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Creating Appreciation and Community Support for Mothers Caring for a Child with an Anxiety Disorder

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Abstract

This research 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 contributes to the generation and perpetuation of stigmatisation, isolation and anxiety disorder. Within a Western capitalistic and individualistic culture, mental illness has become predominantly pathologised 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, there is the potential for health and wellbeing to increase for them, their children and the community.

Introduction

A COLLECTIVE APPROACH TO ANXIETY

As we re-engage with 'normality' in the world of the Covid-19 Omicron variant, the burden of our collective anxiety is held by our children and the mothers who care for them. Omicron is new, but it is preceded by many other threats to our collective existence, including the war of drugs, the stock market collapse and climate change. Clayton et al. (2017) have defined eco-anxiety as a "chronic fear of environmental doom" (p. 48) and Benoit et al. (2022) argue that this is widespread in youth and largely unaddressed. Thus, we need to bring a different perspective to anxiety disorders – 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).

Anxiety disorders are prevalent and rising (Bowden et al., 2019). Moderate to severe anxiety disorders are the most common psychiatric illnesses affecting one in four children and adults in Aotearoa New Zealand 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 December 2021 population of 5,122,300 (Stats NZ Tatauranga Aotearoa, 2022a), we can estimate that more than 717,122 people in this country 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 the most prevalent type of disorder, affecting 1 in 6 (16.8%, or 3.3 million) Australians" (Australian Institute of Health and Welfare, 2022, p. 5), 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 (2021a) 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 things contributing to … mental health concerns" (Mental Health America, 2021b, p. 43).

The most recommended treatments in Aotearoa New Zealand for anxiety disorders are individualised therapeutic sessions with a counsellor/psychologist/psychiatrist, and antidepressant medication (Bowden et al., 2019; Anxiety NZ, 2020; Health Navigator New Zealand, 2020), despite the fact that "antidepressant medications, especially SSRIs (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) cites Harvard research that concludes 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 specifically 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) concludes 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. (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. In a 2020 article, Haslam et al. show that the collective (joining social groups) has the power to create wellbeing for people under the greatest level of socioeconomic distress.

APPRECIATIVE INQUIRY

The aim of this research is to uncover parents' 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.

An appreciative inquiry (AI) methodology has been chosen for this research (Cooperrider & Srivastva, 1987). 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 is a proven, researched and purposeful form of generative action research (Fry, 2014), which Kelm (2011), and Stavros and Torres (2018) identify as being well grounded in positive psychology, sociology, medical studies and neuroscience. 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 (Msukwa et al., 2003; Coghlan & Brydon-Miller, 2014; Zandee, 2014; Stavros & Torres, 2018, Armstrong et al., 2020).

AI follows a 4-D process (Moore, 2021):

- Discovery: participants look for the best elements of their lives in relation to the topic – their successes, goals achieved and strengths discovered.
- Dream: 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.

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 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 & Dimitriadis, 2013, p. 6).

My AI process also involves semi-structured paired interviews that began the appreciative inquiry. This facilitated a way of gathering more in-depth experiential information (Kvale & Brinkmann, 2009), 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 pre- and post-inquiry identification-of-concerns questionnaire, a small post-inquiry evaluative questionnaire, and a three-month post-inquiry where-to-next questionnaire were used. Their purpose was to provide quantitative data that could confirm (or not) the impressions gathered from the qualitative methods.

The questions that underpinned the AI were:

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 taking individually and/or collectively in the immediate future?

RESEARCH APPROACH

I sought 4–6 participants who had to be parents of a local intermediate or high-school student in a North Shore, Tāmaki Makaurau Auckland suburb who had experienced an anxiety disorder for a year or more. The parent had to have experienced both distress and the navigational difficulty of sourcing treatment and support for their child. It was important that the parent and child were not in crisis at this time. The research was approved by Unitec's Research Ethics Committee (UREC).

Table 1 sets out how the appreciative inquiry 4-D process was delivered as a series of paired interviews, focus groups and questionnaires covering five different appreciative inquiry sessions over two and a half months. Each of the sessions was recorded and transcribed. The participants received each transcript and were given the opportunity to read and comment if they wanted any changes made.

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 not of 'one truth,' but of stories and metaphors depicting multiple perspectives and realities (Milioni, 2001). Using Braun & Clarke's (2006) guidelines for conducting thematic analysis, 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.

Table 1. Information given and data collection – appreciative inquiry timeline.

WHEN	WHAT HAPPENED
WEEK 1	Recruitment: Selection Questions & Answers. Consent & Confidentiality forms signed
WEEK 2–3	**Pre-Inquiry Questionnaire** on issues of concern sent and responses received
WEEK 4	**Discovery:** Paired Interviews information sheet sent out and two paired interviews done
WEEK 5	After Paired Interviews: Thank-you email with check-in and Support Sheet, Transcript sent Personal Identity symbols & words, and main themes: received and shared with participants
WEEK 6	**Dream:** First Focus Group information sheet sent out and First Focus Group held
WEEK 7	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.
WEEK 8–9	Positive Core Identity symbols and words: received and shared with participants
WEEK 9	**Design:** Second Focus Group information sheet sent out and, with Personal Strengths and Group Strengths consolidated and Second Focus Group held.
WEEK 9	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.
WEEK 13	**Destiny:** Third Focus Group Information Sheet sent out and Third Focus Group held.
WEEK 14	After Third Focus Group: **Post-Inquiry Questionnaire** of issues of concern; **Participation Feedback** Questionnaire. Thank-you email. Transcript sent. School Interview Notes received.
WEEK 42	**Post-Inquiry Questionnaire:** Where to next?

Anxiety disorders and their treatment

ANXIETY DISORDERS

The fifth edition of the *Diagnostic and statistical manual of mental disorders* (American Psychiatric Association, 2013) 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 (PTSD) as anxiety disorders. An anxiety disorder can be distinguished as the feeling of fear when 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) explain that PTSD used to be considered an anxiety disorder in the DSM 4 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) cites 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) concludes 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) cite the OECD 2015 PISA International Survey in which "at 18.5%, Aotearoa New Zealand has the second highest percentage of school children who are frequently bullied, double the OECD average" (p. 23). They also cite 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).

