe space to work together. What doesn't show up on the list, but presented in the actual sessions, were things like having fun and sharing food that created a shared space for developing friendship which enables a deeper sense of connection. In the first focus group that was conducted online, the participants had a break in the middle of the session to just talk together. This was a valuable time for them to relax and get to know each other beyond the research projects' stories and reflections and being online. Laughter sat alongside the stories in each focus group session and the last two in-person focus group sessions started with us sharing pizza, chocolate and wine while catching up before the session and recording started.

4.4.2.2 Group Values Brainstorm

Sienna and Grace shared their values in the lead up to creating their positive core statement. April was absent for this section, and welcomed back to the group with an update in the Positive Core brainstorm. The stand out values for Grace and Sienna had to do with *standing up*, "standing up for children, people, minorities" (Sienna). "I'm laughing because mine's exactly the same," said Grace, adding that "integrity" is also "key" to never let others "walk over you". Grace noticed Sienna's "self-belief", its "why you don't care what people think" because "you know what you're doing is the right thing" and one of those things is "getting [their] children heard" (Grace). They both also highly regard honesty. "The whole of the system falls apart if you're not honest" said Sienna, "I also tell my children too, if anything happens, just tell me the truth … the rest we can deal with, but if you aren't honest with me, I actually can't help you" (Grace).

4.4.2.3 Positive Core Statement

The starting place for the Positive Core statement came from Grace's reflections from listening to Sienna, and that is, "advocating and getting support for those who can't speak for themselves". The mothers aren't doing this for "recognitional payback for ourselves" (Grace), "or any kind of kudos" (Sienna). Grace is motivated, because if she doesn't do this, her son "loses". Sienna agrees when Grace says, "We're doing it for others, not for our own gain". Both Sienna and Grace would actually "love to have a quiet normal life like some of [their] friends".

> It is of course about his wellbeing but … it's stronger than that. These guys are voiceless because they're in this world that's not set up for them and they're on the fringes and schools aren't set up for them and society is not set up for them. So, you've got to be really strongly [advocating]. (Grace)

April now back in the group wondered if "managing the judgement from other people" should be included, but after brainstorming they, engaging at the edge of the socio-political, came up with:

Positive Core Statement #1: "Advocating for children and their parents/caregivers in a world that isn't set up for them; for their wellbeing and potential to be realised."

4.4.2.4 Collective dreams for the future

The mothers' main theme for the future was about social acceptance and valuing difference and if these were in place, the mothers would have more freedom to "focus on what's important" (Grace), and have more "energy to put towards [our families]" (Sienna).

"Children should be accepted" (April) by "society in general, not just schools [that] need to be more adaptable…to differences" (Grace). The mothers didn't want their kids to be "normal"; it was "the uniqueness of my kids and the things that they think about and the things that they do" that Sienna liked. Being "successful…whatever success means" (Grace) was important, but the risks in uniqueness of being "teased or harassed" worried April, and Grace acknowledged "you want them to be who they are, but you want them to be accepted".

A further future dream question was *"Its 2025 - looking back on your team initiative, what will you be most proud of?"* For the children they wanted the transition from complete dependence to self-sufficiency and wellbeing. Sienna would be most proud of the combination of both Grace's wish of "helping her [child]" get to "whatever [they] define as success", together with what April said about "getting [their] self-esteem up and making [them] feel better". With the awareness of no family around, April also wants to help make them "totally independent and self-sufficient".

For themselves the mothers wanted the transition from suspension to freedom. They found it difficult thinking about themselves and their needs from the five-year future perspective. "That's hard…I don't have anything for myself" (Sienna), "I don't want anything for myself at all ever. I've kind of lost that" (April). "I'm the same as April, everything is suspended to try and get him to that point where he is successful and independent and if and when that happens, then it might be a bit more for me for my time" (Grace).

If the word 'suspended' was flipped, Grace said she would have "freedom",

> because right now the negative of what we have is a complete dependence, and we are it. We are the centre … you may have partners, or not, but really, we're it, so we have absolutely no freedom. Whereas if we can achieve success and independence, then we might have some freedom".

April says, "it's like a prison".
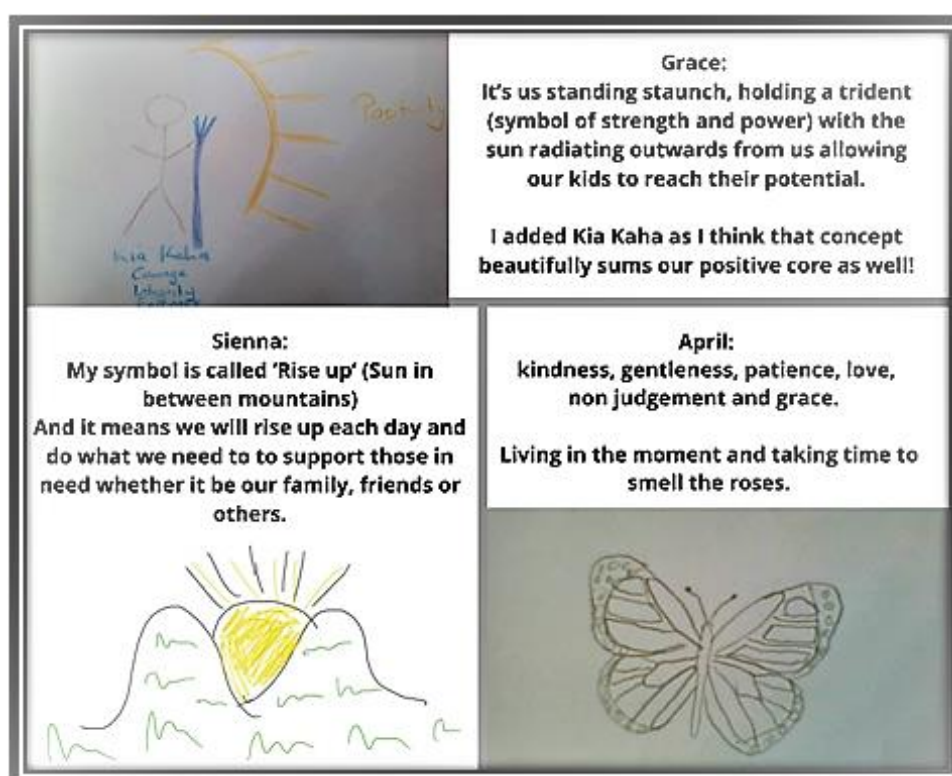
When the second group session started, the Design Phase, the mothers' pictures and words were on the table for them to view. They were asked if there was a sense of something when you see their collective identity ideas together. All three mothers agreed on "kind of like harmony and peacefulness" (April), "life and new beginnings", "feeling good", and "it can only get better" (Grace). "Mama Bear, Mama Cheetah, your ninja – it's that fierceness that we have but then ultimately it's not done in a nasty aggressive way. It's about life and hope and love" (Grace) and "protection" (April). For Sienna, this hope shows up when "you keep carrying on, the sun comes out, [you] get up, help support who needs to be supported, [and] carry on". All the mothers agreed they were up for the challenge, "every day you get up – what challenge will it be today?" (Grace). There is "no room for a doormat" (April).

The mothers were asked to review their positive core, with the phrase "in a world that isn't set up for them" – was there some way to phrase it that is more positive or hopeful? Also simplified, and made shorter? After some brainstorming, their Positive Core statement became:

Positive Core Statement #2: Advocating for families to create an inclusive environment for their wellbeing and potential to be realized.[3]

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[3] The mothers' main priority in the Design brainstorm was "helping teachers to help their children"

In summary, the mothers went through a storying and creative drawing process to establish their personal identity and then together create a collective identity with a positive core statement. The mothers individually identified as strong advocates, as Mother Bear, Mother Duma, and [Mother] Ninja. They were able to convey in their images and words the need to keep advocating for their child they loved, and gave a sense of what that cost them, with what wasn't in their drawings and words – playfulness, lightness of being, rest, relaxation, and joy. From the shared personal identity photos, the mothers chose key theme words like strength, love, advocacy, courage and commitment, that brought life to their newly created group. The mothers determined their group culture and values and then shared their stories of hope for their future. From here, their first positive statement was formed and they went home to create new symbols for their group identity. What was clear upon seeing the group identity symbols and words was the idea of hope and new beginnings, of being able to carry on in brighter and transformational ways.

April's personal identity was a large ninja ready to fight, and through being part of the group. That ninja wasn't present anymore, instead a butterfly appeared for "living in the moment and taking time to smell the roses." The relief for this was almost palpable. Perhaps there was some taking on of Grace and Sienna's wisdom about living in the present.

Grace's personal identity was a Mother Duma (a cheetah), acknowledging both the fragile and fierce, and through being part of the group, there was more hope with strong legs to stand on, a powerful trident in hand, and "the sun radiating outwards allowing kids to reach their potential" – [and the mothers too]. Perhaps a bit of April's ninja has been taken on in the collective.

Sienna's personal identity was a collage of images that included a submerged iceberg, the weight of her children on her shoulders, a large bear looking fierce, and a heart being almost centralised. Being part of the group, there was also more hope with the sun rising between two mountains above ground, the challenges becoming more visible and do-able. "We will rise up each day and do what we need to [do], to support those in need, whether it be our family, friends, or others."

After this creative process, the mothers were able to flip a portion of their original positive core statement into something more generative, removing the "in a world that isn't set up for them" and replacing with "to create an inclusive environment" that celebrates uniqueness in people, allowing more wellbeing and potential to be realised.

4.5 Theme 4: The Difference Appreciative Inquiry Makes

The themes within the narratives demonstrate the need for, and generative capacity of, using Appreciative Inquiry as a framework for supporting parents caring for a child with an anxiety disorder. This will be demonstrated through the exploration of outcomes of each phase of the process. The importance of this type of group process is in creating

appreciation and community support for parents in what is otherwise a very challenging, exhausting, isolating, and judgemental experience for them.

4.5.1 Out of the Silencing, and into the Sharing – the Discovery Phase
In the first paired interview in the *Discovery* phase of the AI, Grace said to Kinsley
> "You know, it's that sharing. Anytime I get a sense of freedom from the stress of it is when you talk to others and you realize lots of people [are] going through it. Maybe you've got some things worse, maybe your son's cutting, hers isn't, but hers won't go to school…that sharing is, sharing to me is freedom".

To which Kinsley replied, "Nailed it!". Grace continued "Kinsley, you said sometimes…you feel isolated, and you don't share as much…sometimes I feel that, and yeah, you do feel that kind of real sense of aloneness, because am I the only one going through this?". Kinsley, who later described herself as *hugely isolated*, responded to the appreciative feedback with, "thank you, that's nice. It's good to hear."

Discovery was the phase where participants shared 'the best of what is' to pursue 'what could be'. The mothers were grateful for not only sharing their stories together, but also having the experience of receiving and giving their reflections to each other. Kinsley feels surprised and affirmed - "and you're doing the right thing, even though you feel like you're not" and Grace describes the process of sharing with someone else who's going through this [as] "quite cathartic really" and later wrote in an email "really enjoyed today's session sharing our stories, even if they are tough stories. It's empowering to know we share the same things and we got this (well most days!)."

There was similar appreciation at the end of the second paired interview between April and Sienna.
> April "Thank you so much for all your honesty."
> Sienna: "Thank you to all of you, it's quite hard to be so raw to people you've never met, thank you."
> April: "Yeah, but we've probably said more to each other than we've said to most of the people we've known."
> Sienna: "Absolutely, I fully agree."
> April: "Because they just don't understand."

In the Discovery phase, there was clear value for the mothers in sharing their stories and appreciating each other, thus gaining a stronger appreciation for their personal strengths and values. After the session, on their own, the participants developed visual symbols for their personal strengths-based identity that led them to creating a strengths-based collective identity in the next phase.

4.5.2 Out of the Isolation, and into the Belonging – the Dream Phase

The Dream phase[4] provided the next step where participants were scaffolded from being an individual with strengths and values in a common challenge, to becoming and belonging to a group with *collective* strengths, values - and hopes for the future – providing much better positioning for them to face common challenges together.

The process of this phase is summarised in s4.4.2.5, where the mothers identified a common theme of advocacy, giving life to their group for the creation of their group culture and values, and created a *positive core statement*. The creation and transformation of symbols in images and words, reflected their emerging group identity and demonstrated the difference being part of a group made in dealing with shared challenges. These included managing an ongoing struggle to find support, feelings of isolation and exhaustion, and learning how to find and create calm in order for them, and their children, to cope better.

The importance of coming out of isolation and belonging to an appreciative group of people is in being able to acknowledge what is often felt as the shaming specifics of living with a child with anxiety, as well as the broader experience. Kinsley's prior inability to share her extremely traumatic experience at the doctors (s4.3.1) is a clear example.   Grace explains,

> The thing is, you guys are perfect strangers, but 90% of my friends do not
> know that my son cuts himself… I know I can just say this… because you get it
> … I just learned to compartmentalize my life and those I can talk to about my
> son and those I can't.

April adds, "no one knows my daughter smashed herself in the face and beat herself". "They just don't get it" (Grace). "They don't actually have the knowledge to actually make a judgement" (April). All the mothers agreed. Now they were getting ready to go from sharing to doing – the Design phase of AI.

4.5.3 Out of Individual Powerlessness, & into Strategic Collaborative Agency: Design Phase

The Design phase provided opportunity for the participants to collaborate together to support themselves in dealing with their common challenges that they have been facing alone. Using the Positive Core statement as their starting point, "Advocating for families to create an inclusive environment for their wellbeing and potential to be realised", the mothers brainstormed three areas of focus they would like to work on together: the education system, peer relationships, and self-esteem. After much discussion about areas of focus in the education system, the mothers agreed on "educating teachers" – "helping them help our children".

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[4] Of note: to help prepare the mothers for the envisioning in the Dreams phase, they listened to a 10min guided imagery meditation (https://www.youtube.com/watch?v=t1rRo6cgM_E), and to a short poem reading: A Thousand Years of Healing by Susa Silvermarie, The Work that Reconnects. In retrospect, this would have been better positioned to do just before the brainstorming in the Design phase.

Table 4.6: Initiative Brainstorm on Helping Teachers Help Our Children.

Topics	Opportunities	Barriers
Training at Teachers Training College (Grace)	• Like teaching doctors their bedside manners, teaching soft skills (Grace) • How to observe (April)	• Not a psychologist or psychiatrist, they are "detrimental" (April) • Not hard science, academic (Grace) • Not textbook (April)
Professional Development training: teachers have to do a certain amount every year (Sienna)	• Increase their knowledge and confidence to make their job easier (Sienna and Grace) • More emotional connection = better outcomes = more job satisfaction = child comes to full potential (all) • This stuff is real! It's what they should be focusing on, rather than all the other writing stuff and proving yourself stuff that they have to do (Sienna) • More job satisfaction if you are actually connecting (April) • Some kids aren't emotional, some kids highly sensitive – you have to be able to know what they need – will be more satisfying (all)	• It's up to each school to choose the training they want (Sienna) • Not a tick box professional development (Grace) • Teachers are so overworked with stuff that's irrelevant, like documentation. (Sienna and Grace) • There's not enough funding from the Ministry of Education (Sienna) • What challenges do they face, what understanding do they have? (Grace) • I can barely get around 5 kids every afternoon, and teachers have like 30 (April) • School management is as important as the teachers because culture is driven top down. So, if the culture at the top is wrong, the classroom reflects it (Grace) • Need an advocate in the school, to own it and drive it like the SENCO (Grace, Sienna) • Only two weeks before school holidays – I don't want to set us up for failure and bite off more than we actually can achieve (April)
Build a relationship up with someone in the school, like the SENCO ((special education needs coordinator)	• Sienna has a good relationship with her SENCO, who will be moving schools.	• Not much luck with the SENCO's at school (Grace and April) • No trust in schools anymore (April)
Own Kids	• Understanding what they would want ideally, and if we can get them to school. (Grace)	• Teenagers as a group are the hardest to talk to unless you're a trained professional (Grace) You also need parents' consent (April)

Sienna, who has recently completed her teacher training, suggested educating teachers "on how to relate to other children," because from her experience in training "you do about one, two papers on it, and that's it". Sienna explained that "unless you're living [it] … or just a really fantastic teacher, you're not always aware or know what to do to support those children". "The big thing" for Grace, is that although she has "huge empathy for what they have to do… my son is the one who suffers" and she thinks the brainstorming initiative "would make a huge difference". Sienna agreed; in her experience with her son's dyspraxia, his teacher "went to classes to know how to teach him and to help him" and that means they could use that teacher for "follow on students as well". Table 4.6 summarises the brainstorming session on *Helping Teachers Help Our Children.*

From the brainstorming, the mothers wanted the teachers to learn how to be in relationship with a child with anxiety. Grace argues that while teachers "all know about anxiety, ADHD… it's just a thing. They can't relate to it". Sienna agrees and April adds:

> They don't get taught themselves how to relate to those particular children. And we are learning on the fly. And we can relate to the teachers because we don't know what we're doing either. They've got access to the resources that we don't have access to, so they're gonna be able to do it.

The brainstorm also highlighted how the barriers are tied to the larger "education system" (Grace) - "it's the structure" (April), "absolutely" (Sienna). Grace says,

> I don't blame the teachers. I don't blame the schools … I know one on one 99% of them are good people, and I will have a drink with them. It'll be great. You need to talk to them and say, 'what are the barriers?'.

4.5.3.2 The Action Planning
The mothers first created some focus on what they would like to achieve:

Aim/Purpose: Educating Teachers: Helping Them Help Our Children

Objectives:
1. **Knowledge**: teachers will increase awareness/skills of how to build relationships with anxious and neurodiverse children
2. **Behaviour**: teachers will act with more compassion and empathy to create better emotional connection with anxious/neurodiverse children
3. **Feeling**: teachers will experience more confidence in creating relationship with anxious/ neurodiverse children, and gain a sense of personal/job satisfaction

The mothers then agreed on the following actions to start scoping for more information at each of their children's schools and identify whether they are receptive. They had two weeks to accomplish these before the school holidays
- Talk to the teachers about their challenges, understanding and barriers
- Talk to their kids about what they want and how things could work better for them
- Find an advocate in the school management team
- Bring on an organisation to help, like Mind Over Manner

4.5.3.3 Mothers' review of the Design phase
1. The mothers experienced value in participating: it was "good" (Sienna), "interesting" (Grace), and "enlightening" (April).
2. Being with others dealing with similar challenges makes a difference. For April it was "quite nice knowing you are not alone".
3. There was potential for their initiative to make a difference to themselves and others. Grace said, "it will be good to see if we can actually make a difference because you do feel totally powerless about [dealing] with the schools".

4. Their participation wouldn't feel too much like work, and that together, they were aligned to something of value and not "just a mother coming in to talk to some teachers" (Grace), although April was concerned "they're not going to receive that well".

4.5.4 Out of the Judgement, and into the Appreciation (Destiny Phase)

For the Destiny phase session, the mothers focused on two things: following up on their scoping initiative and sharing an appreciation of their journey as mothers caring for a child with an anxiety disorder and as mothers being part of this group.

4.5.4.1 Scoping Initiative Follow-up

Table 4.7: Scoping Initiative Follow-Up

Participant	School	What was learned
Sienna	Intermediate School	Sienna spoke to "our wonderful SENCO", who is moving to new school next year She said "{Mind over Manner} is a good idea" and "she will pass it on to the next person" "My youngest son will be coming into that school, so I'll find out who that is, and I'll just say FYI" *Next year Zoe goes to a High School*
April	College	April needed more support to undertake this task. She felt she is "still learning high schools… {and} did not have … [enough] experience with xxx". She wanted to approach xxx Primary, where her younger daughter is in, because she firmly believes the younger that they get assistance the better." However, with the Primary School she felt that you have "to go through so many loops and hoops … pass through so many people… "I can't even ring that office to do much anymore". *Dianna stays at her High School*
Grace	Intermediate School	Grace talked with DP who she knew "from Primary School and sort of personally" who confirmed that there is "very little training on neurodiversity and anxiety – it's really all once you experience it". The DP conveyed that the biggest problem is dollars [and that] programmes like Mind Over Manner all cost and they have a limited budget… Schools have to handle it themselves [with] individual learning plans, [teaching a] growth mindset for positive wellbeing, [having a] counsellor on site, a social worker, and a RTLB. The DP also shared information she thought may help: "The Resilience Project which is part of Tanya Dalton Foundation" "Pause, Breathe, Smile" mindfulness programme from Mental Health Foundation Ministry of Education created a Mental Health Education Resource at government level, recognising the importance of youth mental health. "For most kids what's recommended…would make a difference, BUT they're not equipped for the more extreme kids like Axl because she knows he self-harms". For "the extremes, which I think we have", "they don't know what to do". The DP recommended: Marinoto, GP, and churches as "the other front line" *Next year Axl goes to a High School*

The outcome summary of the scoping exercise is shown in table 4.7. Leading into their scoping initiative, the mothers were faced with five known challenges:

- They only had two weeks for scoping in schools,

- It was the end of the third term, with fourth term normally a winding down time in schools
- High stress in teachers and schools in the year of 2020 Covid lockdowns
- One of the mothers was having a difficult time, "life got hard…it just fell apart for me" (Sienna)
- One of the mothers found it difficult to approach their school, "they hate me anyway" (April)

The learning that came out of the scoping created more deflation than inspiration. Each of the mothers had a different response to their shared learning. April said "it's worth chipping away because I personally can't think of another avenue". Sienna felt as a teacher herself, she "helps quite a bit" by "[giving] a little parenting advice" with other parents going through a similar process. Grace was feeling they would have no influence "at a gross level". The only influence she feels she can have is with her own child,

> This is really hard, you know, because [schools] don't have the funds to do cool things. It's not taught in [teachers training college]. [Schools] get a big book from the Ministry, which can help these kids, but the more extreme kids, which all ours are, they just don't have the resources - they don't really know how to handle it… I think the biggest difference you make is really just with your kid, and advocating for your kid. It's hard to see how you can influence that whole system.

