RESILIENCE CYCLES: A GROUNDED THEORY STUDY OF THE EXPERIENCES OF RESILIENCE IN MOTHERS WHO HAVE CHILDREN WITH AN AUTISM SPECTRUM DISORDER.

A thesis submitted in partial fulfilment of the requirements of the University of East Anglia and the University of Suffolk for the degree of Doctor of Philosophy

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Abstract

Traditional views of resilience have described it in terms of risk and protective factors plus processes, that enable individuals to resist or quickly recover from adversity to achieve a positive outcome. This has led to a conceptualisation of resilience as being a linear, binary construct with some people being considered resilient and others not resilient. Despite this, there is no consensus of agreement as to the definition, operationalisation, or measurement of resilience (Ahern, Kiehl, Sole, & Byers, 2006; Jew, Green & Kroger, 1999). This research explores the experiences of resilience in mothers of children with an autism spectrum disorder (ASD). As an incurable lifelong condition diagnosed from behavioural symptoms, ASD offers an opportunity to study an enduring chronically challenging situation for the mothers to overcome. This study uses a qualitative methodology approach, with a constructivist grounded theory method, due to its strong idiographic focus on exploring what a specific group of people do, as well as it's theory construction potential. Findings demonstrate that all seventeen participants were resilient, as each of them continued to function as mothers to their children despite extreme challenges. Furthermore, resilience in these mothers was demonstrated to be a non-linear circular process, with each part of the process juxtaposed between the past adversity and a future potential adversity. The participants also had a signature way of responding to adversity that was different to the other participants but congruent within themselves. The implications of these findings, provide a kinder conceptualisation of resilience that hopefully will affect the way that people who have experienced adversity are treated.

Keywords:

Autism spectrum disorder, constructivist grounded theory, mothering, resilience, wellbeing.

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Acronyms

ABA – Applied Behaviour Analysis

ACEs – Adverse Childhood Events

ASD – Autism Spectrum Disorder

BPS – British Psychological Society

CBT – Cognitive Behavioural Therapy

COR – Conservation of resources

IPA – Interpretative Phenomenological Analysis

LEA – Local Education Authority

MBI-GS - Maslach Burnout Inventory General Survey

PANAS – Positive and Negative Affect Scale

PECS – Picture Exchange Communication System

PTSD – Post Traumatic Stress Disorder

SEN – Special Educational Needs

VIA – Values / Virtues in Action

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Additionally, I would like to thank the participants who volunteered to take part in this study. Their courage in sharing their stories has enabled me to create this model of resilience which I hope will help lots of people.

I would like to dedicate this thesis to my Dad, who died two weeks before this project was due for submission. He was the one who always encouraged me to aim high and to look for those moments with the “occasional flashes of genius”.

Declaration

I declare that the research contained in this thesis, unless otherwise formally indicated within the text, is the original work of the author. The thesis has not been previously submitted to this or any other university for a degree, and does not incorporate any material already submitted for a degree.

Signed

A E Bishop

Dated: 30th September 2022

CHAPTER 1: INTRODUCTION

In March 2020 the UK entered its first lockdown as a result of the Covid-19 pandemic. As a response to this, a paper was published by the House of Lords Covid-19 committee stating that:

> *"The pandemic has shown that our current understanding of resilience and preparedness is not fit-for-purpose."* (Lane Fox, et al. 2021, pg., 2)

I totally agree with this statement as I think that as a society, we have misunderstood resilience and created a model of resilience that is almost guilty of toxic positivity. Resilience has become a metaphorical 'stick to beat people with' in terms of; if you find something hard in your life and you don't just immediately carry on as if nothing has happened that somehow you are not resilient and that you should do better. I think that is a message that is incredibly damaging to people.

In the above cited government report, they also state that:

> *"We want to see a new resilience agenda that addresses inequality, digital inclusion, and public health, and strengthens civil society and the integrity of our information systems. Such a resilience agenda is not merely an agenda for the Government to enact alone. Resilience comes, in large part, from the capacity and capability of non-government actors, from individuals and communities to businesses and charities, to take action and mobilise; the Government's role is to enable, support and co-ordinate."* (Lane Fox, et al. 2021, pg., 13).

So, although the government is looking for a new model of resilience, they are using the old model to set out their plans. They are also stating that the government's role in making that happen is the smaller part, with individuals being first in line. Additionally, the way that the report suggests determining the success of their strategies, is to have a sole criterion: that of the wellbeing of the people. This pretty much puts all the responsibility onto individuals to maintain their wellbeing. So, although this research project began before the pandemic, the conclusion has become very timely, in that now, more than ever, a new model of resilience is needed. A new model would offer a chance to reconsider how resilience is conceptualised, so that people are supported in challenging times rather than goaded forwards when circumstances are tough.

At the start of the project, people would ask what I was studying, and when I mentioned the word resilience, there was an almost universal reaction, with facial expressions that looked like I had used a 'dirty word', or 'blasphemed in their mothers church'. People would send me memes like the ones below, saying 'hey you are studying resilience, so I thought you would like this:

 *Figure 1 Dark Literata (2021)*	 *Figure 2 Saying images (2022)*	 Lyra IS NOT DAREDEVIL @PinkRangerLB "You're so resilient!" Thanks! My options were that or dead *Figure 3 Pink Ranger (2021)*

I asked them why they reacted in that way, and they responded with two reasons, the first being that they saw resilience as a stick to beat them with and secondly, that resilience is presented like a 'one size fits all' way of navigating challenges in life. They stated that the wellbeing workshops they had been sent on, offered one or two interventions, followed by an expectation that those interventions would be helpful to people in resisting any wellbeing downturn following adversity. I don't believe these explanations of resilience are correct either, so I think this is really important, because what I am hoping to put forward is a model of resilience that is considerably kinder than the message that people are currently given.

There presently appear to be a number of ways in which resilience is conceptualised; firstly, there are social media representations of resilience which are created by individuals and then shared depending on their ability to resonate with the experiences of other social media users. Then there is the 'self-help' industry that run the workshops that are spoken about by the creators of the social media memes. These workshops usually base their methods on a mixture of their own ideas and some academic research findings. Then there is academia, that conducts research into resilience, and defines it in terms of risk and protective factors and processes which can be measured using psychometric scales. There is of course, overlap between these three areas, which further adds to the confusion on the topic.

My desire to contribute a kinder version of resilience stems from the events that have happened in my life. I am the mother of a child with an autism spectrum disorder (hereinafter referred to as autism), who discovered a therapy for him that was based on a philosophy that called itself the Option Process© (Kaufman, 1994) . By studying this philosophy, I discovered the idea of working with my thoughts and beliefs so that I could be a happier and more loving mother. By using this therapy in my own life, I found that I was a lot happier in myself and with my situation. Having found this for myself I soon wanted to make a difference in the lives of more people than just myself and my son. By studying applied positive psychology and coaching psychology, I found a way to do that in a more mainstream academic way.

This study is, therefore, a multidisciplinary thesis. The main lines of discussion are created from theories that are founded in applied positive psychology. There are also theories taken from the various branches of psychology. Additionally, there are theories drawn from sociology, social policy and social work that have informed the discussion and research plan. The benefit of a multidisciplinary thesis is that the implications of the findings are also multidisciplinary. This has enabled what I believe, to be a richer discussion of the findings, as theories from all of the disciplines can be compared to this study's findings to find either support or critique for the new model.

In some ways, this project could be said to be a personal odyssey, a reflexive activity that has helped to explain my own experience of mothering a child with autism. All through the time when my son was younger and more of a 'handful', I was grateful that I mostly managed to take care of myself in a way that others saw as resilient. I am also grateful to have found the therapy that included the Option Process© (Kaufman, 1994). If I felt that my experience was enough to help other people, then I could have set up a coaching business and coached parents. However, if I was honest with myself, I knew that not everyone is like me, and that I did not have a monopoly on the truth about resilience. In the early days of this PhD project, I worked hard to draw a metaphorical line around my own experience so that I could set it aside. I thought about the option of carrying out an auto-ethnography, but decided in the end, that I wanted to hear what others had to say and to learn how others conducted their lives. In setting to one side my own experience, I am not denying or devaluing my own experience, I am adding to my knowledge. As Janesick, (2000, pg., 379) said, research has "an open mind but not an empty mind". Therefore, I carried out this study to find out what adaptation(s) people put in place to move through what Shakespeare (1601, Hamlet, Act 3 scene 1) termed "the slings and arrows of outrageous fortune [….] a sea of troubles." As it is clear that adversity is something that everyone faces in life (Bonnano, 2005; Pemberton, 2015).

The first hurdle that I came to, was in understanding what the component parts of resilience were. Seligman, (2011) stated that the ability to survive despite challenging circumstances is a universally desirable skill to have. However, everyone who is still alive has survived adversity, so survival cannot be the end goal of resilience, there must be something more specific than that.

Resilience was originally conceptualized using language borrowed from the natural science of physics. It describes the properties of a material that can endure stress or external pressure and still retain or return to its original shape after the removal of the stimulus (Tempski, Martins & Paro, 2012). In comparison, searching within the dictionary of psychology, suggests that the term has been utilized to refer to the ability of a person to either be happy again after something bad has happened or to be able to ‘bounce back’ to a previously held form (Cambridge University Press, 2021). However, it is not entirely clear whether the recovery is physiological, psychological, or sociological (Reich, Zautra & Hall, 2010). I found the borrowing of the concept of resilience from the natural sciences somewhat problematic though, as it is hard to equate a life adversity with a stressor such as the application of heat to a substance. If heat is applied to water, it is clear when the application of heat began, how much heat was applied, and when it ended and whether anything external to the water affected the outcome. I, as a researcher can observe dispassionately the process of evaporation and condensation of the water. However, life events are not so easily quantified or observed. Water is a defined, uniform substance, whereas people are unique. Furthermore, it is possible for a researcher to be objective and dispassionate when viewing water, even if they have a theory to support. A researcher looking at the behaviour of other people, has a far more complicated if not impossible, job of retaining their neutrality. This is because their own life experiences can cause them to hold a biased opinion of their observations and expectations of potential outcomes. This makes the whole endeavour of understanding resilience more complex (Bassot, 2016).

It is also not clear whether resilience to one sort of adversity can be generalised to mean that the individual is resilient in all adverse circumstances (Neenan, 2018). If a person loses their job, they might respond completely differently to that challenge, than they would to say a cancer diagnosis. Therefore, resilience in one situation does not mean a person is invulnerable to a different adversity (Pemberton, 2015). Additionally, resilience has been described as a process whereby the adverse event occurs, which is then followed by a period during which a person can adjust, adapt, and return to a previously held form (Olsson et al, 2003). This makes resilience appear to be an orderly, linear event; however, such a model does not really apply to situations where the events occur in an ongoing fashion, or where there are multiple adversities occurring at once. In these circumstances the stressor is never removed, which could mean that the person has no opportunity to recover. Following on from the natural sciences way of looking at resilience, it would seem that a person in a chronically adverse situation would have no possibility to bounce back, as if heat was relentlessly applied to water, then eventually it would all evaporate.

As a result, the psychological study into resilience has found it difficult to reach a consensus regarding; a definition of resilience (Coutu, 2003; Meredith et al, 2011; Shaikh & Kauppi, 2010), a list of risk and protective factors that lead to increased resilience (Gillham et al, 1995; Houser, Allen & Golden, 2006; Wagnild & Young, 1993), a way to measure resilience (Connor & Davidson, 2003; Oshio, et al. 2002; Smith et al, 2008) or an intervention plan to improve it (Chmitorz, et al., 2018;

Gillham et al, 2007; Neenan, 2018). There also seems to have been a pause in more recent studies into resilience, as these studies are quite old. I have not been able to find more recent studies that address these issues. A more recent systematic analysis of resilience interventions by Chmitorz, et al., (2018), had studies that were all dated in a similar period.

What the various theories of resilience do have in common though, is that resilience has two elements. Firstly, that there must be a successful recovery from an adverse event and secondly, that the recovery must be sustained (although nobody has stated for how long) and possibly lead to improvement in functioning or personal growth (Layne, et al., 2009; Reivich, & Shatté, 2002).

That an adverse event must occur, is key, because a person might appear to be doing well in life, but that does not necessarily mean that they are resilient (Neenan, 2018). It is only through a positive adaptation to a stressor that an individual or community can be said to be resilient. However, with reference back to application of heat to water in the natural sciences, it is not stated as to how the stressor is defined and/or measured. It is not clear whether the adversity is a small mishap, a bad day or an ongoing situation. Additionally, there is the problem of who is qualified to interpret the event as being adverse. What one person calls 'bad' might not be interpreted that way by another, so there is no universal notion of what constitutes an adverse event that would require resilience to recover (Luthar, Cicchetti & Becker, 2000; Neenan, 2018). Furthermore, to call an event bad, requires taking a snapshot view of the occurrence, rather than a lifespan view (Ivtzan et al., 2016). Sometimes post traumatic growth can occur after an event in which the person can see the originally unwanted event as a gift. Tedeschi and Calhoun (2004, pg., 1) define post traumatic growth in the following way:

"Post traumatic growth is the experience of positive change that occurs as a result of the struggle with highly challenging life crises. It is manifested in a variety of ways, including an increased appreciation for life in general, more meaningful interpersonal relationships, an increased sense of personal strength, changed priorities, and a richer existential and spiritual life."

It is also likely, that occasionally, the previously held form is impossible to return to, or that changing into something different through post-traumatic growth, might be more effective or adaptive (Joseph, 2011). Adaptation following an adversity does not mean that an individual should not be distressed, but that recovery should be swift and comprehensive in regaining either physiological or psychological equilibrium (Reich, Zautra & Hall, 2010). However, not all individuals react at the same speed which has led researchers to ask what the difference is, between those who experience a fast recovery and those who take their time (Carver, 1998).

The original psychological concept of resilience arose from work with children living in poverty where it was noted that some children had better outcomes when compared to others who had a similar start in life (Garmezy & Nuechterlein, 1972; Garmezy, 1993). This observation led researchers to suggest that resilience was an innate quality or trait and so they focused their attention on individual characteristics of personality or genetics (Block & Block, 1980; Gallo et al., 2005; Hu Zhang & Wang, 2015; Skodol et al., 2007). However, studying resilience in this way has a side effect that in suggesting that there is such a thing as a resilient person, that this then implies that some people are just not resilient. This led to resilience being viewed within what has historically been seen as the 'disease model' in that the area most addressed is the perceived lack of resilience in an individual.

However, there has been somewhat of a paradigm shift (Kuhn, 1962) in thinking about resilience, so that it is now viewed within its own model. The new 'resilience model' suggests that the norm is a positive adaptation to adversity, rather than a maladaptive reaction (Perry 1983). This means that resilience should be analysed as a separate orthogonal concept in terms of antecedent, process, and outcome (Reich, Zautra & Hall, 2010). This approach is in keeping with the emergence of the field of Applied Positive Psychology which seeks to enhance wellness rather than to treat illness (Seligman & Csikszentmihalyi, 2000). Applied Positive Psychology has been the driving force behind the development of interventions designed to improve levels of wellbeing. These activities are scientifically based activities that improve levels of wellbeing, such as mindfulness (Kabat-Zinn, 2001) and gratitude (Emmons, 2008) or using signature strengths (Seligman, 2011). These interventions are also indicated for someone who wants to be more resilient (Seligman & Csikszentmihalyi, 2000).

To demonstrate the efficacy of these interventions are several different scales and measures that purport to quantify levels of the essential factors of resilience, (Connor & Davidson, 2003; Wagnild, & Young, 1993). However, this reveals another problematic part of the research around resilience in deciding how to scientifically measure it.

Psychometric testing has offered researchers a way to test the construct of resilience in a way that suggests objectivity. These tests are created using factor analysis to determine an overall score which is meant to indicate an individual's level of resilience. However, who decides what the factors are? Current research practice suggests that it is possible to produce a shortlist of risk and protective factors that can be measured to determine an individual's level of resilience (Coolican, 2009). This is problematic though as there is, no consensus of opinion on what these risk and protective features are. For example, The Penn resilience program (Gillham, et al., 1995) suggests that: self-awareness, self-regulation, mental agility, strength of character, connection and optimism are protective factors of resilience. Conversely, a study by Wagnild and Young (1993) states that the protective factors are:

equanimity, perseverance, self-reliance, meaningfulness, and existential aloneness. Houser, Allen and Golden (2006) stated; personal agency, concern to overcome, self-reflective style and a commitment to relationships as protective factors. So, it can be seen from these studies that there is no consensus, as to what the protective factors are or how they should be measured, with each scale measuring different factors (Oshio, et al., 2018; Wagnild & Young, 1993).

The Penn Resilience programme (Gillham, et al., 1995) is an example of an intervention designed to improve levels of resilience with exercises such as three-good things, which asks the individual to recall three things that they feel were good, that occurred during the day and to savour them last thing at night. Another one of the Penn Resilience programme's suggested interventions, is using signature strengths in new ways. This involves the completion of a self-report questionnaire which gives a bespoke hierarchy of strengths that the individual has. They are then asked to find new ways to use the identified strengths. The potential benefit of this is that in using a pattern of strengths that are unique to themselves the individual can behave in a way that is congruent with their personality as well as being able to do things that they are already good at (Peterson, & Seligman, 2004). This program claims to reliably prevent depression, anxiety, and behavioural problems in adolescents (Seligman, 2011). However, the message this claim gives, to a person who completes a programme like this and then still becomes depressed is highly problematic, as they not only are facing a challenge, but they also now must make time to write about their day or meditate, which can appear to be an unwanted additionally burden and then realise that they have failed to achieve the outcome advertised by the programme. The danger here, is that resilience training becomes a stick to beat people with rather than something that enhances wellbeing (Held, 2004).

Research by Lyubomirsky (2007) suggests that there is a 'goodness of fit' for Positive psychology interventions and that not everyone is suited to all interventions and so individuals should pick the ones best suited to themselves. This 'goodness of fit' is assessed using a questionnaire that Lyubomirsky (2007) created for this purpose. This is contradictory to the approach taken with resilience interventions like Mindfulness, that take a more 'one size fits all' approach, as Mindfulness is described as being good for everyone (Kabat-Zinn, 2001).

The idea that a person can be resilient regardless of their circumstances can lead to a blame culture that minimises a person's experience of adversity and creates a culture of 'toxic positivity'. This stems from an avoidance of negative emotions using platitudes and 'inspiring' exhortations (Davis, 2021). Toxic Positivity is defined as "the act of rejecting or denying stress, negativity, or other negative experiences that exist" (Sokal, Truddel & Babb, 2020). It is the approach that insists that people are given interventions that must be followed rather than giving the individual the opportunity to access their own wisdom about what is best for themselves. The consequences of this, are that the person experiencing adversity is left alone to deal with their situation and their unhappy feelings, or worse still, left feeling that they failed at achieving the better choice of remaining happy (Davis 2021).

The idea of a ‘bounce-back’ from adversity also gives the impression that there is no effort required to recover as a ball bouncing back, happens immediately and effortlessly due to the physical properties of a rubber ball (Pemberton, 2015). As Post Traumatic Growth theories show, there is benefit in the journey of recovery as valuable lessons can be experienced along the way (Joseph, 2011).

To say that a person is resilient or has innate resilience is however, a somewhat circular logic. It would work in the same way as Becker’s (1991) Labelling theory, which argued that identifying a person as a ‘criminal’ would lead to further criminal behaviour, because the label becomes a self-fulfilling prophecy. Therefore, a person who is identified as resilient would then be resilient, as they would behave in such a way as to confirm their resilient label.

Situating resilience solely within an individual is also problematic as it would require the researcher to believe that a person exists in a vacuum, completely unaffected by their surroundings (Pemberton, 2015). Additionally, to claim that interventions such as a gratitude exercise can increase a person’s resilience does not consider the environment that a person resides in. Using a systems approach changes the way that individual resilience is viewed (Bronfenbrenner, 1981; Masten, Best & Garmezy, 1990). Family Systems theory suggests that there is an interplay between the individual and their immediate family and that each will affect the resilience of the other. Therefore, any intervention would have to include the whole family. Outside of the family there is the school or workplace and the community, with each having an impact on the other (Gillham, et al., 1995). Beyond that there are inequalities in the structure of society that can either be part of the problem or the solution (Hart et al., 2016).

Science attempts to create gold-standards and black and white distinctions as these are held to be the best in their genre (Brodsky & Lichtenstein, 2020). However, the lack of consensus in almost all aspects of resilience theories show that these absolutes either do not exist or have not been found yet. Therefore, a more flexible model is needed that can accommodate each person’s individual style of resilience. This is not intended to suggest that other theories of resilience are wrong, but that there might be a Hegelian style adaptation to the existing models that could act as a flexible synthesis of the existing theories (Forster, 1993). This could then draw together what is already known about resilience, into a model that can be clearly understood and yet flexible enough to allow an individual bespoke functioning within it.

1.1 Research aims and objectives.

This thesis, therefore, focuses on the topic of resilience. The current problems with; defining, operationalising, measuring, and improving resilience are explored by examining the current literature on this topic. This is followed by a critique of the current conceptualisation of resilience, asking what is wrong, or what doesn't work about the current models and theories of resilience. This leads to an explanation of why the current theories of resilience need to be modified with a new model.

To do this in a scientific manner, a group of people facing a common challenge was needed, so that the differences (if any) would be attributable to resilience rather than the nature of their adversity. This would follow in the footsteps of Garmezy's (1985) research in childhood adversity and resilience. By selecting a group who faced a common challenge it was hoped that they would operate like a quasi-case study to elicit a model or adaptation of a theory of resilience.

There are several groups of people who could have been chosen for this research, however, in addition to the reasons given in the methodology section, parents of children with autism were chosen, as it is a group of people that I have contacts with, due to my being a mother of a child with autism. Using a group of people that I know, has several advantages for this study. Firstly, there is immediate access to this group of people as connections are already made with people and organisations. Secondly, rapport is more easily established as the participants immediately feel understood and thirdly, I am already aware of some of the challenges that these mothers may face and so can formulate questions that can more quickly get to the heart of the matter (Creswell, 2007). Additionally, I have conducted two previous research studies on the wellbeing of parents of children with autism and so already possess significant knowledge and experience in this area.

For a while, conducting the study as a piece of auto-ethnography was considered. However, this idea was eventually rejected due my desire to see if my experience was typical or whether there were things I could learn from others, so that a more generalizable picture of resilience could be created.

In addition, carrying out a quantitative study had been conducted before using pre-validated scales as a tool to measure resilience. However, this limits the participant to the factors chosen by the researcher, therefore, this study did not use such scales. Instead, I used the open questions of a qualitative semi-structured interview to ask the participants about their lives. This meant that the participants were free to answer in whatever way that they wanted. It was hoped that by removing the constraints of other researchers ideas on resilience, that the new model would emerge. The research study, therefore, takes a Constructivist Grounded Theory approach due to its theory generating potential from the data (Charmaz, 2014).

Currently, the literature has a few studies exploring the resilient experiences of families including a child with autism, but the majority of these studies are quantitative (Eisenhower, Baker & Blacher, 2005; Estes et al, 2009; Estes et al, 2013). If a new model or adaptation to a theory is to be built, then looking in a place that has been explored before will likely yield the same answers.

The research was designed to ask qualitative questions to this cohort so that new insights on resilience could emerge. The message that asking questions in this way, to elicit a model of resilience gives to this group, is that they are experts on their experience of resilience and that their experience can be useful to others (Neenan, 2018). It also meant that the participants were able to be included in the research from their home rather than having to attend an unfamiliar setting. This is totally different to the balance of power in quantitative research (Sarantakos, 2005).

The research study was, therefore, qualitative and utilized a constructivist grounded theory approach. This method allowed me to gather rich data from the participants that focused on the subjective meanings, interpretations, and significance, that the participants gave to the events in their lives (Punch, 2013). It allowed for a more holistic approach to the research in that the participants could add context to the data that they provided. A constructivist grounded theory approach (Charmaz, 2014) allows the participants voices to be heard first, as the literature review was delayed until after the data was collected, which is different to other methods of data collection and analysis in qualitative research (Dunne, 2011; Glaser & Straus, 2008). The research was therefore idiographic involving seventeen participants. The interviews were conducted until saturation was reached and new data did not elicit new ideas, which means that the conclusions drawn can create possible future generalisations (Charmaz, 2014). Constructivist grounded theory was selected instead of the classic grounded theory method because it acknowledges that I am part of the research process. I have a child with autism and so could not possibly claim to be an external observer. The grounded theory method of memo writing allowed me to play an active part in the research process (Charmaz, 2014).

The semi-structured interview schedule allows the participants the opportunity to tell their story starting from the time before their child with autism was born. They then were able to talk about what had been challenging and what continues to be a challenge. Next, they described how they met those challenges using the resilience strategies that they already have. From these interviews, the transcripts were anonymized and analysed which allowed the possibility of a new conceptual framework model to emerge from the data. (Charmaz, 2014). A more thorough discussion of how this was done can be found in the methodology section.

This study has therefore focused on the following research questions:

Firstly, there is an overarching question, this was created as broadly as possible to highlight the goals of the study, to give room for the sub-questions, and also to provide a broad scope for the initial interview schedule (Janesick, 2000):

To what extent, do mothers of children with autism, experience resilience, given the challenges and stigmas of parenting their child?

Then there are three sub-questions:

1) What does the word resilience mean to mothers that have children with autism?
2) How does being a parent of a child with autism affect the mother's resilience?
3) In what ways do mothers of children with autism demonstrate resilience?

These questions are the final version of the research questions which were honed over the course of the study. There was an interplay between the data collection and analysis process and the formulation of the questions, so that the knowledge that percolated during the analysis could inform the next stage of the research, by reconfiguring the overarching and sub questions (Agee, 2009; Charmaz, 2014)

So, to summarize, I believe that this is an important study for everyone because the entire population will have faced some challenges in life and so will need to be able to recover. Resilience is a topic that has captured the interest of many, but so far, no consensus definition has been found. However, there is an agreement around the idea that resilience is a desirable skill that improves the quality of life for those who are able to utilize it.

Neff (2011) states that part of our human condition is dealing with challenge, and parenting a child with autism is one way that life can be challenging. I have chosen parenting autism, mainly because I come from that community, and it is one that I understand. Primarily though, I chose mothers of children with autism, because I wanted to have a group of people facing the same challenge, so that any differences between their responses would be due to resilience rather than them facing a different challenge. So, exploring autism parenting, operated like a quasi-case study, whereby the participants were facing a challenge of similar severity. Mothers of children with autism are a population of people who are told to 'just get on with it'. From my own experience, there is very little support or sympathy for these mothers and in some environments, there is still a culture of blame for being in this situation (Bettleheim, 1967).

So, this study will be of interest to a wide variety of people. Firstly, for people in the wider field of resilience as the new model incorporates the concepts of other models. It will also be of interest to those working with families of children with autism as it will offer a new way to work with these mothers. It will be of interest to the population studied too, as their struggles and triumphs are highlighted.

It will also be of interest and importance to people because it is politically timely. At this point in time the pandemic furlough support needs to be paid for. On top of this a war in Ukraine has led to price rises in commodities like fuel, which consequently raises the price of everything else due to delivery costs. The political rhetoric at the current time, justifies austerity while talking about high inflation and a cost-of-living crisis, which is particularly challenging for those people living on benefits or a low income. Unfortunately, the response to this situation was a suggestion made by Lee Anderson an MP, who said that ‘the poor should learn how to cook and budget better’ which puts the blame for an inability to provide for themselves and their family onto the individual (Mills, 2022). This demonstrates further how doing better and being more resilient is used as a political weapon. The present society takes an individualistic approach, with everyone exhorted to ‘do their bit’, with the individual effort contributing to the collective success or failure. So, this study can contribute to anti-discriminatory practice by making sure that individual’s personal characteristics cannot be ignored when discussing resilience.

It will also be of interest to employers who organize Continued Professional Development days to support the wellbeing of their staff. The current practice of providing wellbeing workshops suggesting that a few personal interventions can help people to resist a downturn in wellbeing can be reconsidered in the light of the findings of this research. This would then reduce the potential for financial abuse whereby people go on courses to improve their resilience and are given a one size fits all approach to resilience which will be useful for some, but for others will leave them feeling criticised for being unable to improve their levels of resilience.

CHAPTER 2: LITERATURE REVIEW

2.0 Chapter overview

This chapter seeks to provide the academic background and context to the research project. The first section introduces the concept of resilience and explores why it is that further research into this construct is still needed. This section is based on a model of resilience proposed which has been created to represent a summary of the literature in the substantive area of resilience. This is then followed by a demonstration of where this model can be found in the existing literature.

The second section of this chapter looks at the choice of mothers of children with autism as a cohort to use as a quasi-case study. This group is then assessed to ensure that there is sufficient adversity to elicit a resilient response and so provide the answers to the research questions. The chapter concludes by examining whether there is evidence in the literature of resilience in these mothers despite these challenges.

2.1 The method of review

Research has to date, provided no consensus on definition, operationalisation, or method of measuring the construct of resilience. There are now thousands of articles written on the topic of resilience, hence, a rationale is needed to choose which articles should form this document. Firstly, this study has used a method of data analysis informed by constructivist grounded theory (Charmaz, 2014), which prescribes that the review of the literature, should be conducted after the data collection and analysis reaches a late stage. This is advised so that the model that will be proposed later in the study can be said to come from the data rather than the existing literature. Secondly, the nature of an academic paper requires that peer reviewed sources are targeted for inclusion. As resilience is both an academic area of interest as well as a ‘self-help’ topic, identifying only academic sources was important. Thirdly, there were some theorists whose papers are considered ‘seminal’ within this area. This is because they contained new ideas that were influential in providing ongoing stimulus to the discussion of resilience. These papers are considered to be landmarks in the progress of the topic of resilience. Lastly, other papers were included that referenced these seminal theorists if they added a development of an element to the discussion – thus fulfilling Sir Isaac Newton’s (1675) edict to ‘stand on the shoulders of giants’.

The objective for this section is therefore twofold: firstly, it aims to critically analyse those papers identified in the method described above, and secondly to show a gap in the current knowledge on the topic of resilience and thus demonstrate the rationale for this study.

2.2 Conceptualizing resilience

After studying the literature on the subject of resilience, it became obvious that this was an extremely complex topic. To clarify the substantive topic area, a diagrammatic representation of resilience was created to operate as a summary of the literature review. The purpose of this diagram was to provide a solid foundation for the project to stand on, in which the findings could be compared to something concrete. The need for this diagram arose due to the lack of consensus of a definition, conceptualisation, operationalisation, or measurement scale for resilience. The diagram can then operate as a 'clay pigeon', in that it sets up a target that can be metaphorically 'shot down' by competing arguments. To get the best use out of the 'clay pigeon', the diagram is proposed at the beginning rather than at the end, in order to facilitate clarity in the subsequent discussion. The diagram has this quotation from Lines et al, (2020, pg176) as its inspiration:

> *"This conceptualisation helps clarify the distinction between resilience resources (often referred to as protective factors), processes, and outcomes. Resources help maximise the likelihood of a system withstanding or bouncing back from the negative effects of adversity exposure, whereas processes reflect the translation of one's potential for action via cognitive emotional, or behavioural mechanisms into a demonstrable outcome. Thus, resilience as an emergent outcome is displayed when salient resources are activated in response to an adverse event to enact adaptive processes that result in optimal functioning either in terms of withstanding the negative effects of the adversity or bouncing back from deteriorations in functioning".*

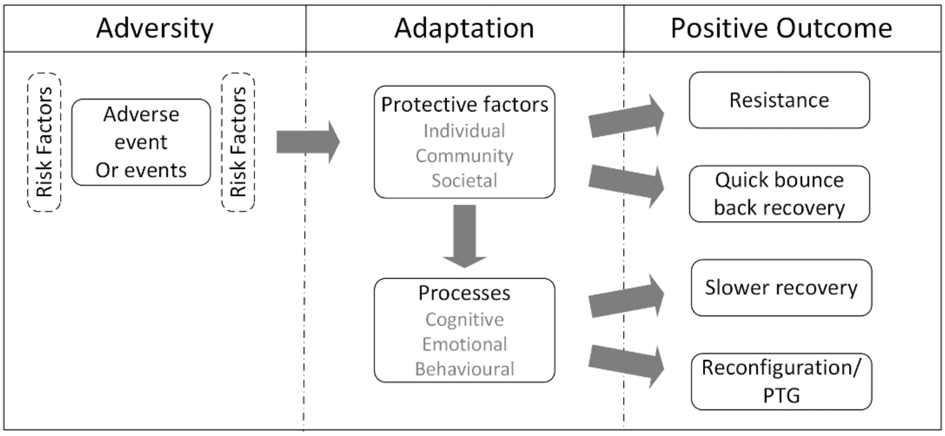

Figure 4 The two-step process of resilience – authors own representation of Lines et al. (2020)

This diagram illustrates a two-step model, which shows how a resilient response to adversity involves firstly the protective factors which either lead to resistance to the adversity or a quick bounce back, which is the traditional model of resilience. If that isn't possible, then the protective factors facilitate the processes which then lead to a slower recovery or post traumatic growth. As this model represents a synthesis of the theories contained herein, they are not given citations at this point. Once this model is broken down in the discussion following, the elements will be attributed to the relevant theorist.

‘Resilience’ has been given as the reason why some people seem to breeze through adversity while others crumble. Two people could experience the exact same challenge in their lives and yet react or recover completely differently. Therefore, the ability to be resilient in life is key because everybody’s life includes adversity (Reivich & Shatté, 2002). The pursuit to understand the reason why people manifest different levels of resilience, has led to many attempts to conceptualise, define, and operationalize resilience (Luthar, Ciccetti & Becker, 2000, Rutter, 2007). However, as can be seen by the following discussion, clarity around the concept of resilience remains vague, ambiguous, and elusive, which underpins the reasoning for researching it further in the hope that some clarity can be brought to the subject.

The word resilience has as its Latin root the word ‘resili’ which means “to bounce or spring back” (re – ‘back’ and salire – ‘to jump’) (Agnes, 2005). To bounce back from adversity or to recover from an ongoing situation is the most commonly accepted meaning of the word resilience. Psychological research into the concept of resilience based its ideas on the theories from the physical sciences, where the idea that a chemical substance could be said to be resilient if it could return to its previous state after a stressor such as intense heat or pressure had been applied (Harriman, 1958; Tempski, Martins & Paro, 2012). This gave the idea that people could do the same and just bounce back to a previous condition following adversity (Rutter, 1985).

Traditionally, research into resilience began in Developmental Psychology, which is a branch of psychology that studies the “processes which underlie growth and changes in behaviour over time” (Glassman and Hadad, 2009 pg., 326). It was observed that some at-risk children could survive and even thrive despite traumatic or extremely challenging circumstances such as birth defects, poverty, parents with chronic illnesses, neglect, and abuse (Garmezy, 1991, Garmezy, 1991, Garmezy, 1993). Later researchers turned their attention to adults and the elderly and looked at resilience in both one-off occurrences and chronic life changing events (Thompson & Cox, 2020). Over the last thirty years, research into resilience has proliferated with studies into almost every aspect of life (Pemberton, 2015), for example, academic resilience (Morales, 2008),disability (Runswick-Cole & Goodley, 2013) teaching (Gibbs & Miller, 2014), and employee resilience (Shoenfelt, 2016). However, despite all this research a definition of resilience has still not found a consensus among researchers (Masten, 1999; Noltemeyer & Bush, 2013), leading some to question whether it is a useful construct to study at all (Luthar, Cicchetti & Becker, 2000).

As there is no consensus around a definition of resilience, a dictionary was used as a starting place. The Merriam-Webster online dictionary (2021) states that: “Resilience is the ability to become strong, healthy, or successful again after something bad happens.” A second definition clearly has the physical sciences as its inspiration as it states: “to return to an original shape after being pulled, stretched, pressed, bent, etc.“ Further definitions from the same dictionary state more aspects of resilience in that “a: a person can be capable of withstanding shock without permanent deformation or rupture and b: tending to recover from or adjust easily to misfortune or change.” One last definition from the Merriam-Webster dictionary (2021) adds yet another dynamic to the concept of resilience: “implies the ability to recover shape quickly when the deforming force or pressure is removed”. This definition is interesting because it addresses the speed at which the resilient response is expected, namely that the clock doesn’t start ticking on the timer until the deforming force or pressure is removed (Merriam-webster, 2021). Therefore, even within one dictionary there is not one single definition of resilience that the researchers of the past thirty to forty years could adopt.

The upshot of this is that every research project has attempted to define the concept themselves. In the table below are a selection of definitions drawn from the literature search that demonstrate some of the theories and concepts of resilience.

Study	**Definition of resilience**
Burns & Anstey, 2010 pg. 527	“A multi-dimensional construct that comprises a network of favourable attitudes and behaviours that enable adaptive coping strategies to acute and chronic stressful life events.”
Egeland, Carlson & Sroufe, 1993 pg. 517	“Transactional process within an organizational framework. Developmental outcomes determined by the interaction of genetic, biological, psychological, and sociological factors in the context of environmental support.”
Fonagy, et al., 1994 pg. 233	“Normal development under difficult conditions.”
Lines et al., 2020 pg. 176	“A system (individual/team) trajectory of functioning over time within the context of adversity exposure, whereby the system (individual/ team) might withstand the potentially negative effects, or bounce back quickly to normal (i.e., pre-adversity) or healthy levels of functioning.”
Luthar, Cicchetti & Becker, 2000 pg. 543	“A dynamic process encompassing positive adaptation within the context of significant adversity.”

Masten, Best & Garmezy, 1990 pg. 425	“Process, capacity, or outcome of successful adaptation despite challenges or threatening circumstances. Good outcomes despite high-risk status, sustained competence under threat and recovery from trauma.”
Masten, 1999 pg. 283	“Patterns of desirable behaviour in situations where adaptive functioning or development have been or currently are significantly threatened by adverse experiences or rearing conditions.”
Masten, 2019 pg. 101	“The capacity of a system to adapt successfully to disturbances that threaten the viability, function, or development of the system.”
Noltemeyer & Bush, 2013 pg. 477	“The product of a rich interplay between risk factors and protective factors.”
Olsson, et al. 2003 pg. 2	“Resilience can be defined as an outcome marked by specific patterns of functional behaviour despite adverse factors, or an active process of adaptation to a risk involving an interplay between the risk and protective factors either from the individual or their environment”
Rutter, 1985, pg. 147; 1987, pg. 316; 1999 pg. 119	“The positive end of the distribution of developmental outcomes among individuals at high risk. A dynamic process involving an interaction between both risk and protective processes, internal and external to the individual, that act to modify the effects of an adverse life event.”
Ungar, 2008 pg. 225	“Both the capacity of individuals to navigate their way to health-sustaining resource and a condition of the individual’s family, community and culture to provide these health resources and experiences in culturally meaningful ways.”
Wagnild, 2009 pg. 105	“Resilience connotes inner strength, competence, optimism, flexibility, and the ability to cope effectively when faced with adversity. Resilience is associated with numerous desired outcomes including physical health and emotional health.”
Zautra, Hall and Murray, 2010 pg. 4	“An outcome of successful adaptation to adversity”.

Table 1 Lack of consensus of definitions of resilience

Furthermore, a literature search by Meredith et al, (2011, pg.20) on the definition of resilience, found one hundred and twenty-two different definitions of resilience, with none being accepted as consensus about how resilience should be defined or operationalised (Herrman et al. 2011).

The above definitions all have in common, the approach that resilience manifests itself in response to adversity. Therefore, a person who has not faced an adversity, should such a person exist, cannot be said to be resilient as their resilience has not been tested (Noltemeyer & Bush, 2013). There are, however, some features of resilience definitions that occur in every attempt to define it. So, firstly, there is the fact that an adverse event must either have occurred or be ongoing, and secondly there must be a positive adaptation and thirdly a state of equilibrium or well-being is reached as an outcome (Garmezy, 1990; Luthar, Cicchetti, Becker 2000).

It is also possible to plot the progress in resilience research as the older definitions such as Egeland, Carlson and Sroufe, (1993), and Fonagy, et al., (1994) talk more in terms of developmental outcomes, whereas by the end of the 1990s the focus was more on the method of reaching the outcomes (Burns & Anstey, 2010; Luthar, Cicchetti & Becker, 2000). This transition in the way of defining resilience, demonstrated a transition in thinking about resilience from it being a trait that some people had into something that people do.

Therefore, for the purposes of this study, the definition given by Zautra, Hall and Murray (2010 pg. 4) "An outcome of successful adaptation to adversity", was adopted as a working definition, as it contained all three of the features that have achieved an element of consensus.

2.3 Operationalizing resilience – Identifying the building blocks.

It is a matter of conjecture as to why it has been so challenging to reach a consensus definition of resilience. Possibly, it is because people are unique, as are the circumstances that they find themselves in. Studies of resilience are either cross-sectional (Werner, 1986; Windle, & Bennett, & Noyes, 2011) and take a snapshot approach with the participant contributing data only on one or two occasions, or they are longitudinal studies that capture data on at least three separate occasions (Singer, & Willett, 2003). These demonstrate trends that occur over time, using psychometric scales that are administered several times (Cosco et al., 2016). With either of these two approaches, a different amount of time has elapsed for each individual, between the day the adversity occurred and the day of participation in the research. This means that people are at different stages in their response to adversity, so 'like' is not being compared with 'like'. On top of this there is huge subjectivity in defining the building blocks of resilience, for example, what constitutes an adverse event and who gets to decide whether something is adverse as not everyone will interpret an event in the same way. Furthermore, there has not been a consensus of opinion in either physical or mental health disciplines around the concept of what it means to recover. The majority of developmental researchers approach this question from the position of believing that it is a minority who recover from adversity (Zautra, Hall & Murray, 2010). However, Masten (2001) describes the process of recovery as 'Ordinary magic' meaning, that it is the most likely outcome. This is supported by other research which suggests that recovery is the modal outcome (Dowrick, Kokanovic, Hegarty, Griffiths & Gunn, 2008; Zautra, 2003). There is also no agreement about what the desired outcome should be, or even what is meant by outcome and when it could be said to have been reached and so ready for inspection.

Additionally, there are problems in using the English language to describe resilience, as not all researchers are using the terms in the same way which adds to the confusion. An example of this is that words for the process of adaptation and the outcome of successful adaptation are used interchangeably to describe resilience (Luthar, Ciccetti, & Becker, 2000; Olsson et al. 2002). This is also true of the word recovery. It isn't clear if this refers to the process of recovery, or the position of having recovered (Zautra, Hall and Murray, 2010). This next section hopes to provide some clarity, by taking every section of the authors own diagram (above Fig, 1) and explaining and critiquing each concept, demonstrating how it contributes to resilience, beginning with adversity.

The research by Garmezy (1991, 1993) began with an observation that not all children who lived in an adverse environment such as poverty suffered the negative outcomes that were expected. A visual diagram of the building blocks identified in Garmezy's original research would look like this:

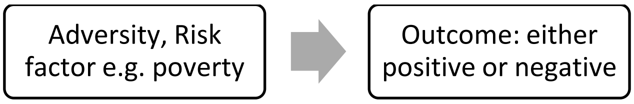

Figure 5 Diagram of Garmezy's observation of children living in poverty (authors own)

The first stage in the resilience model must be the adverse event or events, as a person (if such a person could exist) who has an easy life with no challenges in it, has no need for resilience (Noltemeyer, & Bush, 2013). However, what constitutes an adverse event is subjective and open to interpretation. As each event occurs, it is interpreted through the attitudinal lens of the person involved. It is that interpretation that will determine whether it is an adverse event or not (Lines et al. 2020). An example of this, is that two siblings may discover that their elderly aunt has died. The older sibling may have been very fond of the aunt and so be terribly distressed for many months. Whereas the younger sibling may live some distance away and not be so close to the aunt and consequently, not find their life affected in any way at all. In this case, the younger sibling does not consider this event to be adverse and so has no need for resilience compared to the older sibling who experiences a loss of emotional wellbeing, which must then be recovered to return to their previous level of functioning. Conversely, Luthar and Cicchetti, (2000 pg. 858) stated in their research that an adverse event should statistically be associated with adjustment difficulties. This brings the idea of standardised measurement of adversity with reference to a norm way of responding to a particular circumstance. This suggests a level of objectivity in qualifying an event as being an adverse event rather than the individual subjective identification suggested by Lines et al, (2020). Taking the idea of external assessment further, Riley and Masten (in Peters, Leadbeater & McMahon, 2005 pg. 13 - 25) defined adversity as “experiences that have the potential to produce undesirable outcomes by disrupting normal functioning.” This means, that there is a concept of which adversities have the potential to cause disruption and which ones do not. However, as can be seen in the argument on risk factors which follows, there are other features that affect whether or not an individual experiences an event as being adverse. It is also informative for this present study as it illustrates the necessity for a qualitative study, in that a quantitative study cannot be flexible enough to incorporate the nuances of personal interpretation of an event as being either adverse or not.

Risk factors are issues that are present in a person’s life that intensify the impact of an unwanted event, making a maladaptive outcome more likely (Collazzoni et al. 2020; Rutter, 1987). According to Swadi, (1999) these risk factors have three domains: constitutional predisposition, environmental factors such as family or peers, and life events. These domains of risk factors echo those found in Bronfenbrenner’s (1981) ecological systems theory in that they were: Individual, family, school, peer group and community (Howell and Egley, 2005). An example of a risk factor is that, suppose a student had a paper returned from their tutor with a mark that was lower than expected. If that student came from a dysfunctional family, they may find that instead of sitting down with the student and helping them go through the paper and see where it went wrong, they may instead ridicule the student for their grade. This would then intensify the feelings of failure for the student because they would then be dealing with two unwanted situations: the low grade and the ridicule of their family, the low grade being the adversity and their family being the risk factor. The negative outcome would be that the student might eventually find this too challenging and so drop out of their studies.

2.3.1 Protective factors

As the research concept of resilience was developed, the question was asked as to what made the difference between those children who had a positive outcome compared to the children who suffered negative outcomes. It was concluded that the children who went on to enjoy a positive outcome had some protective factors that enabled them to thrive despite the risk factors like poverty (Garmezy, 1991).

This added a third building block to the diagram:

Figure 6 Revised resilience model based on the concept of protective factors (authors own)

This third block demonstrated that while adversity has the potential to disrupt normal functioning, it is resilience that has the potential via the protective factors, to retain and successfully adapt functioning so that the negative outcome is avoided. The outcome is therefore dependant on whether functioning is disrupted, or whether the individual has the protective factors that enable them to manage the adversity, and so retain their developmental trajectory or to return to normal functioning after a small downturn (Rutter, 1987).

This idea led to research that looked at risk and protective factors that the individual had, that meant they could quickly adapt or withstand the adversity (Masten, Best, & Garmezy, 1991). The concept worked in the same way that the physical properties of a chemical behave in enabling a substance to either not bend and break under pressure, or to return quickly to its previous form once the pressure had been removed (Tempski, Martins & Paro, 2012). Therefore, researchers focused their efforts on understanding what these characteristics were, and how they functioned (Masten, 1999). The benefit of establishing these concepts was articulated by Noltemeyer & Bush' (2013 pg. 476) in stating that resilience is:

> *"…an interactive model where the relationship between a risk factor and an outcome is weakened by the presence of one or more protective factors" […] "This may be because the protective factor a) buffers the risk factor, b) interrupts a risk chain through which risk factors exert their effects, or c) prevents the occurrence of the risk factor altogether".*

Therefore, a person who has these protective factors in abundance has an advantage in the way that they would be protected from the negative consequences of adversity. This however highlights that the presence of something as a protective factor also means that the absence of it becomes a risk factor. For example, high self-esteem may protect in adversity and low self-esteem may make a person more vulnerable to risk (Rutter, 1987).

Bronfenbrenner's (1981) ecological systems theory suggested that people operate in nested systems rather like Russian dolls. The individual is situated in the inner section and their experience is affected by interactions with the outer sections. Therefore, no layer exists in isolation, so it would stand to reason that protective factors in families, communities, organizations, and societies would affect the individual and vice versa (Lomas, Hefferon & Ivtzan, 2014). The following section reviews the studies that address these issues beginning with the individual, the family, the community and lastly the society.

The protective factors of the individual can be divided into biological (Cicchetti & Blender, 2006; Cicchetti & Rogosch, 2009) and psychological factors such as beliefs (Lee et al. 2010) or strong work ethic (Morales, 2010). Biological factors explain (on a level smaller than the smallest of Bronfenbrenner's (1981) system), how a person's gene-expression can affect their ability to adapt (Masten 2019). The genes that an individual possesses affect the way that the stress response system works and makes a person more (or less) susceptible to psychiatric disorders. Allostasis (Sterling & Eyer, 1988) refers to the process the body goes through to adapt to daily stressors and maintain homeostasis. When an adverse event occurs the brain responds by releasing catecholamines and other stress related hormones that prepare the individual to activate the fight or flight mechanisms. The difference between the way that individuals react, is affected by the way that their coordinated function of a large number of hormones, neurotransmitters and neuropeptides occurs in response to stress (Feder et al. in Reich, Zautra & Hall, 2010).