INDIVIDUALISED TREATMENT FOR ANXIETY DISORDERS

Antidepressant medication

In Aotearoa New Zealand, 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 whether 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 systematic review and network meta-analysis based on 89 trials and over 25,000 patients (Slee et al., 2019) compared 22 different medications and a placebo for generalised anxiety disorder (GAD). They concluded that the majority of the drugs were more efficacious than the 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 systematic reviews appear to indicate medication as a 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) cites 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 *Lancet* (Cipriani et al., 2016) verifies 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).

Individualised therapies

In Aotearoa New Zealand, most treatments for anxiety disorders involve prescription antidepressant medication and cognitive behavioural therapy (CBT), one of the most researched and practised 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 as to whether it is more effective than other treatments (James et al., 2015). James et al. (2015) also found 16% of participants recovered 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 the wait-list control group, 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 a placebo, and they further identified that PTSD requires more effective treatments. Also, in the same meta-analysis, CBT benefits were initially shown to be maintained longer after treatment compared with medication.

A 2018 network meta-analysis suggests 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 contrast, 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 that 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; Sebastian & Nelms, 2016, seven randomised controlled trials) showed that EFT produces significant and durable reductions in anxiety and PTSD at about the same level as CBT and eye movement desensitisation 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 & Sylabkhori, 2016). In a small-scale meta-analysis involving 12 studies focused on NLP as a strategy for dealing with psychosocial 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.

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 all members of the 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) describe 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 expectation of "Human Giver Syndrome" that is put on women [and especially mothers] to be selfless, 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 and 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.

DISCONNECTION AS THE MAJOR CAUSE OF ANXIETY

Hari (2018) argues "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.

Disconnection to intrinsic needs

Lack of internal control. Over the past decades, children have been spending more time at school and in structured activities, with less freedom, play and opportunity to develop their internal locus of control (Bregman, 2020). Bregman, citing Rosen (2014), says that "in the US, working mothers spend more time with their kids today than stay-at-home mothers did in the 1970s" (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) observed 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) cites research from Messias et al. (2011), and Wilkinson and 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 around. (2019, 11.15 min)

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 (notably as a hormone that promotes breastfeeding – one of the most profound human experiences of connection [World Health Organization, 2009]). 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%" (Hari, 2018, 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" (5.19 min). 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 describes the disconnection practice of not responding to a child when they cry as embedding anxiety in the child. It is a form of external-control psychology, a power-over position, or “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).

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, in which, 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 behaviours 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.

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, when 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, such as 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. Generally, where such children had well-developed social relationships when they were small, parents were much less isolated by stigma when their children became adolescents than "parents whose children developed problems as teenagers and young adults" (p. 938). At this age their "invisible disabilities … were re-narrated as problems of character [flaws, such as laziness]" (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.

Parental stigma and mother-blame. Francis (2012) claims:

> 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. (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 men are "human beings" who have a duty to express their humanity, and women 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 child'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.

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) evidences 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 refer to a Canadian study (Kirmayer et al., 2001) that argues 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 teachers to reach them*, Glasser (2002) identifies 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) illustrates 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 the power-over position of “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.

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 the importance of social identity for health and wellbeing with over 400 publications on this topic, and that 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 biopsychosocial (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 in which 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] channel 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
- **a sense of personal control** … [with being part of a group with] collective efficacy, agency and power" (pp. 797–798)

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 (pp. 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.

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, such as our systems of education, economics and governance. As described above, inequality is proven to be detrimental to mental health (Wilkinson & Pickett, 2009; Messias et al.,2011), 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:

> 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.

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 in which application of a 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, for 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.

Social identity as pathway to social cure or social curse

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' in which 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.

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) demonstrates 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).

The social-identity and recovery models 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.

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 Table 2 are colour coded into categories (by columns).

Intervention examples: Addressing collective despair

Currently, there are no interventions available in Aotearoa New Zealand 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 this country 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 that connects people and the group to something bigger than themselves.

Table 2. Social-connection interventions.
Y=yes; Green: Addressing Collective Despair; Yellow: Creating Connection and Social Identity; Grey: Group Therapeutic Support for Mothers and their Families.
AI = appreciative inquiry, PDR = priority-driven research.

Intervention Strategy	International service	NZ service	Youth focus	Adult focus	Carer focus	Mental health focus	Arts, enviro focus	Spirit factor	Community partnership & service	Indigenous 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
Empowering Partnerships (PDR)	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					4
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**	**13**	**8**	**13**	**10**	**17**	**8**	**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 is also very effective in tandem with psychotherapy, with the more AA meetings attended the better the outcome. In Aotearoa New Zealand, 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 groups in this country (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 and alcohol use, mental illness and crime amongst youth (Young, 2017). The project increases youth recreational and social opportunities for more meaningful connections with families and friends, plus it provides training in relational and skill development (Volteface, 2020).

The South African Drugs, Hopes and Dreams programme – appreciative inquiry with marginalised young people who use 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 values-based appreciative inquiry to help and support 120 young people with antisocial behaviour and drug and alcohol use. 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.

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 wānanga group approach involving meeting, discussing, learning, and the passing on of wisdom and connection not only with the living present but also to something bigger than oneself – whānau, iwi, ancestors, community and decolonisation. 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 programmes with a mental health focus emphasise social identity through collaboration and partnerships. The Priority Driven Research Project (PDR) for Empowering Community Partnerships (Haswell-Elkins et al., 2009) was an Indigenous community action research project that 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 that broke down isolation through shared experiences and collective action. Some of the best outcomes for the social-identity and recovery models come from Haslam et al.'s (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 theorising, analysis also showed improvements in depression, anxiety, stress, loneliness and increased 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 nine-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 behaviour.

There are many arts-based groups in Aotearoa New Zealand 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 Tāmaki Makaurau Auckland, such as 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), that 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, 2018), in which 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 sociopolitical learning and a goal of liberation. A focus on community change, rather than individual change, focuses on a collective response to systemic oppression.