The mothers discussed the funding and timing hurdles, sharing that although Sienna has "applied to the Lions Foundation for grants", Grace felt it was "so much work" and something the "PTA could and should be doing" and that a focus on mental health should happen at the "Board level". Sienna suggested that special education had "pockets of money" that they could choose to use. The funding was left in the air to discuss the significant timing hurdle: the end of the school year, Christmas, summer holidays, the chaos of term one with two of the children starting new schools, and teachers being so busy starting back meant that the mothers will need to decide what they are going to do. Even though Sienna felt that things won't happen "at the end of the year this year", April wanted to use "that time to kind of plan what we wanted to achieve" and to "think of different ideas". April said she would be "quite happy to keep persevering with the schools" and Sienna said she is "happy to do it next year too" after March. Grace was quiet.

4.5.4.2 Appreciating What the Anxiety is Teaching Them

Before this last group session, the mothers were asked what they appreciated most about their child as they have been going through the challenging experience of dealing with the anxiety; and from this appreciation of their child, what was a learning for them? What kind of difference had this learning made in their lives so far? This inquiry was looking at another

aspect of the anxiety – through the challenges of it, what are the gifts, if there are any, that it brings to them and their mother-child connection?

The narratives in s4.3 have shown how the mothers have learned to cope by creating calm in the home, in the children, and in themselves in the second section of this chapter. This section will be looking at how the child, journeying with the mother through the anxiety, teaches and grows the mother too.

April:

April's appreciation for herself and Dianna can be seen as centring around managing their empathy and compassion, with patience and no judgement. Dianna is "super sensitive" with "so much compassion" and "huge empathy for everyone." April appreciates how her daughter is "trying to manage [those qualities]" while she "desperately wants to change the world." Dianna's compassion is teaching April more about compassion. "I try to imagine being her," said April, which gives her extra motivation to advocate in the world – facing the school system and social stigma.

This journey with Dianna is teaching April "patience" and to "not be judgemental". "I'm trying to think today is today, and don't dwell on yesterday". The 'yesterdays' have included the on-going struggles for finding support and the learning to cope and it's been challenging for both of them. When things are too much for Dianna, she takes herself into her version of 'time-out' at school by hiding in the toilets or just leaving school to go home. When things are overwhelming for April, she does something similar. "If I'm starting to get too highly strung when [Dianna is] losing the plot…I see myself to timeout," then April will go to her room with an agreement that after 5 to 10 minutes they "start afresh" by putting it in "a moment of time basket, and blow it away". April said she needs to be "mentally well myself", and to be that, April has had to learn patience and ways to be calm, as her kids "really need me to be present".

Grace:

Grace's appreciation for herself and Axl can be seen as centring around the valuing of important relationships, and managing the expectations or judgements in those relationships to maintain trust. "[Axl puts] his friends first", like Grace, who values putting her son first. Axl has managed to not let his anxiety "[affect] his peer friendships" by hiding his anxiety until he is alone. For Grace, this learning extends to her own friendships, where, through the stress of parenting a son with anxiety and ADHD, she has had to discern who she shares that information with. "It's less anxiety in myself…that all my friends should know what's going on". This learning enables Grace to "chill out and accept others more", by trying "not to judge".

Grace values that Axl "mostly trusts me as the person he can be anxious with because he knows I won't judge him, I won't turn on him, I won't reject him". Grace has had to pro-actively find those trusting and non-judgemental qualities in new friendships, found mostly in neurodiverse online groups where she visits and chats on a daily basis. "I just focus on the people who do get it, and most of them have neurodiverse kids, and that's fine." (Sienna remarks here: "That's quite a big thing actually")

Sienna:
Sienna's appreciation for herself and Zoe can be seen as being centred around making new choices for calm that ease the pressure in their lives and create respectful personal space. Zoe has been starting to make new choices by "coming out of her shell and wanting to get support"; she has been "acknowledging that there is something wrong". Sienna also wanted to change what was going wrong for her and come out of her shell – the hidden iceberg. "Instead of pushing everything", Sienna has been learning to "calm down" and "take a big step back", acknowledging that "this is gonna take time" with Zoe.

As Zoe has been learning to manage her feelings in the privacy of her room and in the bravery of leaving her room, Sienna has been able to support this better by "not taking everything so big" and managing her own feelings. Sienna came to the realisation that "it's not always on me, that it's just how she's feeling". By not taking Zoe's feelings personally, Sienna has learned to "respect her space and privacy…she's entitled to it, like I'm entitled to my own space". Sienna has learned to "listen more" and when Zoe says "Stop, I don't want to talk about it anymore", Sienna respects it.

This new "going with the flow" attitude "with small steps" has created opportunities for Sienna to notice "all the little things". She is not such "an emotional wreck about what could happen" with the uncertainty of good and bad days. And on the good days, "it's really quite nice to see [Zoe] laugh again", and when "she let me hug her…my heart just burst".

4.5.4.3 Appreciating being part of an Appreciative Inquiry
At the end of the Appreciative Inquiry, the mothers were asked what they got out of participating in this project.

Sienna: "I have appreciated meeting two other lovely mothers who have children with anxiety – although all different experiences, they have taught me about acceptance, patience, and kindness" and "I know it's been a short time but I think we've all sort of grown ourselves a bit." Even though it was "harder than I thought" as it "brought it to the forefront" while "going through a tough time" with Zoe, I hope to meet again (more than once) and follow this on (especially in my children's school)"

Grace: Being part of this "helped me feel what I'm doing is the right thing for my child – realising standing up and advocating for him is exactly what I should be doing, and in fact I

am the **best** person to do that". This takes you beyond "surviving day by day", where you need to "stop and think and draw a picture or comment" together with the "shared experiences mean you can feel validated and confident in yourself as well as getting ideas from those going through something similar". "Great connection with the others, thought-provoking and thinking outside yourself." She realised "there is a role for the broader community in helping kids with anxiety" and appreciated "everyone's flexibility and understanding!".

April: "Loved it", it has "changed my perspective on life. I felt so alone and guilty that my children are different". It has

> made me look at myself [and] … think about myself - I've started to question some of my own behaviour, and so I'm going for an adult ADHD test with a psychiatrist in a few weeks' time… I don't know what the outcome will be, but I would like to know if there's something with me as well … it's made me reflect on certain things I've done since I was born.

For April, with this "awesome group of like-minded people" she really hopes "we make a difference".

Everyone wanted to carry on meeting each other. "Yeah, I don't think there's anything else like it. I think I would have probably coped a lot better being able to share, and just go 'you're not insane' (laughter)" (April). She also thought they could "all benefit" in continuing to share contacts because it's "all about getting good care and support". Grace summarised the experience:

> You always feel like you are in a little bubble, … [so it's about] being able to talk to other people in similar situations, which is rare, but when you do find people, or people are asking for advice because they know you've been through it, being able to give them ideas [is great]. And I think, you know, for me, realizing that, yeah, that I've got a lot of ideas from you guys, but also that what I'm doing is actually okay. And to be able to have other people say, 'yeah, you're okay', that's actually, that's good.

All mothers shared that they preferred face to face sessions rather than online (using Zoom), and that they preferred them spread out over time instead of full day workshops. None of them wanted to change anything about the way the inquiry was structured. For Grace, she appreciated the smaller group size "for an intimate connection, and timing could be an issue with more people".

The participants shared their parting words of appreciation:

April expressed gratitude "to be part of this, meeting all of you, hope we all keep in touch and hope in some way we have made a difference". "Hopefully we have made a difference

to each other", Grace said, "To me, it's mindfulness – very mindful experience for me – it's been great!". Sienna agreed, "Same, great meeting you both, talking, not feeling alone with the problem – it's hard! … I've learned how to cope with it better I think coming to this than I knew how to before". "Me too", said April, "I feel like I'm a better parent from being part of this, learned things…I feel like our house has improved…I'm very happy about that!".

In summary, for the Destiny Phase, there were three key areas: the scoping initiative follow-up, the learning from anxiety, and the appreciation of being part of the study.
The scoping initiative follow-up was more deflating than inspiring with its challenges:

a. Educational System:
   i. Teachers aren't trained for dealing with mental health and neurodiversity in the classroom,
   ii. Individual schools choose the type of training they provide their staff and what programmes they bring in to the school,
   iii. There is a mental health resource book available that is targeted for regular kids' wellbeing - not kids who have higher needs,
   iv. There is a lack of funding for schools

b. Funding: someone has to apply for it (PTA, Board, or Special Education responsibility)
c. Timing:
   i. Two weeks to scope before school holidays
   ii. Schools are in a high stress and winding down time of the year
   iii. Christmas and summer holidays around the corner
   iv. Zoe and Axl starting new schools in 2021, if all goes well
   v. Term one too busy to start new projects that aren't already organised
   vi. April feels challenged scoping and dealing with school management or teachers
   vii. Grace thinks the biggest difference you can make is with advocating for your own child
   viii. Sienna feels she can help in her job as a teacher
   ix. Each mother is at a different school and dealing with that school individually
   x. Two mothers felt like they wanted to meet again to carry on, and one kept quiet

Another part of the Destiny phase was what the mothers learned from their experience with their child with the anxiety. For the mothers there was a correlation, or a mirroring, between what they were appreciating about their child's experience and what they were learning themselves. April and Zoe were learning to manage their huge empathy and compassion with patience and no judgement to change their 'world'. Grace and Axl were learning to manage their expectations and judgements in their valued relationships to maintain trust and connection. Sienna and Zoe were learning to manage the pressure in their lives to create respectful personal space and calm.

Having opportunities to appreciate and support each other through similar challenges in an appreciative inquiry creates more value of ourselves, each other, our learning, and the choices we make for the future. Sienna felt everyone had "grown a bit", Grace felt validated that what she was doing was "actually okay" and she would be able to help others, and it inspired April to look at herself and her behaviour more and to book herself for an ADHD test. The mothers went into this study wanting to make a difference and they all left feeling like they have made a difference, especially "to each other" (Grace) as they "weren't alone with the problem" (Sienna), and for April, she "feels like a better parent from being part of this."

Chapter Five: Discussion

5.1 Introduction

My aim for this research was to explore the parental experiences of caring for a child with an anxiety disorder using a strengths-based appreciative inquiry that would also facilitate a group process that explores possibilities for the participants to co-create a community initiative to address this common concern.

The mothers discussed the following: the limited efficacy of individualised medication and one-on-one therapeutic approaches to anxiety disorder; the interconnected relationship between the mother and child health and wellbeing; the societal disconnection and stigma that perpetuate anxiety and depression; the sharing that works to prevent and reduce anxiety; and possibilities of collective action that would make a difference.

Looking at anxiety disorder from both the parents' perspective and from a community perspective is unique. It broadens the view of anxiety disorder by positioning anxiety disorder not only outside of the child, but also in relationship to the main caregiver, the mother, and with the community.

5.2 Positioning Anxiety Disorder

In the research I wanted to explore the expansion or re-positioning of how anxiety disorders are approached from a strengths-based social collective perspective. In the literature review and from the data, the main caregiver is predominantly the mother and the mother's experience intertwined with that of her children was the focus of the study.

In NZ, most of the focus is on the child with the experience of anxiety disorder, positioning the problem with the child. However, there is very little awareness of the experience of the mother caring for the child, with the ongoing shared experience of managing and healing an anxiety disorder.

The participants in this study for years have been advocating for support for their child within an individualising model of health care focussed on medication and one-to-one therapy. Three of the mothers have been taking citalopram to cope; one mother is receiving counselling; and the other two mothers thought that counselling would be of help. All of the children were on medication and doing one-on-one therapy, apart from Diana, who is using natural health remedies and getting support from her church. Although these children have had many different individualised treatments and have been learning to cope, their anxiety remains powerfully present and the mothers are having a challenging time supporting and advocating for them.

Research has indicated that anxiety disorders are a person's way of coping with trauma or chronic stress. The human body reacts to this in different ways for different people at different times; with every situation and context being unique in its cause and effect. What

has been shown is that without meaningful social support, trauma and chronic stress will very likely transform into anxiety disorders, there to stay unless re-engagement occurs (Hari, 2018; Haslam 2018).

5.3 An Individualistic Experience

5.3.1 Impact of Neoliberalism

Loneliness is a strong precursor to anxiety and depression (Hari, 2018; Haslam et al., 2018), and with the isolating, stigmatising, and on-going experience of caring and advocating for a child with an anxiety disorder, the mother is also at greater risk to develop anxiety and/or depression (Francis, 2012, Ennis et al., 2013; Norup et al., 2013). Each of the mothers participating in the study struggled and advocated to help find support for their child "in a world that isn't set up for them". The places they most expected to find support - family, friends, and their child(ren)'s school - proved to be the most challenging. The mothers all described experiencing a lack of understanding and negative judgement from important people in their social circle and from a school system that they have to push hard to address the needs of their children. The mothers' experiences of finding support became a narrow field of acceptance in their social network (their social capital was limited) and in their ability to access professional support and treatments (social determinants, such as stigma, mother blame, hardship, etc. limited opportunities for them) (Haslam et al., 2018).

Figure 5.1: An explanatory model of mothers positioning in the western culture
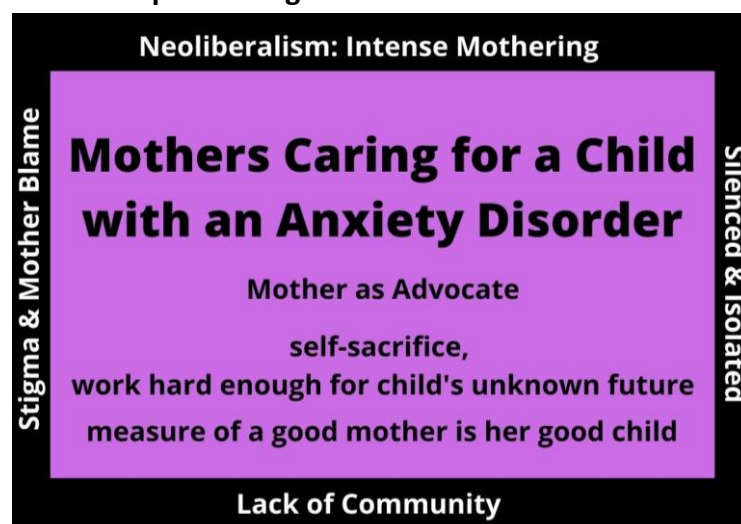
Figure 5.1 is a representation of the positioning of the participants in this project as mothers caring for a child with an anxiety disorder or invisible disability, and a reflection of the wider position of women. The center diagram describes a summary of the literature about societal expectations which position the value of mothers as the primary caregiver of children where they are expected to *self-sacrifice* and *put the children first,* hold responsibility for their emotional needs, and work hard to be *good mothers.* The mother's value is based on how

successful and/or well-behaved the children become. (Carpenter & Austin, 2007; Benard & Correll, 2010; Francis, 2012; Reimer & Sahgian, 2015),

5.3.1.1 Neoliberalism: Intense Mothering

The dark frame of the model represents the constricting environment of the mothers on the fringe, where April says, "it's like a prison". With the age of neoliberalism, since the mid-1990's, more value was placed on contributing to the labour market, and less value on contributing to the community (Benard & Correll, 2010). Less community support led to *intense mothering*, with the expectation for mothers to place the needs of the child above all else. These selfless, intensive mothers prioritised their time, energy and resources to meet their child's needs before their own, in a culture that idealised middle-class heterosexual families with the wealth and education which enabled this focus on the child (Carpenter & Austin, 2007; Francis, 2012; Reimer & Sahgian, 2015). The dissipation of social networks in a neoliberal economy created more pressure and accountability on mothers who were also establishing themselves in male-dominated labour markets. Benard & Correll (2010) demonstrated that intensive mothering standards pushed mothers into holding two different roles as both a mother and a paid worker: if she was successful at work, she was in violation of being a good mother, and if she was a *good mother*, she was in violation of being a good worker. Whereas, the father could hold two roles successfully, and just becoming a father made him more valued as a more mature and stable worker (Benard & Correll, 2010; Francis, 2012).

Another system sitting with neoliberalism was the older patriarchal culture of motherhood. Kingston (2012), Robinson (2013), and Reimer & Sahgian (2015) all contend that mothers are given all the responsibility of the children, but no power, with a devaluing of the labour of caring. Kingston (2012) and Robinson (2013) argue that when mothers aren't valued as experts on their children outside the home, and are met with patronising and stigmatising professionals (teachers, doctors) who control rather than listen, mothers can become *resistors* to stigma and *warriors* ready to self-sacrifice as *good mothers* to create better outcomes for their child. The schools are largely where they become *Mothers as Advocates*, facing condescension and being outnumbered - one mother against the teacher and school management. Grace described it this way,

> [its] that sense of three or four against one. Don't be so silly, 'mum'. 'It's all right dear' It's not fucking all right. My son cuts himself at school. (Sienna: so condescending). Tell me how that's all right, you know, (April: how can you not notice?) … it's that not only do they not treat [our kids] as individuals, but educators think that they - and they don't - know everything, and they are very condescending.

The patriarchal culture of motherhood and neoliberalism helped to create much higher expectations of mothering (e.g. putting the child's needs first) while support was hugely

diminished in one or all of their work, family and social roles. All of the mothers in the study experienced putting their child's needs first. Grace said, "that's what we do as mum's right?", "100%" confirms Kinsley. April admitted, "I don't want anything for myself at all ever. I've kind of lost that" and Sienna describes the responsibility she is holding. "I will do anything for my children…I hold each of my children's issues on my shoulders, although quite heavy". This responsibility and self-sacrifice are magnified with the high needs of a child with anxiety disorder, along with managing the stigma of being perceived as *not a good mother*.

5.3.1.2 Stigma and Mother Blame

Francis (2012) argued that parental stigma is dominant with invisible disabilities and in this time of intense mothering and medicalisation, mothers are blamed for being a *bad mother* while fathers are stigmatised mainly by association. The wide prevalence of Mother Blame in western neoliberal culture and how that stigma magnifies and isolates mothers when caring for a child with an invisible disability has also been claimed by Carpenter & Austin (2007) and Reimer & Sahgian (2015).

When the child's problems are deemed as biological, there is less stigma (Francis, 2012), which simultaneously supports the acceptability and accessibility of the pharmaceutical approach. There are also expectations that the child will grow out of their disability (Francis, 2012), as in Sienna's case when her older son had his school support systems removed because of his age. When their invisible disability doesn't get better with age, it becomes a character flaw, and the mother is to blame (Francis, 2012). Grace had to position her son's anxiety disorder as biological when her ex-husband denied Axl had a mental health issue - "he thinks [Axl's] a bad kid". She put a line in the sand to say, "this is not about being a bad kid, this is a kid with mental issues". Sienna, as a trained teacher, talked about teachers having minimal training, experience, or understanding of anxiety disorders and other mental health issues, "you're not always aware, or know what to do, to support those children… [the teachers] might say, oh, you're naughty, you're bad, or you're dumb, because [they] don't understand". Three of the four mothers left abusive fathers for the sake of their children, and all of the mothers fought and advocated educational systems for the sake of their children.

In relation to *mother blame* stigma, one of the main challenges the mothers experienced was feeling judged and isolated by *friends* not understanding them or their situation. These words *isolate* and *judge* - along with similar words like *alone, quiet, safe, hide, worry, separate, and cope* - were used 209 times; the words *help, support, need*; were used 388 times; and *relationship* 76 times. The use of high frequency words (for comparison expected high frequency words such as child/children are used 201 times and anxiety, 93 times) confirms the mother's experience of isolation through stigma and their desire for connection.

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5.3.1.3 Silenced and Isolated

Ociskova et al. (2013) and Busby Grant et al. (2016) describe three levels of experience of stigma - when it is first noticed, then accepted, then internalised - very similar to the *discernment* of stigma, *acceptance* and *silencing* sequence described by the mothers in s4.2.2.2.   Four of the mothers rated themselves as feeling 'a lot' and 'hugely' isolated, and three of them rated themselves as having 'little to no support', with Kinsley rating 'moderate' support. Only two of the mothers rated stigma in relation to mental illness as 'a lot' and 'huge', with Kinsley rating 'not at all', and Sienna rating 'moderate'. In the focus groups, Sienna said, "I don't feel a stigma attached to it…it's just hard to find support", and Kinsley said, "I haven't experienced too much stigma, mainly because I don't really care…I know what I'm going through, what our children are going through is real… I'm not really looking for validation from them".