Initially the 'recovery resilience' model suggested that there was a resilient personality, and that resilience was correlated with the 'big five' personality traits theory (Costa & McCrae, 1992). The big five personality theory suggests that an individual person has traits in their personality. These are characteristics that are stable over time, and that these traits make up who a person is, and how they might be understood. Each of the five domains of the big five model represents a range along which a measure can be taken, for example the domain named extraversion ranges from extrovert through to introvert, with each person in the population lying somewhere along this line (Maltby, Day & Macaskill, 2013). A meta-analysis study (Oshio et al, 2018) that explored the relationship between the big five and resilience revealed positive small to moderate correlations with the domains of Openness to Experience (0.34), Conscientiousness (0.42), Extraversion (0.48) and Agreeableness (0.31) and a negative correlation with Neuroticism (-0.46). A positive correlation means that when, the levels of Openness to experience, Conscientiousness, Extraversion, and Agreeableness go up, levels of resilience would also go up. A negative correlation would mean that when Neuroticism goes up, that resilience goes down. This provides some support for the theory that a persons' character has an impact on their ability to be resilient, but only a small to moderate one (Oshio et al, 2018).

Duckworth's (2017) 'grit' theory states that 'grit' is a combination of passion and persistence, which together are the key features that predict an individual's success. A 'gritty' individual will approach a task as a process that requires stamina and is therefore not deterred by setbacks. Grit is a non-cognitive stable personality trait which has links to the 'big five' theory of personality traits (Costa & Macrae, 1992) particularly conscientiousness. The grit theory was based on classic research by luminaries such as Galton (1892) who collected biographic data from successful professionals such as judges, statesmen, scientists, and poets. From this data he concluded that success came from a combination of ability, zeal, and a capacity for hard labour. Cox (1926, p218) concluded that "persistence of motive and effort, confidence in their abilities and great strength of force of character" was responsible for their achievements. The culmination of the research into grit was the grit scale. This is a ten-item questionnaire that concludes by giving a score. This score can then be compared with the rest of the population to give a standardized measure of the individuals' levels of grit compared to others (Duckworth et al. 2007). Masten (2019) supported the idea that resilience protective factors were found in personal qualities, such as problem-solving, self-regulation skills, self-efficacy and optimism, and belief that life has meaning, particularly if they were rooted in religious and cultural beliefs and practices. This demonstrates that even if the researchers agree that personal qualities have an effect on levels of resilience, that there still is disagreement about which ones.

Furthermore, thinkers like Marx (1844) have also commented on the importance of personal beliefs and their effect on resilience in stating that "Religion is the opium of the masses," in that it gives hope in suffering, that there is purpose in it and relief from it. The belief that a positive outcome can result from adversity is the backbone of several world religions. Buddhism and Christianity are examples of this. In Buddhism the first of the four noble truths is that life is suffering, in fact the Buddha claimed that he mainly came to teach about suffering (Xingyun, & Lam, 2011). In Christianity, suffering is believed to exist following the fall of man from the Garden of Eden, which led to man's estrangement from God. Jesus' suffering and sacrifice on the cross was necessary to give man a way back to God. Therefore, when suffering in life comes, it gives the Christian the opportunity to grow and be more Christ-like (Emmons, 2008), thus giving suffering meaning and purpose. For this reason, religion and religious practices are seen to be protective factors in theories of resilience (Masten, 2019). This makes resilience a multi-dimensional construct, which means that if an individual possesses the above attitudes and behaviours that they are more likely to experience a positive outcome following adversity (Burns & Anstey, 2010; Lamond et al, 2008; Rutter, 1985).

There is, however, an extra dimension to resilience, in that it can manifest developmentally over time. The lifespan view suggests that resilience works in the same way that physical immunity to illness works. Once a person has had a virus once, it has an inoculating effect on future exposures to the same virus (Rutter, 2007). Therefore, resilience is not merely a matter of a personal reaction in a snapshot moment. It is the accumulation of events that have occurred in life. Some previous events will have been a teacher of valuable tools that a person can draw on in future similar events, which reinforces a belief of an ability to be resilient (Robertson & Cooper, 2013).

Research by Lines et al (2020) developed this idea by showing that a moderate level of adversity was beneficial, however, low, or high levels of adversity or multiple adversities experienced either concurrently or over the course of a lifetime were more harmful. Lines et al (2020) also noted that the skills gained during an earlier adversity may not be useful in a future different type of adversity and so, previous encounters with adversity do not guarantee and easier experience in the future.

Furthermore, the incremental effect of several adverse events may become a risk factor, as can be seen by research on cumulative Adverse Childhood Events (ACEs) (Jacob et al. 2019). ACEs have been shown to increase the chances of an adult developing depression and Post Traumatic Stress Disorder (PTSD), by creating enduring changes in the hormonal, neurotransmitter, and Central Nervous System, that then affects the individual's ability to adapt to future stressors (Heim & Nemeroff, 2001). However, there are many examples of children who have come from backgrounds that have included multiple ACEs but have come through to achieve a positive outcome. One of the mitigating factors has been shown to be a close relationship with a caring adult (Luthar, Sawyer & Brown, 2006; Masten, Best & Garmezy, 1991). This is supported by research that demonstrated that children from Romanian orphanages who were adopted by stable families had positive outcomes (Masten, 2001).

Characteristics of families that provided environments that were conducive to resilience were accord, celebrations, communication, financial management, hardiness, health, leisure activities, personality, support network, time and routines, and traditions. These factors were of varying importance depending on what stage the family was at. These stages were: the couple, childbearing and school-age, teenage and young adult, empty nest, and retirement (McCubbin et al. 1997).

Walsh's (2016) theory adds to this by suggesting that family resilience requires the family to function effectively when impacted by adversity, but that this must apply to all members of the family, which facilitates positive adaptation leading to strengthening of the family unit. This demonstrates that the community that an individual is in, has a part to play in their resilience. Therefore, the building of social capital (Bourdieu, 1997) with strong connections is important, which means that those without the skills to build such capital are at a significant disadvantage. It demonstrates a wider view of adversity and adaptation and suggests that problems exist in an interplay between the individual and their environment. An example of this is an individual who is experiencing stress at work could be seen as a person who has too much to do, or an individual who has a low tolerance of stress. To take the approach that the individual is responsible for their stress response, takes away the responsibility of the organisation to reduce their workload, which increases the adversity for the individual (Zautra, Hall & Murray, 2010).

There has been a shift over the last fifty years in the way that physical and mental health/illness are conceptualised. Where originally the idea of illbeing was the realm of doctors and hospitals, the emphasis has now switched to promoting and maintaining wellbeing as a way to avoid being ill (Seligman, 2011). At a societal level, the concept of maintaining wellness is seen in the governmental decisions regarding welfare. Again, this returns the responsibility to the individual for maintaining their health, for example a person who suffers from obesity is seen as someone who eats more than they need, rather than someone who lives in a food desert – a place where healthy foods are unavailable (National Research Council USA, 2009). It is also seen in the work of activists who seek to change those governmental decisions, (Nettleton, 2013).

Maslow in his hierarchy of needs theory (1943) stated that in order for an individual to reach the higher levels of his model, they must have the needs of the lower levels met, which suggests that a person with no shelter, or personal safety is not able to reach self-actualisation. This theory has implications at a societal level when considering governmental decisions such as funding for health and social services. There are also repercussions for resilience as it demonstrates the existence of an interplay between the individual and society based around the provision or lack of services that would support a resilient response (Blaxter, 2010). Therefore, it can be seen that the protective factors that an individual possesses or enjoys from those around them have a considerable impact on the way that they experience or resist a downturn following adversity or the way that they can quickly recover.

The discussion of risk and protective factors is an important area for this research in that the actions of a child with autism are outside of the control of the mother and so constitute an environmental influence on her experience of possible adversity. Additionally, the way that other people react to the family as a result of the child's challenges contribute to the sense of adversity if those reactions are considered stigmatizing. The interview questions related to the mother's experience of parenting were deliberately designed to encourage conversation on this aspect of resilience.

2.3.2 Processes

As discussed in the above section, resilience research into adaptation following adversity, suggests that there are two mechanisms that are employed to facilitate this. Firstly, there are the protective factors. These are either internal resources that the individual already has that can be deployed, or external resources in the individual's environment such as their family, community, or their wider society, that work according to Bronfenbrenner's (1981) multi-systems theory. Secondly, there are processes that are cognitive, emotional, or behavioural mechanisms that work overtime to lead to positive outcomes (Lines et al, 2020).

These processes operate in addition to these protective factors, and are individual processes that can, over time, help an individual to recover from adversity. Resilience processes are cognitive, emotional, or behavioural mechanisms that the individual either possesses or can learn, that can be instrumental in their recovery from adversity (Lines et al, 2020). The difference between the process and the protective factors is the element of time that is required to see the outcome. Whereas the protective factors might facilitate resistance or bounce back, the processes involve a slower return to either the previous level of wellbeing or an enhanced level of wellbeing as seen by post-traumatic growth (Noltemeyer, & Bush 2013).

Cognitive behavioural therapy (CBT) (Beck, 1967) suggests that the thoughts that a person has following an event, determine how they will then feel and behave. Therefore, if the thought can be changed, the feelings and behaviour will also change in line with the new thought. Therefore, when adversity strikes and there is a downturn in wellbeing, a person can recover their wellbeing through a process of examination and challenge of their beliefs and thoughts. By using a process of examination and challenge the individual can then abandon unhelpful beliefs followed by adoption of new more useful beliefs which can then lead to recovery of wellbeing (Neenan, 2018).

Another theory that utilizes an examination of thought processes is growth mindset theory (Dweck, 2007). This suggests that how an individual views learning will determine how likely they are to persist with their work. If an individual sees their intelligence as being inherited and unchangeable, then they are said to have a fixed mindset. A growth mindset comes from the belief that intelligence is malleable and so consequently, part of a process. Therefore, should some challenges be encountered in the process, the person with a fixed mindset might conclude that they can't do it, whereas the person with a growth mindset might think that they can learn the skills needed to overcome the challenge. Thus, effort is more of an indicator of success than intelligence, meaning that, the person with a growth mindset is consequently more likely to positively adapt in the face of adversity (Masten, 2019).

The meaning making model (Park & Folkman 1997) is another theory that emphasizes the importance of cognitive processes. It states that there are two levels of meaning: Global and Situational. Global refers to an individual's orienting view, which is their world picture, or their overview of many situations. The situational meaning refers to one specific situation. When an adversity occurs the individual finds that they have a disparity between the global level and the situational level which leads to distress and efforts to reconcile the two levels. This reconciliation is achieved either through problem-focussed coping that tries to fix the stimulus and emotion focussed coping which attempts to manage the emotions through strategies like meditation, cognitive reframing, and distraction (Aldwin, 2007).

Another way that these two levels can be realigned is by utilizing hope. This is not just hope that believes that a positive future will materialise without effort, it is hope based on Snyder's (1995) hope theory, that believes that there is both the will to try as well as multiple pathways to get to the goal. Therefore, if one pathway appears to be unworkable, then another pathway will be clear. Snyder (2002) defines hope "as the perceived capability to derive pathways to desired goals and motivate oneself via agency thinking to use those pathways" (pg. 249). Therefore, if a person can think of a way to achieve the desired goal and have the self-belief to imagine that they could achieve that goal then they become hopeful.

This approach ties in with locus of control theory (Parkes, 1984), which argues that individuals with an external locus of control show a stronger positive correlation between stressful life events and ill-being. A person with an internal locus of control will position the solution to their problems within their own capabilities.

Another approach that focuses on cognitive reframing or new patterns of thinking to support resilience, is Fredrickson's (2004) broaden and build theory. This theory suggests that positive emotions lead to new thought repertoires and actions, which in turn creates success which results in more positive feelings. This builds an upward spiral of emotion and success. The new thought processes that are built in this way can also be used to improve cognitive flexibility should the individual find themselves facing obstacles to their progress. This would mean that interventions such as CBT would be more likely to be helpful. This contributes to the individual's resilience in that the upward spiral creates a momentum that enables either recovery or reconfiguration (Ivtzan et al, 2016). Therefore, building positive emotions through an intervention or by good experiences alongside the adversity would enable the change in cognition that builds to a resilient outcome.

An alternative way to build positive emotions is by being grateful (Seligman, 2011). Gratitude involves recognizing and acknowledging the gifts that life presents even during adversity. It is an effortful process rather than a necessarily immediate reaction. Research has shown those people who practice being grateful, experience greater wellbeing, via more optimism, happiness, self-worth, compassion, generosity, forgiveness, stronger relationships, and less loneliness, envy, anxiety, and depression (Emmons, 2008).

Another theory that addresses the idea of building positive emotions is Neff's (2004) self-compassion theory. This research is a useful part of building positive emotions because it deals with the problem of suffering. The word compassion literally means 'to suffer with'. By recognising that we suffer along with all of humanity we can understand that to suffer is literally the same as to be human and be interconnected with other people who are also suffering. When trouble strikes people often become inward looking, and think 'why me?'. Instead, Neff suggests that suffering is inevitable and that turning inward or comparison with others is unhelpful. Instead, she suggests that self-compassion enables the individual to drop judgements of themselves and others and so feel the belonging that comes from being part of a group that are all suffering in various ways. Additionally, Neff suggests that acceptance of suffering helps to ameliorate the experience. Neff (2011) argues that: "suffering = pain multiplied by resistance" (p 116). By acceptance of suffering as a part of life, the intensity of the suffering is reduced. By feeling a part of humanity as a result of adversity, the individual is encouraged to not add in the 'why me' aspect that so often adds to the pain of suffering. Additionally, the person suffering the adversity is encouraged to reach out to others and connect rather than to withdraw, which brings the social support benefits described in the protective factors above.

Acceptance of suffering as a part of life rather than resisting it, is also a component part of the theory of mindfulness (Kabat-Zinn 1994). Mindfulness is a practice of meditation that does not suggest escaping from suffering, but instead to stay present with it and to experience the feelings associated with the adverse event. Mindfulness is a behavioural mechanism because it is a decision to do a practice and to take on the method of the practice. By doing this, a space can be created in which other choices can be made (Chaskalson, 2014). Research by Lee et al. (2021) showed that by practising mindfulness, individuals increased resilience, and reduced emotional exhaustion and escaping behaviour.

Work engagement is often used as an emotional and behavioural outcome in research because it is seen as a consequence of the characteristics of vigour, dedication, and hope across a period of time (Schaufeli, & Bakker, 2004). This description has similar parallels to the theory of resilience put forward by Robertson and Cooper (2013) in their statement that resilience has both behavioural and psychological elements to it in terms of positive mental health and continuity of behavioural functioning. The opposite of work engagement is burnout which is described as a state of mental weariness. The Maslach Burnout Inventory – General Survey (MBI-GS) was created to measure burnout via three dimensions: exhaustion, cynicism, and professional efficacy. A high score on exhaustion and cynicism, and a low score on professional efficacy indicates burnout. Work engagement is therefore the opposite of burnout, as it produces energy, involvement, and efficacy (Maslach & Leiter, 1997). Maslach, Jackson & Leiter, (1986) suggested that burnout occurred when job demands exceeded job resources. Therefore, when demands exceed resources, the resulting stress, if sufficiently chronic will lead to burnout (Schaufeli & Bakker, 2004). Alarcon, Edwards & Menke, (2011) suggests that it is a person's perception of the demands made and their relationship to their own resources that is the determiner of the consequence of burnout, which shows that the way a person interprets events can have a significant bearing on the outcome. The idea of a person's perception of their resources is also supported by self-efficacy theory, which claims that a person's perception of their self-efficacy can affect, coping behaviour, self-regulation of refractory behaviour, levels of physiological stress reactions, resignation and despondency to failure experiences, achievement strivings, growth of intrinsic interests and career pursuits, self-debilitating effects of proxy control and illusory inefficaciousness (Bandura, 1982, Orkibi, 2021). Research by Blackburn and Owens (2015) demonstrated that perception of personal self-efficacy alongside meaning in life was associated with lower levels of PTSD in combat veteran's, thus demonstrating the importance of personal beliefs in resilience.

Lastly, Seligman's (2005) research into signature strengths shows that during adversity, people operationalise their strengths to overcome the challenge. However, some of the strengths that they use are more congruent with who they are as a person. Therefore, those strengths which Seligman named 'signature strengths' act as buffers against adversity and part of the process of recovery. These strengths once identified, can then be used as strategies to speed recovery, so that a person can deliberately call on their strengths when needed rather than trying to improve their weaknesses.

These processes have been shown to be helpful to people to improve their levels of resilience, however, these studies do not state whether the interventions would work for everyone. The third sub-question in the research questions is intended to target this area:

> In what ways do mothers of children with autism demonstrate resilience?

However, one of the difficulties with understanding the concept of resilience is the conflation of the protective factors and the processes. The research question asking the mothers to define their version of what resilience meant to them was designed to include their thoughts on this linguistic challenge. Lines et al (2020) maintain that protective factors and processes are completely separate constructs that lead to different outcomes, and so it is vitally important to use consistent language as descriptors for these concepts to avoid confusion. Firstly, there are the protective factors. These are internal resources that the individual already has that can be deployed. Additionally, protective factors can be external resources in the individual's environment such as their family, community, or their wider society, that work according to Bronfenbrenner's (1981) multi-systems theory. Secondly, there are processes that are cognitive, emotional, or behavioural mechanisms that work overtime to lead to positive outcomes (Lines et al. 2020).

An additional linguistic challenge in understanding the concept of resilience is that the resilient processes and the resilient outcome have both been referred to as resilience (Olsson et al. 2003). By separating them in this analysis it is hoped to provide clarity around the terminology and the operationalisation of these concepts.

This would make the operationalisation of resilience look like this:

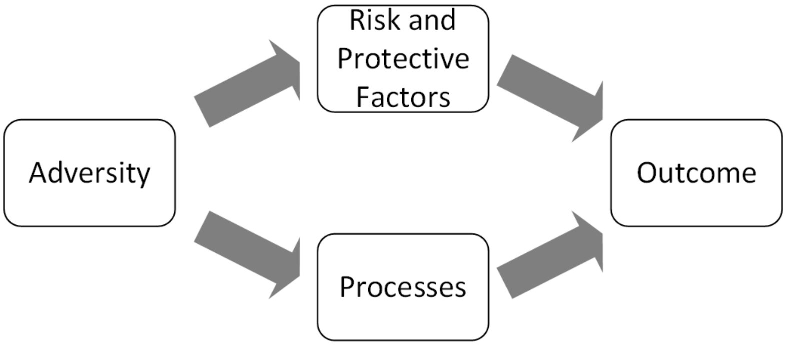

Figure 7 The operationalisation of risk and protective factors and processes (authors own)

2.3.3 Outcome

The outcome is the last part in the model of resilience. Research studying adversity and trauma often cites negative outcomes such as depression (Burns et al. 2016), as being statistically, significantly linked. This has meant that resilience is often conflated with positive mental health outcomes. However, recovery is defined as an ability to quickly regain equilibrium physiologically, psychologically and in social relations following the stressor (Masten, 2001; Rutter, 1987). This recovery of equilibrium must be followed by a sustained trajectory (Bonnano, 2004; Zautra, Hall and Murray, 2010). Confusion still exist over what is meant by the words equilibrium or recovery, as research refers to this in terms of resistance, or bounce back or recovery.

Therefore, a clear understanding of exactly what is meant by a positive outcome is needed. If bounce back is the aim, it would stand to reason that the desired outcome would be the previously held shape. However, it is not clear what exactly the concept of 'shape' refers to. Persaud (2001) stated that "Resilience is the bedrock of positive mental health." Ewalt, (1956, in Jahoda 1958pg. 42) defined mental health as being “a kind of resilience of character or ego strength permitting an individual, as nearly as possible, to find in his world those elements he needs to satisfy his basic impulses in a way that is acceptable to his fellows or, failing this, to find a suitable sublimation for them [….] this resilience of character should be such that he can adapt himself to the vicissitudes of fortune, bouncing back to find new ways of satisfaction or sublimation after defeat” These two quotations appear to suggest that resilience is underpinned by mental health but there are other additional “elements” that have an interplay with mental health that work as a dynamic system. They do not state what those elements are, except that they must be acceptable to others. It appears that satisfaction of basic impulses, or sublimation is the outcome to positive mental health.

Carver, (1998) also widens the scope of resilience beyond mental health by including physical health. He suggests that there are four possible outcomes following an adverse event. The first is that of succumbing, which means that a person suffers an adverse event and then the physical or psychological downturn endures. The second option is that a person would survive but with an impairment. The third option is a resilient recovery in which the person suffers the adversity but then returns to the level that they previously held and the fourth is that they thrive reaching a level above their previous state. However, these outcomes do not then remain static for life as other events follow which alter a person’s wellbeing again (Noltemeyer, & Bush, 2013).

Another theory of resilience that addresses the idea of outcomes is proposed by Ivtzan et al. (2016). They suggest that there are three different ways in which resilience can manifest. The first is ‘resistance resilience’ which occurs when an individual has the strength and resources to stand firm in the face of adversity and not be affected by what has happened. Recovery Resilience occurs when one can bounce back from adversity to restored levels of functioning that were previously enjoyed, this may involve some measure of adaptation to the new circumstances. Lastly, reconfiguration resilience accepts that something has changed since the adversity which requires the individual to stretch and grow into a different way of being. Reconfiguration resilience is related to the theories of Post Traumatic Growth (Ivtzan, et al. 2016). Joseph (2011) describes resiliency through post traumatic growth as being like a vase that gets broken, no matter how careful the repairer is in mending the vase it cannot go back to its ‘pre-smashed’ state. However, if the pieces are taken and constructed into a mosaic then the end-product can be just as beautiful or more beautiful than the original vase was. The vase represents a person’s world view. After a traumatic event occurs the person’s world view, like the vase, is irreparably altered and can never return to the previous naïve state. Post traumatic growth involves reconfiguring life into a new path which accommodates the traumatic event as part of the journey. These models describe the process of moving from the adversity through the adaptation to the outcome as being a linear process with one adversity occurring at a time, it is not clear from these what a would happen in a chronically challenging situation, where another adverse situation could strike before the individual had the chance to respond according to one of these pathways. In this research, the mothers may well experience another challenging situation before they have processed a previous event.

This theory is supported by the research of Reid and Kampman, (2020) who found that enduring expeditionary adventures such as a journey to the South Pole accelerated and magnified the participants growth and psychological wellbeing. Reid and Kampman's model of resilience suggested that each person's resilience exists on a continuum that can move from surviving, through coping into thriving, with behaviours and thought patterns that were typical of each presentation. This demonstrates that personal attitudes and behaviours can affect an individual's level of resilience rather than it being purely a matter of innate factors such as personality. While this is an extreme example of adversity, it was chosen as extremes examples often demonstrate the clearest picture of the studied phenomenon (Feldt, 1961).

Lines et al, (2020) suggests that resilient adaptations occur via either a one step or two step procedure following the adverse event(s). The one step process involves the individual utilizing the protective factors that the individual already possesses. This enables them to either resist the downturn in wellbeing or to quickly bounce back. However, those same protective factors can also enable the person to begin the process of working towards the positive outcome using either cognitive, emotional, or behavioural mechanisms. For example, a protective factor such as the personal characteristic of being hopeful can help the individual to work on cognitive reframes of the event so that they feel better, and their mental health can recover. This two-step process takes more time making the outcome a slower recovery than the bounce back option. However, there is also the option that by using the cognitive, emotional, or behavioural mechanisms that personal growth can occur which in time can mean that the person can function at a higher level than they would have done had the adversity not occurred. Lines et al. (2020) argued that it is the individual's resources (protective factors) that are the catalyst for the processes to occur is at odds with other researchers that suggest that they operate in tandem. However, it may well explain why it is that outcomes occur at varying speeds. This explanation leads to the diagram that was presented at the beginning:

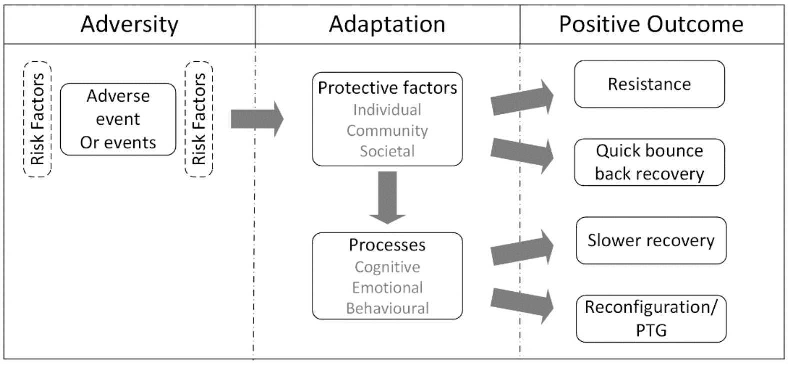

Figure 8 The two-step process of resilience – authors own representation of Lines et al. (2020)

In summary, a study of the multidisciplinary literature has elicited a deeper understanding of what resilience is and how it can be operationalised. Firstly, the adversity, defined by the individual, the impact of which is influenced by the risk factors. Then, the adaptation which has two routes, firstly, just the protective factors or secondly, the protective factors followed by the processes. Lastly the outcome which is governed by the route taken to adapt. If only the protective factors have been utilized, then the person can resist the downturn or quickly bounce back. If the protective factors have led to the processes, then there is the possibility of a slower recovery or reconfiguration and post traumatic growth.

2.4 Improving resilience

Theories of resilience that suggest that possessing the right character traits or innate characteristics imply that resilience is only available to those who possess these required character traits, making resilience a matter of nature rather than nurture. To counterbalance this, considerable effort has been invested in the idea that resilience can be taught (Hanson, 2018; Pemberton, 2015; Reivich & Shatté, 2002).

The work by Carver (1998) showed that thriving was a strong protective factor for individual resilience. Thriving is a situation where a person responds to adversity by attaining a higher level of functioning than they experienced before the adversity happened. Research by Seligman and Csikszentmihalyi, (2000) suggested that it is possible for individuals to improve their levels of functioning from languishing into thriving by regularly carrying out some interventions that are targeted to improve levels of happiness and wellbeing. Languishing is a term used by Seligman and Csikszentmihalyi, to denote a condition whereby someone is not mentally ill, but do not feel that they are doing well either. It was argued by Seligman and Csikszentmihalyi, that a large proportion of the population are vulnerable to succumbing to depression following an adverse event because they are languishing just above the level required to qualify for a diagnosis of mental illness. If this group of people could improve their wellbeing into thriving, they would then have a resilient buffer to mental illness.

One of the first resilience intervention programs to be developed, was The Penn resilience programme. It was developed by Seligman, Jaycocks, Gillham and Reivich in the early 1990s to address this issue of people languishing. This program was based on principles established in CBT (Beck 1967; Beck, 1972) that stated that wellbeing is affected not so much by what happens in life but the thoughts that are connected to the event. These are thoughts like the accuracy of recall of the event, the number of alternative scenarios that can be envisaged, cognitive flexibility and the individual's continued engagement with new opportunities and challenges. A major premise of the programme is that skills can be taught to improve an individual's level of resilience (Reivich, & Shatté, 2002). There are seven factors of resilience that are identified in this programme. These are: three skills to raise personal awareness through analysing beliefs, one skill to bring attention to the present moment to enable life's tasks to be done and three skills to change resilience lowering thoughts. The programme, therefore, seeks to address cognitive and behavioural mechanisms of adaptation. The therapy plan utilises a questionnaire based on a psychological scale that creates a score. This score raises awareness of the current level of resilience so that the areas that are negatively affected can be identified and addressed (Jackson & Watkin, 2004).

An additional Intervention designed to improve resilience is mindfulness. Mindfulness is defined as much more than just paying attention, it is "a way of training the mind, heart, and body to be fully present with life. It is both a practice (e.g., meditation) and a way of being. Fundamentally it is a way of relating to all experience – positive, negative, and neutral -with kindness, openness, and receptivity" (Shapiro, de Souza & Jazaieri, in Ivtzan and Lomas, 2016 p108-109). Many research projects including one by Allen, Romate and Rajkumar, (2021) have shown that mindfulness can improve not just mental illness, but mental wellness as well. However, research into heuristics shows that sometimes mental shortcuts can be more beneficial, than an approach that involves being present to every tiny detail or emotion, not least because it can save time and energy (Kashdan & Biswas-Diener, 2014).

The 'best possible self' exercise is an intervention that involves writing about a future, when a person is living in the best possible circumstances, after all their current goals have been achieved. Used over at least four separate occasions, it was shown to improve mood and optimism, which was assessed using pre-validated wellbeing questionnaires that involved asking about positive future expectancies. These aspects were considered protective factors in resilience which made this exercise useful in defending the resilience of those who participated in the intervention (Peters et al. 2010).

The ability to be grateful in the face of adversity has been shown to have a protective effect in the face of traumatic events (Emmons, 2008). Research by Fredrickson et al. (2003) in the aftermath of the 9/11 attacks on the World Trade Centre in New York involved asking people to rank how much of twenty different emotions they felt. The figures given were compared with data that had been collected from this group prior to the attack. Compassion came out as the top emotion felt, with gratitude in second place. Other emotions such as anxiety, anger and sadness were much lower down. Fredrickson found that those people experiencing at least moderate levels of positive emotions were more resilient and had a lower chance of becoming depressed after the 9/11 attacks. Further evidence of the role of gratitude in resilience comes from a research project conducted by Tsang (2005) who used journaling as a gratitude intervention with people who were carers for a partner with Alzheimer's. By the end of the study the participants who had kept a daily gratitude journal experienced greater wellbeing and a reduction in stress and depression compared to the control group who were asked to write about their hardships. However, there is a dark side to gratitude such as encouraging people to be grateful in all circumstances might lead to a person thanking their current abuser for enabling them to experience personal growth, or the possibility that someone with depression may not be able to come up with three things that they are grateful for each day and so feel worse, because they are incapable of improving their life (Wood et al. in Snyder & Lopez, 2002). In spite of these challenges to the concept of encouraging gratitude, the 'three good things' intervention (Emmons, 2008; Emmons & McCullough, 2003), which involves the individual taking time at the end of each day to identify three good things that have happened during that day is widely promoted as a way to enhance resilience (Seligman & Steen, 2005).

CBT suggests that resilience can be increased at any point in life (Beck, 1988; Neenan, 2018). By examining strengths that a person has utilised in previous challenges, they can then prepare for future adversity. This gives someone an opportunity to see what has previously worked well so that approach can be taken again, it also enables an increase in a person's level of belief in their ability to manage. Additionally, each day requires an individual to exercise their strengths just to achieve the daily tasks required. Furthermore, looking at concerns for the future may elicit additional strengths and skills to create a 'risk plan' (Neenan, 2018). In doing these exercises, an individual can uncover their cognitive distortions (Beck, 1988), which are their beliefs and attitudes. By examining them, they can see whether they are building towards resilience or vulnerability. Should they decide that those beliefs and attitudes are unhelpful, they can then explore whether they want to drop that belief and adopt a new more useful one (Beck, 1988; Ellis, 2001). Grotberg, (2003) suggests that an individual can reflect on their attitudes and beliefs as they unfold and adjust in the midst of the challenge. This puts some of the challenge within the control of the individual. As Viktor Frankl (1959 in Frankl, 2004 pg.86) said **"**Everything can be taken from a man but one thing: the last of the human freedoms – to choose one's attitude in any given circumstances, to choose one's own way."

This section demonstrates that resilience can be improved by carrying out some activities specifically designed to improve resilience. The interview questions chosen in this research were deliberately designed to find out whether the mothers did any activities similar to these. In particular, a question was asked about whether the participants did anything in their day that was just for them.

2.5 Measuring resilience

As previously stated, a person who has not experienced adversity cannot be said to be resilient (Noltemeyer, & Bush, 2013). Therefore, it is not possible to take a random sample of the population and test their resilience because the results would be skewed by those who have never faced significant adversity or not currently facing adversity. Therefore, researchers have sought to identify the building blocks of resilience and measure them instead (Noltemeyer, & Bush, 2013).

If resilience can be taught then it would be useful to know who needs the 'lessons', as then it would be possible to target those that most need help. Additionally, if resilience as a concept is to be included as part of a social science like psychology, then it needs to have an element of measurement or testing capability (Coolican, 2009). As a result, several measurement scales were developed (Bartone et al, 1989; Connor & Davidson, 2003; Smith, et al. 2008; Wagnild & Young, 1993).

Creating a scale is a complex process, as they consist of several statements or questions that have a guided quantified response. Each scale design rests on a decision made by its creators on what will form the rationale for question creation. Each scale is then statistically tested for validity and reliability (Sarantakos, 2005). However, rather than assessing the levels of resilience itself, the scales focus on the building blocks of resilience which are the protective factors or processes (Smith et al. 2008).

The Connor-Davidson (2003) resilience questionnaire, combined theory from a number of other researchers. These theories formed the basis for each question on the risk and protective factors that they believed contributed to resilience. Kobasa's (1979) theory suggested that factors are: hardiness, control, commitment, and change viewed as challenge. Additionally, Rutter's (1985) work was included with the following factors: development of strategies with a clear goal or aim, action orientation, strong self-esteem/confidence, adaptability when coping with change, social problem-solving skills, humour in the face of stress, secure/stable affectional bonds, previous experiences of success and achievement. Then from the work of Lyons (1991): patience and the ability to endure stress or pain. Finally, from the experience of Shackleton's (1912) account of his expedition to Antarctica, the role of faith and a belief in benevolent interventions completed the questionnaire rationale.

Another scale that uses the risk and protective factor rationale for question creation was made by Oshio et al. (2002), who created a resilience scale to use with adolescents. Their scale was based on a three-factor structure: novelty seeking, emotional regulation and positive future orientation. A further example of a resilience scale that uses protective factors to create the domains of questions is Wagnild and Young's (1993) resilience scale. This assesses levels of equanimity, perseverance, self-reliance, meaningfulness, and existential aloneness.

The perceived problem of only measuring risk and protective factors prompted Smith et al. (2008) to create the Brief Resilience scale in the hope of testing the single construct of whether a person can bounce back from stress. This scale has six questions and like the other scales is done by self-report. This scale, however, will only give a snapshot of a person on one day. It does not indicate how a person may respond in a subsequent or different adverse event as stated by the lifespan view of resilience (Rutter, 2007). Despite a lot of effort to create scales that measure resilience, so far, none have been adopted as a consensus measure, as there is a lack of agreement regarding how resilience should be defined and consequently how it should be measured.

There are other measures used by researchers when measuring resilience. These measures are based on the work of other researchers rather than creating a model of resilience themselves. The Positive and Negative Affect Scale (PANAS) (Watson, Clark and Tellegen, 1988) was created following research that showed that positive and negative are actually two distinct constructs. It is not the case that someone can be either totally happy or totally sad. Therefore, it was decided that both constructs should be measured to obtain an overall picture of the well-being of a person. This scale consists of two ten-item mood scales. The scales have high internal consistency and are largely uncorrelated with each other. They are also considered to be stable over time or at least a two-month period. Researchers who are testing an intervention designed to improve resilience such as a gratitude intervention (Emmons & Mccullough, 2003) have used the PANAS scale to assess the efficacy of their intervention.

Seligman's (2011) scale created to measure what he termed the 'blocks of wellbeing' encompass five domains: Positive Emotion, Engagement, Relationships, Meaning, and Accomplishment (PERMA). Again, these domains are similar to the protective factors in the theories of resilience (Rutter, 1985).

Ryff's Singer's (1998) psychological wellbeing scale is based on measuring eudaimonia, a term used to describe happiness. However, eudaimonia is not the same as hedonia, as it is not happiness that rests on all desires being met. Instead, it is more about personal actualisation and life satisfaction or purpose. There are a number of seminal theories that incorporate the idea of eudaimonia. These are: that to think well of oneself or to have positive self-regard, is a cornerstone of good mental health (Jahoda, 1958), optimal functioning (Rogers, 1962) maturity (Allport, 1961) self-actualisation (Maslow, 1968), the process of individuation (Jung, 1933) and self-acceptance including one's history (Erikson, 1959). These elements all contribute towards a life well lived (Ryff & Singer 2008). To have a construct with contributions from so many influential theories emphasizes the importance of an individual possessing it. The psychological wellbeing scale was therefore created to measure it. Ryff and Singer's (1998) scale measures six domains as being constituent elements of eudaimonic happiness. These are self-acceptance, positive relations with others, personal growth, purpose in life, environmental mastery and autonomy. The results from this scale are given per domain and collectively (Ryff & Singer 2008).

The Warwick Edinburgh Mental Wellbeing Scale (WEMWBS) has two versions of the scale: a fourteen-item scale and a seven-item scale. This scale is used by researchers to test the efficacy of interventions designed to improve resilience. It measures positive feelings and positive functioning. The questions are designed to cover key issues within psychological functioning such as optimism, autonomy, agency, curiosity, clarity of thought, positive relationships, and positive feelings such as confidence, feeling relaxed, cheerful, having the energy to spare. It therefore is an accurate measure of resilience and the theories that support the idea of protective factors. This scale is used from age 13 upwards and is available in many languages (Stewart-Brown et al. 2011).

2.6 Problematizing resilience

Since the beginning of research into resilience there have been many attempts to define and operationalize the concept. However, to date, no consensus has been achieved on how to define either the overarching definition of resilience or the constituent parts of resilience (Zautra, Hall & Murray, 2010). The research into resilience has been enthusiastically embraced as a concept as it appears to be a universal panacea for all ills. This is despite the lack of clarity in the concept. The consequence of this is that a cherry-picking approach has emerged that often unproblematically adopts the construction of 'bounce back'. The impression that it gives, is that much like Bandura's Bobo doll (1961, in Bandura, 1978) that continually gets knocked down, kicked, and punched and then continually springs back up, is that individuals can unproblematically immediately do the same. This bounce back seems effortless and like the Bobo doll intrinsic to its design. However, the reality is that while some people do bounce back immediately, others take time and that for them it is a struggle to return to their previous level of functioning (Reivich & Shatté, 2002).

If someone threw a rubber ball at the floor, it would bounce back at the rate it fell, or possibly faster. The ball does not gradually return to its previous height or stay around on the floor for a bit and then bounce back up. Therefore, the idea of bounce back is incompatible with the idea of resilience being a process. Unfortunately, the lack of consensus over the use of language around resilience has meant that definitions of 'bounce back' are conflated with the process of adaptation which then suggests that participating in resilience interventions facilitates bounce back (Olsson et al. 2003). If protective factors and process are separate constructs as suggested by Lines et al (2020) with protective factors and processes being clearly and orthogonally defined, then the process part of resilience can occur either quickly or over time.

At first glance it would appear advantageous for an individual to 'bounce back' quickly so that they can continue to experience good mental health and efficient functioning. However, this approach ignores the value in the journey of recovery that could lead to reconfiguration and personal growth. In the fullness of time this may result in the person functioning at a higher level than before (Ivtzan et al, 2016; Pemberton, 2015). It also ignores the lifespan model of resilience that suggests that it is the struggle to recover that forges the tools of resilience (Robertson & Cooper, 2013; Rutter, 2007; Walsh, 2016).

The problems with defining resilience continue with a lack of clarity regarding the process of adaptation. There is also no consensus agreement on what adaptations are considered to be resilient and which ones are not. For example, a person who loses their job might go to the nearest public house and drink to escape the reality of their job loss. They may have a good evening, enjoy themselves and feel happy. Using the original construct of resilience that identifies resilience based on positive mental health, this would look like a resilient response. However, unless this behaviour is repeated the next day (which eventually would be maladaptive), then those good feelings would not be sustained. This means that using other models of resilience, the end result would be that this person was not resilient. However, without a consensus around the subject, there can be no verdict on whether this person is resilient or not (Bonnano, 2005).

The unintended consequence of positioning resilience as a quick recovery to a previously held form is that it excludes those people who are not 'blessed' with individual, community, or societal protective factors. This therefore means that they are given the message that unless they bounce back quickly from adversity that they are not resilient. In the physical sciences though, it is relatively unproblematic to say that water is not resilient because it changes from ice to liquid and then steam and then takes time and other processes to return to ice. However, the idea that some people have properties that mean they are resilient, and others not so, is somewhat more problematic (Seligman, 2011). Furthermore, the research on resilience interventions now makes it the personal responsibility of the individual to maintain or improve their resilience. If an individual finds themselves experiencing a lack of resilience, then the options presented are that either they lacked the protective factors and so are not a resilient person, or that they could have learned resilient processes, but they failed to do so (Neenan, 2018). This ignores Bronfenbrenner's (1981) theory, which suggests that every part of the multi-level system has a part to play. Therefore, if as an employer, you notice that an employee is suffering a loss of wellbeing and productivity, sending them on a resilience training program will not necessarily resolve the issue.

The theories of resilience promote that wellbeing and continued functioning are the desired goal. If the consequences of resilient wellbeing are happiness, good health and longevity and the consequences of a loss of resilience the opposite, then it is obvious wisdom to think positive and adopt the 'keep calm and carry on' attitude (Held, 2002). This promotes positive thinking as a superior attitude and that negative emotions should be avoided or at least reduced. This approach could possibly lead to what Held (2004) termed the "Tyranny of the positive attitude". This means that when adversity strikes, the message to be positive adds insult to injury as not only does a person need to cope with the adversity, but they also need to deal with the fact that they were unable to adopt what is promoted as the better attitude (Peterson et al, 1998).

In some cases where resilience is actively taught, people are told to add activities like mindfulness to their lives to help them improve their psychological wellbeing, which will then lead to other problem areas of their lives resolving (Bennett & Dorjee, 2016; Hölzel et al. 2011). This is especially true with ill health, where some writers suggest that negative thinking and negative emotion, can actually lead to conditions like heart disease and cancer (Carroll et al. 2012), so actually a person's attitude may even be considered to be the cause of the adversity (Chida & Steptoe, 2010). The research that promotes positivity can lead to the happy person being presented as "a well-defended fortress, invulnerable to the vicissitudes of life" (King, 2001, p54). Negative emotions and actions are, however, a normal adaptive part of human life (Neff, 2011) and can be useful as they can lead to problem solving behaviour (Held, 2004). An example of this is stress, which occurs when a person's appraisal of their resources is less than their appraisal of the demands required to overcome a perceived threat (Lazarus & Folkman, 1984). Historically, when man perceived a threat such as a tiger, the perceived threat would cause a series of events; from seeing the tiger and attributing a 'threat meaning' to what they see. This mental message would cause a cardiac reaction which would activate the fight or flight mechanism in the body. This would allow the body to perform at its peak to deal with the tiger. A single event like this would not cause any long-term problems (provided they overcame the tiger) (Gianaros & Wager, 2015). However, if a threat becomes long term, then the rise in blood pressure and heart rate would eventually cause heart disease and in the worst-case scenario cardiac arrest and death (Carroll et al, 2012). Therefore, a simplistic model of the role of emotions is inadequate. It is thus, unwise to privilege positive emotions over negative emotions as sometimes, (as can be seen with fighting or fleeing a tiger), the fear emotion is significantly more adaptive. A more complex model is therefore needed that has the ability to be used flexibly depending on the circumstances. The next section gives the background to the reasons that mothers of children with autism were chosen for this research. It begins by describing the disorder and then goes on to explain why being a parent of a child with autism might be considered challenging. Finally, it looks at evidence of resilience in those mothers.

2.7 Autism

Autism is a biological, cognitive, and behavioural difference that is diagnosed following a study of behavioural features. It is a lifelong developmental disorder that affects both male, female, and non-binary people of all levels of IQ (Fletcher-Watson & Happé, 2019). At the present time, it is not known what causes autism with no clear biological, neurological, or genetic aetiology being found (Lange 2012).

There are other disorders with a high level of comorbidity with autism. A person with autism has around a 50% chance of also being diagnosed with a learning difficulty (Elsabbagh, et al. 2012). Additionally, poor sleep (Mazurek, et al. 2019), restricted diet (Healy et al, 2019), epilepsy (Chez, 2010), language disorder and delay (Danon-Boileau, 2005), and poor mental health (Mitchell, Sheppard & Cassidy, 2021) can be disabling.

Autism was first diagnosed in 1943 by Leo Kanner in his landmark study on eleven children called "Autistic Disturbances of Affective contact". The word 'Autistic' taken from the Greek word 'Autos' meaning self, had previously been used by Bleuler in 1908 to describe the social withdrawal observed in adults with Schizophrenia. Kanner (1943) described the children that he studied as: suffering from extreme social aloneness, rigidity when faced with change, gross motor clumsiness but skilful with fine motor skills, and islets of ability such as excellent rote memory. The children also suffered from language disorders such as delayed echolalia. Delayed echolalia is repeating of language that they had previously heard but not as a method of communication.

Autism was also separately described by Hans Asperger in 1944, who gave his name to the children he diagnosed with the condition. His description was very similar to Kanner's autism except that he did not include the splinter skills in fine motor activities (Bumiller 2008).

Further research into the description and diagnosis of Autism was made by Wing and Gould (1979) who studied nine hundred and fourteen children. Their theory of the ‘triad of impairments’: social interaction, communication and imagination changed the way that autism was viewed because of the addition of the area of imagination to describe the repetitive and stereotypical behaviour as well as styles of play lacking in symbolic representation. Wing and Gould (1979) also divided children with autism into three groups depending on their social approach style, these were, aloof, passive and ‘active but odd’. Following on from the collaborative work with Gould (1979), Wing (1996) went on to describe the autistic spectrum to denote the uniqueness of each person’s presentation of the disorder. It is the idea of the spectrum that has informed many decisions as to how people with Autism are supported in education.

Alongside these constructive efforts to define and operationalise autism there are some other theories that are much more damaging to people with autism and their families. ‘the psychogenic theory’ (Bettleheim, 1967), blamed the autistic condition on what it called ‘refrigerator mothers’. It claimed that these mothers were guilty of cold and unresponsive parenting which resulted in the child withdrawing into their autistic world. This meant that many children with autism were removed from their families and brought up in an institution.

Current diagnosis of autism is either based on the Diagnostic and Statistical Manual of Mental Disorders – 5th Edition (DSM-5) or the International Classification of Diseases 11th Edition (ICD-11). The DSM-5 was created by the American Psychological Association (2013) to provide a consensus on diagnosis. Diagnosis is made based on presenting observable symptoms in the individual’s behaviour. The DSM-5 now defines autism as a spectrum of disorders instead of the narrow distinction first described by Kanner (1943). The ICD-11 was authored by the World Health Organisation and is updated annually. Diagnosis is made in a similar way to that described in the DSM-5, by observing the symptoms over several occasions and settings.

2.8 Disability

Contemporary debates on disability have concentrated more on concerns of human rights, equality, and citizenship rather than treatment and recovery. The result of which was the United Nations Convention in 2006 to protect the rights of individuals with a disability (Alcock, May & Wright, 2012; Pearson et al., 2011). However, the way in which concerns such as equality are managed will depend on collective conceptualizations in relation to the nature of society, the nature of disability and the interplay between that society and those with disabilities (Saraga, 1998).

The most recent addition to the debate regarding the conceptualization of disability is known as the Social Model. Oliver (2013) proposed that individuals are not disabled by their impairments, such as the loss of a limb or malfunction of a body part. Instead, they are prevented from accessing the opportunities to fully participate by the barriers in society that prevent them. Therefore, society has a duty to remove the barriers they have created, which prevent full participation for people with disabilities. Consequently, adaptations were made to facilitate access for people with a disability including buses with suspensions that lower to kerb level and ramps into buildings. These changes have been useful to those with physical disabilities, however not every barrier can be removed, for example, someone with a sensory processing disorder like autism would need the environment to take out the noise so that they can take part (Heller, 2003). So, with these challenges adaptations such as quiet shopping hours have been created and cinema screenings adapted to keep the house lights on and to lower the film's volume. This means that a separate arrangement is needed, rather than to make every shop quieter or cinema screening quieter.

The Social Model is criticized however, for ignoring the pain and difficulties with impairment that people with a disability experience daily as the model almost completely removes the impaired body from the discussion on disability. This occurred because this model was created as a critical response to the Biomedical Model. However, they did not come up with an alternative way to deal with the impairments endured by people with a disability (Hughes & Paterson, 1997).

The Biomedical Model is based on the theories of Descartes in the 17th century known as Cartesian dualism. It states that humans have a separate mind and body that exist both concurrently and independently (Mehta, 2011). The Biomedical Model states that disease, has a specific cause, with distinguishing identifying features, and so is separate from the individual, meaning that a doctor should concern himself with the disease as an objective entity, independent of the patient (Annandale, 1998).

Therefore, with illness being a departure from the norm, it is the doctor's role to provide a diagnosis and then to recommend treatment that leads to recovery and restoration of a healthy equilibrium to the body (Nettleton, 2013). The patient is therefore a passive recipient of the doctors expertise, simply allowing their sick body to be treated. This is the process that Foucault described as the 'Medical Gaze' whereby the person is seen only in terms of which organ is dysfunctioning (Fulcher & Scott, 2011). This is problematic for disorders like autism that have no established biological cause (Higashijima, 2012; Lange, 2012).

The concept stating that the doctor does not need to consult with the person as a whole being is also erroneous, in that the patient will need to cooperate with the prescribed treatment in order to get well (Giddens & Sutton, 2013). Additionally, the Biomedical Model describes doctors as being the sole expert source of knowledge and authority on the treatment of disease. However, traditional remedies and alternative therapies are known to be useful in recovery from illness and do not rely on explanations of underlying disease mechanisms (Bury, 2005). Furthermore, a person can get treatment from a number of places and not just surgery or hospital. Moreover, the use of advanced medical technology and some treatments can cause more harm than good, such as the side effects of drugs (Giddens & Sutton, 2013). Furthermore, the biomedical model does not take into account socio-environmental factors such as poverty or pollution as contributors to health or illness (Nettleton, 2013). Nor does it take into account the changing nature of illness. Szasz (2007) suggested that the nature of what is an illness, is also changing over time. He cited the case of homosexuality and pointed out that something that had previously been described as an illness is now not seen in that light. Society has now accepted homosexuality as being part of a protected characteristic of a person which means that they should not be discriminated against because they are homosexual (UK government, 2021). This change of construction will have a significant impact on those who identify themselves in this way. Currently, constructing autism as an incurable lifelong disorder has a significant consequence for parents of children diagnosed with this condition as it leads to a search for a cure, a move which is rejected by those who believe that autism is a cognitive difference rather than a disorder (McGee, 2012).