Group therapeutic support for mothers and their families

Aotearoa New Zealand has a variety of individualised support interventions to address anxiety disorder that include helplines, information provision, advocacy, one-on-one therapy and medication. Some of the interventions/support services are directly modelled on or initially inspired by overseas services, such as Parent to Parent USA (2020). Yellow Brick Road (2020) is a decedent of Schizophrenia Fellowship, a parent organisation with offices in many countries. The support groups in Aotearoa New Zealand promote themselves to be therapeutically focused on the individuals giving and receiving support to each other to reduce isolation, sharing strategies to improve their coping and wellbeing, and providing opportunities for self-development. These support groups include:

- Anxiety NZ (2022): Support services provide 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 and individual support, and self-development programmes.
- Emerge Aotearoa (2021): Provides social services to strengthen families/whānau 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.

THE WIDER CONTEXT OF SOCIAL-CONNECTION INTERVENTIONS

While we can point to programmes in Aotearoa New Zealand that reduce social isolation between families/whānau supporting a family member with a mental illness and their local community, success in this area depends hugely on prevailing attitudes around community support for people with a mental illness. There are a number of changes that point to Aotearoa New Zealand becoming more community oriented in the delivery of mental health support systems. These include the extent of deinstitutionalisation, the implementation of a recovery model, the size and nature of the voluntary/not for profit sector, the development of a wellbeing economy, and the influence of Māori and Pacific cultures in making Aotearoa New Zealand a more collective society. These changes have been in part a correction to the individualistically focused policies of neoliberalism in the late 1980s and 90s that emphasised the rights of individuals to pursue their own interests, and a reduction in the welfare state that produced a huge increase in Māori admissions to mental hospitals (Te Puni Kōkiri, 1996) and huge inequalities in Aotearoa New Zealand (Barnett & Bagshaw, 2020).

Deinstitutionalisation in Aotearoa New Zealand – the closing of mental hospitals and the shift to community-based mental health services – has been more complete than in almost any other OECD country (Taylor-Salisbury et al., 2016). Only two European countries had closed all their mental health hospitals by 2005, whereas in Aotearoa New Zealand all but one small unit (Seaview in Hokitika, "Psychiatric hospitals in New Zealand," 2020) had closed by the turn of the century. The World Health Organization's Mental Health ATLAS 2017 Member State Profile states that there were 17 mental hospitals in Australia, 20 in Canada, 605 in the USA and none in Aotearoa New Zealand.

The recovery model provided the guiding philosophy for the shift to a community system of mental health support. Created by US mental health consumers in the late 1980s (Anthony, 1993), the recovery approach emphasised that "recovery can occur without professional intervention," depending on "the presence of people who believe in and stand by the person in need of recovery" (p. 18). Aotearoa New Zealand's Mental Health Commission introduced the recovery approach in 1998 as a set of guiding principles for mental health five or more years before it was introduced in other countries such as Australia, England, Scotland, Ireland, the United States and Canada (Repper & Perkins, 2003; Mental Health Commission, 2007; Piat et al., 2010).

The non-government organisation (NGO) not-for-profit (NFP) sector[1] played a large part in the development of community mental health services after the closure of mental hospitals. Atamira Platform Trust (2020), the peak Aotearoa New Zealand body for mental health and addiction NGOs, notes that 33.5% of all government-funded mental health and addiction (MHA) services are NFPs, compared with 6-7% in Australia (Rosenberg & Harvey, 2021; Productivity Commission, 2022). Rosenberg and Harvey conclude that "this has deprived Australia of a range of psychosocial rehabilitation and support services, as alternatives to or as a means of minimizing prolonged or avoidable hospitalization" (p. 44). The NFP sector has important features that enable it to participate with all cultures and in all areas of Aotearoa New Zealand society (McLeod, 2017). In a 2013 comparison with six other countries (Australia, USA, Canada, UK, Japan and Norway) Aotearoa New Zealand has by far the highest number of NFPs per head of population (1 NFP organisation per 162 people), the highest contribution by volunteers to the total workforce (6.3%), the lowest proportion of government funding (31%) and the highest proportion of funding by philanthropy (24%), and the second highest level of individual giving (0.79% of GDP). This data suggests that Aotearoa New Zealand overall is an engaged and giving community with wide-spreading and very diverse roots (Atamira Platform Trust, 2020).

In 2018, *He Ara Oranga, the Report of the Government Inquiry into Mental Health and Addiction* called for "wellbeing and community solutions," noting the high levels of anxiety and distress in children and young people and the need to address "social and economic determinants of health" and further shift "from district health boards (DHBs) to non-governmental organisation (NGO) providers, which are closer to the community" (p. 9). The Inquiry asks

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[1] Non-government organisations — or NGOs as they are commonly referred to — are non-profit organisations that are set up and operated independently from local, state or international governments, but can receive government funding in some cases. They usually address social and political issues (Turk, 2022).

for a more holistic and collective approach to mental health that goes beyond mental health services and points to the value of collectivism, particularly in relation to Māori and Pacific communities, but also to communities in general.

The Government's 2019 Wellbeing Budget (Te Tai Ōhanga The Treasury, 2019), the first of this type in the world (Mahomed, 2020), was a direct response to the Government Inquiry into Mental Health and Addiction (2018). Progress in this area is mapped by Stats NZ Tatauranga Aotearoa (2022b) in a comprehensive set of 16 measures that show that wellbeing has changed little from 2018 to 2021, although the level of mental wellbeing had declined and loneliness had increased, probably due to the isolation resulting from Covid-19 lockdowns (Adams-Prassl et al., 2020; Chandola et al., 2020). Despite this, Aotearoa New Zealand had per capita in 2020 the seventh largest wellbeing economy (Global Wellness Institute, 2022) and was ranked tenth in happiness out of 141 countries (Helliwell et al., 2022) in the *World happiness report*.

One wellbeing measure is the extent to which people in Aotearoa New Zealand speak te reo Māori (Stats NZ Tatauranga Aotearoa, 2022b). This measure is indication of an improving engagement not only with te reo Māori, but hopefully with Māori understandings of the world. We have noted in the introduction the very high lifetime prevalence of anxiety for Māori (Kopua et al., 2020) and, above, the value that Māori and Pacific communities place on collective approaches to improving wellbeing. In managing mental health and addictions, these are drivers that will shape the decisions of the newly created national Te Aka Whai Ora Māori Health Authority, who have a key objective of "strengthening mana motuhake for whānau – supporting them to take control of their own health and wellbeing" (Future of Health, para. 1). The emphasis of Māori health models on "whanaungatanga (connectedness); whakawhanaungatanga (building relationships) … aroha (compassion and empathy), manaakitanga (kindness and hospitality) ... wairua (importance of spiritual wellbeing)" (Wilson et al., 2021, p. 3539), and the interconnections of health and the mauri (life force) of place (McIntosh et al., 2021) will be a powerful positive influence across all sectors of health.