Carpenter & Austin (2007) and Reimer & Sahgian (2015) argue that stigma places mothers of children with an anxiety disorder on the margins of acceptable parenting even when they are *being a good mother*. Not only are mothers discerningly silent about their experience - they also experience a silence - a lack of validation for their *good mothering*. Their choice is to stay silenced and internalize the stigma or to force themselves into advocacy work, especially in mainstream schools, that requires great effort to get the understanding, time and resources needed for their children (Carpenter & Austin, 2007; Kingston, 2012). Rejection means that the stigma is more likely to be internalised and the burden of care and demand for self-sacrifice increased.

5.3.1.4 Lack of Community

The mothers in the study all adopted a powerful advocate identity which was all-consuming. It drove out any possibility of planning their own future. This involved self-sacrifice and their personal life being "suspended" and was particularly evident in the Dream phase of the appreciative inquiry. This pointed to the strong need for more community support and teamwork/partnership around the mothers and their children, as well as the challenge of opening to possibilities when there is too much stress to think beyond the child's immediate needs into their own needs. Kingston (2012) demonstrated that it's not the disability that causes the grief and sadness, but the lack of community support.

The individualisation of our western culture, and how it approaches mental illness and mothers caring for children with mental illness, demonstrates the need to reposition mental illness outside of the child and in relationship with mothers, families and communities and to put more value on the social aspect of our humanity in community.

5.3.2 Social Identity

Haslam et al. (2018) argued that a social identity approach addresses loneliness, mental illness, and stigma and that it needs to be given more value in the biopsychosocial approach

used in the western approach to mental health. This is highly relevant for mothers caring for a child with a mental illness. Their social capital is significantly narrowed by isolation and stigma, and opportunities for coping are influenced by social determinants in their environment.

Figure 5.2: An explanatory model of viewing mothers' social identity *within the fringe* that exists outside the social norm.

Social Identity Within the Fringe:
Mothers caring for a child with anxiety disorder

Social Capital	Social Determinants
loss of, or compartmentalisation of friends & family	individualised western neoliberal culture
lack of time/energy for new social engagement	mental illness stigma & mother blame
	under-resourced educational & mental health systems
supportive work colleagues	NZ's high rates of social problems: bullying, sexual abuse, domestic violence, material hardship
social media support	
church fellowship	
family dog, dog community	accessibility of parent support: groups, churches, social services
	work environments accepting of role as parent

Systems don't work for us - distress - alone & stigmatised

Systems work for us - comfortable - good parents

Figure 5.2 is a summary of what the experience of being in the fringe (dark box) is like for mothers who are caring for a child with an anxiety disorder. I have flipped the previous Figure 5.1 to see inside the fringe, while maintaining the presence of the mainstream society in the purple frame. The shaded figures within the box represents the 25% of people who will experience anxiety disorder in their lifetime. I have also included a list of the elements the participants experienced that correspond with the social capital and social determinants of the social identity approach to increase understanding.

5.3.2.1 Social Capital

Haslam et al. (2018) demonstrate that social capital consists of the social networks of family, friends, community groups and organisations people belong to, to their cultures of reciprocity, and the trust that develops through their interaction and cooperation. This social capital provides the foundation that empowers participation and empowerment for communities to overcome collective issues through collaborative action.

All of the mothers in the study experienced judgement and isolation in their social circles with the distress of caring for a child with an anxiety disorder. Grace and April experienced anguish in their friend relationships, where Grace and Sienna learned to compartmentalise, only discussing their situation with a couple of key people to maintain their friendships. April lost most of her friendships and contemplated trying mediation to recreate connections. Unlike Ociskova et al. (2013), three mothers found the place where they had the most support was in their working relationships. This was due perhaps to the status of their positions within their working environments and the flexibility of their working environments. April, with the least support, searched and found community support in a local church and in group activities such as yoga and mindfulness. Sienna, who was very time-bound, found support in her new family dog, calling it their "therapy dog"; Grace found meaningful connection in online support groups.

5.3.2.2 Social Determinants

Haslam et al. (2018) define social determinants as social factors that produce inequality in society, which impacts adversely on health. Being aware of these is the first step in creating solutions and actions that address the disparity. In NZ, there are a number of social factors that work to create trauma and distress. These include bullying in schools at double the OECD average (Bridgman et al., 2018; 1 in 3 girls, and 1 in 7 boys being sexually abused, Help, 2021); 1 in 3 women, mostly mothers, experiencing domestic violence (Shine, 2021); and 18.4% of children are living in households with incomes that meet the criterion for poverty (Stats NZ, 2021). Three of the four families in this study have experienced domestic violence in the home, two families are single income, and each of the children has experienced one or a combination of the following: bullying, extreme fear of being judged/self-judging, self-harming, and/or being "shunned" at school.

Grace's interview with her school's Deputy Principal, together with Sienna's experience as a teacher, highlight that schools are under-resourced with a lack of funding, training and time, to address the high level of needs of children with anxiety disorders and to establish productive relationships with the mothers of these children. The mothers, agreeing with Kingston (2012), felt that partnerships and teamwork which value listening and understanding between schools and mothers produce better results for everyone.

The mothers coming into this study experienced decreased social capital and increased negative social determinants that challenged their social identity. Sienna shared the collective experience of the mothers: although people may have an awareness of these challenges, "unless they have teenagers going through the same thing they don't understand". The motivation for change comes from the place of discomfort. It's harder to create personal and social change when people are isolated on the fringes. With the issues of anxiety disorder becoming so big, it's time for mothers to connect together meaningfully to create social change.

5.4 A Collective Experience Using Appreciative Inquiry

The premise of appreciative inquiry is to appreciate each other's strengths and values and to generate new possibilities to common issues. One of the methods for doing this is to flip the negative into a positive. If lack of understanding and judgement created disconnection, isolation and silencing, then the opposite to that would be understanding, appreciation, compassion, connection, and value. These point to some of the generative initiatives and outcomes that can be created in families, schools and communities to make a difference. Appreciative inquiry can be used as a method to transcend the stigma and systems that exclude or are not equitable for people with anxiety disorder in their families.

Below is a synopsis of different models in the literature (figure 5.3) that contribute to creating connections that will be used to frame the mothers' experiences and to review how the AI enabled or missed some of the elements of models.

Figure 5.3 an explanatory model demonstrating a collective social approach to anxiety disorder
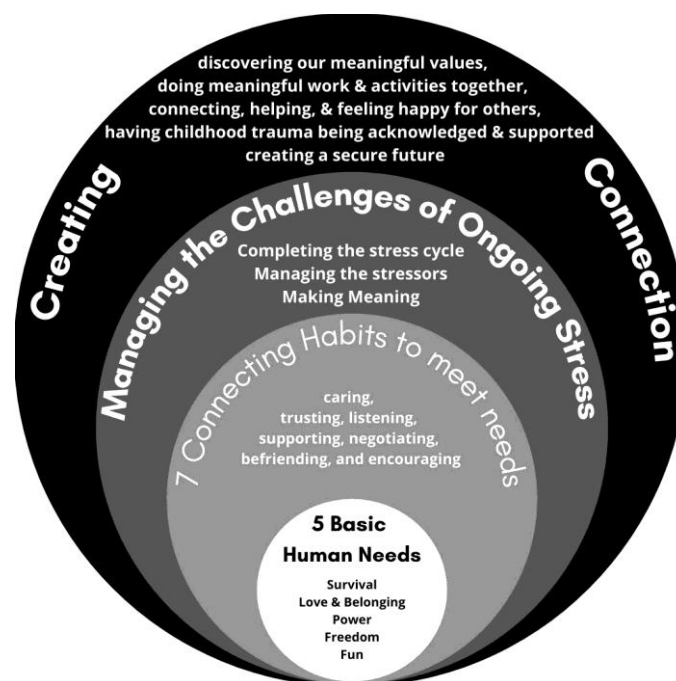
This model represents the social healing journey for mothers caring for a child with an anxiety disorder, integrating the different models from the literature review: the five basic human needs (Glasser, 2002), connecting habits to meet those needs (Glasser, 2002), managing the stressors that challenge along the journey (Nagoski & Nagoski, 2019), and creating connection for healthier personal and social identities (Hari, 2018; Haslam et al., 2018). This model is non-hierarchal; however, the five basic human needs act as the foundation, with the seven connecting habits acting as the building blocks for creating meaningful connection. When stressors come along in life, the connecting habits will need the extra support and discipline of managing strategies to maintain the connecting habits

and to complete the stress cycle so that the stress can leave the body. Creating a strong foundation, building blocks and strategies help create connections for a stronger social identity that positions people to get more of their basic human needs met. It can also flow in the opposite direction of creating connections to help manage the challenges and stress, and practicing connecting habits to strengthen the five basic human needs. The intention of this model is to represent the non-linear flow of the social healing journey.

5.4.1 Five Basic Human Needs: Survival, love & belonging, power, freedom, and fun

The mother's and child's lives are intertwined, and any illness and healing have the capacity to be shared (Norup et al., 2013; Keeton et al., 2013). If we look at the mothers' human needs like balls of energy in a basket, we will see that for all of them their survival balls were larger and brighter as this is where most of their energy is being used. For three of the mothers, their love & belonging and power balls, were smaller and dimmer (high degree of isolation + emotional and mental toll of Mother as Advocate), but they still had some light from one or a few special friends or family, supportive work colleagues, and from being in influential roles in their workplaces. For April, they were smaller and dimmer still, as she had no family or friends, nor a workplace with supportive colleagues; however, she did have connection with two children doing private child care after school. The freedom and fun balls were harder to find in the baskets as they were smaller and dimmer still without much energy being used in these areas. Carpenter & Austin (2007), Francis (2012), and Reimer & Sahgian (2015) demonstrated that the cultural expectations and stigmas put on mothers to hold all the responsibility and do all the self-sacrificing while putting their children first are magnified when caring for child(ren) with mental illness.

The Appreciative Inquiry strengthened the other balls in the mothers' baskets, so that the survival ball could relax and be supported. This process increased:
- a sense of belonging with other mothers dealing with similar situations
- empowerment through appreciative inquiry and creating collective potential
- freedom in the act of sharing their unheard stories
- fun social time by sharing food, stories and laughter

In the last session, the mothers commented on how much they have learned and grown (Sienna), how much it validated them and increased their confidence (Grace), and how it changed their perspective on life and created connection (April).

5.4.2 Seven Connecting Habits to Meet Needs: Caring, Trusting, Listening, Supporting, Negotiating, Befriending and Encouraging

Glasser (2002) identified these seven connecting habits as instrumental for valuing and creating meaningful relationships with others that help to meet our human needs for connection. The mothers in this study learned that the anxiety created a need in the child

that over-rode anything else the child valued, so external control strategies (Glasser, 2002) like "just [turning] off the WIFI" (Sienna) didn't work. When the mothers instead connected with their children with *caring, trusting, and listening* habits, which Glasser (2002) called an internal control strategy, they were better able to develop strategies together for mitigating panic attacks and coming back to calm when there was a panic attack (*supporting, negotiating, and encouraging habits*). Grace and Kinsley called this learning the "fine balance" of when to walk away, or when to stay and comfort their children.

Connecting habits work very well when they are reciprocal, but are challenged when they are met with judgment and distancing that all of the mothers experienced in the majority of their friendships. Through these difficult challenges, the mothers learned discernment to navigate their friendships with new boundaries or with distancing themselves. Two of the mothers had time to explore other social connection options like church and social media groups (*befriending habits)*.

The appreciative inquiry supported the seven connecting habits by the very nature of its positive generative collaborative process and bringing people together with a common issue. April, Grace, and Sienna agreed that they shared more with each other than they've shared with people they know – "because you get it" (Grace). The shared understanding using connecting habits was critical to creating deeper and meaningful connection in the group (Haslam et al., 2018).

This appreciative inquiry also added an environment for social connection that is so valued in the Kaupapa Maori principle of manākitanga (generosity and hospitality - Smith, 1999) to meet basic human needs. It takes time and energy to use the connecting habits to build trust and safety in a group of strangers, especially when they are dealing with a sensitive topic. The Covid lockdown was in place the first two sessions of the inquiry, and so instead of meeting in person, the mothers met each other online using Zoom. Although their online sessions were positively experienced, there seemed to be a deeper experience of connection when they were in the same room sharing a meal, sharing understanding, and sharing laughter together. This environment also created valuable unstructured connecting time for the mothers in their arrival and settling in, and in the time between finishing the recorded session and saying their good-byes.

5.4.3 Managing the Challenges of Ongoing Stress: *Wellbeing in Action*
The mothers in this study all demonstrated their proactive and positive approach to caring and advocating for their child that Norup et al. (2013), McGonigal (2013), Hari (2018), and Nagoski & Nagoski (2019) all argued that the proactive and positive approach would produce better outcomes than passivity and denial, especially when there was meaningful social connection around them for support. Nagoski and Nagoski (2019) identified strategies to manage stress and stressors for *wellbeing in action*: *completing the stress cycle* to ensure the stress chemicals get flushed out of the body to prevent health issues, *managing the*

stressors that are controllable or uncontrollable, and *making meaning*. Although Nagoski and Nagoski (2019) mentioned the importance of social connection in their concluding statements only, the *making meaning* and connection will be discussed in the Creating Connection section.

Completing the stress cycle includes physical activity (including crying), affection and creative expression. Although medication wasn't included in Nagoski and Nagoski's (2019) model, it was the mothers' valued strategy for stress that provided them with the ability to cope better, even when faced with being judged for it. "You've gotta be really strong… which is why it's so important that I am on something like the citalopram, because I can be stronger, not so much ditch down" (Grace). The second stand out activity for all of the mothers dealing with the stress was crying.

- Grace recalled her son telling her, "'I hate it when you cry' and I cried quite a bit this year… 'I didn't want to make you cry'".
- Sienna remembered her son saying to her: "'Why are you crying all the time, mum?'… I actually don't have any more tears that are left in my body".
- April shared that "genuinely screaming [in the car] and crying help me", and that she also uses a punching bag and practices yoga and mindfulness.

Most of the sharing affection (hugs and kisses) talk in the focus groups had to do with Sienna and April and their children. Sienna had a particularly challenging time in the beginning of the study receiving affection from Zoe, "she doesn't talk to me and I'm not even allowed to kiss her, hug her, tell her I love her, she just says it's gross". However, when they got their dog, it brought so much joy. "[Zoe] can't give her affection to me, good for her to give her affection to something else." At the end, when talking about appreciation of Zoe, Sienna said it was

> noticing all the little things… when she let me hug her [it] was huge. I didn't actually let go until she went like this, and she did that kind of patting on the back. Yeah, I don't care, it was so nice. And my heart just burst. Like I was, "did you see that, did you see that?" to my husband. It felt soooo good.

When Dianna had a panic attack, April "just hugged her for probably nearly two hours while she recovered". April also facilitates after school care, where she "looks after three extra kids every afternoon, I hug them and kiss them and … they call me Auntie April". At the end, when talking about what she has learned from Dianna, April said,

> I'm trying to think today is today, and don't dwell on yesterday. Because that can influence your mood, and how you both interact with each other, if you hold grudges, and, and just love and hug, and don't be judgmental.

The mothers didn't talk about utilising creative expression for themselves to destress.

Managing the stressors involves planning for what you can control, positive reappraisal for what you can't control, and making choices to stay or quit, thereby maintaining a sense of agency. The difficulties the mothers experienced were the ongoing unpredictability and intensity of the behaviours of anxiety disorder, the power differential between parents and school health and welfare systems and professionals, and the isolation experienced in their social network.

Real choice to change comes "when we have abundance enough and safety enough to let go of what is broken and reach for something new" (Nagoski & Nagoski, 2019, p. 50). The mothers' choice was the *learned calm* as their main way of *managing the stressors*. However, Nagoski & Nagoski (2019) explains that the Human Giver Syndrome, born of a patriarchal system, prioritises, among other things, that women keep calm and attentive to the needs of others before themselves and leaves the mother operating too much at the level of survival. Learning calm as a coping strategy was not enough, as the mothers joined this study to help themselves help their child(ren). They want to go beyond the well thought out routines and practices of *managing the stressors* (keeping calm) into *making meaning* and thus purpose and creating *wellbeing in action*.

5.4.4 Creating Connection

The Appreciative Inquiry was set up to include the *Creating Connection* activities. The mothers shared their personal values and their strengths-based identity, and together they created group values and developed their group identity to co-create a meaningful initiative. The whole process was about connecting and helping others, appreciating each other, and working towards a more secure independent/interdependent future for their child and themselves. Trauma was acknowledged and supported with connecting habits that are part of appreciative inquiry.

5.4.4.1 Discovering our meaningful values

Overriding everything was the shared value of putting their children first, above their own lives. "I don't want anything for myself at all ever" (April); "everything is suspended" (Grace); "I don't have anything for myself" (Sienna). The AI process gave the mothers opportunity to brainstorm, through story and creative art, their group culture, values, and identity. I have aligned the mothers' brainstorms and feedback with the *seven connecting habits* and *wellbeing in action* in table 5.1 below to demonstrate the benefits of this process. Although I could have used the mother's words in several columns, I chose to use the most appropriate column for each word or phrase to keep it simple, without double-ups.

The purpose of Table 5.1 is to give a sense of the range of topics covered by AI and the progression of awareness, perceptions, capacities and actions for change. Beginning at a listening, non-judgmental stance and moving through the habits of connection that

underpin the positive core to meaning making that transforms going beyond day-to-day survival into actions and community engagement.

Table 5.1: Aligning Mothers' Meaningful Values and Group Culture into a progression				
Seven Connecting Habits		Wellbeing in Action		
Making Connection Habits: *Caring, Trusting, Listening*	Connecting Strategies Habits: *Supporting Negotiating Befriending Encouraging*	Completing the Stress Cycle *Physical Affection Creative Expression*	Managing the Stressor *Plan Reappraise Choice*	Meaning Making *Create meaning together*
Listening	Acceptance - No judgment	Positive experience	Advocacy	Common worthwhile purpose to help each other make a difference
Kindness	Responsibility	Everyone's voice is important	Strength	Giving others self-worth
Confidentiality	Flexibility	Part of like-minded group with shared experiences	Love	Sense of hope
Trust	Integrity	Open	Courage	New beginnings
Honesty	Self-Belief	Positive core	Commitment	Being able to carry on in brighter transformational ways
Respect	Fairness	Honouring achievement	Sharing ideas	Thought-provoking opportunities
Patience	Transparency	Being Calm	Going beyond surviving day by day	Thinking outside yourself
	Helping	Action	Action plan	Role for community to play
				Changed perspective on life

5.4.4.2 Doing meaningful work and activities together, tied into creating a secure future

There were many benefits the mothers experienced being part of this appreciative inquiry:

- Sienna felt everyone had "grown" in the four sessions, and being part of the group taught her about "acceptance, patience, and kindness". It was "harder than [she] thought" to participate while going through "a tough time" with Zoe, and she wanted to see everyone again.

- Grace thought this process took her beyond "surviving day by day" through: "great connection with the others", sharing ideas "from those going through something similar", and "thought-provoking" opportunities that have you "thinking outside yourself". This process made Grace feel "validated and confident in [her]self that she was the best person to advocate for her son. She realised "there is a role for the broader community in helping kids with anxiety".

- April "loved it". It "changed my perspective on life" where she used to feel "so alone and guilty that my children are different". It has "made me look at myself" and "question some of my own behaviour" which inspired her to organise an adult ADHD test. April really hoped "we make a difference with this "awesome group of like-minded people".

The mothers created their personal identities as advocates and maintained that identity for their group's positive core. Their purpose coming into the study was to help themselves help their children, and their initiative was to help teachers help their children. *Managing their stressors* inspired the mothers to proactively search for help that demonstrated a sense of agency and a high level of need. Their themes that shaped their group identity included strength, love, advocacy, courage and commitment, and out of the collective symbols they saw a sense of hope, new beginnings, and being able to carry on in brighter and transformational ways.

Their initiative demonstrated some areas of inquiry.

1. The mothers' need for help: their initiative brainstorm was "Helping Teachers Help Our Children", which stemmed from them joining the study to help themselves help their children

2. Being able to ease into the initiative: The mothers didn't want their initiative to "feel too much like work" (Grace) with action plans, or leaders, instead they wanted shared responsibility and flexibility

3. Timing was problematic:
   a. Sienna was facing big challenges at home, "life got hard… It just fell apart for me"
   b. Auckland recently came out of lockdown stress
   c. There were only two weeks of school before the school holidays, then two weeks break
   d. Term 4 is a difficult time to start anything up when schools are winding down, especially after a year of Covid

4. Collective agreements can have hidden challenges: Due to the problematic timing, the mothers chose to make their initiative a scoping exercise that they would do each at their own school individually. This was fine for Sienna and Grace who both had good contacts at their schools, however they didn't hear the apprehension that April had for doing the scoping at her daughter's school, and April wasn't clearly open with her apprehensions either. For example, when Grace talked about their level of confidence about scoping the teachers and school management, April replied, "I'm OK because they hate me anyway", and when I suggested later that they could scope in pairs, or as a group, April responded, "that could be fun, given I just went up against the panel". However, this wasn't taken up. As Aldred (2009) warned, the majority can sometimes overlook a different view in the collective, and the minority can sometimes not speak up in the collective, which has the potential to become missed opportunities. April didn't approach Dianna's high school because it was too difficult for her.