Despite these problems with the Biomedical Model, it continues to influence political social policy decisions, possibly due to its inception at the time of the enlightenment, replacing traditional and religious knowledge as the authority on the issues facing people's lives with science (Annandale 1998). The industrial revolution brought people to the cities, and the nation state was constitutionalized. Governments recognized that the health of their population affected their productivity and profitability. Therefore, health became a matter of public concern rather than being a private issue (Saraga, 1998). This led to the health of the nation being a matter for what Foucault described as surveillance and control, with the biomedical model being a useful vehicle to enforce this (Giddens & Sutton, 2013).

Talcott Parson's (1952) theory of the 'sick role' enabled the state to monitor and regulate the health of the nation, by allowing the individual certain rights and responsibilities. The individual person is not to blame for their illness, which is seen as being outside their control and unrelated to their behaviour. The sick person should be diagnosed by a doctor as being sick, and is then entitled to withdraw from their role within society such as going to their workplace and to take to bed. In return for these rights the individual has the responsibility to get well by following the doctor's instructions (Annandale, 1998).

Friedson (1970) expanded on Parson's 'sick role' theory to include three positions that a person could occupy. The first is the 'conditional sick'; this person is diagnosed with a temporary illness from which they will get better. Secondly, there is the 'unconditionally legitimate sick'. This person has an incurable illness which they have acquired through no fault of their own. Thirdly, there is the 'illegitimate sick' person who has a stigmatized illness such as alcoholism, where it is clear that their behaviour has contributed to them being ill. These distinctions that Friedson created emphasize the importance of considering the individual's environment when allocating the sick role to them. There are criticisms of the sick role, which suggest that some people will be denied the 'sick role', such as those who are misdiagnosed as not being ill. Furthermore, not everyone is treated equally by the doctor with race, gender and class having an impact, meaning that people with protected characteristics are sometimes denied the 'sick role' even though their condition warrants it. Moreover, knowledge has advanced to the extent that it is now known that many illnesses are rooted in an individual's lifestyle choices and so people bear a greater responsibility for their health, which contradicts the first assertion of the sick role (Beck & Beck-Gernsheim,2001).

Furthermore, advances in knowledge mean that it is now known that many illnesses stem from an individual's lifestyle choices which contradicts the first assertion of the sick role (Beck & Beck-Gernsheim, 2001). There is also no clear position within the 'sick role' for someone with a condition such as autism as there is no medical treatment for it and taking to bed does not lead to a cure. Additionally, many parents of children with autism blame themselves for their child's diagnosis even though there is no evidence to support this (Baylot-Casey et al. 2012).

Within the Biomedical Model, and the Sick Role the aim is to restore an individual to health, which is considered to be the natural, normal, state, therefore illness and disability become by implication unnatural, abnormal, and deviant (Saraga, 1998). Nettleton (2013) suggests that the emphasis on creating normality through the management of symptoms provides society with a measure by which to judge people as deviant who is not achieving this. This can lead to stigmatization, which occurs when others' negative reactions 'spoil' the individuals' normal identity (Goffman, 1968). There is also the possibility that by labelling a person as suffering from the lifelong condition of autism, with all the accompanying stigma and assumptions of deviance that entails, that they may then fulfill the role provided by that label and so blunting any possibility of progressing on another trajectory (Becker, 1991). In addition to this, the families of those stigmatized, could also feel labelled by association, creating a negative experience for the whole family (Stewart, Niccolai & Hoskyns, 2011).

There is now a reinterpretation of autism as being neurodivergent, which is used by the more able people with autism to create a way of inverting the stigma of being diagnosed with a condition described in terms of deficits and disorders (Brownlow, 2010). Their argument is that being autistic gives them abilities and focus that people without autism do not have, especially with tasks that involve measures of intelligence (Mottron, 2011).

2.9 Mothering

Historically the role and task of the mother was created by the understanding of what childhood meant. The first meaning attributed to the early years of life is a biological one, in that we might say that it is a time of growth and development. The second meaning is a more socially constructed one that is dependent upon the time and place that the individual lives in (Coster, in Zwordiak-Myers, 2012). Children are now seen as individuals who should be protected as they don't have full legal rights themselves or the ability to defend themselves (UNCRC, 1989.) In the past the high infant mortality rates meant that parents could not invest emotionally in their children (Aries, 1962, Stone, 1977). As the birth rate in industrialized societies has fallen since the 1960s, Western society has consequently become preoccupied with avoiding risks such as illness, accidents, disability, and death either through crime or natural causes (Hope, in Zwordiak-Myers, 2012). As guardians of their children, mothers are given the responsibility and the expectation that they can, with the correct care, avoid these risks (Rogers, 2007). A huge amount of pressure can be put on mothers to ensure that they make the right choices to avoid risk. For example, the choice about whether to breast feed or bottle feed a baby is said to have lifelong consequences for the health, development, and wellbeing of the child (O'Connor, & Joffe, 2013). This means that mothers are subjected to interference from others including experts in deciding how to feed their child. This leads to what Furedi (2002) has called 'parental determinism', which suggests that day-to-day activities carried out in private are causally linked to failing or harming their children. There are innumerate numbers of books with titles such as 'What every parent needs to know' (Sunderland, 2016). This book, which is based on the author's seventeen years of research, explains what the long-term impact of parenting decisions have on the child's developing brain. Additionally, magazines such as Mother and Baby (2019) offer instruction and advice on every aspect of child rearing with articles such as "14 realisations you'll have in the first 24 hours of having your baby".

There is a cultural expectation that women want to become mothers. This assumption affects the experience of women of all ages, regardless of whether they actually become mothers or not. Motherhood is constructed as being an important valuable function especially if it occurs within the correct circumstances of relationships, financial security, and age. These assumptions do not adjust to encompass the wider experiences of mothering (Hunt, 2009). Thomson et al. (2008) conducted research into the experiences of mothers in the 1950s and compared them to the experiences of mothers in 1970s. He found that the 1950s women did not rely on experts in the ways that women do now. That their experiences were that motherhood was just taken for granted 'Mum knows best'. Lawler (1999) argued that motherhood has now been "claimed" by experts in dictating that mothers should breastfeed and subsume their daily choice of activities to their newborns needs. This leads to the suggestion that motherhood is now another area that has succumbed to Foucault's description of surveillance, in which private practices are subject to public censure (Giddens, 2009). However, mothers of children with impairments often welcome the intrusion of professionals into their lives in order to attempt to restore their situation to normal with the best available help and advice. This intrusion brings with it surveillance of parenting practices and judgements about its efficacy (Rogers, 2007). In addition to possible negative outcomes for the child themselves, poor standards of parenting are blamed for some of societies social ills such as anti-social behaviour, children's mental health problems, lack of educational achievement and poor coping skills (Lee, Bristow, Faircloth & Macvarish, 2014). Courts making decisions that permanently affect the lives of children, have to deliberate on complex issues, consequently, such difficult judgements should be guided by informed opinion. Psychiatrists and psychologists rely on academic arguments based on research evidence, and clinical experience in their professional practice and have access to a collected body of knowledge about child development and family relationships (Shaffer & Kipp, 2014). Assessments about parenting are based on a number of factors but use developmental models like those of Freud and Piaget (Glassman & Haddad, , to see whether children are suffering significant harm. There is no exact definition of what constitutes significant harm even though it is a legal definition. Children's development is based on physical, emotional, social, educational, relationship and behavioural lines and the interplay examined between those measures and how they may be adversely affected by experiences of care. Children's Act has introduced the possibility that parents can be given help via treatment to better meet their children's needs (Reder & Lucey, 2000).

General Issues relating to Parental capacity, such as learning disabilities, mental illness, problems with addictions like alcohol and drug use or domestic violence are associated with problems concerning children's health and development including the extent to which they may pose a risk of significant harm to the child. The legal definition of 'parent' is used in a generic way to refer to any adult responsible for parenting the child. (Cleaver, Unell, & Aldgate, 2011). With these criteria for problematic parental capacity there is the possibility that there are only very few parents who are not under surveillance (Rogers, 2007).

Preparing for motherhood during pregnancy, involves preparing for the imagined child. This can take an almost romanticized view of motherhood (Beck & Beck-Gernsheim, 2004). This does not prepare the mother for the possibility that she may have a difficult or impaired child (Kalmuss, 1992; Rogers, 2007). Finding out that your child has a special need or disability is possibly one of the most devastating experiences that a parent will live through, with acute feelings of physical and emotional isolation (Pugh, De'ath & Smith, 1994). Becoming a parent under normal circumstances is challenging, but having to deal with a child with impairments whose behaviour is difficult can be intolerable when it involves dealing with antisocial behaviour such as aggression or continual screaming and faeces smearing (Rogers, 2007). Having a child that you cannot control in public leads to feelings of inadequacy as a parent, embarrassment, and shame. The felt stigma as defined by Gray, (2002) is experienced as a consequence of the enacted stigma stemming from the judgements of others when faced with behaviour outside the expected norm. This situation creates a different type of stigma called courtesy stigma, where the entire family is seen as disabled (Goffman, 1963). While diversity is celebrated, difference is included, behaviour that is deemed socially inappropriate moves from being a difference into being difficult. This leaves parents of children whose behaviour is judged as difficult rather than different in a marginalized space.

The norms of motherhood involve being devoted to their children and available in every way to support their needs. Mothers of children with intellectual disabilities have to accommodate children who do not behave in the normal expected way. This can lead to disappointment in the way that parenting is not in line with expectations. Children are either moving towards independence, autonomy, and separateness, or as extensions of themselves, to be told what to do until they leave home – the impaired child's position is in conflict with these expectations. However, if a child with autism is non-verbal then they cannot be an extension for their mother without that becoming incongruent with the mother's view of herself. If the role of a parent is to raise a child to become independent, then a child who is unlikely to become fully independent challenges the view of what the role of being a parent actually is (Rogers, 2007).

For parents of a child with a disability, that gap between the expectation and the reality is greater (Batchelor & Duke, 2019; Rogers, 2007). Research by Baylot Casey et al. (2012) found that following the diagnosis of Autism, that 20% of parents were found to be suffering from Post-traumatic stress syndrome. Another study by Lounds Taylor and Warren (2012) found that 79% of mothers were significantly depressed following the diagnosis of autism for their child. Part of the reason that parents find receiving a diagnosis of autism distressing, is that suddenly the way they imagined the life of their child going is irretrievably altered (Rogers, 2007). They might have imagined birthday parties, graduations, weddings, and grandchildren in the future, but now feel that those doors are closed (Roos, 2018). Often when parents are given a diagnosis, it is presented with a gloomy prognosis of the things that their child might never do, like speak meaningful language, or have friends, or have a job, or be toilet trained. It is this prognosis that is devastating, as the future is removed of all meaningful hope (Kaufman, 2014; Ratcliffe, 2013).

In addition to the challenge of dealing with the diagnosis and the realisation that their child is different from the one that they imagined having, there is an ongoing situation. This realisation occurs at the significant milestones of life and can lead to intense feelings of grief and loss of the child that they dreamed they would have. Olshansky (1962) termed this situation ‘chronic sorrow’. It is an unresolving form of enduring loss that occurs episodically throughout life, as the parent is faced with the milestones of life which are not achieved in the expected way. This loss does not follow the stages of grief described by Kubler-Ross (1969) as there is no end point, due the child still living. Research by Batchelor and Duke, (2019) showed that the parents who had a child with autism had the joint highest levels of chronic sorrow measured using the adapted Burke Questionnaire as compared with parents of children with other illnesses and disorders. Part of this may be caused by the nature of autism being such a complex disorder, with parents not knowing which lost future it is they are mourning (Roos, 2018).

As well as losing the child that they thought they had, the parent has to deal the loss of themselves being the parent that they thought they would be. Part of having a child with a disability involves the parent getting involved with the therapies that the child needs. This alteration in their role can lead to challenging feelings of loss of the role they thought they would have as well as feelings of anxiety about their new role as therapist (Roos, 2018). This anxiety comes from a commonly held belief that there is a critical window of opportunity to help children with autism to improve their skills that exists when the child is very young (Fletcher-Watson & Happé, 2019). For those whose children are very young there is huge pressure to act quickly to help their child although often there is not much funded help available for this. For those whose children are diagnosed when they are older, there is the feeling that they have missed this crucial time-period and that the ‘door has closed’ on the possibility of improving their child’s skills. The combination of a critical time-period that may or may not have been missed, coupled with a lack of funded therapies leaves parents to find answers for themselves, usually at their own time and expense (Wetherston et al. 2017).

There is now a bewildering array of therapies to choose from, that all promise either improvement or a ‘cure’ from autism. These therapies can be divided into categories such as behaviour and skill treatment programmes: Applied Behaviour Analysis (ABA) (Lovaas, 1981), The Son Rise Program© (Kaufman, 1994), Floortime (Greenspan & Wieder, 2006), and The Miller Method (Miller & Chrétien, 2007). Sensory interventions including sensory integration (Stock Kranowitz, 1998) Brain Balance (Melillo, 2009), Handle therapy (Bluestone, 2005), yoga (Betts & Betts, 2006) and Neurodevelopmental Delay programme (Goddard, 2002). Then there is Play Therapy (Beyer & Gammeltoft, 2000; Moor, 2003; Seach, 2007) and music therapy (Riggs, 2013). Speech and Language Therapies (Freemand & Dake, 1997) and Picture Exchange Communication System (Pyramid consultants 2021). Lastly, there are biomedical interventions (Edelson, 2015; Jepson & Johnson, 2007) and dietary interventions (Campbell-McBride, 2007; DeFelice, 2006).

An example of the challenge that parents can face with these suggested treatments is found in ABA (Lovaas 1981). ABA advertises itself as an evidence-based treatment for autism based on the largest amount of research. Lovaas suggested that children with autism could be taught very basic tasks using repetitive discreet trials. By pairing wanted behaviours with reward reinforcers and unwanted behaviours with punishment, he believed he could cure autistic behaviours and have children with autism behave like 'normal' children. The techniques employed by ABA are based on the work of Skinner, Thorndike, and Pavlov, and their theories of classical and operant conditioning (Granpeesheh, 2014). It suggests that autistic behaviours such as repetitive movements like rocking and hand flapping, can be extinguished and replaced by normal (meaning non-autistic) behaviour, like using speech to communicate and maintaining eye contact while speaking and listening (Lovaas 1981). ABA can be carried out in an education setting or in the home. It requires thirty or more hours of time each week to carry out repetitive drills to teach the new skills and eradicate the undesired behaviours (Fisher, Piazza & Roane, 2021). This therapy is often presented at the time of diagnosis; however, it is expensive and is not usually funded in the UK, meaning that parents who engage with it can run up huge debts. For those parents who cannot pay for this, they face feelings of responsibility for the possibility of a hopeless future for their child and by association, themselves as can be seen from this blog written by a parent (My autistic son n.d.). There is also the pressure of disagreement among the autism community as to whether this treatment constitutes child abuse (Gorycki, Ruppel, & Zane, 2020).

To add to the pressure, there are plenty of accounts of parents who have successfully used autism therapies and consequently their children have lost their diagnosis (Foli, 2002; Kaufman, 1994; Kirk, 2008; Maurice, 1993; McCarthy2007; Seroussi, 2002; Stacey, 2003; Stehli, 1991; Summers, 2006). The rise of the 'warrior mother', a woman who stopped at nothing in her quest to 'cure' her child is a further challenge as it excludes those who are unable to pay for the expensive therapies or commit the intensive hours that are needed to administer these therapies (Douglas, 2013).

Additionally, Miller et al. (2010) argue that many professionals who specialise in autism impose a 'no hope' mantra on parents by emphasizing the incurable and lifelong nature of autism. The overall message is that the therapies that offer a 'cure' are in fact offering 'snake oil' by giving false hope to parents (Offit, 2010). This exacerbates the situation faced by parents in dealing with challenging behaviour, which is often given as the most difficult part of raising a child with Autism. This behaviour can include self-injury, injury to others, damage to homes, tantrumming, or complex rituals which interfere with daily life (Bessette Gorlin et al, 2016; Bouma & Schweitzer, 1990, Li-Ching et al. 2008) and lack of social interactions (Ludlow, Skelly & Rohleder, 2011). It has been shown that levels of distress observed in parents of children with Autism is positively correlated with the child's levels of challenging behaviour (Allik, Larsson & Smedje, 2006) and negatively related to their language functionality (Ello & Donovan, 2005).

In addition to challenging behaviour, autism has several comorbid challenges such as learning difficulties and visual stress (previously known as Meares-Irlen syndrome (Fletcher-Watson and Happé (2019). This can make the school years challenging as teachers struggle to teach in the way that children with autism can learn. This can make the child with autism a target for bullies (Beardon, 2021). A study by Harris Interactive, Easter Seals and Autism Society of America (2008, in El-Ghoroury 2012) found that 73 % of parents of children with autism were either extremely concerned or very concerned about their child's education. The problem exists because the local education authority has a responsibility to provide an appropriate education, but this does not mean they will provide the most optimal education experience for the child. A lack of funding available to schools means that sometimes good enough is all that can be provided rather than best (Sharpe & Baker, 2007). Recent research by Brede et al. (2017) has shown that children with autism are at higher risk of being excluded from school with one in five receiving a fixed term school exclusion, with one in twenty being permanently excluded.

The poor outcomes from school, lead to issues in finding appropriate employment in adulthood. Data from the Office of National Statistics (ONS) (2020) shows that people with autism have among the lowest rates of employment with only 21.7% being in employment. The rate of employment for people with other disabilities is on average 52.1%. Regarding housing, people with autism were significantly more likely to be living with their parents 74.5% than any other main impairment type group 15.5% (ONS, 2020). These figures would seem to validate parents' concerns about what happens to their child after they are no longer able to take care of them and provide for them (Chan et al, 2018). Therefore, the family of a child with autism will be facing this situation long term.

A further consequence of caring for a child with autism is that parents, and in particular mothers, are disproportionately affected by the need to provide care for their child. So, they are significantly less likely to be employed in paid work compared to other parents, or to be working below their skill level (Baker & Drapela, 2010). Furthermore, parents of disabled children do not benefit from many of the flexible working changes that have recently assisted other working parents. The lack of suitable childcare and the need to attend medical appointments that are scheduled at times requiring time off, or the need to carry out therapies has meant that mothers have had to reduce the number of hours that they work or give up work altogether as jobs simply aren't flexible enough to accommodate these parents' needs (UNUM, 2019). Cidav, Marcus & Mandell, (2011) stated that mothers of children with Autism earned on average 35% less than mothers of children with other health limitations and 56% less than mothers whose children had no limitations. However, there were no corresponding disparities for the fathers across the three groups. That said, family income is 21% less for families with a child with autism compared to families whose child has a different health limitation, and 28% less than families without a child with a limitation.

In addition to facing reduced opportunities for employment, parents that had children with autism reported that they did not participate in social activities outside of the home because their child needed their constant attention. Furthermore, other people did not understand the behaviour of the child or the efforts of the parents and so this made socialising challenging as the parents felt judged (Fox, et al, 2002). This difficulty is said to be caused by the disability of autism being invisible. There is no autistic look, unlike a disability like Downs Syndrome which is apparent to an onlooker from the distinctive facial features (Fletcher-Watson & Happé 2019). Therefore, when a child with autism is feeling overwhelmed by their environment and having a meltdown, those watching, can judge the parents' ability to control their child rather than realising that the child has a disability causing the behaviour (Beardon, 2021).

The search for a cure for autism spectrum disorders has led to the creation of a new movement called the Neurodiversity movement (McGee, 2012). This group object to the idea that it would be desirable to find a cure because it implies that there is a disease or impairment. The movement also stems from what has been termed the disablist society. This claims that society discriminates against those that it sees as disabled. It argues that the Social Model of disability suggests that it is not the individual that has the impairment, but instead it is the society that does not accommodate them, that is disabled. (Oliver, 2013). The existence of the neurodiversity movement has led to the problematizing of the idea that Autism is a disability and so an adverse situation. The theory of neurodiversity suggests that people who have diverse neurology, should be seen as a separate category, much like gender differences or ethnicity (McGee, 2012). It is argued that having differences in cognitive styles is an advantage to society as other viewpoints emerge from those with neurological differences. This therefore means that rather than seeing a person with autism as a burden on society it is possible to find each person a unique niche where their talents can be utilized. Instead of people being seen as normal or abnormal in functioning or dysfunctioning, the idea is that these assessments should be abandoned (Singer, 1998). The aim of the neurodiversity theory is that a kinder more tolerant world can be created for those who are in a 'neurominority' (Chapman, in Bertilsdotter Rosqvist, Chown & Stenning, 2020).

The idea that there is no longer any ‘normal’ or ‘abnormal’ however, becomes unusable in situations where it would be advantageous to form an assessment for a person, for example to recognize a genuine pathology. It is also unclear how the process occurs of deciding who is neurodivergent as the movement suggests a label of ‘neurotypical’ for a person who is not neurodivergent. However, without an assessment, it becomes somewhat of a moving target to know who is who (Chapman, in Bertilsdotter Rosqvist, Chown & Stenning, 2020). Unfortunately for the families of someone with autism, the neurodiversity movements desire to be seen as equal and not as impaired, has led to the politicization of their ideas. If a person is not impaired then the state no longer needs to care for them in an institution, they can be cared for by their families and their struggles minimised (McGee, 2012). This can cause anxiety for parents who see this new way of thinking as potentially undermining the possibility of receiving support for their child’s needs (Silberman, 2016).

However, in spite of this there are some parents who are still recognised as being resilient. Like the studies that found that some children were resilience despite coming from challenging backgrounds (Garmezy, 1993), there are studies that have found evidence of resilience in families that have children with autism. It is key that when picking a cohort of people to study, that there exists some evidence of the phenomenon to be studied is seen in the group selected. Therefore, a brief overview to demonstrate the existence of resilience is given in the table below which shows some of the studies and their respective findings:

Authors	**Methodology**	**Results**
Bayat (2007),	Mixed methods	Mobilization of resources. Positive ‘meaning making’ of the disability. Becoming closer. Working together as a family. Finding more appreciation for life. Appreciation for other people. Spiritual growth.
Beighton & Willis (2017)	Qualitative IPA	No denial of challenges. Increased sense of personal strength. Increased confidence. Change in priorities. Greater appreciation for life. Sense of pleasure in child’s achievements. Increased faith and spiritual growth.

		More meaningful relationships Appreciation of positive effect that child has on wider community.
García-Lopez, Sarriá & Pozo, (2016)	Quantitative	Interplay between partners affect each other cognitively, behaviourally, and emotionally. Self-efficacy Positive contributions by each partner
Greeff & van der Walt (2010)	Quantitative	High socio-economic status Social support Open and predictable patterns of communication Family hardiness Internal and external coping strategies A supportive family that included commitment and flexibility Positive life outlook Family belief systems
Hastings et al (2005)	Quantitative	Active avoidance coping Problem focused coping Positive coping Religious/denial coping
Kapp & Brown (2011)	Mixed methods: Qualitative Quantitative	Social support, the relationship with their spouse, family time, togetherness, and routines. Family hardiness, family problem-solving communication, family time and routines.

Table 2 Examples of studies showing resilience in parents of children with autism.

Many studies suggest that a moderate amount of stress can have a toughening effect (Başoğlu et al., 1997; Dienstbier 1989; Meichenbaum 1976; Rutter, 1987) if it is not too severe and that there is adequate time to recover. As the above discussion has shown, there are many challenges of parenting a child with autism. These adversities continue ongoingly throughout the life of the child. This may mean that parents who have children with autism and are able to be resilient, would clearly demonstrate a model of resilience that may be generalisable to the wider population. This confirms that they would be an ideal cohort of people to study to find out how people recover and sustain their wellbeing in the face of adversity.

2.10 Key debates in this area

2.10.1 Debates about false dichotomies

The Merriam Webster Dictionary (2023, paragraph 1) defines a dichotomy as “a division into two especially mutually exclusive or contradictory groups or entities; the process or practice of making such a division; something with seemingly contradictory qualities” . The creation of a dichotomy has several advantages in that it creates a cognitive shortcut or schema that can easily be used to guide our thinking and behaviour (Glassman and Haddad, 2009). However, when dichotomies are misused, they can lead to an abuse of power as it allows individuals to make assumptions about people that can appear as facts (Shatz, 2023). This then allows for people to be ‘pigeon holed’ according to the dichotomies that have been created, and rights and responsibilities apportioned accordingly. Examples of these can be autistic versus non-autistic, resilient or non-resilient, and having mental health problems or not.

However, it is possible that a person could appear to be resilient when facing one sort of crisis, but then non-resilient in a different set of circumstances. Additionally, people with autism – especially girls, can mask their symptoms so that they can appear not to have autism for a short while, but then go home to their safe space and appear to be clearly autistic (Dean, Harwood & Kasari, 2017). This means that it is not possible to claim mutual exclusivity between either resilient or non-resilient or autistic and non-autistic. Furthermore, people experience a mix of emotions at the same time, meaning that people are not either happy or sad, but a mixture of emotions (Ivtzan, et al, 2016). They can be sad at the fact that a relative has died, and concurrently, be happy that a good friend brought them round a meal to help them. Additionally, the term disabled is used to denote a person who has an impairment in say, one of their limbs. However, usage of the word disabled person appears to describe the individual as a whole whereas in reality it is only one of their limbs that has the impairment, the other three limbs might work perfectly well, meaning that the person is not wholly disabled. This person is therefore, both disabled and able bodied.

These examples demonstrate that using a dichotomy is maladaptive or could be what Beck (1995) referred to as a cognitive distortion. Dweck (2007) in her Growth mindset theory suggested that creating fixed cognitive positions e.g., can or can’t do maths, was not helpful to learning. Using a dichotomy also suggests that the two options given are the only two positions available and that no other position or method exists. The second wave of positive psychology (Held, 2004) also rejected the idea of mental health or mental illness being tied to being happy or sad. The suggestion that being happy was positive and being unhappy is negative is a false dichotomy, especially when viewed from the perspective of someone experiencing post traumatic growth. This person would take longer to recover but then reach a higher level of functioning after the growth is achieved (Joseph, 2011).

This would, therefore, suggest that a more fluid model is required that can encompass these nuances, so that it is possible to make less assumptions about people and so therefore create a model that can be applied in a more flexible way.

2.10.2 Debates about language

Within the autism community, there is an ongoing debate about how a person diagnosed with autism should be referred to. The way that people are spoken about has consequences for the individual due to stigmatisation and dehumanisation of a person deemed to have an impairment or disability. The two options in question are whether person-first language (person with autism) or identity-first language (autistic or autistic person) is preferable (Botha, Hanlon & Williams, 2021.

Historically, the way that a person was described was by using the pathology-first language with the term 'autistic' being used to denote a person afflicted with a *pathology (Rutter, 1968)*. These articles often went on to describe the symptoms of autism in terms that were 'of their time' such as 'mentally subnormal' (Dwyer, 2022). In reaction to this, person-first language stated that individuals were people first and should not be defined by their disability in such a negative, stigmatizing way. This had the effect of positioning autism as one of their attributes rather than their whole self (Blaska, 1993).

However, others, like Sinclair (2013) felt that person-first language did not deal with the root cause of the problem, which was the stigma attached to the diagnosis of autism. Sinclair stated that by 'burying' the term autism, it made it sound as if it was bad and that it could be separated from the person and was unimportant. The solution to this was to place or 'autistic' as an identity in first position, so that the descriptor become 'autistic person'. Superficially, this appears to be the same as pathology-first language as it uses the same word order. However, the underlying construct is completely different, with autistic people being encouraged to be proud of their neurodivergence (Dwyer, 2022).

There is, however, no clear consensus in the autism community as to which method of description is preferable, so it seems that the way forward could be to find the term that is least offensive. In doing this, a compromise has been suggested in person 'on the spectrum', which it was said is similar to person-first language (Botha, et al, 2021).

As part of this research, the above options were considered as I did not want to use terminology that was considered offensive. However, it is clear, that the autism community was divided on this, and so whichever term I chose, I would be offensive to someone. I have chosen to use 'child with autism' throughout this research, for the following reason. My research is about mothers of children and their experiences of mothering their child(ren). The symptoms/traits of autism do not manifest until around the child's second year of life. Therefore, chronologically they are a child first. My own son was diagnosed at 25 months and so from birth until that time, he was a child – autism came later. So, to honour this transition, I feel that for this research project into mother's experiences, that 'child with autism' is the most appropriate term.

2.10.3 Debates about responsibility

The literature has shown that the theories of resilience have moved on past those that suggest that resilience is an innate trait (Garmezy, 1993; Rutter, 1987) to now demonstrate that it is something that people can develop (Olsson, et al., 2003; Masten 2001) . Yet the conversation still seems to suggest that resilience is something that people either are or are not. Historical models of resilience that suggest that it is purely a matter of resistance or speedy bounce back do not take into account the environmental burdens placed on an individual (Neenan, 2018). This means that while it is clear that ten years of austerity and a pandemic would be challenging, that it is an individual's responsibility to stand firm. Supporters of the biomedical model would add to this burden by suggesting that there is plenty of information from so called experts about how to improve our resilience, which then results in the 'sick role' placing the responsibility of the individual to act on that advice and quickly bounce back (Giddens & Sutton, 2013). Then potentially, there is Friedson's (1970) assertion that if a person doesn't bounce back, then perhaps they are the illegitimate sick; ill because their behaviour and lifestyle choices have led to them not recovering quickly.

There is a need for critical reflection on this construct as it is clear that society has built an environment that is so challenging that it has created a need for resilience, as people are being asked to thrive in situations that are impoverished, stigmatized and discriminatory. Maintaining this situation supports those in power who have much to gain from retaining the status quo (Giddens & Sutton, 2013). However, it is time to change the language around resilience, to one that emphasizes the aspect of the sick role that allows the individual to temporarily lay down their responsibilities and to recover. A new model of resilience is needed that challenges these discriminatory practices and allows the individual to acknowledge the impact of the environment, instead of laying the responsibility for resilience solely at the feet of the individual.

To summarise, this section has aimed to lay out the background to the concept of resilience and to demonstrate the problems that exist within the current understanding of the construct. It is hoped that this illustrates the need for this research project into the topic with the aim of finding a place of consensus. This section has also shown the rationale for choosing mothers of children with autism as the participants for this study.

CHAPTER 3: METHODOLOGY

3.8 Introduction

This chapter explains the process of research design, with justifications given for each decision. Section 3.9 seeks to justify why a qualitative methodology and constructivist grounded theory method was chosen for the research along with the assumptions and epistemological decisions that led to that choice. Section 3.10 details the sequence of events that were carried out in the course of conducting the research including: the procedures, the research setting, the recruitment processes, research participant selection and ethical considerations that needed to be incepted to protect both the participants and me. Section 3.11 explains the research implementation that involved the concurrent processes of collecting, coding, analysing, and interpreting the data. Section 3.12 on reflexivity concludes the chapter.

3.9 Research Methodology and Methods

When designing a research project, it is vital to do so with sufficient rigour, situating the process within a broader theoretical framework so that the results of the study can carry a level of credibility as a scientific endeavour (Merriam & Tisdell, 2016). Crotty (1998) argues that researchers often move from the research questions, to choosing the method of data collection without consideration of the consequences of such a decision. It is important that the decisions I made, are congruent with my methodological standpoint. Therefore, the research design for this project, is situated within Crotty's (1998) four step process, which involves exploring: epistemology, theoretical perspectives, methodology and methods. The four-step process follows careful consideration of the purpose of the research, so that the decisions made are supportive to the research objectives.

3.9.1 Development of research objectives.

The current knowledge of resilience in mothers that have children with autism, has been mostly generated within traditional quantitative methodology (Costa, Steffgen, Ferring 2017; Lloyd & Hastings, 2009; Ming-Hui, Guang-Hai, Hao, Meng-Liang, Rui, & Fan 2018; Nolcheva & Trajkovski, 2015; Phelps, McCammon, Wuensch & Golden 2009; Twoy, Connolly & Novak, 2007). The questions asked within this paradigm have a guided or restricted choice of responses. The consequences of this are, that participants can only answer a question that has been asked, which leaves no room for them to add in additional items of importance to them. It also restricts them, in that they can only answer within a prescribed way, meaning that to an extent, their voices have not yet been heard (Sarantakos, 2005). A possible upshot of this has been, that the current knowledge on resilience has found no consensus of agreement between researchers (Coutu, 2003; Meredith et al, 2011; Shaikh & Kauppi, 2010). This is because the results have mainly been lists of risk and protective factors that either confers or denies resilience on an individual (Garmezy, 1993), with each research project testing different factors (Connor & Davidson, 2003; Wagnild, & Young, 1993). This approach appears deterministic as someone who does not possess the right protective factors would appear to have little chance of appearing resilient. It is not clear whether resilience is a quality that is dichotomous in being possessed or not, or whether it is a spectrum that a person can move along depending on where they are in a resilience process (Reid and Kampman, 2020). Whether the 'so called' resilient people have always been resilient and are always resilient or whether there is a time when they weren't resilient and then developed it isn't clear (Lines et al., 2020). Additionally, a loss of resilience has not been clearly described, as to whether a person needs to have a downturn in their mental health and their level of functioning practically and socially, or whether just one type of downturn is sufficient (Carver, 1998). This research project therefore aims to find some answers to some of these questions and build a new conceptual model of resilience. Therefore, another quantitative study will not address the research objectives. An inductive method is needed which will generate a more substantive theory or model of resilience. As resilience is a construct that occurs in reaction to adversity, a cohort of people facing a chronic adversity has been chosen. Autism is currently constructed as a lifelong incurable disorder which is diagnosed from symptoms that include challenging behaviour. Therefore, having a child with autism could be described as an ongoingly challenging experience for the parent. The questions constructed for the research aims, were structured to provide the opportunity to ask questions that would elicit a picture of how these parents dealt with enduring adversity. From this data a new conceptual model of resilience emerged.

The overarching research questions have been established as:

To what extent, do mothers of children with autism, experience resilience, given the challenges and stigmas of parenting their child?

Then there are three sub-questions:

1) What does the word resilience mean to mothers that have children with autism?
2) How does being a parent of a child with autism affect the mother's resilience?
3) In what ways do mothers of children with autism demonstrate resilience?

By using one cohort of people as a quasi-case study, a model of resilience was developed that can now be used as a basis for further research. The model that has been produced needed to be situated in everyday real-world experiences so that it has 'usefulness to practice' in enhancing resilience (Robson, 2002). Therefore, the area of exploration for this study was rooted in the processes of feelings and behaviours of the participants and the meanings that they attributed to their experiences. Furthermore, the study design required a methodology that went further than a measurement of wellbeing or the provision of a list of risk and protective factors. An additional requirement is that the method provided an analysis that went beyond a collection of individual accounts to an examination of concepts and interpretations that uncovered what these mothers were thinking, feeling, or doing that was behind their resilient reactions to their situation. In providing a theory of resilience for these mothers it was hoped to enable others to use those same concepts or techniques to improve their resilience.

3.9.2 Exploring Ontology and Epistemology

This section contains an explanation and justification of the philosophical standpoint of this research. Each of the chosen paradigms and positions are explained throughout. A pragmatist paradigm based in a symbolic interactionist theoretical framework, was the viewpoint used to study the research aims. This enabled a 'what works' approach in a real-world setting (Robson, 2002). This allowed for the following philosophical positions to be considered and adopted. Blaikie (1993, pg. 6) states that the root definition of ontology is "the science or study of being […] it is the claims or assumptions that a particular approach to social enquiry makes about the nature of social reality." Ontology or 'theories of reality' asks the question 'what is reality'? Is reality objective, meaning out there waiting to be found, or constructed, or subjective meaning only existing in the minds of those who observe and give meaning to the phenomenon (Sarantakos, 2005)?

Epistemology is "concerned with providing a philosophical grounding for deciding what kinds of knowledge are possible and how we can ensure that they are both adequate and legitimate" (Maynard, 1994, pg. 10). Therefore, epistemology is a study of the characteristics, source, and validity of knowledge, which asks 'How do we know what we know?' (Lincoln & Guba, 2016, pg. 86)

Traditionally, social research was carried out quantitatively in the Positivist tradition (Coolican, 2009). This held that knowledge was purely a matter of uncovering pre-existing, universal explanations through external, neutral, observation and experimentation producing a grand theory that could be tested (Sarantakos, 2005). The positivist position suggests that reality is out there, independently existing objectively whether we are conscious of it or not. This is the ontological position of realism (Crotty, 1998). Criticism of this approach suggests that reality is interpreted through human interaction with the studied objects and that subsequent meaning made of that interaction. The ontological position of interpretivism attempts to identify the meaningfulness of social life. It holds that there is not one absolute truth, but that reality is represented by multiple truths that are negotiated through interaction and so are equal in value (Merriam & Tisdell, 2016).

Therefore, reality is not out there to find, it is created by the actors involved, it is as if meaning could be created in a vacuum (Blumer, 1979). A third position exists which argues that knowledge and reality is neither objective and ‘out there to be found’, nor subjective and created, but is instead constructed. The ontological position of constructionism suggests that there is no meaning without the consciousness that makes meaning from experience (Cooper, 1998). This, therefore, means that different meanings can co-exist in relation to the same phenomenon. This position proposes a marriage between objectivism and subjectivism in that they depend on each other to explain reality (Crotty, 1998; Wener & Woodgate, 2013). That a child is given a diagnosis of Autism is an event that has historically occurred and is therefore an objective reality. However, resilience theory suggests it is the following application of the protective factors or absence of risk factors and processes that determines the level of resilience (Lines et al. 2020). Therefore, the meaning making of the respondents when reacting to their lives as parents of a child with autism is the piece that this study aimed to uncover. This study aim is therefore best served by a constructionist ontology such as relativism, as each parent constructs meaning around their experience of parenting a child with autism. This ontology suggests that entities only exist in the minds of those observing and thinking about them (Lincoln & Guba, 2013).

There are two epistemological positions which present, these are empiricism and constructionism. Empiricism supports the view that knowledge comes through experience obtained via the senses, and that facts can be learned through experiencing the world around. An example of an empirical approach would be to observe a phenomenon without interfering with it in any way, for example what happens when heat is applied to water. Hence, observation and experience offer the basis of knowledge (Sarantakos, 2005 pg. 33). However, the ontological position of relativism within constructionism maintains that there is no absolute objective truth and no true interpretation. Therefore, each respondent in research has their own truth, which means that research needs to take an idiographic approach, which is one that focuses on the nuances presented by each person as an individual (Coolican, 2009). Furthermore, the constructionist approach suggests that knowledge is constructed through interactions with other actors and is influenced by the cultural norms of the society in which the individual lives. People do not encounter phenomenon and then make sense of them separately to every other experience around them. Each person is born into a world that has a system of symbolic meaning and view the world through lenses inherited from that culture (Crotty, 1998). This then creates an environment whereby meanings are constructed, reflected upon, and then reconstructed. This creates what Giddens (1976) termed the ‘Double Hermeneutic’. When a scientist observes a rock, his observation does not change the rock. He can observe that rock again and the rock will not have changed. However, people are different, a social scientist can observe the behaviour of their participants and then publish that research. The findings can then inform public policy which then changes the environment for subsequent research studies, which means that I would be observing something different in any later study. This creates a research process which is dynamic and subject to multiple possible changes and developments (Crotty, 1998). This means that a constructionist epistemology would be most appropriate for this study as it is flexible enough to accommodate multiple meanings and truths collected through idiographic study. Within this constructionist epistemology there is the presupposition of transactional subjectivism, which again denotes the relationship between the knower and the known (Lincoln & Guba, 2013).

3.9.3 Exploring Theoretical Perspectives

The theoretical perspective elaborates on the assumptions that are brought to the research task and reflected in the selection of the methodology.

Symbolic Interactionism states that explanations can be found both by traditional methods and by an emerging consensus within a community of observers as they make sense of what they have observed. Therefore, shared meanings and collective interpretations of phenomena can also elicit knowledge (Suddaby, 2006). This leads to the understanding that multiple realities can exist within a shared community (Wener, & Woodgate, 2013). Symbolic interactionism has three basic assumptions according to Blumer (1969, pg. 2):

1) "That human beings act towards things based on the meanings that these things have for them.
2) That the meaning of such things is rooted in and emerges from the social interaction that a person has with others.
3) That these meanings are engaged with, and modified through, an interpretive process used by the individual in dealing with the things he meets.

According to Shakespeare's Hamlet, "There is nothing either good or bad, but thinking makes it so" (Shakespeare, 1599/ 1956 pg. 1141). This demonstrates that it is not so much the fact observation of the adversity that interests the resilience researcher, but that the thinking that occurs after that denotes the event as being adverse. The assumptions of symbolic interactionism fit the aims of this study well, due to the emphasis on the meanings that individuals place on their experiences. Additionally, in this study, the mother will have interactions with their child with autism and other members of their family and social circle, that will impact their experience and interpretation of their experience. This means that the participants can be viewed as people who exist within a context that has relevance to their story. This context may explain some of the differences between the participants' accounts of their lives. By choosing a cohort of participants with a common situation it could be seen as if the research is attempting to create a homogenous situation. However, the assumptions of symbolic interactionism would claim that this is not possible as no two contexts are alike even if the person faces the same adversity.

3.9.4 Exploring methods

The primary aim of this research is to provide a new model of resilience. It is hoped that by taking an inductive approach, that a new model will emerge from the responses of the participants. Three different qualitative methods were considered for suitability for data collection and analysis: thematic analysis, Interpretative Phenomenological Analysis (IPA) and grounded theory.

Thematic analysis is a method used for analysing data that involves searching across a data set to identify, examine and report repeated patterns. It is appropriate to use if the research aims involve wanting to understand the experiences behaviours or thoughts of a group of participants (Braun & Clarke, 2006). This method is compatible with a wide variety of philosophical positions and epistemologies, so in this sense it would work with the current study. However, it is useful for describing and explaining data rather than theory creation, so it is not the method required for this research (Kiger & Varpio, 2020).

IPA is a method of data collection and analysis that allows the participant to describe their personal experiences and the meanings that they make of those. IPA then provides a structure that explains the underpinning features of those experiences and meanings. This method was first used in the health sciences to describe the physical experiences of those who were ill (Smith, & Shinebourne, 2012). It is a highly subjective, interpretive method with an emphasis on the individual viewpoint (Smith & Osborne, 2003). Due to the in-depth nature of this approach any research conducted using this method usually has a small number of participants (Reid, Flowers, & Larkin, 2005). Although the current research project is interested in the lived experiences of mothers of children with autism, it is interested in knowing what they do as well as what they think. Therefore, the study is interested in more than their experiences. The philosophical position of constructionism is incompatible with the interpretivist idiographic stance of IPA. Additionally, IPA produces an explanation of a phenomenon rather than theory creation. Therefore, IPA as a method for this study was rejected.

Glaser and Strauss' (1967) grounded theory, has at its root the pragmatic concerns of symbolic interactionism. It views the participants as taking an active role in the events of their lives by interpreting their experiences. The development of grounded theory occurred as a result of their joint research on dying in hospitals. Glaser had a background in inductive quantitative research whereas, Strauss' influences were interpretivist and pragmatist including ideas around human agency, processes, and actions. They suggested that data analysis attempted to create a rule for everyone, which divorced the analysis from the lived experience of the individual stories collected using semi-structured interviews. Glaser and Strauss argued that their qualitative grounded theory methodology requires the field work to be done first before studying the literature. This ensures that the theoretical understanding of idiographic events, meanings and actions comes from the data. Participant's narratives therefore represent a 'truth' that should be privileged, as they are grounded in everyday experiences, thinking, and understanding (Corbin & Strauss, 2008). By creating a connection between symbolic interactionism and grounded theory, Glaser and Strauss believed they had married the rigour and logical linearity of quantitative research to insights gained through interpretivist interactionism. It was this combination that enabled a theory to be built from the collected data that demonstrates a relationship between the relevant constructs. (Urquhart, 2013). This claim was highly disputed by many researchers, who disagreed over how the process of data analysis should occur, in order to demonstrate that the theory had actually been grounded in the data. This has led to difficulties for this study in choosing grounded theory as a method, as there are now different and diffuse conceptualizations of the theory (Corbin, 2017). Charmaz (2014) argues that the newer versions of grounded theory, kept it relevant to contemporary ideas regarding how research should be carried out. In the 1990s a group of researchers (Conrad, 1990, Ellis, 1995 & Richardson, 1993) wanted to develop grounded theory away from its positivist roots. This created a new way to use grounded theory that was less mechanical in its approach and therefore more flexible. It was thought that the original Glaser and Strauss model of grounded theory created a fragmented version of the participant's stories and privileged the voice of the researcher. This method also contested the idea that it is possible for a researcher to come at the project with no bias, therefore, the method found a way for the researcher to constructively interact with the data (Charmaz, 2014).

Charmaz' (2014) constructivist approach to grounded theory is a perspective that does not hold to the notion of the objective passive observer. The researcher is neither an expert, nor a value-free observer on the stories told by the participants. Constructivist grounded theory acknowledges the constructions within the data and the researcher's own constructions in their subjective interaction with the data. Furthermore, constructivist grounded theory focuses on actions and processes. This is key in this project as a theory is sought to explain resilience as actions and processes rather than a list of risk and protective factors.

Constructivist grounded theory method (Charmaz, 2014) was also deemed compatible with my own ontological and epistemological position. Therefore, it was adopted for use in this study. Constructivist grounded theory was also chosen because it's systematic methods of data analysis are aimed at constructing theories (Birks & Mills, 2015; Coolican 2009). The process of data analysis is rigorous, iterative, and comparative. It also involves an interaction between me and the data in selecting the parts of the data to continue to explore in later iterations. As the process of analysis took place, the conceptual model emerged, and was checked, revised, and honed until there was nothing new to add, as saturation was reached (Charmaz & Belgrave, 2018). I interacted with the data by choosing which portion of the data to highlight, and also which codes I attributed to those portions of data. In doing this I must acknowledge my own philosophical position and processes in the construction and so be reflexive as to their emotions and opinions, through the process of memo writing (Charmaz, 2014). This contrasts with the traditional methods of Glaser and Strauss' (2008) grounded theory, which aimed to create more objective findings.

3.9.5 Exploring methods

The original method of data collection for this study was designed as a three-stage strategy. Firstly, semi-structured interviews were to be carried out with all of the participants, to gather data. The purpose of this was to allow the participants to tell their story, including the individual context in which their story exists. These contexts include aspects such as culture and socio-economic status (Braun & Clarke, 2013). This gives the opportunity to create knowledge outside my own experience and privileges, by asking open ended questions (Charmaz & Belgrave, 2018). Therefore, the questions (see Appendix one) have mostly been structured to ask for examples from their lives, rather than to talk about the subject matter of resilience in an abstract way. Once the data was collected, it provided the opportunity to study the phenomena of the participants' lives and theorize about their experiences (Miller & Glassner in Silverman, 2011).

The second part was a more creative plan of data collection, which involved a case study of a small number of the participants where data was collected using two methods: a photo elicitation and a 'rant box'. The case study method can be defined as "an approach capable of examining simple or complex phenomena, with units of analysis varying from single individuals to large corporations and businesses to world-changing events; it entails using a variety of lines of action in its data-gathering segments and can meaningfully make use of and contribute to the application of theory (Berg & Lune, 2012 pg. 325)".

Photo elicitation is a method of 'action research' which gives the participants an opportunity to play a more proactive role in the study (Glaw, Inder, Kable, & Hazelton. 2017). It was hoped that this would create a deeper relationship between the participant and myself and give the participants the experience of being worked 'with' rather than worked 'on'. Additionally, this more 'sociable' method would give participants more control over which areas of their lives would be included, which may mean that participants bring up areas of their life that I do not ask about, giving the resulting collected data greater authenticity. This overcomes the situation that might have arisen, whereby I only based questions in the semi-structured interviews on the part of the phenomena known to myself (Robson, 2002; Sinha & Back, 2013. Furthermore, parents of children with Autism are often in stressful situations that will not allow for time to write a journal. However, taking a photo that can be used to recall the experience on a future date is a quick way to provide a thorough account of what happened. The participants are asked to take three photos of a scenario where they feel that they were resilient. The photos are then brought to an interview and are discussed in answer to the question “tell me about the pictures”.

The second method is the creation of a ‘rant box’. This novel method of data collection was designed to provide a window into the thought processes or ‘interior monologue’ of the participants during intense moments in their lives. The participants would have been asked to write or record by a video their thoughts and feelings using a ‘stream of consciousness’ style from the moment that something they perceive to be challenging occurs until the intense thoughts and feelings have dissipated. It was hoped that this method would have revealed their process of resilience (James, 1890).