Taken together, the factors described in this section show the zeitgeist of care and support for mental illness and for anxiety (the leading cause of mental illness) in particular needing to be acknowledged and addressed primarily as a social and collective concern rather than as a problem of individuals and their families. This zeitgeist is worldwide, but Aotearoa New Zealand demonstrates a unique combination of factors that suggests that it is moving strongly in this direction.

Emerging themes

INTRODUCTION

A four-phased appreciative inquiry was used to collect raw data with a group of mothers. Due to the Covid-19 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

Table 3 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. Pseudonyms were used in this study.

Table 3. Some demographic features of the participant mothers and their families.

	SIENNA	GRACE	APRIL	KINSLEY
Ethnicity	Pākehā	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, tics, Asperger’s	Left abusive marriage, single	Left abusive marriage, single 2nd daughter, 8yrs	Left abusive 1st marriage, married 2nd husband, living with husband’s daughter too 2nd son, 16yrs: Anxiety, self-harms
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

THEME 1: ON THE FRINGES, NAVIGATING THE QUAGMIRE OF SUPPORT

Four main themes have been identified. The first theme illustrates the mothers' challenges of being on the fringes and navigating the quagmire of support around them, including mental health professionals, friends and family, and their children's schools. The second theme demonstrates 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 describes the mothers' experiences in their freedom of sharing within an appreciative inquiry.

In each of the three sections on this first 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.

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 GP 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 come] 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.

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.

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, who asks 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 that “unless they have teenagers going through the same thing, they don't understand … it’s just hard to find support.”

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.

Table 4. Participant ratings prior to commencing the appreciative inquiry.
For Q1–3: Not at all = 0 A little = 1 Moderate amount = 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**

Pre-research questionnaire. Table 4 shares how, prior to appreciative inquiry, 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. April, who experiences, on average, the least support, matches Kinsley's experiences of a huge amount of isolation.

Table 5. 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	3–4 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			

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 church community and family service (see Table 5 – I was only able to get partial data for Kinsley).

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 my 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 every day 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," 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 to find support from 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.

Schools: Advocating for support is ongoing

Each of the mothers experienced the ongoing 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. Advocating for support meant challenging a school system that isn't set up for the needs of children with high anxiety, and collaborating with mothers, so that both mothers and educators can help each other help the children.

Pushing, advocating, fighting for more support in schools. All the mothers had to fight to get help in school for their child with special needs.

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."

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 realise, 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 of 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, during lockdown April's daughter "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 whether 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."

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 mums, 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" in which educators and mothers work as a team in supporting their children with special needs. This teamwork has been challenged in the past, in situations where the mothers experience being:

- "Ignored" when trying to help educators help their children (Grace & April).
- "Outnumbered" (Grace and 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 escalate 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 and 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 Deputy Principal 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 ten of them are neurodiverse … [the government should be] putting the money into education, so that we can have more teachers. We need bigger schools."

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, by his coach, to be "a bit of a mentor for the other kids." 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 wraparound support that is effective. The Dean at 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 says, "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 ten kids, and it's just silent. And that's where [Dianna's] happiest."

In summary, the mothers experienced the ongoing 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 wraparound 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 learned 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.

THEME 2: LEARNING TO COPE

Coping mechanisms

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 it's 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. "It's 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 has three parts: creating calm in the home, in their child, and in themselves. The mothers' shared experiences in this appreciative inquiry include a journey from learning to cope, to appreciating their learning.

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 three and a half 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."

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.

Each mother's experience. Kinsley says, "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), Kinsley put her confidence in the external supports she located to help keep her son calm. This included the wraparound 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) felt a lack of trust in the external support for her son. Most of Axl's "anxiety is generated firstly by his dad," whom 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." As a result of 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). 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), 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" and 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 is 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."

From external control to learning internal control. The mothers shared stories of external control strategies, in which, if the child didn't do something the parent wanted them to do, the parent would take something the child valued away from them, such as "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 [wants] 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 [to her] 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 in 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.

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, in order to be 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.

Self-sacrifice/internal disconnection in order to cope. The effects of the mother 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 mother, potentially keeping them disconnected to their emotions and/or their external environment in order to cope in the world.

Kinsley says, “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 empathises 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 appears to be a deep self-sacrifice when April says:

> *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 adds, "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 mothers' working environments appears to be how supportive their colleagues and work culture are (see Table 5: 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 (through counselling and mindful practices, see below).

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, and 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 shares, “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-19 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.”

Table 6. Post-research participant ratings of support, confidence, isolation and stigma.

For Q1–3: Not at all = 0 A little = 1 Moderate amount = 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 prior to commencing the appreciative inquiry, 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 SCORE EXPERIENCED PRE-QUESTIONNAIRE	**1.4**	**1.4**	**0.6**	**1.8**
AVERAGE SCORE EXPERIENCED POST-QUESTIONNAIRE	**3**	**3**	**1**	**n/a**

Post-research questionnaire. Table 6 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 ratings. 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.

THEME 3: MOTHER AS ADVOCATE – PERSONAL 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, to 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, in which 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 Theme 4 section.

Personal strengths-based identity (discovery phase)

Sienna

The words Sienna used to describe herself were "strength, love, responsibility, commitment." Sienna created a drawing of four different images: 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, "What people see is the outside of me, but inside, I have a whole lot going on to stay afloat."

Figure 1. Sienna's symbol.

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 and standing still.

The iceberg identifies a significant amount of herself that is hidden from others, with only the top portion able to be seen. 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 central 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, positivity" to describe herself. She created an image of a Mamma Duma (cheetah) who is "Fragile but Fierce!"