5. The Education system was seen as too big to have an effect as a group of three mothers: The mothers were disheartened with what they found out in their scoping. Grace discovered that,

They don't have the funds to do cool things. It's not taught in AUT or whatever it is. They get a big book from the Ministry, which can help these kids, but the more extreme kids, which all ours are, they just don't have the resources - they don't really know how to handle it.

Grace determined she would have more effect on her own with her own son, rather than as part of this group initiative, "I think the biggest difference you make is really just with your kid and advocating for your kid, it's hard to see how you can influence that whole system".

6. Intermediate School Initiatives have short time frames: Grace and Sienna's children were going to high schools the following year, so follow-up wasn't likely to happen there.

The group stopped at the fourth phase of the study feeling positive about what they had learned and shared. There were no expectations for them to continue beyond the study, and although they said they would like to meet up in the new year, in the new year, two of them felt that they didn't need to meet up anymore.

5.4.4.3 Connecting, helping and feeling happy for others

The interesting thing about creating connection is *feeling* connected. There were a number of things to note in how the mothers rated themselves before and after the study.

- Kinsley rated herself as 'moderately' supported (highest in group), yet rated herself as 'hugely' isolated, one of the highest ratings in the group.
  - Kinsley had a supportive second husband, supportive work colleagues and environment, long-term close friend with lots of knowledge, an understanding father to talk with online, and some school support set up for her first son, not her second. Kinsley found it difficult advocating for support, but she will for her sons.

- April rated herself as "not at all" supported and "hugely" isolated before the study, and after the study she rated herself as "a little" supported and "hugely" isolated. So not much change happened for her in this area, although being part of this process changed her perspective on life.
  - April had no family or friends, no work colleagues, and a small role with a couple of children in after school care at her home - but she did have weekly counselling, new church fellowship, yoga and mindfulness classes. April was a single mother also dealing with the effects of a brain injury. April had some fear about the scoping initiative at her daughter's high school.

- Sienna and Grace rated themselves as "a little" supported and "a lot" isolated before the study, and after the study they rated themselves as "a lot" supported and "a little" and "not at all" isolated.
  - Sienna and Grace both had supportive work colleagues, influence at work, a few close friends, talk therapy for their children, confident in approaching school management – Sienna had a husband and a family 'therapy' dog – Grace had a sister she talked with every day, and social media support groups she belonged to. Her son had friends and a helpful basketball coach,

Social identity can help to figure out why a person who has more support, experiences a huge amount of isolation. So far, the appreciative inquiry findings in this *Creating Connection* section back Haslam et al.'s (2018) claim that bringing people together of similar experience, and approaching their common concerns in a collective strengths-based generative process provides valuable social support. It can change personal distress into collective eustress, acting as a buffer with a focus on an appreciative shared "we" instead of on an isolated blamed "me" (Haslam et al., 2018).

5.4.4.4 Having the support of acknowledging childhood trauma

An element was introduced to deepen connection with their children who experience anxiety and who were present in the space (just not physically). The mothers were asked to share their appreciation and what they have learned from their children as mothers. This helped to position the child as a teacher for their parents – a unique person with coping strategies, not a broken person with a disorder. It also helped position anxiety outside of the child, more in relation to their external environments and interconnected relationships.

- April appreciated her and Dianna's patient empathy and compassion, with no judgement.
- Grace appreciated her and Axl's valuing of important relationships that included managing expectations and judgements to maintain trust.
- Sienna appreciated her and Zoe's practice of making choices for calm, respectful boundaries and personal space.

These all point to connecting habits that help meet basic human needs.

5.5 Key Findings

5.5.1 The Invisible Need: The rise of mothers caring for child(ren) with anxiety disorders

This study focussed on the mothers caring for a child with an anxiety disorder. At the time of this study, there was little research or support available on mothers, on mothers of children with disabilities, and on mothers caring for a child with an anxiety disorder. Consequently, there is little understanding of how the mother child relationship is reciprocal and can influence the health and wellbeing of each other. In New Zealand at present, there are no

social-identity community action/parent advocacy groups set up for parents/mothers caring for a child with an anxiety disorder; however, there are some general parent support groups whose function is more about informing and comforting rather than engaging with the socio-political conditions which give rise to so much trauma and anxiety.

5.5.2 The Challenges for Mothers to become visible, valued, connected and supported

The systems of patriarchy and neoliberalism make the mothers' experiences invisible in society and make the support needs of children with moderate to severe anxiety disorder invisible in education – the systems are not set up to support the high needs of children with anxiety disorder, or the mothers caring for them. This gap in the systems demonstrated the strong need for the mothers in this study, and possibly most mothers, to become advocates for their children, with the consequence of needing to put their lives on hold in the hope one day their children gain more independence.

The prevalence of biological and psychological approaches to anxiety focuses attention on what is wrong in the child's brain (biology) or thinking (psychology), placing responsibility – and blame – on the mother. With this approach, the problem of anxiety is located within the child rather than held within the societal context in which it is arising. Using the social identity approach to understand the position of mothers caring for a child with an anxiety disorder in the western world, the literature and the findings highlight that mothers' social capital decreases and she becomes increasingly isolated, exhausted, and silenced in the face of social determinants such as: lack of support in an individualised society, elusive mental illness stigma and mother blame, under-resourced educational and mental health systems, and NZ's high rates of social problems (bullying, sexual abuse, domestic violence, and material hardship).

5.5.3 Appreciative Inquiry as a strategy for creating connection

This appreciative inquiry approach can be considered counter-cultural as it helped to make visible and valuable what is unseen or unheard for mothers on the fringes caring for a child with an anxiety disorder. It supported building social connection by developing and valuing social identity through a generative strengths-based action-oriented process. In developing the explanatory model (5.3), what became especially apparent was the opportunity for appreciative inquiry to meet most aspects of the different approaches. For instance, through AI, the mothers:

- had more of their human needs met (love and belonging, power, freedom and fun), so their over-worked survival need could be more supported.
- practiced the connecting habits in the strengths and value-based questions and received the appreciative feedback that helped validate them and give them more confidence
- brainstormed and co-designed a scoping initiative to help manage their stressors

- created connection through meaningful sharing of values, activities, helping each other, acknowledging and appreciating the learning from the trauma, and working together to provide possibility for a hopeful future.

The learning from this study is to include more opportunity for completing the final stages of the progression set out in table 5.1. Possibly there has not been enough time devoted to completing the stress cycle and managing the stressor plan. This may have limited the ability of mothers to help each other - helping that clearly April needed in approaching her school. Their role as mother as advocate has been burned into their psyche in the form of "if I don't do it, then [my child] loses" and the meaning-making as a collective is not sufficiently experienced for them to see the power of group advocacy – mothers as advocates.

The mothers were asked, through the challenges of caring for a child with an anxiety disorder, what were the gifts, if there were any, that it brought to their mother-child connection? This question did two things: it acknowledged the *connecting habits* the mothers were learning and practicing by parenting a child with an anxiety disorder, and it delved into the *managing the stressors* of *wellbeing in action* through the re-appraisal of challenges. The gifts of those challenges for the mothers were learning how to create connection: patience, acceptance, empathy, compassion, being present, being mentally well, trust, discernment, taking time, listening, and going with the flow.

The gifts of the challenges of anxiety are learning how to create connection.

5.6 Limitations of this study

There were limitations in this study.
- The three main participants who volunteered to join the appreciative inquiry are only a small sample of all mothers caring for a child with an anxiety disorder. Having a larger group as intended, an additional two members, may have helped in generating a stronger presence of the collective.
- All the mothers were predominantly within the same sociodemographic: they were middle-aged, middle-class, Pākehā women who had their children in heterosexual relationships. The explanatory models that I have called upon, including the definitions and explanations of anxiety, may very well not apply to other cultural groups.
- The children went to different schools, which challenged the collective initiative when the mothers did this separately at their own schools.
- Although this project advertised for parents, only mothers were committed to participating. This meant the fathers experience wasn't included in this study.
- This study didn't include spirituality, nature, or consciousness-based strategies for coping and healing.

5.8 Recommendations

1. **Run more versions and make the following changes:**
   a) Do all of the sessions face to face as much as possible, and value the connecting non-structured time, sharing food, and having fun to build relationship and trust
   b) Include elements that help to *complete the stress cycle* to support participants in the group
   c) Connect with external networks so the initiatives have an opportunity to be supported in the community, as in the appreciative inquiry workshop in Drugs, Hopes and Dreams (McAdam & Mirza, 2009)

2. **Facilitate AI with parents at school: making it one step closer to being a group in action.**
   a) Develop groups for mothers in the same school to increase potential for stronger group identity, and for levelling out the power differential for more teamwork with school management and teachers
   b) Start earlier in the school year, allowing more time for the process to create relationship, initiatives and outcomes in schools
   c) Develop an AI project for low decile schools, where the experience of anxiety and the support systems available may be very different.

3. **Facilitate AI with teachers at school: need for a collaborative approach, advise teachers about practice**
   a) Develop an informed team approach with parents and social services to support children with anxiety
   b) Share learning and approach with other schools

5.9 Conclusion and Researcher Reflections

The results from this study point to the value and effectiveness of a collective approach like appreciative inquiry for prevention and reduction of anxiety disorder in community. Using this approach in places like schools, universities, and workplaces would increase awareness, challenge stigma and isolation, and create meaningful connections and actions in communities. The approach has the capacity for groups to be connected regionally and nationally to inform and create social change.

The anxiety coping behaviour the child is presenting has the capacity to propel the mother's coping experience into anxiety and depression through their interconnected and reciprocal relationship, especially if the mother is lacking meaningful social support.

This study provided an opportunity for mothers' voices and experiences to be heard, understood and appreciated. Here, the value of the mothers' experience has the capacity to

inform and improve social supports and systems that promote inclusiveness and the value of difference to effect positive change in families, communities, schools, workplaces and in mental health approaches. Most importantly, it has the capacity to support mothers in deeply appreciative ways.

I initially experienced parenting a child with anxiety on my own, with all of my family living overseas, and a few exceptional friends in support. I was informed by my brother who experienced depression and took his life six years ago. He was very brave and strong and loved his family very much, but he moved away and became isolated. I am informed by my son who didn't want to live anymore at 11 years old and coped by avoiding school and going outside the house, and since then it's been five years of learning and growing together and he has become very wise and kind and is starting to explore again. I am informed by my discerning and powerful daughter who was our amazing support, and who found her way through anxiety by being with horses and doing animal rescue. Covid made anxiety worse for her, and the horses thankfully support her in amazing ways. My sweet dog developed anxiety during Covid, and became unpredictably reactive; she gave me my first taste of experiencing for myself what anxiety must be like, as I became too scared to take her to the beach. Anxiety, I have discovered is an invitation for all of us to learn and practice connecting habits and practice wellbeing in action, and for me especially, with 20 second hugs, exercise, and meditation.

I wanted my research to be objective, so I didn't include myself as a participant. I kept a reflective journal, practiced co-counselling and (mostly) daily meditation, talked with my supervisor, and did regular acupuncture and herbs to support me during the research. I also participated in a monthly equine women's circle and joined another consciousness-based women's circle, both of which supported me immensely.

There are two stand-out moments for me during the research. One was when the mothers were talking about taking medication and how they felt judged by it, so they kept it secret. My experience was the opposite: I didn't use medication and I experienced being judged all the time for not taking it or giving it to my son. From the mothers' stories and my own, the experience of being judged for what you do and don't do means you are constantly working hard to never have a chance at doing well. The word quandary kept coming to me, as mothers are navigating so many options to try and help their family, and it's a challenge. I saw this piece of art when I was getting a romiromi massage, and it made me think of the quagmire of our journeys.

The second stand-out for me was changing my position from single mother experiencing this, isolated – to being in a group of mothers experiencing this, not alone – to doing the research and understanding the systemic factors at play that have contributed to our challenges, becoming very angry and sad at the same time. Although each stage of this research presented its challenges, this was probably the most challenging part for me personally. Coming out the other side, it has been the greatest gift of growth and shedding some of the internalised stigma I didn't know was there. Now, at the end of this research, I feel freedom and peace. And I feel an incredible amount of respect for the mothers in this study, and all mothers in similar situations, who are journeying such a challenging and insightful road - One that has the potential to create the deepest connections with their child, and a deeper appreciation for friendships and all the little things in life.

I am exploring looking at anxiety disorder in a new way. I am particularly inspired by Sarah Wilson's (2017) book, First, We Make the Beast Beautiful. People with anxiety are generally highly sensitive, and that may be seen as their gift, and also their challenge. That special gift of being aware and observant of the environment, and the relationships happening within the environment, provides a radar for society that lets it know when things aren't quite right. Looked at in this way, with the amount of people having anxiety, there are a number of things going wrong, and there are a number of things we can do to change it. There are many social determinants in NZ that have the capacity to trigger anxiety disorder, as well as a couple of the obvious global situations of climate change and the Covid pandemic. If we value and make time and energy for creating meaningful social connection, we will be in a much better place to manage those stressors and thereby prevent and reduce anxiety disorder.

By sharing appreciative inquiry together, the journey to recovery is underway. It has excellent healing and resourcing potential for parents as they are caring for their child with an anxiety disorder. It values the recovery journey with deep compassion, appreciation and connection instead of blame, stigma and isolation.

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Appendices

Appendix A: Unitec Human Ethics Application

Application number: Research start date: Feb 2020

Date received: **Research end date: March 2021**

Unitec Human Ethics Application – **Form A**

FOR APPROVAL OF PROPOSED RESEARCH INVOLVING HUMAN PARTICIPANTS
For all research that involves or may involve potential for contentious or sensitive issues.

> (All applications are to be typed and presented using language that is free from jargon and comprehensible to lay people)

Section A: General Information

1. **Project title:**   **Creating appreciation and community support for parents caring for a child with an anxiety disorder**
2. **Projected start date:**   **May 2020**
3. **Projected end date:**   **March 2021**

Student Applications
Full Name: Kristi Shaw
Telephone: 021 300 328
Email Address: kristi@totallyconnected.co.nz
Postal Address: 99 Deep Creek Road, Waiake, Auckland 0630
Employer (if applicable):   n/a
Full Name of Principal Supervisor(s):   Geoff Bridgeman
School: Social Practice
Degree Title: Master of Applied Practice
Campus (mark one only): ☐Albany   ☒Mt Albert   ☐Waitakere
Telephone: 09 892 7464
Email Address: gbridgman@unitec.ac.nz

Other Applicants – Co-researchers/co-supervisors/organisations
Full Name: N/A
Name of organisation (*if applicable*):
Role in project (co-researcher, supervisor, sponsor, etc):
Telephone:
Email Address:
Postal Address:
School:

4. **Summary of Project**

Please outline in no more than 200 words in plain, non-technical language why you have chosen this project, what you intend to do and the methods you will use.

Anxiety disorders are prevalent and on the rise in NZ with one in four New Zealanders experiencing anxiety in their lifetime. The literature suggests that: anxiety is a collective problem, with individual symptoms; support for parents and the child with anxiety is needed and reciprocal; we have human needs that require reconnection for individual and collective health; and coming together collectively to meaningfully create and contribute to solutions improves our wellbeing. In NZ, the predominant evidence-based approach to anxiety disorders is using the medical model that focuses on the individual, with treatments that include cognitive behavioural therapy and/or antidepressant prescription medication that is evidenced with only modest beneficial outcomes. This research will be using an appreciative inquiry approach, aligned with a recovery-type model with the aim of supporting wellness, strength and resilience in a local community.

Using interviews and focus groups, in an appreciative inquiry, this research will uncover parents' lived experiences caring for a child with an anxiety disorder, and through this process, discover possibilities for creating community action to address the community component of anxiety. I will be using a thematic approach to analyse the data.

5. **List the Attachments to your Application**
    Consent forms – participant and organisation ☒
    Information sheets ☒
    Interview questions ☐
    Paired interview and Focus group schedules ☒
    Questionnaire/s ☐
    Other (please specify): Advertisement, Post Session Support Handout

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Applications that are incomplete, lacking the appropriate signatures or submitted after the specified application deadline date will not be processed. This will mean delays for the project.

Applications must be submitted in the following formats:

One signed hard copy to be sent or hand delivered to the Ethics Secretary at:
- Research and Enterprise
  Building 112, Room 2004
  Unitec Mt Albert Campus
  Gate 4, 139 Carrington Rd
  Mt Albert, Auckland

One electronic copy complete with supporting documents to be emailed to the Ethics Secretary at:
- ethics@unitec.ac.nz

Note: If no hard copy, complete signed e-copies of applications will be accepted.
E-copies to be sent to: ethics@unitec.ac.nz

Note: Email trails are unable to be accepted in lieu of signature/s.

Section B: Project Information

6. Does this project have any links to previously submitted ethics application(s)?

☐ *YES* / ☒ *NO*

If yes, list the UREC or HDEC application number/s (if assigned) and relationship/s.

7. Is approval from other Ethics Committees being sought for the project?

☐ *YES* / ☒ *NO*

If yes, list the other Ethics Committees.

8. **Provide a brief rationale for the research, including justification and benefit of the project.**

Moderate to severe anxiety disorders are the most common psychiatric illnesses affecting 1 in 4 children and adults in NZ (Anxiety NZ, 2020). The most recommended treatments in NZ are both cognitive behavioural therapy, and antidepressant medication (Bowden, Gibb, Thabrew, Audas, Camp, Taylor, Hetrick, 2019; Anxiety NZ, 2020; Healthline, 2020; Health Navigator NZ, 2020), despite the fact that "antidepressant medications, especially SSRI's (serotonin-specific reuptake inhibitors) have been shown to be [only] *modestly* beneficial for the treatment of anxiety and depression in children and young people" (Bowden et al. 2019, p. 56). Anxiety disorders are prevalent and rising in NZ (Bowden et al., 2019).

> "According to the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), anxiety disorders include disorders that share features of excessive fear and anxiety related to behavioural disturbances. These disorders include separation anxiety disorder, selective mutism, specific phobia, social anxiety disorder (social phobia), panic disorder, agoraphobia, generalised anxiety disorder, substance/medication-induced anxiety disorder, and anxiety disorder due to another medical condition." (Medscape, 2019, para 2)

The alternative to the medical model focused on individual/family-based treatment, is a community recovery model based on a collective approach with the aim to address anxiety in a local community. Hari (2018) cited Brown and Tirril's research in his book *Lost Connections*, where they discovered that the lack of social support in your life overwhelmingly increased your chances of developing anxiety and depression when you have a severe negative event and/or long-term stress and insecurity. Hari (2018) concluded that the social and psychological causes of depression and anxiety are all forms of disconnection. Glasser (2002), in his book *Unhappy Teenagers: A way for parents and teachers to reach them*, names the 'external control' process, found worldwide, as something that precedes disconnection and argues for self-control using the practices of Choice Theory.

Hathaway (2017), Hari (2018), and Wilkinson (2016), using case studies, demonstrate that shared action in response to a collective issue can lead to social change which shifts people from feeling anxious/depressed/despair to having a sense of empowerment. Using an Appreciative Inquiry action research process (Fry 2014), this research will use parents' lived experiences caring for a child with an anxiety disorder, to set the framework for discovering possibilities for creating community action to address the community component of anxiety disorder.

In summary, the collective has a role to play in supporting the individual, and the individual has a role to play in supporting the collective. We are interconnected. That makes anxiety a collective problem with the opportunity for collective solutions.

The benefit of this research is that:
1. There is very little research on parent's lived experience caring for a child with an anxiety disorder which is a prevalent and rising concern for families throughout NZ.
2. Evidence has shown that anxiety disorders stem from many factors that lead a person to disconnect from many things in their life. By using a focus group in appreciative inquiry research, there will be opportunities to discover reconnection: with the parent focus group, in their families, and in the local community. I haven't found evidence that indicates this action research has been done for this issue before.

3. This research could benefit the families directly involved in the research, and the learning could extend to benefit local organisations and schools who support families who are caring for a child with an anxiety disorder.

Anxiety NZ (2020) Welcome to Anxiety NZ Trust. Retrieved 8 March, 2020 from https://www.anxiety.org.nz/

Bowden, N., Gibb, S., Thabrew, H., Audas, R., Camp, J., Taylor, B., Hetrick, S. (2019) *New Zealand Medical Journal. Vol 132*, No 1505. ISSN 1175-8716 https://www.mendeley.com/viewer/?fileId=12015d5c-c399-f28d-78cd-738fa5fe2c69&documentId=096e5bf0-24a1-385f-8631-6646c19a060e

Fry, R. (2014) Appreciative Inquiry. In D. Coghlan and M. Brydon-Miller (Eds) *The Sage Encyclopedia of Action Research* (pp 44-48) Sage Publications, London.

Glasser, W. M.D. (2002) *Unhappy Teenagers: a way for parents and teachers to reach them*. HarperCollins Publishers, New York.