Unfortunately, the Covid-19 pandemic began shortly after the start of the data collection period for this research project. This meant that I could not, in all good conscience, ask the participants to discuss the challenges of raising a child with autism while the child was in the room because of the school closures during lockdown. This caused lengthy delays and times when no data collection was possible. In the end, as this is a time limited project, it was decided to use the interviews that I was able to do, and to not do the case studies as they were a much more involved experience for the participants. This was a very disappointing situation which will no doubt be remedied in future research, rather than to extend this project.

An alternative method of data collection that is popular within qualitative methods is participant observation (Silverman, 2011). Using this approach was considered for this study, because by watching a participant interact within their environment, a researcher can see the processes unfolding and so be able to note the parts of the interactions that inform the research objectives. This approach would have been highly beneficial for this research, as the observer would have been able to see resilience in action. However, children with autism spectrum disorders have a high need for consistency in their environment, so having an unknown adult in the room would change the dynamic thus preventing the observation of typical interactions and prevent parents from answering any questions openly (Wing, 1998). Other more creative methods can be used to gain some of the benefits of observation such as photo elicitation and journaling, as these methods allow the participant to create an ‘in the moment’ account of their daily lives for me to view from a distance.

This would provide the benefits of observation without the intrusion into their lived experience (Glaw, Inder, Kable, & Hazelton. 2017), therefore, this possible method was discounted.

3.10 Research Procedures

This section details the process of conducting the research and includes a rationale for each step of the way.

3.10.1 The research setting.

The original intention for the interviews was to carry them out either in the University of Suffolk, for those recruited within the university, or in the participants' homes, while their child was at school. This was chosen as the participants would hopefully feel more comfortable in a familiar environment. Also, it is possible in these settings to have a quiet room, where the participants were free to share without fear of being overheard. As much of the data collection took place during the Covid-19 pandemic, the majority of the later interviews were conducted via Microsoft Teams© as that was considered to be a more secure platform than Zoom or Skype.

3.10.2 The research participants

A set of criteria was devised to identify a group of people that would act as a quasi-case study to facilitate this research.

To select this group a few questions, were posed to find a group of people who are facing a moderate to high level of adversity. It was acknowledged that more than one group might have fulfilled these criteria, but one group needed to have been selected so that there was an homogeneity of challenge:

1. **Would a single adversity or a chronically adverse situation be best to elicit the model of resilience?**

   Lines et al. (2020) stated that a moderate level of adversity might be beneficial, so the group chosen for this study needs to be a group of people who are facing a moderate to high level of adversity over a significant period so that they can display their resilience. This decision would therefore rule out studying a group of people facing single adversities like redundancy, the ending of a relationship, or being a victim of a one-off crime incident. An ongoingly stressful situation would mean that the participants would display 'like with like' as they would all still be in that adverse situation.

2. **How long must that chronic adversity have existed for?**

   Theories of resilience, describe adaptation (Connor, & Davidson, 2003; Olsson et al, 2002) and persistence (Cox, 1926, Duckworth, 2017), these processes take time to achieve, therefore, a group of people who are facing a chronic challenge must have been facing it for a significant time-period to have had a chance to do this. So, the group of people studied must be in an enduringly chronically challenging situation. This could be an ongoing illness, disability, ageing, or something like poverty.

3. **What does the prognosis for the adversity need to be, to elicit the model of resilience?**

The definition of adversity given in the Merriam-Webster dictionary (2021) stated that it needs to be fortuitous. Therefore, the group of people chosen for this study need to be in an ongoing challenge, but that situation needed to have some element of randomness or unpredictability about it going forward. A person with an illness such as cancer or a degenerative condition, would be facing an unknown future with an internal condition that behaves unpredictably. Conversely, a person with a stable disability would know the extent of their limitations. However, a carer for a person with a disability would not be able to know everything about the person they were caring for. In the case of a carer for a child with a developmental disability, they would not be able to control the behaviour or the choices of that child, which may have a significant impact on any future outcomes for that child and by association the parent (Gravelle, 1997).

Research on resilience has focused on life experiences that are temporary. This is shown in the frameworks that are studied involving processes and outcomes (Zautra, Hall & Murray, 2010). The concept of an outcome implies that there is an endpoint to the adversity and adaptation process. Therefore, circumstances where there is no end point to the situation would add to the adversity, but not in an acute way. Most experiences in life have end points even if that end point is the individuals own mortality (Cozzolino, 2006). This would suggest that an adverse situation that endures even after the death of a person, would constitute an adversity as there would be concern as to how the person with the disability would be cared for. This would, therefore, rule out situations like cancer patients or people living in poverty. It would suggest that a parent who was caring for a child with a significant disability that prevented them living independently for their entire life would be the group to study. It would need to be an incurable disability that did not have a reduced life expectancy so that the child would possibly outlive the parent.

Studies measuring stress levels of parents that have children with autism have shown that they suffer from higher levels of distress than parents of children with other conditions such as Down Syndrome or Cerebral Palsy (Eisenhower, Baker & Blacher, 2005; Li-Ching et al. 2008; Wang Michaels & Day, 2011). The prevailing reason given for this is the challenging behaviour of their children (Butrimoviciute & Grieve, 2013; Eisenhower et al, 2005).

Challenging behaviour is defined as “culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit the use of, or result in the person being denied access to, ordinary community facilities” (Emerson, 1995, pg. 4). Padencheri and Russell (2002) state that dealing with this type of behaviour leads to parents losing their hope for the future which again leads to the experience of adversity through stress. The level of stress in parents that have children with Autism has led to 20% of those studied having post-traumatic stress symptoms (Baylot Casey et al. 2012) and 79% of them being significantly depressed after receiving the diagnosis for their child**.** (Lounds Taylor and Warren, 2012).

4. **Is there are difference in the experiences of mothers compared to fathers?**
   Research by Lashewicz, Shipton and Lien (2019) showed that the experiences of fathers raising children with autism are distinctly different to those of mothers. However, there is significantly less research into the experiences of fathers. Research into the experiences of mothers of children with autism showed that mother’s employment and leisure activities were dependent on the continuation of services being provided and that their discontinuity created an imbalance on the impact of the child’s disability on the mother (Hodgetts et al. 2014).

Therefore, the participants will be recruited from a cohort of mothers that have children with autism. Using a group of people all facing a similar challenge will mean that they can operate like a quasi-collective case study (Sarantakos, 2005). This will enable the phenomenon of resilience in a challenging environment to be explored in a ‘real-world’ setting (Robson, 2002).

Having established the target group, the participants were then recruited using a five-step ‘site-based’ approach suggested by Arcury and Quandt (1999). This method of recruitment is useful in the important task of obtaining a sample of participants in an ethical manner. It also reduces the possibility of bias in the selection of participants through favourable selection of participants known to me.

The first step of Arcury and Quandt’s (1999) recruitment method was to make a clear specification of the characteristics that the participants should have to meet the research aims. This method is consistent with the requirements of grounded theory in that recruitment is carried out using purposive sampling initially and then subsequently theoretical sampling (Glaser and Strauss 2008). Purposive sampling is a non-random method of sampling which rests on the assumption that only a select group of people can make a meaningful contribution to the data collection. This is because their life experience gives them a perspective that is deemed to be useful to the research aims (Coolican, 2009). However, as families of children with autism sometimes form themselves into a community it is also anticipated that some snowball sampling will occur as mothers tell their friends about the research (Coolican, 2009).

The participant selection criteria for this study are:

a) Parent(s) of a child with a formal diagnosis of autism spectrum disorder.
b) The diagnosis of autism spectrum disorder should have been given five or more years ago.
c) The parents should be at least 18 years of age.
d) The child should be living at home with their mother.
e) The family should be resident in the UK (unless an online interview is arranged).

These selection criteria were chosen for the following reasons:

Criterion (a) is necessary to make sure that the family fit the criterion of having a child with autism. It is possible that a family would have a child that the parents believe to be autistic who might in the future go on to receive that diagnosis, however, the literature review demonstrated that receiving the formal diagnosis was part of the considered adversity. Therefore, it is necessary for this to have actually taken place for this mother to be included in the study.

Criterion (b) this was desired so that the mother would be able to give a more long-term perspective on the life that she was living. If someone had only just received the diagnosis, they would still be in the middle of the crisis and so would only have that part to discuss. Therefore, it was decided that a period of approximately five years was needed to allow for some ‘rubber to the road’.

Criterion (c) was required so that the research involved only adults. This was purely an issue related to the ethical issues of working with children. It was decided that a mother who was less than 18 years old would also be facing additional challenges that were separate to the child’s condition and so as part of the effort to have all the mothers in a similar position, that mothers under the age of 18 years old would be excluded. It was also acknowledged that it was unlikely for a mother to volunteer who was under 18 years of age due to children only being diagnosed with autism after the age of 2 and then needing 5 years after that to fulfil criteria b, making the possibility of someone under 18 volunteering, unlikely to occur.

Criterion (d) was chosen for similar reasons to criteria (a) and (b) in that it was desired that the participants would have a similar level of challenge in parenting. Having a child living away from the family home still has its challenges for the parents, but they are different to the challenges of having the child in the house every day.

Criterion (e) was a practical one, in that it was hoped in the beginning to conduct the interviews face to face, so the participants were asked to be living within a small radius of Ipswich. However, this criterion became less important once the pandemic hit, as all the interviews had to be conducted online or via the telephone.

There was also some thought given as to whether to exclude volunteers who had a mental health diagnosis. This began as an ethical discussion and was purely about safeguarding people who were mentally ill from being asked questions about a part of their life that was a challenge. In the early days of conceptualizing this project the current conversation about resilience suggested that people who were mentally ill were not resilient (Chmitorz et al, 2017). Therefore, if they were not considered resilient, then they would not be able to contribute to the question of what is resilience. However, even though an early criterion was that there should be no one with a mental health diagnosis, one mother disclosed halfway through the interview that she did have a mental health diagnosis. Looking back on the comments that she had made it was clear to see the ways in which she was resilient. Another aspect to this decision was that excluding this group might also exclude some really useful data and as part of the method of grounded theory is to let the data speak for itself, it was decided that this criteria should be dropped.

Usage of a quantitative scale such as the Connor-Davidson resilience scale (2018) was considered, to ascertain which of the volunteer participants were resilient. This would have made this research project a mixed methods study, rather than a purely qualitative one. However, each resilience scale has been constructed based on a predetermined theory of resilience risk and protective factors. To select one scale as opposed to another would mean subscribing to one theory of risk and protective factors over another, for example, using a scale that supports social support (Connor & Davidson, 2003) and not equanimity (Wagnild & Young, 1993). This would then undermine the main purpose of the study, which is to let the theory emerge from the data which requires a blank sheet approach with no preconceived ideas about what creates resilience (Charmaz, 2014). Therefore, it was decided to carry out a purely qualitative study and to leave recruitment open for all parents to participate, and for those parents who were considered not resilient, to then become background cases (Seawright and Gerring, 2008). However, in the early stages of data collection it became obvious that there would be no background cases, as all participants were resilient in their own way and that this belief about there being resilient and non-resilient was incompatible with the findings.

The second step in Arcury and Quandt's (1999) recruitment process was to produce a list of sites on the internet where the participants with the characteristics detailed above might be found. Facebook has several support group pages covering this area, that provide support and information to parents of children with autism. Appropriate pages were selected which then led to the third step, which was an approach to the group's gatekeepers to check their groups suitability to this research and then to request permission to post a recruitment notice on the group wall. The fourth step was a general post advertising for participants to be posted on the wall of the group (see Appendix two). This gives everyone in the group an equal chance to participate in the research, if they meet the selection criteria. The last step in the recruitment process for the initial stage of the research was to monitor the applications from potential participants and then when sufficient requests to participate had been received to update the posts within the groups to put a hold on any further applications.

Due to the nature of grounded theory research, it was only necessary to recruit a few participants at a time as data collection, data analysis and data comparison all occurred concurrently (Birks & Mills, 2015). Therefore, recruitment was an ongoing process which happened in waves. It was therefore not necessary to approach all the Facebook groups in the first instance, but to allow the number of groups involved to grow as the study progressed. Once the theory or model began to emerge from the data, the last few participants were recruited to verify the accuracy of the theory using theoretical sampling.

The first round of recruitment involved one participant, who was recruited to be the pilot. Feedback was sought following this interview and the questions amended in line with her suggestions. Then five more people were recruited and interviewed. There then followed a gap in time to allow the data analysis to commence. Then another group of five people were recruited. This recruitment took place just prior to the initial pandemic lockdown. This meant that the interviews were delayed as the children were constantly at home, which made conducting the interviews unethical, as the children would overhear their parents describing their behaviour as challenging. Some of the participants withdrew from the research which meant that more recruitment took place once the schools reopened. These interviews were then carried out online as visiting the homes of the participants houses was still forbidden under the government Covid-19 pandemic rules. Then another period of time allowed for data analysis, followed by recruitment of another five participants. One of these then dropped out meaning that four interviews went ahead. The final group of participants had three recruited, making a total of 17 participants.

Consideration was given for the last group of recruits as to what should change to facilitate the move from purposive sampling to theoretical sampling. The requirement at this point in the process was finding out more about possible categories that could contribute on the different ways that people kept going in difficult circumstances. For example, when in the middle of a difficult situation, what was their primary, (emotional, practical, spiritual, cognitive etc.) way of coping with what was happening. Then whether that method of coping changed after the challenging moment had passed. This theoretical point was explored by one of the questions within the interview that asked them to explain the process of coping with a challenging situation. So, the requirements for selection of the participants remained the same. Instead, more time in the interview was spent in this area so that the emerging concepts could be developed more thoroughly.

The demographic details of the participants are shown in the table below. They were aged between 25 and 62. Some of the participants were married, some had partners who did not live with them, and some were single, and one was widowed. Most were white British; one was American, one Bulgarian and one Asian participant, but all of them lived in England. The table also shows the number of children they had with autism, the age of their child with autism and where that child was in the birth order.

Participant Number	**Age**	**Marital status**	**Ethnicity**	**Location**	**Number of children with autism**	**Age of child with autism**	**Birth order of child with autism**
Alicia	43	Married	White British	Suffolk	1 possibly 2	19	1st /3
Bianca	54	Single	White British	Norfolk	1	23	3rd/4
Cara	50	Married	White British	Suffolk	1	18	1st /2
Diana	45	Married	Asian	Yorkshire	1	13	1st /2
Eliza	57	Widowed	White British	Wiltshire	1	25	1st /2
Fiona	45	Married	White British	Suffolk	1 possibly 2	21	2nd /2
Georgia	41	Single	White British	Suffolk	2	22 & 8	2nd & 3rd / 3
Helena	50	Married	American	Essex	3	19,17,15	1st, 2nd & 3rd /3
India	25	Married	White British	Suffolk	1	7	1st /2
Joanna	28	Married	White British	Suffolk	1	21	2nd/ 2
Keira	62	Single	White British	Suffolk	1	25	3rd /3
Lydia	42	Single	White British	Suffolk	1	13	1st /1
Monica	34	Partner not living together	White British	Suffolk	1	12	1st /2
Nina	43	Divorced	Bulgarian	Suffolk	1	17	1st /3

Olivia	42	Married	White British	Suffolk	1	12	1st/ 1
Petra	36	Married	White British	Suffolk	1	9	3rd /4
Rhianna	42	Married	White British	Suffolk	2	12 & 15	1st & 2nd / 2

Table 3 The participant demographics

3.10.3 Ethical considerations

Ethical issues are key standards that determine how research should (or should not) be carried out. They are based on the principle that anything done in the name of research should do no harm to those taking part (Anderson & Corneli, 2018).

Approval for the ethical standing of this research project was given by the University of Suffolk Ethics Board prior to the commencement of the recruitment of participants, see Appendix three for the approval letter. The research was conducted in accordance with the British Psychological Society (BPS) (2018) ethical guidelines, which focus on four key areas: respect, competence, responsibility, and integrity.

In seeking to address the issue of respect I always endeavoured to treat the participants with the utmost respect. This began by keeping all data collected confidential and anonymously stored. This involves de-identifying the data by removing all names and identifying features from the transcripts. Each of the transcripts was given a pseudonym which will allow the reader to follow each of the stories without compromising the integrity of the deidentification.

In addition to holding the participant data confidentially, is also the requirement to keep it anonymously. This is slightly more complicated in a qualitative study as the participants met with me for the interviews, meaning that I know who said what. However, when the interviews were transcribed, the names of the participants and any other people in their narrative were omitted and numbers were initially used to differentiate the interviews. These numbers were then converted to pseudonyms in the write up to enable the individual stories to be easier for the reader to follow. Significant steps were also taken to ensure the security of the storage of the data, which was held on a password protected computer, with a backup stored on a password protected memory stick. At no point were any transcripts printed off for analysis as all of the analysis was conducted on the same computer as the one used for storing the transcripts. The only person to have seen to transcripts is me, as I have not even shared them with my supervisory team. The signed copies of the informed consent forms were all signed electronically and so are stored on the same password protected laptop as the transcripts. However, they are held in a completely different file area, so that anyone other than me would not know to connect the two files to attempt to uncover the participant identities. The data will only be stored on the computer until the completion of the project, at which point the transcripts and informed consent forms will be deleted.

Additionally, I was mindful of the shared values within the autism community. This manifested by always referring to the participants as parents of children with autism. They were never referred to as autism parents or parents with autistic children as these terms are deemed to be disrespectful as the participants are first and foremost parents and their children are children first.

Another aspect to respecting the participants, regards privacy. A person volunteering to take part in an interview, still has a right to privacy, which means that if a participant appears to not want to go down a particular avenue of discussion that the interviewer should not pry further, as it is up to the participant to choose what they share (Anderson & Corneli, 2018).

The method of using an interview to collected data raises issues regarding an inequality of power. These can be issues such as gender, ethnicity, age, social class, and religion. To conduct research without thought to the inequalities inherent in these characteristics would lead to the dangers of conducting self-centric research. This means that I needed to be aware of the lived experiences of the researched, so that an awareness is held of any negative experiences that a person may have had which may lead to them feeling in a lower power position than myself. In this instance, I am a white, educated, woman which may therefore lead to a mother who is black or who does not possess a university degree feeling disempowered (O'Leary, 2021). In addition to these characteristics there is a perceived inequality also for parents of children with a disability due to the many appointments that parents have previously had to attend when meeting with doctors, teachers, and social workers, where the share of power has not been equal. As the participants are being asked about their lives, it is important that the interview should not be reminiscent of those other interviews that the parents have attended (Sinha & Back, 2013). It was important that the tone of the conversation was kept very friendly, with it being made clear that the interview would not lead to any actual analysis of the participant or diagnosis regarding their resilience.

The participants were asked to sign an informed consent form (Appendix four) this requires that the participant feels that they are volunteering, so an atmosphere free of coercion or undue influence was created so that the person felt free to say yes or no. As the participants were recruited via social media websites where I did not offer a service there could have been no danger of the participants feeling that they would be penalized for not participating. There was also no inducements or rewards given for participating, so the participants only opportunity, was in telling their story to a person who would listen with interest, and the personal belief (if they held it) that their participation would make a difference in the lives of mothers of children with autism in the future.

To obtain informed consent involves dealing only with people who are deemed able to understand the information given regarding the research. Therefore, it was important to make sure that the volunteers were of sound mind and of an age (over 18 years old for this study) to be able to understand the nature of the research. This includes details such as the time commitment, the sort of areas that the interview is likely to cover, and the potential emotional risks of being involved (O'Leary, 2021). For this purpose, a participant information sheet (Appendix five) was prepared and sent to the participants at the point of volunteering. They were then given time to digest the contents and ask questions before signing and returning the consent form.

They were also made aware of their ability to determine the limit of their participation including their right to withdraw (Coolican, 2009). The participants were reminded of the right to withdraw during the interview if they became upset at any of the questions. The participants were told that they could withdraw with no penalty at any time before, during, or within fourteen days after their interview, which was given as a cooling off period. After this point, considerable time and effort would have been invested in the transcribing of their interview and so unless there was a very compelling reason the right to withdraw no longer existed.

The second area of the BPS (2018) guidelines is competence. This was fulfilled by always being mindful of the level of skill and knowledge that I possessed and not going outside that (Punch, 2004). I have a master's degree in Coaching Psychology and a counselling qualification from The Autism Treatment Centre of America. This is also not my first piece of qualitative research; therefore, I have some competence in carrying out interviews. Furthermore, there was the possibility that content shared by the participants might have shown either the parent themselves or the child to be at risk. I completed safeguarding training with the University of Suffolk and so am aware of the signs of safety and so knew when the information shared should be held confidentiality and when it should be shared due to the need to report concerns. Additionally, the participant might have requested something that required me to move out of the role of researcher, such as asking for advice. This eventuality was also covered by my experience as a counsellor and a coach who is trained not to give advice, as the coachee's own answer is always more powerful for them. It is important not to create any type of dependency on me and so giving advice was outside of my role. As part of the debrief process at the end of the interview, the participants were given a sheet (Appendix six) containing contact numbers of organizations where they could obtain either emotional support for themselves (Samaritans) or information on Autism (www.nas.org). Additionally, a further safeguard is in place in that this research must remain inside the conditions approved by the University of Suffolk Ethics board and attendance is required at all supervision meetings.

The third requirement under the BPS (2018) guidelines is responsibility. This required me to be responsible in the way that I used the knowledge that I have and to place the wellbeing of the participants as paramount priority. Furthermore, remaining accountable to the research supervisors acted as a safeguard. I need to be responsible for myself as well as the participants. In this research, the plan was for me to visit the participants in their own home. Before beginning the data collection, I undertook some lone worker training provided by the University of Suffolk, and so consequently, put in place a person to notify when I was entering a participant's house, with another phone call to check in when leaving.

The final part of the code of ethics (BPS, 2018) is integrity. Acting with integrity involves honesty, openness and candour between myself and the participants. It involves accurate and unbiased reporting of the data and its use in a way that does not exploit the participants. One area which could have been problematic was in the maintaining of professional boundaries. As I come from within the autism community, I already knew many people already. It was hoped that I would find participants that I did not know, so that appropriate boundaries could be maintained. I do not however believe that there is a conflict of interest in doing this research as there is no preferred outcome.

3.10.4 Data Management

The interview transcripts were recorded and subsequently transcribed onto a Microsoft Word© document. Each piece of data was allocated a participant number which meant that the data could be stored anonymously. For the purposes of this thesis, pseudonyms replaced the numbers to make the individual stories of the participants easier to follow. These were stored on my own password protected computer. They were then uploaded with their participant number to Atlas ti 8© which is a computer software programme that facilitates qualitative data analysis. This programme was used for the open and axial coding. For the last stage of coding – the theoretical coding, a more manual method was used.

For ease of reporting, there were some minor edits made in the course of transcription, to maintain reading flow. This means that hesitations such as ums and errs were removed. Also, where the participant has repeated herself, unless the repetition is needed to denote emphasis given by the participant, then it has also been removed. Additionally, where the context of a quotation is needed to maintain its meaning, a word has been added in brackets so that the meaning is retained. For example, where a quotation is used in chapter 4 of this thesis, if a participant refers back to something they said in a previous sentence, and that sentence has not been included in the excerpt, then a defining word has been substituted in brackets for a word like 'it' or 'them'.

Another alteration to the verbatim statements has been used where the participant has used a word that compromises the anonymity either of themselves or someone else in their story. This can either be a person's name or a place name. In this case, the name has been reduced to an initial.

A further alteration to the verbatim text, occurs where the quotation has been used in this thesis, when the participant says something that is relevant to the illustration of a code, but then changes subject for a short while. If they then return to the original subject with a statement that is deemed important to include, then, rather than placing the entire quotation in the findings section, the subject change is removed and replaced by three dots (e.g., …). Once the editing was complete, the quotation was re-read and compared to the original quote to ensure that the edited version retained the character of the participants voice and meaning.

3.10.5 Data Trustworthiness

The third and last stage of the interview procedure was a checkback interview whereby I asked one of the participants to sort the subcategories that have come from the data and place them under the category that they feel is most appropriate. This will ratify my coding process to see if it is congruent with the understanding of the participant's experience. The concluding explanations were also checked with the participant to ensure that they are congruent with the participants own experience (Birt et al. (2016). This part of the procedure is based on Guba's model of trustworthiness (1989) with the purpose of ensuring the integrity of the data analysis.

3.11 Research Implementation

This section sets out the procedure for the simultaneous process of data collection, coding, comparison, and analysis (Glaser and Strauss, 1967). For the sake of clarity, the process of data collection and analysis is described as if it were a linear process. It is however, following the principles of grounded theory, a simultaneous, ongoing, interactive, iterative, and intuitive process. A literal rendition of these processes would result in a protracted and confusing account. Therefore, following the established norms of grounded theory, it is presented as having a single trajectory (Suddaby, 2006).

3.11.1 Data collection

Materials

Participants were recruited using a poster (See Appendix two) that was used online to advertise the research. Once the participants were recruited, they were given an information sheet (Appendix five) which provided brief details about the nature of participation. Having read this, they were then able to decide whether they wanted to participate. If they did, then they were asked to sign the informed consent form (Appendix four).

A strategy was created for participation online during the pandemic lockdown. The table below summarizes the procedures that were put in place to enable the transfer to online interviewing:

Online interviewing space (Salmons, 2014)	Strategies for this research study
Will the participants have the necessary equipment: Consistent Wi-Fi signal, and technical knowledge to access the video platforms	During the pandemic there was a necessity for many people to work from home. This meant a great deal of upskilling had to happen so that people could continue to work. Once participants were recruited, they were asked which platform they preferred. At the time it was believed that Microsoft Teams was the most secure and so that was chosen if the participant had no preference.
Will the participants be excluded if they didn't have the required equipment, Wi-Fi internet access, or ICT know-how?	There is the possibility that a participant could have been excluded if they didn't have the equipment, however, most mobile phones can be used to access online platforms. Therefore, the possibility of this happening was considered minimal. However, if this occurrence had come up then a telephone interview to their landline would have been offered
Will participants be more uncomfortable in an online interview?	Sometimes people are concerned about speaking in an online environment due to not being able to see the usual physical cues that reveal that someone is about to speak. Therefore, there is concern about talking over another person. As part of the interview procedure, it is important that the interviewer does not interrupt the participant while they are speaking, so waiting just that little bit longer meant that this worry didn't occur. Spending extra time at the start establishing rapport also helped with this.

	Another worry that participants may have, is that by switching on their camera, the interviewer is given sight of their home in the background. Some people can feel uncomfortable about this. This situation can be avoided by using a virtual background on platforms like Teams.
How will distractions in the physical environment be minimised?	I conducted in the interviews from a quiet room in my house. The participant was also asked to find a quiet space. However, in houses with children, it is inevitable that there were interruptions. So, I just waited while the participant dealt with the situation and then the interview was resumed.

Table 4 Strategies for online meetings

An audio recording of the interviews was made on an iPhone app. This enabled them to be transcribed verbatim to a word file held only on my password protected laptop. Once the interviews were transcribed, the recordings on the iPhone were then deleted. Following the interviews, the participants were given a debrief sheet (Appendix six), which explained more about the purpose of the research. It also gave them my contact numbers and the details of support organizations.

Semi-Structured Interviews

The first part of any interview process is to establish a rapport with the participant. Rapport occurs by having a light hearted easy conversation before the start of the interview on a subject unrelated to the topic of the interview. By establishing rapport trust is built with the participant, which enables them to openly share their story (van Nieuwerburgh, 2014). Some thought was given as to whether it would help to build rapport if I was to disclose that I am the parent of a child with autism. In the early stages of interviewing, this detail was not disclosed because it was thought that it might mean that participants didn't mention certain things in what they were saying, because they would assume I already knew about them. However, this then meant that the advantages of being 'within the community' were not realised. So, from the second round of interviewing I disclosed my life experience to the participants as well as asking them to still fully explain everything so that it was captured by the interview process. This disclosure had the desired effect in that participants answered the questions more fully and were able to share experiences that they had possibly not shared before perhaps because they felt a sense of shame or divided loyalty over them due to the story beginning in a place where they felt that their child's behaviour was challenging.

Once rapport was established the I collected the brief demographic details of the participant (See table 3). Then, the following questions were asked to ensure that the volunteers fitted the selection criteria:

- What is their child's age?
- Whether the child had received a formal diagnosis of autism?
- Whether they had any additional diagnoses?
- How long ago was it since their child received their diagnosis of autism?
- Whether they had only one child with autism?
- Whether they have other children without autism?
- Whether their child with autism lived with them?

After it was established, that the participant could contribute to the research the attention turned to the interview schedule. The overall interview process was expected to last for around an hour. This was an amount of time that was deemed to be the maximum as it was the time included in the advertisement for participants.

The questions were devised with the following objectives in mind:

1) To ask open ended questions so that the participants could tell their story. These questions asked about experiences from the past as well as the present. The questions on the past were intended to see whether present resilience was a demonstration of past overcoming of adversity. An example of this question type is: tell me a little bit about your life before having children?
2) To ask questions that were specific enough to encourage the sharing of detail. An example of these questions is: can you tell me about one specific significantly challenging event that occurred with your child and explain the process of your thoughts, actions, and feelings, from the moment when the event happened through to a time when you felt OK about what had happened?
3) To emphasize meanings, perspectives, and experiences over other information. An example of this is the question: have your thoughts and feelings about your situation changed at all since your child was diagnosed?

As the interview process progressed the questions were refined and those that didn't work were removed and replaced with other questions. For example, asking the participants to describe a typical day didn't really reveal anything e.g., they got up, they ate breakfast, they went to school etc. so this was discarded.

In addition to the interview schedule of questions some prompts were prepared. These included questions like: Can you tell me more about that? How did you feel about that? What happened next?

These prompts were especially useful in the theory building part of the process, as it enabled me to 'drill down' further in areas of interest to the emergent concepts. There was also the flexibility within the interview to ask follow-up questions if the participants comments led down a novel path. Also, the intention for the interviews was to conduct them in an informal way, so that the participant's experience felt more like a chat than an interview.

The interview process continued until the interviews were not adding anything to the theory that was emerging. This is referred to as 'saturation' (Charmaz, 2014). However, the idea of something being so full that nothing else can be added is somewhat misleading, as it is impossible to tell that continuing would yield no new insights. Charmaz, (2014 pg. 213) therefore, recommends considering saturation in the light of this principle: "you have defined, checked and explained relationships between categories and the range of variation within and between your categories". This means that reaching saturation becomes a process rather than a moment in time. Once the emergent theory or concept, has sufficient depth of evidence, then the data collection can stop (Charmaz, 2014).

3.11.2 Data Analysis.

The method of data analysis was informed by Charmaz, (2014) Constructivist Grounded theory method. The first round of semi-structured interviews involved a pilot interview plus five more interviews. In the first round of coding, which is known as initial coding, gerunds were used, to gain familiarity with the data, and also to describe the action processes revealed in the participant responses. Gerunds are verbs that are used as nouns e.g., the verb 'to write' is converted into a gerund by adding 'ing' to become 'writing'. The purpose of coding in this way is "a heuristic device to bring myself into the data, interact with it, and to study each fragment of it" (Charmaz, 2014 pg. 121). By using gerunds, I created a picture of what was happening in the data, and identified implicit meanings (Charmaz, 2014). The following is an example of a segment of the first interview with the gerunds added:

Excerpt from Interview 1	Gerunds applied to every line
Oh wow, I had children quite young so erm, I did a music degree, a post graduate two year course in performance, music performance which I failed by 2% because by the time that I finished it I knew that I didn't want to be a	Having children young Doing a music degree Failing the music degree by 2% Rationalizing failing the music degree. Knowing she didn't want to be a performer.

performer and I was getting married and I had	Getting married
just converted to Judaism and all of that kind of	Converting to Judaism
side of my life had just taken over erm so my	Family life taking over.
husband and I were living in H in London and I	Living in H in London
became a music teacher and taught violin and	Becoming a music teacher
piano and I absolutely hated it and thought	Hating teaching music/ thinking what shall I do.
what shall I do and thought I know I'll have	Thinking I'll have babies.
babies. So, between the ages of 24 and 29 I had	Having three children.
three children and we moved from L to North Y	Moving from L to North Y
and that was really essentially kind of what I	Doing music
did, it was music, converting studios which was	Converting studios
a big thing really erm and getting married.	Getting married

Table 5 Example of the application of gerunds

Following this stage, focused coding was carried out to identify the most salient codes that were taken forward in the coding process. Additionally, important concept codes that had been identified were repeated so that they stayed current in the analysis (Charmaz, 2014). In this study, those codes were the ones that demonstrated the thoughts, feelings, and behaviours of the participant. Codes that related to the actions of those in the participants' family were left behind as they would not be contributing anything in answer to the research questions, as they only related to the experience of resilience of the mothers.

Another part of the data analysis process is memoing. The memos contained my thoughts and decision-making processes, so that there was transparency and clarity in every part (Saldaῆa, 2016). This process took place in all parts of the data analysis process. Birks, Chapman, and Francis (2008) explain the reasons for memoing using a mnemonic MEMO which stands for M = Mapping research activities, E = Extracting meanings from the data, M = maintaining momentum and O = Opening communication. The memoing process enabled me to maintain an interactive relationship to the data, by having an outlet for creative writing in an unstructured, spontaneous, uncensored way (Charmaz, 2014). By writing operational memos I was able to create an audit trail of all decisions made which provided a readily available account of the analysis process. This meant that when learning events occurred that they could be captured immediately and then easily returned to, in the theoretical stage. An example of such a memo is below:

Research task	Memo script
Deciding the rationale for the focused coding	I have now finished the initial coding of the first few interviews and need to come up with a way to convert all of these codes into something more manageable with the focused codes. I think that going forward the rationale should be this: I need the codes that are most relevant / significant to the research aims. So only coding that relates to the thoughts, feelings, behaviours of the mother need to be brought forward. This would also be ethically sound as she is the only one who has consented to participate. Therefore, all other coding should remain as initial codes and not go forward.

Table 6 An example of an operational memo

In addition to the operational memos, there were reflective memos. These captured my thoughts and feelings in relation to every aspect of the interviewing and analysis process. These memos provided a means to manage my previous life experiences and bias reflexively and transparently.

> *"Wow, this is research progress on steroids. After so few interviews, I am already changing my own view on resilience. This last participant is someone who didn't think they were resilient and by the usual ways of measuring resilience they would probably be judged as not resilient too. BUT there is no way that I can listen to their story and all that they are doing and not conclude that they are resilient in spades. The effort that they have put in over a long time to help their child, is inspirational. It seems that the vision/ theory of resilience really does need to change, and it starts with me."*

Memos also enabled conceptual ideas to percolate when participant comments resonated with theories that I was aware of:

> *"There are so many ideas that have come out of this interview, the most novel one is about the importance of resting. I had not thought about resting being part of the resilience process before. It reminds me of the theory on peak performance where they talk about sports competitions and the idea that the athletes don't compete every day, they allow themselves rest days. These rest days are there to facilitate the peak performance on other days. I need to make sure that I don't lose this idea as it seems important to note."*

Once concepts were derived from that initial data via focused coding, the interviews were then compared to each other for similarities and differences during the third round of coding, known as axial coding. After this, another five participants were recruited, and the process was repeated, and then after this, another four participants were recruited, and the process repeated. This process enabled the emergence of categories, with the core category forming a major part of the model (Ravindran, Rempel & Ogilvie, 2012). Following this analysis, the research questions and interview questions were reviewed and then three more participants selected using theoretical sampling. As it is the concepts that drive the analysis, each case adds to the ongoing evolution of the theory. This theory is then said to be grounded in the data (Glaser & Strauss, 2008).

The final process of coding was the theoretical coding from which the model of resilience was built. The process of arriving at these codes occurred by first examining how the axial codes related to each other, these relationships or associations were then allocated a theoretical code name. Then, codes were created, that reflected core constructs that had been observed within the data. Some additional codes were also created that reflected a means of representation of the data. These were positioned as a proposition that were drawn on when the model of resilience was described.

The following diagram (next page) demonstrates the process of data analysis:

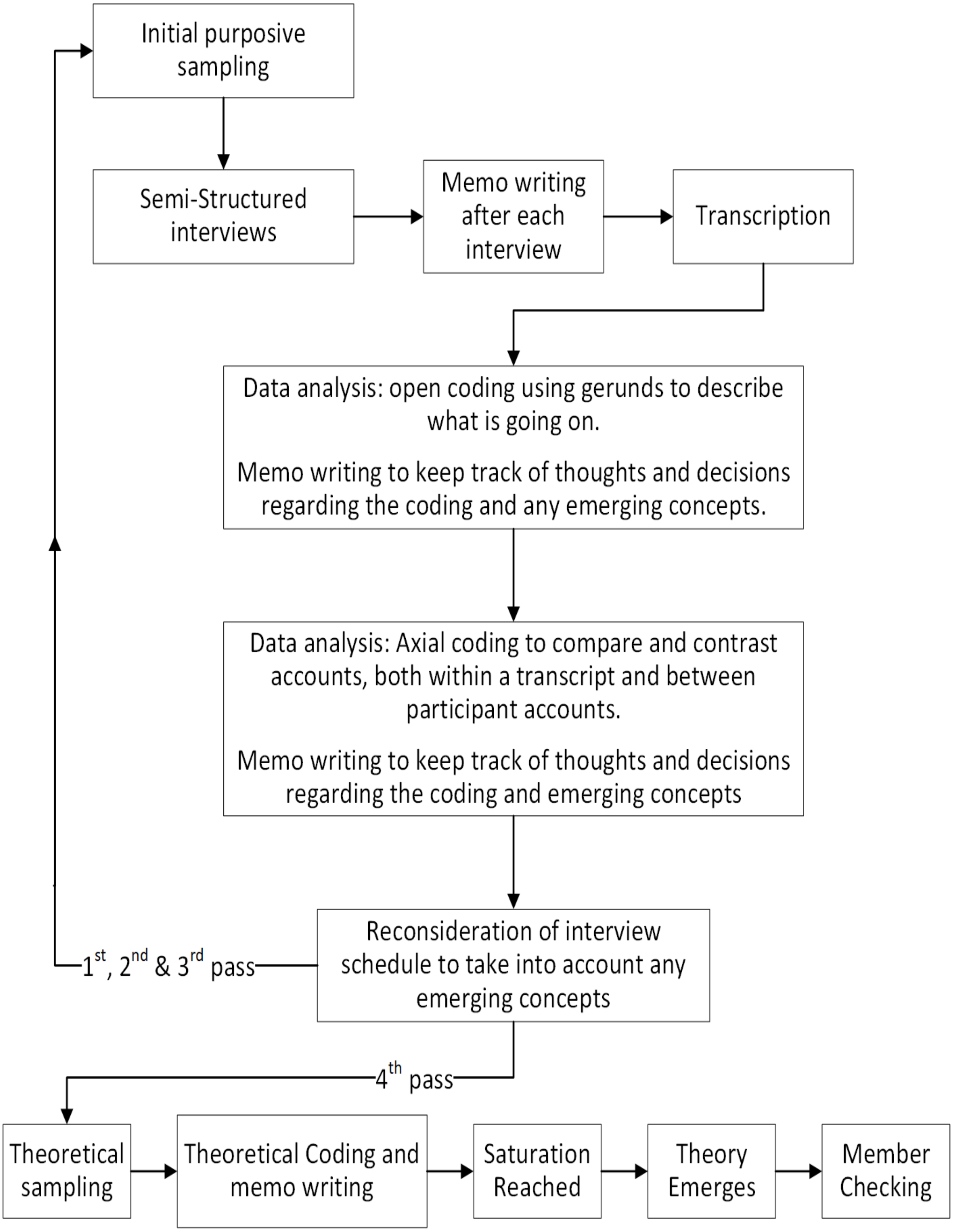

Figure 9 The process of data analysis

3.12 Reflexivity

> *"Those of us who attempt to act and do things for others or for the world without deepening our own self-understanding[…]have nothing to give to others."* Thomas Merton 1971

At the heart of every qualitative research project is a researcher like me with a strong reason for giving up time, energy, and skills to research a subject. Therefore, from the beginning, I was personally invested in the project. This was especially true due to the subject of research being connected to my own lived experience. It follows then, that my autobiography cannot be divorced from the research as I have brought my own belief system to the choices that I made in data analysis within the research (Lumsden, 2019). Positivist scientific investigations rest on the notion that the research deals with the object of enquiry with neutral detachment, claiming an unproblematic relationship between the item in the world and the manner in which it is spoken about, However, qualitative research is interpretivist and therefore acknowledges the socially situated nature of research enquiry (Shaw, 2010). It argues that we are not just conscious beings, but we are conscious of things too. An example of this is Brentano's chair (1995); when we walk into a room and see a chair, we not only notice that it is a chair, but we are conscious of whether it is a dining chair, an office chair, or a piano stool. We are also aware of how to appropriately use that chair – we wouldn't take the piano stool into the garden to sun bathe. The realm that a researcher might find themselves in, is a subjectivity that cannot be escaped from in the analysis of data in any research (Shaw, 2010). Gadamer (1975) suggests that each person has beliefs, values, presuppositions, and predilections which together create our sphere of understanding, or our 'horizon'. When an individual encounters another person with a similar horizon, there is understanding. It is key to be self-aware and transparent, so that it is possible to 'connect' with others. It is also imperative in research to examine ourselves so that our unelucidated value system does not dominate the research. By engaging in self-aware reflexivity, the researcher assumes the co-constitution of meaning within a socially constructed research scenario (Shaw, 2010), by accepting that their very presence means that they are part of the world that they are investigating (Lumsden, 2019). A well-used definition of reflexivity is "thought as bending back upon itself", and is literally thinking about previous thinking (Bouzanis, 2017). However, the goal of this reflexivity is not about removing my bias. It is about self-awareness of my opinion on the subject of study. By actively exploring myself, I can then engage in dialogue with the participant and use each person's presentation of themself to enhance or revise my previous foreknowledge and then make further sense of the phenomenon under study (Shaw, 2010).

However, mere reflection on previous thoughts and actions is insufficient to constitute useful reflexivity. Woolgar's (1988) continuum of reflexivity suggests that benign reflection without any analysis is situated within a positivist framework as it presents itself as an accurate account or simple verification of events. As qualitative research is interpretivist or in the case of this study constructivist, then something must happen to a simple reflection by way of critical evaluation to uncover assumptions and beliefs. Knott and Scragg, (2013) suggest that this analysis can be done by asking questions of the reflection such as What is happening? What assumptions am I making? What does this say about my underlying beliefs? Are there alternative ways of looking at this? If so, what? This model does not include any reflexivity with regard to the method of the study or the impact of the discipline on the type of knowledge produced. Wilkinson's (1988) model includes three forms of reflexivity; firstly, personal reflexivity as described by Woolgar (1988). Secondly, functional reflexivity looks at the form and nature of the individual study and how that will affect the knowledge gained and then thirdly, disciplinary reflexivity examines the impact that positioning the research within a specific school of thought affects the knowledge outcome. This reflexivity section will aim to combine these three approaches to produce a thorough account of my position with regard to this research project.

Personal reflexivity

To do this, I followed Bolton's (2014) 'six-minute write' plan, which involves writing non-stop for six minutes. The key to this is non-censored stream of consciousness style writing for six minutes. In doing this I found I had a lot to say on the substantive research subject, so I did this exercise several times to make sure that I had captured everything.

To give the historical basics, I am a white, middle aged, middle class, healthy, straight, non-religious, divorced, non-disabled female. I grew up in London UK in a family of four children with a Baptist Minister and a GP Doctor for parents. No one from my birth family or my extended family had Autism. I was married for twenty years and had two children. The oldest child has no disabilities, and my youngest child has very significant Autism which was diagnosed when he was 2 years and 1 month old.

The analysis of the basics would be, that I can see that my parents' occupations put them in positions of power and privilege and so growing up, I noticed people treated me in a privileged way because of my membership in the family. However, I only experience that occasionally now, and do not particularly enjoy it. In terms of beliefs, my upbringing in a strict Christian family will have had an impact on my beliefs and values, although I don't belong to a church now, so this is something that I can watch for. I also witnessed my parents working from home and noticed the way that they behaved with their congregation/patients. It was an unequal relationship with a clear power dynamic in their favour. In order to create rapport for my participants, I need to create either a 'level playing field' or one stacked in their favour as they are the experts on themselves, and I am there to learn.

To reflect on my thoughts about the substantive research area I noticed that this was the area where I had the most thoughts. After my son was born, I suffered from significant post-natal depression, which went on for two years. When the diagnosis of autism was received, I remember thinking to myself that I needed to get myself back on top of things and that I should put my own troubles to one side, as my son now needed me. It has been this driving purpose that has seen me free of any mental illness for 21 years. This is in spite of the challenges of raising a child with autism. The main challenges that I experienced of raising a child with autism are challenging behaviour, not being able to speak with my son, fighting for services, isolation as invitations to play/parties never came, six years of home schooling, siblings not being able to play together, constantly searching for something that would help and finding money to pay for it.

Looking back, I can see a number of tools that I have used that have significantly supported that strong purpose. These are shown in Appendix seven and are divided into cognitive, practical, inspirational, self-awareness, meaning making and historical tools.

These tools demonstrate evidence to show that I have a really clear idea why I have remained mentally well during my son's life. To use Knott and Scragg's (2013) framework for analysis, it shows that I have created a reliance on cognitive strategies, as all of the tools require thought or effort based on thought. The danger with this is that I might decide that someone who did things differently to me (e.g., send their child away to a residential boarding school) was avoiding the issue rather than facing it and so would not value their story equally to another participant that had kept their child at home. However, I do not believe that I have the monopoly on tools and so I am keen to learn about what other people do too. Shaw's (2010) stated goals of reflexivity also help in this situation, because by adding to my list I am not denying or devaluing my own experience, I am improving my knowledge. What I am aiming for in this research is "an open mind but not an empty mind" (Janesick, 2000 pg. 379).

As this study has progressed and I have had opportunity to reflect on my reflections, it is clear that at the beginning, I thought that there were some people who were resilient and some people who were not resilient, and that my hope was to be able to teach those non-resilient people how to do it differently (better). The focus of my thinking was that I would be able to produce tools that could be used to create interventions that would facilitate this. Also at the beginning, I was conflating resilience with positive mental health, and so believing that a person with poor mental health was not resilient. This situation changed over time as the data was collected. The progress of my thinking is shown in the results and discussion section through the use of the memos that were written during the data analysis process.

I have always been aware that I had strong feelings on this subject and so because of that wanted to do qualitative research. I wanted to give the participants free reign to say what they wanted to say and not be constrained by the limited style of responses typical of a quantitative project. Additionally, a quantitative project is deductive, resulting in my bias playing a much larger role in the design of the method and choice of questions or scales. There are many resilience scales available, but they are built using a factor structure that has assumptions built in as to what traits lead to resilience. These scales have been tested for reliability and validity many times and so I could be sure if I had used them that I would have created results that could be considered additional knowledge. However, all research in this area is quantitative and so I would not be adding to the current knowledge by carrying out another quantitative study.

Qualitative studies lead to more nuanced knowledge as each individual participant is given space to tell their story. This is the piece that I believe is missing from the current knowledge. The hope of this study is to ‘do some good’ rather than to explain something. So, the detail of each life experience is important, as it could contain the missing piece of knowledge that is needed to produce the model or theory that would help every person who is interested in developing their resilience.

Therefore, my own experience in parenting a child with autism, and wanting to use research to do some good, may well result in a mutually beneficial arrangement both in terms of the findings and what happens to the findings afterwards. It also means that when I approach my participants, I am coming from a place of empathy with them and knowledge of their struggle. I am acutely aware of the normative power relations between institutions and the ‘subjects’ in research and so will strive to not replicate those scenarios in the conducting of my interviews. It therefore seems that my lack of objectivity could well be an opportunity rather than a problem.

As I carry out analysis of the data, I plan to use Wilkie's (2015) reflexivity model.

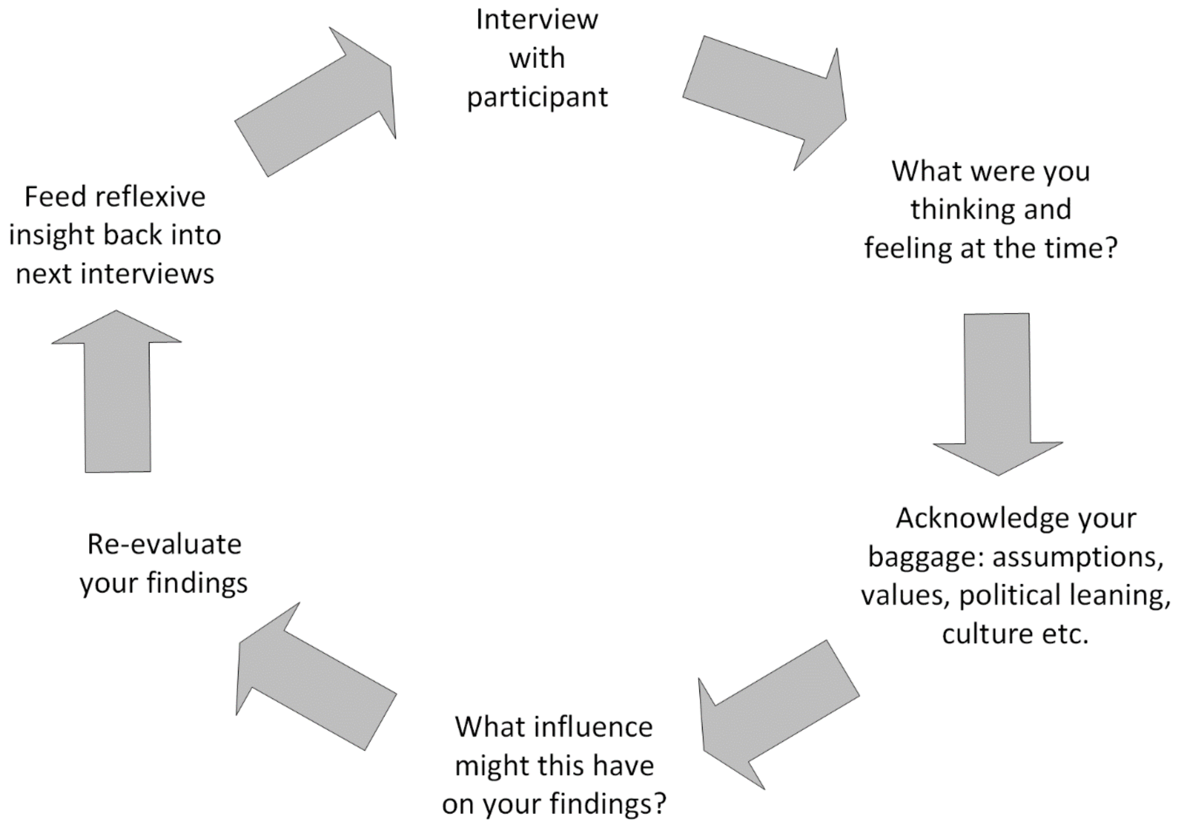

Figure 10 Wilkie's (2015) reflexivity model

Using this model, has led to my being a lot more aware of what has been going on for me during the process. I also reflected while 'in action' (Bassot, 2016) during the interviews to notice whether I was experiencing any reactions while the participants were speaking. I hope, that by using these two processes, that I have made the most of the opportunities in this project.