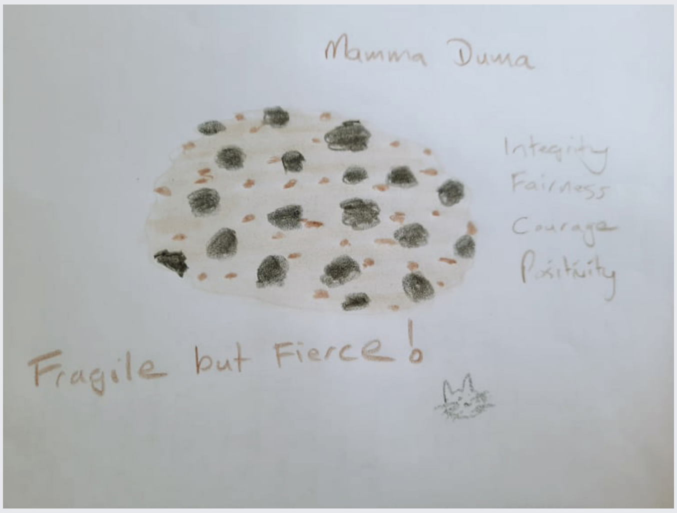

Figure 2. Grace's symbol.

Some noticing

When Grace places her symbol strongly centre, with the words "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, tough." She created an image of a mother "ninja – I am constantly trying to find the strength to keep fighting for those I love."

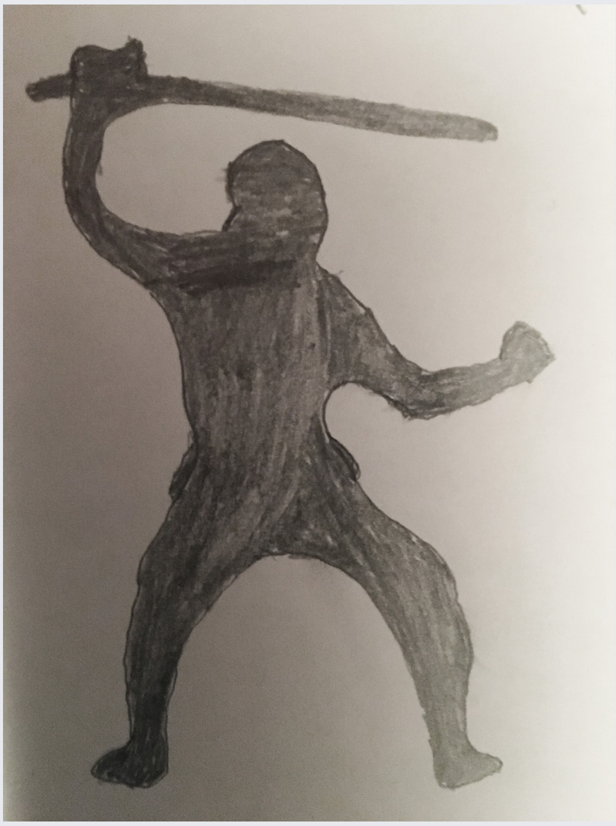

Figure 3. April's symbol.

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 any 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 as if 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

Collective identity – the creation of their Positive Core (Dream Phase)

Table 7. Group culture and shared values.

GROUP CULTURE	SHARED VALUES
Positive experience Common worthwhile purpose to help each other Respect and listen to each other Kindness, no judgement Confidentiality Trust Responsibility and flexibility	Integrity Self-belief Advocacy Fairness Everyone' voice is important Giving others self-worth Honesty Transparency

Table 7 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.

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 don't show up on the list, but were present in the actual sessions, are things like having fun and sharing food, which created a shared space for developing friendship and enabled a deeper sense of connection. In the first focus group, which 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 project's 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.

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 have to do with standing up, "standing up for children, people, minorities" (Sienna). "I'm laughing because mine's exactly the same," says Grace, adding that "integrity" is also "key," to never let others "walk over you," Grace notices Sienna's "self-belief," it's "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," says 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).

Positive Core Statement. The starting place for the Positive Core Statement came from Grace's reflections on 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, wonders whether "managing the judgement from other people" should be included, but after brainstorming, and engaging at the edge of the sociopolitical, they 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."

Collective dreams for the future. The mothers' main theme for the future is about social acceptance and valuing difference; if these are in place, the mothers will 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 don't want their kids to be "normal"; it is "the uniqueness of my kids and the things that they think about and the things that they do" that Sienna likes. Being "successful … whatever success means" (Grace) is important, but the risks in uniqueness of being "teased or harassed" worry April, and Grace acknowledges "you want them to be who they are, but you want them to be accepted."

A further future dream question is "It's 2025 – looking back on your team initiative, what will you be most proud of?" For the children, they want 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 says 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 want the transition from suspension to freedom. They find 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 says 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.”

GRACE
It’s us standing staunch, holding a trident (symbol of strength and power) with the sun radiating outwards from us, allowing our kids to reach their potential.

I added Kia Kaha as I think that concept beautifully sums up our positive core as well!

SIENNA
My symbol is called Rise Up (sun in between mountains) and it means we will rise up each day and do what we need to, to support those in need, whether it be our family, friends or others.

APRIL
Kindness, gentleness, patience, love, non-judgement and grace. Living in the moment and taking time to smell the roses.

Figure 4. Collective positive symbols.

Positive Core symbols consolidated + Positive Core re-vamp. 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 they saw 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 Statement, 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 realised.[2]

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 drawings (Figures 1–3), 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 Core 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 now 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.

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[2] The mothers' main priority in the Design brainstorm was "Helping teachers to help our children."

Sienna's personal identity was a group of images that included an iceberg, the weight of her children on her arms, a large bear looking fierce, and a heart being almost centralised. Being part of the group, there was now 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 phrase "in a world that isn't set up for them" and replacing it with "to create an inclusive environment" that celebrates uniqueness in people, allowing more wellbeing and potential to be realised.

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.

Out of the silencing and into the sharing – the discovery phase

In the first paired interview in the Discovery Phase of the AI, Grace says 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 realise 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 … to me is freedom.*

To which Kinsley replies, "Nailed it!" Grace continues, "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 describes herself as "hugely isolated," responds to the appreciative feedback with, "Thank you, that's nice. It's good to hear."

Discovery was the phase in which 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.

Out of the isolation, and into the belonging – the Dream Phase

The Dream Phase provided the next step, in which 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 by the mothers consolidating their Positive Core Symbols and identifying a common theme of advocacy, giving life to their group for the creation of their group culture and values, and creating 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 doctor's 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 compartmentalise 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.