Hathaway, M., (2017) Activating Hope in the Midst of Crisis: Emotions, Transformative Learning, and 'The Work That Reconnects'. *Journal of Transformative Education, Vol. 15(4)*, p296-314. DOI: 10.1177/1541344616680350. https://www.mendeley.com/viewer/?fileId=39034f22-d373-db9b-122f-fc4d8ab824a1&documentId=e5802315-5b88-38f7-b24a-f517ed8601de

Hari, J. (2018) *Lost Connections: why you're depressed and how to find hope*. Bloomsbury Publishing, London.

Healthline. (2019). Drugs to Treat Anxiety Disorder. Retrieved 12 March, 2020 from https://www.healthline.com/health/anxiety-drugs#takeaway

Health Navigator. (2019). Anxiety. Retrieved from https://www.healthnavigator.org.nz/health-a-z/a/anxiety/

Wilkinson, W. (2016) *Now or Never: a time traveller's guide to personal and global transformation*. Natural Wisdom Press, Oregon

9. State concisely the aims, question and/or hypothesis of the project.

My aim, through an Appreciative Inquiry research process with parents, is to:
1. Describe parents' lived experience of caring for a child with an anxiety disorder
2. To use parent experience to set the framework for discovering possibilities for creating collective action to address the community component of anxiety disorder.

My questions are:
4. What are the stories of parents' lived experience caring for a child with an anxiety disorder; especially in relation to coping, stabilising factors, hopes for the future, and taking action?
5. What are the ideas for change that emerge from appreciative inquiry discussions and connection?
6. What kinds of actions can parents see themselves taking individually and/or collectively in the immediate future?

10. What methodology best describes your research approach?

An Appreciative Inquiry (AI), using social constructionist theory, and underpinned by Kaupapa Māori values, has been chosen for this research. The AI model has four focus areas of engagement that take focus groups on a journey leading to action, that includes: Discovery, Dream, Design, and Destiny (Clossey, Mehnert, Silva, 2011; Fry, 2014; Zandee, 2014). Underlying Appreciative Inquiry are the principles of social construction which is "based on the theoretical assumption that reality is socially constructed and mediated through language" (Milioni, 2001, p.12). This research isn't challenging the current medical model that emphasises expert knowledge on mental illness and pathology (Milioni, 2001); it is exploring, through AI, more of a recovery model that emphasises the creation of an empowering community focusing on wellness, strength and resilience (Clossey et al., 2011).

Underpinning all research is an axiology or set of values. I have chosen the principles of Kaupapa Maori research (Smith, 2015), to define the process of participant engagement in recognition of the comprehensive nature of these principles and their ability to relate to a wide range of cultural circumstances. In doing so, I concur with Love and Tilley (2014) who argue that Kaupapa Maori principles and values should be included in all public engagement

in NZ. Although my project doesn't target Māori participants, the philosophy of my method is aligned with these values in the following ways:

Ata: Principle of Growing Respectful Relationships (key understandings that build healthy relationships and wellbeing). This principle is highly aligned with Appreciative Inquiry's 4D phases (Discovery, Dream, Design, Destiny) as this focus group process includes: holding safe and respectful space (in time and place) for sharing stories; focus group planning, strategizing and actioning their co-created plan; and discovering their 'positive core' that is the recognised collective strength in the group (Fry, 2014). Holding the Ata Principle will be very important for the participants to be open to each other, reflecting on themselves and each other's stories, negotiating their boundaries, and committing to the group process and the responsibilities they have agreed to (Rangahau, 1992).

Kaupapa: Principle of Collective Philosophy (the collective vision and hopes in the community, and how knowledge and action contribute to that). This principle is aligned with both the topic of research and the Appreciative Inquiry process. Through this process, the participants are helping not only themselves and their families in caring for a child with an anxiety disorder, they are also supporting the community directly with developing and delivering a potential initiative, or indirectly by sharing the learning gained by being part of the research. The focus group will decide how their initiative, or learning, is shared back into the community (Rangahau, 1992).

Whanau: Principle of Extended Family Structure (acknowledges ALL relationships, their connections and responsibilities) This principle aligns with a couple of the Appreciative Inquiry principles: the constructionist principle and the anticipatory principle (Stavros & Torres, 2018). Together, all three of these principles remind us (researcher and participants) to keep an open mind and hold our beliefs and reality lightly for new knowledge and new meanings to come through. With curiosity and reflection, we can become more aware of the frame we are looking through, what we are anticipating, and how we create and manage connection and growth with our relationships while we are going through the research process (Love & Tilley, 2014).

Tino Rangatiratanga: Principle of Self-Determination (personal rights to determine your own culture, aspirations and destiny) (Rangahau, 1992). Using this principle, we ensure that each participant in the research process is self-determining, and a co-creative partner in a meaningful way from start to finish. The Appreciative Inquiry poetic principle can be used alongside this, and it says that what we put attention to expands (Kelm, 2011). Upholding these two principles together, being open to and valuing multiple perspectives and realities will be instrumental in co-creating a collective vision and initiative.

Clossey, L., Mehnert, K., Silva, S. (2011) Using Appreciative Inquiry to Facilitate Implementation of the Recovery Model in Mental Health Agencies. *Health & Social Work, Vol 36, No 4*.

Fry, R. (2014) Appreciative Inquiry. In D. Coghlan and M. Brydon-Miller (Eds) *The Sage Encyclopedia of Action Research* (pp 44-48) Sage Publications, London.

Kelm, J. B. (2011) What is Appreciative Inquiry? Retrieved on 1 June 2020. https://www.youtube.com/watch?v=ZwGNZ63hj5k

Love, T., Tilley, E. (2014) Acknowledging Power: the application of Kaupapa Māori principles and processes to developing a new approach to organisation-public engagement. *Public Relations Inquiry, Vol 3(1)* 31-49. DOI: 10.1177/2046147X14521198 https://journals-sagepub-com.libproxy.unitec.ac.nz/doi/pdf/10.1177/2046147X14521198

Milioni, D. (2001) Social Constructionism and Dramatherapy: creating alternative discourses. *Dramatherapy Vol 23* No. 2 https://journals-sagepub-com.libproxy.unitec.ac.nz/doi/pdf/10.1080/02630672.2001.9689579

Rangahau (1992) Principles of Kaupapa Māori. Retrieved on 24 April, 2020 from http://www.rangahau.co.nz/research-idea/27/

Smith, L. T. (2015) Kaupapa Māori Research- Some Kaupapa Māori principles. Retrieved on 18 May 2020, from https://researchcommons.waikato.ac.nz/bitstream/handle/10289/12026/Kaupapa%20Māori%20Research.pdf?sequence=21&isAllowed=y

Stavros, J. & Torres, C. (2018) *Conversations Worth Having*. Berrett-Koehler Publishers Inc., Oackland, CA.

Zandee, D. P. (2014) Appreciative Inquiry and Research Methodology. In D. Coghlan and M. Brydon-Miller (Eds) *The Sage Encyclopedia of Action Research* (pp 48-51) Sage Publications, London.

11. **What methods are you using to address the aims, questions and/or hypothesis identified in question 9?**

(Mark the appropriate boxes)

Questionnaire ☐

Paired interviews and Focus Group ☒

Interview ☐

Experimental, Observational or Interventional Study ☐

Other (please specify): Participant reflections and clarifying conversations as appropriate

Will electronic media (e.g. email or the internet) be used for the collection of data from participants? ☒ Yes / ☐ No

12. Where will the project be conducted? Include information about the physical location(s) /setting(s).

While safety precautions are in place during the corona virus pandemic, the focus group sessions will be conducted online using the Zoom app. Should the safety precautions ease, and participants in the group decide they would like to meet offline, I will be flexible, and work with them to provide the situation that best meets everyone's needs.

The project's data analysis will take place at 99 Deep Creek Road, Waiake. The project's supervision sessions will take place online using the Zoom app, or when possible at Unitec Waitakere campus.

13. If the project is based overseas: N/A

i)   Specify which countries are involved:

ii)   Outline how overseas country requirements (if any) have been complied with:

iii)   If the research is to be conducted overseas, describe the arrangements you will make for local participants to express concerns regarding the research.

14. Describe the experience of the researcher and/or supervisor to undertake this type of project?

As the researcher, I come with a lived experience of caring for a child with an anxiety disorder, including suicidal ideation. I am a trained Narrative Therapist, successfully gaining my PGDip at Unitec in 2012 and working primarily facilitating groups and in community development. My group facilitation includes: developing student leadership teams to address bullying and online harm in high schools (4 years); facilitating the Upper Harbour Youth Caucus in creating local youth engagement opportunities (3 years); developing and delivering teen girls' empowerment programmes in schools and workshops (3 years); teaching sexual assault prevention programmes in high schools and night schools (5 years); and developing and delivering outdoor recreation and education programmes to children and adults (5 years).

My community development work has included managing Manukau on the Move, a mobile recreation team and community store with Manukau City Council (3 years), and managing the East Coast Bays Leisure Centre with North Shore City Council (3 years). I was the Albany Community Coordinator (3 years) managing and developing the programmes at the community house, and working collaboratively in the community with a variety of Council Departments (Communities, Parks, Recreation, Libraries), Local Board, community organisations, schools, local businesses, and the local residents/communities to develop programmes and events, and facilitate a variety of network groups including: the Upper Harbour Strategic Network, the Upper Harbour Community Network, the Albany Newcomers

Network, the Upper Harbour Community Garden Network, and member of the Asian Network (TANI) and the North Shore Newcomers Network.

The Principal Supervisor: Dr Geoff Bridgman is a lecturer in Social Practice at Unitec. He has long experience in supervising research students as a principal supervisor in similar projects. He has a special interest in mental health and community development issues and social services and has been actively involved in mental health research for many years.

Section B.2: Participants

15. **Describe the intended participants.**

Participants need to be the parent:
1. Of an intermediate or high school student who has experienced an anxiety disorder for a year or more. The child is/has been demonstrating avoidance behaviour such as refusing to go outside or to school, and/or experiences panic attacks
2. Who has experienced both distress and the navigational difficulty of sourcing treatment and support for their child who has an anxiety disorder (The parent and child are not in crisis at this time)
3. Who live in a North Shore Auckland suburb, preferably in the East Coast Bays area

I have chosen the criteria in question to ensure that the participants will have a length and breadth of experience navigating support for their child who is of similar ages to other children in the group. I also want to ensure parents are as local as possible to create opportunity for community action and support.

16. **How many participants will be involved?**

Four to six participants that meet the criteria will be chosen.

17. **What is the reason for selecting this number?**
    (Where relevant, attach a copy of the Statistical Justification to the application form)

This research aims to understand parents' lived experience caring for a child with an anxiety disorder while discovering how, as a focus group, they are able to address anxiety collectively in their local community. Peek and Fothergill (2009) both concluded that "focus groups that included between three to five participants ran more smoothly than the larger group interviews that [they] conducted" (p. 37).

The research process has four stages, one paired interview stage and three focus group stages which fit with the four phases of Appreciative Inquiry design (Clossey, Mehnert, Silva, 2011).

Clossey, L., Mehnert, K., Silva, S. (2011) Using Appreciative Inquiry to Facilitate Implementation of the Recovery Model in Mental Health Agencies. *Health & Social Work, Vol 36, No 4*.
Peek, L., Fothergill, A. (2009) Using Focus Groups: Lessons from studying day care centres, 9/11, and Hurricane Katrina. *Qualitative Research Vol. 9(1):* 31-59 Sage Publications, London. DOI: 10.1177/1468794108098029
https://journals-sagepub-com.libproxy.unitec.ac.nz/doi/pdf/10.1177/1468794108098029

18. **Describe how potential participants will be identified and recruited?**

Purposeful sampling for homogeneity (Palinkas, Horwitz, Green, Wisdom, Duan, Hoagwood, 2015) will be used with clear criteria for creating a small group of four to six participants who have lived experience of being a parent of a child with an anxiety disorder. As the topic of this research may be deemed sensitive, and the participants may be hard to access, I will also be

using the snowball sampling method (Cohen, Manion, Morrison, 2007) to enlist the help of key people to help find participants for the research. There are several places to start: Te Kura Correspondence School, Northern Health School, and Youth in Transitions Trust, all of which my son has received support from. I will also inquire in the 'Support for Parents when it can be Tough2Love' Facebook group, of which I am a member. I also have connections with Anxiety NZ and Youthline as well.

Palinkas, L. A., Ph.D., Horwitz, S. M. Ph.D., Green, C. A., Ph.D., M.P.H., Wisdom, J. P., Ph.D., M.P.H., Duan, N., Ph.D., Hoagwood, K., Ph.D. (2015) Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Adm Ment Health 42(5)*: 533-544. DOI: 10.1007/s10488-013-0528-y

Cohen, L., Manion, L., Morrison, K. (2007) *Research Methods in Education.* Routledge. London. https://www.mendeley.com/viewer/?fileId=5b2974a9-b116-ac87-33c5-c67014004961&documentId=24f86fe9-5a13-3ef7-ad38-56c4cbcaf397

19. Does the project involve recruitment through advertising?

☒ *YES* / ☐ *NO*

(If yes, please attach an example of the advertisement)

Please refer to Appendix C – Advertisement

20. Who will make the initial approach to potential participants?

In response to the advertisement, potential participants will contact me by email or mobile phone and we will start a conversation to assess suitability for the research. If they are interested, I will email them a letter with an 'invitation to participate in the study' and an 'information sheet for participants' that will give them a very good idea of the research topic, how appreciative inquiry works in a focus group, the questions that may be asked, and an idea of time commitment. The volunteer and collaborative nature of participation will be made clear. I will phone the potential participants within a week of sending them the information to determine their level of interest and answer any questions they may have.

21. Describe criteria (if used) to select participants from the pool of potential participants.

Inclusion Criteria: Participants need to be the parent:
1. Of an intermediate or high school student who has experienced an anxiety disorder for a year or more. The child is/has been demonstrating avoidance behaviour such as refusing to go outside or to school, and/or experiences panic attacks
2. Who has experienced both distress and the navigational difficulty of sourcing treatment and support for their child with an anxiety disorder (The parent and child are not in crisis at this time)
3. Who live in a North Shore Auckland suburb, preferably in the East Coast Bays area

Written answers to the four selection questions below will help determine participant suitability (motivation, intention, and to create group diversity):
6. Confirm they fit the three criteria above
7. Basic Demographics questions: culture, age, gender, occupation, married/single, children in full or shared care
8. What do they hope to get out of participating in this focus group research?
9. What is their motivational level in being part of any collective action that comes out of the focus group sessions?

Exclusion Criteria: If there are more than six people interested in participating in the research who fit my criteria, I will choose the participants based on three things: their location (the closer to each other the better) and their motivation to be part of an ongoing project.

22. How much time will participants have to give to the project?
Due to the nature of the Appreciative Inquiry process, with its four phases of action research, this will require more time and commitment from participants. Approximate overall time: 7.25 hours to 9.25 hours. Please refer to Appendix D: Paired Interview and Focus Group Guide for more detailed information on each element.

    a. Paired interviews: 30 to 45min
    b. Reflection/creative activity/group reflection/review: 30 to 45 min
    c. First Focus Group: 1.5 – 2 hours
    d. Reflection/creative activity/group reflection/review: 30 to 45 min
    e. Second Focus Group: 1.5 – 2 hours
    f. Reflection/review and group activity: 45min to 1 hour
    g. Third Focus Group: 1 hour
    h. Third Focus Group reflection/review: 1 hour

Individual contributions will be noted by their agreed pseudonyms in the transcripts.

23. Describe any professional or other relationship between the researcher and the participants? (e.g. employer, employee, work colleague, lecturer/student, practitioner/patient, researcher/family member).
Indicate how any resulting conflict of role will be addressed.

Participants will be from the general public and unknown to me.

24. Will any payments, koha or other compensation be given to participants?

☐ YES / ☒ NO

If yes, describe what, how and why.

(Note that compensation (if provided) should be given to all participants and not constitute an inducement. Details of any compensation provided must be included in the Information Sheet.)

Section B.3: Data Collection

25. Does the project include the use of participant questionnaire/s?

☐ YES / ☒ NO

(If yes, attach a copy of the Questionnaire/s to this form and include this in your list of attachments (Q)
If yes:

i)   Indicate if the participants will be anonymous (i.e. their identity be unknown to the researcher and no information collected on the participant's identity?

ii)   Describe how the questionnaire will be distributed and collected.

26. Does the project involve observation of participants?

☐ *YES* / ☒ *NO*

If yes, please describe.

27. Does the project include the use of focus group/s?

☒ *YES* / ☐ *NO*

If yes, describe the location of the focus group and time length, including whether it will be in work time.

If yes, ensure the researcher asks permission for this from the employer.

The focus groups will be either be online using the Zoom app or face-to-face. The introductory phase of the appreciative inquiry process are the paired interviews that will be done online using the Zoom app. These paired 'discovery' sessions are a gentle, close, method of sharing stories and making connection with another person.

The focus group sessions will be facilitated using either zoom or face to face depending on what the group finds most suitable and convenient.
   a. Paired interviews: 30 to 45min
      • Discovery phase – Our Coping & Our Stabilisers
   b. First Focus Group: 1.5 – 2 hours
      • Dream phase – Our Strengths & Hopes
   c. Second Focus Group: 1.5 – 2 hours
      • Design phase – Ideas for Change
   d. Third Focus Group: 1 hour
      • Destiny phase – Preferred Future Through Action

For more detail, please refer to Appendix D: Paired Interview and Focus Group Guide

28. Does the project include the use of participant interview/s?

☒ *YES* / ☐ *NO*

If yes, attach a copy of the Interview Questions/Schedule to this application form.

If yes, describe the location of the interview and estimated time length, including whether it will be in work time.

If yes, ensure the researcher asks permission for this from the employer.

Please refer to Appendix D – Paired Interview and Focus Group Session Guide

29. Does the project involve sound recording or image recording e.g. photo/video?

☒ *YES* / ☐ *NO*

If yes, please describe.

(If agreement for recording is optional for participation, ensure there is explicit consent on the Consent Form)

All paired interviews will be done online using the Zoom app and possibly some focus groups. I will use a second recording device as a back-up should anything go wrong. Consent to be recorded will be required to be part of the research.

Please refer to Appendix G: Confidentiality and Consent Form

30. If recording is used, will the record be transcribed?

☒ *YES* / ☐ *NO*

If yes, state who will do the transcribing.

If not the researcher, a Transcriber's Confidentiality Agreement is required – attach a copy to this application form. Normally, transcripts of interviews should be provided to participants for review, however, if the researcher considers that the right of the participant to review is inappropriate, a justification should be provided below.

I will be using the Zoom transcription service wherever Zoom is used as the method of connection. I will be transcribing the recorded face-to-face focus group sessions. Transcripts will be provided to the participants for reflection/review. Any identifying information will not be included in the transcript; instead, pseudonyms or other agreed identifiers will be used. Participants will have an opportunity to review the transcript and feedback to the researcher.

If transcribing needs to be outsourced, the person employed to do the transcribing will complete the 'Confidentiality Agreement for Transcribers' before any transcribing work starts. Please refer to Appendix E – Confidentiality Agreement for Transcribers.

31. Does the project involve other methods of data collection not covered in Qs 25-31?

☐ *YES* / ☒ *NO*

If yes, describe the method used.

32. Does the project require permission to access databases?

☐ *YES* / ☒ *NO*

If yes, attach a copy of the draft request letter/s to this form. Include this in your list of attachments (Q).

33. Who will carry out the data collection?

If this is to be carried out by anyone other than the named investigators on this application, please provide their details and ensure a confidentiality agreement is in place.

34. Will any information be obtained from any source other than the participant?

☐ *YES* / ☒ *NO*

If yes, describe how and from whom.

35. Will any information that identifies participants be given to any person outside the research team?

☒ *YES* / ☐ *NO*

If yes, indicate why and how – ensure this is explained on the information sheets.

Confidentiality outside of the research team and the participants will be guaranteed unless there is an agreement by the group as a whole.

Please refer to Appendix G: Confidentiality and Consent Form

36. Will the participants be anonymous (i.e. their identities are unknown to the researcher and no information collected on the participant's identity?)

☐ *Yᴇs* / ☒ *Nᴏ*

If no, explain how confidentiality of the participants' identities will be maintained in the treatment and use of the data.

The participants will choose as a group whether they would like their names included in the research paper itself. If they wish their identity to remain confidential, they can choose how they would like to be identified (number, letter, or a pseudonym). If the participants decide to go out in the community for the action part of the research, and they want their identity to remain confidential, the participants will agree on how that can be accomplished. It may be that the group is happy for some participants to remain confidential while other participants use their own names

37. Will an institution (e.g. school) to which participants belong be named or be able to be identified?

☐ *Yᴇs* / ☒ *Nᴏ*

If yes, explain how you will make the institution aware of this and how organisational consent will be obtained from the institution - attach organisational consent forms/templates to this application.

38. Outline how and where:

   i)   The data will be stored;
(Pay particular attention to identifiable data, e.g. recordings, videos and images)

   All digital media and data collected will be kept private and confidential. Transcripts of paired interviews and focus groups and reflections will be saved in password protected files. Any hard copies of material such as pictures, will kept in a locked filing cabinet at 99 Deep Creek Road, Waiake.

   ii)   Consent Forms will be stored;
(Note that Consent Forms should be stored separately from data. UREC expects Consent Forms to be stored on site at Unitec)

   Consent forms will be stored in a secure filing cabinet within the office of Dr Geoff Bridgman, Unitec Waitakere Campus

iii) Who will have access to the data/Consent Forms?