CHAPTER 4: FINDINGS

4.0 Introduction

This chapter presents the findings from the research which aimed to explore the experiences of resilience in mothers of children with autism. The analysis took place using constructivist grounded theory method described in the previous chapter (see chapter3). The findings chapter consolidates the research data to demonstrate the significant findings uncovered in response to the research questions:

To what extent, do mothers of children with autism, experience resilience, given the challenges and stigmas of parenting their child?

Additionally, the three sub-questions formed the structure of the research process:

1) What does the word resilience mean to mothers that have children with autism?
2) How does being a parent of a child with autism affect the mother's resilience?
3) In what ways do mothers of children with autism demonstrate resilience?

Each question will be examined in turn with excerpts taken from the interview transcripts to evidence the grounding of the coding structure. Verbatim quotations have been selected for their relevance and significance to the codes and their ability to demonstrate succinctly the rationale for the code's inclusion.

The chapter begins by presenting an overview of the study findings and then proceeds to evidence those findings by expounding the deeper explanation of the emergence of the coding structure from the data.

Throughout the chapter, illustrative quotations from the participants own accounts are integrated into the text to ground meaning to the findings.

4.1 Overview of the findings

This overview demonstrates how the findings address the overall research question, which was: To what extent, do mothers of children with autism, experience resilience, given the challenges and stigmas of parenting their child?

Experiences of resilience were evident from the narratives of all the seventeen participants in this study, as they all were actively engaging with the task of mothering their child despite challenging circumstances. This meant that resilience was conceived to be something that the participants did, rather than something to either be or not be. The mothers also went over and above the 'normal' role of mothering to take on roles such as the therapist, the nurse, and the advocate for their child.

This led to the conclusion that all the mothers demonstrated resilience. When asked about adversity, all of the mothers had very clear descriptions about the challenges that they faced. However, none of the mothers talked about outcomes, for them, as they occupied a space in the present moment for themselves with only the occasional comment about their fears for their child's future.

When answering the questions about what happens when they find themselves in the midst of adversity, the mothers all talked about a series of actions and activities that followed on from the adversity. The actions and activities involved managing the adversity, coping in the immediate aftermath of the adversity followed by a recovery period involving resting and self-care, then taking part in activities that gave them a break from their caring responsibilities. The last part of this process involved reflecting on what had occurred and then thinking about how to avoid a similar event in the future. The mothers then resourced themselves with strategies like the planning of ways to avoid their child's triggers, or further education on autism. This was a major finding of this research as previous research has always observed a linear trajectory from adversity to outcome. This research suggests that instead, resilience occurs in a cyclical manner with the interim activities positioned between the adversity that has occurred and potential future adversities.

The resilience cycle, it emerged had distinct stages that all the participants passed through in the same order. These stages are reflected in the theoretical codes. Additionally, it transpired that the participants way of moving through these stages were different from each other, but congruent with themselves. The differences with each other are reflected in the axial codes. This led to the construct of the resilience signature which was the second major findings and is evidenced in the final theoretical code.

The last finding relates to the role of the environment, as it was observed that there is an interplay between the environment and the experiences of the participants in terms of either being a cause of adversity for the mothers of the source of support.

The following section shows how the research sub-questions were answered by the data. The structure is based around the sub-questions with evidence given of the way that the focused and axial codes constructed the theoretical codes. The theoretical codes are then applied to the overarching question to demonstrate the results of this project.

4.2 Research sub-question one

The first question was 'What does the word resilience mean to mothers that have children with Autism?' The participants were directly asked to define resilience as an abstract construct and then asked if they could reflect on how their life has led them to that definition. The answers that the participants gave, demonstrated a lack of clear consensus on resilience as a construct. There were some participants who did not answer this question, as they said that they did not know the answer. The participants that had an answer to this question, described resilience as a concept that mostly reflects the resist and quickly recover model of resilience (Ivtzan et al, 2016). This would mean that most of them would have decided that they weren't resilient.

4.2.0 Theoretical code one: resilience defined.

As the overarching aim of the research project was to generate a model of resilience from the data, it seemed expedient to just ask for what I wanted, to see if this elicited any new ideas. The ideas that the participants gave were then gathered under the theoretical code resilience defined. Mostly their ideas reflected the existing conversation on this topic, however there were some novel contributions that are shown below under the resilience deconstructed axial code. Under this theoretical code there are three axial codes that came through. These were: problems with the construct of resilience, responses to challenges and resilience deconstructed.

4.2.1 Problems with the construct of resilience

Focused codes	**Axial code**	**Theoretical code**
Not knowing how to define resilience.	Problems with the construct of resilience	Contributing to: RESILIENCE DEFINED
Finding it hard to describe.		
Using analogies.		
Not liking what they think it means.		

Table 7 Evidence pathway for the axial code of Problems with the construct of resilience

As part of the first axial code, problems with the construct of resilience, India, Nina, and Petra said they didn't know how to define resilience, and so did not answer the question. Diana, Eliza, and Fiona stated that they found it hard to describe, but then went on to have a go at describing it.

> *"that sense of perseverance and stamina no matter what life throws at you,"* *Diana.*

Two participants used analogies to explain their view of resilience:

> *"I think it is that ability to go through something and experience the ups and downs of life but be able to ride that wave and get to the top of it and not fall out of your boat and just keep going and then get over it."* Fiona.

> *"Well, I suppose that as you grow up, that everything that happens that you kind of it builds your resilience doesn't it. I guess it's like a brick wall that every time that something bad happens that you add more bricks to your wall."* Joanna.

Three of the participants did not like what they felt that resilience meant:

> *"I think the problem with [resilience] is it puts it all back onto the individual and it becomes yet another thing that you can measure somebody by, and they can fail. You know it is because they are not resilient enough, they aren't doing the right things to make themselves be able to cope with these hard situations."* Alicia.

The concept that is problematic is that resilience is cited in a person and that the absence of it is the responsibility of that person. Therefore, the solution to this, for Alicia was to position resilience in the environment surrounding them:

> *"…so, I don't really see it as located in one person. I see resilience as a relationship or a web of what you can build up around yourself…. actually, you deal better during that long time when you are dealing with it pretty well if you do have some kind of support around yourself. So, I think that resilience is something that actually is to do with relationships and a back and forth between lots and lots of different people that you have in your life. I think actually resilience comes from other people really listening to you and acknowledging what it is that you are going through."* Alicia.

The idea of personal resilience was a concept that Bianca also felt had an environmental aspect to, although, they felt that there was a combination of aspects located in the person as well as in their environment:

> *"It can be the combination of your, what is coming from inside you, but it also can be partly what is coming from outside of you, your circumstances, the people around you, your mental health your physical health."* Bianca.

Bianca went beyond this by suggesting that they believed that an individual did not have a fixed level of resilience by saying:

> *"I don't think it's like stuck like set at one level I think there will be times when you would be able to get through something more easily and the same experience you might not get through so easily." Bianca.*

This idea of levels of resilience was echoed in the comments of two other participants who suggested that resilience involved peak performance:

> *"Working at your peak even though things might be challenging."* Helena.

This idea of peak performance is mentioned in Olivia's account:

> *"I think that being a parent of a child with autism requires you to perform at your peak. When they are having a meltdown, you have to be on top of your game, otherwise you could not deal with it. So, looking at peak performance, I know that exists in a cycle race, coupled with rest periods….the tour de France is not raced every day. There are rest days."* Olivia.

Olivia talked about what they currently understood resilience to be and why this was problematic for them:

> *"Well, the idea of resilience can be a bit of a stick to beat yourself with can't it. This idea that nothing can bring you down. It is like you have to be strong no matter what happens to you. It sounds like something that I just wouldn't want to be, because it sounds hard, harsh, and unfeeling. To be vulnerable, to care when something goes wrong, that sounds more like a human being. So, I am not sure that the current view of what resilience is, is that appealing to me."* Olivia.

What is problematic here is the suggestion that being resilient is a good thing as it rests on a good/bad divide, but that life is not as simple or as black and white as the idea of resilience suggests:

> *"I don't think it is necessary in life to be happy all the time. Sometimes being sad about something important is the better pathway, stopping to notice the suffering is part of what makes us all human. The idea of resilience in being able to keep going no matter what makes us more like the Duracell bunny. Life is about ups and downs, things we plan and things we don't and who knows whether those unplanned things that we totally didn't want at the time are bad, sometimes in the end they turn out to be great, so why would we resist them. So just powering on regardless is not my idea of resilience."* Olivia.

Another participant found the current common-sense view of resilience a problem, stated that:

> *"It's something that is kind of rammed down our throats at work."* Monica.

This refers to the idea that resilience is not innate in a person, but that it can be developed, which leads to the experience that this participant had of a CPD workshop on stress management, in which she described her reaction:

> *"I had to leave, I just walked out of the training, and I burst into tears outside the training room"* Monica.

This axial code-problems with the construct of resilience, shows that the findings reflect my thinking from a memo which was written after the first group of interviews was concluded:

> " There is clearly some truth in the saying 'if you do what you have always done, you will get what you always got'. I have asked these participant to define resilience and they have provided the current conversation on this topic. Perhaps consider removing this question … but if I do remove it, then potentially I am deciding that these participants (or any others in the future) cannot contribute a new idea, which is a bit of a leap to say that. So, for now I think I will keep the question."

However, it is not a problem that the participants find it a problem as it highlights the need to find a new model.

4.2.2 Responses to challenges

Focused codes	Axial codes	Theoretical codes
Responding to challenge	Responses to challenges	Contributing to RESILIENCE DEFINED
Keeping going		
Resisting the challenge		
Recovering		

Table 8 Evidence pathway for the axial code of Responses to challenges

The second axial code of resilience being a response to challenges was the most common opinion expressed by the participants. All of the participants who answered this question made a statement about this conceptualization of resilience. Firstly, the idea of responding to challenge came through in their statements:

> *"I would describe resilience as one's capacity to problem solve maybe to make decisions that are the right decisions and strength in yourself to manage your environment." Cara.*

> *"I feel like maybe resilience has come over time about all the setbacks that I've had… all the knock backs that I've had saying no he's not [autistic] or it's all in your head."* Rhianna.

However, these challenges were not described as huge adversities. They were put more into an ongoing context of keeping going:

> *"Resilience just generally, stamina being able to just keep going mental strength. So yeah, I see it as strength, there's physical strength and there's mental strength yeah and just that sense of perseverance and stamina no matter what life throws at you just keep going and think I haven't got time to stop I have to keep going."* Diana.

> *"I also think it is all really very much about mindset, resilience, it's about learning to look after yourself as well not doing what others want or looking after others. It is about being able to change perceptions and situations and not allowing things to become really negative in your mind about your life."* Lydia.

Looking at what the response to that challenge was, there were two separate opinions. Firstly, there was the idea of resisting the challenge:

> *"…people who can withstand anything you know like just keep going"* Eliza.

> *"Resilience is ignoring all the ignorance around, try not to let anything other people say, or the children say bother you, you've got to sort of get on with it don't let it fuss you just move on."* Georgia.

Then there was the idea of recovery:

> *"…. bounce back quickly when something bad happens?"* Eliza.

> *"Being able to bounce back from a setback in your life… you know it could be anything couldn't it… but I think it is how you react to something that has an adverse effect on you."* Rhianna.

With the axial code of responses to challenge is the clear link between adversity and response. There was no discussion of resilience without the idea that first there had to be an adversity.

4.2.3 Resilience deconstructed.

Focused codes	**Axial code**	**Theoretical code**
Preparing and adapting	Resilience deconstructed	Contributing to RESILIENCE DEFINED
Resting		
Being human – feeling the feelings		

Table 9 Evidence pathway for the axial code Resilience deconstructed.

The third axial code is that of resilience deconstructed.

This was the place where some of the comments made by the participants, drilled down a little more into the component parts of resilience, and so broke new ground. Monica introduced the idea of preparing and adapting:

> *"So, for me resilience is the ability to pick yourself back up again but also to prepare yourself for things that are going on as well and to be able to kind of adapt and move forward."* Monica.

Bianca was first to identify resting as important:

> "*I see it as a mixture of moving forward and a mixture of just resting".*

Olivia had a slightly different take on it, talking about the importance of allowing yourself to feel the feelings following a challenging situation:

> *"I don't think it is necessary in life to be happy all the time. Sometimes being sad about something important is the better pathway, stopping to notice the suffering is part of what makes us all human. The idea of resilience in being able to keep going no matter what makes us more like the Duracell bunny. Life is about ups and downs, things we plan and things we don't and who knows whether those unplanned things that we totally didn't want at the time are bad, sometimes in the end they turn out to be great, so why would we resist them. So just powering on regardless is not my idea of resilience."*

An interview that challenged my view of resilience was Nina's interview. Nina had a secret agenda for agreeing to the interview which was to use the interview as a platform for her view on the inadequacy of services for children with autism in the UK compared to her home country. Therefore, after the interview was over, I wrote a memo as a reflexivity exercise to process the thoughts and feelings generated by this experience. The memo read as follows:

> *"I feel a bit duped by this participant who only agreed to the interview so that she could put forward her opinion on the lack of provision of services. I need to take a pause and understand why I feel like this. I don't disagree with her point of view, so why am I feeling a bit let down? ….. [thinking]…. I suppose it is because my questions were about what I thought resilience is and she has not answered the questions in the way that I hoped she would. She has used the interview as a platform for what she wanted to say…. [more thinking]…. to say she deliberately didn't answer the questions isn't fair because she perhaps doesn't know the answers. I could conclude that it means she isn't resilient, but actually that would just be about my view on what I think resilience is. She is persisting on pushing for support. She is standing up for what she believes in and promoting it at every opportunity. How could it be said that she is not resilient, she is on task (her choice of task). So, this is yet another version of resilience."*

Part of the reason that this interview felt challenging for me, was that Nina seemed unhappy. However, as a result of processing my thoughts via the coding memo I concluded that even if these mothers were unhappy from time to time, they could not possibly be described as non-resilient.

Over the course of the interviews the question asking the participants to define resilience earned its place in the interview schedule, as it elicited some new elements to resilience; that of adapting to move forward, resting, and feeling the feelings. These findings emphasize a more fluid model of resilience in that it allows the individual time to acknowledge the challenge and adapt. These views state the exact opposite of the view of resilience that some participants felt was problematic.

In summary, research sub-question one asked what the word resilience meant to the mothers of children with autism. There were some participants who didn't answer this question, but most of the participants had a go at answering it and some who used analogies to describe their ideas. Others had clear reasons why they didn't like the construct that they held because they felt it was judgemental and others who felt that the construct was something unattractive as it would make them inhuman. This demonstrated the need for this research, as these mothers have a challenging life and so it is crucial that further burdens are not added to their load.

4.3 Research sub-question two

The second of the research questions relates to how does being a parent of a child with autism affect the mother's levels of resilience? This question looked at what challenges being a parent of a child with autism brought to their lives and what they immediately did about those challenges. The responses from the participants showed a very clear picture of the challenges of parenting a child with autism. The stories that were told were detailed, heroic accounts of times in their lives when they had kept their children safe and well despite the behaviours associated with autism. This research question has three theoretical codes that relate to the way that the mother's resilience was challenged. Firstly, the theoretical code adversity is used to describe the challenges faced by the mothers, and secondly the theoretical code adversity management describes what the mothers did in the midst of the adversity. In all cases, the stories that were told demonstrated that the mothers triumphed in keeping their children safe and well and that the mothers knew exactly how best to handle the situations they faced (even if they told themselves that they didn't). This meant that one of the findings was that everyone is resilient and that there is no such thing as non-resilient people. The third theoretical code is adversity aftermath. The key finding here was that in all cases the mothers dealt with the challenge first and then after it was all over and everyone safe, did they allow themselves to experience their own feelings. Not once, when their child was in danger, or experiencing a meltdown, or being in trouble with others, did the mother stand and cry about it. They always dealt with the crisis first with the tears coming later. Due to the separate nature of challenge first and response later, it felt appropriate to create the first theoretical code for this question as adversity, followed by the second theoretical code of adversity management and then following on with adversity aftermath. These separate areas occur in order in the accounts given by these women and so have been coded as distinct from each other to demonstrate this.

4.3.0 Theoretical code two: adversity

So, looking first at the theoretical code of Adversity. The axial codes demonstrated the nature of the adversities faced by these mothers and are: Struggling with getting a diagnosis, Struggling with getting the right support, Dealing with challenging behaviour, Dealing with other people's negative reactions, and Dealing with the physical challenges of autism.

4.3.1 Struggling with getting a diagnosis.

Focused code	**Axial code**	**Theoretical code**
Waiting years to get a diagnosis	Struggling with getting a diagnosis	Contributing to: ADVERSITY
Mourning the lost child		

Table 10 Evidence pathway for the axial code Struggling with getting a diagnosis.

Within the first axial code of struggling with getting a diagnosis is the code waiting years to get a diagnosis:

> *"…she was already on the waiting list to be seen by the autism service, so she was then diagnosed. That was about this time last year when she was fourteen, about this time October half term that she was diagnosed privately and then she was seen about 8 or 9 months later by the NHS autism service, they had looked at all of the stuff that the private doctor had sent, my letter, saw her for an hour and then said yes, we accept this diagnosis, and we wouldn't dispute it."* Alicia.

> *"…he had missed all of that because he was undiagnosed for so long and the process of diagnosis was so drawn out that it meant that he was stagnating at school because he wasn't getting the right support, so he has just fallen further and further behind, and it is at every stage we have been blocked at every stage."* Monica.

> *"I then sort of fought tooth and nail to get his diagnosis and I didn't get his diagnosis for four years so a long time of going through the mill."* Rhianna.

Unfortunately, waiting years to get a diagnosis was an experience that was common among the participants which means that it is well grounded in the data.

The second part of this axial code relates to mourning for the child that they imagined that they would have, that now no longer can exist because of the autism diagnosis.

> *"…mourning and grief that you go through when your child's diagnosed and getting through that process" Fiona.*

> *"You imagine the life that you want for your child, including the play dates, birthday parties and Saturday morning football etc. You never set out to have a child who does none of that. So, there is a loss of all the things that you imagined and looked forward to. So of course, I felt sad and still do sometimes, each time another missed event occurs." Olivia.*

4.3.2 Struggling with getting the correct support.

Focused codes	**Axial code**	**Theoretical code**
Getting no support after the diagnosis	Struggling with getting the correct support	Contributing to: ADVERSITY
Going to tribunal		
Providing paperwork to get support		
Meeting with the school		
Meeting with professionals		
Feeling abused by the system		
Fearing the future		

Table 11 Evidence pathway for the axial code Struggling with getting the correct support.

There was thirteen out of the participants who contributed to this code, meaning that this is a big part of the adversity experienced by mothers of children with autism. There was a lot of frustration felt by the mothers who had battled to get a diagnosis believing that having that would mean that they would be offered the support their child needed, but then finding that was not the case:

> *"I think the only thing is that I thought that once he had got his diagnosis that he would have a bit more help put in place and that hasn't been the case."* Joanna.

> *"…the problem is there is no support in the autistic children in England, no support at all…… It shouldn't be like that as soon as the child is diagnosed, the GP must take care of the child and provide necessary therapy, behaviour… cognitive behavioural, this is whatever they do sensory or whatever help the child, and it should be provided immediately. The children shouldn't be waiting years to be diagnosed. And after they are diagnosed… what happens?... Nothing only the diagnosis on a piece of paper. That's all no help at all it's embarrassing, actually it's really bad." Nina.*

The second area was going to a tribunal, which is the legal recourse to parents who are unable to secure the school that they believe is needed for their child. Five of the participants had been through this experience, with examples as follows:

> *"…he was put into a mainstream school because they wanted him to try it out, but I obviously knew that it wasn't what he needed and, in the end, I had to go to tribunal to get him a place at a specialist school which wasn't very nice as it was really stressful for all of us, and it was really stressful for him being in a mainstream school because he didn't understand…" India.*
>
> *"I wasn't prepared to keep on having lots of these awful situations at school where he is being restrained and locked in rooms and going through internal exclusions or being called naughty or lazy or whatever else, I sort of hung out and went to tribunal to get a school who I thought would understand him and be able to meet his needs." Lydia.*

Part of the tribunal process involves the preparation of paperwork. The participants described their feelings about this part of their lives:

> *"…because when you are applying to go to tribunal you have so much paperwork you have to go and fill it all out and so when you have not done it before you don't know what you are doing. So obviously there are people that will help you but a lot of it will have to come from you. So, the whole process was quite stressful and then just being a mum on top of that, to two boys as well is obviously really hard. I found it really stressful"* India.
>
> *"…you know you would fill out a form and then you would go to submit it and then they would say that actually we have changed the form for that, so you now have to submit the evidence on a different form and I think what the system forgets is that there is a family in all of this you know, J's needs don't stop while I am filling paperwork out, you know you still have a child that has autism in the middle of this and needs more reviews than any other parent would need and yet you are having so much of you taken away by all of the paperwork and the bureaucracy around having to try and get him what he needs and it was a long time coming it was about three and a half years in total."* Monica.

The next focused code in this section is meeting with the school. This was considered an adversity because of the things that the participants heard the school saying to them about them, and their children:

> *"There were loads and loads of little things that they were saying but they put it all on her, it's her fault, she isn't concentrating she is very easily distracted, she's a bit naughty she's an attention seeker." Alicia.*
>
> *"I bought the class a tub of chocolates" to have for Christmas before they went home and I dropped them up the school for him and when I walked in the headteacher was in the room with the teacher and they had just received her copy of the form and she said 'Oh we were*

> *just talking about you, we have just received this and I don't know what you are not understanding about this… your child hasn't got autism and there is no such thing as autism, just badly raised children."* Joanna.

> *"…you are getting a phone call during the day to say that J has received the second incident in a week where J has sustained a head injury in a week because he has been left unattended by staff – it's just a catalogue of things going wrong …..it's keeping him safe at that time, it's dreading getting home from work and getting the report of what has happened during the day or getting a phone call from school saying there was an incident that has happened." Monica.*

On a similar line, the appointments with health professionals were also challenging:

> *"I took her to the GP once and the GP just said, 'Oh the school would tell you if there was really a problem, go away.' We took her to an Ed Psyc. and they said, 'she has a massive range of skills' she was in the top 99.8 centile for somethings, and she was in the bottom 0.2 centile for other things and the Ed Psyc. said that she had 'never seen a profile like it', and she still didn't say this means I can't diagnose this. She said it's kind of like 'dyslexic dyspraxic umbrella type things', but she didn't ever say, actually what you need to do is take her back to your GP and get her seen by a paediatrician."* Alicia.

> *"So, he was under community paediatric services for maybe… now during this four years, maybe two years we were going for appointments to see the paediatric services in Suffolk and then they discharged him with no diagnosis. Yes, they discharged him with no diagnosis, so I wasn't happy with that."* Nina.

These experiences of dealing with education and health professionals left the participants feeling that they had been abused by the system and so that is the next focused code:

> *"Number 2 [challenge of being a mother of a child with autism] I think would be – unsupportive and abusive behaviours from the system.* Bianca.

Part of what seems to motivate the parents for the fight is fear for the future:

> *"I in the back of my head have that awful statistic that 6% of children on the autistic spectrum go on to full time employment as adults."* Monica.

> *"I do worry about not necessarily who will look after him but how his life will be." Keira.*

4.3.3 Dealing with challenging behaviour.

Focused codes	Axial code	Theoretical code
Having no sense of danger	Dealing with challenging behaviour	Contributed to: ADVERSITY
Having a meltdown		
Wandering/running off		
Breaking things		
Being violent		
Getting into trouble with the police		
Feeling isolated		
Bumping into people		

Table 12 Evidence pathway for the axial code of Dealing with challenging behaviour.

The third axial code that forms part of the adversity theoretical code, is dealing with challenging behaviour. Again, this code is well grounded as it had comments from sixteen out of the seventeen participants. The first focused code in this category was having no sense of danger:

> *"I turned round, and T was standing on top of the wall that overlooked a squash court and there was no… it was focused, and he looked like he was about to jump. I don't what level of time, I thought how do I get to him without alarming him so that he does jump. So, I just ran fast as silently as I could fast but gently no sound from him. I put my hand in front of him so that he couldn't fall and just took him down and sort of held him. My heart was beating so fast I was just so relieved that I had got him. I could never forget that moment I just thought what if?"* Bianca.

The second focused code is wandering off/running away. Six of the participants contributed to this code too:

> *"I said to the boys to wait outside the door and to not go anywhere. When I came out of the rest room with M, K was nowhere to be seen. I asked S (oldest) where he had gone, and he said that he didn't know where he had gone except that he had gone out of the corridor outside the bathroom doors. So, we set off to look for him, but he was nowhere to be seen…. age 4 and no speech. I was starting to panic and started to run around looking for him dragging the other two by the hand around the shop…. I realize at this point that there is every possibility that K could have gone out of the door and now be in the car park. I am beyond stressed. I don't know whether to stay with my daughter or go and run around the car park."* Helena.

By far the most widely experienced challenging behaviour is seen in the focused code having a meltdown. Fourteen out of seventeen participants described experiences with this challenge:

> *"…after half an hour being there, he had a complete meltdown I mean he laid on the floor he screamed he headbutted the floor he punched the walls he hit himself it was very very extreme…. and all I could do was just hold him at the time to stop him lashing out [at] other people. I said to my partner, you know find out where the quickest way to get out is I said just quickly go while I'm holding him, and he found out and came back and we carried him straight outside."* Georgia.

Closely allied with the code of having a meltdown, are the next two codes, breaking things and being violent:

> *"Things came to a head when he took it out on his younger brother. My younger son who is not autistic enjoyed playing football and he had won a trophy which he was proudly displaying on the mantlepiece in the front room. The trophy was especially precious, because he had won it on the last day that his dad had been able to come and watch him playing. S, for no obvious reason got up and while me and my other son were watching he snapped the trophy in half and then threw one part at his brother and the other half at me. My other son was so upset that his trophy was broken that he threw the piece of metal back at his brother which hit him square in the face."* Eliza.

> *"…as I got to a massive tree he managed to slip out and run into some long grass and what I didn't realize at the time was that around the base of the tree was broken up bricks so he turned round and I have got E [younger child] on my hip and he starts throwing bricks at me… so I said if you can just take E to one side, so I went up to J and as I was approaching him he was still throwing bricks at me and one caught me in the shin and the adrenaline just took over at that point and I bundled him up and just kind of flopped him on the floor."* Monica.

A consequence of the previous codes is that sometimes the mothers have to deal with the police as their children's behaviour occasionally means that they end up in trouble. So, the next code is Getting into trouble with the police:

> *"…the police got involved …and because he was an adult the policeman and a policewoman came round to interview him… R generally sits in the corner, he won't speak he won't say anything, so I do all of the talking, so this policeman was questioning him and asking him leading questions of why…I really think that now that I should have put a stop to it there and then. I didn't realise what this policeman was doing we spent a whole year going up and down to the police station at M including the last interview that we had…we had my solicitor*

> *who understood that obviously R had no idea what he had done [was] wrong or anything not a clue, she told him not to answer anything and I could see this policeman getting really frustrated as he really wanted to book him, he wanted to charge him and that did upset me."* Georgia.

Another consequence of the above behaviour is that when parents take their children out of the house, they end up just dealing with these challenges, which often means that they choose to stay at home. The next focused code stems from this decision, which is feeling isolated:

> *"He is like 6 years old, and he is a really big boy, so I just stay in with them both. I think that is one of the things in that it can be really isolating."* India.

When exploring the adversities that the mothers of children with autism face, the sheer numbers of the participants who made comments that were subsumed by the codes in this section, show that not only do the mothers have a clear sense of adversity, but that this is the largest area of challenge on a day-to-day basis.

4.3.4 Dealing with other people's negative reactions.

Focused codes	**Axial code**	**Theoretical code**
Not accepting Mum's viewpoint	Dealing with other people's negative reactions	Contributed to: Adversity
Saying nasty things		
Staring,		
Being blamed for child's behaviour		

Table 13 Evidence pathway for the axial code Dealing with other people's negative reactions.

The first code that makes up this category is not accepting Mum's viewpoint:

> *"…so, I went back into school and had many, many conversations saying 'what's underlying it then?' You can't simply say that a child is naughty, for all of these other children who are not as intelligent as she is, because you keep on telling me that she is highly intelligent, if they are not as intelligent but socially coping, surely, we are looking at something….[the school said] 'Oh, we don't believe in giving labels' (laughs) … but you have kind of given her a label here as you have called her naughty. Which isn't helpful."* Alicia.

Alicia had gone to the school for a review of her child who at the time did not have a diagnosis. The school insisted that she was naughty and did not pursue a diagnosis, or support Alicia in her efforts to find out what was 'wrong' with her child.

The second code in this category is linked to the above code and is saying nasty things:

> *"…my son suffered from suicidal ideation back when he was 5 to 6 years of age and he was going through lots of external exclusions at that time, not that it bothered him because it got him time out from school, but it was the negative labels, it was the people saying nasty things about him and blaming him along with the fact that his needs weren't being met at school"* Lydia.

The emphasis placed by the mothers on this code was key in that mothers do their best to defend their children and yet it is the professionals that they are giving their child to every day at school in the hope that they are looking after them, that appear to be making the nasty comments.

Another challenging part of other people's reactions, is the feeling that people are staring at them while they are dealing with their child's behaviour, so the code for this is being stared at:

> *"M realizes what is going on and starts to loudly wail. She then throws herself on the floor and is wailing out loud saying that her brother is gone. A crowd is now starting to gather. I ask them if they would help me look for my youngest child, but instead of heading off to look, most of them are just standing staring at my daughter as she lies on the floor"* Helena.

Coupled with this, are the times that the mothers feel that they are judged and blamed for their child's behaviour, either because people are staring or because people actually say something to that effect. Therefore, the next code is being blamed for child's behaviour:

> *"I thought, not only are you insinuating that there is no such thing as autism and I know it does exist, but then you are saying that all the things that he is struggling with are my fault. She was awful… such a horrible lady." Joanna.*

> *"I think that is one of the things in that it can be really isolating I find that people do judge when you are out and about because people don't know the situation and they do just think they are just a naughty child."* India.

4.3.5 Dealing with the physical challenges of autism.

Focused codes	**Axial code**	**Theoretical code**
Having an epileptic fit	Dealing with the physical challenges of autism	Contributed to : ADVERSITY
Being awake at night		
Losing words		
Having problems with digestion		
Seeing my child suffer		
Having a restrictive diet		
Having sensory issues		
Bumping into people		

Table 14 Evidence pathway for the axial code Dealing with the physical challenges of autism.

Autism is diagnosed from the behavioural symptoms, but behind many of those issues are comorbid biomedical issues. The first of these is the code having an epileptic fit:

> *"So, A was drinking his milk and basically had a seizure, he had never [had] any, there had been a vague possibility, I think when he was very little, there was talk of maybe having some absences, but I think that was more to do with him you know processing what was going on around him. So, A had a full seizure, drop seizure and obviously it was a huge shock"* Fiona.

The most common challenge in this section is having a child that cannot sleep at night time. Therefore, the next code is being awake at night:

> *"He is medicated for sleep because he has melatonin for sleep, because he doesn't go off easily, but we have just had his medication reviewed because he is not settling and then waking up at like 2 in the morning."* Petra.

Another thing that the mothers commented on, was that at the time when they started to realize that there was a problem, was when skills that their child did have, started to disappear. This is demonstrated in the code losing his words:

> *"Then at the 18-month check, I highlighted my concern that he seemed to have stopped using words that he had been using and the health visitor was like well he's only 18 months. I said oh yeah, it's not like he should be saying lots of things. I just think that he should be using the words that he was saying. He isn't actually saying any more."* Bianca.

Another physical issue that was prevalent among the participants is problems with digestion. The code for this is having problems with their digestion:

> *"… he's had very extreme problems with going to the toilet to the point where he'll hold his bowels for a week"* Georgia.

Problems like this, lead to the child experiencing a lot of pain, so seeing him suffer is another code:

> *"K has huge problems with his digestion and often is in pain. Because he has no language, he can't tell me what is wrong, but I can see on his face that he is in pain – that tears me up to not be able to fix it for him*." Helena.

These children also self-select a very restricted diet, which leads to a lot of issues with mothers trying to get the child to eat a well-balanced diet, so the code having a restrictive diet reflects this:

> *"I couldn't get him off the boob he wouldn't eat food he wouldn't have anything with texture near him, it wasn't like the normal weaning stage when they would try new things and sort of gagging at things and things like that, it was almost like he was really petrified of it, and this went on for months I don't think …. I finally got him to eat a bit of toast when he was 18 months, up to that he just literally lived on just milk so he was very tricky, but we didn't know quite why."* Joanna.

One possible explanation for the child selecting a restricted diet is that children with autism can be either hypo or hyper sensitive. The focused code having sensory issues brings together the comments on this:

> *"…I have to restrict a lot my other children because of him you know we can't go to certain places he has a severe sensory perception disorder as well so we can't go to place where there is bright lights which is why he will never go shopping in places like Sainsbury's he can't ever go shopping never go to crowded places because he is scared that someone will touch him accidentally."* Nina.

Alongside the fear that other people will touch the child with autism is the opposite issue where the child cannot regulate their sense of their personal space, and so they end up walking into other people when out. The code bumping into people reflects this:

> *"So, A doesn't really see people when she walks, and she can be a bit of a bulldozer, she tends to walk and knock people out of the way if she needs to so that can be hard dealing with other people and it's not necessarily their fault, I mean no one wants to be knocked out of the way do they, if I was walking down the street and someone knocked me out of the way I wouldn't like it either."* Diana.

All of the above codes have been allocated to the participants descriptions of the sense of adversity that they face on a day-to-day basis. The level of difficulty that they continue to experience clearly demonstrates that they have a lot to contribute to the topic of resilience. Therefore, the above section has all been allocated to the theoretical code adversity.

4.4.0 Theoretical code three: adversity management

The next theoretical code that addresses the question of how being a mother of a child with autism affects their resilience is 'adversity management' and describes what the mothers do during the situations that they find challenging.

Feeding into the theoretical code of adversity management are three axial codes: cognitive task, practical task, and social task.

4.4.1 Cognitive task

Focused codes	**Axial code**	**Theoretical code**
Using intuition	Cognitive task	Contributing to: ADVERSITY MANAGEMENT
Thinking quickly		
Not knowing what to do (but doing something anyway).		

Table 15 Evidence pathway for the axial code Dealing with the physical challenges of autism.

The first axial code in this section is cognitive task which demonstrates the thought processes that the mothers go through during adversity. The first focused code in this section is using intuition to help:

> *"In the end from my own idea intuition after going through the whole system which was through her GP, they put me onto youth pathway, and they talked to me, and they would suggest medication."* Cara.

Intuition appeared to be a kind of fast logic that, without a clearly defined pathway helped the mothers to decide what to do. Kahneman (2012) describes intuition as being an innate skill that we have alongside other animals that helps us to perceive the world around us, recognize objects, orient attention, avoid losses and fear spiders. In addition, there are learned skills such as reading and understanding the nuances of social situations. Other mothers also talked about not having a clear rationale for their actions but did not attribute it to intuition, they said they didn't know what to do. In each case, even though they did not know what to do, they still did something. Therefore, the next code is not knowing what to do, but doing something anyway:

> *"S then went on a rampage around the house throwing things and breaking them. I didn't know what to do, so I called the Police.* Eliza.

There were other participants who did know what to do, but still emphasized the need for speed in dealing with the situation, this is reflected in the code thinking quickly:

> *"I thought how do I get to him without alarming him so that he doesn't jump*." Bianca.

4.4.2 Practical task

Focused codes	**Axial code**	**Theoretical code**
Fighting the system	Practical task	Contributing to: ADVERSITY MANAGEMENT
Keeping the children safe		
Getting on with it		
Getting him out		
Getting him home		
Lying on child to calm him /stop him lashing out.		

Table 16 Evidence pathway for the axial code Practical task.

The next axial code in this section is practical task and demonstrates what the mothers actually did in the middle of the crisis. Every participant has at least one code attributed within this area. The first code has the most participants commenting within it and is fighting the system:

> *"As far as those who are supposed to help, - and this is where I feel super angry, it is deliberately going out of their way to not help, social disservices, it is deliberately putting you in situations where you have to force them to do something, even the smallest thing and it comes on my time and expense. It's like they deliberately try and trip you up so you make a mistake and then they can justify not giving any support or forcing something on you that you don't want because you know it won't help your child or will actually make things worse."* Olivia.

Another key focused code within this area is that of getting on with it. The idea that this is their life and so they just need to do it:

> *"The getting on with life yeah just getting on with it 24/7"* Keira.

A significant number of comments in this area relate to dealing with the child's challenging behaviour. Several of the episodes described by the mothers showed their children doing things that were potentially harmful to themselves, this is covered by the focused code keeping the child safe:

> *"I had to make a decision between containing him and keeping E safe. So, I looked around for some of the players and because at this point people were watching but for them, they were watching a naughty child they are watching a child having a tantrum and throwing bricks at their mum, so I went over, and I explained quite clearly that my son is autistic, and he is*

> *having a meltdown this is not bad behaviour I need to contain it. They were like what can we do so I said if you can just take E to one side"* Monica.

Keeping their child physically safe was a concern for about half of the participants, Monica mentioned her concerns about safety seven times during the course of a one-hour interview which shows her level of concern about this issue.

Other codes in this area, show the participants direct actions to manage the situation. This next code relates to a common method of dealing with a child in meltdown and that is to remove them from the situation. The code getting him out relates to this:

> *"…in my little girl's assembly, when [I] had taken B with me and he was screaming and running around and then he used to try and pull his trousers down. Which again I just got up and walked out with him and thought I just can't stay with this"* Petra

On a similar level to this is the next code which is getting him home. Home is an area that the parents can (to an extent) control, and so bringing the child back to that place enables them to manage:

> *"…we thought what the heck are we going to do?... and we thought right my logic said I want to get a little bit closer to home."* Fiona.

If a situation is so severe that there is immediate danger to either the child or someone nearby, the mothers were prepared to put themselves into physical danger to diffuse the situation. They did this by using their own bodies as a source of sensory input to provide deep pressure to the child. The code lying on the child to calm/stop them lashing out is next:

> *"I have had time when he has been in a room, and he has literally thrown things at walls, and I have had to lay on him. I have had to lay on him in order to desensitize him because something has obviously stirred him up, so I have had to do that before. I haven't got a huge, weighted blanket, so I use myself as a weighted blanket and put myself over him…and always remain calm"* Rhianna.

4.4.3 Social task

Focused codes	**Axial code**	**Theoretical code**
Asking strangers for help	Social task	Contributing to: ADVERSITY MANAGEMENT
Asking partner to help		
Standing back, and getting everyone to wait until they had calmed down		

Table 17 Evidence pathway for the axial code Social task.

The next axial code within the theoretical code of adversity management is social task. This is used to show how mothers use those immediately around them to manage in an adverse situation. The first focused code in this category is asking strangers to help:

> *"After a while I realized that I hadn't seen J for a while, so I asked a child if they could see if they could find J. They came back and said they couldn't. I was beginning to have this uneasy feeling in the pit of my stomach, so I asked the assistant if I could go in and look for him. The assistant agreed and came in with me….I could hear a message describing J going out over the tannoy….so as others were looking, I decided to stay in the place where we last had him, so I was there if he came back."* Olivia.

As well as asking strangers to help, the mothers called on their partners to help too. So, the code asking partner to help covers this:

> *"I said to my partner, you know find out where the quickest way to get out is I said just quickly go while I'm holding him, and he found out and came back and we carried him straight outside"* Georgia.

One of the challenges of caring for a child with autism, is knowing the difference between a meltdown and a tantrum. When it appears that a child is having a tantrum because they are not getting what they want, then the method applied by the mothers is to stand back and wait for it to finish. This appears in the social category because sometimes this involves getting others to stand back and wait too. So, the code name for this is standing back and getting everyone to wait for them to calm down:

> *"she is very distressed shall we say but every time I approach her, or anyone approaches her it gets a million times worse, so you have to leave her, you have to stay away, make sure she is safe make sure that she is not going to harm herself and just stay back. So, for the public there is this 13/14-year-old in the middle of a field having the most enormous tantrum and nobody is going over to her we are just standing by waiting for it to pass. So that was the action we did."* Cara.

4.5.0 Theoretical code four: Adversity aftermath

Once the situation has passed there is the aftermath of dealing with the thoughts and feelings of both the mother, the wider family, and the child themselves. The next theoretical category relates to what happens in the aftermath for the mothers, and so is titled adversity aftermath.

Feeding into the theoretical code of adversity aftermath are three axial codes: emotional response, social response, and reconnecting with the child.

4.5.1 Emotional response

Focused codes	**Axial code**	**Theoretical code**
Feeling depressed	Emotional response	Contributing to adversity aftermath
Crying		
Feeling stressed / worried		
Feeling wiped out/exhausted		
Feeling guilty		
Shaking		

Table 18 Evidence pathway for the axial code Emotional response.

The first axial code is emotional response, in which all participants featured. The focused code describes the specific emotions that the mothers' felt and were:

Depressed:

> *"So, you know in that respect coping with it was difficult and I do sometimes suffer with depression."* Keira.

Crying:

> *"So, I just walked out with him and then cried when I got home sort of like, I can't do this anymore, why have I got to have a child like this?"* Petra.

Stressed:

> *"I obviously knew that it wasn't what he needed, and, in the end, I had to go to tribunal to get him a place at a specialist school which wasn't very nice as it was really stressful for all of us"* India.

Exhausted:

> *"We return home in pieces with no shopping while I quietly vow never to attempt that again"* Helena.

Guilty:

> *"the minute I raise my voice I usually straight after that I start feeling bad and I'm like I forgive you it wasn't your fault" Diana.*

Angry:

> *"I can remember thinking 'Oh my gosh I'm going to do something illegal right now, just thinking about what I would like to do to you!' She was really vile, she refused to have any part of helping because she just didn't believe in it."* Joanna.

Shaking:

> *"I just need a few minutes to kind of regroup and refocus because I am shaking at the moment" Monica.*

Another aspect of the adversity aftermath theoretical code was sharing the event with family and friends, which is reflected in the axial code social response.

4.5.2 Social response

Focused codes	**Axial code**	**Theoretical code**
Ranting to family	Social response	Contributing to : ADVERSITY AFTERMATH
Talking to friends		

Table 19 Evidence pathway for the axial code Social response.

Finding someone to share the adverse experience with follows immediately after the adversity in many of the accounts of the participants reactions to challenging events, firstly ranting to family:

> *"She was awful… such a horrible lady. So, a lot of ranting to my family I think got me through that one….I mean I come from a really small family anyway, at that point I had both my grandparents, so I had them, my mum, and my husband and then obviously the kids. No not massively but enough to listen to me whinge I suppose."* Joanna.

With the second focused code being talking to friends:

> *"I had friends who had experience of diagnosing Autism etc…. all of them instantly said anything we can do to help you; you know let us know. So, I had a really nice supportive group of people."* Bianca.

4.5.3 Reconnecting with their child

Focused codes	Axial code	Theoretical code
Asking forgiveness	Reconnecting with their child	Adversity aftermath
Sitting with them until they were calm		
Doing some fun things together		

Table 20 Evidence pathway for the axial code Reconnecting with their child

Following on from this, there is a need to reconnect with the child that has been at the centre of the situation. Therefore, the axial code applied is reconnecting with the child. The first code here involves asking for forgiveness. This happens particularly if a mother has shouted at their child:

> *"I usually forgive her very quickly the minute I raise my voice I usually straight after that I start feeling bad and I'm like I forgive you"* Diana.

Often doing a fun activity together is a way to reconnect:

> *"I try to do it by just giving her a little bit more of my time… and will want to talk about Peppa Pig anyway so I suppose in that sense she doesn't hold grudges, so things move on quite quickly."* Diana.

Alternatively, another way that parents can reconnect with their children is to sit with them until they have calmed down:

> *"I could feel his whole body tighten, and then it just kind of let go and he burst into tears in my arms, and in between sobbing he said, 'I hurt you, I know I've hurt you, do I need to ring an ambulance' and I was like' you don't need to worry about any of that' he was like 'I'm so tired I've talked to school about this, I can't control it I can't manage it.' He was really like stumbling around his words and trying to get out what had happened, and I said, 'you don't have to worry about any of that we just need to focus on you.' So, he sat with me for a while until he had calmed down and he wanted to see my leg and I said, 'I don't think we want to do that it's fine'."* Monica

In summary, the second research question asked about how being a parent of a child with autism affects the mothers resilience. The responses to this area showed that the mothers all had a clear idea about the adversities that they faced. The stories that they told revealed a significant level of danger to themselves and their children that occurred and the frequency of these types of incidents. This means that this cohort of participants do face a chronically challenging situation in their lives. Additionally, their responses showed a clear set of priorities in that an adverse situation must first be managed before the mothers allowed themselves to express their emotions. This set-in motion the idea that there was a process with clear distinct stages: act first, emotions second. Therefore, the theoretical codes for this research sub-question are adversity, adversity management and then adversity aftermath, in this order.

4.6 Research sub-question three

The third research question asks in what ways do mothers of children with autism demonstrate resilience? The findings for question three show how the mothers of children with autism recover from the place they found themselves in following the adversity aftermath. The concept of resting here was a fascinating discovery to come through from several of the accounts. Resilience is so often portrayed in terms of how well a person can take a hit and not fall down, but these accounts demonstrated that taking time to rest and recover was pivotal to their continued ability to carry on mothering their children. The theoretical code of recovery from adversity reflects this finding. Another major finding for this question was that following the recovery period there was a time of adaptation. Interestingly, the mothers reflected on what had happened and how they could have done it differently, but the motivation for the exercise came from the desire to prevent a recurrence of the event. This is a major break from previous linear views of resilience which has been portrayed as a linear process because it means that resilience is a cycle with the stages positioned between the adversity that has occurred and a potential repeat of the adversity in the future. The theoretical code adaptation to past and future adversity reflects this stage in the process.

The third major finding for this research question, was that the mothers were all different in the way that they chose to respond to their challenges, but they were congruent with themselves. This meant that a mother who responded in a primarily cognitive way, continued to do that throughout all of the stories that she told. This gave rise to the idea of a resilience signature which was the last theoretical code.

4.6.0 Theoretical code five: recovery from adversity

Within the first theoretical code of recovery from adversity there are four axial codes: resting and self-care activities, social activities, cognitive activities, and spiritual activities. These axial codes demonstrate the things that the mothers did to recover from the adverse experiences. The idea of resting as being an important part of recovery and resilience is novel to the field of resilience as it means that activities that have previously been judged as a lack of resilience are actually an essential part of resilient behaviour.

4.6.1 Resting and self-care activities.

Focused codes	Axial code	Theoretical code
Taking a break	Resting and self-care activities	Contributing to: RECOVERY FROM ADVERSITY
Listening to music		
Going for a walk		
Doing mindfulness		
Doing yoga		
Watching trashy TV		
Using work/ study as downtime		
Eating well		
Having a bath		
Doing make up		

Table 21 Evidence pathway for the axial code Resting and self-care activities.

The concept of time out to rest, is the first of the axial codes for this subject area. It was a theme that ran through all of the interviews. The concept of resting occurred as early as the second interview, but was most clearly expressed by Olivia whose comment became an in vivo quote:

> *"I think that being a parent of a child with autism requires you to perform at your peak. When they are having a meltdown, you have to be on top of your game, otherwise you could not deal with it. So, looking at peak performance, I know that exists in a cycle race, coupled with rest periods. Like I said earlier, the tour de France is not raced every day. There are rest days, and the rest facilitates the peak and the endurance. So, taking care of myself involves anything that means I am resting from the task of parenting J. So, it might be going out for a run, or taking the kayak on the river and just absorbing the calm of the water. If we get a break together, we like to go out for a meal, just so we have time to sit and talk." Olivia.*

The first focused code of taking a break appeared in all of the interviews and is the only code in this study that is attributable to all of the participants:

Taking a break:

> *"I think every now and again having a break, because you definitely need that because it is very full on… it is really nice to like to have a bit of a breather and a bit of time to myself but other than that it's hard because like being a mum is a full-time job, so you can't just go and like do whatever you want whenever you want, but I think it is nice to have a break."* India.
>
> *"Sometimes S goes to his respite carer and T goes to stay with my sister and I can get a break and go away for a bit. That does me the world of good."* Eliza.