Out of individual powerlessness and 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."

The brainstorm on Helping Teachers Help Our Children. 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 explains 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 agrees; 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 8 summarises the brainstorming session on Helping Teachers Help Our Children.

Table 8. 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, 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, 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 co-ordinator)	• Sienna has a good relationship with her SENCO, who will be moving schools	• Not much luck with the SENCOs at school (Grace, 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)

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?"*

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
> Knowledge
> Teachers will increase awareness/skills of how to build relationships with anxious and neurodiverse children.
> Behaviour
> Teachers will act with more compassion and empathy to create better emotional connection with anxious/neurodiverse children.
> 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 would be 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.

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 is potential for their initiative to make a difference to themselves and others. Grace says, "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 won't feel too much like work, and that together, they are 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."

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.

Scoping initiative follow-up. The outcome summary of the scoping exercise is shown in Table 9. 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 Term 3, with Term 4 normally a winding-down time in schools.
- High stress in teachers and schools in the year of 2020 Covid-19 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).

Table 9. 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	High school	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, 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 the DP, whom 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 an 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. The 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 high school*

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 issue was left in the air, and the discussion moved to the significant timing hurdle: the end of the school year, Christmas, summer holidays. The chaos of Term 1 with two of the children starting new schools, and teachers being so busy starting back, meant that the mothers would need to decide what they were going to do. Even though Sienna felt that things wouldn'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 was "happy to do it next year too" after March. Grace was quiet.

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 under Theme 2: Learning to Cope have shown how the mothers have learned to cope by creating calm in the home, in the children, and in themselves. 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," says 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 ongoing struggles to find 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 [send] myself to time out,” 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[ing] it away.” April says she needs to be “mentally well myself,” and to be that, she 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 part of the 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 has come 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 that.

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."

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 research.

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 process takes you beyond "surviving day by day" to where you need to "stop and think and draw a picture or comment," and 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 realises "there is a role for the broader community in helping kids with anxiety" and appreciates "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 summarises 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, realising 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 share their parting words of appreciation. April expresses 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 says. "To me, it's mindfulness – very mindful experience for me – it's been great!" Sienna agrees, "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," says 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:

> EDUCATIONAL SYSTEM
> Teachers aren't trained for dealing with mental health and neurodiversity in the classroom.
> Individual schools choose the type of training they provide their staff and what programmes they bring into the school.
> There is a mental-health resource book available that is targeted for regular kids' wellbeing – not kids who have higher needs.
> There is a lack of funding for schools.

> FUNDING
> Someone has to apply for it (PTA, Board, or Special Education responsibility).

> TIMING
> Two weeks to scope before school holidays.
> Schools are in a high-stress and winding-down time of the year.
> Christmas and summer holidays are around the corner.
> Zoe and Axl start new schools in 2021, if all goes well.
> Term 1 is too busy to start new projects that aren't already organised.
> April feels challenged scoping and dealing with school management or teachers.
> Grace thinks the biggest difference you can make is with advocating for your own child.
> Sienna feels she can help in her job as a teacher.
> Each mother is at a different school and dealing with that school individually.
> Two mothers felt like they wanted to meet again to carry on, and one kept quiet.

The learning from their experience with their child with 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.

The appreciation of being part of the study. Having opportunities to appreciate and support each other through similar challenges in an appreciative inquiry creates more valuing 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 closely and to book herself for an ADHD test. The mothers went into this study wanting to make a difference and they all left feeling that they have made a difference, especially "to each other" (Grace) as they "weren't alone with the problem" (Sienna); and April "feels like a better parent from being part of this."

The way forward

POSITIONING ANXIETY DISORDER

In the research I wanted to explore the expansion or repositioning 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 Aotearoa New Zealand, 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 have been advocating for years for support for their child within an individualising model of healthcare focused 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. Two of the children are on medication and doing one-on-one therapy, while one 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).

AN INDIVIDUALISTIC EXPERIENCE

Impact of neoliberalism

Loneliness is a strong precursor to anxiety and depression (Hari, 2018; Haslam et al., 2018), and with the isolating, stigmatising and ongoing experience of caring and advocating for a child with an anxiety disorder, the mother is also at greater risk of developing 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]). Rios et al. (2021), interviewing mothers of children with developmental disabilities, confirm that the mother-as-advocate role is very stressful, even when it is successful.

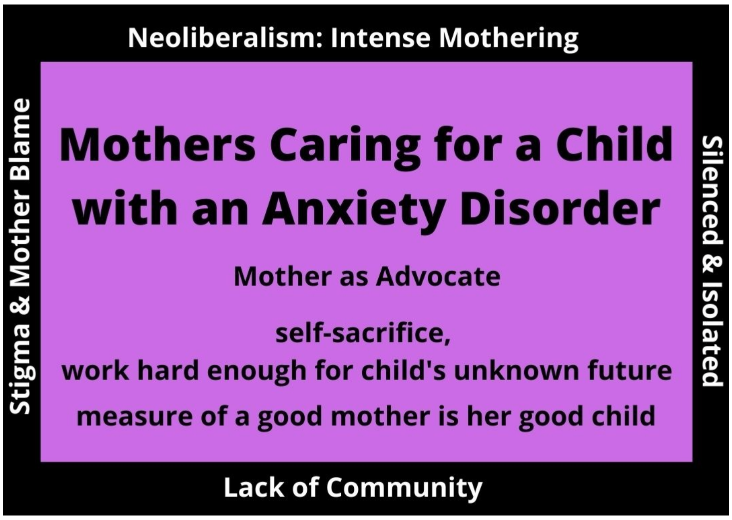

Figure 5. An explanatory model of mothers' positioning in the Western culture.

Figure 5 is a representation of the positioning of the participants in this research as mothers caring for a child with an anxiety disorder or invisible disability, and a reflection of the wider position of women. The centre diagram presents a summary of the literature about societal expectations that 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).

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." From 1985, the "catastrophic impact in Aotearoa New Zealand of neoliberlism" (Barnett & Bagshaw, 2020, p. 78) placed more value 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 that 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 and Correll (2010) demonstrate that intensive mothering standards create conflict, pushing mothers into holding two "incompatible" (p. 640) 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 and Sahgian (2015) all contend that mothers are given all the responsibility for 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 describes 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 says, "That's what we do as mums, right?" "100%" confirms Kinsley. April admits, "I don't want anything for myself at all ever. I've kind of lost that." 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.