My Supervisor and myself

iv) How will the data/Consent Forms be protected from unauthorised access?

Both will be kept in locked filing cabinets which only me and/or my supervisor have access to.

39. **How long will the data from the project be kept, who will be responsible for its safe keeping and eventual disposal? (Note that health information relating to an identifiable individual must be retained for at least 10 years, or in the case of a child, 10 years from the age of 16).**

All data will be stored for 5 years following the conclusion of the study and will then be destroyed. The researcher will be responsible for this.

40. **What are the criteria for participants who wish to opt out of research/right to withdraw from research?**

Participants are free to withdraw from the research at any time and may withdraw all of their data from the study at any point up until 5pm 7 days after receiving the transcript for the final focus group. After this point it may not be possible to remove or change data relating to a particular participant due to commencement of the thematic analysis process.

Please refer to Appendix B: Information letter

41. **Do you anticipate that the results of your research may be subject to an embargo? If yes, outline the possible reasons your research may be embargoed. (It is expected that research is made available for public access through publication or other means, unless there is compelling reason for restricting access to it).**

No, there is no anticipation that the results of this research may be subject to an embargo.

Section C: Benefits/Risk of Harm

42. **What are the possible benefits (if any) of the project to individual participants, groups, communities and institutions?**

Possible benefits to participants: being in a position of caring for a child with an anxiety disorder can be very isolating and stressful. The parents in the focus group may benefit from sharing their stories with others who are in similar situations and thereby become more knowledgeable, aware, strengthened, supported and feel less alone. With an appreciative inquiry approach, they may also feel more empowered with an opportunity to help themselves, their child and family, and the community by being part of a team that creates something together to address the issue. Should they decide to continue to action an initiative together, or on their own, they may carry the feeling of teamwork, inspiration and possibility. After doing the action research, participants may feel a sense of satisfaction that

they were part of a group that contributed to research intended to make a difference to help others.

Possible benefits to the community: the findings or actions that result from this research may positively influence families in the community, community organisations, and/or schools.

43. What discomfort (physical, psychological, social), incapacity or other risk of harm are individual participants likely to experience or at any risk of as a result of participation?

Participants will not be at any risk of physical harm during this research. There is a chance, depending on what initiative they agree to action, that they will be more public in addressing anxiety, and may come up against some social stigma or critique that could affect them or their family. The risks of this will be discussed in the design phase of the research, and participants will have time to think about what they would like to action and the power to choose how they would like to participate in any action.

This project will be discussing in an appreciative way, the experiences parents have had and how those experiences have created meaning for them. Although this research is strengths-based, there may be something in the stories that a participant shares that may trigger something in themselves, or in others, that may cause someone to feel troubled emotions or some vulnerability. Participants may want to consider that this may be a possibility for them and are asked in the 'Information Sheet to Participants' to carefully consider the nature of this project before deciding to participate.

44. Describe the strategies you will use to deal with any of the situations identified in Q43.

To avoid any physical or social harm, the online focus group sessions will follow the safety and privacy guidelines recommended by the Zoom app. To develop and maintain a private and safe environment for everyone in the group, it will be recommended that participants find a room that is secluded, without distractions, and wear headphones so other people in the house can't hear the conversations. This will enable confidentiality of participants.

In the recruitment phase of this research, the psychological risk will be addressed in the 'Information Sheet to Participants' so they can make an informed choice regarding their participation in the study. They will be asked to carefully consider their participation due to: the sensitive nature of the study, sharing their stories and ideas in a focus group made up of other parents in similar situations, and they will be involved in a way of their choosing to help create an initiative during the action phase of the research.

In the unlikely event a participant gets distressed, the session will pause in order to support the person feeling distress. When they are ready to continue, the session will continue. If the person is highly distressed and can't manage to return to the group session, the session will stop and the researcher will support the participant in distress. If the participant requires more support, they will be given the Support Handout to choose the support they need. The researcher will contact the participant in three days to ensure they have the support they need. Please refer to Appendix F: Post Session Support Handout

There are reflection phases during this research process, so should anything come up for anyone, they can discuss with me privately, and/or with the group the next time they meet, so that everyone feels safe and comfortable with what they share and the choices they make to participate. Should a participant need more support when not in session, they can contact me to talk, and if needed, they will be referred to an appropriate support centre and/or helpline, as listed on the 'Post Session Support Handout.' I will follow up within three days to

ensure they have received the appropriate level of support, and discuss any such incidents with my supervisor.

For more detail, please refer to Appendix D: Paired Interview and Focus Group Guide

45. Is there any risk of harm of the project to the researcher?

As I will be listening to experiences relating to this topic that could potentially involve some sort of abuse, I may be at risk of experiencing vicarious traumatization and compassion fatigue.

46. Describe the strategies you will use to deal with any of the situations identified in Q45.

I will maintain my regular daily meditation practice and I will also establish a regular practice of writing in a reflection journal during data collection to analysis. When I become aware of issues arising for myself, I will seek support from my supervisor, and if that isn't enough, I will seek professional support for myself.

47. What discomfort (physical, psychological, social) incapacity or other risk of harm are groups/communities and institutions likely to experience as a result of this research?

It is not expected that there will be any risk of harm to groups, communities or institutions from this study.

48. Describe the strategies you will use to deal with any of the situations identified in Q46.

49. Is ethnicity data being collected as part of the project?

☒ *YES* / ☐ *NO*

If yes, please describe how the data will be used.
(Note that harm can be done through an analysis based on insufficient sample or sub-set numbers).

Only in the demographic questions in the application process. Issues of cultural identity can be part of the cause of anxiety and its solution

50. If participants are children/students in a pre-school/school/tertiary setting, describe the arrangements you will make for children/students who are present but not taking part in the research.

(Note that no child/student should be disadvantaged through the research)

N/A

51. Is deception involved at any stage of the project?

☐ *Yes* / ☒ *No*

If yes, justify its use and describe the debriefing procedures.

Section D: Informed and Voluntary Consent

52. By whom and how, will information about the research be given to potential participants?

(Attach copies of information sheet/s to the application form.)

As the topic of this research may be deemed sensitive, and the participants may be hard to access, I will be using the snowball sampling method (Cohen, Manion, Morrison, 2007). I will enlist the assistance of key people to help promote the targeted recruitment of North Shore parents caring for a child with an anxiety disorder. I will send the advertisement to the organisations I have chosen (ie. Te Kura, Northern Health School, Youth in Transition, Youthline, Anxiety NZ), asking them to send it to the families they work with. Initially the potential participants will receive an advertisement scoping for participants through an agency that includes my details.

Potential participants will contact me by email or phone to enquire for more information. Information sheets will be provided by me to all potential participants by email and they will be invited to talk by phone if they wish. A copy of all Information Sheets are attached to this application.

Cohen, L., Manion, L., Morrison, K. (2007) *Research Methods in Education.* Routledge. London. https://www.mendeley.com/viewer/?fileId=5b2974a9-b116-ac87-33c5-c67014004961&documentId=24f86fe9-5a13-3ef7-ad38-56c4cbcaf397

53. Will consent to participate be given in writing?

☒ *Yes* / ☐ *No*

(Attach copies of Consent Form/s to the application form)
If no, justify the use of oral consent.

Please refer to Appendix G: Confidentiality and Consent form

54. Will participants include persons under the age of 16?

☐ *Yes* / ☒ *No*

If yes, indicate:

  i) The age group and competency for giving consent.

  ii) If the researcher will be obtaining the consent of parent(s)/caregiver(s).

☐ *Yes* / ☐ *No*

(Note that parental/caregiver consent for school-based research may be required by the school even when children are competent. Ensure Information Sheets and Consent Forms are in a style and language appropriate for the age group.)

55. **Will participants include persons whose capacity to give informed consent may be compromised (this includes children)?**

☐ *YES* / ☒ *No*

If yes, describe the consent process you will use.

56. **Will the participants be proficient in the language the research is being conducted in? (e.g. English. It is important the participants are able to understand the consent forms)**

☒ *YES* / ☐ *No*

If no, all documentation for participants (Information Sheets/Consent Forms/Questionnaire etc.) must be translated into the participants' first-language.

(Attach copies of the translated Information Sheet/Consent Form etc. to the application form, as well as verification that the translations are correct and have been professionally checked.)

Section E: Conflict of Interest

57. **Please provide details of any potential conflicts of interest throughout the course of research.**
(Attach relevant documentation to the application form.)

Participants will be from the general public and unknown to me.

58. **Is the project to be funded or supported in any way, e.g. supply of products for testing?**

☐ *YES* / ☒ *No*

If yes:

    i)   State the source of funding or support:
    Unitec Academic or Faculty Unit
    Unitec Strategic Research Fund
    External Organisation (provide name and detail of funding/support)

    ii)   Does the source of the funding present any conflict of interest with regard to the research topic?

☐ *YES* / ☐ *No*

If yes, identify any potential conflict of interest due to the source of funding and explain how this will be managed.

59. **Does the researcher/s have a financial interest in the outcome of the project?**
☐ *Yes* / ☒ *No*

If yes, explain how the conflict of interest situation will be dealt with.

Section F: Māori Social and Cultural Responsiveness

Important note: Applicants should read <u>Guidelines for Researchers Regarding Māori Social and Cultural Responsiveness</u> to answer the questions in this section adequately.

60. **Is it apparent that Māori will be directly involved in or impacted by the project?**

☐ *YES* / ☒ *NO*

If no, answer the following three points below. If yes, answer Q60–61.

i)   What Māori involvement there may be:

Participants may be Māori but the project does not deliberately select any particular ethnicity.

ii)   How this will be managed:

I will consult as required if I do end up with Maori participants. I have extensive experience facilitating groups of people with multiple ethnicities in co-creating projects that improve wellbeing. I will be respecting and practicing Kaupapa Maori values, such as those shared in Q. 10:

Ata: Principle of Growing Respectful Relationships (key understandings that build healthy relationships and wellbeing); Kaupapa: Principle of Collective Philosophy (the collective vision and hopes in the community, and how knowledge and action contribute to that); Whanau: Principle of Extended Family Structure (acknowledges ALL relationships, their connections and responsibilities); Tino Rangatiratanga: Principle of Self-Determination (personal rights to determine your own culture, aspirations and destiny).

iii)   What impact on Māori this project may have:

The relevancy of the findings will be at the discretion of the reader. I do not see this research as impacting on Māori (positively or negatively) more than any other societal group.

61. **(To be answered when "yes" is indicated in Question 60). Identify the person/s and/or group/s with whom consultation/advice has taken place or is planned and describe the consultation process. Include information on the processes in place for the ongoing provision of cultural advice and support, and the ongoing involvement of the group/s consulted.**
    (Attach any evidence of consultation/planned consultation to the application form, e.g. a letter from an iwi authority.)

62. **(To be answered when "yes" is indicated in Question 60). Describe how information resulting from the project will be shared with the group/s consulted?**

Section G: Cultural Issues

63. **What ethnic or social group/s (other than Māori) does the project involve?**

A range of ethnicities may be involved in this research project, it is open to the general public.

64. Are there any aspects of the project that might raise specific cultural issues?

☒ *Yes* / ☐ *No*

If yes, explain and complete questions 63–66. Otherwise, proceed to Section H.

Childhood anxiety is an issue in all cultures and managed in culturally specific ways. The research process outlined in 60 (ii) enables a deep connection with people from a wide range of cultural backgrounds

65. Does the researcher speak the language of the target population?

☒ *Yes* / ☐ *No*

If no, specify how communication with participants will be managed.

The participants will need to speak good English.

66. Identify the group/s with whom consultation has taken place or is planned.
(Where consultation has already taken place, attach a copy of the supporting documentation to this form.)

67. Describe any ongoing involvement of the group/s consulted in the project.

68. Describe how information resulting from the project will be shared with the group/s consulted.

Section H: Sharing Research Findings

69. Describe how information resulting from the project will be shared with participants and disseminated in other forums, e.g. peer review, publications, conferences.
(Note that receipt of a summary is one of the participant rights.)

The research findings will be shared as a dissertation report to the Unitec Social Practice department. It will be available to the public through the Unitec library's institutional thesis repository. Participants will receive an electronic copy of the dissertation. I will be seeking to share the findings of this research in a peer-reviewed journal article and/or conference and/or in community mental health networks.

70. **Does the project involve the collection of tissues, blood, other body fluids or physiological tests?**

☐ *YES /* ☒ *NO*

If yes, complete Section **I,** otherwise proceed to Section **J.**

If yes, are the procedures to be used governed by Standard Operating Procedure(s)? If so, please name the SOP(s). If not, identify the procedure(s) and describe how you will minimise the risks associated with the procedure(s)?

71. **Describe the material to be taken and the method used to obtain it. Include information about the training of those taking the samples and the safety of all persons involved. If blood is taken, specify the volume and number of collections.**

72. **Will the material be stored?**

☐ *YES /* ☐ *NO*

If yes, describe how, where and for how long.

73. **Describe how the material will be disposed of (either after the research is completed or at the end of the storage period).**

(Note that the wishes of relevant cultural groups must be taken into account.)

74. **Will material collected for another purpose (e.g. diagnostic use) be used?**

☐ *YES /* ☐ *NO*

If yes, did the donors give permission for use of their samples in this project? (Attach evidence of this to the application form.

If no, describe how consent will be obtained. Where the samples have been anonymised and consent cannot be obtained, provide justification for the use of these samples.

75. **Will any samples be imported into New Zealand?**

☐ *YES /* ☐ *NO*

If yes, provide evidence of permission of the donors for their material to be used in this research.

76. **Will any samples go out of New Zealand?**

☐ *YES /* ☐ *NO*

If yes, state where. (Note this information must be included in the Information Sheet)

77. **Describe any physiological tests/procedures that will be used.**

78. **Will participants be given a health-screening test prior to participation?**

☐ *YES /* ☐ *NO*

(If yes, attach a copy of the health checklist)

Section J: DECLARATION (Complete appropriate box)

ACADEMIC STAFF RESEARCH
Academic Staff Applicant
I have read Unitec's Research Ethics Policy and Research Ethics Guidelines. I understand my obligations and the rights of the participants. I agree to undertake the research as set out in Unitec's Research Ethics Policy and Research Ethics Guidelines. My Head of School knows that I am undertaking this research. The information contained in this application is to the very best of my knowledge accurate and not misleading. It has been peer reviewed before submission.

Staff Applicant's Signature   Date:

Print Name

STUDENT RESEARCH
Student Applicant
I have read Unitec's Research Ethics Policy and Research Ethics Guidelines and discussed the ethical analysis with my Supervisor. I understand my obligations and the rights of the participants. I agree to undertake the research as set out in Unitec's Research Ethics Policy and Research Ethics Guidelines.
The information contained in this application is to the very best of my knowledge accurate and not misleading.

Student Applicant's Signature   Date: 8 May 2020

Print Name: Kristi Shaw

SUPERVISOR
I have assisted the student in the ethical analysis of this project. As supervisor of this research, I will ensure that the research is carried out according to Unitec's Research Ethics Policy and Research Ethics Guidelines.

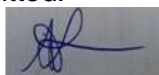Supervisor's Signature   Date: 26/05/2020

Print Name Geoff Bridgman

HEAD OF School
I declare that to the best of my knowledge, this application complies with Unitec's Research Ethics Policy and Research Ethics Guidelines and that I have approved its content and agreed that it can be submitted.

Head of School Signature   Date: 26/05/2020

Print Name Aulola Lino

Appendix B: Follow up email to prospective participants

Hi XXX,

It was a pleasure talking with you this afternoon. Thank you for making the connection and sharing a bit about your situation.
From what you have shared, it sure sounds like you are in a great position to participate in the research.

We talked about you meeting the 3 basic criteria, that you are a parent:
1.   Of an intermediate or high school student who has experienced an anxiety disorder for a year or more. The child is/has been demonstrating avoidance behaviour such as refusing to go outside or to school, and/or experiences panic attacks
2.   Who has experienced both distress and the navigational difficulty of sourcing treatment and support for their child with an anxiety disorder (The parent and child are not in crisis at this time)
3.   Who live in a North Shore Auckland suburb.

From here, there are a few more things to read and do, to a) see if it's something you want to participate in, and b) help me select participants for the focus group.
I have attached the invitation letter and information letter. Please take your time to read to ensure this is something you want to participate in. If you have any questions, just give me a shout and I will reply as soon as I can.

If you decide you would like to participate, will you please answer these questions below and email them back to me? Thank you.

1.   Basic Demographics questions:
a.   Parent Ethnicity:
b.   Parent Age:
c.   Parent Gender:
d.   Parent Occupation:
e.   Married/single:
f.   Children in full or shared care:

2.   What do you hope to get out of participating in this focus group research?

3.   What is your motivational level in being part of any collective action that comes out of the focus group sessions?

I look forward to hearing from you. I will give you a call on the weekend, unless I hear from you beforehand.
Thanks so much for your interest, your time, and your consideration.

If you decide you don't want to participate, would you please let me know as well?

Talk again soon and all the best,

Kristi Shaw

An invitation for you to be part of a unique research project…

Creating appreciation and community support for parents caring for a child with an anxiety disorder.

Would you like to join 4 to 6 local parents on the North Shore Auckland who will have the opportunity to experience and participate in an 'appreciative inquiry' process? This focus group process provides a unique opportunity to explore how our child's anxiety disorder has shown up in our lives, how we as parents are navigating to care for our child and ourselves, and how together we may discover something we all wish for, and can work together to create, to support ourselves and our families in our local community.

My name is Kristi Shaw, and I am currently enrolled in the Master of Applied Practice programme in the Social Practice group (School of Health and Social Practice) at Unitec New Zealand. Your participation in this strengths-based research will do at least three things: it will enable me to complete a dissertation that forms a substantial part of this degree; it will fill some important gaps in current research – which is describing parents' experience caring for a child with an anxiety disorder; how to use that experience to discover possibilities for creating collective action to address the community component of anxiety disorder; and to build something together for our local community that really makes a difference.

There will be four phases of the appreciative inquiry research, where together, you and other parents discover more about your coping and supports, identify your strengths and hopes, innovate ideas for change you want to see, and choose one of those ideas to develop and action together. The first phase is a paired interview done online using the Zoom app. This will be followed by three group sessions, of which participants will decide which is most suitable for them: continue using Zoom or start doing face to face.

The sessions will be digitally recorded, transcribed by me, and include your feedback for data analysis. Please view the attached participant information sheet for further details of the project. Your participation in the research will be confidential; you will not be identified in the dissertation, unless you wish to. You are free to ask me not to use any of the information you have given, and you can, if you wish, ask to see the dissertation before it is submitted for examination.

Participants are free to withdraw from the research at any time and may withdraw all of their data from the study at any point up until 5pm 7 days after receiving the transcript for the final focus group. After this point it may not be possible to remove or change data relating to a particular participant due to commencement of the thematic analysis process.

I hope this invitation has piqued your interest and made you a little excited to be part of it. If you would like to participate, please contact me through email kristi@totallyconnected.co.nz or by phone 021 300 328.

If you have any queries about this research, you may contact my supervisor at Unitec New Zealand. Geoff Bridgman email: gbridgman@unitec.ac.nz or by phone (09) 815-4321 ext. 7464

UREC REGISTRATION NUMBER: 2020-1021. This study has been approved by the UNITEC Research Ethics Committee from 2/7/20 to 2/7/21. If you have any complaints or reservations about the ethical conduct of this research, you may contact the Committee through the UREC Secretary (ph: 09 815-4321 ext 8551). Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

Creating appreciation and community support for parents caring for a child with an anxiety disorder

Information Sheet for Participants

It can be very challenging parenting a child with an anxiety disorder. Parents will be called upon to use all of their wits, love, humour, and strength; and very often they will discover skills and awareness they didn't even know they had, or they had to learn. Through an appreciative inquiry process with parents, this project aims to:

1. Describe parents' lived experience of caring for a child with an anxiety disorder
2. To use parent experience to set the framework for discovering possibilities for creating collective action to address the community component of anxiety disorder.

Anxiety disorders are prevalent and on the rise, with 1 in 4 New Zealanders experiencing anxiety in their lifetime. The literature suggests that: anxiety is a collective problem, with individual symptoms; support for parents and the child with anxiety is needed and reciprocal; we have human needs that require re-connection for individual and collective health; and coming together collectively to meaningfully create and contribute to solutions improves our well-being. This research will will be using a creative strengths-based recovery model focusing on supporting wellness, strength and resilience collaboratively in a local community.

The research will be framed around these questions:

1. What are the stories of parents' lived experience caring for a child with an anxiety disorder; especially in relation to coping, stabilizing factors, hopes for the future, and taking action?

2. What are the ideas for change that emerge from appreciative inquiry discussions and connection?

3. What kinds of actions can parents see themselves taking individually and/or collectively in the immediate future?

Participants need to be the parent:

- Of an intermediate or high school student who has experienced an anxiety disorder for a year or more. The child is/has been showing avoidance behaviour, such as refusing to go outside or to school, and/or experiences panic attacks.