Having ‘me time’:

> *“maybe if I go and clean the chickens out, I’ll be on my own because nobody seems to like that job” Joanna.*

Listening to music:

> *“I use music that’s good a positive energy to it, you hear it in a different frequency. It helps sleep and promotes positivity; it is like 417Hz I think it is. You can get like these on You Tube so if you find 417Hz positive energy music, you just listen to it while you meditate, and it is supposed to help the neurotransmitters fuse better and make you feel better. So, I have been trying that”* Rhianna.

Going for a walk:

> *“I like to go for walks, love really long walks. I don’t do them as much as I want to.”* Bianca.

Doing mindfulness:

> *“So, I do that, and some mindfulness colouring in” Rhianna.*

Doing yoga:

> *“…there are things that I like to do to take care of myself. I enjoy yoga so I love to take a class or just do some in my garden. Finding a calm centred space inside while I am holding a pose is very calming and healing. It teaches me to be present and to not spend time worrying about the future… just standing in the garden and feeling the sun on my face is so refreshing and grounding*.” Helena.

Watching trashy TV:

> *“…watching real housewives on the tele rubbish tele watching”* Fiona.
>
> *“I recently just discovered TV after about a decade of watching CBeebies and Disney Movies and Peppa Pig I finally discovered TV and I thought this is an amazing invention how come no one told me about it. Once the kids have gone to bed, I sit there with the iPad and go onto iPlayer or YouTube or anything and sort of like catch up on things that I might want to watch whether it is a movie or a drama series you know.” Diana.*

Using work/ study as downtime:

> *“…probably going to work if I’m honest. Yeah, going to work gives me a break, I enjoy what I do”* Petra.

> *"…my [study] has been a bit of an escape from it all because you can't think about things that deeply and have that nagging worry at the back of your head that things are not great. It's kind of a cut off."* Alicia.

Eating well:

> *"Yeah, I aim to eat well myself, partly because of time and cost T has a really healthy diet so I like to go with that."* Bianca.

Having a bath:

> *"I have a glass of wine and a bath when I get to his [boyfriend's house] it's having that kind of downtime.* Monica.

Doing make up:

> *"Also, I am a trained beautician and makeup artist. So, sometimes if I have an hour spare, I will do my own make-up. Somehow being able to choose the style and look of my makeup and then pick colours gives me a sense of being in some control over what is happening in my life."* Helena.

4.6.2 Social activities

Focused codes	**Axial code**	**Theoretical code**
Being reassured	Social activities	Contributing to: RECOVERY FROM ADVERSITY
Seeing friends		
Family support		
Socializing during the day		
Spending time with husband/ partner.		

Table 22 Evidence pathway for the axial code Social Activities.

Within the axial code of social activities, there are activities that the participants carry out because they know that they will help them to recover from the last things that have happened. The first code of these is being reassured and denotes the activity of the participant talking to her husband to gain reassurance:

> *"I think really my husband is really good with that reassurance, you know this is how he is, and that there is help out there." Petra.*

Sometimes, just spending time with their partner, is helpful, just in getting a break or doing something to distract them from the situation with their child:

> *"I text the guy that I was supposed to be going on a date with and said I've had a really bad day today and I am not sure that I am really in the best place to go out and he said look what can I do to help, he booked three different restaurants at three different times and he said I'll come and pick you up and I ended up going out in the evening, he came and picked me up and we went out for a drink" Monica.*

The participants also see their family as a way to recover:

> *"Occasionally, my parents will come and stay for a few days and then I can go out for an evening with my husband. It's nice to get away from the house for a bit, and my parents enjoy time with their grandkids. So, it's a win/win."* Helena.

Friends can also help in the same way:

> *"…so, without having any friends or any family nearby that can help you out once in a while that can be an awful struggle for a lot of people and we have no family living nearby as they are a few hours away and most of my friends are in a similar situation to us, I do have one friend who can occasionally help me out whether it is with a bit of baby sitting or whatever. So yeah, the isolation is quite a big challenge although I am lucky because I have got quite a big support network although a lot of it is online. But even getting bits of advice practical advice or emotional support, all of that is so important and I think social media has sort of grown and is able to give more support to autistic people and parents and carers of autistic children as well."* Lydia.

Many of the participants did not work full-time, so this gave them an opportunity while their child was at school to go out and socialize:

> *"I meet some friends on Friday before I go to work for a coffee and it's like once a month because they also work" Nina.*

4.6.3 Spiritual activities

Focused codes	**Axial code**	**Theoretical code**
Sustaining religious festivals	Spiritual activities	Contributing to : RECOVERY FROM ADVERSITY
Going to the synagogue/Mosque		
Praying giving the day structure		

Table 23 Evidence pathway for the axial code Spiritual activities.

The next axial code is spiritual activities. This was a minor theme, which was only discussed by two of the participants. However, it was very important for them, and so it is included as an axial code. The first focused code is about maintaining religious festivals:

> *"…it was Yom Kippur recently which is a huge, long service and you fast for 25 hours but also you are in synagogue from 10am until 7pm… she quite likes it, it happens every year, so she recognizes it and understands it. When you think about the fact that she did her entire Bat Mitzvah, a full-on Bat Mitzvah, when she was thirteen which is two years of learning Hebrew and then stand up in front of 200 people a congregation and sing it and take [?] the idea of a Bat Mitzvah is it's not like a confirmation, it's when you are now a Jewish adult, and you are now able to take a service and Jewish services are long like two or three hours long and she did all of it."*

The second and third codes are going to the mosque and praying giving the day structure and are applied to this quote:

> *"I feel that my faith helps me a lot, so I make sure that I pray 5 times a day, it gives me routine and structure. I make sure that I go to regular mosque activities."* Diana

4.6.4 Cognitive activities

Focused codes	**Axial code**	**Theoretical code**
Reassessing everything	Cognitive activities	Contributing to: RECOVERY FROM ADVERSITY
Deciding she could manage by herself		
Meaning making		
Choosing your attitude		
Going to CBT		
Celebrating herself		
Journaling		
Studying		
Stopping looking for fair		
Remembering you are not to blame		
Seeing the upside of autism		
Understanding her child's challenge		

Table 24 Evidence pathway for the axial code Cognitive activities

The last axial code in this section is cognitive activities and describes deliberate thinking about the event that happened from the perspective of 'later in the day'. This is a time when the intense emotional reaction to the event has passed, allowing the participants time to think. The first focused code in this section is reassessing everything:

> *"Later in the day after I have calmed down, I think about how I could have done that better and realise that I was unable to manage this task alone as there is no way I could have done it better. I also realise that although this felt like a new low, that it was useful information to know and that it is better to know what the dangers are rather than to be oblivious."* Helena

Several of the participants have been to CBT counselling as part of helping themselves deal with adversity. This therapy involves looking at the client's schemas to change ones that are maladaptive into more useful ones (Beck, 1967; Padesky, 1994). They can then use the skills they learned there, in coping with the ongoing adversities of parenting a child with autism:

> *"I went to a CBT counsellor for a couple of years, and I have learnt to explore my feelings rather than to block them out and push on. Now I am kinder to myself and do not push myself to do things when I am not feeling up to it. I also understand that if I am feeling down, then I can explore my beliefs and understand what is going on in my thoughts. I know how to drop one belief for one that leads to a happier destination."* Eliza

The focused code of journaling shows an activity that helps with using the CBT skills:

> *"I also enjoy writing a journal. If I am trying to explore my beliefs, I can use the journal to kind of have a conversation with myself. I think to myself 'what would Mike ask?' (He is the CBT counsellor) and then I ask the question and try and come up with an answer."* Eliza.

Another cognitive activity that the participants engage in is meaning making, therefore this has also been selected as a focused code. One way in which this works, is by making meaning out of their position as a parent and knowing that their child needs them:

> *"…depression is not something that really sort of happens to me much. There is just kind of no room for it and when you have a child that kind of depends on you, you have just got to you know, you learn to kind of ride over that, and you know there is always hope and you are always striving towards something more."* Lydia.

Another way of making meaning for themselves, was in deciding that they had what was needed to handle the situation on their own. The focused code of deciding that she could manage by herself reflects this:

> *"…by that time, I thought yeah, she probably has got some autistic tendencies here. Nothing I can't manage or handle or need any support with"* Cara.

The question of 'Why me?' cropped up in many of the interviews and showed the way that the mother's came to terms with what had happened in their life. The question then resurfaced when further adversities occurred. However, the participants that had this thought process found a way to stop asking the question. The focused code stopping looking for fair demonstrates this:

> *"There are some days when I just want to go to the bottom of the garden and scream and shout at how unfair it is. Why could I not have just one child without autism? Then I realise*

> *that I am just having a bit of a pity party and that if it is unfair on me then it is more unfair on them. Life's not fair, none of this is fair. So, I stop looking for fair. That was very freeing, to realise that there is no fair meant I could then give my attention to what is, rather than constantly looking for something I didn't have, the life I thought I wanted. To understand that my life expectations were broken and not my heart meant that I could be OK with what was happening. It's realisations like that, that mean I can carry on."* Helena.

Additionally, an understanding of their child's challenge meant that when challenging behaviour occurred, the mother was able to know that the child was doing the best that they could to cope with a difficult set of circumstances themselves. This was a helpful belief for the mothers to hold as it meant that they didn't take what was happening personally. The code understanding the child's challenge was applied here:

> *"…because I wanted to understand her more and it's just coming to that place of acceptance and knowing that this is who she is, and she is wonderful the way she is she is not intentionally making things difficult"* Diana.

As well as not blaming the child, the mothers saw that blaming themselves did not help either. This was reflected in the code remembering you are not to blame:

> *"I think just to remember that it isn't their fault, that it's nothing that they have done or ever have done or will do is to blame for any of it and that child will be the same child that that child was the day before the diagnosis. I think the problem is with a diagnosis is that sometimes it can be a blessing and a curse because while you have got the relief of having an answer for why a child is behaving in the way they are it also brings a lot of mums a lot of guilt because they feel like they are to blame somehow."* Joanna.

As well as knowing that they are not to blame there is a more positive way to view things, in that the mothers are actually doing really well. Eliza brought this up when asked what advice she would give to mothers whose child had just been diagnosed:

> *"…remember to celebrate yourself. You are doing a wonderful job – no one else will tell you that, so you need to tell yourself."* Eliza.

This quote was given the code celebrating herself. Another way of looking at the positives of the situation is to see that in some way, having a child with autism has positives. The code that was applied, is seeing the upsides of autism, and was reflected in over half of the transcripts and so was well grounded in the data:

> *"…my daughter would have gone off to university last year and would be doing very, very different things you know kind of living a different kind of a life and so I would have very different worries about her kind of more the worries that I hear my friends talking about – are they taking the pill how often do they get drunk (laughing), I know where she is in her bedroom playing Pokémon (laughing)."* Alicia.

4.7.0 Theoretical code six: adaptation to past and future adversity

The second theoretical code that relates to the third research question is: adaptation to past and future adversity. This reflected activities that the participants did, that meant that they were better equipped to face future adversities. Within this theoretical code are six axial codes as shown in this table:

4.7.1 Educating yourself.

Focused codes	**Axial code**	**Theoretical code**
Learning about autism	Educating yourself	Contributing to: ADAPTATION TO PAST AND FUTURE ADVERSITY
Joining Facebook support groups		
Befriending other 'autism parents'		
Talking to specialists/ attending conferences/ workshops,		
Using charities like IPSEA and SENDIAS		
Working with other children with autism		

Table 25 Evidence pathway for the axial code Educating yourself.

The first axial code in this section related to activities that the mothers did to educate themselves. The focused codes are as follows:

Learning about autism:

> *"…when he was first diagnosed, I didn't really properly understand it, so I feel like I have sort of educated myself a lot more about it really. It is the way he is though really; I wouldn't change him at all. It is just that their brains are just wired a different way really."* India.

Joining Facebook support groups:

> *"I think the groups of Facebook, so there's really good groups on Facebook that you can join and talk to other parents and ask for advice."* India.

Befriending other autism parents:

> *"…find another autism parent, they are now your tribe. You have more in common with them than you do your own sister. Find out where to go to get help, find out how they manage. Then educate yourself, but then allow yourself to not do everything all at once"* Olivia.

Talking to specialists/ attending conferences and workshops:

> *"I have met various specialists as well and I have been to conferences and workshops and done a lot of learning to help my son but ultimately it is also helping me as well"* Lydia.

Using charities like IPSEA and SENDIAS:

> *"Also, the charities like IPSEA and SENDIAS especially with the education side of things because they really helped and it's free and I did look into getting a solicitor and I went to these charities and they said you don't need one, you can take advice from us and then sometimes as well with tribunal they will come along with you, so that's really handy if some people are going through tribunal to get advice from them and obviously it doesn't cost anything."* India.

Working with other children with autism:

> *"…by this time, I was working at the special needs school that my mum used to work at, so I was working with autistic children and children that have been… had emotional issues and things like that at the time so I was more aware of what it involved."* Georgia.

4.7.2 Financial resourcing

Focused codes	**Axial code**	**Theoretical code**
Sending older son to boarding school	Financial resourcing	Contributing to: ADAPTATION TO PAST AND FUTURE ADVERSITY
Paying to go private		
Needing to work to pay bills.		

Table 26 Evidence pathway for the axial code Financial resourcing.

The second axial code in this area is financial resourcing, this relates to things that the participants did to lessen the impact of the adversity, both past adversities and potential adversities in the future. The first focused code in this area is sending older son to boarding school. This enabled her son to do his A levels without disruption:

> *"…that is one reason that my son is at boarding school because trying to do his A levels with all of that going on around him would have been very difficult and he needed some kind of stability and a break from it."* Alicia.

Being able to use money to lessen the adversity is also demonstrated by the action of using private practitioners to shortcut waiting lists. The focused code paying to go private demonstrates this:

> *"… let's go and diagnose him privately, let's see what a private psychiatrist will say. So, we took him to London to a clinic specializing in psychiatric disorders only. So, he was seen by a children's psychiatrist specializing in [..]and he was diagnosed there, it took only two hours. So, the doctor who diagnosed him said how is that possible that people didn't diagnose him for three or four years."* Nina.

The last focused code in this section is about the need for participants to work to pay the bills.

> *"…people say to me I don't know how you do it. I don't know how you are a single mum and work full time and going through 500 pages of evidence to make sure that the lawyer that you are paying an absolute fortune for hasn't missed anything… even before J was diagnosed it never has been an alternative, working full time has been an issue since J was four months old, I had to go back to work full time because there was no other way to pay the bills."* Monica.

4.7.3 Protecting the child.

Focused codes	**Axial code**	**Theoretical code**
Knowing the triggers	Protecting the child	Contributing to: ADAPTATION TO PAST AND FUTURE ADVERSITY
Being one step ahead		
Being the eyes and ears for my child.		

Table 27 Evidence pathway for the axial code Protecting the child.

Another way that the participants dealt with potential future adversity, was by being vigilant on behalf of their child. This meant that they had to know what the meltdown triggers were so that they could avoid them. This is reflected in the following two focused codes that were applied to this excerpt:

Knowing the triggers and being one step ahead:

> *"It's putting the strategies in place in order to manage the outward behaviour I suppose. So, it's knowing what the triggers are before it happens. You almost have to be one step ahead with the children on the spectrum and it is knowing how to pitch it. So, say for instance I can hear H upstairs and he is beginning to have a wobble and he is getting a bit argumentative with me and I'm thinking OK well you are normally really placid, and you are getting gritty*

> *with me, so I ask him if he has had a poo, a wee or is he hungry? Usually it will be one of those three."* Rianna.

4.7.4 Environmental adaptations

Focused codes	**Axial code**	**Theoretical code**
Changing the house	Environmental adaptations	Contributing to: ADAPTATION TO PAST AND FUTURE ADVERSITY
Moving to be nearer to family		
Home-schooling		
Creating planned strategies		
Not going to certain places		
Getting out of the house		

Table 28 Evidence pathway for the axial code Environmental adaptations.

The next axial code is environmental adaptations. The mothers made significant changes to their surroundings and lifestyle so that their child had an environment that was more supportive to their wellbeing. The first code in this area involves some elements from the previous section, in that the mothers desire to protect the child means they are expert at knowing the triggers and how to avoid them. Leading on from this, the mothers control their child's environment by creating a carefully curated experience for their child, by organising activities outside the home that are well thought through. Therefore, the code creating planned strategies was applied:

> *"…we went for five days to Italy because it was booked last year so I actually didn't expect that we were going to go to Italy this year but the lockdown was lifted up so we went for five days and we had quite a good time there he was stressed at times but it would have been worse if Venice was the normal Venice, but before because of the lockdown there were not so many tourists there, it was fairly calm I have to say, still lots of people but not the usual amount they said. We had a good time there, but always we have to think about what we are going to do and how he is going to cope."* Nina.

There are some children for whom being indoors all of the time is not helpful. Those children often feel calmer being out in nature. The code getting out of the house, represents this need:

> *"We try to get him out as much as possible as he likes to be outside, and we try and include the other children. He likes to go to the forest a lot and be out exploring, so that's how we deal with it, just to get out of the house. Sort of try and focus on him being outside and enjoying himself rather than being indoors and going crazy."* Petra.

There are, however, places that the mothers know are distressing for their children, and so part of controlling the environment and avoiding future adversity, involves not going to certain places. This description has therefore, been applied as a focused code:

> *"J had a meltdown in the airport because we went into the toilets, and he didn't like the sound of the hand dryers. It hurt his ears. So now we ask to use a bathroom with no hand dryer."* Olivia.

Many of the participants had so many difficulties in getting the school support that they needed, that they choose in the end to home-school. So, the code home schooling was choosing to bring forward in the analysis as a focused code:

> *"…there was a window that you could see in, and every time T saw me, he would run to the window happily seeing me and they would push him to sit him down and wait until they told him to get up. I hated it, I hated what they did that was when I had found someone else who was doing Son Rise. I knew that I was going to take him out of school. I didn't discuss it with anyone because I knew the resistance the women there who run it thought she knew everything was angry about being asked any questions."* Bianca.

In addition to this there were some mothers who radically changed their homes to accommodate their child's needs. The code changing the house reflects this:

> *"…every time that something happens, and you have to change everything that you do at home, every routine that you have changes, even things in your house, you have to move things about so things aren't here anymore, things aren't there every little change in him, you have to change your life according to that."* Georgia.

Several of the participants moved house in order to be nearer to the wider family. The code moving to be nearer to family applies:

> *"…we moved so the girls were both born in L, and we lived in E, but things started getting difficult because I had two young children, and they were a lot to manage so I persuaded my husband to move back to S where my family are so that helps."* Diana.

4.7.5 Practical strategies

Focused codes	**Axial code**	**Theoretical code**
Getting diagnosis to get support	Practical strategies	Contributing to: ADAPTATION TO PAST AND FUTURE ADVERSITY
Using therapies		

Table 29 Evidence pathway for the axial code Practical Strategies.

The next axial code is practical strategies. This involves things that parents did either to get more support, or to improve their child's condition. The first focused code is called getting diagnosis to get support:

> *"…all I wanted was a diagnosis so that I could then get him support."* Rhianna.

Several of the participants looked for therapies to use with their child so that their child improved their skills, abilities, and physical condition. The focused code applied for this is using therapies:

> *"I suppose that I am constantly looking for ways to help them. I try to keep medications as natural as possible and so have educated myself in natural remedies like aromatherapy and medicinal use of essential oils, Eden energy medicine is useful to them too to help regulate them. I like doing yoga and so will sometimes try to get them to engage with that. I have run numerous different therapy programs to help with things like speech. In the end with K, we needed to stop trying different therapies and go for facilitated communication as he has oral dyspraxia and so can't make his mouth make the shapes of the words. He is doing really well with that."* Helena.

4.7.6 Emotional resources

Focused codes	**Axial code**	**Theoretical code**
Accepting the child as they are	Emotional resources	Contributing to: ADAPTATION TO PAST AND FUTURE ADVERSITY
Feeling proud of their child		
Loving their child		

Table 30 Evidence pathway for the axial code Emotional resources.

The final axial code under the fifth theoretical code is emotional strategies. These involve ways that the participants use their emotions to keep going. The first of the focused codes is accepting the child as they are:

> *"I wanted to understand her more and it's just coming to that place of acceptance and knowing that this is who she is, and she is wonderful the way she is."* Diana.

Other emotional strategies involved holding onto the parts of their child that they were proud of. So, the focused code is feeling proud of their child:

> *"It's a gift, F's brain is a gift, she has got a very high functioning mind. So, I go along to the parents evening on a Friday, and they said she is expected to get three A's at A level and I am like Oh, so I am quite happy with that. So yeah, it is kind of focusing on the positive and then managing the not so positive… now I am at the very proud mum stage." Cara.*

The last focused code in this section is loving their child. Love enables the parents to do all sorts of things. It is the main motivating factor for everything else:

> *"…loving someone and knowing that you might not necessarily get anything back from them, they might never – well not never, but they may never be able to do anything for you. But yeah, just coming to that place of unconditional selfless love…yeah, I suppose."* Diana.

4.8.0 Theoretical code seven: the resilience signature

The last theoretical code is 'resilience signature'. This is different to the other codes in that it appeared only at the comparative stage and was the result of the reflexive review of the memos. As part of the data analysis method, there was a process that involved comparing chunks of text in one interview with a comparative piece from another interview. It became clear that different participants faced the same adversity using different methods. An example of this is when Cara was faced with her child having a meltdown, she stood back and waited, whereas Monica approached her child and used herself as a weighted blanket to prevent him from continuing to throw bricks. So, there were clear differences between the ways that the participants dealt with the challenges. However, the next part of the process involves comparing a portion of data from within one interview with another portion of data from the same interview. What emerged from here showed that each participant dealt with their situations in ways that were congruent with themselves. An example of this is Alicia, who often used consultation with health professionals as a way to resolve challenges:

> *"It was all really complicated because she failed her hearing test when she was little, so we knew that she had glue ear and every time that we went to the hearing specialist at St Helens, it always seemed to be at a good point in her hearing and then two weeks later she would get a cold and lose her hearing. So, we would've been discharged and then we would go back to the GP, and he would say Oh her hearings terrible so we will get you back on this waiting list and it was this endless cycle of trying." Alicia.*

Later in the interview:

> *"…she got put on the SEN register for kind of concentration and focus and being able to organize her work and those kinds of issues and I was still saying 'what is the issue what is the underlying issue?' Do I take her to the GP do I take her to an Ed Psyc all of these sorts of things'. I took her to the GP once and the GP just said Oh the school would tell you if there was really a problem, go away. We took her to an Ed Psyc, and they said she has a massive*

> *range of skills she was in the top 99.8 centile for somethings, and she was in the bottom 0.2 centile for other things and the Ed Psyc said that she had never seen a profile like it." Alicia.*

Another clear way that Alicia dealt with her challenges was by creating a lot of practical strategies that supported her child's independence:

> *"I get up and have a shower, by which time four different alarm clocks have gone off in her room including one that goes light so that she is hopefully awake by the time that I knock on her door and say are you awake and I've had my shower and we are trying very hard because she is now 19 to not manage her out of bed and into the shower and getting dressed and everything else so we have put in place a lot of routines over the last few months which are around her being organized for herself because she is desperate not to be treated as a child." Alicia.*

Then later in the interview:

> *"…she is now kind of much more in control of what is going on in her own head [….] learning how to cope with the situations, I'm not needed on a minute-by-minute day by day basis in quite the same way so there are times you know where I kind of jump in and say let's sort out your routines because that's such a big thing for her." Alicia.*

These observations led to this memo:

> *"In comparing the interviews with each other, it is apparent that the participants are different to each other but that they have a congruency with themselves. Alicia is really task orientated, whereas India relies on her social skills. Bianca is very dominant on cognitive reframes and activity whereas Fiona has a strong faith which both is a source of comfort and structure to her life. I find it odd that I am surprised by this discovery as surely it is a well-known fact that people are different to each other, but that personality traits are enduring!"*

This led to the theoretical code of resilience signature as a way to capture the uniqueness of each participants way of responding.

In summary, the third research sub-question asked in what ways do mothers of children with autism demonstrate resilience. This question's responses were key in revealing the major findings of this study, due to the novel nature of the mothers' activities. The idea that rest should follow adversity management is new in relation to the conversation on resilience. It is puzzling that the theories of resilience do not include this element as part of their models as it seems like common sense to rest and recuperate after a challenging event, but they don't and so this is considered a novel finding.

Another novel finding is that after this recovery period, the participants talked about how they engaged with activities that would lead to adaptations that were both related to the event that had occurred and a potential future event, in an attempt to prevent a repeat performance. By linking the activity to both the event that has occurred and a potential future event, the mothers resilience becomes a circular process rather than a linear one. Lastly, the mothers all demonstrated resilience using the cyclical process just described, however, they all had their own style of operating which led to the construct of a resilience signature, which means that each person was congruent with themselves, but different in style to others. This too is a novel finding, which possibly explains why everyone defines resilience differently.

4.9 Summary of the findings in relation to the overarching research aims.

Sub-Question number	**Question**	**Theoretical code**
One	What does the word resilience mean to mothers that have children with autism?	Resilience defined
Two	How does being a parent of a child with autism affect the mother's resilience?	Adversity Adversity management Adversity aftermath
Three	In what ways do mothers of children with autism demonstrate resilience?	Recovery from adversity Adaptation to past and future adversity Resilience signature

Table 31 Application of the codes to the research sub-questions at the highest level.

The findings show that seven theoretical codes were generated from the data in response to the research questions. The narrative from all the participants clearly demonstrates the ongoing resilience of these mothers and the wisdom that they have found in knowing how to take care of themselves and their child(ren). Their commentaries show the organizing of priorities to handle the adversity first and then dealing with their emotions later, followed by self-care through resting and time out before any adaptation to avoid future adversity. The importance of this process to their continued resilience cannot be overstated as it was the same for each participant. This flies in the face of the popular view of resilience of being able to just carry on without even flinching. Additionally, although the process of resilience had the same stages for each participant, the method was different with each participant having their own style of responding which was coded as a resilience signature. Together these findings inform the conclusions discussed in the next chapter in response to the overarching research aim of exploring, to what extent, do mothers of children with autism, experience resilience, given the challenges and stigmas of parenting their child?

CHAPTER 5: DISCUSSION

5.0 Introduction

The purpose of this study has been to provide a model of resilience that can no longer be utilised as a stick to beat people with, or used in a one size fits all fashion. Its aim has been to find a kinder version of resilience that is inclusive of everyone. As we move through the Covid-19 pandemic, it is clear to me that this is now needed more than ever, as the consequences of two years of lockdowns are becoming apparent.

The study has focused on a group of people who are normally considered to not be resilient due to the ongoing challenges of their lives and the high proportion of mental ill health reported (Lounds Taylor and Warren 2012; Baylot Casey et al. 2012). Additionally, my own experience of being a part of this community, led me to have an interest in finding out more, as I have always considered myself to be resilient. So, stemming from my desire to help others, coupled with the knowledge that I don't know everything about how to be a mother of a child with autism and to stay resilient, led to the commencement of this project and the formation of these research aims.

Therefore, the study employed the following overarching research aim:

> To what extent, do mothers of children with autism, experience resilience, given the challenges and stigmas of parenting their child?

This aim was then broken down into three sub-questions:

1) What does the word resilience mean to mothers that have children with Autism?
2) How does being a parent of a child with autism affect the mother's resilience?
3) In what ways do mothers of children with autism demonstrate resilience?

The main thrust of these research aims and questions, did not change much during the course of the study, with the major changes merely being alterations to make the questions more clearly stated. From the semi-structured interviews came rich data that led to the findings presented in the previous chapter, that answer these questions. Emerging from the data was an explanation as to how the mothers of children with autism remain resilient in the face of enduringly challenging situations. In this chapter I have synthesized the findings of the data analysis process, with existing literature on resilience and proposed a new substantive conceptual model of resilience based on the coding structure previously described in Chapter 4. This new model will elucidate the process of resilience and demonstrate why other models have been unsuccessful in finding consensus among researchers and acceptance by the general public.

This section, therefore, builds on the findings demonstrated in the previous chapter to take each theoretical code and to compare that with the literature expounded in chapter 2. Also, where the findings have broken new ground, further literature has been brought in to position the novel findings within the wider literature on the topic of resilience. The chapter begins with an overview of the coding structure created through the analysis of the data collected from the participants. We then drill down into each theoretical code to examine the findings and situate them within the current knowledge on the topic of resilience. Then there is a section titled 'implications for theory and research which takes the theoretical codes at the highest level and reviews them in the light of the literature on disability, mothering, and resilience. After this, the new conceptual framework model is presented, with a demonstration of how this has been built from the codes, again this is compared with the literature. This model is then critiqued to ensure that it meets a sufficient level of rigour to be proposed as a new model of resilience.

5.1 Overview of the coding structure

FOCUSED CODES	**AXIAL CODES**	**THEORETICAL CODES**
RESEARCH QUESTION ONE		
Not knowing how to define resilience	**Problems with the construct of resilience**	**RESILIENCE DEFINED**
Finding it hard to describe resilience		
Using analogies		
Not liking what they think resilience means		
Responding to challenge	**Responses to challenges**	
Keeping going		
Resisting the challenge		
Recovering		
Preparing and adapting	**Resilience deconstructed**	
Resting		
Being human		
RESEARCH QUESTION TWO		
Waiting years to get a diagnosis	**Struggling with getting a diagnosis**	**ADVERSITY**
Mourning the lost child		
Going to tribunal	**Struggling with getting the correct support**	
Getting no support after the diagnosis		
Providing paperwork to get support		
Meeting with the school		
Meeting with professionals		
Feeling abused by the system		
Fearing the future		
Having no sense of danger	**Dealing with challenging behaviour**	
Having a meltdown		
Wandering/running off		
Breaking things		
Being violent		
Getting into trouble with the police		
Feeling isolated		

Bumping into people		
Not accepting Mum's viewpoint	**Dealing with other people's negative reactions**	
Saying nasty things		
Staring		
Being blamed for child's behaviour		
Having an epileptic fit	**Dealing with the physical challenges of autism**	
Having a restrictive diet		
Having sensory issues		
Losing words		
Having problems with digestion		
Seeing my child suffer		
Being awake at night		
Using intuition	**Cognitive task**	**ADVERSITY MANAGEMENT** **ADVERSITY MANAGEMENT CONT'D**
Thinking quickly		
Not knowing what to do (but doing something anyway)		
Fighting the system	**Practical task**	
Keeping the children safe		
Getting on with it		
Getting him out		
Getting him home		
Lying on child to calm him/stop him lashing out		
Asking strangers for help	**Social task**	
Asking partner to help		
Standing back and getting everyone to wait until they had calmed down		
Feeling depressed	**Emotional response**	**ADVERSITY AFTERMATH**
Crying		
Feeling stressed/ worried		
Feeling wiped out		
Feeling guilty		
Shaking		
Ranting to family	**Social response**	
Talking to friends		
Asking forgiveness	**Reconnecting with the child**	
Sitting with them until they were calm		
Doing some fun things together		
RESEARCH QUESTION THREE		
Taking a break	**Resting and self-care activities**	
Listening to music		
Going for a walk		
Doing mindfulness		
Doing yoga		
Watching trashy TV		
Using work/study as downtime		
Eating well		
Having a bath		
Doing make-up		
Being reassured	**Social activities**	

Seeing friends		**RECOVERY FROM ADVERSITY**
Family support		
Socializing during the day		
Spending time with husband/partner		
Sustaining religious festivals	**Spiritual activities**	
Going to the synagogue/ Mosque		
Praying giving the day structure		
Reassessing everything	**Cognitive activities**	
Deciding she could manage by herself		
Meaning making		
Choosing your attitude		
Going to CBT		
Celebrating herself		
Journaling		
Studying		
Stopping looking for fair		
Remembering you are not to blame		
Seeing the upside of autism		
Understanding her child’s challenge		
Learning about autism	**Educating yourself**	**ADAPTATION TO PAST AND FUTURE ADVERSITY**
Joining Facebook support groups		
Befriending other ‘Autism parents’		
Talking to specialists/attending conferences/ workshops		
Using charities like IPSEA and SENDIAS		
Working with other children with autism		
Sending older son to boarding school	**Financial resourcing**	
Paying to go private		
Needing to work to pay bills		
Knowing the triggers	**Protecting the child**	
Being one step ahead		
Being the eyes and ears for my child		
Changing the house	**Environmental adaptations**	
Moving to be nearer family		
Home-schooling		
Creating planned strategies		
Not going to certain places		
Getting out of the house		
Getting diagnosis to get support	**Practical strategies**	
Using therapies		
Accepting the child as they are	**Emotional resources**	
Feeling proud of their child		
Loving their child		
Memos		**RESILIENCE SIGNATURE**

Table 32 Overall coding structure.

5.1.1 Theoretical code one: Resilience defined.

The first research sub-question in this study asked "What does the word resilience mean to mothers that have children with autism? In response to this question were three axial codes that were collated under the theoretical code 'resilience defined'. These were Problems with the construct of resilience, responses to challenges and resilience deconstructed. To explore these further, we shall examine them separately and compare them to the literature reviewed in chapter two.

Problems with the construct of resilience

With some of the participants the problem was easy to identify in that they declined to answer the question as they said they didn't know. This means that either they had never heard of resilience before, or they had, but didn't know what it meant exactly enough to generate a definition, or that they had heard the definitions given but rejected them and not replaced them with a new idea. Others had a go at defining resilience with some using an analogy to help them. This situation reflects the current situation in resilience research, in that there are almost as many definitions of resilience as there are research studies on the topic (see table 1), with no consensus of agreement (Herrman et al., 2011; Meredith, et al., 2011).

There were others who felt they understood resilience but did not like what they thought it meant. This supports Held (2004), who talked about the "tyranny of the positive attitude" and Peterson et al., (1998) who stated that the exhortion to be positive under all circumstances adds to the burden of adversity as an individual feels judged at not being able to adopt what is promoted as the 'better attitude'.

Responses to challenges

This code is the area where the voices of the participants mostly reflected the current conversation around resilience. Their comments related to 'keeping going, resisting challenges, and recovering'. This is consistent with models of resilience that talk about resistance and recovery (Carver, 1998; Ivtzan et al.2016). However, Ivtzan et al., (2016) also talked about reconfiguration and post traumatic growth, which interestingly none of the participants mentioned when asked to define resilience although they did mention it in other places.

Glaser and Strauss (1967) stated that creation of a new theory requires the researcher to go beyond the public discussion of a topic. By asking the participants what their definition of resilience was, mostly just reiterated the current public discussion, however some participants started to break down the construct, which took the findings beyond the public discussion, to break new ground. here.

Resilience deconstructed.

Contained within this code was the idea of preparing and adapting. The concept of adapting is not new to resilience research (Joseph, 2011; Lines et al, 2020; Reivich, & Shatté, 2002), however, the idea of preparing to ward of a future adversity is new. Previous research on resilience has focused on a linear process that runs between the occurrence of the adversity to a point in the future which is described as the outcome (Collazzoni et al. 2020 ; Rutter, 1987; Zautra, Hall & Murray, 2010). However, the findings in this research suggest that there is a motivation to adapt that is fuelled by the possibility of a future adversity. This is potentially clearer in the minds of mothers of children with autism, due to it being a lifelong, incurable disorder (Fletcher-Watson & Happé, 2019).

Another novel aspect of this theoretical code is the idea of resilience including the act of resting after adversity. This is almost the antithesis of resilience research which talks about resistance. The idea of resting is more consistent with Neff's (2011, pg. 116) idea of suffering being pain multiplied by resistance. What Neff suggests is that when pain occurs that we should instead accept the event rather than resisting it, and that being kind to ourselves in not resisting the pain lessens the suffering. The concept of resting featured several times in the stories of the participants and so will be further discussed in the section on recovery later in this chapter. The idea of being human is also supported by Neff's (2004) self-compassion theory. Neff argues that suffering is the 'tie that binds' us all together in common humanity. Acknowledging experiences of suffering and being permitted to express those emotions was for some of the participants an important part of what resilience meant to them.

5.1.2 Theoretical code two: Adversity

The second theoretical code of adversity reflected the participants clear ideas that there were things occurring in their lives that they found challenging. The axial codes attributed under this theoretical code detailed experiences of struggle and things that had to be dealt with. These related either to things that their child did as part of their autistic symptoms, things that other people did or said in response to their child, or the battle to get the diagnosis and support that they felt their child required. Adversity was discussed by all the participants who had a clear articulation of the adversities that they faced. They described experiences such as their children having meltdowns or wandering off, breaking precious possessions in the house, or having a seizure. All of the participants stated that being a parent of a child with autism was challenging and that it had changed their lives. Lines et al., (2020) argued that what constitutes an adversity was subject to personal interpretation, however, there was a significant consensus between the mothers as to the sorts of things that they found challenging. Using individual semi-structured interviews rather than a focus group meant they each arrived at their conclusions separately, as they were not aware of each other's responses, meaning that the consensus of opinion that was found between them, adds weight to the argument that these events are indeed adverse for the mothers and potentially brings a level of objectivity to their claims.

Riley and Masten (in Peters, Leadbeater & McMahon, 2005 pg. 13 - 25) defined adversity as "experiences that have the potential to produce undesirable outcomes by disrupting normal functioning.", however, it was noticeable that the very act of struggling and dealing with challenging situations, some of which were 'life and death' situations, required the mothers to perform 'at the top of their game'.

The early theories of resilience used hindsight to define adversity arguing that adversity is defined as such, because it is an event or a series of events, that would be expected to lead to a negative outcome (Luther & Cicchetti, 2000). However, the participants never talked about an outcome, meaning that for them adversity had to be defined by their own subjective interpretation in the way suggested by Lines et. Al., (2020).

5.1.3 Theoretical code three: Adversity Management

The theoretical code of adversity management denotes the mothers reactions to adversity. In each case, when the mothers were faced with adversity, they responded with action. The axial codes show the types of action required to manage the adversity and these were cognitive task, practical task, and social task. In every situation described by the participant, the actions required to manage the adversity preceded any physical or psychological downturn:

This puts an extra step of adversity management in the reaction to adversity that involves resolving the situation first and then feeling the feelings afterwards. This concept that the adversity must first be managed before the emotional response is supported by biological psychological theory. This would suggest that in adversity the fight, flight, freeze, or fawn mechanism occurs (Walker, 2013) . This ignites the sympathetic division of the autonomic nervous system. The norepinephrine released by the sympathetic nervous system, accelerates the heartbeat, relaxes the airways, stimulates sweat glands, dilates the eye pupils. In addition, digestion is inhibited along with other functions like the ability to produce tears from the lachrymal gland. It is not until the aftermath when threat has passed, that the body changes over to the parasympathetic division, which enables reactions like tears to occur and for the heartbeat to slow and equilibrium is restored (Breedlove, Watson & Rosenzweig, 2010).

In every story of challenge that the mothers told, there was also a description of how they had managed to overcome it. The original research by Garmezy and Nuechterlein (1972) concluded that some children were resilient, and others were not, with the difference being down to risk and protective factors. Other research disagreed with this view, with Masten (2001) suggesting that resilience was 'ordinary magic' and Zautra (2003) suggesting that a resilient response was the modal outcome. However, Garmezy's (1991) observation somehow seems to have become the dominant discourse leading to the idea that some people are not resilient, or that they are not doing enough to be resilient. This has created a binary situation where people can be sorted as being either resilient or non-resilient, an approach which has problematic consequences for those deemed non-resilient (Held, 2004).

When this research began, I had accepted this idea that some people were resilient and others not resilient. However, it became quickly obvious that all of the mothers were champions in overcoming adversity and were still completely engaged with the activity of mothering their children. Part of the recruitment criteria specified that the mother's child had to have held a formal diagnosis of autism for at least five years. This was important to ensure that the mothers had been mothering a child or children with autism for some time and so would have plenty of experience of life in these circumstances. This means therefore, that this research supports Masten (2001) in suggesting that resilience is 'ordinary magic' as all the participants were in my opinion resilient.

5.1.4 Theoretical code four: Adversity aftermath

The theoretical code of adversity aftermath covers the events that follow the successful management of the adverse event. Once everyone is safe and everything is over, the mothers found that their own reaction occurred. This led to the axial codes of emotional response, social response, and reconnecting with the child.

This concept that emotional distress follows an adverse event is supported by the Power Threat Meaning Framework, which asks a person 'what has happened to you?', rather than 'what is wrong with you?' (Johnstone & Boyle, 2020). This denotes a change from the standpoint that being distressed is wrong and instead sees it as a natural consequence of adversity. This supports the construct of this stage existing within the concept of resilience.

An additional point to consider, is that when a person is reacting to an adversity like death of a loved one, that an aftermath demonstration of upset is expected. To cry when someone dies is considered to be a healthy way to deal with that adversity (Kubler Ross & Kessler, 2014). However, that rationale does not seem to permeate through to other adversities within resilience research.

These feelings of upset never occurred during the adversity, they always came afterwards. This supports the research by Carver (1998), that stated that the majority of resilient responses follow a downturn in wellbeing. So there needs to be an opportunity for this to occur and then for the participants to find their way back.

One of the original recruitment criteria stipulated that the mothers should not have a mental health diagnosis themselves. This decision was taken for two reasons, firstly, some thinkers conflate resilience with mental wellbeing (Pemberton, 2015) An example of this conflation, is The Penn resilience program (Gillham et al., 2007), which claims that it can reliably prevent depression and anxiety in those that engage with the programme. The program is based on CBT principles, which supports its claim that it can help to avoid depression. Unfortunately, this approach makes it seem as if resilience and maintained positive mental health are the same thing. The second reason was that mothers of children with autism have high rates of mental illness (Baylot Casey et al., 2012; Lounds Taylor and Warren, 2012), which led to my concluding that those mothers would not be resilient and so not be able to contribute. However, even though the recruitment criteria was advertised, three of the participants disclosed that they either had, or had previously had, a mental health diagnosis, part way through the interview. It would have been possible to stop the interviews at the point that these diagnoses were shared, however, it was decided that seeing as the participants were clearly demonstrating resilience in terms of task completion in their daily lives, that the interviews could continue. There was only one interview, where the participant became tearful, and at that point, the interview was paused, and the participant given the opportunity to withdraw. She, however, was determined to finish the interview. This challenges the idea that a downturn in a person's mental health can mean that they are not resilient. This view of resilience levels is supported by the research by Reid and Kampman (2020) who suggested that resilience exists on a continuum that ranges from surviving through coping into thriving, not that some people are resilience and others are not. Looking at the adversity aftermath code of resilience, it is possible that the emotional reaction to adversity can become a situation where a person might be diagnosed with a mental illness, however in this research even those participants who had a mental health diagnosis were still able to function as mothers at a very high level.

Seeking social support by ranting to family or talking with friends is consistent with research into coping mechanisms (Clauss-Ehlers, 2008). Dowrick, (2008) suggests that individuals can flourish in life despite feeling distress in the current moment by drawing on existing social support and affectional bonds. Another key aspect that supports the idea of seeking social support is the wellbeing models that include positive relationships as part of their factor structure such as the PERMA model (Seligman, 2011) and the Positive wellbeing scale (Ryff & Singer, 2008).

The last finding in this section is that reconnecting with the child is important in the aftermath of an adverse event. Doing a fun activity or just sitting and having a cuddle with the child is key in maintaining a positive relationship with that child. This supports the findings of Walsh (2003), that stated that family connectedness was an important aspect of resilience.

5.1.5 Theoretical code five: Recovery from adversity

The next theoretical code is recovery from adversity. The findings in this section are key, because in the literature, the recovery from an adverse event is often described using personal traits as if resilience is something to be. The findings in this research suggest that resilience is something to do rather than be. Therefore, the axial codes that support this theoretical code are based on the activities that the participants engaged with to recover. These activities occurred after the intensity of the aftermath had passed and were resting and self-care activities, social activities, spiritual activities, and cognitive activities.

The first key finding in this section refers to the need to rest, this idea does not appear in any of the research in resilience and so can be considered a novel finding. The participants suggested that the rest facilitates the peak, which is important to note as often the act of resting is seen as a lack of resilience. This concept is supported by the sport psychology theories of burnout, which suggest that chronic stress can lead to emotional and physical exhaustion, reduced sense of accomplishment and potential drop out. In sports psychology, one possible cause for burnout is overtraining, which is an imbalance between training and recovery periods. Once the athlete has reached a stage where the normal rest and recovery period do not facilitate their usual level of performance on return to training, then they are said to have reached burnout (Williams & Krane, 2021). Therefore, if dealing with challenging behaviour requires a parent to perform at the peak of their ability due to the degree of adversity or potential adversity, then it would stand to reason that they cannot do that indefinitely, unless there are inserted some periods of rest.

When an individual suffers an adversity such as a physical illness, there is an expectation that the recovery period would involve some rest. Indeed, the sociological theory of the ‘sick role’ (Parsons 1952) suggests that the period of rest is part of the recovery which facilitates the resuming of all the normal duties of life (Giddens & Sutton, 2013). However, there is no application of this principle of justified rest applied to other adversities.

It was clear from the number of activities listed by the participants that resting was an important part of keeping them able to continue dealing with the challenges of parenting a child with autism. As not only do they take part in activities that provided them respite from their caring responsibilities, but it was one of the top pieces of advice that they said they would give to other parents whose child had just been diagnosed with autism.

These activities were divided into resting and self-care activities, social, cognitive, and spiritual activities. These activities are some of the ones recommended by the literature on resilience as being part of the process to raise levels of resilience. Research by Chiesura (2004) suggested that spending time in spaces incorporating natural greenery was good for a person's wellbeing, this means that the participants who went out walking in the countryside were aiding their recovery. Another way that the participants recovered was through cognitive activities such as working on changing beliefs that are upsetting them through counselling methods such as CBT (Neenan, 2018).

Meditation is another self-care activity that some of the participants used to recover. Mindfulness meditation is described as being present and paying attention on purpose to the present moment, without judgement (Kabat-Zinn, 1994). Our past can be loaded with regrets and our future weighed down with worries, but the present moment is free of all that. By being mindful, the participants can create a pause in their life (Chaskalson, 2014). This provides a rest, because it allows an individual to stop trying to change anything (Kabatt-Zinn, 1994).

Additionally, taking time to engage in religion and spiritual activities, also provided a recovery space for the participants. This was helpful for a number of reasons. Firstly, it provides a sense of purpose in life in terms of understanding our existence and significance (Steger & Frazier, 2005). It also provides a sense of belonging to something that is bigger than themselves and that service within that aligns us with that greater purpose (Seligman et al, (2006). Religion can also encourage practices that are also linked to wellbeing, such as gratitude (Emmons, 2008), forgiveness, (McCullough & Worthington, 1999) and hope (Snyder, 2002)

All of the mothers in the interviews spoke lovingly of their children. By focusing on love and celebrating their child, the participants are focusing on 'meaning making'. Another part of this activity is to create meaning around their role in caring for the child and the importance of what they are doing. Knowing that the child needs them to be there for them, helps them to keep going (Deci & Ryan, 2000).

Creating these positive emotions has another function, in that they facilitate new thought repertoires and behaviours. According to Fredrickson's (2004) broaden and build theory, it is the positive emotions that enable adaptation by starting an upward spiral of feelings. As can be seen in the following diagram, the positive emotions enable a broadening of thinking, which allows the building of lasting personal resources which improves health, which then comes full circle back to positive emotions and so the upward spiral continues:

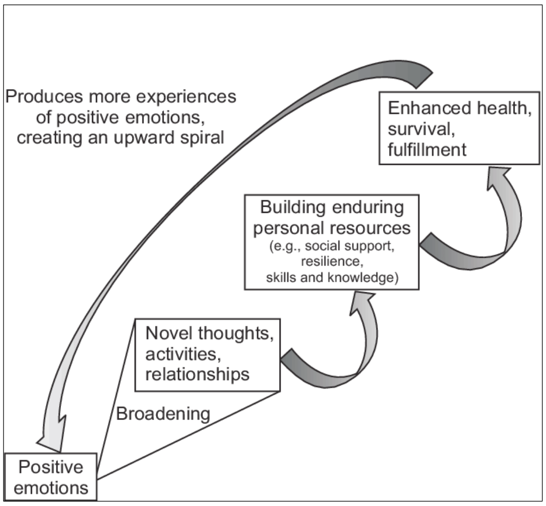

Figure 11 Fredrickson's (2004) Broaden and Build model.

This demonstrates the importance of what the participants have chosen, in seeking time to do activities that they find pleasant. It means that those activities are more than just 'nice things to do', they are fundamental to the next stage in the participant's resilience.