Stigma and mother-blame. Francis (2012) argues that parental stigma is dominant with invisible disabilities and, in this time of intense mothering and medicalisation, mothers are blamed for being bad mothers 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 and Austin (2007), and Reimer and 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, talks 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 husbands for the sake of their children, and all of the mothers fought educational systems and advocated 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. In the focus groups, these words ‘isolate’ and ‘judge’ – along with words like ‘alone,’ ‘quiet,’ ‘safe,’ ‘hide,’ ‘worry,’ ‘separate’ and ‘cope’ – were used 209 times; the words ‘help,’ ‘support’ and ‘need’ were used 388 times, and ‘relationship’ 76 times. The use of these high-frequency words (for comparison, expected high-frequency words such as ‘child/children’ were used 201 times and ‘anxiety’ 93 times) confirms the mother’s experiences of isolation through stigma and their desire for connection.

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 – which are very similar to the discernment of stigma, acceptance and silencing sequence described by the mothers in the findings. 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 says, “I don't feel a stigma attached to it… it's just hard to find support,” and Kinsley says, “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 internalise 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.

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) demonstrates 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.

Social identity

Haslam et al. (2018) argue 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.

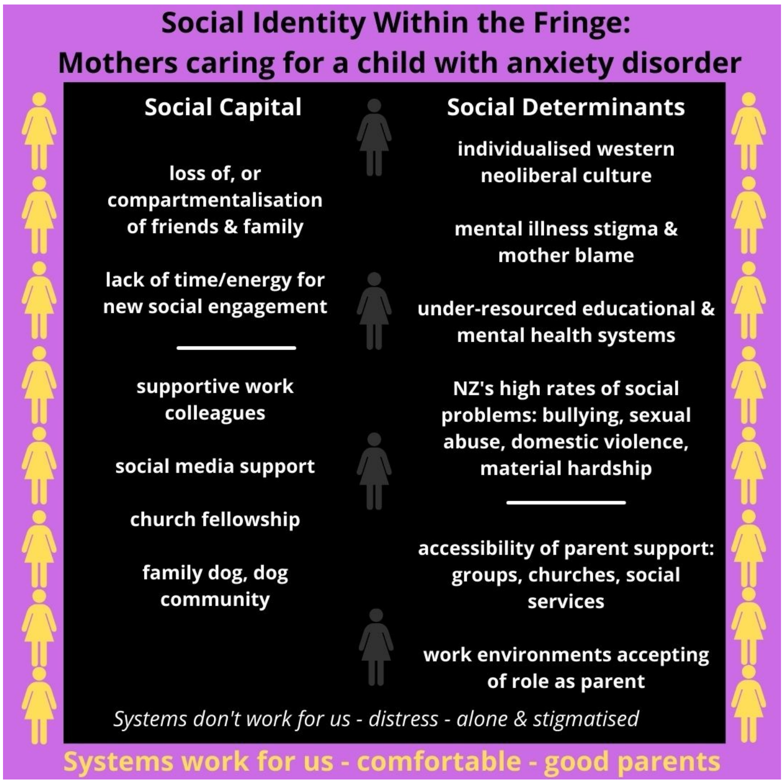

Figure 6. An explanatory model of viewing mothers' social identity within the fringe that exists outside the social norm.

Figure 6 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 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 experience that correspond with the social capital and social determinants of the social-identity approach to increase understanding.

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 co-operation. 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, and 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 for and found community support in a local church and in group activities such as yoga and mindfulness. Sienna, who is very time-bound, found support in her new family dog, calling it their "therapy dog"; Grace found meaningful connection in online support groups.

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 Aotearoa New Zealand, 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); one in three girls and one in seven boys being sexually abused (Help, 2021); one in three women, mostly mothers, experiencing domestic violence (Shine, 2021); and 18.4% of children living in households with incomes that meet the criterion for poverty (Stats NZ Tatauranga Aotearoa, 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 that 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.

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 for common issues. One of the methods for doing this is to flip the negative into a positive. If lack of understanding and judgement create 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 7) that contribute to creating connections that will be used to frame the mothers'

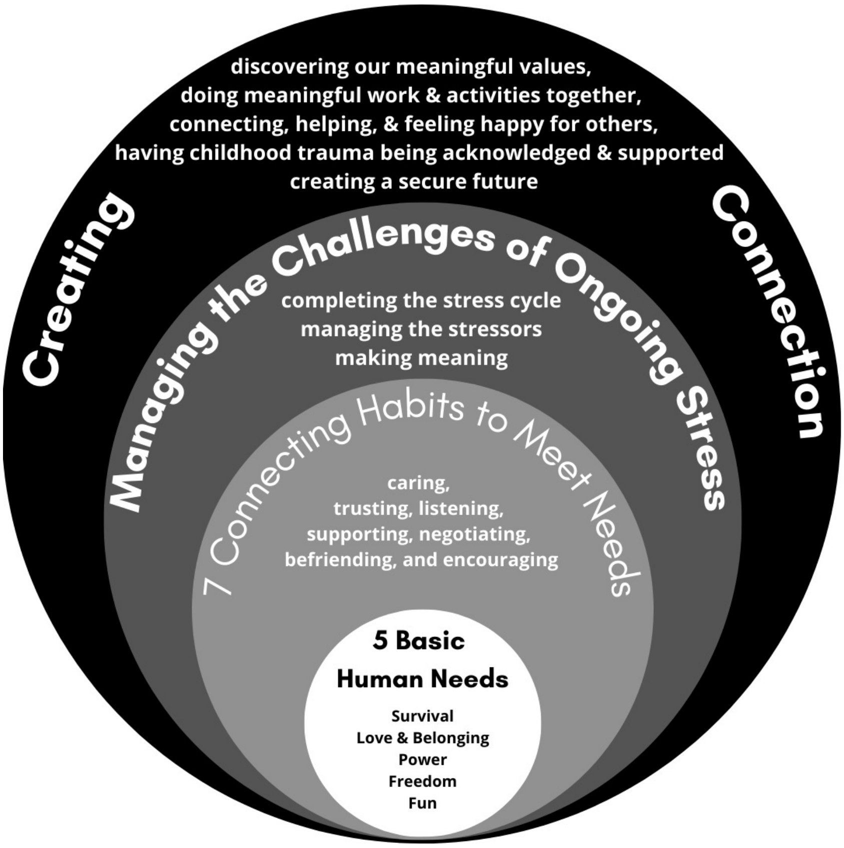

Figure 7. An explanatory model demonstrating a collective social approach to anxiety disorder.

experiences and to review how the AI enabled or missed some of the elements of the models.