- Who has experienced both distress and the navigation of sourcing treatment and support for their child. (The parent and child are not in crisis at this time)

- Who live in a North Shore Auckland suburb, preferably in the East Coast Bays area

This criteria has been chosen to ensure that the participants will have a length and breadth of experience navigating support for their child and to ensure parents are as local as possible to create opportunity for community action and support.

Possible benefits of participating:

Parents may benefit from sharing their stories with others in the focus group who are in similar situations: parents may become more knowledgeable, aware, strengthened, supported, and feel less alone.

With an appreciative inquiry approach, parents may feel more empowered with an opportunity to help themselves, their child and family, and the community, by being part of a team that creates something together to address the issue locally.

Should parents decide to continue to action an initiative together, or on their own, parents may carry the feeling of teamwork, inspiration and possibility.

After doing the action research, parents may feel a sense of satisfaction that they were part of a group that contributed to research intended to make a difference to help others.

On the community side of things, the possible benefits may be that the findings or actions that result from this research positively influence families in the community, community organisations, and/or schools.

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TE WHARE WĀNANGA O WAIRAKA

Information Sheet for Participants - page 2

The Plan:

The researcher will facilitate a small focus group of four to six parents that meet four times, from **July to Sept 2020.** Reflection and a short creative activity will follow the first two sessions, and the group will brainstorm something that is meaningful and helpful to them that they can action, or start to action, in the third and fourth sessions. Approximate time commitment is 7 to 9 hours.

Session Timing	
Paired sessions: Discovery - Our Coping, Our Stabilisers	30 to 45 min via Zoom
Reflection/Creative Activity/Group Reflection	30 to 45 min via Individual time
Focus Group 1: Dream - Our Strengths, Our Hopes	1.5 to 2 hrs via Zoom or Face 2 Face
Reflection/Creative Activity/Group Reflection	30 to 45 min via Individual time
Focus Group 2: Design - Ideas for Change	1.5 to 2 hrs via Zoom or Face 2 Face
Reflection/ Group tasks	45 min to 1hr via Individual time
Focus Group 3: Destiny - Preferred Future Through Action	1 hr Zoom or Face 2 Face

At any point after the paired sessions via Zoom, participants will decide as a group if they want to continue on Zoom or meet face to face.

The sessions will be recorded using the Zoom app and a recording device and then transcribed by the researcher. The collected data will be analysed by the researcher and her supervisor, using qualitative methods, for common themes regarding creating appreciation and community support for families caring for a child with an anxiety disorder. It will be written up as a research dissertation as part of a Master of Applied Practice course (School of Health & Social Practice) course. The dissertation will become part of the Unitec Commons held by the Unitec library.

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What to expect and consider first:

- You will be participating with other parents in 4 online/offline group sessions lasting from 30 minutes to two hours at a time, in the privacy of your home using Zoom, or in a private room at a local community house.

- The sessions will be:
    - scheduled to suit everyone in the group.
    - semi-structured, giving each session a focus and starting point while allowing each participant time and space to share their stories, ask questions, and express their thoughts and ideas.
    - recorded using the Zoom app and a recording device. The researcher will take notes to help keep track of the information and share the brainstorms with everyone.

- This project will be discussing, in an appreciative way, the experiences parents have had caring for a child with an anxiety disorder, and how those experiences have created meaning for them. Although this research is strengths-based, there may be something in the stories that you or someone else shares that may trigger something in you where you feel troubled emotions or some vulnerability. There will be four avenues of support should this happen. The participant will receive support:
    - organically through participation in the group, and/or
    - by talking with the researcher privately, and/or
    - by talking with the research supervisor privately, and/or
    - professionally through recommended agencies in the community

- Participants may want to consider that this may be a possibility for them and are asked to carefully consider the nature of this project before deciding to participate.

Some Sample Questions:

- In thinking about you and your child who is experiencing the anxiety disorder, can you describe a situation where you were at your best?
- If you were a bird in the sky looking on your situation, what would that bird notice about the support around you?
- When you think of one of your valued strengths, what success story comes to mind of you using that strength in relation to the anxiety at home? Work? Community?

The creative activity will be using clay or coloured pencils/pens to portray an idea; it is not meant to be a work of art, just an idea generator.

Are you keen to participate in this project?

Yes - great! I would love to hear from you and answer any questions you may have. I would also like to find out a bit about you too - like why you want to be involved and your time commitment. If there are more than six people applying, I will choose the six people based on group diversity and location of participants.

Please contact Researcher: Kristi Shaw
E: kristi@totallyconnected.co.nz or M: 021 300 328

Also, at any time, if you have any concerns about the research project you can contact my supervisor:
Dr Geoff Bridgman
E: gbridgman@unitec.ac.nz or P: (09) 815-4321 ext. 7464

Preparation Prior to Paired Interview or Focus Group Work:

An advertisement and invitation will be sent to my key contacts. Interested parents will make contact with me by phone or email to discuss the opportunity and I will share the information letter. If they are interested, they will:
1. Confirm they fit the three criteria for selection
2. Complete basic demographic questions: culture, age, gender, occupation, married/single, children in full or shared care
3. Share what do they hope to get out of participating in this focus group research?
4. Share what is their interest level in being part of any collective action that comes out of the focus group meetings?
5. Determine paired interview participants. I will be trying to connect people who I think will relate well to each other in the first instance on the basis of my initial interview.

Information given to participants, and received before focus paired group sessions start:
o *Participant Information Sheet*: confirm they have read and understood (in writing), including sensitive nature of the research and possibility of triggering psychological distress for some people. Each of us have copies.
o *Confidentiality and Consent form*: signed, each of us have copies. I will keep one and one will be kept with Supervisor at Unitec. Agree on pseudonyms to use in the transcript and report.
o Link to Zoom privacy and safety guidelines sent
o Link sent to paired interview session participants.
o Outline of what to expect with paired interview session: the session will begin with questions exploring stories of our coping and what's acting as our stabilisers while caring for a child with an anxiety disorder. Participants will be invited to listen, ask questions, and feedback appreciation to their partner. Have pen and paper ready to take notes.
o Examples of questions they will ask each other and they can prepare to share their stories: In thinking about you and your child who is experiencing the anxiety disorder, can you describe a situation where you were at your best?" and "Can you share a strategy that you or your family started that worked well and how it works?" and "If you were a bird in the sky looking on your situation, what would that bird notice about the support around you?"

Paired Interview: 2 to 3 pairs x 30 to 45min each
AI 'Discovery' + Macy's 'Honouring Our Pain for the World'
Topics: Our Coping + Our Stabilisers
Welcome and Introductions:
• Introduce self, thank them for agreeing to participate in the focus group research
• Ask them to introduce themselves to each other by sharing what one of their favourite foods are, or something they enjoy doing
• Set the scene for our online focus group sessions and how to manage interruptions and privacy
    o Review Zoom guidelines – send participants the link before the sessions start
        ▪ https://www.theverge.com/2020/4/17/21196104/how-to-keep-your-zoom-meetings-safe-security-privacy
    o All forms signed and received
    o Outline the session and general content: The session will begin with an open-ended question which you will then be invited to answer and reflect on for each

other. At any time you are able to pause or ask for comments to be deleted from the session.
  - o Ask if the participants have any questions. Check it is now OK to begin the session.
- Speak the date, the purpose of the session and who is present - my name, and the participants' pseudonym they would like to use.)
- *Learn and practice Appreciative Inquiry*: I ask each of them: "What's the best thing that's happened to you today?" After they each speak for one minute, I will ask them to write down what they noticed and admired about the storyteller: skills, abilities, values, resources. I will ask them to share what they noticed with each other.
- *Honouring Our Pain in the World*: I will ask each participant to actively and genuinely listen to the other's stories, looking for those times of pride and competence, and encourage them to ask more questions and note down what they notice, admire, or are inspired by. After each storytelling, they will share their noticing with each other.
  - o *Questions they will ask each other*: "In thinking about you and your child who is experiencing the anxiety disorder, can you describe a situation where you were at your best?" and "Can you share a strategy that you or your family started that worked well and how it works?" and "If you were a bird in the sky looking on your situation, what would that bird notice about the support around you?"
- After the session, I will ask if they have anything they would like to add.
- Each participant will be asked:
  - o to take a picture of their notes to give to the other participant and me.
  - o Within a day or two, each participant will reflect on the paired interview by writing what they noticed during and after the interview.
  - o Creative Activity: After their reflections, each participant will create a symbol out of clay/or sketch a picture that will act as a token about what strengths stand out for them about themselves. They will give the token a sentence, or a word or two, then take a picture with the token and the word(s), and send to me with their written reflections within a week of the interview.
- Close by reminding the participants of withdrawal conditions (participants are able to withdraw anytime up to 5pm 7 days after this session), how they will get a copy of the interview transcript and how they might respond. Ask if they want reminders of any of these actions.
- Thank the participants and remind them how to contact me by email
- Give the participants the 'Post-Session Handout' (Appendix F) with information regarding the way in which they can access support and discuss any concerns that they may have

After the Paired Group session:
- Make immediate notes in my reflection journal about my impressions, feelings, observations and reflections.
- Make a note of things to remember for the next session.
- Review the recording within a week of the session, taking note of concepts or topics that do not appear in the literature review but have shown up in the session, as well as any improvements to be made for the next session
- Follow up on any participant who indicated they needed post-interview support.

Prior to first Focus Group Session:

- A few days before the first focus group session with all participants, I will share all the participant reflections with the group and ask them to read and reflect on them.
- Prep sheet about what to expect in the first focus group session:

- o Group culture: share what has worked the best for them in group situations so there is space for everyone to share, be listened to, and they feel safe and respected.
- o Share their reflections on Paired sessions (Coping and Stabilisers) – what stands out about the others, themselves, and their key relationships
- o Two questions to prepare for: When you think of one of your valued strengths, what success story comes to mind of you using that strength in relation to the anxiety at home?" or in relation to something you are very proud of? And, what would you like to see happen that will help you, your family, and your community?"
- o Zoom meeting link sent to all participants

First Focus Group (approximately two to three weeks after the last paired group session): 1.5 - 2hrs
AI 'Dream' + Macy's 'Seeing with New Eyes'
Topic: Our Strengths and Hopes
Welcome and Connection Activity: 'Gratitude'

- Overview of session, any changes or additions to be made?
- Group Culture: ask everyone to take turns sharing what has worked the best for them in group situations so there is space for everyone to share, be listened to, and they feel safe and respected. I will write it on the whiteboard and once agreed upon, send everyone a copy.
- Share reflections: participants reflect on the group reflections from the paired interviews – share what stands out about the others, themselves, and their key relationships.
- *Seeing with New Eyes*: I will ask participants: "When you think of one of your valued strengths, what success story comes to mind of you using that strength in relation to the anxiety at home?" After each participant shares their story, the group will ask questions and feedback their appreciation to them, keeping notes.
- Thank everyone for their sharing, listening and appreciation. Invite them to add anything.
- Do we need a water break for 5 min?
- *Positive Core*: I will ask the participants to brainstorm the group's core strengths/values and write what they say on a whiteboard. The group will come up with a 'positive core' strength and value for their group. I will take a picture and share with the group after the session.
- *Hopes & Dreams*: "If this 'positive core' had a magic wand, what would you like to see happen that will help you, your family, and/or your community?" Write down the ideas on the whiteboard, take a picture and share with the group in preparation for the next focus group meeting.
- After the session, I will ask if they have anything they would like to add before we finish.
- Each participant will be asked:
  - o to take a picture of their appreciative feedback given during the session to give to me to share with the group.
  - o Creative Activity: After reflection, within a day or two, each participant will create one symbol out of clay/or sketch a picture that will act as a token about the group's 'positive core'. They will give the token a sentence, or a word or two, then take a picture with the token and the word.
  - a. Next each participant will reflect on how their personal strengths are positioned in relation with the 'positive core'. They will demonstrate that positioning with their initial tokens and any new words, and take a picture.
  - b. They will send me the picture with their written reflections within a week of the first group session.

After the First Focus Group session:
- Make immediate notes in my reflection journal about my impressions, feelings, observations and reflections.
- Make a note of things to remember for the next session.
- Review the recording within a week of the session, taking note of concepts or topics that do not appear in the literature review but have shown up in the session, as well as any improvements to be made for the next session
- Follow up on any participant who indicated they needed post-interview support.

Prior to the Second Focus Group Session:

- A few days before the second focus group session with all participants, I will share all the participant reflections and pictures with the group and ask them to read and reflect on them.
- Prep sheet about what to expect in the second focus group session:
  - Group culture: any changes or suggestions
  - Share their reflections on Group session (Strengths and Hopes) – any insights about themselves, each other, key relationships? Any changes to our group's 'positive core'?
  - Brainstorm ideas for change – what are our hopes and dreams - what energises us the most?
  - Zoom meeting link sent to all participants

Second Focus Group (about two weeks after the first focus group): 1.5 – 2hrs
AI 'Design' + Macy's 'Going Forth'
Topic: The Ideas for Change
Welcome and Connection Activity: 'Gratitude'
- Overview of this session, any changes or suggestions to be made?
- Group Culture: check-in – any feedback on improvements to make?
- Share reflections: participants reflect on the group reflections from The Seeing with New Eyes. Any insights to themselves, each other, key relationships? Any changes/additions to our group's 'positive core'?
- Going Forth: Brainstorm and Mindmap on the whiteboard the hopes and dreams ideas for change and vote upon what energises participants the most. If there are multiple ideas for inspiring change, the group will decide how to manage that. I will take a picture to send to the group.
  - For each initiative, participants will create an aspiration statement, and map out an action plan.
  - The group agrees on what they want to do and see happen by our next meeting, and when that next meeting will be.
  - They will organise a method of communication with each other and perhaps designate a person to help organise or lead the initiative. I will take a picture of the plans to send to the group
- After the session, I will ask if they have anything they would like to add before we finish.
- Each participant will be asked:
  - to action what they need to do for the initiative they have agreed on.
  - to be in communication with each other for updates and support

After the Second Focus Group session:
- I will send participants any notes about changes to the group culture or the positive core
- I will send a picture of the brainstorm and action plan to all participants

- I will share the communication strategy with everyone
- Make immediate notes in my reflection journal about my impressions, feelings, observations and reflections.
- Make a note of things to remember for the next session.
- Review the recording within a week of the session, taking note of concepts or topics that do not appear in the literature review but have shown up in the session, as well as any improvements to be made for the next session
- Follow up on any participant who indicated they needed post-interview support.

Prior to the Third Focus Group Session:

- A week or two before the third focus group session with all participants, I will check in with them to see how they are doing. Do they have any questions or need support?
- Prep sheet about what to expect in the third focus group session:
  - We will review the initiative
  - How does everyone want to progress from here?
  - What have we appreciated being part of this research project?

Third Focus Group (about one month after the second focus group): 1hr
AI 'Destiny' + Macy's 'Going Forth'
Topic: Preferred Future Through Action
Welcome and Connection Activity: 'Gratitude'
- Overview of this session, any changes or suggestions to be made?
- Group Initiative: participants give updates and reflect on their action plan
  - What's working well, why is it working well, and how do we do more of it?
  - Additions, changes, suggestions?
- How does the group want to be from here? Keep 'going forth', move in another direction?
  - Participants share feedback on their hopes and plans with, or outside of, the group
- What have we appreciated the most about being part of this research project?
- Looking back on the research project as a whole: what worked well, and why did it work well?

After the Third Focus Group session:
- I will send participants any notes about the group initiatives
- I will send a thank you letter to the group, giving them an indication of the progress of the transcripts and expectations of the research progression.
- Make immediate notes in my reflection journal about my impressions, feelings, observations and reflections.
- Review the recording within a week of the session, taking note of concepts or topics that do not appear in the literature review but have shown up in the session.
- Follow up on any participant who indicated they needed post-interview support.

Appendix G: Confidentiality Agreement for Transcribers

Research Title: Creating appreciation and community support for parents caring for a child with an anxiety disorder.

Researcher Name: Kristi Shaw

Address: 99 Deep Creek Road, Waiake, Auckland 0630

Phone number: 021 300 328

Email: kristi@totallyconnected.co.nz

I _____ (full name - please print)
Agree to treat in absolute confidence all information that I become aware of in the course of transcribing the interviews or other material connected with the above research topic. I agree to respect the privacy of the individuals mentioned in the interviews that I am transcribing. I will not pass on in any form information regarding those interviews to any person or institution. On completion of transcription I will not retain or copy any information involving the above project.

I am aware that I can be held legally liable for any breach of this confidentiality agreement, and for any harm incurred by individuals if we disclose identifiable information contained in the audiotapes and/or files to which we will have access.

Signature: ………………………………………………….   Date: …………………………………………

UREC REGISTRATION NUMBER: 2020-1021
This study has been approved by the UNITEC Research Ethics Committee from 2/7/20 to 2/7/21. If you have any complaints or reservations about the ethical conduct of this research, you may contact the Committee through the UREC Secretary (ph: 09 815-4321 ext 8551). Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

Support for Participants

If you experience any distress or upset after the focus group sessions, or need support for your family, please use the below resources. Please feel free to contact the researcher or her primary supervisor directly should you require any further information or need support.

Kristi Shaw – kristi@totallyconnected.co.nz or 021 300 328

My Supervisor is: Geoff Bridgman email: gbridgman@unitec.ac.nz or phone (09) 815-4321 ext. 7464

COMMUNITY RESOURCES FOR FAMILIES AND WHANAU

If you or someone you know is at risk of harm: dial 111 or visit your nearest hospital emergency department.

Service	Helpline	Info	Website
Anxiety NZ	0800 ANXIETY 0800 269 4389	24/7 Counselling, peer support, workshops	**www.anxiety.org.nz**
Need to Talk	Free call or text 1737	24/7 for support from a trained counsellor.	**www.1737.org.nz**
Lifeline/Kidsline Suicide Crisis Helpline	Lifeline: 0800 543 354 Kidsline: 0800 54 37 54 Suicide: 0508 828 865 Free text 4357 (HELP)	24/7 for support from a trained counsellor. *Specialist parent counselling training*	**www.lifeline.org.nz**
Youthline	0800 376 633 Free text: 234 Webchat	8am to midnight Counselling, mentoring, programmes, resources for parents	**www.youthline.co.nz**
What's Up (5 – 18 yrs)	0800 942 8787	Phone counselling: Mon – Fri: 1 to 10pm Online chats: Daily: 7pm – 10pm	**www.whatsup.co.nz**
Outline (LGBTIQ+)	0800 688 5463	6-9pm every night	**www.outline.org.nz**
Supporting Families	0800 732 825	8.30 – 5 (Mon - Fri) Support, information, education, advocacy	**www.supportingfamilies.org.nz**
Home & Family Counselling	N Shore: 09 419 9853 Orewa: 09 419 9853	Donation based counselling service	www.homeandfamily.org.nz
DHB Mental Health Crisis Team	0800 800 717	24/7 for emergencies only (mental health and addiction)	**www.health.govt.nz**

Appendix I: Participant Consent & Confidentiality Agreement

Participant Consent & Confidentiality Agreement

Title: Creating appreciation and community support for parents caring for a child with an anxiety disorder

I have had the research project explained to me and I have read and understand the information sheet given to me, therefore *I,*

_____ *(full name - please print)*

1. *agree to treat in absolute confidence, all information that I become aware of during the course of participation in the above research project. I agree to respect the privacy of those involved and will not divulge in any form, information with regard to any participating person or institution and agree to not retain or copy any information involving the above project.*

2. *I am aware that I can be held legally liable for any breach of this confidentiality agreement and for any harm incurred by individuals or organisations involved, should information be disclosed.*

3. *I understand that I am free to withdraw from the research at any time and may withdraw all of my data from the study at any point up until 5pm 7 days after receiving the transcript for the final focus group. After this point it may not be possible to remove or change data relating to a particular participant due to commencement of the thematic analysis process.*

4. *I understand that everything I say is confidential and none of the information I give will identify me and that the only persons who will know what I have said will be the researcher, their supervisor, and the other focus group participants (refer to 1.). I also understand that all the information that I give will be stored securely in a locked filing cabinet for a period 5 years.*

5. *I understand that my discussion with the researcher will be recorded using a digital audio recording device and transcribed.*

6. *I understand that I can see the transcription of the focus group sessions and the finished research document.*

7. *I have had time to consider everything and I give my consent to be a part of this project.*

Participant Signature: …………………………………………………………….. Date: …………………………………

Participant Mobile: ……………………………………… Email:………………………………………………………….

Project Researcher: ……………………………………………………………………… Date: …………………………

Signature: ……………………………………………………………………………….Date: …………………………

UREC REGISTRATION NUMBER: 2020-1021

This study has been approved by the UNITEC Research Ethics Committee from 2/7/20 to 2/7/21. If you have any complaints or reservations about the ethical conduct of this research, you may contact the Committee through the UREC Secretary (ph: 09 815-4321 ext 8551). Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

Creating Appreciation and Community Support for Parents Caring for a Child with an Anxiety Disorder
A few questions before we begin…

Thank you for taking the time to complete these questions before we start our Appreciative Inquiry together. You will have an opportunity to answer these questions after the appreciative inquiry too. The idea behind these questions is to discover any difference that being part of this action research may have made to you. *It should only take a few minutes…*

Would you please rate the following questions by placing an 'X' where appropriate?