5.1.6 Theoretical code six: Adaptation to past and future adversity.

By the time that the participants have engaged with these activities it would seem that they have recovered their wellbeing and are able to carry on with the task of mothering their children. Theoretical code six, adaptation to past and future adversity is a key finding because it changes the process of resilience from a linear construct in a cyclical one. The starting place for the axial codes in this section is the motivation of the mothers to avoid a repeat of the adversity that has just occurred. So, the mothers engage in upskilling in order to improve their chances of protecting themselves and their child(ren) from the same happening again. These activities are described in the axial codes and involve educating themselves, financial resourcing, identifying how best to protect their child, making environmental adaptations, creating practical strategies, and finding emotional resources through reframing their attitude towards their child and their child's difficulties. This activity is supported by Snyder's (1994) hope theory which suggests that people believe that they can create a route to their desired goal (pathways thinking) and that they possess the required motivation to use those routes (agency thinking). Having put the past adversity behind them, they are now in a place where they can decide to manage things differently and also the hope that they can achieve that.

As autism is currently constructed as a lifelong incurable disorder (Miller et al. 2010) the participants know that other similar adversities like the ones they have already experienced are likely to reoccur. Therefore, it is clear that it would be advantageous to do whatever is possible to improve their adversity management skills. This is a more complex part of the process of the participant's resilience, because it applies to both the past adversity and the potential future adversity. It is about acknowledging that the past adversity has occurred and preparing for the possible future adversities. The participants spent time thinking about the event that had occurred as a way to improve their management of future events. They asked themselves, 'what could I have done differently?'.

So much of the participants lives involves the environment either causing the adversity or supporting them to deal with the adversity that it would be easy for the participants to feel dependent on whether their environment treated them with benevolence or malevolence. This is consistent with Bronfenbrenner's (1981) ecological systems theory. Engaging in the activities described by these axial codes situates the locus of control internally within the participants, which Burns & Anstey (2010) argue is conducive to increased resilience.

Education is one of the ways that the mothers can improve their level of knowledge about autism. By learning more about autism not only can they help themselves to be more proficient at looking after their child, but they can also develop their social capital which can then help to increase their cultural authority (Bourdieu 1997). This becomes useful when dealing with professionals who are not being helpful in providing either a diagnosis, or the desired support for the child. By making connections with other parents of children with autism, the parents are building social capital. These networks of parents have a strong sense of shared identity in the challenges of raising their children. They are a source for increasing individual resources that can be utilized to help their child (Fulcher & Scott, 2011).

The relationship between resources and resilience is also covered by theories of work engagement. Schaufeli & Bakker's, (2004) work engagement model is called the JD-R model and suggests that burnout and turnover intention is predicted by the demands of the job exceeding the resources available. Jones and Fletcher (1996, pg., 34) define job demands as "the degree to which the environment contains stimuli that peremptorily require attention and response…the things that have to be done." When looking at the demands of being a mother of a child with autism, it can be seen that this definition still works, as some of the tasks that need to be done are related closely to the child’s continued safety, and so therefore constitute a lack of choice for the mother as to whether they engage. It is possible that being a mother of a child with autism is a more extreme version of the job demands though, as the consequences of not engaging in a job would result in the individual being fired, whereas the consequences of not engaging for a mother is potential injury or death of their child.

Schaufeli & Bakker’s (2004) model suggests that job resources are physical, psychological, social, or organizational parts of the job that either reduce the job demands and the psychological and physiological consequences of those demands, facilitate getting the job done or lead to personal growth, learning and development. This shows the importance of the activities that the participants are choosing to help them to continue in the mothering of their children.

The theories on work engagement have been developed further by some research that was carried out by Ouweneel, Le Blanc and Schaufeli (2010) who studied student engagement. They argued that the definitions applied by Schaufeli and Bakker’s (2004) model as to the demands of a job would also apply to students who also have to engage with tasks such as submission of assignments. Ouweneel et al (2010), however, added an extra element to the model using Fredrickson’s (2004) broaden and build theory and Hobfoll’s (1989, 2002) conservation of resources (COR) theory. They concluded that there was a significant relationship between Fredrickson’s (2004) broaden and build theory with conservation of resources theory (Hobfoll, 1989, 2002) and student engagement. Research by Gorgievsky and Hobfoll (2008) suggested that those personal resources were things like hope, self-efficacy, optimism, and resilience. According to COR theory, people are constantly trying to accumulate resources and that eventually once sufficient resources are accumulated that this will lead to engagement (Hobfoll, 1989, 2002). One of the resources listed is self-efficacy, which is defined by Bandura (1997, p.3) as “belief in one’s capabilities to organise and execute the course of action required to produce given attainments. That belief in an ability to mother your child efficiently is part of the process of resilience. The ‘given attainment’ described by Bandura (1997) is that all the participants wanted to improve their child’s life, and how they work tirelessly at what they see as their purpose in life:

One part of Schaufeli and Bakker’s (2004) model that has not been discussed yet is personal growth. There are some personal resources that an individual can build in the course of their life that improves their ability to function to a higher level than it was before the adversity occurred. This means that during the recovery the individual finds benefits in their journey (Affleck & Tennen, 1996; Joseph, 2011). This improvement in functioning and the benefits found, is referred to as post traumatic growth. This is referred to as reconfiguration resilience, which is recovery to something that is different and improved on the pre-trauma levels of being that accommodates the trauma as part of life's experience (Ivtzan, et al. 2016). If a participant was to experience personal growth, it would provide them with a greater buffer of wellbeing should adversity strike again (Seligman, 2011).

The concept of post traumatic growth brings into sharp focus the habit that people have, of labelling events as good and/ or bad. So, when a person gets what they want, they decide that it's good and then when they don't get that, or they get something they didn't want, then it is bad. However, if something happened and it led to post traumatic growth so that life continued in a way that they decided was better, then is it all still considered bad (Kashdan, Biswas Diener & Philos, 2014; Lazarus, 2003)? This realisation has led to what is now known as the second wave of positive psychology, which suggests that the darker side of life is embraced (Ivtzan, et al., 2016). If a slower recovery and post traumatic growth is possible then it begs the question as to whether it is better to resist or immediately bounce back from adversity, or to take time in recovering so that there is opportunity to experience this enlightening journey (Joseph, 2011).

Financial resourcing occurred, when the participants used their money to facilitate appointments with professionals, or to create environmental changes to their accommodation. Knowing that further adversity is possible, also led to the participants trying to safeguard the lives of their other children. Therefore, the resourcing and preparation described as part of adapting to the adversity that occurred, has a dual purpose as it relates not just to what has already happened, but it also relates to the possibility of it occurring again.

Kristin Neff (2011) in her study on self-compassion talks about suffering being a part of the human condition, which means that adversity in the future is a part of life that should be expected. This means that life will consist of continuous cycles of resilience.

5.1.7 Theoretical code seven: resilience signature

An observation that came through during the comparative stage of the data analysis process was that the participants had a very different way of responding to their situation, even though the challenges that they faced were very similar. These observations led to the final theoretical code of resilience signature. That people are unique is not new knowledge, however, the idea that uniqueness is expressed in the way that people are resilient is not something that has been seen in research so far on this construct, as a 'one size fits all' approach has been taken. This may be why there are almost as many definitions and operationalisations of resilience as there are research studies (Coutu, 2003; Meredith et al, 2011; Shaikh & Kauppi, 2010).

It seems therefore, that the process of recovery is a very individual nuanced process. Indeed, when conducting the data analysis, the participants displayed very different ways of doing their lives. This possibly explains why resilience is such a difficult concept to define and operationalise. It could also explain why the idea of offering tools and techniques as a way to improve resilience, may feel 'toxic' to people who are not at that point in their recovery to engage with that or that the suggested tool is not congruent with their resilience signature (Davis, 2021).

However, there are other theories that touch on resilience that demonstrate a unique personal style. Peterson and Seligman (2004) created a taxonomy of values or virtues in action (VIA) by consulting with the authoritative or seminal texts from the world's philosophical and religious traditions. They were searching for ubiquitous values and virtues which were taken from texts like the ten commandments written in The Bible (New International Version Bible, 1978, Deuteronomy 5 6-21). They deduced a list of 24 virtues from the taxonomy and stated that each person had a hierarchy of strengths that was as unique to them as their signature. Therefore, their pattern of strengths was called their signature strengths. From this concept they created a questionnaire that would elicit the hierarchy for each person. They suggested that by utilizing a person's signature strength that the person is living authentically and that then leads to greater wellbeing (Seligman, 2005). It is therefore possible that the observation seen in the data analysis is the same phenomenon that Seligman (2005) described, except that in this case it is a resilience signature.

5.1.8 The environment

Bronfenbrenner (1981) suggested as previously discussed, that the individual exists within an ecological system, and that there is an interplay between the different levels of the system. The biggest challenge that the participants talked about by far, exists within the exosystem. This system refers to the structures in society, that 'impinge upon or encompass one's microsystems (Bronfenbrenner, 1977 Pg. 515). It is their opinion that the social systems that deny their child the help and support that they feel they need, has the biggest impact on their lives beyond the effects of the symptoms of autism:

This ongoing challenge affects every aspect of the participant's response to the adversity of autism. Not one of the participants said that they had found it easy to get a diagnosis and that it was followed with efficacious support. This situation therefore adds adversity on top of adversity even though all of the participants who went to tribunal, actually won. This failure to provide the support that the child needs, also provides the possibility of future adversity as an adequate education is supposed to set children up for the ability to be employed in future.

Within the microsystem - which is the immediate social setting of the person (Bronfenbrenner, 1981), the participants reported both positive and negative effects on their resilience. For some they found talking to their family about their child challenging. However other people did not have family nearby and so did not have that possibility for support. This idea of the environment adding to the adversity is supported by the social model of disability that suggests that impairment does not exist within the person, instead, it is found in the inhospitable environment that the person finds themselves in (Annandale, 1998 ; Hardcastle, 2021).

5.2 Implications for theory and research

5.2.1 Resilience

The literature presented in chapter two was based on this model, which was created using a summary of the theories presented. It most closely mirrored the conclusions of Lines et al, (2020).

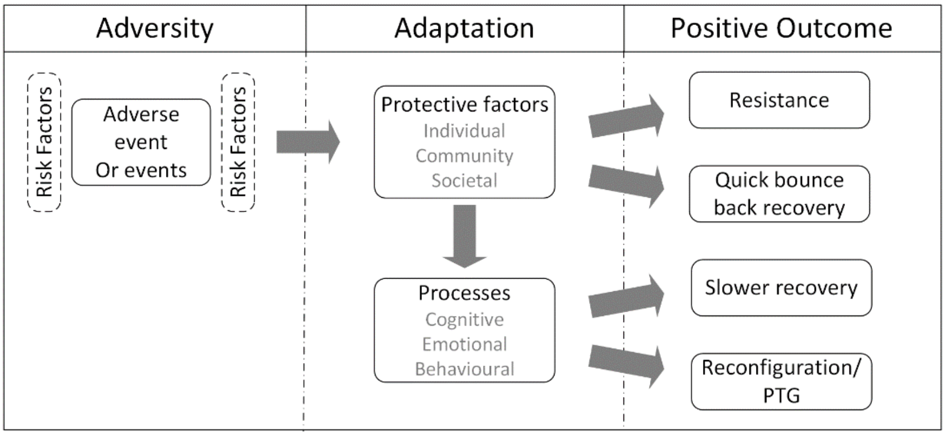

Figure 12The two-step process of resilience – authors own representation of Lines et al. (2020).

The theoretical code of adversity showed that the mothers all experienced similar adversities when dealing with the challenges of mothering a child with autism. When comparing this finding to the idea of risk factors, it seems that an adversity such as not getting a diagnosis for several years, was equally challenging despite the participants age, nationality, financial security, intellectual ability, or marital status. This supports Luthar and Cicchetti, (2000 pg. 858) view that there is a way to standardize the measurement of adversity and so create a level of objectivity. However, this means that none of the mothers risk or protective factors provided a buffer for dealing with this situation, or made them more vulnerable to the challenge. This contradicts Noltemeyer & Bush' (2013 pg. 476) research that suggests that protective factors provided a buffer to adversity. The evidence for this is shown in the adversity management of the situation, in that all of the mothers who had to wait to get a diagnosis actively pursued one. The adversity aftermath demonstrated how hard the mothers found the adversities that they faced.

The theoretical code of recovery from adversity is a novel finding that is not discussed in the resilience literature, as all of the literature occurs to the function of moving forward and maintaining positive trajectories (Garmezy, & Nuechterlein, 1972). The literature uses the concept of outcome as the way to assess resilience in an individual, however, for these mothers there was no discussion of outcomes, so this can also be considered to be novel.

The next theoretical code is that of adaptation to past and future adversities. This again is novel in that in the literature, adaptation is linked only to the adversity that has occurred and is therefore linked to the recovery process (Olsson et al, 2003). In the data the adaptation occurred once the participant felt recovered and ready to continue. This difference is that the data collected in this project found very clear stages to resilience that could be separated out as the occurred in sequential order rather than all at once.

Looking at the theoretical code of resilience signature, this again was a novel area in the findings. It proposes that people have a unique, defined pattern of responding to adversity that is congruent with their character. This develops the idea of personal characteristics that make up a person's individual protective factors (Garmezy, 1991; 1993) and combines it with Peterson and Seligman's (2004) ideas of strengths. It also challenges the original research by Garmezy and Nuechterlein (1972) that suggested that resilience was something that either the children were or were not, as if it was part of their character or personality. This meant that resilience was something that a person could be (or not). Conversely, Olsson et al, (2003) suggested that resilience was a process of adaptation following on from an adversity. This meant that there was something that a person could actively do to improve their resilience. The concept of the resilience signature is different to these theories in that it combines the ideas together. So rather than resilience being something to be, it becomes something to do, but the way that the individual would do resilience is based on who they are. This concept also supports the idea of resilience being something that is the modal response (Masten, 2001), because anyone can do resilience, however, when exploring resilience, researchers need to be open to ways of doing resilience that are outside their own way of responding, so that they don't discount a person's resilience because they were only looking for a fixed set of responses.

The last code of resilience defined offers yet another set of possibilities for a potential way to define resilience (Meredith, et al, 2011), however, if there is a conceptual framework that can provide a more fluid, flexible model, that encompasses and draws together other theories, then the definition that supports that model would find consensus too.

5.2.2 Disability

This project has looked at the experiences of mothers of children with autism. However, the mothers were not disabled themselves and so are one step away from the literature on disability. Instead, they are caring for a person with a disability and so are disabled by association with that person (Stewart, Niccolai & Hoskyns, 2011). Therefore, some of the stigma and sense of isolation described by Goffman (1963) as having a spoiled identity was felt by the participants and described under the theoretical code of adversity. The lack of definition around what constitutes an adversity that is described in the literature, concludes with the suggestion that the individual defines whether an event constitutes an adversity (Lines, et al., 2020). This, however, cancels out the possibility of applying the biomedical model to the process of being resilient. Were there to be an expert on declaring an event an adversity there would then be sanction for the mothers to rest and recover according to the 'sick role' (Parsons, 1952), which is the step necessary for resilience found under the theoretical code recovery from adversity. The Power threat meaning framework (Johnstone & Boyle, 2020), suggests that asking 'what has happened to you?' should replace the question What's wrong with you? when speaking to someone diagnosed with a mental illness. This suggests a link between an adverse event and a diagnosable illness, which could lead to the proposition that the sick role could therefore be applied to an adversity, and thus allowing someone to rest and recover.

The social model of disability states that it is the barriers in society that disable those with impairments (Oliver, 2013). This is supported by the adversities described by the mothers that were caused by those in the mother's environment. It suggests that barriers that exist in a school, are the feature that disables the child, which then makes it the wrong school unless those barriers to participation can be removed.

The upskilling that the mothers engaged with under the theoretical code adaptations to past and future adversities are also supported the social model of disability which suggests that society should adapt by removing barriers to participation for everyone, no matter what their impairment (Oliver, 2013). This positioning of adaptation is the same as that suggested by the mothers as it has a focus both on past and future access needs.

5.2.3 Mothering

As there is currently no known cure for autism (Fletcher-Watson & Happé, 2019), these mothers know that they will always have a child with this challenge for the whole of their lives, as there is a possibility that their child will outlive them. Additionally, even though there is no known cure, there are lots of therapies claiming to help manage the symptoms or improve the levels of functioning of children with autism (Wetherston et al. 2017). This means that in addition to the normal tasks of mothering that these mothers become the child's therapist and nurse. They also become the child's advocate in obtaining services for their child. All of the mothers in this study were involved in the activity of helping their child, either by delivering therapies and medications or advocating for services. In doing these tasks the mothers had gone above and beyond the usual tasks of mothering a child. This increased workload added to the mothers sense of adversity as these tasks took them away from the task of just being a mother.

Another aspect of the adversity theoretical code was the mothers experiences of surveillance (Giddens, 2009). These came from the many appointments and assessments which then had implications for the services that would be offered. The debates around discourses of power were also demonstrated under the theoretical code of adversity as the mothers had an unequal power positions compared to the professionals that they had to meet due to the professionals holding all of the resources that the mothers sought e.g., diagnosis and school places being held by those in power such as the Local Education Authorities (Dale, 2008).

The theoretical code of adapting to past and future adversity demonstrates this, as the mothers prepare for the future adversity through upskilling. The process of looking at what had happened and then preparing for the next event was reminiscent of the literature which talks about mothers preparing for motherhood. However, for these mothers preparing for motherhood is a more continual process than that described in the literature by Beck & Beck-Gernsheim, (2004).

5.3 Presentation of the substantive theory/model – Introduction

One of the aims of this research project has been to develop a new theory or model of resilience that would overcome the challenges faced by the current models. The main challenge that it was hoped to overcome, is the idea that some people are just not resilient enough, or that people can be declared to not be resilient at all. So, it is hoped that this is a kinder version of resilience, that can find a place within the model for everyone. This theory aims to be parsimonious in its explanation (Urquhart, 2013) so that it can be easily understood and applied. Its aim is to be simple enough that it can be user friendly so that it can do some good in the world. The theory should also include all of the data collected, with none omitted just because it doesn't fit (Coolican, 2009). It also needs to be based on the codes generated in the analysis (Flick, 2018). The model should also have the capacity to be modifiable, should future research demonstrate extra areas that should be included (Glaser, 1998). This study has been conducted using constructivist grounded theory (Charmaz, 2006). In the early stages of the coding process, gerunds were applied, line by line, by asking, 'what is happening here?'. This then leads to codes that describe action. This therefore has an effect on the outcome of the coding, in that the codes that come through describe action. The consequence of this approach to coding, is that it produces an alternative outcome to the research on a topic that is typically described in terms of personal qualities rather than personal actions, as it means that something different has emerged in terms of ideas about resilience.

The theoretical categories that emerged during the analysis were: resilience defined, adversity, adversity management, adversity aftermath, recovery from adversity, adaptation to past and future adversity and resilience signature. The difference between this research project and previous research by for example, Carver, (1998), Garmezy (1991, 1993), Lines et al., (2020) Masten, (1999, 2001) and Olsson, (2003) is that these research projects conceptualise resilience as a linear event. When Garmezy described resilience, he said that some children living in poverty had managed to thrive in spite of their adverse circumstances. He, therefore, saw a linear cause and effect situation occurring, with an unidentified middle ingredient which he termed the risk and protective factors. This finding was developed by others who treated resilience in a similarly linear way. Another benefit of the action identification approach facilitated by grounded theory is that each stage of the actions of the participants is coded separately. This means that every step of the participants' resilience is separately described. In Olsson's (2003) research, the resilient response was described as a process that happened over time that enabled the individual to regain their former level of functioning. The definition of resilience put forward by Olsson (2003, pg., 2), was "Resilience can be defined as an outcome marked by specific patterns of functional behaviour despite adverse factors, or an active process of adaptation to risk involving an interplay between the risk and protective factors either from the individual or their environment." This makes it clear that there are various elements to a resilient response that occur concurrently in an either/or fashion. These elements work in a linear way leading to the outcome of patterns of functional behaviour. However, from this quotation it is hard to see what actually constitutes these processes. The results from this study may illuminate some of these processes, however, the findings contend that resilience is not linear, it is instead cyclical.

5.3.1 The substantive model – the resilience cycle

This section begins with the presentation of the authors own diagram of the conceptual framework generated from the theoretical codes produced by the data analysis procedure. The diagram is presented first to facilitate the readers understanding of the process by which this model was conceived.

The resilience cycle is thus presented, and in doing so presents a non-linear model of resilience:

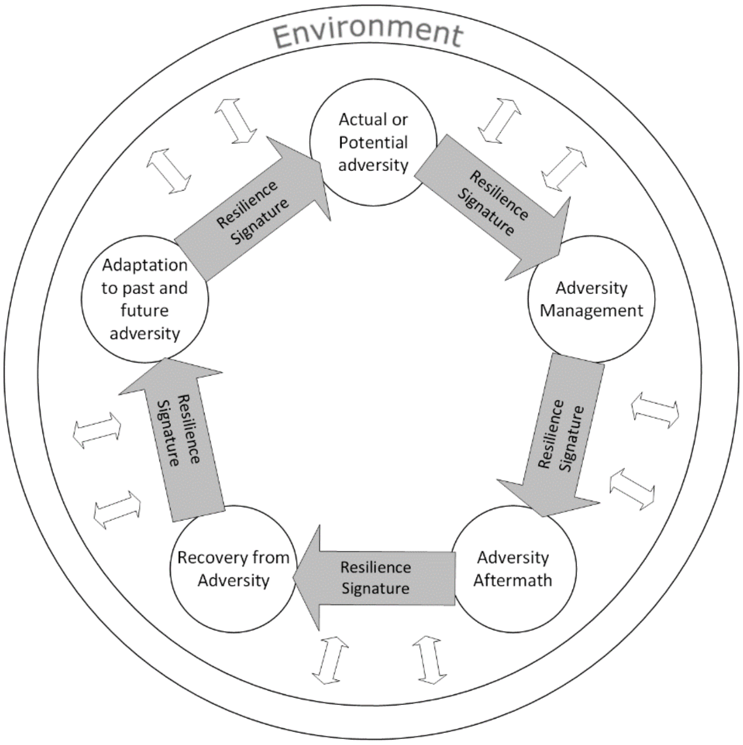

Figure 13 The resilience cycle – authors own diagram.

This model presented, contains all the theoretical codes except resilience defined which came from the participants opinions of what resilience was. So, while it doesn't appear explicitly within the diagram, it could be said that the model in its entirety, actually represents resilience defined. So, this code will be discussed later in the chapter, after the explanation of this model.

The theoretical codes included in this conceptual model are represented by the smaller circles in the diagram and are thus: adversity, adversity management, adversity aftermath, recovery from adversity, adaptation to past and future adversity. The last theoretical code, resilience signature, is shown by the grey arrows which demonstrate the method of moving around the cycle. This, model therefore, includes all of the theoretical codes generated by the data.

The model consists of a number of distinct stages that occur in sequence. The cycle starts with the adversity, which is managed by the participant. Once the adversity is managed and the situation has passed, the participant moves into the aftermath stage, this stage involved expressing emotion either via some form of distress emotion or by connecting to others to share the experience and receive some comfort. Following that stage there is a time when the participant rested and had some time out from their parenting role. Once that point is passed, the participants all involved themselves in adaptive activities that would upskill themselves for potential future adversities. This is one of the novel parts to the findings, because the choice of activity that the participants chose to engage with, related to the adversity that had passed. However, the reason that the participant selected each particular activity related to the possibility of a repeat future adversity. This last part of the cycle, the adaptation to adversity activity is the part of the model that ‘closes the circle’, as it relates to both the past adversity and a future potential adversity.

Another example of how this component works is, that suppose a man has a heart attack as an adversity, he rings for an ambulance and gets taken to hospital to manage the heart attack. Fortunately, he survives, but in the immediate aftermath he feels distressed that this has happened to him. He then rests and recuperates in the hospital and then at home. He then moves to the adaptation stage, where the focus of his attention is on the fact that he has had a heart attack and that he never ever wants another heart attack. So, he changes his diet, he gives up smoking and drinking, he loses weight, and he starts to exercise. Therefore, all this activity is related to the past adversity, but motivated by avoiding the potential future adversity of another heart attack.

To illustrate how this part of the model works with the data collected, an adversity described by Petra is distributed around the central part of the model:

> *“So, one was in my little girls assembly, when [I] had taken B with me and he was screaming and running around and then he used to try and pull his trousers down. Which again I just got up and walked out with him and thought I just can’t stay with this and couldn’t cope with this. He still does it a bit now. So, I just walked out with him and then cried when I got home sort of like, I can’t do this anymore, why have I got to have a child like this? So, of you know, that sort of thing, and then I think really my husband is really good with that reassurance, you know this is how he is, and that there is help out there. I sort of just have a bit of me time and then I feel alright. You just think when is it going to happen again is it always going to be like this… you know for the rest of his life you know when things like that happen. You know screaming… in Tesco, he’s got this repetitive … like he will jump and flick his legs back. Now I just ignore it and say come on B, whereas before I would be like ‘stop doing that’ ‘stop doing that’ but yeah, people look at you, but I have learned now, I have accepted that yeah, he has autism that’s what he is going to do, and his brain is telling him to do it. So yeah, I don’t really care what people think or says, but I think that is… obviously I wish it didn’t happen, but it does, and I just sort of have to get on with it.”*

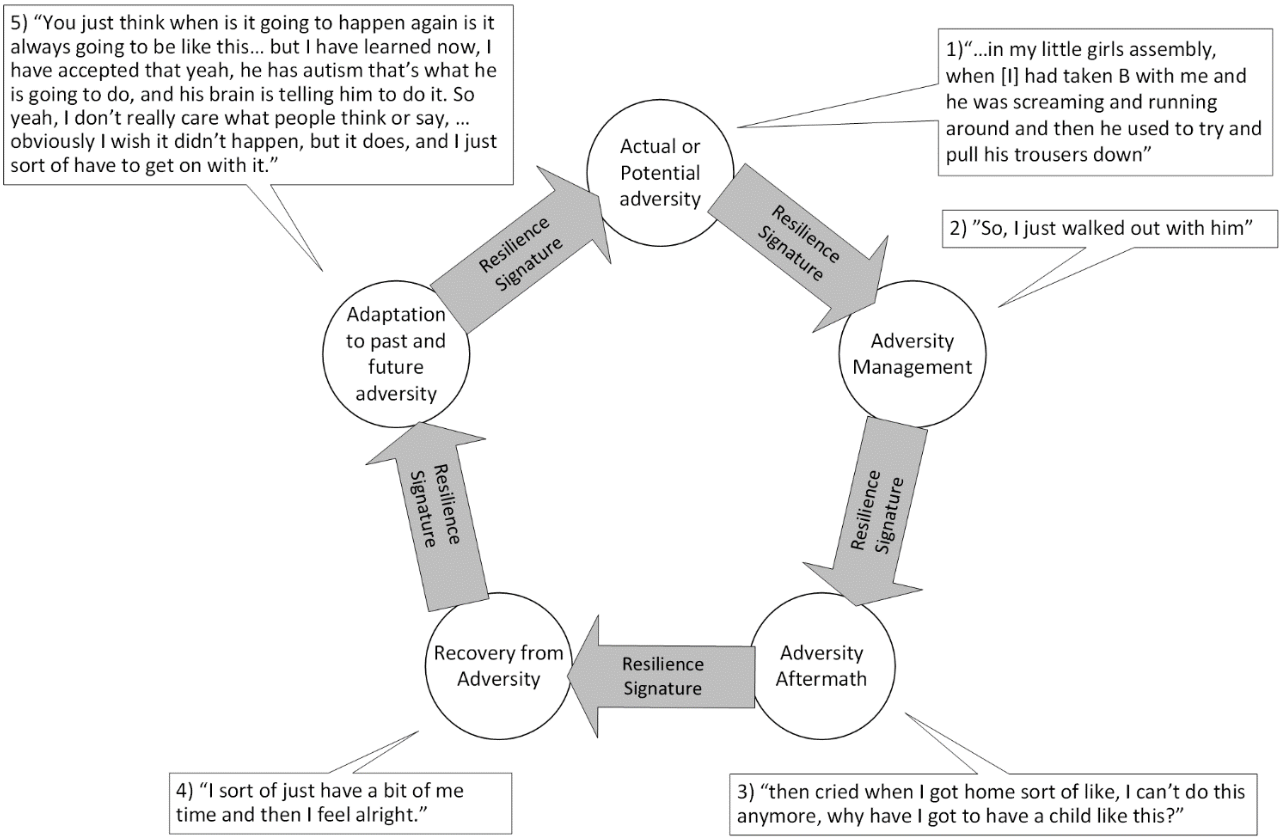

Figure 14 Resilience cycle applied to Petra's story of a challenging event.

Another novel part to this model is regarding the importance of resting. This idea came through time and time again from the participants, that this part was an essential component to their continued resilience. It is proposed that without this vital stage that the participant may not then go onto the next stage of adaptation and therefore become stuck in the previous stage for longer. This concept will be addressed later in the discussion on timescales. The concept of resting occurs in response to their 'peak performance' reaction in adversity management.

The position of the recovery stage within the model is important too, as there is a clear sequence to the events described. The period of resting and recovery comes once the intensity of the adversity, and the immediate aftermath has passed. This sequence is important to note, as the activities that are engaged with would be inappropriate to do during the adversity. The reason that this is important, is that current approaches to improving individual resilience, involve activities that come within the resting stage of this model. These are things like mindfulness and yoga. Obviously, during an adversity, like a child wandering off, or having a meltdown is not the time to be trying to rest using the meditation part of mindfulness. The 'being present' part of mindfulness is useful in a crisis, however, there is no opportunity to sit and meditate when a child is missing. This shows that the model being a sequence of stages is important. Once sufficient resting has occurred, then the adaptation follows which is renewed effort to re-engage with the task of parenting. The belief that the child needs them, seemed to be the catalyst to move the mother back into action mode with adapting to past and future adversity.

The idea of resting though appears to be contrary to Grit theory (Duckworth, 2017), which suggests that passion and perseverance are the keys to getting a job done. However, a closer look at Grit theory shows that the core concept of Grit is all about not giving up, rather than not resting. When the participants are resting, they have not given up on the task of mothering their children. Grit theory suggests that temporary pauses to feel the effects of adversity do not denote a lack of Grit, however, Duckworth (2017) does suggest that the period of time spent resting must not last long.

One obvious omission from this model is the risk and protective factors that have been described in such detail in previous models (Gillham et al, 1995; Houser, Allen & Golden, 2006; Wagnild & Young, 1993). The first reason that they are missing is that there weren't any explicit references to them in the data. In order to create a list of risk and protective factors for the participants, I would have had to infer from their comments that a feature of them or their environment was either protective to their resilience, or a risk factor that increased their vulnerability. To conceptualise what is known about risk and protective factors and to see where they could fit into the model would lead to a suggestion that perhaps, they could be included via the arrows that represent the interplay between the individual and the environment.

5.3.2 The resilience signature

Another novel part to this diagram, is the observation from the participants' narratives of the resilience signature. This signature is represented by the arrows that show the movement around the cycle, and demonstrate the congruence between the different parts of the model. So, while each participant has a different signature to other participants, their signature would remain congruent with themselves. The resilience signature denotes the personal style of each mother in responding to adversity. Within the data collected, the following domains presented themselves: Physical, Emotional, Spiritual, Social, Cognitive, Material, and Practical. The following diagram explains further what is meant by resilience signature:

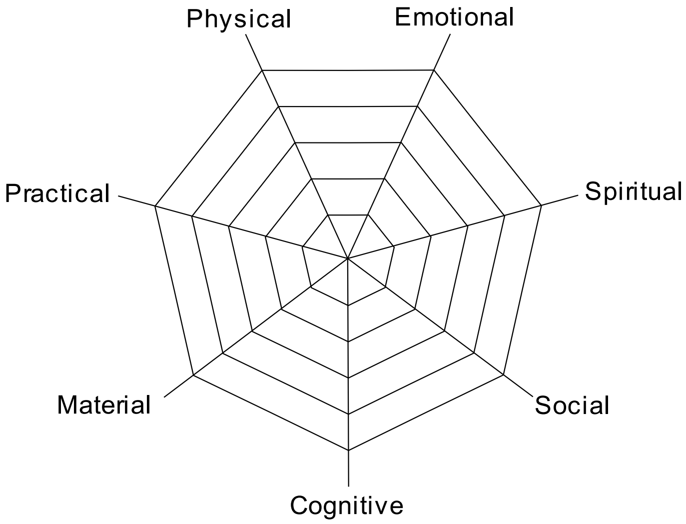

Figure 15 The resilience signature

The way this would work, is that the participants would create a shape on the diagram by giving themselves a score out of 5 based on their way of moving through life. This would then show them their ‘go to’ strategy for dealing with adversity. For example, Bianca had a very cognitive way of talking, so she might score herself as a 5 on that area. She had no spiritual practices, so she would score a 1 for that section. Social was probably her second most dominant style, so maybe a 4 for that. She said she was happy, although not all the time, and that things were easier now that her son was older, so perhaps a 4 for the emotional section. She was living on benefits and so described herself as not having a lot of money and so maybe scores a 2 for the material section. She had come up with some practical solutions to some of her challenges, so perhaps a 3 for that. She enjoyed going for walks but generally, this did not seem to be a dominant way of behaving so perhaps a 2 in the physical section. So, Bianca’s signature would look like this:

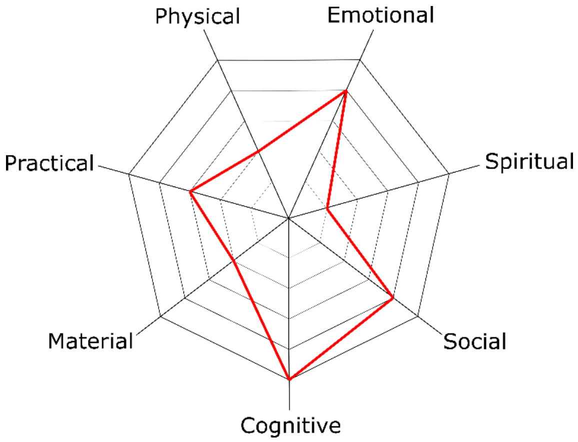

Figure 16 Bianca’s proposed resilience signature.

This is just a make-believe response to illustrate the way that the signature could work and has not been completed by the participant. Therefore, it should not be used as any kind of report or diagnosis for Bianca. This was created from comments made during one interview. This model, if used to identify a person's resilience signature, would be completed by the individual as they are the expert on themselves, whereas one interview only gives a snapshot view of the day that the interview occurred. However, that said, for illustration purposes only, it can be seen that once these areas of life have been considered, that a strengths-based approach becomes possible. Seligman (2011) suggested that there is a traditional way of evaluating skills that suggests that effort should be spent on improving a person's weaknesses, for example, if a person is bad at maths, then they should spend as much time as possible improving their maths. Seligman (2011) suggests, that instead effort should be directed at a person's strengths which if built up can then be useful to support their weakness. So, in the case of the person that is bad at maths but good at music, if they focus on music, then that skill can be used to improve their maths, as there are a lot of mathematical skills involved in music. This approach leads to greater wellbeing as the individual gets to spend more time doing something they enjoy because they are good at it. This therefore supports the concept of having a 'go to' strategy of using a resilience signature as it is the method most used already and so congruent with the individual and also more enjoyable for them.

Lyubomirsky, (2014, pg. 70), supported this idea of people being different. She created the concept of 'Goodness of Fit' when describing how to apply positive psychology interventions. She said:

> *"…if there is any secret to becoming happier, the secret is in establishing which happiness strategies suit you best. Once you have done so, half the battle is won – the way to greater happiness is in your hands. "*

Using this concept, it would seem that if a person knew their resilience signature, they would be able to know how best to tackle adversity and how to recover in the way that would help them to feel most rested and then how to adapt to past and future adversities. This may possibly speed up the time it takes for them to move around the cycle.

Another theory that supports the idea of a resilience signature is that of the theory of Multiple intelligences put forward by Gardner (1993). Gardner suggested that there are eight different types of intelligence: Linguistic, Logical/Mathematical, Spatial, Bodily-Kinaesthetic, Musical, Interpersonal, Intrapersonal, and Naturalist. Out of these intelligences, the profile that an individual may have, is unique to them and is formed from a combination of experience and genetics. The consequence of having a unique profile of intelligence, is that the way a person moves through life and deals with the challenges presented by life will be different. It is not much of a stretch to propose that this means, that each individual will respond to adversity differently, according to a combination of a number of theories in combination.

The big five theory of personality is another theory that suggests the uniqueness of the individual. The five domains suggested by Costa and Macrae (1992) are Openness to experience, Conscientiousness, Extraversion, Agreeableness and Neuroticism. Each of these domains has a spectrum in which a person can be measured using the international personality item pool (Goldberg, 1992). It is possible that the domains of the big five model, may correlate with the sections of the resilience signature diagram. For example, a person who scores low on extraversion under the big five, would be expected to obtain a low score on the social section of the resilience signature, as social activities as a primary response, would be incongruent with being an introvert.

The existence of a resilience signature may also explain why it is, that no consensus has been found in conceptualising the component parts of resilience. If each person does resilience differently, then it may be that for example, Connor-Davidson's (2003) conclusions about which domains should be measured are correct, and at the same time, Wagnild and Young's (1993) conclusions are also correct, even though they are completely different.

The adversity aftermath section of this model refers to a part of resilience that is commonly thought to demonstrate a person experiencing a drop or loss of resilience, because they are experiencing negative or unhappy emotions (Carver, 1998; Pemberton, 2015). However, expressing unhappy emotions following an adversity is in some respects considered a healthy reaction, for example following the death of a loved one (Kubler-Ross, 1969). Olshansky (1962), argued that it was non-pathological, natural, and understandable that parents faced with a diagnosis of a disability would feel a sense of bereavement. He stated that this sorrow would last for the child's entire life as milestones or life events were not realised. It was suggested that this loss is lifelong because it represents a 'living loss' that has no end point, and so no possibility of adaptation that would occur following mortality. Olshansky cautioned the professionals who work with these parents, not to expect them to 'get over' their loss of the imagined child. Roos, (2018, pg. 25) defines this chronic sorrow as being:

> *"A set of pervasive, profound, continuing, and recurring grief responses resulting from a loss or absence of crucial aspects of oneself (self-loss) or another living person (other loss) to whom there is a deep attachment."*

This theory gives 'permission' for sorrow to exist in response to the adversity of having a child with autism and for the loss of the imagined child (Lowes & Lyne, 2000). This was an experience that several of the parents talked about and would suggest that unhappy emotions are non-pathological and so should not mean something negative about a person's resilience. Therefore, a model of resilience needs to include space in it for the expression of unhappy feelings.

Furthermore, theories of resilience that emphasize resistance or immediate bouncing back would suggest that either bypassing this section or only allowing these emotions an expression for a very short time, would be the resilient response, with anything different being deemed non-resilience (Ivtzan et al, 2016; Meredith et al, 2011). However, mindfulness is often recommended as an intervention that builds resilience. Part of mindfulness requires being present to what is happening without trying to change it in any way. So, if a person is feeling sad, then mindfulness suggests meditating by taking in the full experience of that sadness without changing it, or trying to shut it out (Kabat-Zinn, 2006). Neff (2011) supports the concept of staying present with feelings of suffering too, by stating that suffering is part of our humanity and that resisting the experience of suffering is what actually causes pain. So, the theories surrounding resilience and adversity, appear to suggest that the adversity aftermath is to be expected and embraced.

5.3.3 The place of the environment

The environment is represented in the resilience model, by a large circle that envelops the rest of the diagram. This was positioned like this in the diagram, to denote the omnipresent nature of the environment in the lives of the participants. This shows that the participants are all constrained by their environment and that there is an interplay between the individual and their environment, as shown by the arrows that point between the sections of the resilience cycle and the outer ring of the environment.

The environment both increased the sense of adversity felt by the mothers, but also separately offered support. The axial codes that referred to the environment covered these areas:

- Adversity created by people other than their child.
- The fight for a diagnosis and support services.
- Social support – being able to rant to family and friends.
- Social activities – e.g., going out with friends.
- Environmental adaptations - such as changing the house.
- Moving house to be nearer family.
- The comfort, familiarity, and safety of home – just wanting to go home.

One slightly controversial model and coding decision taken, was to include the area of the environment so prominently in the model when it was not chosen as a theoretical code. There are several reasons for this. Firstly, this is because of the pervasive nature of the environment. The environment both impacted the individual and was impacted by the individual, meaning that there was an ongoing interplay between the individual and the environment. An example of this is that many of the participants talked about how it impacted their lives to not have their child in an appropriate school setting, and their ongoing struggle to get the right placement. All of the participants who talked about going to a tribunal to get the school setting that they felt was right for their child, were successful in securing the desired place, due to the tribunal provision. This demonstrates the adversity of the experience for the mothers, but also their success in using the tribunal process to get what was needed from the environment.

The second reason why the environment was not a theoretical code is for parsimonious reasons. The environment has codes that have a relationship with all of the theoretical codes within this study. However, if the environment had been created as a theoretical code, it would have made it extremely complicated to show the relationships between the theoretical codes. The ensuing diagram would have looked as if the environment was a core category, which in terms of representing the data and the research questions it was not. Furthermore, within the coding process, each decision is taken one at time. The different areas of the environment were often mentioned, but didn’t come through with the same emphasis as the other areas that were made into theoretical codes. This is possibly because the research project is about individual resilience rather than environmental resilience, which is a completely separate subject. Therefore, coding decisions were taken with one eye on the research questions all the time, meaning that the environment, while important, was not an obvious pick for a theoretical code. Another aspect to this, is that individual resilience is situated in the individual’s interior environment whereas the environment discussed here is exterior to the participants, which requires some sort of attention, but should not be a main focus in this project.

The diagrammatic representation of the environment as a circle is also deliberately illustrated in this way as a reminder of Bronfenbrenner’s (1977) ecological systems theory, as that theory is congruent with the findings of this study with respect to the environments that the participants find themselves in. The decision to represent the environment as a circle that surrounds the rest of the diagram follows a precedent set by Howell and Egley (2005) who stated that the types of risk that they found in their study followed Bronfenbrenner’s (1977) ecological systems theory domains, the majority of which are environmental domains.

It should also be noted that the majority of domains that were identified as either contributing to vulnerability or protective factors were situated within the environment. Lines et al. (2020), suggested that protective factors fell into three areas: individual, community and social. In this study, the individual protective factors have been coded in separate ways, and are described within the resilience signature. However, the community and social factors have been subsumed into the environment. Swadi's (1999) discussion of risk factors, stated that there were three domains of risk factors: constitutional predisposition, environmental factors such as family and peers, and life events. The idea that a significant number of the risk factors are situated within the environment supports the findings in this study too and justifies the inclusion of the environment in the model.

5.3.4 Resilient timescales

Another finding that related to the cyclical nature of resilience is that none of the participants talked about there being a specific point in time where they could say that any outcome was reached and so was ready to be assessed. This highlighted the benefit of the qualitative method, as asking people to give a narrative, means that the data is not totally a snapshot view as it would be if the method used a scale or questionnaire. With a snapshot view that results in a score of resilience, there is a possible issue with timescales, in that some participants might have recently suffered adversity with no time for recovery or adaptation to take place, and others might have had years to adapt. Therefore, in a study using a scale, the research does not compare like for like, as the participants will be in various stages of recovery. This may explain why no measure of resilience has been acclaimed to offer a 'gold standard' of measurement (Windle, Bennet & Noyes, 2011).

Carver (1998) suggested four different outcomes following adversity that had a time element to them. He suggested that for everyone there was a physical and/or psychological downturn after adversity had occurred, followed by either succumbing to the adversity, surviving it with impairment, a resilient recovery or thriving. This Carver suggested, occurred over time and so if a measure had been taken immediately after the adversity, no one would have appeared to be resilient. It is not clear from Carver's research though; how much time is needed between the adversity and the moment when the outcome can be declared. The findings from this study did not find a point either where it could be said that an outcome had been reached. Therefore, this research suggests that the idea of conceptualising resilience using the idea of an outcome point is somewhat unhelpful to the understanding of the topic.

Much of the previous research into resilience could possibly be critiqued on account of timescales. The research by Garmezy (1991) for example pointed to the child's positive outcome as evidence of their resilience. However, what is not currently known is how long Garmezy allowed between the adverse event(s) and the outcome that was assessed as being positive, or even if an equal amount of time elapsed between the event and the assessed outcome for each of the participants in his study.

Additionally, it also isn't clear what is meant by outcome. If a person participates in a psychometric test and is given a score, then it is possible that their score can be compared with the general population and some conclusions drawn about their level of wellbeing on that day. However, that doesn't account for what may happen to them in the next minute that might affect their resiliency outcome. This means that any measurement of resilient outcome is only a snapshot of one moment in time. It also isn't clear, whether the score might be affected were the participants to carry out a positive psychology intervention (Seligman, 2011) to improve their mood prior to the administration of the test.

The model proposed by this study suggests that the participants work their way around the resiliency cycle over a period of time. If a resilience scale were to be used to measure a person's resilience and the score was low, the traditional conclusion would have been that the person was not too resilient. However, this model suggests a different conclusion. This model suggests that a person returning a low score would be situated in the adversity aftermath or recovery from adversity stages of the model. This does not mean that they are not resilient, it just means that they are doing what they need to do and that they will move on to the next stage in time, provided that no further adversities occur. This proposition is supported by the humanistic viewpoint that everyone is doing the best that they can and that they are working towards self-actualisation (Rogers, 1967). This viewpoint leaves no room for suggesting that someone could do better than they are, in terms of their desire to recover and their pace of recovery. This would suggest that moving around the cycle faster does not then denote higher resilience. It also does not mean that moving out of the aftermath and recovery stage more quickly demonstrates higher resilience. Should a second adversity strike a person before they have completed their recovery, it is anticipated that it would mean that the cycle begins again. Theories of post-traumatic growth (Joseph, 2011) suggest that there is value in the journey of recovery and that a swift return to normality might not allow for the lessons that lead to growth to be learned. So, a fast return does not actually lead to the optimum outcome, as post traumatic growth leads to a person functioning at a higher level than they did before the adversity. Therefore, this model would propose that there is no preferred timescale for a person to traverse the resilience cycle. This means that a person can and should recover at the right pace for them. This is a kinder model of resilience as people are not under pressure to recover quickly.

There is a question however, about whether it is essential for all the stages of the model to be completed. Looking back at developmental theorists such as the psychodynamic theorists like Freud (1905) and Erikson (1963) and Cognitive theorists such as Piaget (1936), they all suggested that developmental processes require the individual to complete each stage in turn before progressing to the next. Failure to complete a stage would result in a crisis such as role confusion or identity crisis (Erikson, 1963). It is therefore possible to conjecture that in this model of resilience that individuals need to complete each stage too, however, it is perhaps too early in the conceptual models' development, to be too sure on this.

5.4 Presentation of a new definition of resilience

This study sought to find a new kinder model of resilience. In the light of the findings, I propose a new definition of resilience based on the theoretical codes and subsequent model presented rather than the participants answers to the specific question of what does resilience mean. This takes into account the advice proffered by Glaser and Strauss (1967) that suggested the need to go beyond the current conversation on the topic. The definition, therefore, includes the novel comments that deconstructed resilience, rather than the comments that found resilience problematic.

The new definition proposed is:

> *'Resilience is an intrinsic human behaviour that operates via an interplay with the persons' environment in a cyclical nature. It is based on a personal signature style of responding to adversity that leads from management of the crisis, through the aftermath into recovery, and then finally by way of adaptation to the past to prepare for potential future adversity.'*

5.5 Evaluation of the substantive theory/model

The above section has sought to explain the proposed model of resilience, coupled with an analysis of the way that it evolved from the data. What remains now is an evaluation of the theory to examine to what extent it can be said to be adequate as a model for resilience. Therefore, a framework was needed to ensure that the evaluation was thorough. Fawcett (2005) proposed a set of criteria for middle range theories as opposed to grand theories. She conducted her work within a nursing context, and it was decided that the therapeutic nature of nursing was consistent with the desired therapeutic outcomes for resilience theory. Fawcett's, (2005) framework proposes the following criteria for evaluating a model or theory. These are significance, internal consistency, parsimony, testability, empirical adequacy, and pragmatic adequacy. The inspection of the model in the light of these six facets should be done in an objective and non-judgmental fashion so that it can be decided if the model is of any use going forward.

The first criterion of significance explores the context of the model. This part justifies the importance of the model to the discipline that it has been conducted within. This study has been a multidisciplinary study, informed by research in psychology, positive psychology, sociology, and social policy. For the fields of psychology and positive psychology the importance is seen in the motivation for the research, which has been to change the narrative surrounding resilience from one that suggests that being happy no matter what, is the preferable option. The expectation in the beginning of the research project was to find out why certain people were resilient, and some were not, however what has been uncovered is that in the instance of this research that everyone was resilient. The proposed model suggests that everyone is resilient as resilience is not conflated with positive mental health. When previous research had looked at people who had experienced a downturn in their mental health, the researchers had concluded that they were not resilient. Instead, this model suggests that there is an important stage in resilience that involves expressing the emotions that stem from a challenging experience and that in time people move through those negative emotions onto the next stages. This would make a huge difference in the way that people's mental health is seen and the expectations that are made on people to 'pull themselves together' 'have a stiff upper lip' and 'keep their chin up' following adversity.