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 them 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 practising 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.

Five basic human needs: Survival, love and belonging, power, freedom, fun

The mother 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 as balls of energy in a basket, we will see that for all of them their survival balls were larger and brighter as this was where most of their energy was being used. For three of the mothers, their love and belonging and power balls were smaller and dimmer (a high degree of isolation, and the emotional and mental toll of being 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 childcare 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 and Sahgian (2015) demonstrate 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 had 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).

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) calls 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 have 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 Māori principle of manaakitanga (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-19 lockdown was in place for 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 goodbyes.

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, which Norup et al. (2013), McGonigal (2013), Hari (2018), and Nagoski and Nagoski (2019) all argue will produce better outcomes than passivity and denial, especially when there is meaningful social connection around them for support. Nagoski and Nagoski (2019) identify 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) mention the importance of social connection in their concluding statements only, the making meaning and connection elements will be discussed in the Creating Connection section.

Completing the stress cycle includes physical activity (including crying), affection and creative expression. Although medication isn't included in Nagoski and Nagoski's (2019) model, it is the mothers' valued strategy for stress management that provides 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 recalls 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 remembers 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 shares that "genuinely screaming [in the car] and crying help me," and that she also uses a punching bag and practises yoga and mindfulness.

Most of the talk in the focus groups about sharing affection (hugs and kisses) 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 says it is:

> *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 says:

> *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) explain 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.

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.

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 10 below to demonstrate the benefits of this process. Although I could have used the mothers' words in several columns, I chose to use the most appropriate column for each word or phrase to keep it simple, without double-ups.

Table 10. 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

The purpose of Table 10 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.

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," saying it "changed my perspective on life." She had previously felt "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 hopes "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, which demonstrates a sense of agency and a high level of need. The themes that shaped their group identity include 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 demonstrates 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:
    - Sienna was facing big challenges at home, "life got hard … It just fell apart for me."
    - Tāmaki Makaurau Auckland had recently come out of lockdown.
    - There were only two weeks of school before the school holidays, then two weeks' break.
    - Term 4 is a difficult time to start anything up, when schools are winding down, especially after a year of Covid-19.
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 apprehensions that April had about doing the scoping at her daughter's school, and April wasn't clearly open with these, 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) warns, 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 create 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 on as a group of three mothers: the mothers were disheartened with what they found out in their scoping. Grace discovered:

   > *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 school 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, two of them subsequently felt that they didn't need to meet up anymore.

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 (the highest rating in the 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, a 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, but not her second. Kinsley found it difficult advocating for support, but she would do it 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. She 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, respectively.
    - Sienna and Grace both had supportive work colleagues, influence at work, a few close friends, talk therapy for their children and confidence 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 reveal why a person who has more support can experience 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 together people 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).

Having the support of acknowledging childhood trauma. An element was introduced to deepen the mothers' connection with their children who experience anxiety and who were present in the space (just not physically). They 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 parent – 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 Dianna's and her patient empathy and compassion, with no judgement.
- Grace appreciated Axl's and her valuing of important relationships that included managing expectations and judgements to maintain trust.
- Sienna appreciated Zoe's and her practice of making choices for calm, respectful boundaries and personal space.

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

Conclusion

SUMMARY

This study focused on mothers caring for a child with an anxiety disorder. They have been described as having an invisible and thus unacknowledged responsibility. At the time of this study, there was little research on, or support available for, mothers of children with disabilities, or 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. In Aotearoa New Zealand at present, there are no social-identity, community action or 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 sociopolitical conditions that give rise to so much trauma and anxiety.

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. 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 demonstrates 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. Rausch (2021), in a study on working mothers of children with "high functioning autism" states that "advocacy is an inherent quality within the role of 'mother' that supersedes refusal, yet does not constitute deliberate choosing" (p. 10). Similarly, for our mothers, 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 they are not sufficiently experienced in meaning-making as a collective to be able to see the power of group advocacy – mothers as advocates.

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 a mother's 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 Aotearoa New Zealand's high rates of social problems (bullying, sexual abuse, domestic violence and material hardship).

The appreciative inquiry approach 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 (Figure 7), 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.
- Practised 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.

In our conclusion to the section Anxiety Disorders and Their Treatment, we refer to the zeitgeist pushing for collectivism and social connection. This is an example of what it is becoming.

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 practising by parenting a child with an anxiety disorder, and it delved into the managing the stressors element of wellbeing in action through the re-appraisal of challenges. The gifts of these 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.

RECOMMENDATIONS

- Run more AI versions doing face-to-face sessions as much as possible, including elements that help to complete the stress cycle and value the connecting non-structured time, sharing food and having fun, to build relationship and trust.
- Facilitate AI with parents in the same school, early in the year, to increase group identity and teamwork with school management and teachers, making it one step closer to being a group in action. Focus on low-decile schools, where the experience of anxiety and the support systems available may be very different.
- Develop a collaborative and AI-informed team approach with parents, teachers, schools and social services to support children with anxiety.

RESEARCHER REFLECTIONS

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 at 11 years old didn't want to live anymore and coped by avoiding school and going outside the house; 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-19 made anxiety worse for her, and the horses thankfully support her in amazing ways. My sweet dog developed anxiety during Covid-19, 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 practise connecting habits and practise 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, practised co-counselling and (mostly) daily meditation, talked with my supervisor, and did regular acupuncture and herbal treatments 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 has 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 number of people having anxiety, there are a number of things going wrong, and there are a number of things we can do to change them. There are many social determinants in Aotearoa New Zealand that have the capacity to trigger anxiety disorder, as well as a couple of the obvious global situations of climate change and the Covid-19 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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