As a parent caring for a child with an anxiety disorder, to what extent…	Not at All	A Little	Moderate	A Lot	Huge Amount
Are you experiencing **distress** currently?					
Are you experiencing **support** currently?					
Do you experience **isolation?**					
Do you experience **social stigma around mental illness**?					
Do you **worry** about what the **future** may hold for your **child**?					
Do you **worry** about what the **future** may hold for **yourself/your family?**					
Are you open to **relatives** about the anxiety in your home?					
Are you open to **friends** about the anxiety in your home?					
Are you open in your **workplace/community** about the anxiety in your home?					
Are you feeling confident in your abilities to **personally** help & support your child?					
Are you feeling confident in your abilities to **source** help & support for your child?					
Are you feeling confident that your child is getting all the help and support they need to **manage** the anxiety?					
Are you feeling confident in sharing and working together with other local parents experiencing similar situations?					

Any Comments:

Appendix: Information Sheet for Paired Interviews

Creating Appreciation and Community Support for Parents Caring for a Child with an Anxiety Disorder

Getting ready for our Paired Interviews this weekend… What you need to know and bring with you:

Schedule:

Date	Time	Participants
Saturday 15 August	4 to 5pm	Grace + Kinsley
Sunday 16 August	7 to 8pm	Sienna + April + Kinsley's husband

Being Prepared on the tech side

Zoom Link: I will send you the link before the meeting. I am using Unitec's Zoom account that will record and transcribe our conversations. Your name will show on the transcriptions, and I will use pseudonyms for the final report to maintain your confidentiality. At any time during the interview, you are able to pause or ask for comments to be deleted from the session.

Zooming Tips: Some suggestions from the link below to help reduce distractions, be engaged, and **maintain confidentiality.**

1. Important - Find a private space and use headphones
2. Ensure you have a simple background behind you
    a. set up a virtual background,
    b. or clean & non-reflective surfaces behind you
3. Set camera to have a good view of your face (also well-lit and best at eye level)
4. Before the call,
    a. Test your Zoom app, make sure you have good Wifi, and that you are plugged in/battery is charged
    b. Come early to the call so you are comfortable and ready when it starts
5. During the Call,
    a. Mute when you aren't speaking
    b. Create visual cues to help find the right times to speak, or use the chat
    c. Speak clearly, in a normal volume
6. Stay Focused.
    a. Be attentive and engaged, without distractions of phone or emails
    b. Look into the camera when you speak
    c. Keep your face visible on the screen

https://www.theverge.com/2020/3/19/21185472/video-confere-call-tips-zoom-skype-hangouts-facetime-remote-work

<u>Being Prepared on the Paired Interview side</u> (Please bring some paper, a pen & a glass of water)

Theme: Discovery: Searching for the Best of What is (Our Coping + Our Stabilisers)

> **A brief intro to Appreciative Inquiry:**
> **Appreciative Inquiry is a cooperative search for strengths, passions, and life-giving forces that are found within every system – those factors that hold the potential for inspired, positive change. This strategy for purposeful change identifies the best of 'what is' to pursue dreams and possibilities of 'what could be'. It seeks to create an alignment of strengths that make weaknesses irrelevant and liberates our collective capacities.**

In the beginning: I will get us started and settled in with a welcome and introduction.
After the introduction, you will be invited to ask questions of each other and share your stories. It's important we are sincere with our curiosity and actively listening to each other. We can be encouraging with phrases like 'that's interesting' or 'tell me more about…', and we can ask for more information (ie. who, what, where, why). While listening, we will be noticing aspects of each other's stories and taking some notes to share with them at the end. I will help you for the first question, to give you an idea of what we are looking for in the interviews, and then you will be talking between you using the questions below. If you need some help at any point, you are welcome to talk with each other about it, or ask me.
"Trust that meaningful conversations can change your world" ~Meg Wheatly

Our Key Questions: Please have a think about the questions and the stories that you want to share before the interview.

1. Recall a story about an exceptional empowering experience in your life. What made it remarkable?
2. "In thinking about you and your child who is experiencing the anxiety disorder, can you describe a situation where you were at your best?" (before the anxiety came, and during the anxiety happening) Describe one of your best coping strategies parenting that held you through the difficult times - what made it work so well?
3. "If you were a bird in the sky looking on your situation, what would that bird notice about the support around you?" (at home, in the community, at work, on holiday) Describe when you have been free of the stigma of mental illness… was there something that brought on the feeling of freedom?

Supporting Questions (if there is time):

4. Tell about a time when you felt your family was at its best – when energy and enthusiasm were particularly high. What was happening? How did this make everyone feel?
5. "Can you share a strategy that you learned that worked well to reduce the anxiety? How did this strategy come about?

After the Paired Interviews:
You will be asked:

1. to take a picture of your notes to give to your partner and me after the session.
2. After the session, or within a day or two, using your own self-reflection and partner's notes, write what stood out for you about your strengths, values, wishes, supports, and any new learning from the interview.
3. **Creative Activity:** After your reflection, sketch/paint/colour something that will act as a token/symbol about what strengths stand out for you about yourself. Please give your token/symbol a sentence, or a word or two, then take a picture with the word(s), and send to me with your written reflections by **Sunday 23 August**. (this is not an art activity, it is a tool for generating ideas only)

Thank you so much for agreeing to participate in our Appreciative Inquiry, I look forward to meeting and learning with you!

All the best,

Kristi Shaw

Appendix L: Information Sheet for First Focus Group

Creating Appreciation and Community Support for Parents Caring for a Child with an Anxiety Disorder

In preparation for our first group session (Sun 30 Aug, 7 to 9pm)

Participant reflections before Sunday:

I have attached each of our reflections (notes, key strengths, and symbols) from the paired interviews. **Would you please review them and look for 1 to 3 themes (main connecting ideas) that 'give life' to our stories?** (*Themes can be thought of as those parts that relate to our shared feelings of success, sense of purpose*)

Thank you, this is important to reflect on as we will be building on what we have discovered here to enter into the next phase of our appreciative inquiry.

Two questions to prepare for in our session: (We will have 2min each to share each answer)

1. What are 1 or 2 things you value deeply – specifically, what you value about yourself, your family, your work, and/or your community? Tell a story about when that value was present and the difference it made.

2. If a genie came out of a bottle and granted you three wishes, what would you wish for that will create a preferred future for you, your family, and/or your community?

Something to think about to share (choose one): (We will have 1-2min each to share)
Tell a story about a time when you were really excited to be a part of a group
Or,
Tell a story about a time when a new way of doing things helped your group to achieve something important.
Or,
Tell about a time when you felt your group was at its best – when energy and enthusiasm were particularly high

Our Group Session: please bring paper/pen/water to the session. We will be taking notes and sharing them with each other again.

Overview:

- **Welcome Activity**
- **Group Culture**: Share and Brainstorm
- **Share Reflections/Themes from Paired Interviews**
- **Discovery:** What are 1 or 2 things you value deeply – specifically, what you value about yourself, your family, your work, and/or your community? Tell a story about when that value was present and the difference it made.

- **Break/Chat? (5/15min)**
- **Positive Core:** Group Brainstorm – give it a sentence/word or two

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3. **Hopes & Dreams Brainstorm:** If a genie came out of a bottle and granted you three wishes, what would you wish for that will create a preferred future for you, your family, and/or your community?

At the end of the session, you will be asked:
- o to take a picture of your notes/feedback given during the session to give to me to share with the group.
- o Creative Activity: After reflection, within a day or two, please create one symbol (sketch a picture) that will act as a token about the group's 'positive core'.
- a. Next, please reflect on how your personal strengths are positioned in relation with the 'positive core'. Demonstrate that positioning with your initial tokens and any new words, and take a picture.
- b. Please send me the picture with your written reflections by **Sunday 6 Sept**

Thank you so much for energy and thoughtfulness for our Appreciative Inquiry - I am excited to discover what we will come up with in our brainstorming together!

See you soon,

Kristi Shaw

About Appreciative Inquiry:

Appreciative Inquiry is a cooperative search for strengths, passions, and life-giving forces that are found within every system – those factors that hold the potential for inspired, positive change. This strategy for purposeful change identifies the best of 'what is' to pursue dreams and possibilities of 'what could be'. It seeks to create an alignment of strengths that make weaknesses irrelevant and liberates our collective capacities.

Appendix M: Information Sheet for Second Focus Group

Information Sheet for Our 2ⁿᵈ Group Session

Hey team, here is an overview about what we are up to for tonight, and a summary of what we did last session:

Our Group Culture - where we are at our best:
1. Positive experience
2. Common worthwhile purpose to help each other
3. Listen to each other
4. Respect
5. No judgement
6. Confidentiality
7. Trust
8. Communication: Online – group chat is good, emails are good too

Positive Core:
Advocating for children and their parents/caregivers in a world that isn't set up for them: for their wellbeing and potential to be realised.
- Of note: I am just wondering about this part of the statement 'in a world that isn't set up for them', and if there is a way to flip it into a more life-giving way…? (Would love to hear your thoughts, I will share in the FB group)

Dream/3 Wishes:
Successful children: achieved their positive goals; self-worth; self-managing; happy and self-esteem
Parents: healthy independence, freedom, sense of achievement – living happy lives
ACHIEVEMENT, OVERCOMING ADVERSITY

Reflections Overview:

Part 1: symbol/token of our personal strengths, with 3 to 5 key words

Part 2: symbol/token of our collective strength/positive core as a group, with 3 to 5 key words

Part 2a: putting the two together, what are we noticing

Tonight's Topic: Design - Ideas for Change

Group Culture: check-in – any feedback or additions/changes to make?

Share reflections:
a. Any insights for yourself, and in relation to the group's 'positive core'?
b. Fine tune Positive Core: Any changes/additions to our group's 'positive core'?

Design: We will…
a. brainstorm/mindmap our hopes and dreams ideas for change and vote upon what energises us the most.
b. create an action plan.
c. agree on what we each want to do and see happen by our next meeting on 18ᵗʰ October
d. organise a method of communication with each other

Creating Appreciation and Community Support for Parents Caring for a Child with an Anxiety Disorder

In preparation for our 3rd Group Session (Wed 28 Oct, 7.30 to 9.30pm)
Please bring paper/pen/water to the session.

Overview of 3rd Group Session:

- **Welcome Activity**
- **Two Questions & Reflection**
- **Update on Initiative – Going Forth**
- **A few questions to finish the research component**

Two questions to prepare for our session: (We will have 3 min each to share each answer)

1. What are 1 or 2 things you most appreciate about your child as they have been going through the challenging experience of dealing with the anxiety? Tell a story about when you recognised this/these qualities in them.

2. From this appreciation of your child who is going through these challenges, what have you noticed as a learning for you? Describe how this learning may have made a difference in your life so far, or how you expect it to (personally, professionally, socially)

Our Initiative Action Summary (taken from Sept 13 notes): please come prepared to share what you have learned, actions you have taken, and where this may have led you…

Educating teachers: Teacher training
Aim/Purpose: Helping Them Help Our Children
Objectives:
1. **Knowledge**: increase teachers' awareness/skills of how to build relationships with anxious and neurodiverse children
2. **Behaviour**: teachers will act with more compassion and empathy to create better emotional connection with anxious/neurodiverse children
3. **Feeling**: teachers will experience more confidence in creating relationship with anxious/neurodiverse children, and gain a sense of personal/job satisfaction

Actions Discussed with the Aim of Scoping and Identifying receptivity by October meeting:
Mind over Manner – building understanding and relationships
Ideas to start: Talk to:
- Some teachers – their challenges, understanding, barriers they experience
- Our children – what they want, how work for them
- School Management (SENCO) – find an advocate
- Mind Over Manner – advocate/collaborate, professional development

Kristi to send Mind Over Manner link to team on Monday (done)
Kristi to send intro email to Susan from MOM including Sienna (done)
Kristi to send research blurb to team on Monday (done)

April to create a team intro email (incl blurb) for scoping school management/teachers by **Wed**

Grace will write out some key questions for school management and share with the team on **Tuesday**

Grace will create a Google Doc for team organisation

Sienna will set up Messenger Chat for team communication (done)

Sienna will follow up with Susan from Mind Over Manner

Sienna meeting with SENCO team on **Thursday**

Grace and **April** setting up meetings at their schools to happen **before the school holidays**

Creating Appreciation and Community Support for Parents Caring for a Child with an Anxiety Disorder

A few questions to finish the research…

Thank you for taking the time to complete these questions after we have accomplished the research component of our Appreciative Inquiry together.

Here is an opportunity to discover:

1. Rating Chart (below): any difference that being part of this action research may have made to you.
2. Open Questions (2nd page): your reflections on being part of this appreciative inquiry as a group and as an individual

Would you please rate the following questions by placing an 'X' where appropriate?

As a parent caring for a child with an anxiety disorder, to what extent…	Not at All	A Little	Moderate	A Lot	Huge Amount
Are you experiencing **distress** currently?					
Are you experiencing **support** currently?					
Are you experiencing **isolation?**					
Are you experiencing **social stigma around mental illness**?					
Are you **worrying** about what the **future** may hold for your **child**?					
Are you **worrying** about what the **future** may hold for **yourself/your family?**					
Are you open to **relatives** about the anxiety in your home?					
Are you open to **friends** about the anxiety in your home?					
Are you open in your **workplace/community** about the anxiety in your home?					
Are you feeling confident in your abilities to **personally** help & support your child?					
Are you feeling confident in your abilities to **source** help & support for your child?					
Are you feeling confident that your child is getting all the help and support they need to **manage** the anxiety?					
Are you feeling confident in sharing and working together with other local parents experiencing similar situations?					

Comments:

1. **What have you appreciated the most about being part of this research project?**
   a. What's it been like **for you** (the good and not so good):   How did it meet your expectations?   How has it changed anything for you?

    b.   How has it been **as a group** (the good and not so good): What hope do you hold for this group and this appreciative inquiry process?

2. **Reflections on structure:**
    a.   Do you prefer doing by Zoom OR face to face?

    b.   Would you prefer four group sessions spread out OR one-day workshop to get to action plan then monthly meet ups?

    c.   Would you prefer a different way of structuring the inquiry?

3. **If this appreciative inquiry was run again, what changes (other than structure) would you suggest?**

Appendix P: School Interview Notes

Email blurb

I am part of an Appreciative Inquiry group that has been created on the North Shore. It is part of a Master of Applied Practice research project working on the topic of: Creating Appreciation and Community Support for Parents Caring for a Child with an Anxiety Disorder. This project aims to:

1. Describe parents' lived experience of caring for a child with an anxiety disorder

2. To use parent experience to set the framework for discovering possibilities for creating collective action to address the community component of anxiety disorder

   This research will be using a creative strengths-based recovery model focusing on supporting wellness, strength and resilience collaboratively in a local community.

   As educators you have a big role in supporting wellness, strength and resilience in the community. Would you have 30 minutes to help me next week to talk about your experiences with anxiety in kids in the school environment?

Question ideas for meeting with schools

Thanks for meeting with me today**.** As I said I'm part of an Appreciative Inquiry group focused particularly on anxiety in kids and looking at possibilities for creating collective action to address the community part of anxiety disorders.

Obviously as educators you have a big role to play in supporting wellness, strength and resilience collaboratively in a local community.

So I'm really interested in your experiences and thoughts on what we could do as a community to help anxious kids. Obviously as you know I have a kid with anxiety (and ADHD) but it's more your general experiences and ideas particularly around anxiety that I'm interested in. But appreciate that we will probably end up talking about neuro diversity quite a bit!

Can you tell me about your experiences as an educator with anxiety in kids?

How do you see it/experience it in kids in your care?

How do you handle it/what do you do?

How have you learnt what to do? Where have you got ideas/training from if any?

Do you have personal experience with anxiety in kids?

What resources if any has the school/MOE provided to help? Any specific training around anxiety and/or neuro diversity in general?

What are the barriers you feel might prevent you from doing what you would ideally like to do?

What would you like to do differently? What resources or support would you need to do this?

Who else needs to be involved with creating better outcomes for kids with anxiety? Who else should I be talking to? How could this be achieved?

If you were the Principal what things would you put in place to support yourselves and kids who are anxious (neuro-diverse)?

Mention Mind Over Matter and show workshop brochure:
Have you heard of this group? Or been involved with anything similar? Is this sort of thing something the school would consider?

Interview with DP at Intermediate School

Can you tell me about your experiences as an educator with anxiety in kids.

There are always anxious kids in class - very prevalent, but there is very little training given at AUT or subsequently.

How do you see it/experience it in kids in your care?

Negative behaviours, avoidance of tasks esp academic, social anxiety, can be bossy and controlling, inability to regulate extreme emotions, separation anxiety - generally quite high school avoidance in general.

Kids who are neuro diverse are nearly always anxious but not necessarily the other way around. Can also then lead to depression.

How do you handle it/what do you do?

A range of strategies:

Home-school partnership key, listening to families as they know the kids best. So ensuring whatever strategies are in place at home are also used at school eg breathing exercises

Open, honest dialogue with parents - it is easier when you have your own experience/kids with anxiety, can have greater empathy. And you develop more intuition with that experience.

When anxiety becomes out of control then need clear routines and sometimes a little bit of tough love.

How have you learnt what to do? Where have you got ideas/training from if any?

Mostly from own experience, not a lot of hands-on training. But school provides:

Counsellor on site

Social worker

RTLB support

But big barrier is $$ and getting access to publicly funded services.

Also put in place wellness plans with individual kids so they have something tailored for them eg can leave class and go to a safe place etc. All about building resilience.

Teaching Growth Mindset for positive wellbeing

Do you have personal experience with anxiety in kids?

Own son suffers from anxiety, school avoidance etc

What resources if any has the school/MOE provided to help? Any specific training around anxiety and/or neuro diversity in general?

Budgets are very tight and free access can be difficult. Can try to get grants but they are a lot of work. Better if you can do it yourself.

For example The Resilience Project (Tania Dalton Foundation), Pause Breath Smile mindfulness, Mind over Manner (had heard of it) but all costs and have to prioritise resources.

NZCER - Mental Health education partnering with MOE, new initiative.
https://www.nzcer.org.nz/

MOE just released a new mental health education resource, very good. There is awareness of the importance of youth mental health at the government level, and for most kids what's recommended would make a difference. But schools definitely are not equipped for more extreme kids (like Axl who self-harms).

There are some very good educational conference speakers who focus on teacher and student wellbeing eg. Nathan Wallace, Kathryn Bekett

What are the barriers you feel might prevent you from doing what you would ideally like to do?

Key barrier is cost and time within the school to focus more on individual kid's mental health.

The Community of Learning spent $359m with no measurable impact on student learning and success. Money wasted!

Kids won't achieve if they are not safe and happy, and therefore wanting to learn. Schools need strategies to help them manage anxiety but this goes against a focus on national standards. Schools are often the frontline for dealing with mental health issues, sometimes the safe, trusted place.

What would you like to do differently? What resources or support would you need to do this?

Greater focus on total health and wellness in the curriculum - but for some parents school should be all about learning and getting on with academics, they don't want their kids doing 'wellness' things.

Removing stigma of mental health, esp in kids

Ability to have open discussions with parents - the home-school relationship is key so the schools can really know the kids, their backgrounds, challenges and how parents handle their anxiety.

Who else needs to be involved with creating better outcomes for kids with anxiety? Who else should I be talking to? How could this be achieved?

GP incredibly important for referring as required, medication and general advice and guidance. People generally really listen to their GPs.

Public health system in general important but under-funded. Marinoto over stretched. Priority of funds goes to most severe kids so others slip through the cracks.

Educational Psychologists to help strengthen families - but only one public for the whole of the North Shore.

Churches can be really important in some cultures as places of support

Local services such as Hearts and Minds https://www.heartsandminds.org.nz/

Mention Mind Over Manner and show workshop brochure:
Have you heard of this group? Or been involved with anything similar? Is this sort of thing something the school would consider?

Heard of but high cost.

Overall, we should still have high expectations for neuro-diverse kids, every kid should work to succeed, must be careful not to lower our expectations of them too much. Teach resilience so they will succeed esp going to college where the pressure is ramped up.

Appreciative Inquiry Postscript Questionnaire

Positive Core Statement: Advocating for families to create an inclusive environment for their wellbeing and potential to be realized.

As a participant in the Appreciative Inquiry, to what extent…	Not at All	A Little	Moderately	A Lot	Huge Amount
Did you want to continue to be part of your inquiry group in order to advocate 'as a group'?					
Did you want to continue to be part of your inquiry group but change your positive core statement to better reflect new needs and wants?					
Did you want to continue to meet up with the other mothers in the group more socially, and with less emphasis on advocacy					
If your group carries on, would you like to invite other mothers to the group?					
If your group carries on, would you like to invite fathers to the group??					
If your group carries on, would you prefer to have a facilitator or organiser?					
Do you want to belong to a group of similar parents who meet as a therapeutic support group only?					
Do you want to belong to a group of similar parents who meet appreciatively and also plan to do things together to support each other – e.g., advocating, having fun, being creative, learning new things, etc?					

What feedback would you give to people who want to belong to an on-going appreciative inquiry group?