Within the disciplines of sociology and social policy, the importance is seen in the role of the environment within the model. Previously, there has been a danger that an individual's resilience was seen as their own personal responsibility, which meant that a person given too much work could be told to be more resilient rather than for their workload to be reduced. This model demonstrates how this is not the case. The model highlights the way that the environment operates in an interplay with the individual with each having an impact on the other. The environment can either support a person's progress around the cycle or it can delay it or even restart it by adding further adversities. Therefore, with the knowledge of how this model operates, decisions can be taken that allow individuals to engage with stages such as resting so that in their own time they can progress to adaptation and then be back to full or enhanced functioning.

Another aspect of the context of this study is the chosen cohort of mothers that have children with autism. It is vital at this early stage of this conceptual model not to 'over sell' the significance of this project by suggesting that it is a generalisable grand theory that is applicable to everyone. At this point in time this would be too big a claim to make. In time, this may be the case, but at the moment the model has been drawn from the stories of seventeen women and so the findings must be seen in this light. It is possible though, that the findings may still be useful to women who are mothers to children with autism. Opportunities for further research are discussed later, however, choosing different cohorts of people may demonstrate this model to be more important in time.

The second criterion of Fawcett's (2005) framework for evaluation is 'internal consistency'. This relates to whether the context and the content are congruent. To assess this, the question needs to be asked as to whether the concepts of the model reflect semantic clarity and consistency. The model reflects the Humanistic belief that all human beings are striving for self-actualisation in suggesting that everyone is resilient. It also is congruent with research that supports a strengths-based approach (Peterson & Seligman, 2004) as being a way to support wellbeing. It also is congruent with the bio-medical model and the sick-role (Parsons, 1952) that talks about a person having the right to rest and a responsibility to get better. This model presents a new process of resilience, however, the idea that resilience is a process is not new (Olsson et al, 2003). Furthermore, the idea that adaptation can lead to improved functioning is not new as theories of post traumatic growth have been around for some time (Joseph, 2011). It is also hoped that as the model has been explained, that there has been a consistency in the terms used, and that consistent definitions and semantic usage of those terms has been maintained.

The third criterion is that of parsimony, which examines whether the model has been stated clearly and concisely. The principle of parsimony (Occam's razor) states that the theory should be the simplest explanation of a phenomenon. The model itself is simple in its concepts, and contains ideas that everyone can identify with. Therefore, the model should not be difficult to understand, so in this respect it can be said to be a parsimonious model. Additionally, I have sought to use diagrams and tables as well as written explanations in order to provide a number of different ways to convey information. I hope that the use of these diagrams will have created greater accessibility to the reader of the ideas presented. In particular the diagram of the resilience cycle is intended to create a visual representation of the proposed conceptual model. This means that the model hopefully becomes more accessible to a wider audience and will require no special training for someone who wants to use this model in their practice.

The fourth criterion is that of testability. This has been a constructivist grounded theory study, with the theory emerging from the data collected. Part of the criteria of a theory is that it can be tested using empirical instruments (Coolican, 2009). However, the current range of instruments to quantitatively measure resilience (Connor & Davidson, 2003; Wagnild & Young, 1993) do not fit with this new model as they are based on a different operationalisation of resilience. However, this is a qualitative study that offers a new model of resilience, meaning that it cannot be tested using scales that fit with the previous conceptions. It is, however, possible to test this model by empirical observation methods. If a longitudinal study was carried out following a group of people who had suffered adversity, it would be possible to see if they moved through the suggested stages proposed in the model in question. Additionally, case studies would elicit a further opportunity to study this model. The two case study methods suggested for this research that were planned for this study but abandoned due to the Covid-19 pandemic would also serve as a test of the model.

The fifth criterion of empirical adequacy is slightly more challenging to fulfil, as this study, has its philosophical standpoint rooted in constructionism. This suggests that reality is not out there waiting to be objectively observed, but created through the double hermeneutic of the participants coupled with the researcher (Giddens, 1976). What can be claimed though is that the outcomes and conclusions drawn are congruent with the philosophical position of the pragmatist paradigm in looking at the question of resilience through the lens of 'what works' here. Additionally, by using Charmaz' (2014) method of constructivist grounded theory, the codes that were generated using gerunds provided a commentary on what is happening in the data. In describing actions using gerunds, I found that I was creating an account of what was happening as if it was an observation. Clearly beyond the initial stages of coding, this process became less distinct as decisions were taken as to which codes to carry forward, however, these codes took the original codes as the starting place, and so as a qualitative study, the grounded theory method comes the closest to the rigour of the empirical observation of the quantitative researcher – which was the intention of Glaser and Strauss (1967)

The last criterion of Fawcett's (2005) framework for evaluation of a theory, is pragmatic adequacy. This relates to the usefulness to practice of the theory, and whether the theory would alter practice in a manageable way. There is a discussion later about how this theory can be applied in practice. However, some aspects of this can be debated here. As this model presents a new way to conceptualise resilience, it has not been used in practice yet. It would further the efficacy of this model if some new interventions were created to use it in an applied fashion, so that the outcomes can be observed. However, there are already in place some positive psychology interventions that would be congruent with this model, such as Peterson, and Seligman's, (2004) strengths-based approach. However, even this approach would need to be adapted as their signature strengths values or virtues in action results are not the same as the areas of the resilience signature identified in this research. Further comparison of these two models might demonstrate that the values in action identified in the VIA survey (Ghielen, van Woerkom, & Meyers, 2017; Seligman, Steen, Park, & Peterson, 2005), may well correlate to the resilience signature areas.

This model offers the opportunity to change the way of thinking about and doing resilience. In changing the way of thinking about resilience it is necessary to drop the idea of either being resilient or not being resilient, as this model proposes that everyone is resilient. There are, therefore, no non-resilient people, nor are there people who are not resilient enough. This model proposes what is claimed to be a kinder model of resilience. Just taking the new alternative perspective on resilience may well immediately create a paradigm shift in the way people view the period of time following adversity. It would therefore be possible to view a group of people facing an adversity under the old way of conceptualising adversity and then study the difference that the new model makes to see if it is efficacious in improving wellbeing. This new view of resilience is accessible to anyone and wouldn't need more than a simple explanation in order for people to understand what is being suggested.

For people to do resilience differently, they need to be able to assess where they are in the cycle and give themselves permission to be in the exact spot that they are in. They also need others around them to respect that they are doing resilience and so need to be where they are. The belief that this model has, is that if people are able to do what they need to do for the stage that they are at, that they resolve that stage and then move forwards. Failure to complete a stage can result in a person becoming stuck or delayed. The idea of becoming stuck, delayed, or moving forward but trying to continue with a previous unfinished stage is a similar idea to models of child development such as Freud's or Erikson's psychosocial theories of child development (Shute, & Slee, 2015). This is one of the benefits of this model is that people are less likely to become stuck or delayed if they recognise what they need and are empowered to deliver that for themselves. Additionally, if they know their resilience signature, then they have a 'go to' strategy for moving forward. This element of timing in completing the circuit is the part of the new resilience model that warrants the existence of the construct, as the ability to move around the circuit more quickly would lead to a happier experience for the individual. This, therefore, would suggest that future measurement of resilience as a construct would involve measuring the amount of time a person spends in each stage, or their level of satisfaction in each stage. Resilience interventions would then revolve around ways to enable people to engage with each stage in a way that is congruent with their own signature, so that they can more efficiently move to the next stage rather than becoming stuck, or make the most of opportunities for personal growth in their current stage.

This part of the resilience cycle might need to be supported by a coach, a counsellor or an online app that enabled people to uncover their resilience signature. Once that is discovered, they can choose an intervention that supports their signature. For example, a person with a strong cognitive style might find that they rest using activities such as mindfulness, journalling, or poetry writing and then adapt, by furthering their training. For this person an activity such as yoga might be less appealing.

5.3.1 Limitations of the study

The benefit of hindsight is a wonderful thing, as it enables me to see what went well and what could have been done differently given the chance.

The biggest limitation of this study was its small size. To have had the data collection period interrupted by a pandemic created an unprecedented situation in the world that meant that collecting data for large portions of time was unethical. To ask a mother to describe the challenges of raising their child while that child was in the same room (because their school was closed) was not something that I was prepared to do. It is clear that in looking back at the transcripts, that the interviews that were conducted face to face resulted in a significantly greater amount of data being given, as the participants were more forthcoming when sat in the same room as me. Later interviews that were conducted online were significantly shorter in length, yielding less data.

Other limitations are related to the methodology. A grounded theory study and its method of reporting the results can mean that the individual voices of the participants can get lost as the interviews are fragmented by the data analysis process. While this enables the creation of codes and theories, it can mean that the individual stories disappear as they are converted into codes that describe actions.

Additionally, part of the nature of a grounded theory study, is that the literature review is carried out after a lot of the data is collected in order to not 'contaminate' the results of the data analysis with prior knowledge of the literature. However, this can be said to operate in reverse too in that the study of the literature can be influenced by the results found from the interviews. This means that the literature search takes place after the data collection, so the results found were present in my mind while the literature search was conducted, meaning that there is a danger that the study exists within its own echo chamber.

Where a study of the literature, is meant to demonstrate a gap in knowledge, and that gap is only demonstrated after the majority of the data collection is done, then the discussion of whether to conduct the study is somewhat a 'fait accompli'. In a subject like resilience, it is impossible to cover every angle on the topic as there are literally thousands of journal articles on the subject. Therefore, it is possible that something has been missed due to this.

Also, if the research was carried out again, then the question about what resilience is, would be thought through and possibly omitted, as the results that came from it, mostly only showed the problems that existed with the current public discourse on the concept of resilience and the lack of consensus thereof. The question did provide a segway into other questions about how the participants manage their lives and the challenges that there are, so in a way the question on defining resilience, had a use. However, there is probably a better way to achieve that.

Other limitations of this study are related to the participants who volunteered to take part in the study. It is possible that perhaps only those coping well volunteered, as possibly those not coping well, might have felt that they didn't have the time or energy to do something like an interview.

Additionally, much of the recruitment was conducted via online social media websites. This again would perhaps limit the accessibility to those without the means to go online. This would possibly exclude a mother who does not have internet access.

5.3.2 Implications for practice

This research project began with the intention to explore why some people appeared to be more resilient than others, in the hope that if the magic ingredient could be discovered, then it could be shared. However, the outcome of the research showed that resilience is something that everyone possesses and does. It shows that resilience is not something that a person is, instead, resilience is something that people do, and that each person does it in a unique way according to a personal signature style. It also shows that resilience is not linear but instead it is a cycle of responding to adversity. In the light of these findings, there are now implications for future research as discussed below in section 5.3.4, for practitioners, parents, and the field more generally.

For parents of children with autism, the outcome means that they no longer need to listen to a narrative that states, that struggling with their situation means that they are not resilient, it just means that they are in the adversity management or aftermath stages of the cycle. It also means that taking time out from looking after their child is not a 'guilty pleasure' but actually, it is a vital part of enabling them to continue doing the valuable job that they are doing.

This study also highlights the huge loving effort that mothers of children with autism pour into the process of parenting these children. This effort goes beyond regular parenting responsibilities as it includes managing the health, wellbeing and behaviour of their child, and the challenges from their environment such as dealing with the Local Education Authority and the child's school. Then beyond that, the adaptations that they engage with, to improve their situation most of which are not just unsupported, but at times vigorously opposed. The narrative around these mothers needs to change to acknowledge this, both in terms of the way that they are seen in society, but also in the mothers own self-talk.

5.3.3 Implications for teaching resilience

At the present time, there is a multimillion-pound industry that provides personal growth programmes that offer tools and techniques to improve resilience. These workshops are given as part of staff away days, or charity events for specific groups of people who have something like being a carer in common. The recommendations are however, presented in a one size fits all fashion, with people being taught either individually, or in groups. While the tools and techniques are based on scientific evidence, they are presented in such a way as a person might think that they are under pressure to remain happy and on task in the future. This kind of reaction is not the intention of those leading the workshops. So, in teaching resilience, this new model gives the option to do things differently. The first implication of this research is that it changes the conversation about resilience from the binary resilient / non-resilient approach, to one of inclusive resilience, as everyone is resilient. This means that everyone is starting from a kinder, inclusive, more positive place. It also means that the conversation is based around identifying your resilience signature and working with your own personal template rather than ‘improvement’ of your level of resilience. This is a kinder conversation to have as it removes the possibility of a failure to be resilient (Windle, 2010). If a person is struggling emotionally to deal with an adverse event, then it means that they are in the aftermath stage and that in their own time they will move to the recovery and adaptation stages, and not that they failed to be resilient.

Another adaptation proposed to the tools and techniques that are taught in workshops is that currently, the aim of the workshops is to increase personal protective factors (Garmezy, 1991, 1993) so that a person can either resist the negative downturn, or bounce back quickly. However, using the concepts of the resilience cycle and the resilience signature, the current way of running a workshop would become obsolete. Instead, it is proposed that the first part of a workshop would involve studying a person’s protective factors as a way to identify their resilience signature. The workshop participants could also use the resilience template shown earlier in this section in Figure 16 and Figure 17 Bianca’s proposed resilience signature.:

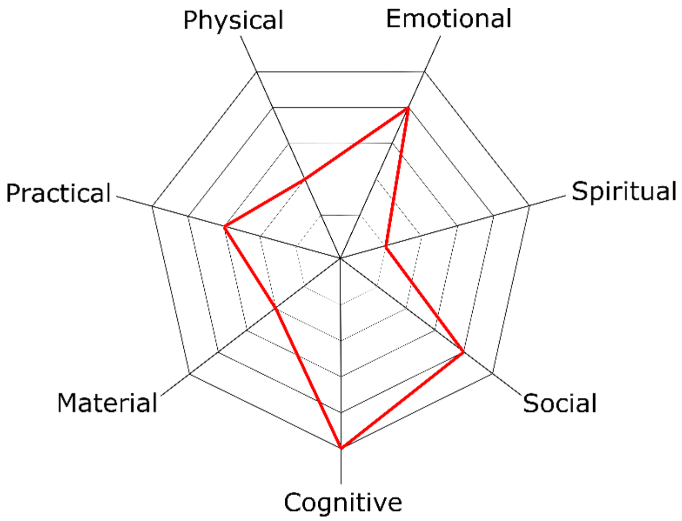

Figure 17 Bianca's proposed resilience signature.

This then becomes a self-report tool that could be used to identify a person's resilience signature. Once a person has identified their signature, it would then indicate which of the interventions taught in the workshop would be the best fit for them (Lyubomirsky, 2014). So instead of teaching resilience techniques like mindfulness as a panacea for everyone, it would be taught with the caveat that some people will find it more conducive to resilience for them than others. A consequence of giving a technique as a ubiquitous tool to improve resilience is that those that don't find the activity enjoyable or beneficial, may feel that they are disadvantaged when it comes to maintaining their wellbeing, or that they can't do it because they are not a resilient person. Teaching a variety of tools that cover all areas of the resiliency template would prevent this situation occurring, therefore, any workshop would need to ensure that they covered techniques that spanned all of the different areas of the resilience template so that everyone had something to take away.

If an individual was to come to a mental health practitioner looking for help with their mental health, they are often now asked the question: what has happened to you, as a result of the power threat meaning framework (Johnstone & Boyle, 2020). This situates mental distress into the context of a response to adversity rather than just being something that is 'wrong with' someone. It also fits with this model in suggesting that distress follows adversity. Therefore, an implication for health practitioners is to ask the question 'what has happened?', so that the individual can see the process and identify their stage of the cycle, which thus removes the judgement that there is something wrong with them. This raises the question as to how mental health is described and the stigmas that are then attached to such a condition (Berger & Luckmann, 1991). To change the narrative will prevent the writing of sentences like this:

> *"Uncovering a person's attitudes may not reveal straight away who is demonstrating resilient behaviour in times of misfortune; a snapshot of a particular moment in the struggle may not provide a reliable prediction of who will make it in the longer term and who won't"* (Neenan, 2018 pg., 2).

The implied threat in this sentence provides that extra burden to a person in the middle of responding to adversity, that this study has hoped to address. In this quotation, the author does go on to suggest that the snapshot is not the whole story and that there is more to come. However, this research suggests that the last part is misleading in suggesting that some people won't 'make it'.

Moving on to the implications for the immediate environment of the individual, there are some suggestions for places like schools supporting children's resilience, or the workplace in supporting staff resilience. This study has highlighted the importance of the environment in supporting rather than undermining resilience. The environment can enable people to move through the resilience cycle at their own speed by allowing them to be the 'expert by experience' (McLaughlin, 2009) in their process, or it can challenge the individual who isn't moving as fast as the organisation would like. However, this model proposes that if individuals are not allowed to take what they need, then there is a possibility that they will in fact move more slowly through the stages as the demands placed upon them add to their sense of adversity. It is also possible that the prevention of taking adequate time, then becomes an additional adversity, which could put someone right back at the beginning of the cycle. Additionally, where a person is in a community situation with people in authority giving demands about what they should do, there is the same possibility that if a one size fits all approach is taken to use training promoting one resilience intervention, then this again may slow the progress around the resilience cycle down as the individual struggles to engage with a technique that does not suit their resilience signature. Therefore, it would be expedient for these settings to take a strengths-based resilience signature approach instead.

Looking at the societal level of the individual's environment, it was seen in this study how social policies that regulate the allocation of funding for schools, added to the sense of adversity felt by the parents. The amount of time that the participants spent on activities such as education tribunals which in all six cases were lost by LEAs, demonstrated that the current policies are not set up to support the individual resilience of these mothers. The number of hours lost to the child because their mother was engaged with preparation for a tribunal, was said to be significant by more than one of the participants. This quite possibly has an additional cost to the public purse down the line due to lost progress that a child would have made had their parent not been engaged in the fight. If the right support was in place from the beginning, then the mother could focus on helping the child to develop, and the child would have been in a better education provision from the beginning.

An additional cost that has not been accounted for, is that of the health cost incurred due to the poor mental health of many mothers of children with autism (Baylot Casey, et al. 2012; Lounds Taylor, & Warren, 2012). The lack of provision for families of children with autism, may save money in one pot, but it may well just transfer the cost to a lifelong pot of money if the child does not become independent or financially viable as an adult. This suggests that opposing the mothers of these children, may in fact be a false economy in the long run.

5.3.4 Further research

The implications of the findings of this research are that future research into resilience no longer needs to be carried out in opposition to other research. Until now there has been no consensus around the definition of resilience or on a way to operationalise and measure the construct. What this research achieves, is a proposed way to bring together the research on resilience, because the model suggests that all the other ways of operationalising resilience were concurrently correct. Where this model differs, is that previous research has looked for a one size fits all explanation of resilience, whereas this model suggests that does not exist, and that the uniqueness of people means that everyone does it differently.

It is important to note though that at this point, the research has produced a conceptual model, as it is a small-scale study based on only seventeen participants. To advance from a conceptual model to a middle range or grand theory is going to need significantly more research.

Firstly, this study needs to be repeated with other cohorts of participants, either with another group operating like a sort of case study or just with people in general. Then it will become clear whether this pattern of responding to adversity is limited to mothers of children with autism, or whether it is a general model.

Additionally, another study needs to be conducted to explore each section of the new model to uncover the component parts of it and what needs to happen to fulfil each stage. Furthermore, another study needs to look at what needs to be achieved to facilitate moving from one stage to the next. For example, in the recovery part, what does the individual need to achieve to recover and then move to adapting.

It would also be interesting to see what happens with the cycle if a second adversity strikes before a person has completed the resilience cycle? This would be a more difficult study to capture, as it would not be known at the start of any study, as to who would suffer a second adversity. However, if there were a large enough number of participants then this would surely occur for some of them.

Further possibilities for study of this model would involve using the resilience signature template to identify a person’s resilience signature and then quantitatively via questionnaires see whether there were correlations between a person’s resilience signature and other theories such as the big five theory of personality (Costa & Macrae, 1992; Goldberg, 1992), emotional intelligence (Goleman, 1996), multiple intelligences (Gardner, 2000) or the VIA (Seligman et al. 2005).

A major premise of this study is that everyone is resilient. This leads to the question of what happens when people commit suicide, and whether this constitutes a failure to be resilient? The data collected in this study did not answer this question, so a further research study might involve interviews with people who have attempted suicide to see how this model fits with their experience. I would postulate that they have somehow become stuck on a stage that is early on in the cycle, thus creating an intolerable experience. This would lead to more research as to why people can become stuck in one stage, rather than moving on.

CONCLUSION

This study was carried out, because the current conversation around resilience includes the idea that some people are resilient, and some are not. Others suggest that individuals can work to improve their resilience by participating in interventions designed to increase wellbeing such as mindfulness. It is believed that having the right protective factors and the absence of risk factors can mitigate against a drop in wellbeing following adversity, however there is a lack of consensus over what these factors are. This has created a narrative that is possibly guilty of toxic positivity, as the onus is on the individual to be resilient and not take a downturn in wellbeing following adversity. This can lead to the weaponization of resilience as a concept, rather than a way to support people, in terms of; if you find something hard in your life and you don't just immediately carry on as if nothing has happened, that somehow you are not resilient. This is a message that could be incredibly damaging to people, as it adds a level of judgement on top of the burden of the adverse experience. Resilience is currently presented in a one size fits all way of navigating challenges in life, which again reinforces the message that some people are not resilient if they don't find the interventions helpful. The intention of this study was to explore the concept of resilience in the hope of creating a new model of resilience.

The study explored a population where people are told to 'just get on with it'. This provided a group of people who faced a chronically, ongoingly, challenging, situation, which would continue even after their own demise. Mothers of children with autism fitted this requirement as autism is a lifelong disorder that doesn't necessarily shorten the child's life expectancy, meaning that the child will still need care after the mother is no longer able to look after them. So, this group of mothers was used in the research as a quasi-case study, in the hope that the construct of resilience would be clarified, due to the ongoing nature of the adversity and the need for the mothers to continue parenting. Using this group of people, has contributed to the current knowledge on resilience, because everyone within the group had similar adversities occurring, therefore, changes in the mothers' resilience could not be attributable to one situation being more adverse than another, so the question that this study hoped to answer, was exactly what made the difference to the mothers' resilience.

The findings for this study will therefore be of interest for the wider field of people who study or work with resilience. The study will also be important for mothers who have children with autism, as it will inform their practice in taking care of their own wellbeing. The model constructed from the findings presents a kinder model of resilience, which can be of use to the wider population, all of whom will benefit from an approach that does not suggest that finding adversity challenging constitutes a personal failure to be resilient.

Another feature of this study is that most of the research carried out with this cohort of people has previously used a quantitative approach. With a quantitative approach, prevalidated scales are used to measure predetermined domains. The consequences of this are, that it only demonstrates a part of the overall picture depending on the decisions taken regarding which traits to measure. Therefore, some people who have a different style of resilience will appear to have low resilience, which may not necessarily be the case. The qualitative approach taken by this study is unusual for this particular cohort of people. This has enabled open questions to be asked that have provided a different picture to the traditional conversation on resilience.

The purpose of this study has therefore been to explore resilience in an open and curious manner, so that something new can emerge. The research questions have been very broad in design, so that the scope of the questions does not constrain the possibility of finding something new.
This study has focused on the following overarching research question, with the aim of exploring, to what extent, do mothers of children with autism experience resilience, given the challenges and stigmas of parenting their child? This was then broken down into three sub-questions:

1) What does the word resilience mean to mothers that have children with autism?
2) How does being a parent of a child with autism affect the mother's resilience?
3) In what ways do mothers of children with autism demonstrate resilience?

Using a qualitative research design was beneficial due to data collection starting from a hypothesis free standpoint. The reason for this was that in the current conversation about resilience, there is no consensus around, definition, conceptualisation, operationalisation, or measurement of resilience. Therefore, new ground needed to be found. By asking open questions of the participants, it was hoped that something new would emerge.

Within qualitative data analysis there were several options of data analysis that could have been chosen, however, only grounded theory offers the possibility of theory generation and so this was selected. Another advantage of constructivist grounded theory is that it applies gerunds to the data, which provides a picture of the actions of the participants. This emphasis on what people do rather than the interpretation of the research has been a very fruitful approach for this study, as it has led to the concept of doing resilience as opposed to being resilient.

The findings of this study suggest that resilience is in fact a cycle rather than a linear process which is juxtaposed between the adversity that has happened and a future potential adversity. The cycle consists of stages that the individual passes through as shown in the diagram below:

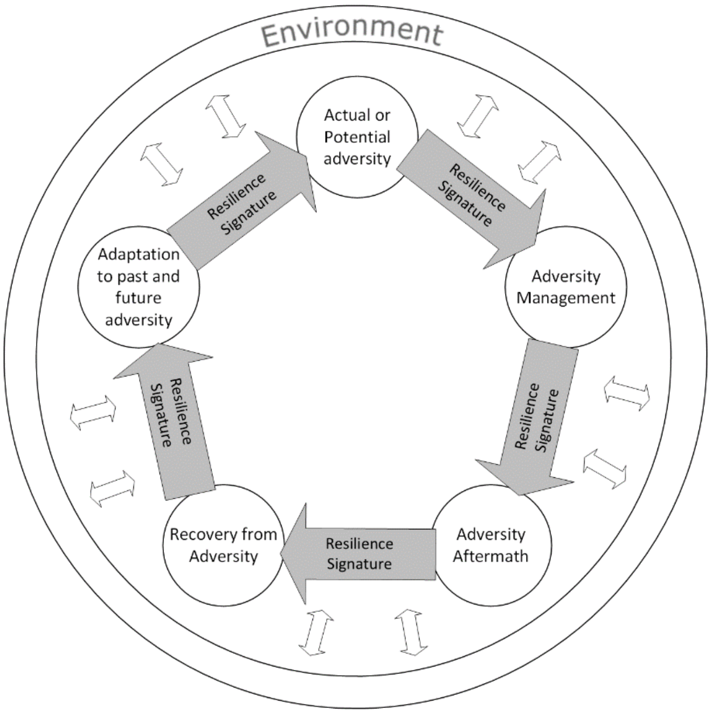

Figure 18 The resilience cycle – authors own diagram.

The findings also demonstrate that each individual has a personal resilience signature that determines a method of moving around the cycle. It has also been demonstrated that by allowing the individual to move around the cycle at their own pace has a beneficial consequence not just for the individual, but also for their immediate community and also the wider society. Additionally, the model shows that there is an interplay between the individual and the environment whereby each can affect the experiences of the other. This means that an individual cannot be held responsible in isolation for their levels of wellbeing meaning that resilience as a construct should not ever be weaponised as a tool to make people try harder. When working using this model of resilience professionals will find it more compatible with anti-discriminatory practice. By focusing on each stage in the model, practitioners wanting to help people, can design and offer interventions that tap into the sections of the resiliency signature, so that people can choose an activity that is congruent with themselves. This then creates a supportive environment for the individual whereby they can do whatever they need to do following adversity – well. This surely is after all, the meaning of wellbeing.

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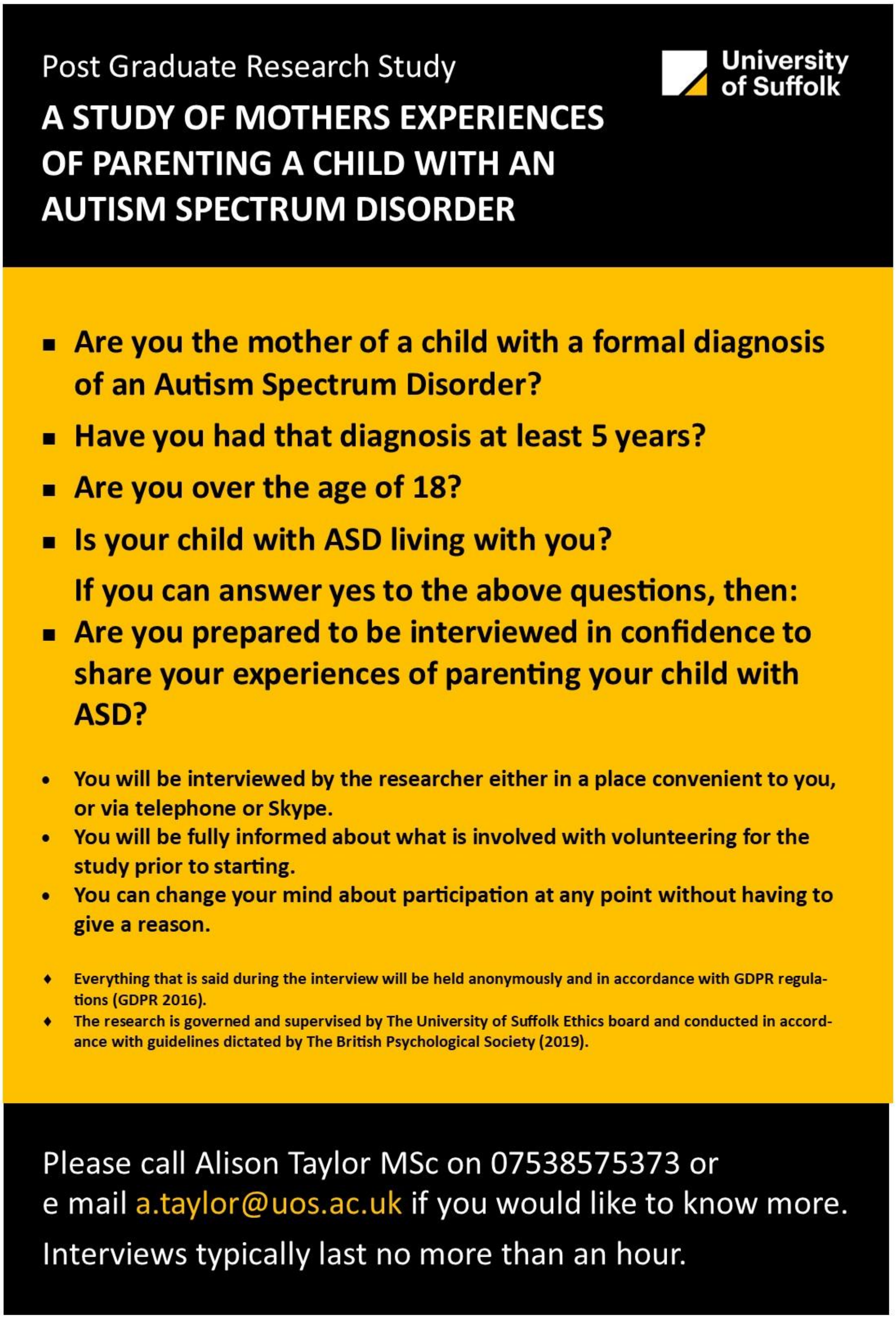
APPENDICES

Appendix one

Final interview schedule

1) Can you tell me a little bit about your life before having children?
2) Tell me about your child with autism?
3) How would you describe resilience?
4) How have you come to know what resilience is?
5) What would you say are the challenges of raising a child with autism?
6) How do you think you have overcome the challenges of raising a child with autism?
7) Can you describe a significant event that has occurred with your child that you felt was challenging and explain the process of your actions, thoughts and feelings from the time it happened onwards until a time when you felt OK about what had happened?
8) Have your thoughts and feelings about your situation changed at all since your child was first diagnosed? In what way?
9) Is there anything specifically that you do to take care of yourself?
10) If you met someone whose child had just been diagnosed with Autism what advice would you give them about how to take care of themselves?
11) Is there anything in your day that is just for you?
12) Do you think you psychological wellbeing would be different if your child did not have Autism?
13) Is there anything relating to your resilience that I have not asked about?

Appendix two



Post Graduate Research Study

University of Suffolk

A STUDY OF MOTHERS EXPERIENCES OF PARENTING A CHILD WITH AN AUTISM SPECTRUM DISORDER

- **Are you the mother of a child with a formal diagnosis of an Autism Spectrum Disorder?**
- **Have you had that diagnosis at least 5 years?**
- **Are you over the age of 18?**
- **Is your child with ASD living with you?**

If you can answer yes to the above questions, then:

- **Are you prepared to be interviewed in confidence to share your experiences of parenting your child with ASD?**

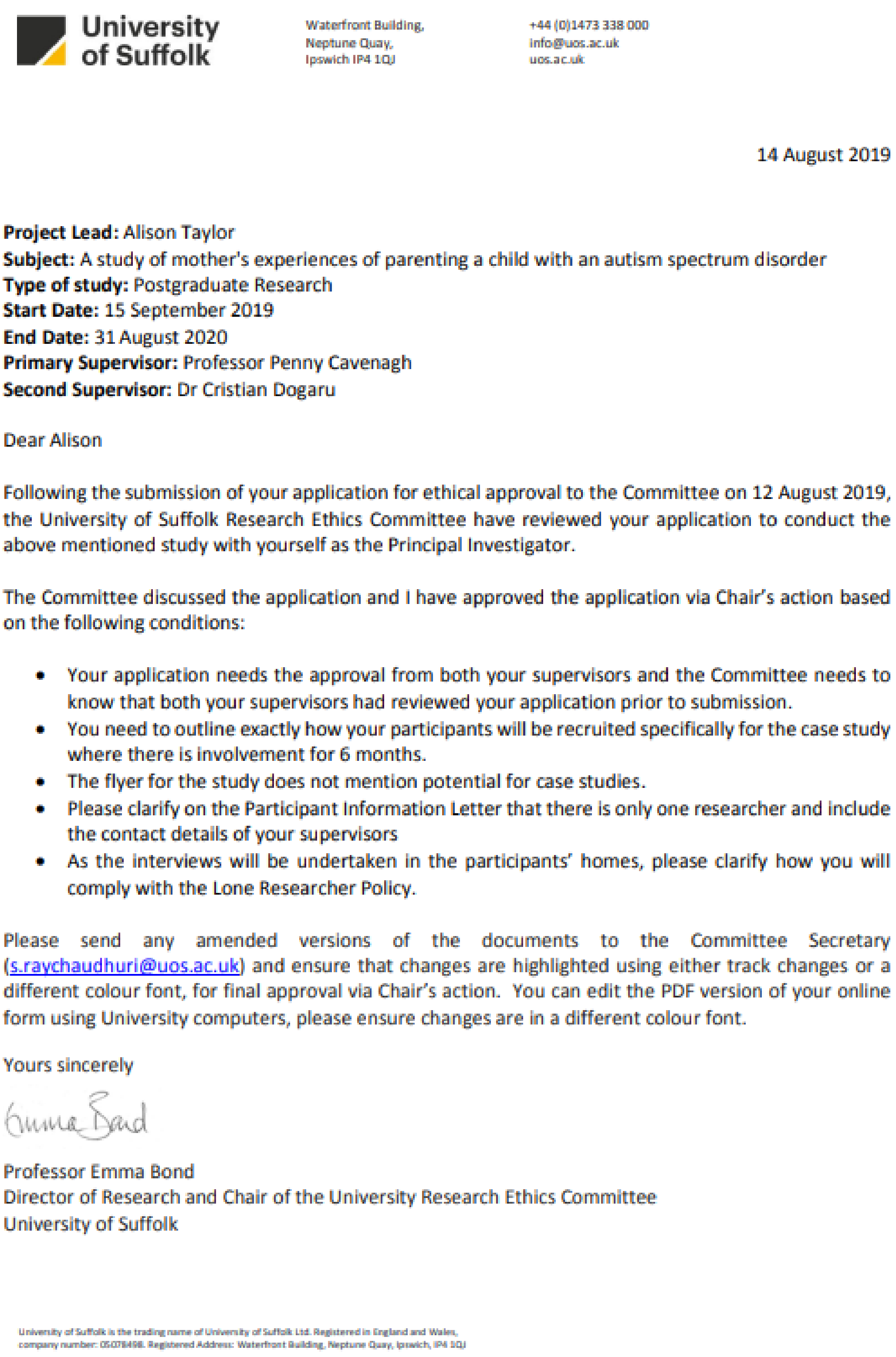
- **You will be interviewed by the researcher either in a place convenient to you, or via telephone or Skype.**
- **You will be fully informed about what is involved with volunteering for the study prior to starting.**
- **You can change your mind about participation at any point without having to give a reason.**

- **Everything that is said during the interview will be held anonymously and in accordance with GDPR regulations (GDPR 2016).**
- **The research is governed and supervised by The University of Suffolk Ethics board and conducted in accordance with guidelines dictated by The British Psychological Society (2019).**

Please call Alison Taylor MSc on 07538575373 or e mail a.taylor@uos.ac.uk if you would like to know more.

Interviews typically last no more than an hour.

Appendix three



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14 August 2019

Project Lead: Alison Taylor
Subject: A study of mother's experiences of parenting a child with an autism spectrum disorder
Type of study: Postgraduate Research
Start Date: 15 September 2019
End Date: 31 August 2020
Primary Supervisor: Professor Penny Cavenagh
Second Supervisor: Dr Cristian Dogaru

Dear Alison

Following the submission of your application for ethical approval to the Committee on 12 August 2019, the University of Suffolk Research Ethics Committee have reviewed your application to conduct the above mentioned study with yourself as the Principal Investigator.

The Committee discussed the application and I have approved the application via Chair's action based on the following conditions:

- Your application needs the approval from both your supervisors and the Committee needs to know that both your supervisors had reviewed your application prior to submission.
- You need to outline exactly how your participants will be recruited specifically for the case study where there is involvement for 6 months.
- The flyer for the study does not mention potential for case studies.
- Please clarify on the Participant Information Letter that there is only one researcher and include the contact details of your supervisors
- As the interviews will be undertaken in the participants' homes, please clarify how you will comply with the Lone Researcher Policy.

Please send any amended versions of the documents to the Committee Secretary (s.raychaudhuri@uos.ac.uk) and ensure that changes are highlighted using either track changes or a different colour font, for final approval via Chair's action. You can edit the PDF version of your online form using University computers, please ensure changes are in a different colour font.

Yours sincerely

Emma Bond

Professor Emma Bond
Director of Research and Chair of the University Research Ethics Committee
University of Suffolk

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Appendix four

Informed Consent Form

The University of Suffolk expects all research to be carried out in accordance with the following principles:

- The emotional well-being, physical well-being, rights, dignity, and personal values of research participants should be secured.
- Research participants and contributors should be fully informed regarding the purpose, methods, and end use of the research. They should be clear on what their participation involves and any risks that are associated with the process. These risks should be clearly articulated and if possible quantified.
- Research participants must participate in a voluntary way, free from coercion. Participants have the right to withdraw at any time.

This research has been approved by the University of Suffolk Ethics Panel. Should you have any concerns about the Ethics of this research, please feel free to contact the Chair of the Ethics Panel, Professor Emma Bond e.bond@uos.ac.uk (01473 338564) or the Research Development Manager, Andreea Tocca a.tocca@uos.ac.uk (01473 338656).

Study Title:

Experiences of resilience in parents that have children with an Autism Spectrum Disorder

Main Investigator: Alison Taylor

Academic Supervisor (for Student Research): Professor Penny Cavanagh and Dr Cristian Dogaru

Please initial the boxes below.

I confirm that I have read and understand the information sheet/letter (delete as applicable) dated *[insert date]* explaining the above research project and I have had the opportunity to ask questions about the project.	☐
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences.	☐

I understand that my responses will be anonymised and any personal or identifying information removed from published materials.	☐
I give permission for members of the research team to have access to my anonymised responses.	☐
I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research.	☐
I understand that the data I provide will be used solely for the purposes of the research study outlined and will not be used for any other purpose. I also understand how long my data will be stored for.	☐
I agree to take part in the above research project.	☐

___________________________ __________________ _______________________

Name of Participant Date Signature

(*or legal representative*)

___________________________ __________________ _______________________

Name of person taking consent* Date Signature

(**if different from lead researcher*)

To be signed and dated in presence of the participant.

___________________________ _________________ _____________________

Researcher* Date Signature

To be signed and dated in presence of the participant.

**Delete as appropriate*

Copies:

Once this form has been signed by all parties the participant should receive a copy of the signed and dated participant consent form, the letter/information sheet and any other written information provided to the participants.

A scanned copy of the signed and dated consent form should be placed in the project's main record by the student/researcher/PI. This must be kept in a secure location.

Appendix five

Participant Information - Interviews

Study Title:

Experiences of resilience in parents that have children with an Autism Spectrum Disorder

Sole Investigator: Alison Taylor

Academic Supervisor: Professor Penny Cavanagh, Dr Cristian Dogaru

You are invited to take part in a study on _____________________________ (date).

This Participant Information Sheet will help you decide if you would like to take part. It sets out why we are doing the study, what your participation would involve, what the benefits and risks to you might be, and what would happen after the study ends. We will go through this information with you and answer any questions you may have. You do not have to decide today whether or not you will participate in this study. If you agree to take part in this study, you will be asked to sign the Informed Consent Form. You will be given a copy of both the Participant Information Sheet and the Informed Consent Form to keep. Please make sure you have read and understood all the pages of the Participant Information Form.

1. What is the purpose of the study?

The study is exploring the experiences of resiliency for parents that have children with an Autism Spectrum Disorder

2. What will my participation in the study involve?

Your participation will involve an interview between you and me. There is no set time for this interview as the length of the interview will depend on the amount of information that you wish to share. You will be asked questions that relate to your life experiences of being a parent of a child with an Autism Spectrum Disorder. The interview will be recorded so what has been discussed can be written down and collated with other interviews for analysis. This will not be an analysis of you and no conclusions will be drawn about you, your actions, thoughts, or feelings. The transcript of your interview will not have your name on it so that it can be held anonymously.

3. What are the possible benefits and risks of this study?

The risks of participation are considered to be confined to any feelings that come up for you as a result of your sharing your life experiences. Telephone numbers of support groups will be provided at the conclusion of the interview. The benefits of taking part are that you will be contributing to a piece of research that will give you an opportunity to tell your story and be heard with compassion. You also will be contributing to a project that is hoped in the long run to provide parents with tools and techniques to be more resilient.

4. Who pays for this study?

The study is funded as part of a PhD. There is no payment to participants for their time and effort.

5. What if I feel uncomfortable with an aspect of the study?

If you feel uncomfortable at any time during the interview you can ask to take a break, or you can ask for the interview to stop.

6. What if I do not want to answer a question being asked of me?

You are free to decline to answer any question during the interview.

7. What are my rights?

You have a right to be treated with respect and caring at all times. I considers myself to be competent to the task of interviewing and processing the information given with integrity. You can ask to withdraw at any time. However, the intention for this research is for it to be published. Therefore, once this has occurred it will not be possible to withdraw your contribution. However, once the interview is concluded, the information will be held anonymously, with no identifying features of yourself or your family attached.

8. What happens if I change my mind?

You are free to change your mind at any time prior to participation. You can ask to withdraw at any time during the interview and in the days afterwards. However, the intention for this research is for it to be published. Therefore, once this has occurred it will not be possible to withdraw your contribution. However, once the interview is concluded, the information will be held anonymously, with no identifying features of yourself or your family attached.

9. What happens after the study?

The recording of the interview will be transcribed onto a computer for analysis. This will be combined with the data from other interviews to produce an overall picture of the group. It is then hoped that this will provide a theoretical explanation as to why some people are resilient despite dealing with ongoing challenges in their life.

10. Who do I contact for more information if I have concerns?

You can contact me if you have any questions by e mail at A.taylor@uos.ac.uk or my supervisors by email at p.cavanagh@uos.ac.uk or c.dogaru@uos.ac.uk

11. How will my data be stored and for how long?

Your data will be held on my lap top. This lap top is not connected to a network, meaning that only I will have access to it. It will be stored anonymously and will be held until the conclusion of the project. This is expected to be finished by September 2023

12. How will my data be destroyed?

Your data will be deleted from the laptop and any paperwork shredded.

Appendix six

Debrief sheet.

Thank you for taking part in my research into your experiences of resilience of parenting a child with autism.

The interview that you have just completed forms part of my studies for my PhD at The University of Suffolk.

The project is looking at what processes are involved in parental resilience when faced with the challenges of parenting a child with an Autism Spectrum Disorder.

The project follows on from numerous research projects that have found that parents of children with autism experience more stress and lower psychological wellbeing than parents of children with any other disability. However, not all parents experience these mental health challenges. This research is seeking to discover what makes the difference between these two groups of parents and what that process of being more resilient involves.

Please remember that the answers you provided in the interview are confidential and anonymous.
If you feel after the interview at all uncomfortable or unhappy about the subject discussed, then please do access some support:

Support is available from

1. Samaritans telephone: 116 123
2. Family Lives: Parental advice and support:

Confidential helpline Telephone 0808 800 2222

http://www.familylives.org.uk/ Plus live chat and e mail support.

3. BACP counsellor – Find a therapist
   http://www.bacp.co.uk/seeking_therapist/right_therapist.php

Fees will vary.

Autism Support

4. The National Autistic Society offers free information and advice.

http://www.autism.org.uk/services/helplines/main/contact.aspx

Telephone advice line **0808 800 4104**

5. **Living Autism: Charity helping autism families get the help they need.** http://livingautism.com/ **Telephone helpline: 0800 756 2420**

6. **Support line: a webpage that lists agencies that provide help, support and information for families with a child with autism. http://www.supportline.org.uk/problems/autism_aspergers.php**

Your participation is very much appreciated. Thank you for taking part.
If you have any questions about the research, please feel free to ask now or email later:
E mail a.taylor@uos.ac.uk

Appendix seven

My own resilience strategies

Cognitive tools

Internal locus of control

Don’t sit there feeling sad – do something to change the situation.

There are many ways to do things, so if something doesn’t work, don’t give up, try something else.

Use mantra’s like ‘I am enough, I have enough, I do enough.’ ‘I am perfectly imperfect’.

Be present – Don’t waste time and energy worrying about a future that might never happen.

Trust that there isn’t a problem that I can’t fix.

Something better is waiting in the wings.

Behaviour that I don’t want is an opportunity to teach behaviour that will be more successful.

I am the expert on my child.

The next great idea is just around the corner.

I am always doing my best.

J is also always doing his best too – remember this when he is destroying my things.

Never ever ever give up hope.

Don’t judge. The Wright brothers didn’t need to hate the ground in order to want to fly.

Accepting the current situation does not mean that you can’t still try to change it.

Other people’s opinions about me have nothing to do with me.

To want change but not need it is the way to encourage and not push.
This is not more important than my happiness.
I don’t need to be unhappy in order to know that I didn’t want my child to do this.
Unhappiness is not the magic that changes things.
Sometimes we have to just sit back and acknowledge that nobody died – putting it all into perspective.
This too shall pass.

Practical tools

Love first, act second.

Know where your boundaries are – uphold them.

Don't blame everything on autism – behaviour is behaviour and should result in consequences.

Find someone to talk things through with, even if they can't fix it for you, the act of talking moves things around in your head which might enable you to come up with another idea, plus you will not be alone with the information.

Be more proactive than reactive.

Ask for help and be creative about the many ways that people could help e.g., cooking foods for SCD diet, fund raising committee to take J to America, prayer chain, circle of friends for J, phoning buddies.

Take breaks.

Create clear goals and take actions towards them.

Find and use a developmental model to set goals.

Communicate goals to everyone who is involved with J and ask for feedback.

Keep a journal to track progress for information and encouragement.

Be ready to take on Goliath.

Keep in touch with friends.

Create good sleeping habits.

Cut yourself all of the slack that you need.

Focus on what my child needs rather than guessing what other people who are watching are thinking.

Make sure to keep up your hobbies/interests so that your whole life is not about your child.

Eat healthy food so that you can stay healthy.

Prioritise relationships over everything else. This includes J and the approaches that I take with him.

Be flexible/ adaptable.

Autism proof my house - be able to quickly shut off the water supply, lock away precious things so they can't be destroyed, make sure that J can't leave the house alone day and night. Always carry the keys on my person. Put locks on all internal doors so that a tantrum can be contained, J can't run away, and his sisters things can be protected – only lock when necessary. Remove stereo cords at night. Remove high stimulus items.

Always know where J is and what he is doing or at least designate someone else to this task.

Create a low stimulus room in the house to provide a safe place for J that allows his sensory system to calm down.
Read prolifically on Google/ books, to find ways to help and to give confidence when talking to professionals.
Attend all appointments and actively participate.
Be lovingly authentic with everyone who is involved with J.

Inspiration tools

Connect regularly to that place of love to give passion and persistence to your effort.

I believe in the sun even when it is not shining, I believe in God even when he is silent, I believe in love even when it is not shown.

Poems:- Do it anyway, Mother Theresa, Phenomenal woman and Still I rise – Maya Angelou

Speeches: It is not the critic – Roosevelt, Our deepest fear – Marianne Williamson

Art work: Banksy – There is always hope.

Find your own growth in your child's journey – your child is your greatest teacher.

Autism is a marathon and not a sprint.

Look for the beauty in everything.

Be grateful.

Self-awareness tools

Comparison of my efforts to raise my first child led me to realise that I had raised my game for my second child and had not seen the same results – autism was not my fault.

Take notice of how I feel and notice if there are any signature signs of surviving rather than coping e.g., skipping on personal tasks such as getting to lunchtime and realising a lack of toothbrushing that morning.

Nurture the ability to explain myself to myself so that I understand my feelings.

Look for the benefit for yourself in your goals because you matter too e.g. I want my child to go to bed on time so that he is not tired the next day and so that I can have an evening to myself.

It is OK not to be OK.

Be kind to yourself.

Meaning making tools

I am a powerhouse for my child.

You might not be able to change the world for everyone, but you can change the world for J.

Let go of the life that you imagined that you would have to enable yourself to embrace the gifts in the life you have.

Know that I am a strong advocate for J – no one else loves him as much as me, I have a lifelong interest in him, I am the expert in J.

Owning my life – it's mine and I will dance to the beat of my drum.

Historical tools

Previous life challenges as a teenager taught me to change my own life rather than wait for it to change.